INFORMATION NEEDS OF BREAST CANCER PATIENTS AT CANCER DISEASES HOSPITAL, LUSAKA, ZAMBIA

BY:

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A dissertation submitted to the University of Zambia, in partial fulfillment of the requirements for the Award of the Master of Science in Clinical Nursing.

The University of Zambia

Lusaka

2019
DECLARATION

I, Beauty Lilala Namushi, hereby declare that the work on which this dissertation is based, is my original work and declare that neither the whole work no any part of it has been, is being, or is to be submitted for another degree in this or another university.

Signed……………………………………….
Date………………………………………….

Candidate

Signed……………………………………….
Date………………………………………….

Supervisor
APPROVAL

I, Beauty Lilala Namushi, hereby declare that the work on which this dissertation is based, is my original work and declare that neither the whole work no any part of it has been, is being, or is to be submitted for another degree in this or another university.

Examiner 1……………………………….. Signature………………………Date………………

Examiner 2……………………………… Signature……………………… Date………………

Examiner 3………………………………..Signature………………………… Date………………

Chairperson

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Examiners

Supervisor ..........................Signature .......................... Date………………
ABSTRACT
Breast cancer is the second most common cancer worldwide and the second most common among women in Zambia. The diagnosis of breast cancer is a stressful experience; therefore information provision is one of the most important factors for providing high quality cancer care across the whole cancer continuum. Understanding the information needs of breast cancer patients is significant in improving the care. The main objective of the study was to assess information needs of breast cancer patients at the Cancer Diseases Hospital in Lusaka, Zambia. A descriptive cross sectional design was used to elicit the information needs of breast cancer patients. One hundred and ten (110) participants were selected using simple random sampling method and data was collected using a modified structured interview schedule adopted from the Toronto Information Needs Questionnaire-Breast Cancer (TINQ-BC). Stata 10.0 (StataCorp, 2008) was employed for all quantitative data analysis. Logistic regression was done to examine the effect of each independent variable on information needs with a level of significance of p< 0.05 while controlling for the confounding effects of the other co-variates. The study revealed that 80% of the 110 respondents ranked information in all the five categories as moderately important. Of the five categories, the most important information participants ranked was from the subscale of investigative tests (76.4%), followed by treatment modalities (73.6%), physical and disease information were at 71.8% and lastly psychosocial needs (70%). The Logistic Regression analysis showed that ‘levels of anxiety, University Education, Presence of co-morbidites and being on treatment were significant factors influencing information needs of cancer patients (p values <0.05). The diagnosis of breast cancer is a stressful experience; therefore information provision is one of the most important factors for providing high quality cancer care across the whole cancer continuum. Appreciating the information needs of breast cancer patients is substantial in improving care. These findings suggest that increased information supply to cancer patients can be used as a management strategy by cancer care professionals, in particular the importance of an awareness of specific patterns of communication which may improve quality of life for cancer patients.

Key words: Information needs, Breast cancer, Breast cancer patients
DEDICATION

To my husband Lichilana, my children Tumelo, Tapelo, Lichilana, Tabo, Tuso, Lumba and my sister Ruth for their support, encouragement, understanding, prayers and being a source of inspiration and hope. May God bless them abundantly.
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# LIST OF ABBREVIATIONS

| Abbreviation | Full Form |
|--------------|-----------|
| ASCO         | American Society of Clinical Oncology |
| CDH          | Cancer Diseases Hospital |
| CMIS         | Comprehensive Model of Cancer Information Seeking |
| CPES         | Cancer Patient Experience Survey |
| DM           | Diabetis Mellitis |
| EBRT         | External Beam Radiation Therapy |
| ESMO         | European Society for Medical Oncology |
| FBC          | Full Blood Count |
| HAM-A        | Hamilton Anxiety Rating Scale |
| HDR          | High Dose Radiation |
| HTN          | Hypertension |
| NIH          | National Institute of Health |
| UNZABREC     | University of Zambia Biomedical Research Ethics Committee |
| UNZAPIC      | University of Zambia Post Graduate International Conference |
| UTH          | University Teaching Hospital |
| WHO          | World Health Organisation |
CHAPTER 1

1.1 Introduction

“Information is a resource that is naturally needed in all human endeavors. One can readily infer that information is indispensable in human life, hence a basic human need, which has an overriding significance to all and diverse” (Olarongbe et al, 2013). Yusuf (2012) stated that “the growth of modern societies as well as individuals depends a great deal upon the provision of the right kind of information”. When information is provided in a right form and at the right time it is able to assist patients make right decisions and reduce uncertainty. Recognizing that the description of tumor characteristics is embedded in medical terminologies which are foreign to most people, the National Institute of Health (NIH, 2015) suggested that communicating among the health care team, the cancer patients and the family care givers is important in improving the patients’ well-being and quality of life. Furthermore moving into an age of personalized cancer care, where treatment decisions are tailored towards individual cancer characteristics, it is important that cancer patients receive information prior to and during treatment (Daly, 2015). Therefore in view of the importance of information exchange and treatment decision-making in cancer care, the study assessed information needs as this is crucial in therapeutic intervention and quality cancer care.

1.2 Background

Cancer is a leading cause of disease worldwide with an estimated 14.1 million new cases for the year 2012 and 8.2 million deaths, representing a rise from the 2008 rates when there were 12.7 million new cases and 7.6 million related deaths (Ferlay et al, 2013). In females breast cancer is the most common cancer diagnosed accounting for 23% of the total cancer cases and 14% of mortality from cancer (Jemal et al, 2011). World Health Organization (WHO) reported an increased burden of breast cancer in both the developed and less developed world which was attributed to the risk factors related to the aging and growth of the population as well as increased prevalence of risk factors associated with economic transition, including smoking, obesity, physical inactivity, and reproductive behaviours (WHO, 2013; Jemal et al, 2011).

In Africa 847, 000 new cancer cases (6% of the world total) and 591,000 deaths (7.2% of the world total) were reported in the 54 countries in 2012 of which three quarters of these were in the 47 countries of Sub-Saharan Africa (Parkin et al, 2014). Parkin and others (2014) further stated that “while the cancer profiles often differ markedly between regions, the most common cancers
in men were prostate (16.4% of new cancers), liver (10.7%) and Kaposi sarcoma (6.7%); in women, by far the most important are cancers of the breast (27.6% of all cancers) and cervix uteri (20.4%)”.

In Zambia, breast cancer is the second common cancer among women after cervical cancer representing 8% of total cancer cases seen at the Cancer Diseases Hospital (CDH) with an age adjusted rate of 45 years (CDH, 2016). A comprehensive assessment of breast and Cervical Cancer Control in Zambia (2015) reported that in 2010, there were an estimated 1,007 new breast cancer cases and 359 breast cancer deaths. While there is limited information on how prevalent the disease is in Zambia, the comprehensive assessment of breast and Cervical Cancer Control in Zambia (2015) report indicates that breast cancer incidence has been increasing.

Cancer is a major life-threatening disease regardless of the stage at which the diagnosis is made. People who are diagnosed with this disease become psychologically and emotionally stressed (Al-Amri, 2010; Katowa et al, 2015). Those diagnosed encounter stress, anxiety, fear of death and sense of loss of hope (Al-Amri 2010). The diagnosis of Breast Cancer is not an exceptional; it also creates emotional distress for patients as well as family members (Holmes, 2008; Ganz, 2008; Ankem, 2015). Although recent breast cancer treatments are advanced and cause less bodily distortion from surgery than before, the disease and more complex and prolonged treatments over a period of time cause patients to experience treatment-related distress, fear of recurrence, altered body image and sexuality, as well as physical toxicities that result from adjuvant therapy which alter the quality of life (Ganz, 2008; Holmes, 2008).

Since breast cancer and the consequent treatment is highly traumatizing the ability of patients to cope with the disease may be dependent on meeting their information needs. Studies have indicated that perceiving information needs and meeting them help patients be well informed, leading to better health outcomes (Husson et al, 2011;). The value of meeting the information needs of patients with life limiting conditions such as Breast cancer is very critical because a patient’s misunderstanding of a condition and its care can result in non-compliance to a doctor’s recommendations, significantly and adversely affecting outcomes. Adequately informed patients are able to manage their disease and are more involved with their treatment choices and health care. Research published in Korea by Yi et al, (2007) showed that patients with Breast Cancer
benefit in terms of knowledge acquisition. The Study stated that “patients with cancer who had been adequately informed about their illness and treatment were better able to reduce their feelings of distress, cope with the uncertainty of the illness, and be more satisfied with the care” (Yi et al 2007). In addition Breast cancer treatments can be extremely intimidating, therefore adequate knowledge about what can be expected during and after treatment is important. Provision of information can help these patients in terms of physiological as well as psychological outcomes, enabling them to regain control over their lives and participate fully with treatment.

Some studies have reported valuable findings regarding the advantages of meeting information needs of Breast Cancer patients which include patients’ improved adherence to therapy, increased abilities to cope with the illness and more appropriate use of health service resources (Husson et al, 2011). In order to achieve these meaningful health outcomes Breast Cancer patients’ participation in the care is very important and this can only be done if these patients have sufficient information to help them make decisions. Vahdat et al (2014) defined patient participation as “patient’s involvement in decision making, which consist of sharing information and accepting health team instructions”. Therefore for patients with chronic illnesses such as breast cancer to be able to participate in the care, they need timely, high-quality information about health and medical issues during the disease trajectory and throughout their lifetime to improve self-care and maximize quality of life (Matter et al, 2009).

Although information satisfaction is a major predictor of quality of life, the patients’ ultimate health outcome is greatly influenced by the way they deal with the information received during their illness. With several studies documenting the benefits of providing adequate information (Yi et al, 2007, Eheman, 2009, Li, 2011, Lei et al, 2011), unmet information needs are associated with negative health-related quality of life (Ladd, 2016); such as high levels of anxiety and depression (Halkett et al, 2012); negative illness perceptions, unrealistic expectations, sometimes costly legal actions and failure for patients to give an informed consent (pif, 2012). In order to mitigate these negative effects Breast Cancer patients’ information needs should be met.

