

# **PATIENTS RESPONSE TO THE DIAGNOSIS OF CANCER.**

**THE CASE OF NAIROBI HOSPICE.**

**A THESIS SUBMITTED IN PART OF FULFILLMENT FOR THE  
MASTERS DEGREE IN PUBLIC HEALTH OF THE  
UNIVERSITY OF NAIROBI.**

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## DECLARATION

I declare that this is my original work and has not been presented to any other institution for the purpose of obtaining a degree.

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Diagnosis with cancer often arouses fear in the patients who tend to equate cancer with death. On the other hand, people cope with crises in life by using a variety of defense or coping mechanisms. This varies from one individual to the other. This coping strategies enables the person to continue to function without excessive anxiety, depression or anger and provides a breathing space during which the person can adapt to the new situation. Cancer, being a chronic ailment, patients have to live with it from day to day over a long period of time. It is this experience that intrigued me into finding out how cancer survivors actually cope with the ailment and seek medical care. I would like to give my deep appreciation to each individual patient for pouring out his or her experiences to me during the study. Although I cannot use their actual names due to confidentiality, my sincere gratitude goes out to them.

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## **LIST OF ABBREVIATIONS**

<b>FGDs</b>	<b>Focus group discussions</b>
<b>HBPC</b>	<b>Home Based Palliative Care</b>
<b>HIV</b>	<b>Human immunodeficiency virus</b>
<b>IARC</b>	<b>International Association for Cancer Research.</b>
<b>KNH</b>	<b>Kenyatta National Hospital</b>
<b>NH</b>	<b>Nairobi Hospice</b>
<b>TIP</b>	<b>Terminally ill patients</b>
<b>UK</b>	<b>United Kingdom</b>
<b>TICP</b>	<b>Terminally ill cancer patients</b>
<b>WHO</b>	<b>World health organization</b>

## **ABSTRACT**

Palliative care is the active total care of patients whose disease is not responding to curative treatment. Control of pain and other symptoms is aimed at improving the patient's quality of life. Palliative care is one institution of health care that has received minimum attention from all sectors of the Kenyan society. Pain is undoubtedly the most important symptom that requires alleviation in terminally ill cancer patients (TICPs). Cancer pain on the other hand is a neglected public health problem. This is mainly due to lack of knowledge regarding comprehensive cancer therapy. Patients' knowledge about cancer and their belief systems are important in determining how they respond to the cancer diagnosis and their health seeking patterns.

The diagnosis and treatment of cancer can cause major problems for patients and their relatives as they try to adapt to a fearful diagnosis and an uncertain future. In the vast majority of the studies pertaining to care of the TICPs the primary informants have been the family members, and not the patients. This has always been done after the patient's death but the accuracy of these surrogate accounts is open to question.

The main objective of this study was to determine the patients' response to cancer diagnosis and identify the various health seeking behaviour patterns. The study also aimed at identifying various coping mechanism with which the patients possessed in trying to live with the illness. These were done using in-depth interviews of patients that were purposefully selected and focus group discussions.

The study was carried out at the Nairobi Hospice. From the onset recorded data over a 10-year period (1991-2000) was studied in order to identify the trend and characteristics of patients who had previously visited the institution.

An analysis of a 10-year recorded data showed a total of 2992 cases. Their demographic characteristics revealed 39% were males while 61% were females. 84.7% of the patients were above 31 years old. The three most common cancers seen according to diagnosis by site included: breast cancer 20.7%, cervical cancer 16.8% and head and neck lesions 16.1%.

An in-depth interview was conducted among eleven patients. All the respondents revealed that they were not aware of the initial signs of cancer. They did not relate the signs they experienced to any disease let alone cancer, thus ignored them. Health provider advice was only sought if the symptom persisted or worsened (increased in size or pain). Complete denial, selective denial, anger, fear and acceptance were some of the emerging responses to cancer diagnosis. One patient responded by denying that he had cancer and thus did not undergo the necessary treatment. Religion played an important role in perceived causality and acceptance of the diagnosis. Most patients said it was the will of God that they were ill. Other patients said they had given their lives to God and were not scared of death because of their belief in life after death and that *“when I die I am going to be with God.”* Similar sentiments came out in the focus group discussions.

In conclusion this study shows that patient awareness of the initial signs and symptoms of cancer is still very low. There is fear of cancer in our society, which tends to equate the disease to death.

Denial is the coping mechanism exhibited by most afflicted cancer patients in trying to live with cancer. The commonest cancers seen at the Nairobi Hospice included breast, cervical and head and neck lesions. Health education and promotion campaigns with respect to cancer especially breast and cervical cancers needs to be instituted to prevent late diagnosis.

## CHAPTER 1

### 1.0. Introduction and Background Information

Health and illness, as biological and social facts can be defined as biomedical as well as the alternative models. WHO defines health in the biomedical model as 'complete physical, mental and social well being and not merely the absence of disease or infirmity. Illness is defined as deviation from the norm of measurable biological variables. The alternative model defines health by including the "moral and spiritual" well-being factors. Illness is then defined as 'a disturbance in the social relationships. The questions of etiology are framed with reference to social rather than biological processes. Whether or not members of a society see a particular behaviour or experience as a sign or symptom of illness depends on cultural values, social norms, and culturally shared views of interpretation. The biological model strips away the social context of meaning. Illness is then viewed as an autonomous entity, defined by standard universal criteria, isolated from the lives and experiences of patients and physicians (Mishler. et al 1981)

Cancer is a pervasive cluster of diseases touching on the lives of many individuals and families. It occurs in persons of all ages, sex, race, socio-economic and geographical background, or geographical areas. In the United States, excluding accidents and suicides, cancer is the first cause of death among females of all ages up to age 75 years (Carnevali. et al 1990).

Cancer can be viewed from two major perspectives,

- Malignant neoplasms, which are addressed in terms of their pathogenesis, pathology and responsiveness to forms of intervention.
- Cancer can also be studied, diagnosed and treated in terms of the patients' experience.



The human experience of cancer includes both the emotional and physical components. The intensity of the cancer can vary from almost no impact to the significant stresses of managing daily living with threatening diseases in oneself, a family member or a friend.

Anxiety, uncertainty, guilt, powerlessness, helplessness, and anger can be generated from individual perception and dread of the prognosis especially due to:

- Difficulties in accepting a diagnosed, life threatening illness and its implications to the family.
- Failure to recognize early symptoms of the cancer or to convince the patient to seek prompt medical attention.
- Occurrence of cancer that is linked to a lifestyle (smoking, tobacco use).
- Occurrence of cancer in a family member associated with a known genetic origin leading to feelings of guilt in parents or grandparents, anger in the patient or fear in the other offspring.
- Impending death and the actual death of the family member (Carnevali. et al 1990).

Illness experience and the meaning of terminal illness are poorly understood and therefore there is a need for work that can unravel and explain the illness process. Although most patients are aware of their illness, the history and progress, few are prepared to discuss death. The carers, whilst providing the patient with every opportunity to discuss the subject openly, must respect this reluctance. If the patient can be gently led to talk about the reality of death and express fears about it, much of the tension and anxiety felt may be alleviated. It is essential to keep lines of communication open between the patient, service providers and relatives. Communication with a

dying patient is not easy, as it is time consuming and provokes emotions; therefore, it is always avoided.

Medical staff and relatives often feel they should shield the patient by erecting communication barriers. There are three guidelines in talking to terminally ill patients:

- Always tell the truth.
- Consideration that patients have an absolute right to whatever they may wish to know about their diagnosis and prognosis.
- Regard it equally as a right for patients not to have information that they have not sought thrust upon them. It suffices, therefore, to give patient's ample opportunity to signify their wishes. It is also helpful to take the patients through their history of illness and their experiences step by step.

Palliative care is a relatively new concept in the Kenyan society. Cultural beliefs and practices play a big role in the diagnosis, treatment and care of the cancer patient. Becoming ill is a social process that involves other people besides the patient. In the African belief system, misfortunes such as ill health, natural disaster or death do not just occur but are perceived to be pre-destined.

The cause of ill health are perceived to be:

- A curse
- Breach of social order
- Witchcraft and sorcery (evil eye)
- Divine will – God allowing a person to go through suffering.

This cultural component of human behaviour and disease can best be understood from the patient response to cancer. Caring for a dying person at home is received with mixed feelings in various cultural backgrounds.

### 1.1 Palliative Care and the Hospice Movement

The word palliative is derived from the Latin word *pallium* meaning a cloak or cover. Thus in palliative care, symptoms are cloaked with treatments whose primary or sole aim is to promote patient comfort. Palliative care is the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems is paramount. The goal of palliative care is the achievement of the best possible quality of life for the patients and their families.

Palliative care according to the WHO guidelines

- Affirms life and regards dying as a normal process.
- Neither hastens nor postpones death.
- Provides pain relief and other distressing symptoms.
- Offers a support system to help patients live as actively as possible until death.
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help the family cope during the patient illness and their own bereavement.

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Palliative care has its origins in the hospice movement. The unit of care is the family rather than the patient alone. It requires a team approach where nurses have a major role to play (WHO, 1989).

## **1.2. Palliative Care In Kenya**

The palliative care concept has not fully developed in the Kenyan medical system. It is not in the curriculum of the undergraduate students. The government has not put in place a policy on drug use in the management of cancer pain. Morphine use is still restricted even when it comes to terminally ill cancer patients.

There are four functional hospices offering palliative care for the terminally ill cancer patients. They all offer home based palliative care. They are located in four major towns, Nairobi, Nyeri, Eldoret and Kisumu. There is no budgetary allocation on palliative cancer care hence they are allowed to operate as charitable non-governmental organizations.

## **1.3. Home Based Palliative Care at the Nairobi Hospice**

The Nairobi hospice is one of the institutions offering palliative care for the terminally ill cancer patients. It was started in 1990 with the help of the late Professor Kasili and the UK Hospice. It is licensed as a charitable organization exempted from taxation. It is located in the Kenyatta National Hospital grounds. According to the 1997/8 annual reports, it has seen an upward trend in both the number of referrals and the actual number of patients under their care since its inception. The aims of the hospice include the provision of palliative care to the terminally ill cancer patients, support and train the families of terminally ill cancer patients. This is to enable them look after the affected individual in a home setting that is familiar to the patient, and extend care to terminally ill patients by running educational programmes for doctors, nurses, pharmacists, other health workers and volunteers.

Palliative care centers demonstrate the value of round the clock administration of analgesia. The palliative care programme at the Nairobi hospice includes the following components: Home care, Daycare, In-patient / hospital care, Bereavement support and Training of health workers and volunteers.

#### **1.4. The Burden of Cancer Globally.**

WHO estimates that 9 million cases of cancer occur in the world every year. By the year 2015, the annual figure is expected to reach 15 million cases; two-thirds of them in developing countries; which have only 5% of the resources available for cancer control in the world (WHO 1998). Palliative treatment and care, including symptom control and pain relief will be important for years to come for the large numbers of patients for whom curative therapy is not possible. This is aimed at improving the quality of life for many cancer patients. Of the eight most common forms of cancer five are most prevalent in developing countries. Even if diagnosis is made at an early stage, treatment is only curative in only three types; therefore palliative care is required in all eight.

**Table 1: Cancer control priorities and strategies for the eight most common cancers (WHO Geneva 1989).**

Site of Cancer	Primary prevention	Early diagnosis	Curative treatment	Palliative care
Stomach	+	-	-	++
Lung	++	-	-	++
Breast	+	-	++	++
Colon/Rectum	+	+	+	++
Cervix	+	++	++	++
Mouth/Pharynx	++	++	++	++
Oesophagus	-	-	-	++
Liver	++	-	-	++

++=Very effective      +=Effective      -=Not effective.

**Table 2: World Incidence of Cancer and Mortality for all Sites but Skin (all ages)**

	Sex	Age standardized incidence rate per 100,000	Age standardized death rate per 100,000
World	Male	201.90	134.44
	Female	157.84	88.30
	TOTAL	359.74	222.74
More developed countries	Male	300.97	173.90
	Female	218.30	103.08
	TOTAL	519.27	276.98
Less developed countries	Male	153.75	112.86
	Female	127.90	77.48
	TOTAL	281.65	190.34
Kenya	Male	186.46	126.52
	Female	176.96	106.89
	TOTAL	363.42	233.41

**Globocan 2000: Cancer incidence mortality and prevalence worldwide. Version 1.0**

**IARC Cancer base no.5. Lyon, IARC Press, 2001.**

### 1.5. The Kenyan Situation

It is estimated by WHO that the incidence of cancer in Kenya is about 30 000 yearly of whom 70% have end-stage terminal illness. This late presentation could be attributed to economic factors; the insidious nature of the disease, the severity of illness and the desperate search for a cure influenced by traditional beliefs. IARC also estimates that the incidence of cancer in Kenya (all sites but skin) is 363.42 per 100 000.

**Table 3: The top ten cancers in the National Registry (KNH 1981-1990)**

No.	Site of Cancer	Total
1	Cervix	1596
2	Lymphoma	889
3	Skin	803
4	Breast	776
5	Oesophagus	690
6	Post -Nasal-space	605
7	Liver	446
8	Eyes	337
9	Connective tissue	369
10	Stomach	357



## **CHAPTER 2**

### **LITERATURE REVIEW**

The central argument is that palliative care aims at improving the quality of life of the terminal cancer patient through control of pain and other symptoms. Home-based palliative care takes care of the patient in a home setting. It aims at reducing the cost incurred during hospitalization. Many terminal cancer patients tend to worry since their hospice or hospital stay eats up a lifetime of savings intended to help the family. A great deal of this literature is based on studies done outside the African setting.

#### **2.1 Need for Hospice/ Palliative Care**

Cancer is becoming a world problem too. Globally the number of cancer patients and the overall cancer mortality are increasing. If the current trends continue cancer mortality can be expected to rise in nearly all regions of the world. The major reasons for this are a general increase in the average age of the population, control of major health problems, and an increase in tobacco use. Tobacco use is increasing by more than 2% a year in developing countries. Freedom from cancer pain should be seen as a right of every cancer patient and access to pain therapy as a measure for this respect. Although palliative care is the only realistic option for most cancer patients, it attracts few of the available cancer control resources. Most of the resources are devoted to curative treatment. In developing countries most of the diagnosis of cancer is made during the late stages. Most patients then end up being terminally ill (WHO, 1989).

WHO estimates that some 4.3 million people die worldwide from cancer or stated differently one out of every 10 deaths from all causes is due to cancer. Some 9-million cancer cases occur

annually worldwide: more than half in the developing world, where at the time of diagnosis, most cases are incurable. Some 3.5 million suffer daily from cancer pain. In the industrialized world not all are treated. In the developing world most are untreated. Cancer pain is a neglected public health problem. Little is done to alleviate pain simply because of:

- The inadequacy of medical education in cancer pain therapy, medical students are trained to treat cancer but not to manage cancer pain.
- Fear of addiction both by doctors and nurses, who tend to prescribe under-dose analgesics.
- An insufficient supply of drugs as a result of national regulation and legislation that limit availability of analgesics.
- Lack of patient awareness who, in most cases, suffer without complaint.
- Lack of concern by many governments (WHO, 1986)

The pain experience involves loss and change. Individuals experiencing pain may change lifestyles and daily routines to accommodate the pain, for example a construction worker with advancing cancer and pain may lose employment as well as the identity of being strong (Betty et al.1993).

In her study using qualitative data (n=30: TICPs, caregivers and nurses) to find out the meaning of pain Betty et al. (1993) realized that the immediate cause of pain is perceived to be the disease itself and the immediate cause of the increased pain is the progression of the disease. ***“Pain means I got cancer (sick).”*** Death also meant relief from pain: ***“seen some of them suffer with that cancer, and if he is going to have to lay and do that, I’d just as soon the Lord takes him.”***

This perspective suggests caregivers' and nurses experience a level of pain as well and the patients' relief is also their relief even if that means the patients' death. For patients, cancer pain meant many losses including loss of control, normalcy, ability to work, usefulness and physical comfort. Among the emotional experiences reported by patients, were feelings of depression, powerlessness, embarrassment, and fear (the pain will get worse, fear for loved ones affected by their illness and fear of indignity).

A study carried out in Saudi Arabia to assess cancer care and the need for establishment of hospice / palliative care for cancer patients and their carers indicated that the level of cancer care in the Ministry of Health hospitals was poor compared to private institutions. This was perhaps due to:

- absence of home care services
- shortage of drugs used in cancer management
- severe restriction of prescribing narcotic analgesic
- lack of cancer care knowledge

The results also illustrated a need for initiating the provision of palliative care services due to:

- The strong inter-relationship among Saudi families
- The present poor status of cancer care
- Cancer patients and their cancer acceptability of hospice services
- The willingness of health care professionals to receive training in palliative care.

## **2.2 Response to Cancer Diagnosis.**

Cancer is a disease that is feared. Many view it as a nearly certain sentence of pain and death. In addition, as a chronic disease its meaning includes living with these dangers overtime. Persons living with cancer often find meaning for their illness by constructing benefit from their illness.

Patients' knowledge and beliefs about cancer is important because it affects their health-seeking behaviour. Misinformation and misconceptions regarding cancer and its treatment among patients may contribute to inappropriate care seeking behaviour. Examples include a patient with operable lung cancer refusing surgery because of the belief that exposure to air will lead to the spread of the malignancy or a patient foregoing proven treatment for non-traditional medicines (Porzsolt, 1993).

Americans living in poverty experience a higher incidence of and a greater mortality from cancer than the non-poor. At least 50% of the difference is believed to be due to delay in diagnosis, although risk promoting lifestyles and behaviour also contribute to decreased survival. A potential exacerbating factor among the poor is inadequate information and knowledge about cancer and its treatment (Loehrer et al. 1991).

In his study to find out about knowledge and beliefs about cancer in a socio-economically disadvantaged population Loehrer (1991) found out that although most patients relied primarily on their physicians for information about their disease and treatment, a number of misconceptions regarding cancer existed in that population. Over a third believed that surgery caused cancer to spread; two thirds thought that a bump or a bruise could cause cancer and a

third stated that cigarette smoking did not cause cancer and the other 13% did not know if smoking was related to the development of cancer. Misconceptions and misinformation regarding cancer and its treatment may contribute to inappropriate care seeking behaviour.