While information has the potential of helping Breast Cancer patients make sound decisions in their care, several views have been noted by different studies on the concept of information needs. Researchers have stated that its definition is either “ambiguous” or it has “several meanings
depending on the situation” (Calza et al, 2010; Pieper et al, 2015). Calza and others (2010) studied information needs of patients in Europe and found that information as a concept is related to “meaning, knowledge, instruction, communication, representation, and mental stimulus. In a systematic review of studies analysing the need for health-related information in Germany, information needs were defined as a patients’ recognition of having insufficient knowledge to satisfy a goal within the context they found themselves in at a specific time (Pieper, 2015). In addition theories of information seeking refer to the concept of information needs, a state in which an individual is motivated to seek information because of the situation they find themselves in and this is done in order to lessen uncertainty, find answers or make sense of a situation (Case, 2002; Yusuf, 2012).

With the growing use of the internet in gathering health information, the idea of the informed patient has become very vital (Hans, 2010; Yusuf, 2012). However, according to the Cancer Patient Experience Survey (CPES) conducted in 2013, it was found that 18–30% of all people affected by cancer do not receive sufficient information. Tucker et al, (2017) noted that in meeting the information needs of Breast Cancer patients, important considerations must be put in place as there are several factors that may affect these patients as they seek information. Patient information needs may be affected by psychological characteristics such as being an ‘information seeker’ or not, preferences for different information formats or learning styles, sociodemographic characteristics such as age, educational level, presence of comorbidities, and where a patient is on the cancer journey.

Even with great efforts put across with regards to palliative care, radiotherapy and chemotherapy treatment in ensuring that patients receive quality care at Cancer Diseases Hospital, challenges still remain in meeting information needs of breast cancer patients and these include; Patchy and poor coverage of palliative care services due lack of trained personnel and increase in cancer burden though meeting the information needs of patients with progressive, life limiting conditions and their families, in a timely and appropriate way, is a key concern of palliative care. Shortage of oncology trained clinicians leading to insufficient information provision from the few who are stressed out and lack of training in breaking of bad news leading to insensitivity when breaking bad news and fear of scaring patients.
Despite, literature showing an association between meeting information needs and quality cancer care (Shea-Budggel, 2014). In Zambia not many studies have been conducted to explore the information needs of Breast Cancer patients. In an effort to assist the clinicians in understanding and addressing the information needs of breast cancer patients, this study provided an insight on the health information needs of breast cancer patients.

1.3 Problem Statement

The high burden of non-communicable diseases that Zambia is experiencing has significant consequences on mortality and morbidity and cancer has a substantial contribution among the major four non-communicable diseases (MOH, 2016). The high burden of disease in Zambia has also been seen in patients with Breast Cancer. According to data from CDH, Breast Cancer new patients seen at Cancer Diseases Hospital increased from 6.4% in 2014 to 8% in December, 2016 and yet the two year survival rate among women treated remains below 50% due to late stage at diagnosis (CDH, 2016). Breast cancer can lead to limitations in daily activities, reduce health-related quality of life, contribute to debilitating pain and depression and increase the use of emergency healthcare and hospitalizations.

Due to the high burden of breast cancer patients seen at CDH, it is likely that information giving to patients maybe lacking. In view of this, it may not be possible to elicit for information needs of patients because as the number continues to grow at a steady pace health care workers are spending less time with patients leading to lower contact time. This leads to inadequacies in identifying information needs at the point of care, and accurately and efficiently meeting this need.

In addition the human resource crisis can also be a hindrance to information giving. Inadequate numbers of trained specialized health care workers can lead to decreased attention towards information provision and needs due to the gap between the health care provider and patient ratio (MOH, 2016). Unpublished survey that was done at Cancer Diseases Hospital in 2016 revealed patients being inadequately informed about their condition. In addition patients observed that information provided was not standardized and the mode of transmission was limited. Therefore, there was need to assess the information needs among Breast Cancer patients as recognizing these needs is one of the important aspects in health care delivery because it makes the health care provider-patient encounters more meaningful.
1.4 Significance of the Study

This study was conducted to assess the information needs of breast cancer patients at CDH. The study of assessing the information needs of breast cancer patients was very important as it has brought out information needs of breast cancer patients which will help health care professionals to provide information that is important, in turn facilitating decision making and helping patients to cope with the whole cancer trajectory. In addition the study has provided useful information that will help in setting more effective models of delivering information and thereby providing support to breast cancer patients.

1.5 Conceptual Framework

Johnson’s Comprehensive Model of Cancer Information Seeking (CMIS) was used to conceptualize information needs of patients with breast cancer (figure 1.1). CMIS is categorized into three components that include antecedent factors, information carrier factors and information seeking behaviors (Han et al, 2011). The CMIS theorizes that four health-related factors (demographics, direct experience, salience, and beliefs) and two information carrier factors (characteristics, utility) combine to influence information seeking. Studies have shown that demographic factors such as age, income status and education predict differential use of various health information resources (Han, 2011; Pang, 2014). In these studies age influenced information seeking as it was shown that younger aged Breast Cancer patients were more likely to seek information than the older ones. In the context of health information seeking, direct experience refers to an individual personally having the health issue motivating them to look for information (Han et al, 2011). This shows that direct experience with a stressor predicts health information seeking. Therefore a person’s own symptoms or experience with the cancer diagnosis or treatment may influence information seeking.

Salience refers to the perceived threat of the health issue and personal significance of health information, and beliefs are individuals’ perceptions that they can do something about the issue. The challenges resulting from breast cancer diagnosis and its treatment are diverse and complex hence the need for information needs to be met. Salience and beliefs are motivational factors for seeking health information to fill a knowledge gap (Ladd, 2016). Pang (2014) explained that Salience is one of the concepts in CMIS which refers to the personal importance of health information that provides a key stimulus to seek information. For instance individuals may
perceive risks with their health and how the missing information is recognized to be significant will result in seeking information to determine the implications of health events for themselves. Beliefs on the other hand, can constrain or empower individuals to seek information. If an individual believes that the information accessed will be helpful in improving the condition they are in or coping with the crisis, they will likely seek information (Pang, 2014; Ladd, 2014).

Information carrier characteristics refer to the content and style of the message presented (e.g., quality), while utility refers to the perceived personal usefulness of the message. Information carrier factors determine the purpose to seek information from certain carriers. The term “carrier” in the CMIS model is used to describe any informational source or information channel which may include the print, video or physician (Ladd, 2014). For most Breast Cancer patients, CMIS studies have shown that sources with authority like physicians are typically the most respected and sought after (Johnson, 2003). Below is the figure of Johnson’s comprehensive model of cancer information seeking (Figure 1.1)
Figure 1.1: Johnson’s Comprehensive Model of Cancer Information Seeking

Source: Ladd, 2014
1.6 Research Questions

1.6.1 What information do breast cancer patients desire to receive and understand regarding their disease?

1.6.2 Do certain demographic and clinical characteristics (age, education level, stage of cancer, time since diagnosis) influence the information needs of breast cancer patients at CDH?

1.7 Research Objective

1.7.1 Main Objectives
The main objective of the study was to assess information needs of breast cancer patients at Cancer Diseases Hospital in Lusaka, Zambia.

1.7.2 Specific Objectives

1.7.2.1 To determine the information that breast cancer patients’ desire to know with regards to their disease.

1.7.2.2 To establish the factors influencing information needs.

1.8 Conceptual and Operational Definitions

1.8.1 Conceptual definitions

Information

These are facts that are accurate and timely, specific and organized for a purpose, presented within a context that gives meaning and relevance and can lead to an increase in understanding and decrease in uncertainty (Online business dictionary, 2012).

Breast cancer

Breast cancer is a malignant (cancerous) growth that begins in the tissues of the breast (Williams et al, 2011).
Information needs

A patient information need is a recognition that knowledge is inadequate to satisfy a goal, within the context or situation that someone finds themselves in at a specific point in time (Ormandy. 2011).

Diagnosis

The identification of a disease condition based on a specific evaluation of physical signs, symptoms, the client’s medical history and the results of diagnostic tests and procedures (Potter and Perry, 2009).

Cancer treatment

Cancer treatment is the involvement of medical procedures to destroy, modify, control, or remove primary, regional, or metastatic cancer tissue (National Institutes of Health, 2015).

Prognosis

Guess of the likely order and outcome of an attack of a disease and the projections of recovery as indicated by the nature of the disease and symptoms of the case (Medical dictionary, 2012).

1.8.2 Operational Definitions

Information

These are facts concerning breast cancer diagnosis, treatment and prognosis given by medical personnel to breast cancer patients that gives it meaning and relevance, and can lead to an increase in understanding and decrease in uncertainty.

Information need

Information need is breast cancer patients’ desire to locate and obtain information to satisfy a conscious or unconscious need and a requirement that drives them into information seeking. It evolves from an awareness of something missing, which necessitates the seeking of information that might contribute to understanding and meaning.
1.9 Study Variables

1.9.1 Dependent Variable

The dependent variable for this study was Information needs of breast cancer patients.

1.9.2 Independent Variable

The independent variables for this study were the following:

1.9.2.1 Anxiety

1.9.2.2 Age

1.9.2.3 Education level

1.9.2.4 Stage of cancer

1.9.2.5 Time since diagnosis

1.9.2.6 Co-morbidities
### 1.9.3 Variable cut off-points

Below is a table for variable cut-off points

**Table 1.1 Variable cut off-point**

| VARIABLES                  | INDICATORS                           | SCORE       | CUT-OFF POINTS              | QUESTION NUMBER |
|-----------------------------|---------------------------------------|-------------|-----------------------------|-----------------|
| **Dependent Variables**     |                                       |             |                             |                 |
| Information needs           | Low importance                       | Less than 100 | Less than 50%               | 26- 68          |
|                             | Moderately Important                  | 100 – 140   | 50%- 70%                    |                 |
|                             | Highly important                      | 141-200     | 70 % and above              |                 |
| **Independent variables**   |                                       |             |                             |                 |
| Age                         | Young                                 | Less than 50 | Below 50 years              | 1               |
|                             | Old                                   | above 50 yeas | Above 50 years              |                 |
| Marital status              | Married                               | Yes         | Married                     |                 |
|                             | Single                                | No          | Single/Widowed/Divorced     |                 |
| Education level             | Educated                              | Yes         | Primary/Secondary/College/ university | 2 |
|                             | Non educated                          | No          | Not been to school          |                 |
| Anxiety                     | Mild Anxiety                          | 14 – 27     | Less than 50%               | 12-25           |
|                             | Moderate Anxiety                      | 28-39.2     | Between 50-70%              |                 |
|                             | Severe Anxiety                        | Above 39    | Above 70%                   |                 |
CHAPTER 2
LITERATURE REVIEW

2.1 Introduction
A literature review surveys books, scholarly articles, and any other sources relevant to a particular issue, area of research, or theory, and by so doing, provides a description, summary, and critical evaluation of these works in relation to the research problem being investigated (Arlene, 2014). It is designed to provide an overview of sources explored while researching a particular topic and to demonstrate how the research fits within a larger field of study. This chapter focuses on information needs of breast cancer patients. Various search engines were used to search for literature and these included; Pub Med, Google Scholar, Google books, Medline, online journals and others. In this study the literature review is arranged according to the study objectives.

2.2 Overview of Information Needs for breast cancer patients
Information needs of breast cancer patients have been investigated by several studies especially in the western countries, which have revealed the importance of information provision in cancer care. A study conducted in Switzerland on the exploration of cancer information-seeking experiences revealed that information is vital for patients in coping with the diagnosis of cancer and making decisions about treatment plans (Germen et al, 2015). Information needs lead to information seeking and Germeni et al (2015) defined cancer information seeking behavior as the “purposive or goal driven acquisition of cancer related information” and identified it as a key coping strategy that can enable individuals to deal with stressful illness-related events, such as the shock of initial diagnosis. The concept of health information seeking behavior is an important notion in the field of health communication as information is an essential part of cancer management access to it is a basic fundamental right (Yusuf, 2012). Studies of information needs are not new in the field of health communication, both previous and current studies that have investigated the importance of meeting information needs of Breast Cancer patients have shown that these patients need information to help them understand the disease, its treatment and allow them to interpret the aversive events and action taken, so that the threat inherent from the diagnosis becomes lessened (Lee et al, 2004; Teriman et al, 2014).
Individuals in life-threatening situations need information to understand the implications for their well-being. Breast Cancer patients want more information on why and how they can expect to physically respond to treatment, the medical management of the disease, and side effects of treatments (Lee, 2004; Teriman et al, 2014). In a longitudinal study that was conducted in Malaysia by Lei et al (2011) they found that Breast Cancer patients have high levels of information needs and it is helpful for them to gather information because it empowers them to take control of their healthcare and comply with the treatment. Similarly Teriman and others (2014) noted that there is an association between patient empowerment in meeting information needs and satisfaction with care. Patients who have no access to quality information are more likely to seek information elsewhere from less trustworthy sources. Hence unreliable information can lead to incorrect self-diagnosis and/or increased feelings of anxiety and stress (Macmillan Cancer Support, 2010).

However, much as studies in the field of health information have shown that a well-informed patient may also be better equipped to guard against medical error; other studies have shown that not all patients need information for fear of mental discomfort (Germeni et al, 2015). In a study conducted by Leydon (2000) among cancer patients on the factors affecting patients’ uptake of information, He concluded that patients’ orientations toward faith, hope and charity may cause them to avoid disease related information in order to maintain hope.

2.3 Information Needs of Breast Cancer Patients

The concept of information need is a complex and difficult notion to describe even though information has been around for ages and a basic fundamental right (Yusuf, 2012). According to Yusuf (2012), information need is described as a recognized mental state in which an individual’s need causes the search behavior of information seeking in a given context. The diagnosis of breast cancer can be so disturbing that it causes several adverse reactions for the majority of women. Many women develop symptoms of psychological distress such as anxiety, depression, fatigue and pain among others (Al-Aziri, 2014; Kalusopa, 2014). The situation necessitates an inquiry of the information cancer patients need. An understanding of their information needs can help tailor patient education to empower and to support coping. It can also guide health care professionals in delivery of care (Ankem, 2015). To cope with the stress of this diagnosis, women tend to adopt a number of strategies on how to deal with the diagnosis and redefine themselves and their lives
accordingly. These may include turning to God through prayer, seeking for information and family support (Katowa, 2015).

Abrahamson (2010) in United States of America conceptualized need in the context of cancer treatment as a resource necessary for patients and families to live and function with the diagnosis of cancer. Information needs are prevalent among Breast Cancer patients. The information needs of Breast Cancer patients are caused by a variety of factors including the disease itself, treatment, side effects, investigations, fear of death and social life. Therefore, information needs assessments are essential because they guide care planning, in that many caregivers and patients do not communicate concerns to their health professionals. In a European survey conducted by Maddock (2010) the study showed that patients are becoming more active consumers of health-related information. It is clear that information is vital in coping with breast cancer; therefore information is an important part of cancer care. With the improved cancer treatments Breast cancer patients are becoming long term survivors and are experiencing long term side effects from the treatments. Assessing which information needs are of highest priority and prioritizing them has been reported to make patient encounters more meaningful (Teriman et al, 2014). Teriman et al, (2014), further found out that the top three information priorities included prognosis, disease, and treatments. In addition Lorefice et al (2013) found that despite the overall satisfaction of sclerosis patients with how they were diagnosed the majority (76%) sought information about the disease.

Similarly many patients desire to be informed about the exact nature of their disease, despite cultural and geographical differences among them (Al-Amri, 2010). Motlagh et al (2014) also found that in many different studies 79% to 98% of patients desired to know their diagnosis. Other researches have reported home self-care, effect of disease on family and friends, effect of treatment on social activities, and effect of treatment on sexual attractiveness as information needs (Li et al., 2011).

In addition, researching on preferred information Mekuria et al (2016) also concluded that the principal information regarded as the most important by the majority of the patients was on the specific type of cancer (name and stage of cancer), followed by the side effects of chemotherapy and its management (63.29%) and “prognosis (survival)” (51.8%). They further added that the majority of their respondents (70.3%) were not satisfied at all or satisfied a little with the
information regarding cancer. Therefore these findings suggest that breast cancer patients want information on disease, treatment and prognosis.

**Treatment information needs**

Diagnosis and disease have a significant bearing on patients' medicine-information desires (Duggan and Bates, 2008). In addition studies by Ladd (2016) and Greco et al (2016) reported patients searching for medical information which included facts on chemotherapy, radiotherapy, and surgery. Following 104 patients in a study on whether information needs decrease over the course of radiotherapy treatment, the researchers found that the needs remained high despite the duration between the initial consultation and first follow-up (Douma et al, 2012).

**Prognostic information needs**

Prognostic information is necessary for cancer patients to be fully informed about the likely course of their disease and the information is needed for practical planning and treatment decisions (Cartwright, 2014). Although it was important for cancer patients to be informed about their prognosis, this need was not met as the study found that it was uncomfortable for both the physicians and patients were quick to shift from discussing the patient’s cancer and diagnosis to discussing treatment options (Ghandourh, 2016).

2.4: Factors influencing information needs

Studies suggest that there are several factors that have been found to influence information needs which include anxiety, age, education level, stage of cancer, presence of comorbidities and time since diagnosis (Ankem, 2012, Jensen et al, 2014, Tan et al, 2015). Demographics and clinical background of patients have contributed to different patients having various information needs. Tucker (2017) noted that understanding that demographics influence information needs and meeting them are crucial to improving the quality of care for Breast Cancer patients. Similarly in a study conducted in China by Bei (2015) demographic and clinical characteristics were shown to influence information needs.

**Anxiety**

In her study on defining information needs in health, Ormandy (2010) noted that psychological states of anxiety, depression and feelings of control affect information needs. She further stated that “an individual could experience cognitive uncertainty manifesting as anxiety resulting from
their judgment of the knowledge required to overcome challenges or problems”. A study by Beekers et al (2015) showed a relationship between the severity of the disease and the patients’ anxiety and depression which they concluded that providing cancer patients with information decrease concerns about the adverse effects of psychological disorders on physical performance, life expectancy and personal and social relationships.

In another study Zadeh et al (2016) showed that some cancer patients prefer to first receive information about stress disorders, because many patients develop psychological complications such as anxiety and depression after the diagnosis of cancer which is intensified by difficult therapies such as surgery and chemotherapy.

**Age**

Younger age has been associated with actively seeking information (Eheman et al, 2009). In addition Chaudhuri et al (2013) noted in the study examining health information–seeking behaviors of older adults for cancer survivors that older women were less likely to seek information compared with their younger counterparts. Generational differences were also noted to affect information needs and source preferences as young patients were likely to seek information from other sources such as the internet compared to older women who prefer more passive roles and express less need for information (Tucker, 2017). She further found that younger women with breast cancer experience difficult situations that cause them to look for information such as treatment-related sexual dysfunction.

**Education**

Higher educational attainment has been associated with actively seeking information beyond that available in the medical care setting (Tucker, 2017; Eheman et al, 2009). In a study on understanding health information seeking behaviors of adults with low literacy, it was found that the uneducated do not seek information as they are likely to miscommunicate with their health providers (Feinberg et al, 2015). Similarly Tucker (2017) stated “that inadequate health literacy poses barriers to patients’ understanding of their disease and treatment options”. Hence lower educational level has been found to be associated with less active information-seeking style.
Time since diagnosis and stage of cancer

The time since cancer diagnosis and the degree of illness have also been shown to influence how much and what information a patient desires (Eheman et al, 2009). According to a study by Zadeh et al (2016) they suggested that cancer patients’ information needs are determined by the progress of the treatment and the time elapsed since the diagnosis of the disease. They further found that those who have been living with the disease for a long period and completed treatment have less information needs compared to the newly diagnosed. In addition King et al (2015) noted that patients’ still receiving treatment had more information needs than those on palliative care or recovering. In another study the information needs were necessitated by the type of cancer and the need was more pronounced in patients with early-stage disease (Nagler et al, 2010).