Personal meaning of the cancer experience is derived and may change over time. The impact of cancer involves human responses to the experience. Families often respond actively and positively to events that affect them. The human abilities to be hopeful and optimistic to endure discomfort, to work at keeping life normal in the midst of major disruptions, to live with uncertainty, to laugh together and to grieve for what has been lost and then go on with life are all positive examples of the scope of active human responses to cancer. Some of the enabling factors in coping with cancer include, social support systems, hopefulness, religion, information seeking, open communication, problem solving ability and control. Hindering factors include denial, anger, depression, avoidance, guilt, hopelessness and powerlessness (Baird et al. 1991).

The current theories on death and dying as postulated by Kubler-Ross (1969) indicate the five stages in the process of psychological response to dying: denial, anger, bargaining, depression and acceptance. According to this theory, the dying person reacts to the shock of the news of an incurable illness initially by refusing to believe that it is true and thus denying the situation. The concept of denial may come to mind when a person has delayed seeking diagnosis and treatment for a life threatening condition. This denial stage is followed by the second and third stages of anger and bargaining. In the latter stage, the person may engage in bargaining, for instance, by making promises to God in exchange for more time to live. This stage is followed by depression when it becomes clear to the person that he/she can no longer deny the progression of the

disease. The fifth stage of acceptance may occur if sufficient time and help are given to enable the individual to work through his/her grief and sense of loss.

Denial has long been considered one of the worst things to do when trying to cope with a stressful situation, especially a situation as serious as a life threatening illness. It is a strategy that may be effective for a short period of time and for situations in which there is one particular overwhelming threat. In addition patients may show acceptance of some aspects of their illness but reject other aspects, for example, patients may acknowledge that they indeed have cancer but may ignore the fact that cancer is incurable (Baird et al. 1991).

Other investigators have studied the meaning of illness among cancer patients by exploring causal explanations. Approximately three quarters of Gotty's (1985) patients including women with cancer and their husbands reported they did ask the 'why me' question and identified specific answers including predetermination, God's will, hereditary, past behaviour and re-evaluation of illness as positive.

Dying from cancer is often a process characterized by significant patient and family emotional anguish. In 1988, a public opinion survey showed that fear of cancer still exceeds that of acquired immune deficiency syndrome (AIDS). This may be explained by the fact that AIDS is often viewed as avoidable whereas cancer is perceived by most people as a "real, unavoidable, and indiscriminate threat" (Winstanley et al. 1988).

Researchers estimate that 20%-60% of cancer patients experience depressive symptoms, which can make it more difficult for women to adjust, participate in treatment activities and take advantage of whatever sources of social support are available. Some women become so disheartened by the ordeal of having cancer that they refuse to undergo surgery or simply stop going for radiation or chemotherapy and hence may get even sicker (Alice et al. 1997).

In the largest research of its kind, Ohio state University researchers have shown that the stress women experience after breast cancer diagnosis and surgery can weaken their immune response, based on three different biochemical indicators: natural killer cells, gamma interferon and the T-cell response (Andersen. 1998).

Despite aggressive campaigns to improve early case finding for breast cancer symptoms, approximately 41% of women have regional or distant metastasis at the time of diagnosis (Wingo, 1995). Women themselves discover 60%-80% of breast cancers through self-breast examination. Noreen et al. (1995) in their study to find out help-seeking for breast cancer using women's narratives (N=39) found out that 82.1% of the women discovered their initial breast cancer symptoms, 12.8% by routine mammography and 5.1% on physical examination. Of these women 56.3% reported seeking immediate evaluation of their self discovered symptoms (less than a week). The remaining 43.7% did not seek immediate evaluation because of several reasons: some had just had their regular mammography and professional breast examination and hence this examinations made them unlikely that their symptoms represented cancer, hence evaluation was only sought when the symptom(s) worsened, that is, increase in lump size and number, increased pain, or breast asymmetry.

Health Providers advised 69.2% of the women by moving them towards a diagnosis by ordering mammography or biopsies and the remaining 30.8% described their providers as reassuring them that the changes in their skin were normal and nothing to worry about or a skin problem.

In her study to investigate the experience of cancer patients, Gotay (1984) found out that the problems experienced by most cancer patients were fear of the cancer itself. The fears varied ranging from the fear of the diagnosis, to progression and the recurrence of the disease, to worrying that having had one kind of cancer might make a person susceptible to other cancers. Other problems included restrictions on activities, side effects of the treatment and the family's future. The coping strategies adopted by these patients were taking firm action, seeking social support, talking to oneself, seeking more information and seeking comfort in prayer. Coping with fear of the disease was mainly by denial, trying to forget, accepting the inevitable, living for today and social contact with other people. For persons who have been previously diagnosed with cancer, the social stigma associated with the disease hinders discussion of the basic fear of the disease with others. After people have lived with the cancer for a period of time, however, such as occurs in advanced disease, it may be that individuals can identify those persons who are able to discuss cancer and fears about the disease can be shared. In advanced disease individuals are more likely to share their fears with other people and their God.



### 2.3. Choice of Place of Care

Townsend et al. (1990) in their prospective study to determine patient preference of place of death; found out that 58% of terminally ill cancer patients preferred to die at home. Brown P et al. (1990) in her study on Families in Supportive care II also found out that patients explained this preference by identifying the advantages they perceived home care afforded them. Five interrelated concepts: being there, normalcy, self-determination, reciprocity and sustaining relationships represent these advantages.

**Being there:** by having the patient at home, he or she can continue with established systems of interaction, communication, social and emotional involvement. Home is the centre of meaningful activity and connectedness to the family and community. The patients' identity and integrity in relation to meaningful interactions is maintained.

**Normalcy:** refers to living as normally as possible despite the illness and its ramifications, away from the hospital beds and the sick. Patients ate meals with the family at the kitchen table, family members continued with their regular patterns of school and work.

**Sustaining relationships:** being at home enabled the sustaining of mutually supportive relationships with each other and with friends. From the patients perspective friends can phone or drop by the home for visits that are much more meaningful than visits in the hospital where it always seemed that there were too many visitors when the patient was ill and not enough when the patient was up to more company.

**Self-determination:** Patients and families equated care at home with the concept of freedom and control. At home they determined their own routine of when to rise, bath, dress eat and visit. They didn't have to conform to the hospital routine and regimes.

**Reciprocity:** Family members indicated that having the patient at home and participating in his/her care indicated states of reciprocity. Involvement in the caring procedures also created opportunities for 'shared awareness'. The decision to choose home care and the success of home experience rested upon the presence of a willing and able caregiver.

Shinonda et al. (1995) in their study to analyze the economics of home care showed that home care saved medical expenses. Revenue and expenditures of both hospitalization and home care in a private hospital were calculated. The expenses of patients were about 33.7% less with home care. It was then concluded that home care might be a favourable medical care if some problems are solved.

There are four important subjects for successful care at home. These include; prompt consultation at any one time when the patient or his/her family is in need, effective palliative care especially pain control with morphine, truth telling and informed consent hence the patient's care must be started under the patient's will, organizations of the health care system (Ashino et al. 1995).

In a study done in Japan (Kawaguchi et al. 1994) it was shown that some of the problems faced in caring for terminally ill cancer patients at home included: emergency - a sudden change in the

patients' condition. Concerns of the patient and his family increase when the pain is getting worse.

Despite an initial wish to stay and receive treatment at home many people with terminal cancer become inpatients. Brown et al. (1990) found out that the decision to choose hospital care was related to loss of control. There were two dimensions of control mentioned, control in relation to the patients' physical condition and the caregivers' abilities. Hospital care was the 'only other choice' when the patient became too ill, that is, loss of mobility, inability to manage elimination needs and poor pain control. The caregiver felt out of control in situations where they felt they lacked adequate knowledge and skills to care for the patient, caregiver fatigue and lack of home support.

This is in agreement with the Wilkes (1984) study that found out the reasons for admission according to the relatives to be that there was better care at the hospital (41%), the relatives felt physically unable to cope at home (26%), and that the relatives felt emotionally unable to cope at home (19%). He also found out that 7% of the relatives of patients who died in the hospital would have preferred that the death had occurred at home and only 3% of the relatives of patients who died at home would have preferred that the death had occurred in hospital.

## CHAPTER 3

### 3.1. Statement of the Research Problem

Cancer is a disease that creates fear and uncertainty to individuals within our society. This is mainly due to its poor prognosis. It is therefore regarded as not only a fatal disease but also a symbol of death.

Living with cancer and dying from it can therefore, be a painful and traumatic experience.

Patients living with the diseases have to find ways of coping with the situation and be able to live the life a head as quality life. Patient's response to the news of cancer diagnosis is an important determinant of the manner in which they react, positively or negatively. Health workers have the responsibility to instill hope in these patients so that they can live quality life without having to blame themselves, God or their background for their condition.

The way patients in our social set up cope with cancer diagnosis information have yet to be adequately assessed. There is little documented information on how cancer patients within our society perceive cancer as a disease, how they seek medical evaluation of the initial symptoms and cope with their illness, living with it everyday. Without knowing the specific problems and coping mechanisms in our population it is difficult to estimate the extend to which cancer patients in general respond to cancer diagnosis news.

Researchers, therefore, need to provide systematic data that can guide policy makers and health care providers on how to care for patients with terminal illness.

### **3.2. The Research Question**

- How do patients respond to the cancer diagnosis news?
- What are some of the factors that are exhibited by patients who visit the Nairobi hospice institution?
- Where do terminally ill cancer patients prefer to be cared for?

### **3.3. Justification of the Study**

Palliative care and cancer pain control is a public health problem that has been neglected. There is little or no research that has been carried out on palliative care in the Kenyan social context.

Cancer poses a particular explanatory challenge for those afflicted with the disease. From a scientific point of view, the etiology of most cancers has not been established: the disease may strike without pre-warning symptoms and once diagnosed, the course of cancer may be unpredictable and uncontrollable.

Psychosocial considerations are of great importance in understanding the experiences of cancer. Increased awareness of the experiences and needs of patients with a malignant disease will enhance the ability of professional health care workers to provide more effective care to meet the physical, psychological, social and spiritual needs of cancer patients. The purpose of this study was to explore and investigate patients' response to cancer diagnosis and their health seeking behaviour patterns. This study focused on the cancer patients themselves and tried to get views from the patients' perspective.

### **3.4. Study Objectives**

#### **3.4.1. Overall Objective:**

To determine the patients' response to cancer diagnosis and their health seeking behaviour at the Nairobi Hospice.

#### **3.4.2. Specific Objectives:**

1. To determine the patient response to cancer diagnosis information.
2. To identify the trend and some of the characteristics exhibited by TICPs receiving treatment at the Nairobi hospice.
3. To identify factors that influence health seeking behaviour among TICPs.
4. To determine patients' preferences of place of care

#### **3.4.3. Study Hypotheses**

1. Patients' response to the diagnosis of cancer is not significantly influenced by
  - Patients' knowledge of the nature and severity of illness.
  - Patients' knowledge of treatment modalities.
2. All TICPs to be taken care of at home rather than the hospital.

## CHAPTER FOUR

### METHODOLOGY AND MATERIALS

#### 4.1 Study Area

The study was carried out at the Nairobi Hospice. This is an institution offering home based palliative care to TICPs. It is located on the Kenyatta National Hospital grounds. It offers outpatient services, hospital visits to the admitted patients, and home visits to those who are unable to visit the out patient clinic. There are no admission facilities within the hospice center. In order for a patient to be admitted to the hospice treatment program, there must be the presence of an able and willing primary caregiver who is identified by the hospice center.

#### Reason for Choice of Study Area.

Nairobi hospice is the main hospice present in Kenya today. It has been in operation for over ten years. It is a well-established center offering palliative care to TICPs. It is the only one of its kind in Nairobi province and hence caters for patients of different cultures.

#### 4.2 Study Population.

The target population was the TICPS receiving home-based palliative care at the Nairobi hospice. The inclusion criteria were patients with a cancer diagnosis, which has to be confirmed by biopsy results. The patients had a referral letter from the attending physician. The patient should have been able and willing to converse easily. Any physical discomfort was made tolerable by treatment.

#### 4.3. Study Design: Case study

#### 4.4. Study Variables

**Dependent Variables:** these were variables related to the patients' response to cancer diagnosis.

They included

- Knowledge of the disease.
- Response to cancer diagnosis.
- Health-seeking behaviour.
- Place of care

**Independent Variables:**

1. **Demographic factors:** Age and sex, residence, marital status, family size, ethnicity, education, occupation, religious background, home district, diagnosis and the previous treatment received before attending the hospice care.
2. Social, cultural, economic and psychological factors that influence their response to cancer diagnosis with respect to trying to cope with the illness.

#### 4.5. Subject Selection

The patients who were included in the study were purposely selected on the basis of how able they could communicate and their willingness to participate in the study. Under the guidance of the hospice medical staff, the investigator identified the study subjects. The investigator took one week to review the records and familiarize herself with the patients. A total of 11 patients were interviewed. The patients were then classified according to the site / type of cancer suffered. Following the initial meeting each patient was assessed regarding his / her suitability for the



study. This depended on the patient's ability to communicate, knowledge of the disease, willingness and ability to articulate his/her experiences.

#### **4.6. Data Collection**

The required information was collected from the TICPs through the following means:

1. Qualitative, participatory method of data collection using in-depth interviews. These were put into narratives. The interviews were tape-recorded for patients who were willing to have it tape-recorded. The questions were both open-ended and closed-ended. Questions were asked about the patients' knowledge of the disease and of palliative care, belief about cancer, satisfaction with care provided, help required by patients with the activities of daily living and the patient's symptoms.
2. Focus group discussions of selected group of patients.
3. The records were used to identify the trend of patients seen at the hospice and the socio-demographic characteristics exhibited by some of the patients. Records up to the ten-year period were used (1991-2000).

The objectives of the study were explained to each subject. It was made clear that the participation was voluntary and that any information given was confidential. An appointment was made on a day and venue convenient to the subjects. The venue was either the hospice outpatient clinic or the patients' home. The study subjects were given appointments for the day of the interview.

Since a total of 11 patients were included in the study, the principal investigator conducted all the interviews. This was to minimize the errors and biases. Some of the interviews with the

patients' consent were tape-recorded. Tape-recording was not done to patients who objected to their interviews being tape-recorded. Pictures were also taken in case a point was to be emphasized in that manner.

#### **4.7. Ethical Considerations**

Cancer diagnosis is a very sensitive topic. The disease onset is considered to be a very overwhelming personal experience. It evokes an intense emotional response in the patients and those closely connected to them. If cancer patients are to be used as research participants, there are numerous ethical issues to be considered, such as the right to privacy, confidentiality, informed consent and choosing which information to include and which to exclude from the study.

Participants were approached individually regarding their inclusion in the study. They were told that the information they gave was highly confidential. Interviews between the patients were carried out privately and separately.

#### **4.9. Data Processing and Analysis**

The field notes, recorded tapes and pictures taken provided extracts on specific data to be used during data processing and analysis. Different analytical techniques were used depending on the type and method of data collected and the variables to be analyzed. The data collected using FGDs and in-depth interviews was processed immediately after each session. The information that had been tape-recorded was transcribed as soon as possible (within 24 hours). In the process of constructing the case studies, all the raw data for each case study was assembled to construct a case record. This was then used to write transcripts of a case narrative for each case study. The

data on the transcripts were then labeled and then broken down into different categories. The format used was narrative, family tree and the important points for discussion.

SPSS-package was used to analyze the structured questionnaire. This was aimed at identifying the trend of patients seen at the hospice over the ten-year period (1991-2000) and identifying some of the socio-demographic characteristics exhibited by the patients seen.

## CHAPTER 5

### STUDY RESULTS

#### 5.1. Quantitative Data

A total number of 2992 cases were recorded over the 10-year period from 1991 to 2000. Only 2938 cases had their ages recorded while 54 cases had their ages missing. Gender was recorded for 2970 cases and 22 cases had their gender missing. The male to female ratio of the recorded cases was 1 to 1.6 and 39 % were males while 61% were females. Diagnosis was recorded for 2951 cases.

There has been a general increase in the number of patients seen at the Nairobi hospice since inception. This is shown by the steady increase in the recorded cases. This continues up to 1996 where the cases seen flatten off for three years and then the recorded cases begin to reduce (Table 4). Few cases were seen between the 0-14 age brackets. Most cases seen were 31 years and above (Fig.1). The most common cancers seen according to diagnosis by site were breast cancer (20.7%) followed by cervical (16.8%) and then head and neck lesions (16.1%) (Fig. 8).

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Due to the inadequacy of the data, analysis of the other socio-demographic variables was done according to the records of the two-year period 1999 and 2000. Most patients seen had attained the primary level of education, 43.5% followed by the ones with no education at all 28.4% and the secondary level 23.8%. The least patients had college level of education 4.3% (Fig 4). Most of the patients were married 64.9%, followed by the ones who were widowed 16.2% and single. There were few patients in the divorced category 16.2% (Fig. 3). Most patients were housewives (22.9%) followed closely by the ones in the salaried category 20.2%, (Fig. 5). The Christian faith was predominant among the patients (Fig 6).

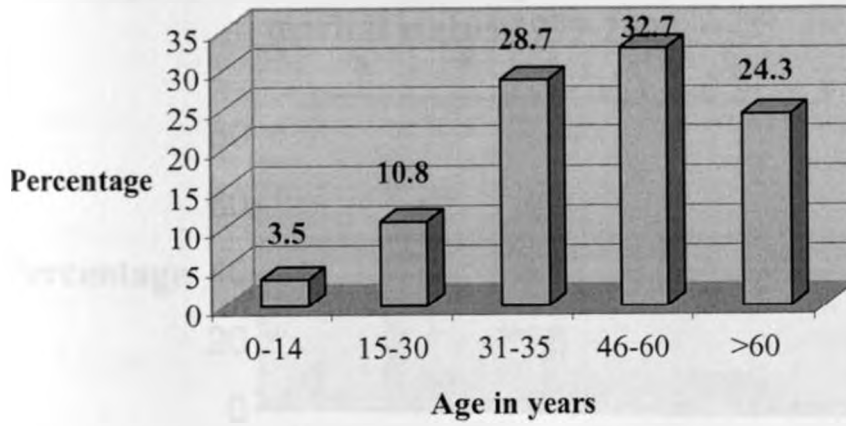
Majority of patients were from Central Province. Nairobi Hospice is based within the city center and is bound to see patients from all over the republic. However, since it is within Central Province and it has no in-patient services it is bound to see more of the patients from within the Central Province and its vicinity (Fig. 7). Most patients seen at the Nairobi Hospice had never had any of the three modes of cancer treatment 27.6% (Fig. 10).

Province	Number of Patients	Percentage
Central Province	110	42.3
Western Province	80	29.6
Eastern Province	60	22.3
Other Provinces	50	18.8
TOTAL	260	100.0

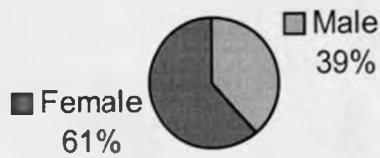
**Table 4: The trend of patients seen over a 10 year period 1991-2000**

<b>YEAR</b>	<b>NO. OF PATIENTS</b>	<b>PERCENTAGE</b>
1991	132	4.4
1992	131	4.4
1993	186	6.2
1994	230	7.7
1995	321	10.7
1996	421	14.1
1997	433	14.5
1998	430	14.4
1999	347	11.6
2000	361	12.1
<b>TOTAL</b>	<b>2992</b>	<b>100</b>

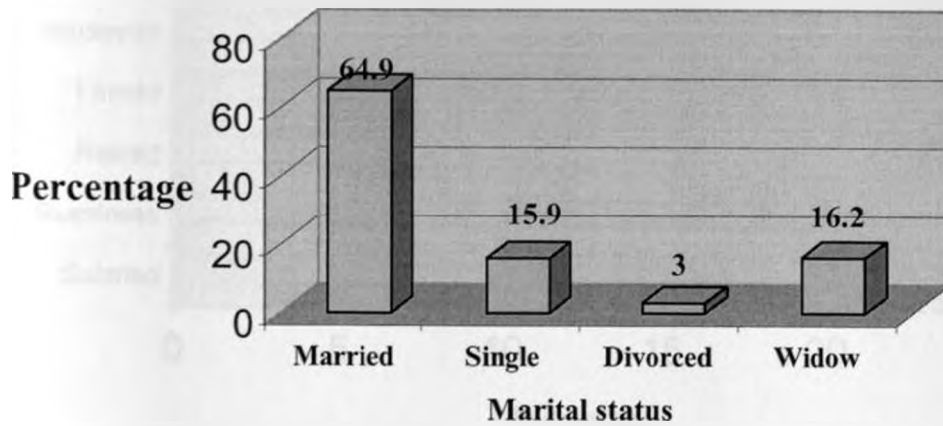
**Figure 1. Age distribution of patients seen over the 10-year period**



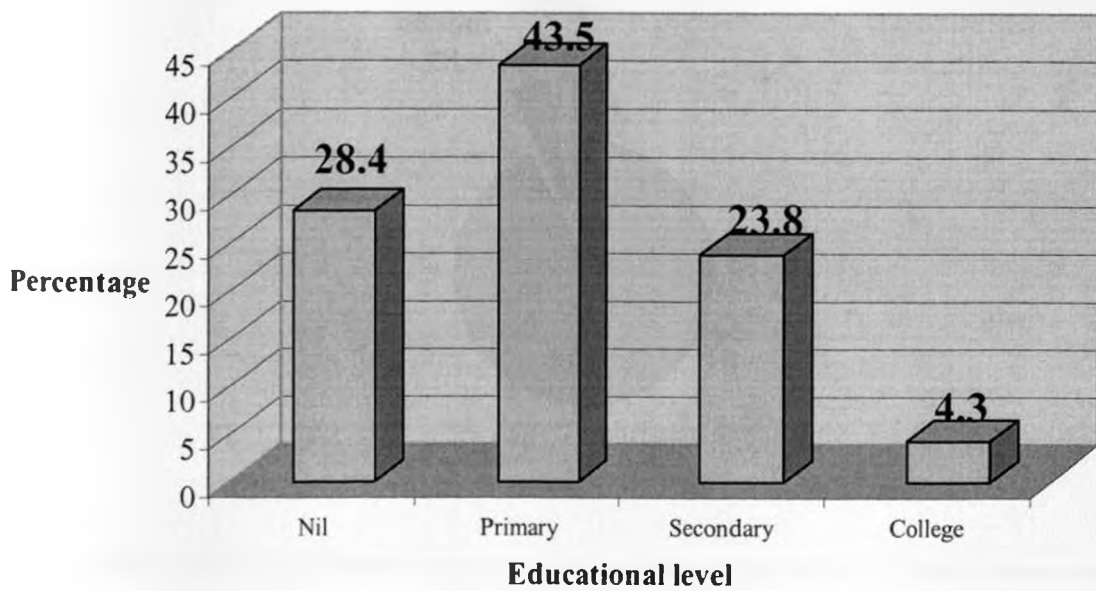
**Figure 2. Sex distribution of patients seen over the 10-year period 1991-2000**



**Figure 3. Distribution of patients according to marital status 1999-2000**

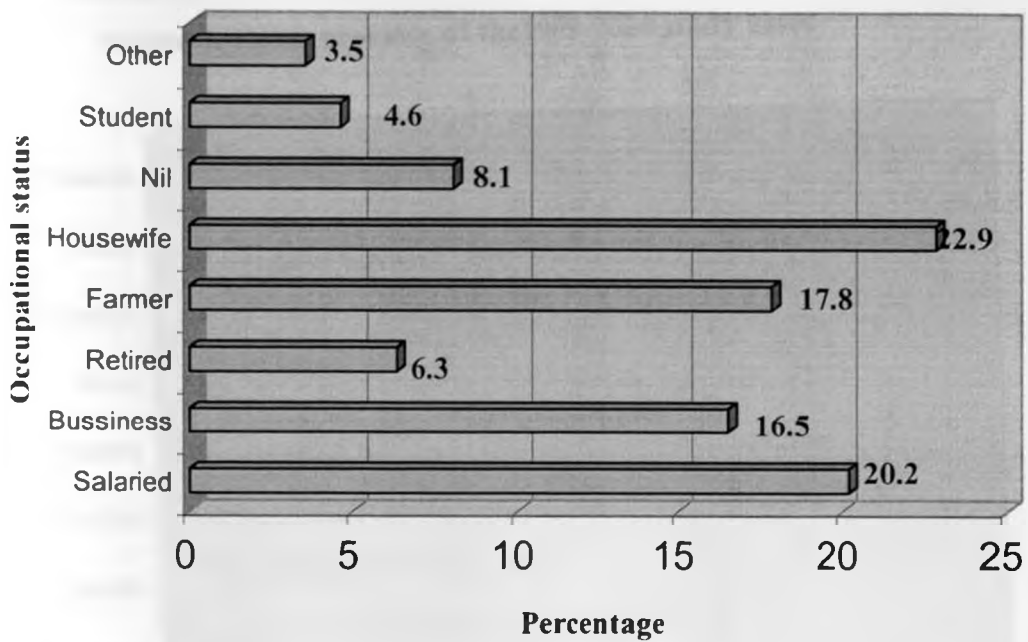


**Figure 4. Educational background of the patients seen 1999-2000**

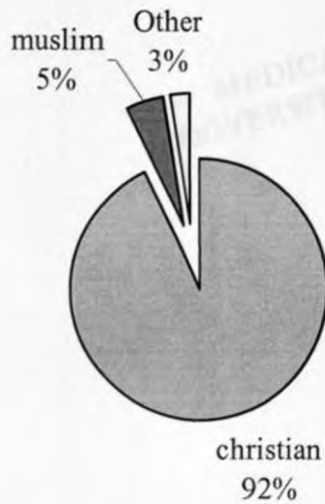




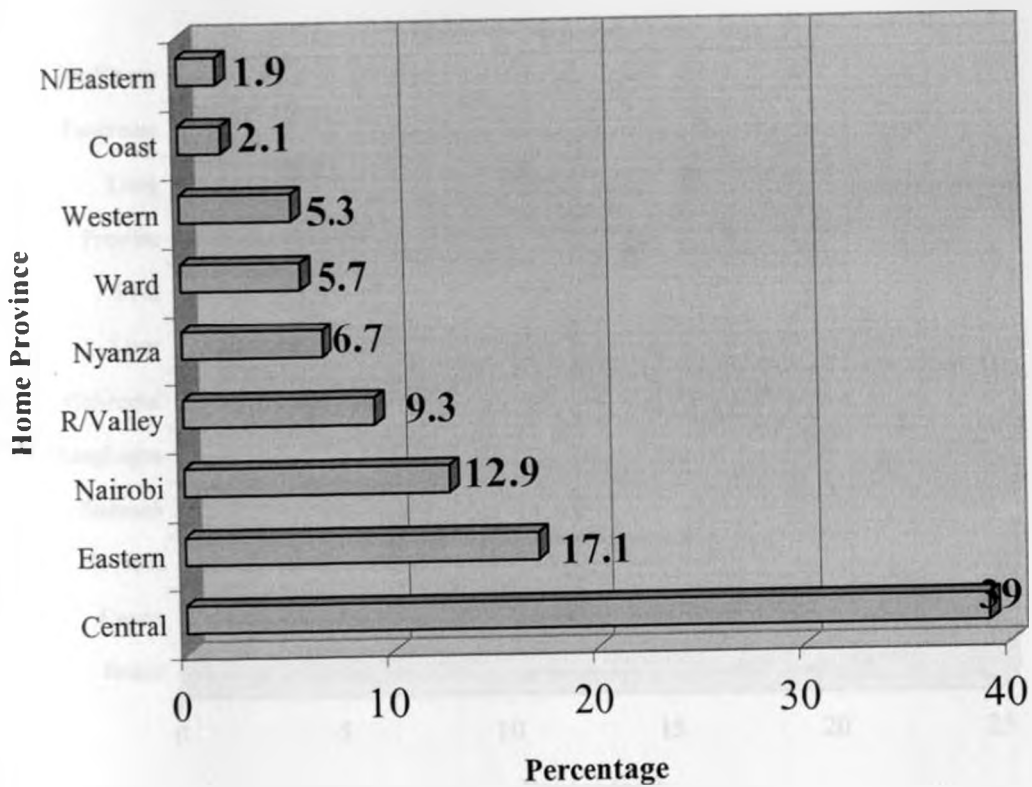
**Figure 5. Occupational status of the 1999-2000 study cases**



**Figure 6. Religious Backgrounds of the 1999-2000 study cases**

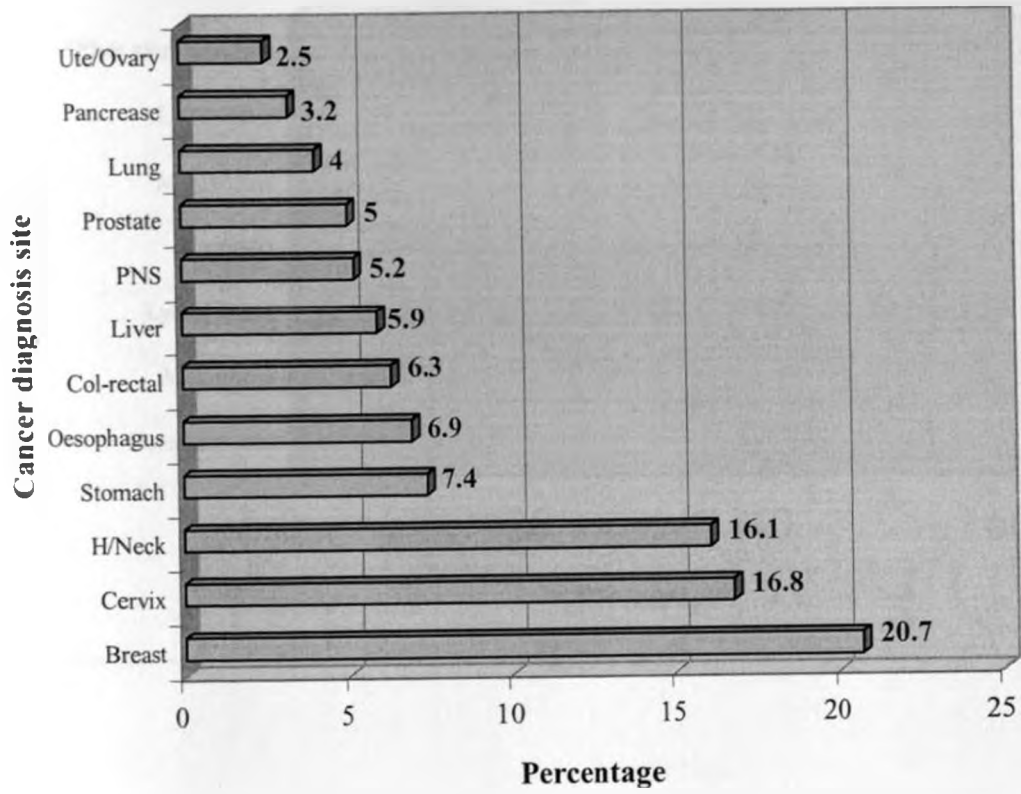


**Figure 7. Home province of the 1999-2000 study cases**

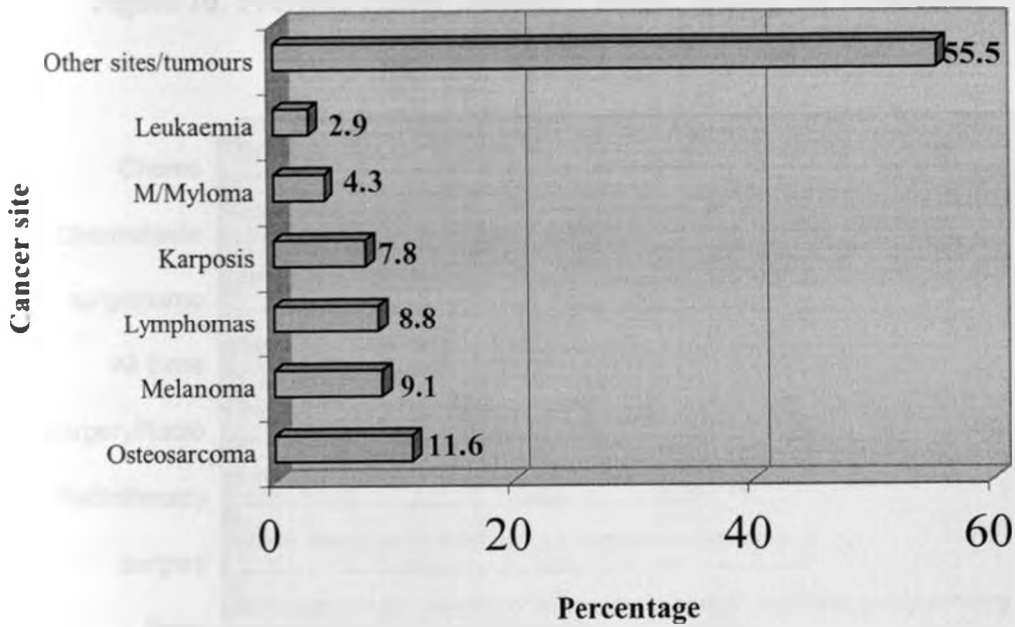


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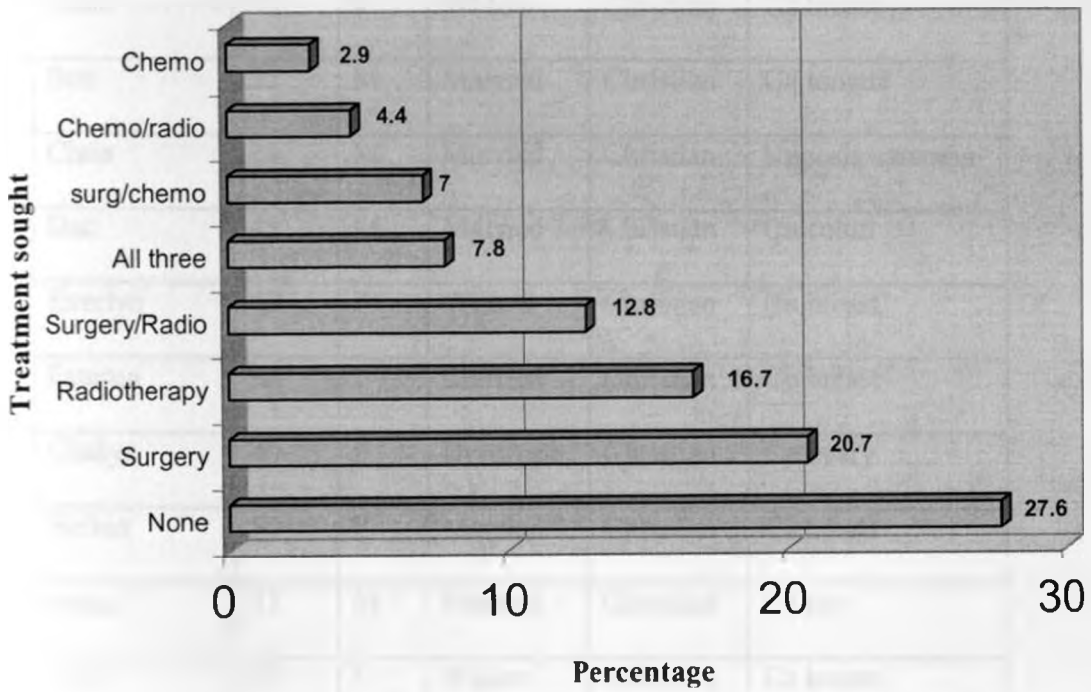
**Figure 8. Cancer diagnosis by site for the 10-year period**



**Figure 9. Cancer diagnosis by non-specific site 1991-2000**



**Figure 10. Previous cancer treatment sought among the 1991-2000 study cases**



## 5.2. Narratives from Patients.

**Table 5. Summary table of the general characteristics of the case study respondents.**

No.	Code Name	Age	Sex	M/status	Religion	Diagnosis
I	Anne	55	F	Widow	Christian	Ca breast
II	Ben	32	M	Married	Christian	Ca tongue
III	Chris	24	M	Married	Christian	Kaposi sarcoma
IV	Dan	48	M	Married	Christian	Ca colon
V	Everlyn	49	F	Widow	Christian	Ca breast
VI	Fatuma	52	F	Married	Christian	Ca breast
VII	Gladys	40	F	Divorced	Christian	Ca ovary
VIII	Hellen	50	F	Married	Christian	Ca breast
IX	Ismail	27	M	Married	Christian	Ca jaw
X	Janet	69	F	Widow	Christian	Ca breast
XI	Kamau	46	M	Married	Christian	Ca tongue

## CASE I:

Anne, (not her real name), a 55-year-old widow and mother of four was diagnosed with cancer of the breast in 1999 and underwent surgery the same year. She had come to the hospice to return the referral form. I had seen her sitting at the reception for quite a while and so I enquired what her problem was. I then asked her to follow me to the examination room where she told me that she had brought back the referral form and needed some assistance. Further probing revealed that she had a growth in one of her breasts, which was operated on in 1996. At the time she was on hormone therapy, which had become too expensive. Her daughter had a similar problem of the breast. She had a lump that was operated on in the year 2000. The medical expenses were becoming too much for her as a widow. The husband had died ten years earlier. The daughter had separated from the husband and had three children.