2.5 Conclusion

Researchers have noted that health information seeking behaviour has become an important concept in the field of health communication and for people diagnosed with cancer, both the opportunity to provide input about their care and having information about their disease; prognosis and options for treatment are vital (Eheman, 2009, Germeni et al, 2015). Abrahamson et al (2010) stated that “Within the context of cancer treatment, needs are defined as resources necessary for patients and families to live and function with a diagnosis of cancer”. These findings suggest that for breast cancer patients to be able to cope with the diagnosis and complex treatments they go through information is important. Hence Henselmans et al (2011) further suggested that physicians require insight in the type and content of these needs in order to improve the quality of cancer care. Noting from above, a large number of studies have been conducted of cancer patients’ information needs, how they seek information and how they use it. Almost all the literature that has been presented is from the western world and not much has been published from Zambia, hence a study in this area will help in identifying strategies that will help care providers offer relevant information needed by this patient population.
CHAPTER 3
METHODOLOGY

3.1 Introduction

This chapter describes the methodological techniques used in this study. They include details of the study design, study setting, sample criteria, instrument, pilot study, data collection tools, data management and analysis. Ethical considerations and plans for dissemination are equally presented.

3.2 Study Design

A descriptive, non-intervention, cross sectional design was used to investigate the problem under study. The study was non-intervention because the investigator did not introduce any form of intervention or any control group. A Cross-sectional design was used in this study because the designs of this nature are useful in assessing practices, attitudes, information and beliefs of a population in relation to a particular health related event. Therefore a descriptive study was used so as to collect rich data in large amounts that could be a basis for further research using different research techniques. The results from this study will not only give an indication of the information needs of breast cancer patients at CDH, but also provide a basis for designing appropriate planned and systematic approach of meeting information needs of cancer patients.

3.3 Research Setting

The study was conducted at Cancer Diseases Hospital (CDH), a government hospital serving patients from across the country and neighbouring countries. It offers specialist in-patient and out-patient services and serves as a referral hospital for all confirmed cancer cases in Zambia. The hospital offers various services which include treatment with chemotherapy and radiotherapy as major treatment modalities for management of cancer. Other services offered are patient screening, laboratory, and follow-up care. There are two days in a week namely Tuesday and Wednesday allocated to breast cancer patients in terms of screening of new patients follow-up respectively.

Being the only Cancer Diseases Hospital in the country, the in- patient department was opened in 2016 with a bed capacity of 262 for admissions and has wards for paediatric, adult male and
female patients. The study setting was the most suitable place for the researcher to capture the target population as cancer patients from all over the country are treated at this facility.

3.4 Study Population

The population for the study comprised all breast cancer patients aged 18 years and above who were being treated for cancer or being followed-up at Cancer Diseases Hospital from April 2006 to September 2017.

3.5 Sample Selection

Convenience sampling a non-probability sampling method was used to select the study setting because it is the only Cancer Diseases Hospital in the country. This was the most suitable place for the researcher to capture the target population as cancer patients from all over the country are referred and treated at this facility. Participants were selected using simple random sampling method. In simple random sampling each member of population is equally likely to be chosen as part of the sample. It has been stated that “the reasoning behind simple random sampling is that it removes bias from the selection procedure and should result in representative samples” (Gravetter and Forzano, 2011). At CDH twenty-five breast cancer patients are seen every week as out patients. Therefore twenty-five pieces of paper were written and put in a box, twenty of them had a YES written on them while the other five had a NO and those patients who picked a YES were recruited in the study excluding those with a NO.

3.6 Eligibility Criteria

3.6.1 Inclusion criteria

The inclusion criteria included all breast cancer patients seen at CDH from 2006 to September 2017. These included those who were aged 18 years and above, confirmed diagnosis of breast cancer and living with breast cancer diagnosis, those willing to participate in the study and those who were physically and cognitively able to participate in the interview process.

3.6.2 Exclusion Criteria

The study excluded new patients who were just being screened on the day for interviews. Those who were eligible but did not consent and the physically and cognitively unstable patients also excluded.
3.7 Sample Size

The sample size was calculated using the proportion precision formula;

\[ n = Z^2 \times P(1-P) / d^2 \]

Where;

- \( n \) = Sample Required
- \( Z = 1.96 \) is the standard normal variate at 95% confidence level
- \( P = \) the expected prevalence (0.08)
- \( d = \) acceptable accuracy range (+/-0.05)

The sample size was calculated at 95% confidence level \((Z = 1.96)\) with 8% \((p = 0.08)\) prevalence of breast cancer cases at CDH \((CDH \text{ Annual report, 2016})\) and Precision of ±5% \((d = \pm 5\%\).

Sample size calculation

\[ n = Z^2 \times P(1-P) / d^2 \]

\[ n = 1.96^2 \times 0.08 \times (1-0.08) / 0.05^2 \]

\[ n = 113 \]

The sample size was one hundred and thirteen respondents (113).

3.8 Data Collection Tool

A structured interview schedule was used to collect data for this study. The tool had five sections which included (a) Demographic data, (b) Medical related data, (c) Anxiety rating scale, (d) information needs and (e) Barriers to information provision. The interview schedule was constructed in English. Translation of the information sheets was done into the four common languages in Lusaka and these were Nyanja, Bemba, Tonga and Lozi so as to help the participant’s understand the purpose, benefits and risks of the study.

Two separate tools were adopted and used which contained constructed questions. These were the Hamilton Anxiety Rating Scale (HAM-A) which was used to measure the anxiety section and the Toronto Information Needs Questionnaire-Breast Cancer (TINQ-BC) which was used to evaluate the informational needs of breast cancer patients. The Hamilton Anxiety Rating Scale (HAM-A)
was also adopted from occupational medicine and used in measuring the patient's anxiety (Thompson, 2015). It is a widely used and well-validated tool for measuring the severity of a patient's anxiety. The scale consists of 14 items, each defined by a series of symptoms and measures both psychic anxiety (mental agitation and psychological distress) and somatic anxiety (physical complaints related to anxiety) with the sensitivity of 85.7% and specificity of 63.5% (Thompson, 2015). Each item is scored on a 5-point scale, ranging from 0 = not present to 4 = severe with a total score range of 0–56, where 14 – 27 indicates mild anxiety, 28-39 moderate anxiety and more than 40 as severe anxiety. The HAM-A was one of the first rating scales developed to measure the severity of anxiety symptoms, and is still widely used today in both clinical and research settings (Shear et al., 2001; Thompson, 2015).

A modified structured interview schedule adopted from the Toronto Information Needs Questionnaire-Breast Cancer (TINQ-BC) was used to evaluate the informational needs of breast cancer patients (Galloway et al., 1997). The tool was developed to assess the specific information needs of women with breast cancer and comprised five subscales which included disease, investigative tests, treatment options, physical, and psychosocial needs. Each item on the questionnaire began with the stem: “To help me with my illness it is important for me to know.” Participants were asked to rate the importance of each item on a Likert-type scale with one = “not important”, two, = “slightly important”, three = “moderately important”, four = “very important”, and five = “extremely important”. The overall score for information needs was obtained by adding all the scores across all the 5 information needs categories. Therefore, for each patient the information needs score was between minimum 40 units and maximum 200 units. Further, the scores on the information needs were divided into three categories; low important scores were less than 50% of 200, moderately important was from 50%–70% and highly important scores ranged above 70%. This tool was chosen for this study because it meets the criteria of measuring the information needs of breast cancer patients as it had been tested and found effective by many researchers. It also afforded patients to rate the important information that they need. The operational definitions of the subscales are shown below as adopted from Spittler (2011).
Table 3.1: Operational Definitions of the TINQ-BC Subscales as adopted from Spittler, 2011

| Subscale                | Definition                                                                                   |
|-------------------------|---------------------------------------------------------------------------------------------|
| Disease                 | Knowledge of the disease process of breast cancer                                           |
| Investigative Tests     | Procedures used to assess the type and extent of disease process, how and why tests are performed and side effects that may be experienced |
| Treatment Options       | Breast Conservation Surgery, Mastectomy, Mastectomy with Reconstruction, Chemotherapy, Radiation therapy, Anti-Hormone Therapy or a combination of therapies |
| Physical Needs          | Knowledge needed to prevent physical problems, restore body systems, and maintain body care and functioning. |
| Psychosocial Needs      | Body image concerns, relationships with others, emotional concerns, spirituality issues, financial worries, and fears of death and dying |

3.9 Validity
Content and construct validity was used to ensure validity of the research instrument. Content validity is concerned with the relevance and representativeness of items, such as individual questions in a questionnaire, to the intended setting (Roberts and Helena, 2006). To ensure the validity of the instrument, the questionnaire had content validity based on findings in the literature and opinions of expert researchers and questions were constructed in a simple and specific way in order for the respondents to understand clearly so as to avoid vagueness. The instrument used was adopted from the Toronto Information needs questionnaire- breast cancer which was developed and tested in Canada and had been successfully utilized by various studies (Yi, 2007; Ankem, 2005; Galloway et al, 1997).

3.10 Reliability
To ensure reliability of the research instrument, a pilot study was conducted to test the research instrument before the main study. Adjustments were made to the questionnaire as only those question which where applicable were included.
3.11 Data Collection Techniques

After the ethical clearance was granted from the University of Zambia, Biomedical Research Ethics Committee and permission sought from CDH, each interview was conducted by the researcher over a period of six weeks. The researcher introduced herself to the participants in order to make them feel at ease and participate without fear. The purpose, benefits and risks of the study were explained to the participants to enable them to get involved in a study that they are aware of. To enable the participants participate without fear, confidentiality was assured and they were informed that the interview was face to face in a private room. Written permission was sought from the participants to conduct interviews.

Participants were given time to go through the information sheet (appendix I) and afterwards were availed with the consent form (appendix II) on which they appended their signatures as endorsement to participate in the study. Assurances were given that all the information that was provided by the participants was treated with confidentiality. The researcher read the questions carefully to the participant so as to make them understand. Questions that were not understood were repeated without giving answers to the participants. All the responses were immediately noted down on the interview schedule to avoid missing out any information. The interview took approximately 20 minutes.

3.12 Pilot Study

A pilot study was conducted at Cancer Diseases Hospital to determine the reliability and validity of research instruments and test for feasibility of the study. CDH was used for testing the tool as it is the only hospital providing cancer services. The sample size of the pilot study was 10% of the actual study sample population, which translated to 11 respondents. The pilot study was conducted on patients who had come for review. Breast cancer patients who have finished treatment come for follow-up every three, four, six months or annually, therefore patients who participated in the pilot study could not be interviewed again within the six weeks in which the researcher collected data.

3.13. Ethical Considerations

Ethical clearance was obtained from the University of Zambia Biomedical Research Ethics Committee. Permission to conduct the study was also obtained from the CDH Management. Verbal
and written consent was obtained from the participants who participated in the study following a brief explanation on the purpose, procedure, discomforts and benefits of the study. Respondents were reassured of the right to participate or withdraw from the study and that no privileges were to be taken away if they decided not to take part while those who were willing to participate were made to sign the consent form.

The participants were assured of anonymity and confidentiality of personal information that was to be shared with the researcher, as no name was written on the interview schedule and the information given was not attached to any name.

Participants were not subjected to any physical harm as the research was not involving any invasive procedures. Since cancer is a traumating chronic disease some patients who experienced discomfort or stress due to the interview, were made to receive counselling immediately or afterwards depending on the need. Counselling was done by researcher who is a psychosocial counsellor and has been involved in counselling cancer patients and their families and thus the psychological needs were met as well as appropriate referrals. The participants might have been inconvenienced by the time that was spent when collecting data as collecting from an individual over a prolonged period might have affected them and this was addressed by making sure that the interview was conducted within twenty minutes or less. No rewards or monetary incentives were given to participants.

3.14 Data Analysis

After data was collected, the questionnaires were checked for completeness, consistency, legibility and accuracy in order to correct mistakes. Categorization of the open-ended questions, which involved reading through all responses and grouping answers that belonged together, was done. This enabled the researcher to report percentage of respondents giving answers that fell in each category. Codes were assigned to each category, entered and analysed using Stata10.0.

3.14.1. Statistical Analysis

Stata 10.0 (StataCorp, 2008) was employed for all quantitative data analysis and graphical presentation of data. Association between breast cancer patients’ information needs and eight independent variables including demographic and disease characteristics namely, Level of
Anxiety, Marital Status, Age Group, Education, Cancer Stage, Length of Illness, Presence of Co-morbidities, and Occupation were investigated.

The crude strength of association between having information needs and posited predictors information needs was estimated with Pearson's chi-squared test. All the variables determined to be having a statistically significant association with the primary outcome (significant level of p < 0.05 on the Chi$^2$ Statistic) were employed to conduct multivariate analysis in a logistic regression model. These variables also present as a priori determinants in future research. However, variables that do not indicate a crude association with the information needs (i.e. p>0.05) were all included in the final logistic regression multivariate model to be examined as possible confounders of information needs.
CHAPTER 4

PRESENTATION OF FINDINGS

4.1 Introduction

Chapter four presents the results of this study. The aim of the study was to assess the information needs of breast cancer patients at Cancer Diseases Hospital, in Lusaka. One hundred and ten (110) participants took part in the study representing the response rate of 97%. Structured interview schedules adopted from the Hamilton Anxiety Rating Scale (HAM-A) and the Toronto Information Needs Questionnaire-Breast Cancer were used in measuring the patient’s anxiety and evaluating the information needs of Breast Cancer patients respectively.

4.2 Data Presentation

Research findings have been presented according to the sections of the questionnaire. Some data were grouped together to give an overall picture. Data were presented using frequency tables, percentages and histograms to communicate research findings.

4.2.1 Section A: Socio-Demographic Data

The Social-demographic data that was collected comprised of age, marital status, education level and occupation. Findings have been presented in table 4:1 below.
Table 4.1 above shows that out of 110 participants recruited more than 50% of participants 63 (57.3%) were aged above 50 years. Most of the respondents, 56 (50.9%) were married. The least 13 (11.8%) participants were not educated. Close to 50% of the participants 50 (45.5%) were unemployed.
4.2.2 Section B: Breast Cancer Medical Information

This section included respondent’s medical related information such as, how long the respondents had lived with the diagnosis of breast cancer, the stage of the tumour at diagnosis, if they were on any treatment and the type of treatment they were receiving and if they had any co-morbidities. Findings have been presented in table 4.2 below

Table 4.2: Medical characteristics (n=110)

| Variable                      | Frequency (n=110) | Percent |
|-------------------------------|------------------|---------|
| **Duration with Breast Ca**   |                  |         |
| 1-4 years                     | 92               | 83.6    |
| 5-9 years                     | 14               | 12.7    |
| 10 years and above            | 4                | 3.6     |
| Total                         | 110              | 100     |
| **Tumor stage at diagnosis**  |                  |         |
| 0                             | 1                | 0.9     |
| I                             | 11               | 10.0    |
| II                            | 25               | 22.7    |
| III                           | 18               | 16.4    |
| IV                            | 15               | 13.6    |
| Unknown                       | 40               | 36.4    |
| Total                         | 110              | 100     |
| **On cancer treatment**       |                  |         |
| Yes                           | 93               | 84.6    |
| No                            | 17               | 15.4    |
| Total                         | 110              | 100     |
| **Type of treatment**         |                  |         |
| Chemotherapy                  | 41               | 37.3    |
| Radiotherapy                  | 9                | 8.2     |
| Chemo radiation               | 7                | 6.4     |
| Hormonal                      | 36               | 32.7    |
| N/A                           | 17               | 15.5    |
| Total                         | 110              | 100     |
| **Co-morbidity**              |                  |         |
| No previous illness           | 68               | 61.8    |
| Hypertension                  | 30               | 27.2    |
| DM & HTN                      | 5                | 5       |
| Others                        | 7                | 6.3     |
| Total                         | 110              | 100     |

 Majority 92 (83.6%) of the participants, reported to have been living with breast cancer for at least 1 – 4 years while those who had lived with the condition for 10 years or more were 4 (3.6%). A
total of 40 (36.4%) participants did not know the stage of cancer. Majority 93 (84.6%) of the participants were still on cancer treatment and among these, 32.7% were on hormonal treatment, 37.3% on chemotherapy, 8.2% on radiotherapy, and 15.5% had completed their treatment regimes. Among those with co-morbidities, 30 (27.2%) had hypertension while most of participants 68 (61.8%), reported not having any other illness apart from breast cancer.

4.2.3. Section C: Anxiety Levels of the Participants

This section consists of findings on the anxiety levels of the participants after the diagnosis. The Hamilton Anxiety Rating Scale (HAM-A) was adopted and used in measuring the patient’s anxiety (Thompson, 2015). This section covered 14 questions on a five point Likert scale: 0- Not present 1- mildly present, 2- Moderately present, 3- Severely present, 4- Very severe. This part of the questionnaire was giving a minimum score of 14 and maximum of 56. Further, the scores were divided into three categories; mild anxiety ranged from 14-28 scores, moderate anxiety from 29-39 and severe anxiety ranged above 39 scores.

A histogram below was used to present the results of the respondents’ anxiety levels.
Fig 4.1: Respondents anxiety Overall Levels (n=110)

Figure 4.1 above shows the respondents’ anxiety levels. When the respondents’ responses where collapsed into mild, moderate and severe anxious moods, the majority 80% of the respondents were moderately anxious, 10.9% had severe anxious mood, and only 9.1% had mild anxiety.
4.2.4. Section D: Information Needs

This section consists of findings on the information needs of Breast Cancer Patients. In order to assess the information needs of the participants, Item analysis determined that 41 items in five subscales should be retained in the questionnaire. The subscales were categorized as Disease, Investigative Tests, Treatments, Physical, and Psychosocial. Disease items were assessing information need about the nature, process and prognosis of disease. Treatment items assessed information need about various cancer treatments, how they work, performed, sensations that may be experienced and possible side effects. Investigative tests items assessed information need about procedures used to assess the extent of disease, how, why they are done and sensations that may be experienced. Physical items assessed information need about the preventive, restorative and maintenance care that may be needed as a result of the disease and treatments. Psychosocial items assessed information need about how to handle the patients' feelings. The section covered the questions on a five point Likert scale. The Likert scale scored informational needs items from 1 to 5 with 5 indicating the highest level of need. The scores were defined as: 5 = Extremely Important, 4 = Very Important, 3 = Moderately Important, 2 = slightly important, 1 = Not Important. The overall score for information needs was obtained by adding all the scores across all the 5 information needs categories (Table 4.1). Therefore, for each patient the information needs score was between minimum 40 units and maximum 200 units see table 4.3. Further, the scores on the information needs were divided into three categories; low important scores were less than 50%, moderately important was from 50%-70% and highly important scores ranged above 70% of 200 total scores.

Tables and histograms below were used to present the level of respondents’ information needs.
Table 4.3: Total overall scores of information needs categories

| Information Needs Categories | Number of information need questions | Minimum possible Rating | Maximum possible Rating per question | Minimum score per patient | Maximum score per patient |
|------------------------------|--------------------------------------|-------------------------|--------------------------------------|---------------------------|---------------------------|
| Disease Process              | 7                                    | 1                       | 5                                    | 7                         | 35                        |
| Investigative tests done     | 5                                    | 1                       | 5                                    | 5                         | 25                        |
| Treatment Modalities         | 15                                   | 1                       | 5                                    | 15                        | 75                        |
| Physical Needs               | 10                                   | 1                       | 5                                    | 10                        | 50                        |
| Psychosocial Needs           | 3                                    | 1                       | 5                                    | 3                         | 15                        |
| Total Possible Overall Score |                                      |                         |                                      | **40**                     | **200**                   |
Fig 4.2: Disease process information needs among Breast Cancer patients (n=110)

Figure 4.2 above shows the participants’ indication of information needs on disease process results. Out of the 110 participants that were recruited in the study, 71.8% of the participants were of the opinion that information was moderately important, 21.8% of them attached great importance to most indications of the disease process information needs and 6.4% were of the opinion that the information was of low importance.
Figure 4.3 above shows the participants’ indication of information needs on investigative tests. Out of the 110 participants who took part in study 76.4% of them were of the opinion that the information was moderately important whereas 18.2 % of the participants indicated that the information was highly important and only 5.5% indicated that it was of low importance.
Fig 4.4: Information on treatment modalities of Breast Cancer Patients (n=110)

Figure 4.4 above shows the participants scores of the information needs on treatment modalities. Out of the 110 participants who were recruited in the study, most 73.6% of the participants indicated that the treatment modalities information was of moderate importance whereas 18.2% of them indicated that it was highly important and 8.2% indicated it was of low importance.
Fig 4.5: Physical information needs of Breast Cancer Patients (n=110)

Figure 4.5 above shows the participants’ rating of the information on the physical needs. Out of the 110 participants who were recruited in the study, most 71.8% of the participants indicated that the information on physical needs was of moderate importance whereas 14.5% indicated that the information was of low importance and only 13.6% of them indicated that it highly important.
Fig 4.6: Psychosocial information needs of Breast Cancer Patients (n=110)

Figure 4.6 above shows the participants ratings of psychosocial information needs. Out of 110 participants who were recruited in the study, 70% of the participants indicated that the information was moderately important, 17.3% indicated the information was highly important and 12.7% participants’ were of the opinion that the information was of low importance.
Figure 4.7 above illustrates the opinion of the participants on all the scores of the combined subscales of information needs. The sample consisted of 110 breast cancer patients aged 18 years and above. Out the 110 participants recruited 80% of them indicated that the information was moderately important, 10.9% participants thought it was highly important and 9.1% had the opinion that the information was of low importance.
4.2.5: Section E. Association of Information needs and posited determinants.