"So how would you like us to assist you?" I implored.

"I want to be coming here for medication since I cannot afford to see the doctor who has been attending to me." I asked her to come back after two days so that I could open a file for her. She then broke down and started crying. I asked her why she was crying and she replied, "I am not sure. I just felt like crying. I am not in pain or anything but just felt like crying." I asked her to follow me to a quiet room where I could talk to her privately. When she got composed I asked her to give me a short history of her problem.

"My problem started early in 1998 with a small growth in my right breast. I felt it but ignored it thinking it was nothing serious. I thought it would go away but it did not. After several months, I became worried. The swelling though painless, was getting bigger and bigger instead of disappearing." I then decided to seek medical advice. "The first doctor I visited told me that it was nothing serious. He said that I should not worry and that the swelling would go away with

time. He then gave me some medication to use. In spite of the medication, the swelling still persisted and did not go away. I went back to the doctor. This was around the month of December 1998. The doctor told me to go back after Christmas so that he could refer me to another doctor. He again gave me some medication to use in the meantime. I was not satisfied with this doctor. I wondered why he could not refer me straight away to this other doctor? Why wait till after Christmas?"

"Although I was not in pain, I got determination to find out what my problem was. I talked to a friend of mine who is a nurse about the problem. She became concerned and asked if she could examine me. After the examination, she told me to see a doctor immediately. She referred me to her doctor. I went to see the doctor who took some fluid from the growth for examination and told me the results were bad, and that I should undergo an operation immediately. I went back to my employer and explained everything to him. He told her that his wife had a similar problem and her breast had been removed."

"My employer then sent me to his doctor. His doctor confirmed the diagnosis and I was admitted immediately in the hospital. The breast was removed and now the place has healed." She paused for a moment and then continued.

"The big problem is my daughter. She also has the same problem. Early last year my daughter told me that she had something in her breast similar to the one I had. I was very shocked and asked her to have it examined. After a few months she told me that it was disappearing. One day as we took her child to the hospital and I insisted on finding out whether whatever she was telling was the truth. I examined her breast and found out that she was lying to me. I asked her to go to Kenyatta National Hospital and have it examined immediately. It was found to be cancer and was then operated on in October 2000."



Anne thinks that her daughter's operation was not done properly. "First it was not stitched the way mine was done, it was clipped. There was a big muscle layer above and below the operation line. When we went for the clips to be removed, they forgot to remove one. I used to take my daughter for daily dressings of the wound. It was a very bad experience. I asked the doctor if at all the healing would take place but he did not give me a definite answer. He said it might heal but the wound did not heal. Worse still the area got infected. I became concerned and asked the doctor if it could be operated again, especially to align the muscles. He told me that the infection had to be controlled first. Finally she went in for the second operation and it is now healing well. She now attends the out patient clinic at KNH." Her main problem is now financial. She wants some assistance to get medication. She also wants her daughter to be coming here. I informed her that was possible and that she could bring the daughter anytime she wished. As we were leaving she told me that she knew some of the staff around because she used to bring her sister who had cancer of the cervix and died in 1996.

The next time I met Anne was after a few days and this time I wanted to explore her knowledge of cancer as a disease and her response to the cancer diagnosis.

"In speaking of cancer as a disease, what do you think is the cause?" I enquired from her.

"Cancer is normally in the family. Sometimes it can be due to some foods but I don't know which ones specifically." She replied.

"In your case, can you identify the cause of your problem?" I probed further.

"I had a problem after I delivered my last two children, she went on to say. I used to produce a lot of milk during my breast-feeding period. The milk was so much that the baby could not cope with the large quantity. I tried squeezing it out and putting it in a bottle for the baby to feed but that did not help. The milk was so much that my mother-in-law had to make some incisions on

the breast to release the pressure, (She showed me the incision scar on one of her breasts). I think that is when the problem began.” Anne’s last two children are 29 and 26 years old. This implies that she thinks that her problem began over 29 years ago.

Anne understands that cancer is not contagious or communicable. She knows about the three forms of cancer treatment, that is surgery, chemotherapy and radiotherapy. She has undergone both surgery and chemotherapy. On finding out if she understood how cancer spreads to other body parts she replied, “it moves to other areas. My sister was not operated on since the cancer had spread. Cancer once touched can spread very fast. It is like putting *Omo* detergent in water and bubbling it. The way it bubbles is how cancer spreads to other areas.”

She knows some of the measures to be used in prevention of cancer. This includes avoiding alcohol and smoking, and undergoing regular medical examinations. She gets most of her information about cancer from hospital staff, newspapers, magazines and she is a member of a breast cancer support group.

“How did you feel when you were initially told of the cancer diagnosis?” I enquired from her.

“I cried a lot, She replied. I have been through a terrible experience before with someone close to me who ended up dying due to cancer. My husband died in 1991. At first we thought he had ulcers and had been on treatment for ulcers for quite sometime, but then it turned out to be cancer of the stomach. The doctor who was seeing him said he needed to do an operation on him to determine exactly what the problem was. He was then admitted for the operation. During the operation, they found cancer in the wall of the stomach. The doctor called me after the operation and informed me of the diagnosis. He had found the cancer inoperable and left it in place. He

stayed in the hospital for one week. The doctor advised us to seek hospice care/home care. A day before the discharge date, I was at his bedside when he developed a breathing problem, he could not speak. I called the doctor and when he came in and saw him, he asked me to wait outside. My husband then died as I stood outside.” She paused for a while and then continued, “In 1995 my sister was diagnosed with cancer of the cervix. She only underwent radiotherapy treatment. Surgery could not be done since the cancer had spread. She was then put under hospice care up to 1996 December when she died. When I was told of my diagnosis because of the bad experience I had undergone, I cried a lot, I was confused to the extent that I was almost hit by a vehicle as I went home. I then started praying a lot in Church and the women groups. I went for confession and took the sacrament.” “After 3 days other women from the Nairobi Baptist Church, who had had their breasts removed due to cancer came to visit me. They gave me a words of encouragement so that I could undergo the surgery and invited me to their monthly meetings.”

This women’s group has been a good encouragement to Anne since it has helped her find a way of coping with her illness and the loss of her body parts. Due to the illness, she is unable to read because of too much sleep. She lacks the energy she used to enjoy in the past.

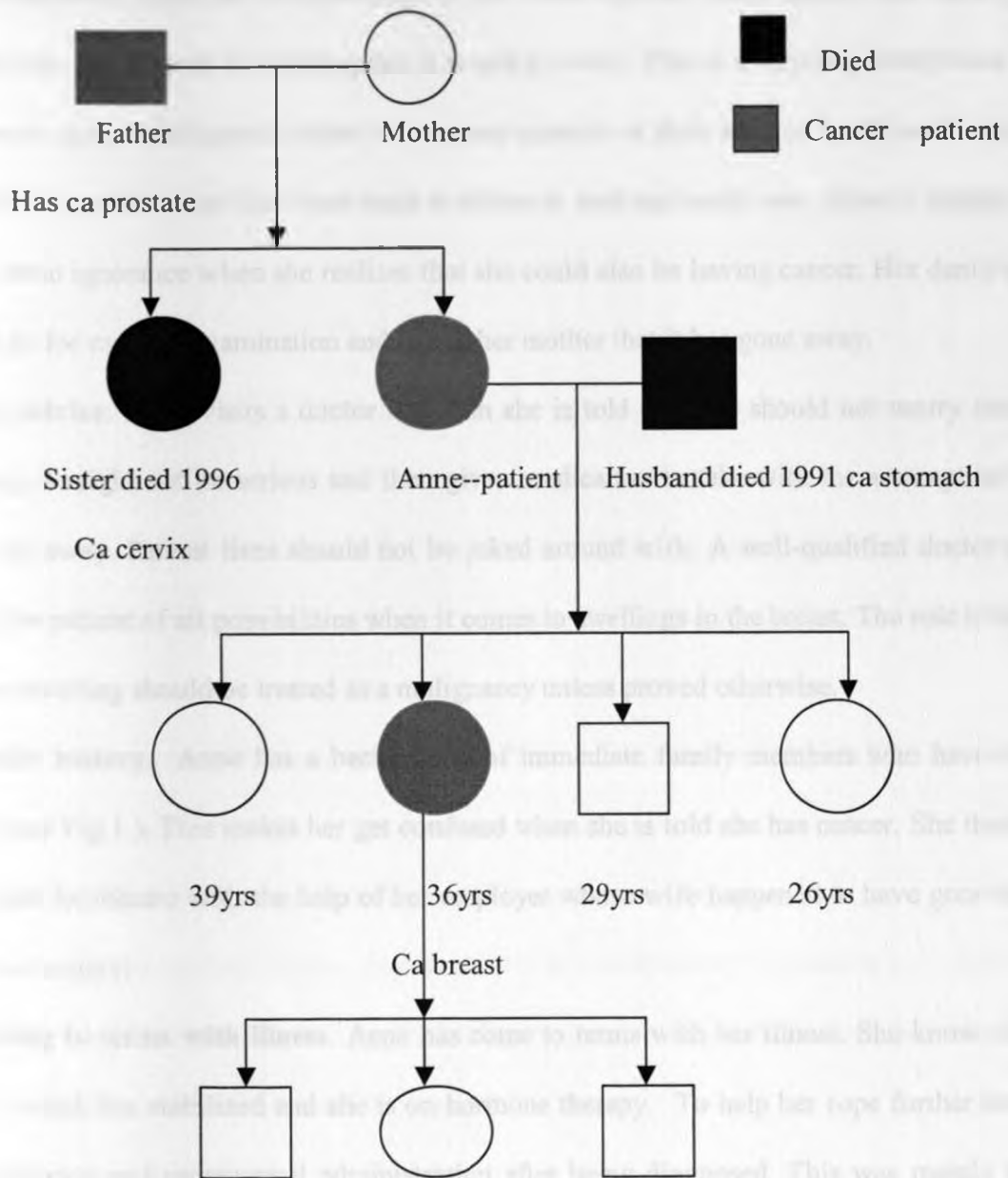
“What do you plan for the future?” I enquired from her. “I have no big plans at the moment because I do not have money. She replied. I wanted to put up houses, which I could rent out, but money has been the problem. My prayer is that God may help my daughter get better.”

“What do you know about the situation of your illness now?” I probed further.

“I am stable now. She responded. When I go to Kenyatta National Hospital and I see other patients who are also very sick, I see myself as better off. Some other patients who underwent their operation after me have already died.”

Anne knows that she is receiving symptom control at the Nairobi Hospice and that is all she expects. She knows some forms of alternative treatment, which she is taking. This includes taking some honey, 5 spoons of whisky per day, special leaf and juice extracts. She prefers homecare to hospital care. Hospitalization is expensive and will require money. She would opt for hospital only when she becomes ill to be cared for at home. .





**Figure 1. Family tree of Anne.**

**Issues emerging.**

Some of the factors, which affected Anne response to cancer, include the following;

**1. Unawareness.** Anne had no knowledge of the initial signs of breast cancer. She felt a growth in the breast and ignored it, thinking that it would go away. This is a very important factor when it comes to delay in diagnosis. Most women are ignorant of their state of health with respect to the initial signs of cancer and these leads to delays in seeking health care. Anne's daughter also shows some ignorance when she realizes that she could also be having cancer. Her denial makes her not go for medical examination and lies to her mother that it has gone away.

**2. Poor advice.** Anne visits a doctor and then she is told that she should not worry about the swelling. It might not be serious and then given medication to take with the assumption that it would go away. Patient lives should not be joked around with. A well-qualified doctor should inform the patient of all possibilities when it comes to swellings in the breast. The rule is that any painless swelling should be treated as a malignancy unless proved otherwise.

**3. Family history.** Anne has a background of immediate family members who have died of cancer (see Fig 1.). This makes her get confused when she is told she has cancer. She then seeks immediate healthcare with the help of her employer whose wife happened to have gone through the same surgery.

**5. Coming to terms with illness.** Anne has come to terms with her illness. She knows she has cancer, which has stabilized and she is on hormone therapy. To help her cope further she went for confession and sacramental administration after being diagnosed. This was mainly for her peace of mind. She had visits from Churchwomen groups and those who have had a similar experience. Her major concern though is that of her daughter who has undergone surgery because of the same illness

**6. Limited Finances.** Mrs. Anne now is in a financial drain situation. She has retired from her job. Her daughter has had surgery and is also on medication. She has to support her three

grandchildren. She then resorts to the Nairobi hospice since she knows it is a charitable organization that might assist her in terms of medication.

**7. Worry transfer.** From the mother to the daughter.

**8. Misinformation and mismanagement.** By the health provider.

## CASE II

I had done a patient assessment on Ben (not his real name) and the brother. During the interview Ben came with the wife so I interviewed them together. Ben is a 41 years old man with a diagnosis of cancer of the tongue. He has three children; one son and two daughters aged thirteen, twelve and seven years. At the moment due to his illness, he has been unable to work.

Ben says he understands what he is suffering from and that he knows that it is cancer of the tongue. He is not sure of whether it has spread to other areas.

“What do you think is the cause of the cancer?” I enquired.

“I don’t know.” he replied. “Some people say it is due to drinking or smoking but I have never smoked in my life. Others say it is in the family, but it is not in our family. My parents are okay and there is nobody who has been sick of cancer.”

“Some people say it is inherited,” interjected the wife.

“But from where?” he replied. “My father does not have it; my mother does not have it, now from where, eeh! Where did I get it from?”

“Maybe you could have inherited it from your forefathers.” Insisted the wife.

“That would be wrong.” Ben interjected.

Ben and the wife understand that cancer is not contagious or communicable. His wife is also comfortable taking care of the husband because she understands that it does not spread that way.

“Tell me a short history about your problem.” I asked.

“My problem started in June (the year 2000). I went to the Seventh Day Adventist clinic for a check up since that is our church clinic. The doctor I found examined me and referred me to an Ear Nose Throat (ENT) surgeon. When I went to see the ENT he took a sample of the swelling and had it examined at the Nairobi hospital laboratory. I went back for the results after one week and it was found to be cancer. The ENT then referred me to an oncologist. The whole process took around a month. Before that we did not know about it.”

“Can you tell me about cancer treatment and the treatment you have received?” I continued to explore.

“We only know about radiotherapy since it is the only one which I have undergone.” Ben replied, “We are not sure about surgery. About chemotherapy: the doctor wanted to start but I still do not find it necessary. I don’t think I have reached the stage where I need it. The doctor wanted to do surgery but we found it to be too expensive. That was before he sent us for radiotherapy. He wanted to open up the jaw from the front, get another doctor to open and subdivide the tongue. The thing is that he was not sure whether the surgery would finish the whole problem. He was also not sure of what he wanted to do. He also did not guarantee us that the surgery would solve the problem. I did not want to risk my money, and the doctor was not sure of what he wanted to do. It was going to be too expensive and the doctor did not guarantee us of the results.” He paused for a moment and then he continued.

“For now, after radiotherapy we are not sure whether the growth is still there. Nobody has checked to tell us exactly how far we have gone with it. The doctor wanted to do chemotherapy



but still I had a problem with swallowing. I took time off in seeing the doctor and having the chemotherapy because I wanted to see how I was going to get along with the food. On the other hand chemotherapy was also too expensive.” He smiled and continued, “these days when you are not working you cannot say yes to anything that comes your way. You might end up not finishing the treatment. I will try to see the doctor for follow up but seeing him is also money. His consultation is Ksh 1000.”

“The swelling was big before the radiotherapy but now it has become smaller,” added the wife. “Before we started the radiotherapy treatment I could see it when he opened the mouth. I think it has been controlled somehow.”

Ben and the wife are not sure if cancer spreads or if it can be prevented. They get their information about cancer through the hospital staff, family members and friends.

“Do you read any literature with regards to cancer?” I asked them.

“I have not read books,” replied Ben. “Some people make you have fear. They make it look so serious that you feel you won’t be able to live for another week or month before you collapse and die. You cannot read more about it because you think you are already finished.”

“Even people who come to comfort you tell you that you have a short time to live,” said the wife. “We are even wondering because since August last year, we had been told that he won’t be able to finish two months,” she said with laughter.

“I did not even check pamphlets because I thought I did not have time,” said Ben. “I do not need to know more because you are told there is no time. People around you are the ones who would make you want to know more. If you are not sure of tomorrow, why do you need to know more about it? Why do you need to know more about it when you are told that by next month you will be gone (dead)?”

“Coming to the hospital was also a problem,” the wife continued to say. “He was saying that since he has a short time to live, what is he going to do there? We would be spending money for nothing.”

“You don’t have to check the pamphlets because they are of no use to you”, he continued. I did not even want to be in hospital because I thought I had a short time to live. If you have less than a month and they are not sure it might even be less than that, why do you need to go to hospital and spend the little money you have?”

“We all have friends we are not sure of,” Mr. Ben went on to say. “The time they see you, they start asking *how is that man still getting around?* They stop coming to see you because they are afraid of you.”

“They look at you from a distance,” the wife said. “They see you still walking around and they wonder how and why? When they come to see you in hospital they want to confirm whether you are going (dying). Even people whom you have never seen before come just to see you to confirm.”

“They want to be sure whether the cancer you have is the same cancer they have heard of,” said Mr. Ben. “You even fail to understand whether you have cancer or it is something else. The friends who told you about your illness had told you that with cancer you couldn’t finish a month. You go past that month and they now wonder what is happening. You then fail to understand how to communicate with such people because they want to be sure you are going. They don’t come to tell you ‘pole’ and that you will be okay. They tell you *do you know you have a short time to live? From now anything can happen to you.*”

“How did you feel when you were initially told of the cancer diagnosis news?” I continued to probe. “I just accepted it because I was not sure of who is telling the truth. I was not sure that I

have the cancer or it is something else they are bringing up and trying to make it into cancer. I am telling you; with cancer you cannot finish a month. At times you fail to accept that you have cancer. I even now feel that it might be another thing altogether, only that they have not found the actual diagnosis that is proper for me.”

“I felt as if the world was coming to an end,” said the wife. “With time I became stronger.”

“Initially I could see around twenty people coming to the house to see him,” she went on. “Some come just to see how one is.”

“To be sure you are going,” Ben adds.

“They want to confirm whatever they have heard,” the wife went on to say. “Others exaggerate that he cannot even swallow saliva.”

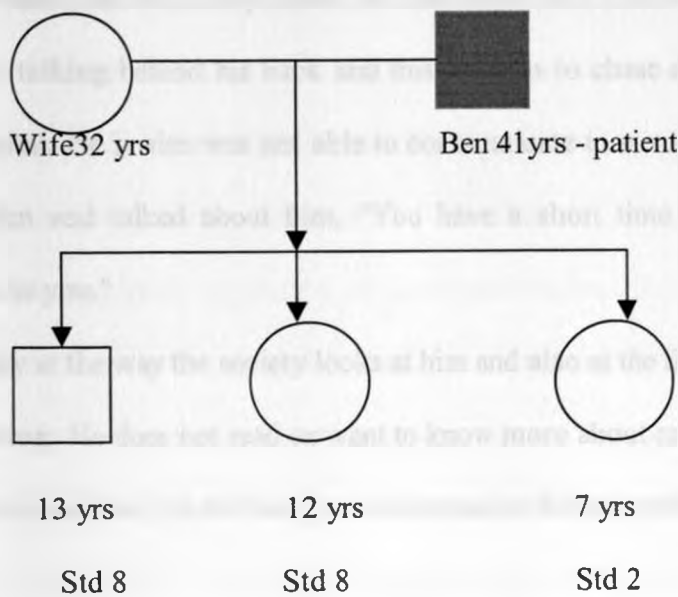
“You are a dead man moving,” Ben joked. “I even used to chase away visitors at the hospital. They were coming for fun and not because they felt sorry for me. There were so many people and I did not want them to waste their time coming to see me. Not all friends like you.”

Due to the illness, Ben is not able to work as before. He feels he has a short time to live hence he cannot think of working. He cannot go asking for employment knowing that tomorrow he is going to die. Still Ben has not lost hope with himself or in life. “I don’t think that it is really cancer that I have,” he goes on to explain. “I want to see how my children will grow up. I really do not think it is cancer as they call it, he laughs. I am becoming stronger daily.”

Ben knows he is receiving symptom control at the hospice mainly pain. Otherwise he doubts he has cancer. Hospice care has improved the way he is feeling. His pain is controlled at the moment. He is able to feed properly. He believes that if the pain around the neck and the swelling are controlled he will be able to swallow without a problem.

Ben prefers to be taken care of at home than in the hospital because he receives good care. The doctor wanted him to stay in hospital until he was able to swallow but he realized that it would be too expensive. He can only choose to go to hospital when he is too ill.

### Family tree



**Figure. 2. Family tree for Ben.**

### Issues emerging.

**1. Denial.** Ben is in denial at the moment. On asking him what he is suffering from he says he has cancer of the tongue. At the end of the interview, he gives me the impression that he does not believe whatever he has is cancer. According to him someone with cancer cannot stay alive for more than one month. Hospice therapy has been able to control his pain and now he believes he is getting better. This really convinces him that he doesn't have cancer.

**2. Financial constraints.** This has limited his undergoing specific treatment modalities especially surgery. He found it too expensive. The doctor's advice was also not very convincing. He says that the doctor did not guarantee him that the surgery could solve the problem. The surgical procedure also scared the patient away and the fact that several doctors were to be involved in the surgery.

**3. Fear of cancer.** Some people made him have fear by telling him that he has a short time to live. People tend to have fear when they know one has cancer and associate cancer to death. He thought people were talking behind his back and this led him to chase away whoever came to visit him at the hospital. He is also was not able to communicate to some people because of the way they look at him and talked about him, "You have a short time to live, from now on anything can happen to you."

**4. Anger.** He is angry at the way the society looks at him and also at the illness he has.

**5. Information seeking.** He does not read or want to know more about cancer since he thinks he has a short time to live and that this will not provide a solution for his problem.

### CASE III

Chris (not his real name) is a 24-year-old patient with a diagnosis of Kaposi sarcoma of the left foot that is secondary to HIV infection. He is married with three children. He got an education only up to the primary level. He understands that he is suffering from cancer whose primary site is the left foot. He does not think that the cancer has spread to anywhere else. He does not know of any cause of cancer but was told by the nurse that it is something that occurs naturally. Further probing revealed that meat diet could be the cause of the cancer. During his childhood, meat was not part of their diet. He started eating meat, as an adult, when he came to Nairobi to visit his brother and he thinks that is the cause of his illness. To him cancer is not contagious.

“Can you tell me a short history about your illness?” I asked him.

“I started having problems with my leg during the month of October 1999. The left foot was very painful and hence I could not wear my shoes. By December the problem became very severe, there was a boil, which had since formed, and it was very painful. I went to KNH to seek medical care. After examination a biopsy was taken. I was then referred to a private clinic in town where I took the biopsy for examination. A blood sample was also taken for examination. I was then told to go back after two weeks for the results and then take them to KNH. After two weeks I went back for the results, which had been put in an envelope, but did not take them to KNH. I just went straight home. I did not open the envelope since it was sealed.”

“Why did you not open the envelope to read the results?” I enquired.

“I was scared of what the results would read.” He replied. “I stayed with the results without opening for sometime. By then, the growth was continuing to be bigger and more painful. A doctor friend of mine came to visit me and asked to read my results. He told me that I had cancer of the skin. He suggested that I pay him Ksh. 3 000 so that he could give me some medication. I

paid him Ksh 2000 so that he could start the treatment. He gave me two courses of medication but I did not improve. My friends started telling me that I had been *bewitched* and that I had stepped on something bad. I then decide to go home to look for alternative treatment from the herbal doctors. While at home my father took me to a herbal doctor who came up with the diagnosis that I had stepped on something bad. He gave me two types of medications. One was in form of liquid, and the other one for massaging the wound on the leg. I was to use the medication for three days and then go back if there was any change. After the three days there was no change so I did not go back to see him again.”

“How much did you pay the doctor?” I asked him.

“We paid him Ksh 1000. A relative came to tell me about another herbal doctor. We traveled with my father to see him. After examining, me he came up with the diagnosis that I had been bewitched. We gave him Ksh 200 so that he could go and look for the medication. The following day my father went to collect the medication. The medicine was to be applied directly onto the wound. The medication after application started eating away the muscles of the wound and making it rot and produce a foul smell. This was a very painful experience. My parents were happy since they thought that the wound was healing and that the sickness was coming out.”

“On the contrary, I was suffering. The pain was just unbearable. The wound was bleeding a lot and the foul smell produced was too much. My father then went to see the *'mganga'* so that he could tell him the progress. The *mganga* said that the medicine was working well and gave him some more. I declined to use this medication because of my previous experience. After serious thinking I decided to go to the hospital where they would at least control the pain. I then traveled to Homabay to my uncle's place. From there we went to Homabay district hospital. By that time the leg was very swollen, the whole leg up to the thigh. It was also very painful especially to

touch and any slight movement. I was carried up to the hospital where I was admitted. I stayed in the hospital for one week without any medical attention. When my mother came to visit me, she was disappointed that nothing had been done for me so she requested that I be discharged. From there we went to Kakamega hospital where I was again admitted,” he continued to say. “I was given an injection, two bottles of intravenous fluids and then discharged. I was then to be attending the clinic where I was to be given weekly injections. I went to my brother in-laws, who stayed near the hospital, where I stayed for one month. We then came back to Nairobi. After one week the pain intensified and I had no appetite. I then came to KNH where more tests were done. I was then given medication and told to be attending weekly clinics, which I still do attend up to now.”

“How did you come to the Hospice?” I implored.

“Some Catholic nuns who used to visit me and give me painkillers, bandages and hydrogen peroxide for cleaning the wound brought me to the hospice. Hospice medication is good since it strongly relieves the pain.”

Chris is aware that he has cancer and that it is not curable.

He is also aware of the three modes of cancer treatment, surgery, chemotherapy and radiotherapy. He has undergone chemotherapy and he is still receiving the treatment. He asked if they could do surgery but they said they could only give him chemotherapy. He is aware that cancer spreads through the blood system within the body. He is aware of some of the known measures one can undertake to prevent cancer, especially lung cancer that is prevented by avoiding smoking. He gets most of the information about cancer from the hospice staff.

When he was told that he has cancer, he felt very bad since he had heard that the disease is untreated in Kenya. At the moment he is not able to go to work and does not know when he will



go back. He has to rely on his wife for support. He is glad that his wife is from a different tribe otherwise if she were a Luo she would have left him.

Chris thinks that he will get better with time. There was a time he was unable to wear his trousers but now with the treatment he is receiving he can wear them. At the moment he does not think of his disease all the time. He has come to accept the situation and to live with it. He is aware that he is receiving symptom alleviation especially pain at the hospice.

He would like to be cared for at home where the environment is familiar. His wife can take care of him and visitors are not restricted. He also hates the smell of hospitals.

I talked to one of the staff about Chris and I was informed that he had just given me half his story. His Kaposi sarcoma is secondary to HIV infection. When he went back to pick his results he read it and found he was HIV +ve. That is why he did not go back to KNH after picking the results. Secondly, Chris has changed his name and given himself a new name.

I asked him why he decided to change his name and he told me that he just did not like his former name. Change of name probably helps him to cope with his illness.

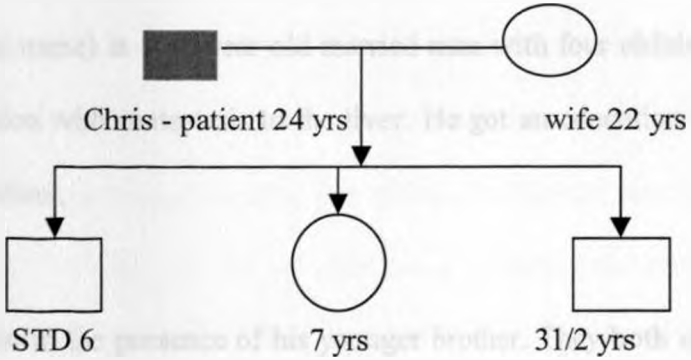


Figure 13. Family tree of Chris

## Issues emerging

- 1. Treatment seeking pattern.** This is a case of multiple health-seeking patterns. He has sought treatment from both the traditional healers and the hospital facilities. He got disappointed with the traditional treatment and has now resorted to modern medicine.
- 2. Denial.** He was informed of his diagnosis when he went to pick his results. He says he did not open the envelope but in the real sense he opened it but did not want to believe whatever was written inside or whatever he was told. He also did not want to reveal it to the wife. He then travels to the rural home to try and identify the cause of his problem. The traditional healer then tells him that he has been bewitched and starts him on medication.
- 3. Fear of the diagnosis.** Chris fears to be associated with his diagnosis and so he goes on to change his identity. He changes his name so that he could be referred to with a different name.

## CASE IV

Dan (not his real name) is a 48-year-old married man with four children. He has a diagnosis of cancer of the colon with metastasis to the liver. He got an education up to the secondary level and works as a driver.

I interviewed Dan in the presence of his younger brother. They both agreed to participate in the interview, as there was no secret. Dan understood that he was suffering from cancer whose primary site was the liver. I asked him to give me a short history about his illness,

"I started having stomach problems in August 1999. I was feeling as if I had gas, constipation and loss of appetite. After visiting the doctor, he asked me to go for a scan, which revealed a tumor in the intestines. I was to undergo surgery, which took place in January 2000. I was referred to see an oncologist for chemotherapy. The oncologist did his tests and found that there was no cancer in the blood so he advised me not to have the chemotherapy. He said it was not necessary. I had bought the chemotherapy drugs and up to now they are still in the house. In January 2000, I had another scan done which revealed that the tumour had recurred, which was removed during the second operation. During the second operation the doctor also found the liver infected. Now I have cancer of the liver, which is not related to the initial tumour, that was removed." He believes cancer is inherited in the family and that it is not contagious. He knows that cancer is not curable.

"We all understand what cancer is all about," added the brother. "Anybody who has cancer dies, and we know my brother here is going to die. My mother died of cancer of the breast in the seventies and our elder brother also died of cancer of the colon in the year 2000, and now it is Dan's turn. We now think it is a family disease and maybe I am the next in the line. What we want to know is where to go from here. When my late brother was sick he was in a lot of pain and he died a very painful death. The diagnosis was made very late and so no surgery or any other treatment was performed on him. We would not like my brother here to go through the same situation." I informed him that we were going to control the symptoms as much as possible to make him more comfortable.

When Dan was initially told of the cancer diagnosis, he felt very sad. "I knew it was not curable hence I had to understand that I had it. Death should not be scaring to anybody." Cancer has affected him such that he cannot work. He is on sick off at the moment.

He has no plans at the moment but he would like to see his children have a good education.

For now, he has accepted his illness. Friends come to the house and they hold prayers together.

At the moment he is not suffering but he knows a time will come when he will want to give up,

due to the suffering he and his family will be undergoing. "The family suffers when you are

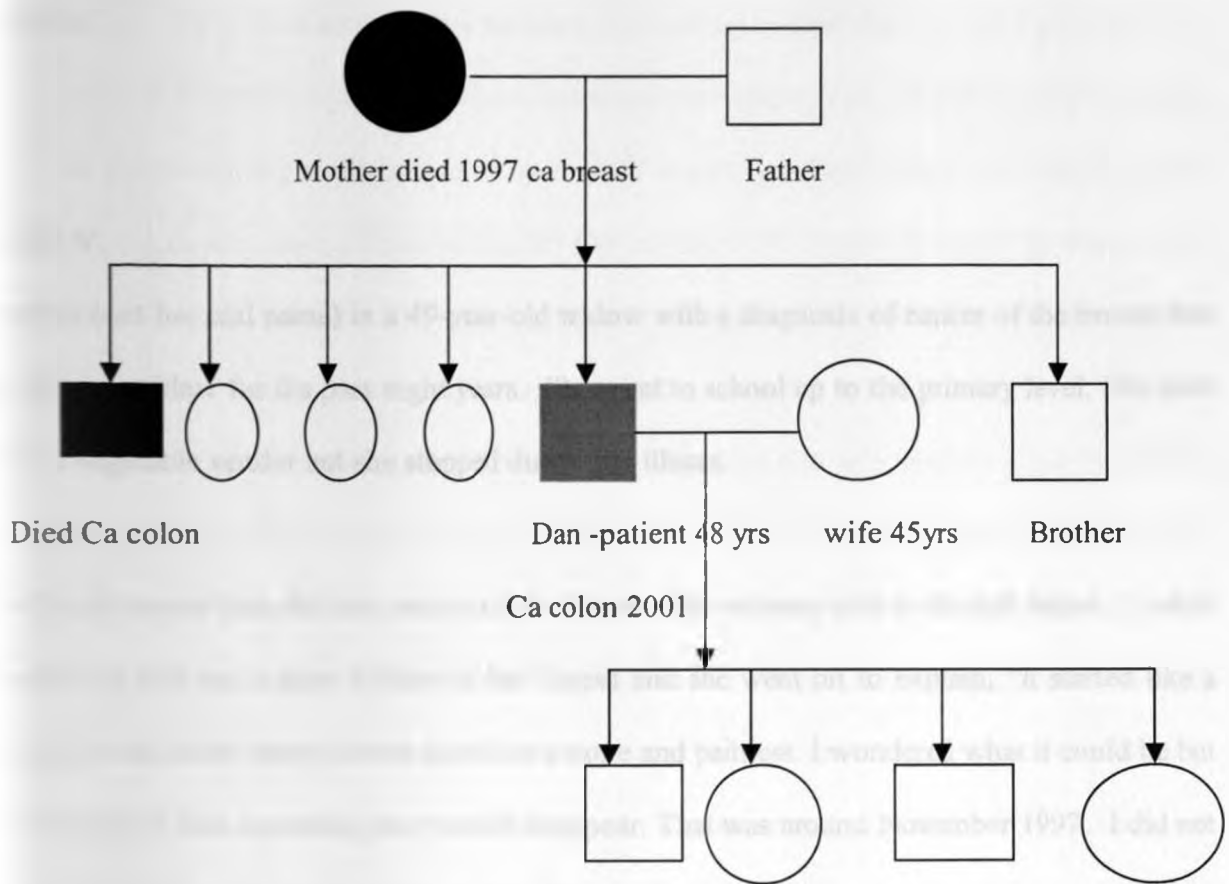
suffering and you end up suffering even more." He comes to the hospice mainly for the control

of pain and expects to be made comfortable as much as possible. He would like to be cared for at

home since he is more comfortable and is being taken care of by the wife. He would not choose

to be cared for at the hospital at any one time.





**Figure 14. Family tree of Dan**

**Issues emerging**

- 1. Family history.** Dan knows that cancer is a disease that is in the family as people close to him have died of the disease.

**2. Acceptance.** Has accepted the fact that he has cancer and that it has no cure. He would like to know the way forward. He does not expect cure but wants to be made as comfortable as possible.

#### **CASE V**

Everlyn (not her real name) is a 49-year-old widow with a diagnosis of cancer of the breast. She has been a widow for the past eight years. She went to school up to the primary level. She used to be a vegetable vendor but she stopped due to her illness.

Everlyn is aware that she has cancer of the breast. The primary site is the left breast. I asked Everlyn to give me a short history of her illness and she went on to explain, "It started like a small growth in the breast. It was hard like a stone and painless. I wondered what it could be but just thought it was something that would disappear. That was around November 1997. I did not know it would swell and become so big. In January 2000, which is after 3 years, the breast became very big. The inside part became like a stone. The nipple was retracted or pushed inside. The whole breast got lifted upwards such that it was not inline with the other one. I talked to friend of mine who is a matron here at KNH. She told me that I had to go to KNH and be examined. She brought me to see her doctor. The doctor examined me and told me to attend the surgical clinic No.24. I attended the clinic, a biopsy was taken and was told to come back after 2 weeks for the results. When I came I was told I had cancer and that I had to go to theatre to get the breast removed. First the doctor took a chest X-ray, and found that the cancer had not spread, it was only involving the breast. I decided to have the surgery."