This section presents results of the Logistic regression of information needs and posited determinants. After conducting the Logistic Regression, from the measures of effect (Odds Ratio, p values) and confidence intervals in it was determined that anxiety levels; education level; presence of co-morbidity; and whether on treatment or not were significant determinants of patients’ informational needs (Effect’s p=<0.05). Tables of the association between information needs and posited needs determinants are presented below.

Table 4.4: Association between the information needs of breast cancer patients and the Anxiety levels (n=110)

| Factors influencing information needs | Odds Ratio | P-Value | 95% confidence interval |
|--------------------------------------|------------|---------|------------------------|
| Anxiety (Ref: Mild Anxiety)          |            |         |                        |
| Moderately Anxiety                   | 0.5        | 0.550   | 0.06                   |
| Highly Anxiety                       | 11.7       | 0.028   | 1.30                   |

After adjusting for the confounding effects of Education Level; presence of Co-Morbidity; and Whether on Treatment or Not, and Treatment Length, compared to patients reported to have No Anxiety, patients with High Anxiety were 12 times more likely to have information needs (OR=11.7; p Value 0.028). There was no difference between those with mild Anxiety and those with Moderate Anxiety (OR=0.50; p Value =0.550).
Table 4.5: Association between the information needs of breast cancer patients and the education levels (n=110)

| Factors influencing information needs | Odds Ratio | P-Value | 95% confidence interval |
|--------------------------------------|------------|---------|------------------------|
| Education (ref: No formal Education) |            |         |                        |
| Primary                             | 2.6        | 0.545   | 0.12                   |
| Secondary                           | 7.8        | 0.176   | 0.40                   |
| College                             | 11.0       | 0.120   | 0.53                   |
| University                          | 45.8       | 0.027   | 1.55                   |

After adjusting for the confounding effects of Anxiety; presence of Co-Morbidity; and Whether on Treatment or Not, compared to patients reported to have No Formal Education, patients with University Education were 46 times more likely to have information needs (OR=44.8; p Value 0.027). There was no difference between those with No Formal Education and those with Primary, Secondary and College Education.

Table 4.6: Association between the information needs of breast cancer patients and the presence of co-morbidities (n=110)

| Factors influencing information needs | Odds Ratio | P-Value | 95% confidence interval |
|--------------------------------------|------------|---------|------------------------|
| Presence of Co-morbidity             |            |         |                        |
| No                                   | 1.5        | 0.615   | 0.33                   |
| Yes                                  | 39.0       | 0.028   | 1.49                   |

After adjusting for the confounding effects of Anxiety; Education Level; and Whether on Treatment or Not, and Treatment Length, compared to patients reported to have No Co-morbidity, patients with Co-morbidity were 39 times more likely to have information needs (OR=39; p Value 0.028).
Table 4.7: Association between the information needs of breast cancer patients and the Treatment Status (n=110)

| Factors influencing information needs | Odds Ratio | P-Value | 95% confidence interval |
|--------------------------------------|------------|---------|------------------------|
| On Treatment                         | Yes        | 1.1     | 0.946                  | 0.09                    |

After adjusting for the confounding effects of Anxiety; Education Level; presence of Co-Morbidity, and Treatment Length compared to patients who are Not on Treatment, patients on treatment were 99% more likely to have information needs (OR=0.01; p Value 0.004).
4.2.6 Section F: Barriers to accessing information and recommendations

4.2.6.1: Barriers to accessing information

Table 4.8: Barriers to accessing information by Breast Cancer Patients

| Barriers faced                                  | Frequency (n) | Percentage (%) |
|-------------------------------------------------|---------------|----------------|
| Health providers ‘lack of ample time to attend to patients | 60            | 81%            |
| Health care givers are too busy                 | 56            | 75.6%          |
| Too many patients                               | 54            | 72.9%          |
| Understaffing of hospitals                      | 33            | 44.5%          |
| Fear in patients to question doctors            | 37            | 50%            |
| Professionals scared of patients reactions      | 20            | 27.2%          |

Table 4.8 above shows most respondents (81%) cited health providers’ lack of ample time to attend to them as a common barrier to accessing information. 75.9% of the respondents alluded to health care providers as being too busy to give them information. 72.9% thought there were too many patients and 50% of the respondents thought patients were scared to ask questions.
CHAPTER 5
DISCUSSION OF FINDINGS

5.1 Introduction

This chapter discussed the results of this study. The main objective of the study was to assess information needs of breast cancer patients at cancer diseases hospital in Lusaka. Information needs of breast cancer patients, age, educational level, stage of cancer, time since diagnosis co-morbidities and anxiety were variables under analysis.

5.2 Sample Characteristics of respondents

5.2.1. Demographic characteristics of the respondents

These were included so that they provide the researcher with a better understanding of how they may influence the information needs of breast cancer patients. Most of the respondents were in the age group of 50 years and above (57.3%). This could be attributed to the fact that cancer affects the elderly more than the young ones. This has been affirmed by White et al (2014) who suggested that cancer can be considered an age-related disease because the incidence of most cancers increases with age. In addition Anders et al (2009) also noted that breast cancers diagnosed among premenopausal women was relatively uncommon. About (50.9%) of the respondents were married. This could be attributed to the spousal support enjoyed by married couples which help them seek medical attention early for worrisome symptoms. This reason is in support with Adekoluyo et al (2016) in a study conducted in the United States that reported similar results.

The findings revealed that there were 11 (9.6%) respondents with no education, 34 (29.6%) with primary level education, 36 (31.3%) with secondary level education, and 34 (29.6%) with tertiary level education (Table 4.1). Using the odd ratio there was an association between information needs and level of education for those who had reached University education (OR=44.8; p Value 0.027). It was determined that patients with University Education were 46 times more likely to have information needs. There was no difference between those with no formal education and those with primary, secondary and college education (Table 4.5). This could be attributed to good health seeking behaviour of the educated people. Educated people are well informed hence can ask more questions and are able to communicate with the health care providers freely.
5.2.2. Medical characteristics

This section discusses the medical characteristics of the respondents. A greater majority of the respondents, 92 (83.6%), reported having been living with breast cancer for at least 1 – 4 years. The duration that they had lived with cancer did not influence the information needs of the participants in this study (Table 4.4). This could have been influenced by the hope that these patients had towards recovery as most of them could have had faith that they will be cured of their disease. In contrast (Tucker, 2017) reported that those who had lived with cancer for a short duration had more information needs compared to those who had it for longer years. Most of the participants (84.6%) were on treatment either chemo-radiation or hormonal and only (15.4%) had completed their treatment and were just on reviews. This is attributed to the fact that Breast cancer treatment takes long as a patient has to go through all the common four modalities namely Surgery, chemotherapy, radiation and hormonal treatments.

More than half of the participants (61.8%) did not suffer from any conditions such as hypertension and diabetes. Using the odd ratio there was an association between information needs and presence of co-morbidities (OR=39.0; pValue 0.028). The patients who had other conditions such as hypertension and diabetes were 39 times likely to have information needs compared to those who had none. This could have been due to the reason that cancer is already a distressing diagnosis, having another diseases could be a source of extra stress which needs to be alleviated by having more information.

5.3: Information Needs of Breast Cancer Patients

The first objective was to assess the information that breast cancer patients desired to know about their disease. The findings of this study revealed that the majority of the participants 80% showed significant information needs on all the categories of information (Figure 4.7). The participants were interested in receiving moderate information in all the categories of information needs. This could have been attributed to the questions asked in the adapted TINQ –BC questionnaire were participants may be comfortable rating themselves neither low no high. This is supported by McLeod (2008) who stated that sometimes the “validity of Likert Scale attitude measurement can be compromised due social desirability” meaning that “individuals may lie to put themselves in a positive light”. This finding could also be attributed to the fact that patients want to retain hope and therefore only want to receive positive information. In a study conducted in London by Leydon
et al, (2000) it was suggested that patients may not be interested in information beyond what their physicians could offer in order to maintain hope. In addition Holmes (2008) noted that women placed a high importance on information that is tailored to meet their specific need in managing their illness.

Among the five categories of the information needs that were presented in this study, the findings indentified a ranking of information needs according to what most participants perceived as important. Participants ranked information about the investigations done (76.4%) as most important, followed by the information on treatment (73.6%), then information on their disease and physical needs (71.8%) was third and lastly the psychological information (70%) in the fourth position. The study revealed that investigative information needs was considered the highest important while psychosocial information was the least for the respondents. In their study in Hong Kong among Chinese Breast Cancer patients Bei et al (2015) stated that “although the information needs of breast cancer patients can theoretically be very diverse, according to background and personal factors, the patient’s viewpoint is a key issue when assessing information needs”. Their perception of the information during the interview or interaction is relevant to the manner in which they understand and process the information they are given. The findings of this study are similar with the study done by Mooney et al (2014) which reported, patients relatively less interested in receiving information related to the psychological aspects of disease. The study suggests that this does not mean that the information is not important but could be attributed to patients avoiding bad news and fear of information overload during a stressful time. This section contained questions like if the cancer will come back, how to tell if the cancer comes back and what to do if they become concerned about dying. The results of this study were consistent with the results by Bishop (2012) who reported patients being selective in what they wanted to know as ‘hope’ emerged essential to coping strategies in cancer patients and information therefore which lessened hope was avoided.

In this study information on Investigative tests were positioned as first in priority of information needs. This could be attributed to that investigative tests in cancer management are done so often in order to monitor patients’ treatment. The findings corresponds with the study findings of Holmes (2008) which revealed that women desire information regarding the rationale for the test as blood work often signifies how their body is adapting to treatment. This study found information
regarding treatment as the second priority. The reason could be that these patients want to know what is involved with treatment, including the benefits and risks, any options, and what may happen if the patient chooses not to go ahead with treatment. The findings are similar to the finding by Holmes (2008) who found that treatment information is necessary to help women cope with and understand what is ahead in their cancer trajectory. Information regarding the disease process provides women with the information needed to make informed decisions regarding their treatments.

Findings of this study were that the information regarding the disease and physical needs was fourth in priority. This could be due to that the disease items were assessing information needs about the nature and process of the disease and physical items assessed information need about the preventive, restorative and maintenance care that may be needed as a result of the disease and treatments. Hence Breast Cancer patients in this study were already aware of their diagnosis and could have started coming to terms with what they were going through therefore making both the disease and physical needs fourth in priority. This was contrary to what Teriman et al (2010) found in their study where the information on the disease was second in priority. The study suggested that was natural for patients to want to know what type of cancer and what stage of the disease they have, as most patients fear certain types of cancer and advanced stage of the disease since they are usually associated with shorter survival.

5.4: Factors influencing information needs

The second objective was to establish the factors influencing information needs of breast cancer patients. In order to establish this, strength of association between having information needs and suggested predictors of information needs was estimated with Pearson's chi-squared test. From the Chi-squared association only anxiety (p-value 0.018) was significantly associated with information needs statistically. Therefore in order to obtain the true effects of these variables we conducted a multivariate analysis with logistic regression and controlled for the confounding effects (Tables 4.4-Table 4.7). The final results in the multilevel model showed the presence of confounding effects as some of the variables that showed no association on crude chi square analysis were significantly effecting the information needs after logistic regression multivariate analysis. In this study, anxiety, attaining university education, presence of co-morbidities and being on treatment were significantly associated with information needs.
In our study, after adjusting for the confounding effects of education level, level of co-morbidity, whether patient was on treatment or not, and treatment length, compared to patients reported to have no anxiety, patients with high anxiety were 12 times more likely to have information needs (OR=11.7; p Value 0.028). This finding shows that a diagnosis of breast cancer causes a state of anxiety as breast cancer is a life-threatening disease. The findings of this study agree with the findings of You (2017) which revealed that approximately 30% to 54% of patients suffer from anxiety within two years after diagnosis and 13% to 15% have symptoms of anxiety that persist for years. When a client experiences anxiety the need for information increases and consequently health care providers should provide the necessary information. This study suggests that anxiety is common in cancer patient populations, and it’s essential for health care professionals to recognize and manage it. The finding of this study suggest that increased information supply to cancer patients can be used as a management strategy by cancer care professionals. Therefore the result of this study collaborates with results by Faller et al (2016) who found that there was a relationship between information satisfaction and symptoms of depression and anxiety. Hence, stating that “provision of information may reduce subsequent depression and anxiety, while reducing depression and anxiety levels may increase satisfaction with received information”.

In this study, attaining university education was found to affect the information needs of the participants (OR 45.8, pvalue-0.027). This finding suggests that educated patients have more information needs than those who are not. This could be attributed to that those who are educated are able to communicate with health professional freely hence they ask questions where they are not clear. The other reason could be that the educated patients seek medical attention early and are usually involved in their care and would want to understand whatever the health professionals are doing on them. The results are similar to a study conducted by Eheman (2009) which indicated that higher education attainment did influence the importance ratings of information needs and influenced coping skills and those. These findings therefore have an implication for how health professional interact with well- and less-educated patients.

The findings in this study were that the presence of other diseases such as hypertension and diabetes were associated with information needs (OR=39; p Value 0.028). This could be that breast cancer is already a distressing disease, having two conditions makes the patient stressful hence having a lot of questions on how they will cope. The results are similar to a study conducted by Baine et al
(2011) which showed that the psychological stress caused by other diseases were the motivating factor for seeking more information. Further more patients with comorbidity have poorer survival; poorer quality of life, and higher health care costs was the most important determinant of information seeking.

In this after adjusting for the confounding effects of anxiety; education level, presence of co-morbidity, and treatment length, patients who were not on treatment compared to patients on treatment were 99% times less to seek for information (OR=0.01; p Value 0.004). This could be due to that patients on treatment were still experiencing the fear of whether they will recover or not, probably they could have been still experiencing side effects of treatment. This reason is in support with Adekolujo et al (2016) in a study conducted in the United States that reported that married women on cancer treatment needed information. ). In addition studies by Ladd (2016) and Greco et al (2016) reported patients searching for medical information which included facts on chemotherapy, radiotherapy, and surgery. Therefore the study suggests that special attention should be paid to the breast cancer patients as information and social support may help improve their prognosis.

In this study the other factors such as age (p value-0.271), stage of cancer (p value-0.281), and length of illness (p value-0.331) did not affect the information needs of breast cancer patients. This could have been probably due to the current trends in cancer treatment modalities or the accessibility to cancer treatment which has led to individuals living as normal as possible. These results are in contrast with some previous studies which reported that information needs in breast cancer patients are associated with patients’ demographic characteristics such as age, education, stage of cancer, duration of illness, presence of co-morbidities and occupation (Omady, 2008; Eheman, 2009; Nolke, 2015; Tucker, 2017). The current findings suggest that the patients’ information needs could have decreased slowly with time as they came to terms with their diagnosis.

5.5: Barriers to accessing information

Respondents were asked to state the problems they encountered when looking for information as shown in Table 4.8 above. The study revealed that respondents indicated that the health providers did not have adequate time to attend to patients as a common barrier to accessing information. Respondents noted that there were few doctors to attend to too many patients; hence they were
mindful of the time to talk and ask questions. Thus, most respondents cited limited interaction time with doctors due to high patient volume as a barrier to accessing information, as doctors were too busy. The findings are similar to those conducted by Eames et al (2010) in the United States of America who noted similar results which included not knowing what to ask, patients being “pushy” to get information, and busy or inadequate numbers of health professionals.

5.6: Implications to Nursing

The implications are going to be discussed under the following headings: nursing practice, nursing administration, nursing education and nursing research.

5.6.1 Nursing Practice

The findings have provided information on the information needs of breast cancer patients. This study found that women with breast cancer at Cancer Diseases Hospital need information related to their diseasey. An understanding of the information needs from the patients’ perspective is an important aspect in improving quality care. This study also demonstrates that patients with breast cancer are psychologically distressed and need information (Table 4: 4) and because distress is a common symptom among this patient population, it is important to include measurement of psychological distress into nursing assessment procedures. The study has also revealed that educated patients have more information needs than those who are less educated but because they easily communicate with healthcare providers, there needs may easily be met. Therefore there is need to engage those with less education as they may not be able to easily give out their views.

5.6.2 Nursing Administration

The study has shown that provision of information that match patients’ informational needs assists patients with recovery as some studies suggests that information seeking among breast cancer patients was associated with improved quality of life. The study also has shown that there is shortage of health staff compared to the number of patients hence making it impossible for health professionals to spend a lot of time with patients. Therefore nurse managers should influence development of strategies related to information delivery to breast cancer patients where the information giving session will be based on the needs of the patients themselves, considering the appropriate ways that information is delivered to them using various forms like in a written form, oral communication, using graphic display or multimedia presentation.
5.6.3 Nursing Education

The findings of this study show that there is need for Nursing Training Institutions to design educational resources and clinical services that enhance acquisition of skills in information provision that is necessary in clinical practice. This will in the long run lead to improvements in the training of nursing students; hence producing competent graduates who will be able to deliver comprehensive and quality care to cancer patients.

5.6.4 Nursing Research

The literature review during this study reveals that a lot of studies have been done in assessing the information needs of breast cancer patients but all these are done in the western countries. More research is to be done in information needs of cancer patients as there is a need for further knowledge on patient information in lifelong disease trajectories. The information obtained by a nurse researcher can be disseminated to nurses who work directly with the individuals to whom the research applies. Practice that has shown to be effective through research allows nurses to better advocate for patients and provides the best possible care.

5.7: Conclusion

The study was conducted to assess the information needs of breast cancer patients at Cancer Diseases Hospital, in Lusaka. The findings of this study and literature support the idea that breast cancer patients are seeking more information on their disease. The study findings may show that there were some relationships between the findings of this study with other studies that could be generalised to all breast cancer patients although the patients in this study could have their own experiences. The findings also have provided information that breast cancer patients are anxious and need information about their disease, investigations, treatment, physical and psychosocial needs which should not just start when the patients start receiving treatment but ought to begin from the period of testing to diagnosis to prognosis. Although shortage of human resource may compromise the need for information our study shows that time-relevant information and support in susceptible stages may be as significant as adequate information. Thus researchers and health professionals need to consider the role of information in improving patient outcomes when designing interventions for these clients. However future research should include expanding the questionnaire to include an exploration of whether informational needs are met or not and whether
patients are satisfied with the information received as this is an important step to improving the breast cancer patient experience.

5.8: Recommendations

Based on this study the following recommendations have been made:

1. The government through the Ministry of Health should effect the decentralization of cancer services to all provincial headquarters for easy accessibility, reduction in patient overload and cost effectiveness of cancer services.

2. The Ministry of health to train more oncology health workers so as to increase on the staffing levels that will in turn reduce on the clinician patient ratio.

3. It is required for CDH to develop an assessment tool to detect the information needs of breast cancer patients and to encourage oncology nurses to actively assess the information needs of patients.

4. There is need for CDH to develop a training module for educating medical professionals in disclosing bad news so as to enhance communication with cancer patients.