"Did you have the surgery done immediately," I enquired.

"No I did not have money. I got my results in February 2000. I was to pay an admission deposit of Ksh 8000, which I did not have. I went home. I stayed up to June that is when I came back but still without the money. I told them that I could not raise the money. The doctor told me to go and look for something small or half the amount. I went to my local church and told the pastor about it. The church made a fund raising for me of Ksh 4500. I came and paid the deposit and that is when I went to theatre." Everlyn is not sure if the cancer had spread to any other part of the body. She said that the cancer had not spread at all.

"What do you think is the cause of cancer," I asked her. "I am not very sure but I hear people say that it could be explained in several ways. The first reason is if while breast-feeding the child gets satisfied and then belches while the nipple is still in the mouth. The second option is if one had an infant and then it dies without having breast-fed enough. The milk in the breast gets "sour" and this makes the breast to swell and get cancer." She attributes the cause of her illness to the second option. This is because she had an eight-day-old infant who died. "I had a baby who died after 8 days. The baby had not breast-fed enough and that is when my problem started. The milk got sour in the breast and that is what made the breast to start swelling".

"How is cancer treated?"

Everlyn knows the three modes of cancer treatment since she has undergone surgery and chemotherapy. She is waiting to undergo radiotherapy.

On asking her how cancer spreads, she said it could be due to the operation. "Since the operation the pain has increased. I feel a lot of chest tightness."

Everlyn gets information about cancer from the hospital staff and the media (radio programmes).

"How did you feel when you were initially told of the cancer diagnosis?" I asked her. "I was very shocked but left everything to God." Her family in the rural area doesn't know about her illness yet.

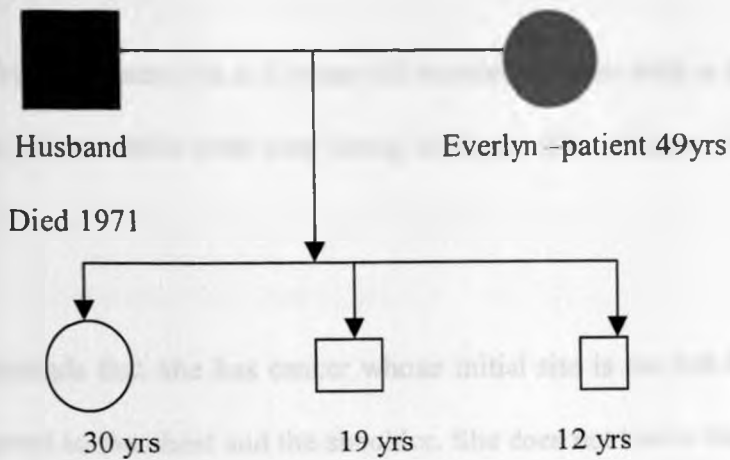
Everlyn used to be a vegetable vendor but due to her illness, she has not been able to continue with her work. She lives on donations from her church and friends. The church pays the rent of the house where she stays. She doesn't know if they will continue to pay for her or they will get tired.

"What do you feel or plan for the future?" I enquired. "If I had money I would buy a small farm at Kitale (this is near her home area) i.e. a quarter of an acre and put up my own small house. I would then operate my business from there. This would also be good for my son so that he can have his own home. At the moment this cannot be done since I don't have any money and I am not able to work." Everlyn is okay if she takes her medication for pain control. If the drugs are out of stock she feels very weak and gets a lot of pain.

She thinks she is receiving active cancer treatment at the hospice. She also knows that she is receiving medication to control pain. Her expectations are complete cure and pain control. She understands that she will continue to take medication up to the last time, which is, getting cured, dies or the hospice gets tired of her. At the moment she is only on hospice medication. She tried the traditional medication when she left the ward after surgery but it did not help her. It could not go down her throat. She used to vomit everything immediately. The interactions with other patients have given her strength. The medication also makes her feel better.

She would prefer to be cared for at home. Hospitalization will require money, which she doesn't have. Some hospitals (public) still do not have medication. One has to buy. She would only accept to be cared for at home when she becomes too ill to support herself.





**Figure 15. Family tree of Everlyn**

**Issues emerging.**

- (1) **Delayed health-seeking behavior.** This is due to the fact that she was unaware of the initial signs of cancer. She did not know what the swelling in her breast implied.
- (2) **Financial constraints.** This led to her delayed treatment.
- (3) **Causal attributions non-scientific causes.** Everlyn has some non-scientific explanation of why she has cancer.

## CASE VI

Fatuma (not her real name) is a 52-year-old married woman with a diagnosis of cancer of the breast. She is a housewife with four living children. She attained up to the primary level of education.

Fatuma understands that she has cancer whose initial site is the left breast. She thinks that the cancer has spread to the chest and the shoulder. She does not know the cause of her cancer since it is not in her family, but she knows that it started just like a small growth.

“If I think very much I don’t know the cause because it is not in our family. There was something small and painless that got swollen in the breast. When doctors in Kenyatta reviewed me, they told me that it was cancer but I know cancer is not contagious.”

“Tell me a short history of your illness?” I asked her.

“The problem started around January 1997. It was just like a small swelling that was painless. A lady friend of mine invited me to attend a funeral of her friend. I asked her why she had died and she told me it was due to cancer of the breast. I told her that I also had a growth in my breast. She advised me to come to KNH and have it examined since it could be something serious. I then came immediately to KNH and had the examination. The doctors told me that it was cancer. I had the operation done in June 1997.”

Fatuma understands the three modes of cancer treatment since she has undergone all of them, surgery, chemotherapy and radiotherapy. She is not aware if cancer can spread within the body system but she thinks that cancer is a disease, which just comes, and it cannot be prevented. She gets information about cancer from the hospital staff and the family members.

“How did you feel when you were initially told of the cancer diagnosis?” I enquired from her. “I was very shocked but I called upon the Lord and told him that whatever is happening to me, did not make me feel bad. Since it is not something good, I would not prefer the illness to go onto somebody else instead of me. These days I am used to it.”

“Why should you be used to it?” I asked her.

“When I came into this world, I knew I would leave it one day. Some people even leave this world without being sick of cancer. This makes me feel okay and be able to cope with the illness. I also have a chronic illness (high blood pressure), which I have learnt to live with.”

“How has the cancer affected your daily activities and work?”

“I don’t work; my husband is also not working. We rely on our children for support. I used to have a business that collapsed when I became sick.”

“What do you feel or plan for the future?”

She laughed and said, “I have no plans for the future. I stay *’ndwee’* and calls upon God. When I was okay and working, I used to plan what to do with my money. I would plan that during a particular month I would do this and buy that. Since I became ill I have stopped thinking about that. ‘Is there a patient who plans on what to do?’ She asked me. ‘Do sick people really plan? Sick people? A patient to make plans? There is nothing one can do except to pray to God so as to be given more days to be able to see your children and grandchildren grow. There is nothing one can plan. Illness takes a lot of your money. You cannot think about it. If you do, you will die.’”

“What do you know about your situation now?”

"I know that I have cancer which has no cure. I have come to accept that. I don't ask God why me because if it affects someone else instead of me, it is a human being like me who will also feel bad. Illness does not affect trees but human beings."

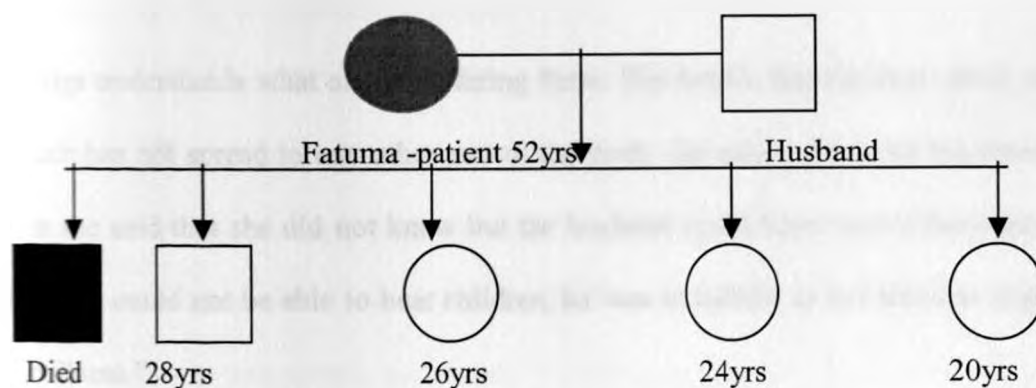
Fatuma understands that she is receiving symptom control at the Nairobi hospice. This is to take her through the day. She is not sure whether the drugs also treat cancer. She has not tried receiving any other alternative treatment.

**Fatuma's comment.** "You should try to get a cure for this problem, something like a vaccine. People are dying a lot and it is a heavy disease. There is no happiness. Sometimes you are in pain other times you are okay. I do not know what to say because when one is ill, she is like a fool. You do not think. You do not see good or bad. You cannot go to the garden even if it rains. Your life is up to God, if he wants he can give you another day. If you sleep and wake up, thank God. A patient cannot know that she will start this week and go up to the end. With illness, God can decide to take you at any time. Should I see the end of the year I thank God."

Hospice care has really assisted her. The medication improves her health and relieves the pain. Hospice staffs are very welcoming and this makes one feel better even when sick. Patient interactions during the day-care center have also assisted her a lot. It has made her realize that she is not suffering alone. She is very grateful now that the cancer pain has been controlled. Before it was very painful.

"Cancer pain is very bad and unbearable." She continued to say. "If I could give you a practical example. It is like putting your finger in red-hot fire for it to burn. The advantage with the burning finger is that you will withdraw it from the fire, with cancer pain, it continues to hurt over and over again. Using your imagination you can now see how bad it is."

She would prefer to be cared for at home since she gets assistance from her family. “Nobody likes hospitals. You sleep close together. Your neighbour dies and you remain thinking that you will be the next. Food is bad at the hospitals. I would only choose the hospital as a last resort, but not at my own will.”



**Figure 16. Family tree of Fatuma.**

### Discussion points

1. **Lack of awareness.** Fatuma saw the initial breast cancer symptom but ignored it since she did not know what it represented.
2. **Acceptance.** She has come to accept the situation and understands that she has to take medication each day. This has been a lot easier for her to accept the situation since she also has a chronic illness (hypertension) on which she is on daily medication.
3. **Pain.** Cancer pain is the most distressing symptom that she experiences.

## CASE VII

Gladys (not her real name) is a 40-year-old lady with cancer whose initial site is the ovary. She is a mother of three, the children she got from her first husband, and separated from her second husband who is polygamous. She went to school up to the primary school level. Previously she was house help but at the moment she is not working.

Gladys understands what she is suffering from. She knows that she has cancer of the stomach, which has not spread to any other part of the body. On asking her what the cause of her cancer was she said that she did not know but the husband could have caused her cancer. The second husband could not be able to bear children, he was unfaithful to her and that might have caused the illness.”

“Tell me a short history of your illness. “

“My problem started with my stomach swelling. I thought I was pregnant since I was missing my periods. I used to attend the antenatal clinic at Kibera. When I was due I was referred to Pumwani maternity hospital. At Pumwani, I was then told that the condition I was in was not due to a pregnancy. It was due to an illness. I was then referred to Kenyatta National Hospital where cancer was diagnosed. When I was admitted at Kenyatta, my husband abandoned me there and said that I was a dead person. He thought I was not going to get out of the hospital alive. He has since married another wife.”

Gladys understands that surgery and chemotherapy can treat cancer. She also believes traditional medication can also help. She gets information about cancer from the hospital staff.

“How did you feel when you were initially told of the cancer diagnosis?”

"I was very shocked. I thought I was going to die the next day. My aunt encouraged me and told me to leave every thing to God. I used to be a house help but now I cannot work. I have lost my source of income. I have become a burden to my aunt who now has to take care of me. I cannot go back to my husband because he has married another wife, and he left me when I was sick in hospital."

"What do you feel or plan for the future?"

"If I get well, I would like to look for a job. I will then save some money and go to buy a small farm in Kitale. I will then put up a small house and forget about my husband and marriage. I will then start a small business at my new home."

"What do you know about your situation now?"

"I have come to understand my illness. I know I have improved since I started hospice care. Comparing my situation now and how I was initially, I have seen a marked improvement. That is why deep down inside me I think I will get better and be cured of my illness."

Gladys understands that we are treating her pain and the cancer. She believes that with divine intervention she will be completely healed. Hospice has given her life. She gets her medication from the hospice and this has improved her health. She would have died in March 1999 while at Kenyatta hospital. KNH requires that you pay money before any other treatment is given. At the hospice the staff first enquire how one is feeling, the financial capability and the family background. She would like to be cared for at home than in the hospital because, "the home environment is familiar. I am in my own house. I can cook whatever I want and eat. Visitors can come anytime they feel like with no restrictions. At the hospital one can get other diseases. Food is not well prepared. Many people die in the hospital. There is also the issue of the sharering of

beds hence one can get other diseases. Visitors are limited or restricted. I would only go to hospital when I am too ill to manage on my own.”

After our discussion I asked her if she had a question to ask and this was the reply, “Will I get better or will I continue to be sick until I die?”

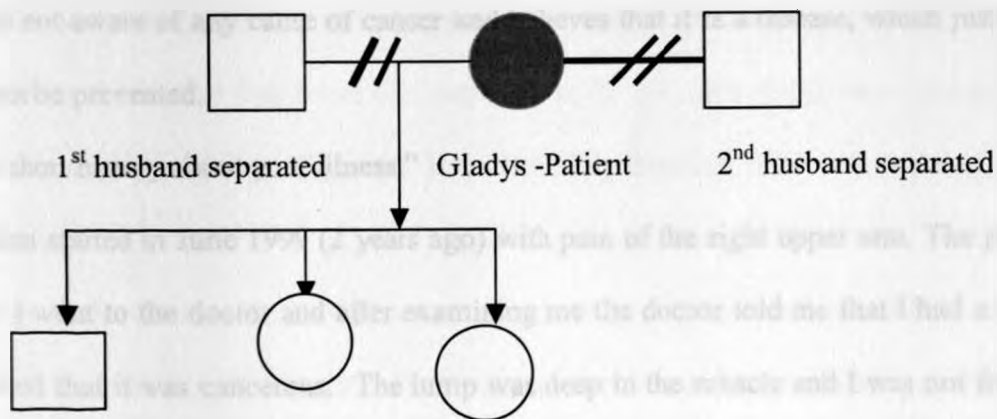


Figure 17. Family tree of Gladys.

### Emerging issues

1. **Poor advice (misinformation).** She used to attend the antenatal clinic thinking that she was pregnant. It is only after she went to deliver that her problem was detected.
2. **God's will.** She knows she has cancer, which has no cure, but with God's intervention she is going to get better.
3. **Unfinished business.** She feels that she is not settled. She has no home and so she is bargaining with God to give her more time so that she can fulfill this wish.
4. **Selective denial.** Accepts that she has cancer but still asks whether she will get better.



## CASE VIII

Hellen (not her real name) is a 50-year-old lady with a diagnosis of breast cancer. She is married with two daughters. She went to school up to the primary school level. She is a retired secretary. She retired after falling ill.

Hellen understands that she is suffering from breast cancer, which has now spread to the neck area. She is not aware of any cause of cancer and believes that it is a disease, which just comes, and it cannot be prevented.

“Tell me a short history about your illness.”

“My problem started in June 1999 (2 years ago) with pain of the right upper arm. The pain was so intense. I went to the doctor and after examining me the doctor told me that I had a lump in my breast and that it was cancerous. The lump was deep in the muscle and I was not feeling it. He told me that I had to undergo an operation to remove the breast and this was done in October 1999.”

Hellen knows about surgery and chemotherapy as the modes of treatment of cancer since they are the ones she has undergone. She knows that cancer spreads in the body. She gets her information about cancer by reading newsletters/magazines and through the media.

“How did you feel when you were told of the cancer diagnosis?”

“When the diagnosis was made, I was in a lot of pain, I asked the doctor when the surgery was going to take place. Due to the pain I had at that moment, I told God to do whatever he wished with me. I wanted desperately something to relieve the pain. After the surgery I have not experienced that kind of pain again. I left the pain in the hospital. The illness has made me into

someone who has to be fed always. I cannot be able to work on my own and I have retired from my work.”

“What are your plans for the future?”

“I pray to God that he may add me more days to see my children get an education. I have given my life to God and I know he has a plan for my life. He can do with my life whatever he wishes.”

Hellen knows that she is receiving symptom control at the Nairobi hospice. She is pleased with the care because she knows that we at the hospice care for her. The drugs were very expensive but now she can get them free of charge. The counseling sessions were very encouraging and well co-coordinated.

She would prefer home care to hospital care because she is with the family, and receiving good family care. When one is in the hospital the family worries a lot. She would only go to hospital when too ill and she has no other alternative.

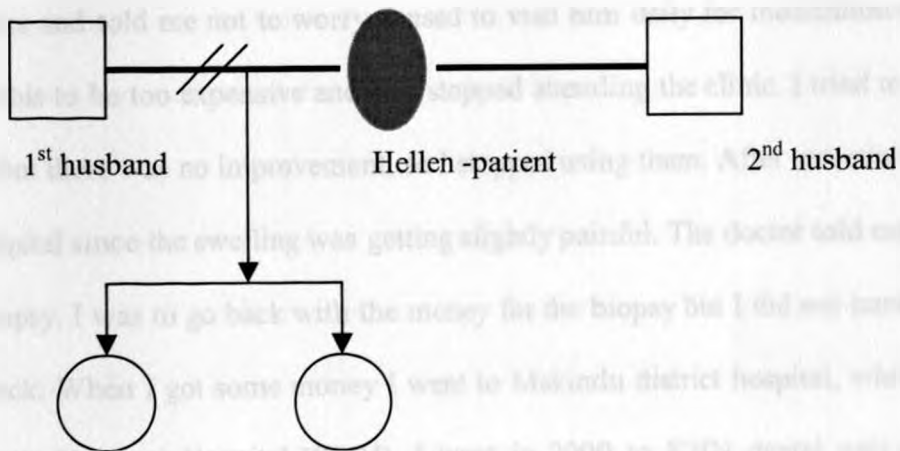


Figure 18. Family tree of Hellen.

**Acceptance.** Hellen has come to terms with her illness and learned how to live with it by appreciating the existence of God.

#### **CASE IX.**

Ismail (not his real name) is a 27-year-old man with a diagnosis of a malignant jaw tumor. He is married with one child. He went to school up to the secondary school level and does casual work to earn a living.

Ismail understands that he is suffering from cancer of the lower jaw, which has not spread to any other area. "Tell me a short history about your illness." I asked him.

"In 1993 I noticed a small swelling of my jaw. It was painless so I did not do anything for a long time. I just thought it would go away. In 1995 I decided to go and see a private doctor, he gave me some antibiotics and told me not to worry. I used to visit him daily for medication and pay Ksh 250. I found this to be too expensive and so I stopped attending the clinic. I tried to use the herbal medicines but there was no improvement, so I stopped using them. After sometime I went to the mission hospital since the swelling was getting slightly painful. The doctor told me that he needed to do a biopsy. I was to go back with the money for the biopsy but I did not have money so I did not go back. When I got some money I went to Makindu district hospital, where I was referred to Kenyatta National Hospital (KNH). I went in 2000 to KHN dental unit where a biopsy was taken. I went back for the results after two weeks and it was found to be cancer. I was then told to go back for the operation with Ksh 8000.deposit. I did not go back. I went back after

4 months when I got the money only to be told that the tumor was beyond surgery. I was then given some antibiotics, discharged and then referred to the Nairobi Hospice.”

Ismail just hears of cancer as being a chronic illness. He doesn't know about the cause, but just knows that to him it just happened. He thinks that taking medication can prevent cancer.

“How did you feel when you were told of the cancer diagnosis?”

“I just hoped for a cure.”

“What do you plan for the future?”

“I have made some plans. I have put up a small shop at home, which is being run by my wife. At the moment it is closed because my wife has gone back to her parents. I got very sick up to the extent that I could not walk. My wife then got terrified and ran away. Friends also influenced her. They came and when they looked at me, said that I was a dead man. It is normal for one to leave especially when one is very sick. At the moment we are not in good terms because of the illness.”

“What do you know about your illness now?”

“The way I see it, my illness can be cured if only it is taken care of seriously. If the wound is cleaned nicely, if I take the medication and if the growth that has come out can be surgically removed. If the growth is removed I can be freer, since the growth/wound is not progressing very much. It has come out so it would be easier to remove. It is not painful, pus is still coming out, if it dries up, it can be all right. It needs regular dressing at least twice a day. At the moment I am doing the dressing myself.”

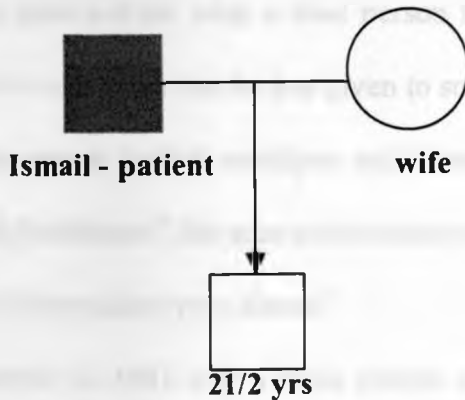
Ismail thinks that he is receiving chemotherapy at the hospice. He expects symptom control and eventually complete cure. Hospice care has assisted him very much especially in relieving the pain and cleaning and dressing of the wounds. At the moment he prefers to be taken care of at

the hospital. He will be closer to the doctors and nurses. While at home he had a serious backache and he could not take care of himself. That is why the wife got scared and ran away. This has gone on for three weeks. "The way I am feeling, I think I should be in hospital. I am just with my mother; it is a burden in her trying to take care of me."

After three weeks I had a second encounter with Ismail and on enquiring how he was feeling, he replied, "I am not doing fine. I am not improving, the back pain has become worse and I cannot move around. The wound has no problem at the moment, it is not paining, and the back pain is the problem. What I need is just to be in hospital."

I explained to him that we could not admit him because we did not have inpatient facilities.

"I think I should go and stay with my aunt for the time being. You people can then visit me and treat me till my back gets cured, then I can travel home. If I travel home right away I will have to be carried home just the way I came, I was carried on the back."



**Figure 19. Family tree of Ismail.**

### **Emerging issues**

- 1. Delayed diagnosis and treatment.** Due to the lack of medical evaluation of the initial symptom. The initial doctor he saw was treating him of an infection.

2. **Financial constraints** lead to delayed diagnosis and treatment.
3. **Health seeking pattern.** Multiple health providers.
4. **Denial (selective denial).** Still wants to get cured irrespective of his condition.

## CASE X

Janet (not her real name) is a 69-year-old widow and mother of three. She is a widow with three children. She is a housewife and had an education up to the primary school level.

Janet understands that she has cancer of the breast and that it has not spread to any other part of the body. She understands that cancer is a disease that does not get cured or healed.

“What do you think is the cause of cancer?”

“I do not know the cause of cancer but I think it is just a disease. It may be due to a curse, which can come if one does not do what a dead person had requested them to do. If one does not honour a request or a promise that he had given to someone who has died. Other diseases, which can be caused by curses, include smallpox and tuberculosis. Cancer can also be inherited from grandparents and forefathers.” She also understands that cancer is not contagious.

“Tell me a short history about your illness.”

“The problem started in 1981 with a small pimple which was removed. I was okay until 1994 when the swelling came back again. The second operation was then done to remove the breast. I then was given chemotherapy and I have just finished a course of radiotherapy. I know cancer can catch you anywhere even on the finger and then it can be operated to remove it, but I do not know if there is any other medication apart from God. You can get it and stay for a long time or die immediately. The worst cancer is the stomach since one cannot eat. If there is no treatment

## CASE XI

Kamau (not his real name) is a 46-year-old man with a diagnosis of squamous cell carcinoma of the tongue (oral cancer). He is married with three children. He went to school up to the secondary school level. He is retired and makes it clear that he retired sometimes back so that he could go into business and not due to his ailment. I started the interview by asking him to tell me a short history about his illness and whether he knew what his problem was.

“My problem started in 1998 as a small wound on the left side of the tongue. I could feel a little bit of pain but it was on and off. I just used to take some painkillers. I did not think it was something serious but I thought it was a small wound that would heal. It continued to be a big wound that was not healing. This went on for a period of eight months before I went to visit the doctor. In 1999 I went to see a private doctor in Mombasa, he took a specimen and took it to the laboratory. When the results came out it showed that I had cancer. The doctor said it had spread to the floor of the mouth so he referred me to Kenyatta National Hospital for radiotherapy.”

“When I came for the radiotherapy the doctor examined me and recommended surgery. In November 1999 I underwent the surgery where two-thirds of the tongue was removed. After the operation it healed well, I was put on chemotherapy (6 sessions) and radiotherapy (30 sessions), which I completed successfully. I was then coming for regular check-ups. In early 2001 I started feeling a swelling and some pain in the neck. Some test with a needle was done which showed that the disease had spread to the neck. I then underwent seven sessions of radiotherapy, which I completed. I stopped for a short while and then this swelling started (pointing to the shoulder swelling). The swelling has grown and now it has burst. There is a deep wound, which is leaking. I have to change the dressing twice a day. A month ago I came and was told to start radiotherapy

and another dose of chemotherapy. I have done one course and I am remaining with five more. Currently I am living on painkillers.”

“What do you know about cancer?”

“I know it is a bad disease. At some stage it is incurable but I do not know at what stage.”

“What do you think is the cause of cancer?”

“Mostly I have heard people talking about smoking, drinking alcohol, some air pollutants, the foods we eat and radiation.”

“What was your feeling when you were told of the cancer diagnosis news knowing it is a bad disease?”

“I was shocked. I asked myself, ‘why me? Where did it come from? What next? I had some feelings of uncertainty and these were partly because I used to smoke and drink. I decided to stop smoking. But there are people who smoke and they do not get cancer. I asked myself about the environment where I used to work maybe I could have mishandled some dangerous chemicals or gases but you find that there were several of us who were working under the same conditions. There are several of them still working there and they don’t have cancer and me I left long time ago and I got it.”

“What do you know about your situation now?”

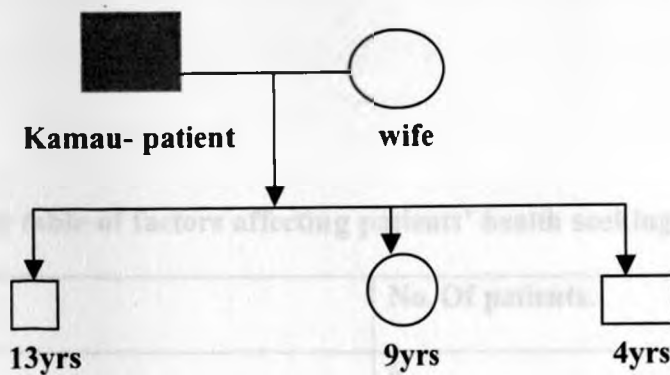
“I know nothing much about my condition. I have been coming to KNH but the staff has not been able to talk to me and answer my questions. Infact, after the treatment, you leave the hospital with even more questions. The staff is busy because there are too many patients waiting to be seen. The doctor is the one who knows about your condition but I believe the information should be shared between the doctor and the patient. Initially after the surgery, I used to be embarrassed to talk to people because they could not understand my words. Even on the phone I



was not able to talk because no one could understand me. Now they have become used to me, I only talk to people who are aware of my problem and they know how I talk. At the moment my problem is the pain and the wound. I live on painkillers.”

“How did your wife react about the diagnosis? I enquired.

“She reacted very badly. As far as she is concerned, I am already dead. When she sees me dressing the wound, she begins to cry. The word cancer scares people and they equate cancer to death. The children are keen to see where the tongue was cut and they want me to pronounce words the way they should be pronounced.



**Figure 21. Family tree of Kamau.**

**Table 6. Summary table of patients knowledge and causes of disease**

<b>Cause of cancer</b>	<b>No. Of patients</b>
Genetics	5
Stress	1
Previous occupation	1
Smoking/Alcohol consumption	3
Food	3
Exposure to radiation / Pollutants	1
Did not know	5
Non-scientific explanations	5

**Table 7. Summary table of factors affecting patients' health seeking behaviour.**

<b>Factor</b>	<b>No. Of patients.</b>
Unawareness	6
Pain	8
Financial constraints	7
Health provider advice	Poor 7
	Proper 4

**Table 8. Summary table of patients' response to cancer diagnosis information**

Response	No. Of patients
Complete denial	1
Selective denial	4
Anger	2
Fear	4
Acceptance	Family history 2
	Religion 5

### 5.3. Focus group discussions

There were two focus group discussions, which were carried out. Patients were females with various diagnostic sites, which included breast, cervix, uterine, liver, but all were in the advanced stages. The patients were purposefully selected depending on their availability and willingness to participate in the discussions. Each group consisted of six patients.

From the focus group discussions it was revealed that patients had various reasons as to why they had cancer. These included

- Genetics: They could have inherited it from the grandparents
- Food: Some food cause diseases and this included meat (goat /dog meat)
- Shifting blame: They attributed the cause of their illness to other people e.g. their husbands being unfaithful (for a lady who had ca cervix, ca uterine).
- Stress: Patients complained that if one thinks a lot, illness comes into the body. Most women said their husbands brought to them stress by coming home drunk and abusing them.

Patients also coped with their illness in a variety of ways

**I. Denial:** Patients ignored the fact that they had cancer, which is incurable. They tended to focus on the fact that cancer is like any other illness and they will get better. *“Cancer is like any other illness such as malaria, or fever and one either gets better or dies, since all sicknesses kill”.*

*“I did not accept the diagnosis and up to now I think I do to have it. I am continuing with my work as usual.”* The patients therefore failed to acknowledge the fact that they had cancer, which is an incurable illness.

2. **Partial acceptance:** Like in the in-depth interviews, most patients accepted some aspect of their illness but blocked out other aspects of the illness. The existence of the supernatural power also aided them in trying to cope with the ailments. Most patients said it was God's will that they were sick. *"This sickness is not mine, it belongs to God. I have told God who carries all our burdens to take care of me."*

*"I don't fear anything, God is able to take care of all of us and I am waiting for my day to come."* The fact that the patients believed their lives were in God's hands helped them live with the disease.

#### 5.4. Limitations of the study

1. The study sample was small hence not representative of the whole population and this makes detecting possible significant differences difficult.
2. The data was based on self-reports of the patients and so they could have been affected by pressures of self-presentation, social desirability i.e. patients only shared only what they wanted to share.
3. The interviews only captured one particular point in time and the changes that occur from day to day could not be detected.
4. Since the design was a cross-sectional case study a number of differences may have occurred since the initial diagnosis to date.

## CHAPTER 6

### 6.1 STUDY DISCUSSION

The diagnosis of cancer has a profound psychosocial impact on patients and their loved ones. The effects of cancer extend long after the time of initial diagnosis. Since many cancer patients live with the disease for extended periods of time, cancer becomes part of their existence: one aspect of life they must respond to.

According to the findings of the recorded data there has been a general increase in the total number of patients seen at the NH. These could be due to an increase in the awareness and the increase in the number of referrals. Most patients seen were females (61%) while only 39% males. Most patients were above 31 years of age (84.7%). Most patients were married (64.9%) with a primary-school level of education or below (71.9%). This explains the fact that most patients were housewives (22.9%). Most patients seen (92.8%) were of the Christian faith. Religion plays a vital role in the patients' response to their illness. The existence of a supernatural being and the belief that someone above cares and understands their suffering is very essential to the way they cope with the illness. The fact that a patient says that whatever they are suffering from is because of a reason and a plan God has for their life is very important to the way one tries to cope with their illness.

The current study is in agreement with various studies that have been carried out to investigate patients' response to cancer and their subsequent view of life. The essence of this study highlights patients' knowledge of the disease symptoms, their subsequent health seeking behaviour, and response to the diagnosis of cancer.

### 6.1.1 Knowledge and causes of disease

The study indicates that most patients were not aware of the symptoms they had to be representing cancer or any illness initially. This was mainly due to the nature of the initial presenting symptoms. Most cancers were painless and hence patients did not attribute this to any illness. At the time of the interview patients knew they had cancer, which was terminal.

Most patients had various reasons of why they had fallen ill. There were both scientific and unscientific explanations (Table 5). The scientific explanations included:

1. **Genetics.** They had inherited the illness from the family. They referred to it as a family disease. Genetics has been shown to play a major role in cancer causation and most patients knew about that.
2. **Stress.** Thinking a lot brought about stress. Stress was also identified as a contributing factor to the cause of cancer. The women attributed the cause of their stress to their husbands and alcohol. This was mainly unanimously agreed upon during the focus group discussions where the women said their husbands brought stress upon them by drinking alcohol and later shouting at them, *“stress makes one have a lot of thoughts and this brings about sickness. After he is drunk my husband comes home and quarrels me. If one is not calm illness comes to the body.” (FGDs ca Liver)*. This shows that ones piece of mind is important to ones health.
3. **Smoking and alcohol consumption**
4. **Previous occupation.** One patient talked of previous exposure to chemicals at a factory he worked could have contributed to the ailment.
5. **Food.** One patient singled out the meat diet as a contributing factor to his illness. *“Since childhood, meat was not part of their diet. I started eating meat when I came to Nairobi*

*and that was after over 18 years. That is what caused my problem.” (Mr. Caleb 24yrs Kaposi sarcoma). Some patients talked of food but they could not specify which food.*

**6. Exposure to radiation and Pollutants in the air.**

The non-scientific explanations included the following

1. **God’s will.** A factor that came out in all the patients. Patients said that God had a plan for their lives and that is why he could allow the cancer to be a part of their lives.
2. **Self blame.** Some patients attributed their illness to their past behavior i.e. smoking, drinking.
3. **Did not know.** Patients could not explain to why they had the disease. They attributed it to chance or something they had no control over and could not prevent.
4. **Shifting blame.** Other patients blamed either their husbands for bringing about the stress and being unfaithful. Husbands' being unfaithful to their wives was a major contributing factor to their illness.

*“My husband could not have children and so was unfaithful to me.” (Ms Gladys. 40yrs ca ovary)*

*“My husband is the one who brought to me this illness. He was unfaithful to me” (FGDs ca cervix).*

5. **Milk production.** Excess milk production during breastfeeding.

*“I had a problem after I delivered my last two children (29 yrs ago). I used to produce a lot of milk. The milk was much that the baby could not cope with the large quantity. I tried squeezing it out and putting it in a bottle for the baby to feed but that did not help. The milk was so much that my mother-In-law had to make some incisions on the breast to release the pressure.” (Mrs. Anne, 55yrs ca breast).*



There was a patient who brought out some aspect of **milk getting sour** in the breast during two occasions. *“If while breast feeding the child gets satisfied and belches while the breast is still in the mouth. ---, If one had an infant and then it dies without having breast-fed enough, the milk gets sour and this makes the breast swell.”* The belief that the breast begins to swell because the milk gets sour inside the breast is a factor, which needs to be understood among women with breast cancer.

### **6.1.2 Health seeking behaviour**

The study reveals that patients kept to themselves the discovered symptom but kept monitoring it for any changes. They expected the symptom to disappear. When the symptom got slightly painful, the patients resorted to self-medication by taking some painkillers. If the symptom persisted, increased in size, or the pain intensified, the patients either talked it over with a friend / family or decided to seek health provider advice directly. The family / friend advised the patient to seek medical advice or alternative treatment. The health provider could either lead the patient towards a diagnosis by carrying out the necessary investigations (biopsy), or give the patient empirical treatment and reassure the patient not to worry and that the symptoms would disappear. If the symptoms persisted, patients sought alternative treatment or went to a second health provider. Once there was no improvement on seeking alternative treatment, the patient sought advice from a second health provider. The second health provider being at a higher referral level always led the patient towards a definitive diagnosis by carrying out the necessary investigations. After diagnosis financial constraints hindered the patients from undergoing the necessary treatment and this led to delayed treatment or no treatment at all. (Figure 22).

The results of this study indicate that health-seeking behavior was therefore influenced by the following factors

**(a) Ignorance**

This depended on whether the patients viewed particular symptoms to correspond to an ailment or not. Most cancer patients had their cancer symptoms for a long period of time before seeking medical evaluation since they did not know what it represented. This was mainly due to lack of knowledge on the initial presenting symptoms of the various forms of cancer. *"I felt it but ignored it since I thought it was nothing serious."* (Mrs. Anne 55yrs ca breast.)

*"It was hard and painless, I asked myself what could this be but just thought it was something that will disappear. I did not know that it would swell and become big"* (Mrs Evelyn 49 yrs ca breast).

*"In 1993 I noticed a small swelling of my jaw. It was painless so I did not do anything for a long time (5 yrs). I just thought it would go away."* (Mr Ismail 27 yrs, malignant ameloblastoma).

*" I did not think it was something serious. I thought it was a small wound that would heal"* (Mr Kamau. 46yrs oral cancer). Most patients did not seek immediate evaluation of their symptoms since they did not associate it with something serious, any illness or cancer. This took from between 1-5 years.

**(b) Nature of Symptoms**

Medical advice was only sought when the symptom persisted or it became worse by increasing in size, body asymmetry and pain intensity.

***“The swelling though was painless was getting bigger instead of disappearing. I then decided to seek medical advice.” (Mrs Anne 55yrsca breast).***

***“The breast became very big. The whole breast got lifted upwards such that it was not in line with the other one.” (Mrs Evelyn. 49yrs ca breast).***

***“The wound was not healing and very painful.” (Mr Kamau 46yrs ca tongue).***

### **(c) Pain**

This was the most important symptom when it came to health seeking behaviour. Pain was also seen as a sign of an illness or disease. The intensity of pain also indicated the seriousness of the disease. Mild pain was dismissed as something not serious while intense pain was seen as the worsening of the disease condition. One patient compared cancer pain to burning one’s finger in red-hot fire. Most patients sought medical evaluation of their symptoms when they had episodes of continuous intense pain. Since pain was generally equated with disease, most patients failed to understand why pain had not been experienced at the initial time of their illness.

***“The ulcer was not healing and very painful so I decided to seek medical advice.” (Mr. Kamau: 46yrs-ca breast.)***

***“The problem became very severe, there was an ulcer that had since formed and it was very painful.” (Mr. Caleb: 24yrs, Kaposi sarcoma)***

#### **(d) Financial Constraints**

Lack of finances led to the delay in the health-seeking pattern and delayed treatment even after the diagnosis had been made.

A case of Mr. Ismail where a biopsy was not performed because he did not have money. Upon coming to KNH he could not be admitted for treatment because he did not have the initial deposit required. He went and stayed for four months looking for money and when he came back, he was told the surgery could not be done since the tumor was beyond surgery.

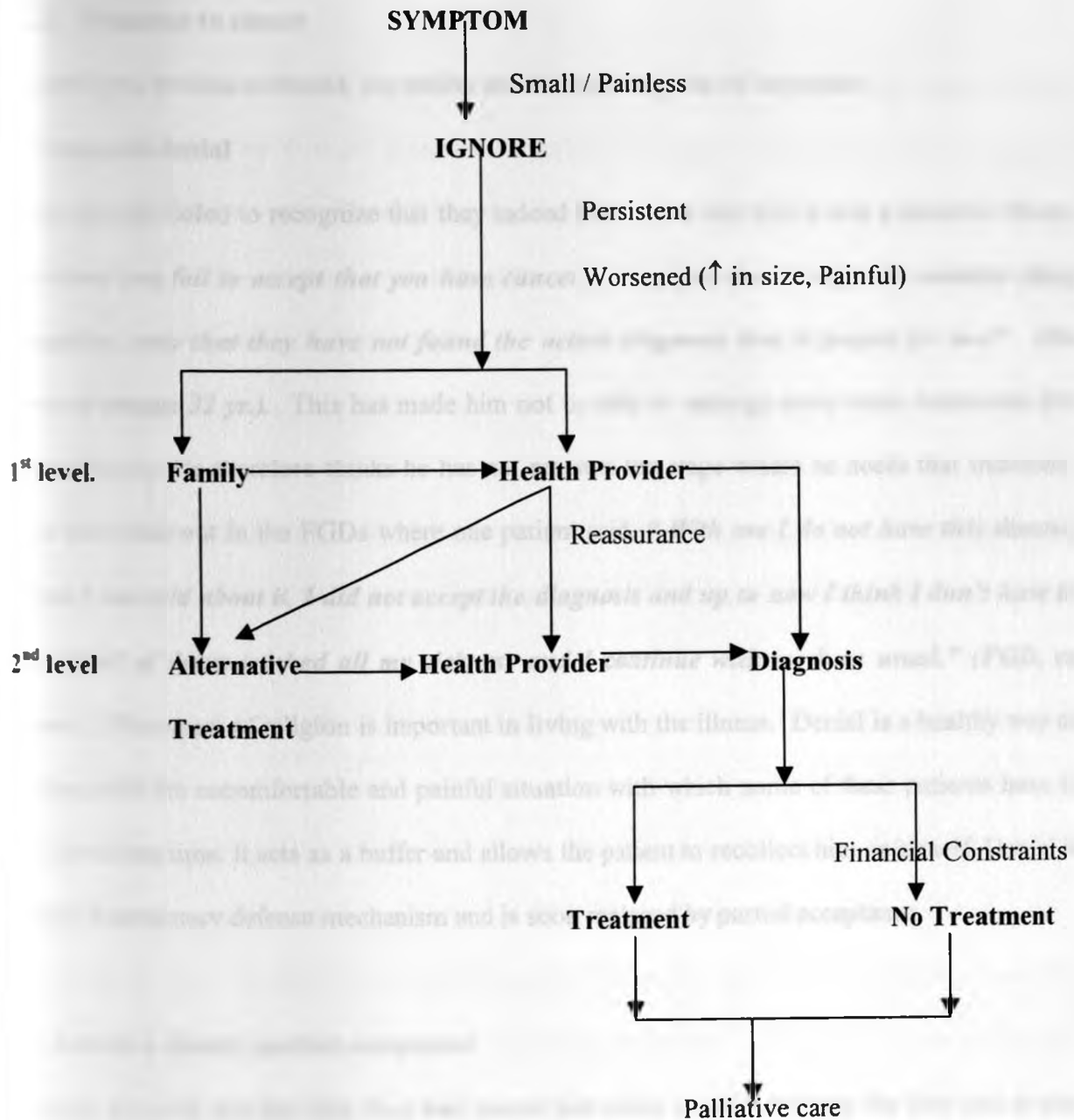
Mrs. Everlyn could not be admitted since she did not have enough money. A fundraising had to be done for her by her church that she could get money for admission. Mr. B could not undergo surgery and chemotherapy since it was too expensive.

#### **(e) Health Provider Assistance**

Some patients had their health provider moving them towards a diagnosis i.e. by ordering the necessary investigations such as biopsies, and specialist referral.

Other patients had false reassurances about their initial symptoms that the changes were normal and nothing to worry about. *"The first doctor I visited told me that it was nothing serious. He said that I should not worry and that the swelling would go away. He then gave me some medication to use."* (Mrs Anne: 55yrs-ca breast.)

*"In 1995 I decided to go and see private doctor, he gave me some antibiotics and told me not to worry."* (Mr Ismail: 27yrs ameloblastoma).



**Figure 22. Summary figure showing the health seeking behaviour pattern for the case studies.**

### 6.1.3 Response to cancer

According to the data collected, the studies show various aspects of responses:

#### (a) Complete denial

Some patients failed to recognize that they indeed had cancer and that it was a terminal illness.

*"At times you fail to accept that you have cancer. I even feel that it might be another thing altogether, only that they have not found the actual diagnosis that is proper for me."* (Mr

*Ben: ca tongue 32 yr.).* This has made him not be able to undergo some more treatments like chemotherapy. He therefore thinks he has not reached the stage where he needs that treatment.

This also came out in the FGDs where one patient said, *"With me I do not have this disease.*

*When I was told about it, I did not accept the diagnosis and up to now I think I don't have it.*

*The blood of Jesus washed all my sickness and I continue with work as usual."* (FGD, ca

*cervix.)* The aspect of religion is important in living with the illness. Denial is a healthy way of

dealing with the uncomfortable and painful situation with which some of these patients have to

live for a long time. It acts as a buffer and allows the patient to recollect him or herself. Denial is

usually a temporary defense mechanism and is soon replaced by partial acceptance.

#### (b). Selective denial / partial acceptance

Patients accepted the fact that they had cancer but failed to acknowledge the fact that it was

incurable. An example is a patient with right arm lymph-oedema which was secondary to a

mastectomy who kept on asking if her arm would get better, a patient with malignant

ameloblastoma who kept on asking whether his tumor could be excised so that it healed faster,

and a patient with Kaposi sarcoma of the leg asking whether his leg would get better.

### (c) Anger

When denial cannot be maintained any longer, it is replaced by feelings of anger, rage, envy and resentment. The anger is directed at anyone at random. An example is a patient who was angry at the society and hence chases his visitors away from his hospital bed, and a woman who thought that the doctors who operated on her daughter who had cancer of the breast were not good enough and did not perform proper surgery.

### (d) Fear

Patients had fear partly due to the fact that they had cancer and might die and also due to the societal influence. There was a case where a patient was told by his friends, "*with cancer you cannot finish a month*"

Fear of cancer is brought about by the social support system. Patients with cancer often feel stigmatized. This is an important aspect when one is trying to cope with bad news. The study suggests that society equates cancer with death. "*My wife feels I am already dead. When she sees me dressing my wound she begins to cry.*" (Mr. Kamau, 46yrs oral cancer.)

*"They do not come to tell you pole and that you will be okay, they tell you 'do you know you have a short time to live? From now on anything can happen to you.' I even used to chase away visitors at the hospital. Mr. Ben, ca tongue* talking about visitors who came to see him.

This is similar to the finding of Brian (1995) whose respondents reported that they often experienced difficulty in their relationships with others in their social setting especially when it came to communication.

## **(e) Acceptance**

Patients accepted the fact that they had cancer and this was attributed to various factors.

### **Family history**

Past family history was significant in-patient being able to accept the reality of the diagnosis and the eventual impending death. *"We all understand what cancer is all about, anybody who has cancer dies and we know my brother here is going to die. My mother died of cancer of the breast in the seventies and our elder brother also died of cancer of the colon in the year 2000, and now it is Dan's turn. We know it is a family disease and maybe I am the next on the line."*

*(Brother to Dan 48 yrs, ca colon)*. Past experience with the illness made them realize that cancer has no cure, it is a terminal illness and patients who have advanced cancer eventually die.

### **Religion**

The study indicates that most patients had a supernatural explanation of their illness. On being asked about their feeling and response to cancer diagnosis news, *"I was shocked but left everything to God."* *(Mrs. Everlyn, 49 yrs ca breast)*.

*"I was shocked but cried unto the lord."* *(Mrs. Fatuma, 52yrs ca breast)*.

*"I told God to do whatever he wished with me."* *(Mrs. Hellen, 50yrs ca breast)*.

*"I was shocked and thought I was going to die the next day. My aunt encouraged me and told me to leave everything to God."* *(Ms Gladys, 40yrs ca ovary)*. Patients' believing that God is the giver and taker of life is adaptive and so patients left the illness and their lives to be controlled by God. Religion therefore plays a central role in patients trying to cope with loss and any bad news. In being our creator patients were convinced that God has a right to do with their lives whatever he wished even if it meant dying. This is in agreement with findings of Gotay (1984) where faith and religion were relatively frequently mentioned ways of coping for women with



advanced disease. Religion therefore becomes more important over the course of illness as death becomes near.

#### 6.1.4 Summary of preferred place of care

All interviewed patients preferred to be taken care of at home. The reasons given were

- Hospitalization is expensive.
- They received good care at home. Patients were comfortable at home since they were with their families and in a familiar environment. They hated hospital food, since it is not well prepared, and if at home they could ask whatever they wanted to be cooked for them.
- Visitors could come anytime they wished and were not restricted.
- The hospitals were congested. Sometimes they had to share beds with other patients and in that way one can easily get other diseases. There is death in the hospitals, your neighbour dies and you keep on thinking whether you will be the next.
- Some hospitals do not have the necessary drugs.

## 6.2. CONCLUSION

Cancer remains a devastating disease that continues to create feelings of fear and despair in those who suffer from it. The effects of cancer on the individual are often psychological, social and spiritual in nature as well as physical.

The major concerns revealed in this study are the prevailing lack of patient information on the initial symptoms of cancer. This leads to delay in diagnosis and hence most cancer patients have their diagnosis made when the cancer is in its advanced form. Most patients with curable cancers like breast cancer and cervical cancer end up being terminally ill.

Financial constraints continue to be a major hindrance to accessibility to health care. This leads to delayed diagnosis and treatment. Some patients fail to undergo the necessary treatment due to lack of the financial resources.

Home is still the preferred place of care for most patients. This is mainly due to the advantages homecare has over hospitalization. Hospital is the only other choice when the patient is too ill and has no other alternative.

### **6.3. RECCOMENDATIONS**

#### **National level**

1. The government should establish a national health policy and programs for cancer pain relief and palliative care. National healthcare systems must explicitly define guidelines for cancer pain management. This should be incorporated into the existing health care system.
2. The governments should ensure the availability of both opioid and non-opioid analgesics, for terminally ill cancer patients, particularly morphine for oral administration.
3. Health care workers should be adequately trained in palliative care and the relief of cancer pain.
4. With poverty on the increase in our population, the government should ensure that health care is available to the population to lessen the late diagnosed of cases.

#### **Community level**

5. The referral system in to finding out a diagnosis should be adhered to. When a patient consults a doctor for an evaluation of a symptom, he/she has done her part of the job and it is the health providers' job to follow each consultation until resolution of the symptom or referral for biopsy.
6. Cancer support groups should be established to assist the patients cope with the illness and live normal lives.
7. The government or Non-Governmental Organizations (NGOs) should institute health education campaigns and promotions, on the early signs and symptoms of cancer, especially for breast and cervical cancers. Emphasis has to be put on prevention programs such as self-

breast examination and pap-smears through the mass media and barazas. This will avoid late diagnosis.

3. A study needs to be carried out to identify the awareness of the population of the existence of the Nairobi Hospice and the services it offers. One of the patients mentioned that the hospice **"finishes people"** meaning they give patients medication to fasten their death. This is already a sign of negative publicity. Cancer pain relief is a service that should be accessible and available to all terminally ill cancer patients.

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7 Home district -----

8 Ethnicity -----

9 Do you belong to any church? 1. Yes.

2. No.

If yes which one -----

If no state why-----

10. What is your level of education? -----

11. Family position/status of the respondent. -----

**SECTION C: KNOWLEDGE AND RESPONSE TO CANCER**

12. Do you know what you are suffering from? 1. Yes

2. No

13. If yes, what are you suffering from?

---

14. Where is the primary site of the cancer? -----

Can you identify any areas of metastasis? -----

State the site -----

If no to no.12 what do you believe your problem is? -----

15. In your thinking what causes cancer? -----

16. In your case, do you think you can identify a specific cause? (*Probe about the belief system, other non-scientific based causes*)-----

---

17. Is cancer contagious / communicable? 1. Yes 2. No

18. What do you think is the time lapse between when you first saw the initial symptom and when the actual diagnosis was made? \_\_\_\_\_

19. How is cancer treated?
1. Surgery \_\_\_\_\_
  2. Chemotherapy \_\_\_\_\_
  3. Radiotherapy \_\_\_\_\_
  4. Other, Specify-----

20. Among these treatments which one {s} have you undergone? (*Indicate the order in which they were received*) -----

21. How does cancer spread? (*Within the body system*) -----

22. Are there known measures one can undertake to prevent cancer? 1. Yes \_\_\_\_\_  
2. No \_\_\_\_\_

If yes, name some

1. Avoid alcohol.
2. Avoid smoking
3. Regular medical check up, including Pap smear, breast examination.
4. Others, specify \_\_\_\_\_

23. From whom do you get information about cancer?

1. Hospital staff \_\_\_\_\_
2. Newspapers /magazines \_\_\_\_\_
3. Family members \_\_\_\_\_
4. Other, specify \_\_\_\_\_

24. How did you feel when you were initially told of the cancer diagnosis?

---

25. How has the cancer affected your daily activities and work?

---

26. What do you feel or plan for the future?

---

27. What do you know about your situation now? (*Probe for whether they have come to terms with the disease, Spiritually they may have come to accept the situation, are bitter, or ask the why questions*).

---

**SECTION D: KNOWLEDGE OF PALLIATIVE CARE**

26. What type of treatment are you receiving at the Nairobi Hospice

1. Active cancer treatment.
2. Symptom alleviation ----- pain.
3. Do not know

Comment \_\_\_\_\_

27. What do you expect from this treatment?

1. Complete cure
2. Alleviation of symptoms – pain
3. Do not know
4. Other, specify. \_\_\_\_\_

28. Apart from the hospice care, are you receiving any other alternative treatment?

---

29 How has hospice care improved your attitude towards life?

---

### SECTION E. CHOICE OF PLACE OF CARE

30 Where would you like to be cared? At home or in the hospital?

---

31 Why is it the preferred site of care?

---

32 When would you choose the other care setting?

---

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## **APPENDIX II. GUIDELINES FOR FOCUS GROUP DISCUSSIONS.**

### **KNOWLEDGE AND RESPONSE TO CANCER**

1. Can you tell me what type of disease cancer is?

Probe -let the patients talk freely about their illness and the experiences they have had.

2. What causes cancer?

Probe for the patient belief system regarding the disease causation

Other non-scientific based causes, whether cancer is contagious?

3. How is cancer treated? Surgery, Chemotherapy, Radiotherapy?

Probe for the treatment undergone among these three

Probe for knowledge on surgery, chemotherapy, and radiotherapy: The purpose of each

treatment, the expected results of each. Given the knowledge they have on each treatment

what they would prefer know.

Probe for any other treatment received apart from these three modes of treatment i.e.

traditional therapy.

4. How did you feel when you were told of the cancer diagnosis initially?

5. What do you know about the state of your illness now?

Probe whether they have come to terms with the disease

Spiritual comfort---whether they have come to accept the situation, are bitter, or are still

asking the why question.

### **KNOWLEDGE ON PALLIATIVE CARE.**

6. What type of treatment are you receiving at the Nairobi Hospice? Any other treatment?

Their expectations from this treatment.

7 Can you explain how this hospice has improved your attitude towards life?