5.9: Limitation of the study

The study was a cross-sectional study, therefore it couldn’t measure the information needs of patients in different stages of the disease trajectory and further longitudinal studies will be needed in this area. The other limitation was the adopted TINQ-BC collection tool which could compromise the quality of data because the respondents may only give the answers they thought were socially acceptable. Another limitation is that respondents were not asked about satisfaction with information received medical professionals therefore it was difficult to elicit if their needs were met or not so as to know which information they needed.

5.10: Dissemination of study findings

The findings of this study will be disseminated as dissertations submitted to the University of Zambia, School of Medicine Library, School of Nursing Sciences, Cancer Diseases Hospital and Ministry of health. Presentation of the research findings will also be disseminated at the University of Zambia Post Graduate International Conference (UNZAPIC).
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Appendix I: Information sheet: English

Study Title: Information Needs of Breast Cancer Patients at Cancer Diseases Hospital in Lusaka, Zambia

Introduction

Beauty Lilala Namushi, a student at the University of Zambia in the School of Nursing Science is requesting you to participate in a research whose title is mentioned above. The study to explore breast cancer patients; information needs is important because the findings will help in improving the quality of care for cancer patients. Before you decide whether to participate or not in this study, I would like to explain to you the purpose of the study, the procedure, any risks and discomforts, benefits and what is expected of you. Your participation in this study is entirely voluntary. You are under no obligation to participate, you may choose to participate or not to. If you decline to participate, no privileges will be taken away from you as you seek treatment or support from any organization or individual. If you agree to participate you will be asked to sign this consent form in the presence of a witness. Agreement to participate will not result in any immediate benefits.

Purpose of the Study

A diagnosis of cancer is a fearful experience that has cultural, social and psychological consequences and many patients and their relatives experience physical, psychological, spiritual and family problems (Ankem, 2006; Motlagh et al, 2014). Newly diagnosed patients embark on a journey with uncertain destination, laden with stress and anxiety and desperate for hope and support. Provision of information can help these patients in terms of physiological as well as psychological outcomes enabling them to regain control over their lives and participate fully with treatment. Therefore this study will obtain information on what breast cancer patients desire to know during the illness trajectory. This information will be identified by analyzing participants’ information lived experience. The identified desired information will be used in developing more culturally effective models to deliver information and support to breast cancer patients. Identifying the actual needs of the patients will produce better resource allocation and provide health services more efficiently to meet the needs hence improving the coping mechanism of patients and in turn quality of life.
Procedure

After you have signed the informed consent form and have had a chance to ask questions, you will be requested to answer the questions concerning the information you would desire to know concerning your diagnosis, treatment and prognosis. Then thereafter, you will be asked to make a recommendation on how you want the information delivered to you and how we can improve information delivery to patients.

Risks and Discomforts

No risks are involved in this study; however you might become emotional during the interview as some questions or the process of recalling past experiences may cause discomfort. Should you become emotional and wish not to continue, I will stop and reschedule the interview. With your permission, I will counsel you myself or ask the counsellors who work in the clinic to counsel you.

Benefits

There are no direct benefits to you as a participant, however, the findings will increase our understanding of the desired information that breast cancer patients need. The information provided will help relevant authorities and policy makers to come up with strategies that will be used in developing more culturally effective models to deliver information and support to breast cancer patients.

Confidentiality

I will keep information confidential. The people who will know that you are a research participant are members of the research team and all the research materials will be kept in strict confidence. For the purpose of anonymity, you will be identified by a number not by name and personal information will not be released without your written permission.
Appendix II: Consent Form: English
The purpose of this study has been explained to me and I understand the purpose, benefits, risks and discomforts and confidentiality of the study, I further understand that: If I agree to take part in this study, I can withdraw at any time without having to give an explanation and that taking part in this study is purely voluntary.
I________________________________________________ (Names)
Agree to take part in answering the questionnaire.
Signed: _________________________ Date:_______________________(Participant)

PERSONS TO CONTACT FOR PROBLEMS OR QUESTIONS

1. Beauty Lilala Namushi, Cancer Diseases Hospital, P.O Box 51337, Lusaka. Cell: 0955832541.
2. Dr Marjorie K. Makukula, University of Zambia, School of Nursing Sciences, P.O Box 50110. Cell: 0977889430.
3. The Chairperson, University of Zambia Biomedical Research Ethics Committee, P.O Box 50110, Ridgeway, Lusaka, Telephone: 260-1-256067.
Appendix III: Ipepala Lya Kusuminishanya: (Information sheet- Bemba)

Umulandu: Ubushibwisho Ubufwaikwa Kubalwele Ba Kansa Yamabele Pa Cipatala Ca Kansa Mu Lusaka, Zambia.

Umusapu

Beauty Lilala Namushi, Umusambi wapesukulu likalamba ilya bundapishi mu Zambia, alemwipusha ukusendamo ulubali mukufwailisha umulandu ulembelwe pa mulu. Umulandu wakufwailisha abalwele ba kansa yam abele; ukufwaya kwa bwishibisho ku kankala pantu fyonse ifyalasangwa fikafwilisha utuwamya ukusakamana ukupelwa kubalwele ba kansa. Ilyo tamulasala ukusendamo nangula uukukana sendamo ulubali, cuti nafwaisha ukulondolola kuli imwe, ubukankala bwa uyu umulandu, ifyakukonka, ususaso, usubuma elyo nefyo tulechetekekela ukuma kuli imwe. Ukusendamo ulubali kwenu kwa kuipeleshafye. Tamulepatikishiwa ukusendamo ulubali ulubali, cuti mwasalala ukusendamo ulubali nangi iyo. Nga mwakana ukusendamo ulubali, tapali ifyalafumishiwapo pali imwe ilyo mulekabila ubundapishi nangula ukutungililwa ukufuma ku kabungwe akali konse nangula abantu. Ngamwasumina ukusendamoulubali mwalaipushiwa ukusaina icipepala caku sumunshanya pa menso yakwa kambaru. Ukusuminina kwa kwakusendamo ulubali takwingafuma mukumipelako icily conse.

Ubukankala Bwa Mulandu

Ukusanga kwa bulwele bwa kansa ninshila imo iyitinya ukupitamo kabilii ilufyanya ubwapano elyo na matontokanyo. Abalwele abengi na lupwa lwabo balapita mumafya aya ku mubili, mu mantontokanyo elyo na ku mupashi (Ankem, 2006, Motlagh et al, 2004). Abalwele abapya abalesangwa na bulwele baleba pa bulendo ubu shaishibikwa impela, baleba abnashiwa, abasakamana kabilii abalefwaisha isubilo na ukutungililwa, ukepela kwa bwishibisho kuti kwa afwa abalwele ku mubili elyo na mumatontokanyo ukubalenga ba kwata ukulungika imyeo yabo elyo nokusendamo ulubali ukwafikapo mu ku ndapwa. Eico isambililo ili lya lasenda ubwishibisho pafyo abalwele ba kansa ya mabele bafwaisha ukwishiba ilyo balepita mu kulwala. Ubwishibisho ubu bakasanwa nkupitila mukwishiba ifyo abalesendamo ulubali bapitamo. Ubwishibisho ubulefwaikwa ubwalasendwa bukabofiwa mukusanga inshila iiisuma iyakwishibishamo na ukutungilila abalwele ba kansa yamumabele ukukabila ukufwaikwa ukwalasangwaku ku afwilisha
inshila isuma iya kupelelamo ifiifwaikwa elyo na ukupela imilimo lisuma iya bumi ku kumanya uku kabilwa kwabalwele elyo nokuwamya imyeo yabo.

Ifyakukonka

Panuma na musaina icipepala ca kusuminishanya na uku kwata ishuko iilwa kwipusha amepusho, mwalakwata ukuasuka amepusho ukulingana na ubwishibisho mwingafwaya ukwishiba ubukumine ukulwala kwenu ubundapiishi elyo nokuposhiwa. Panuma ya ifyo mwala ipushiwa ukulanda pafyo mwingafwaya ubushibisho bwa pelwa kuli imwe, na pafyo twingawamya inshila yakwishbishishamo abalwele.

Ubusanso

Tamuli ubusanso ubuli bonse muli uku ukufwailisha; lelo kuti mwakwata ubulanda ilyo tule mipusha pantu amepusho yamo nangula ukwibukisha kwafyo mwapitamo kuti kwa mulenga ukakana kumfwa bwino. Nga mwaufwa ubulanda kabiili mwafwaya uukana kokanyapo, kuti naleka twaisakumana ishita imbi. Nokusuminishako kwenu kuti namikansha nangula kuti na mifwaila kasansha umbi uubomba micipatala.

Amalipilo

Takwingaba amalipilo ayengapelwa pamulandu wa ku sendamo ulubali lelo fyonse ifyalasangwamo fyatalulenga ifwe ukufwikishwa ubushibisho ubufwaikwa ku balwele ba kansa yam abele. Ilyashi ilyakupelwa kuli ifwe likafwa ifiputulwa ifikwetepo amak ukusanga inshil lisuma iya ku pelelamo ubushibwisho na ukutungilila abalwele ba kansa yamabele.

Imisungile Ya Nkama

Nkasanga ilyashi ukwabula abantu bambi ukwishiba. Abantufye abakeshiba ukutila mwalisendelemo ulubali niabofye abakumine ibumba lya ba kufwailisha. Nafyonse ifyalebofiwa mukufwailisha fikasungiwa bwino. Eico imwe mukeshibikilwa pa pendwa le peshina iyo, elyo nelyashi lyenu teti lifumishiwe ukwabula imwe upela isambu.
Appendix IV: Ipepala Lya Kusuminishanya (Consent form - Bemba)
Ubukankala bwaisambililo ili na bulondololwa kuli ine, kabilini ningufwikisha ubukankala, ubusuma, ubusanso, elyo nemisangile ya nkama ye lwashi. Nikwata na ukufwishina kabilini ukufila; nganasumina ukusendamo ulubali kuti naleka panshita ili yonse ukwabula na ukulondolola, kabilini na nkusendamo ulubali kwa kuipeleshafye.

Ine………………………………………………………………………………(Amashina)

Nasumina ukusendamo ulubali.

Ukusumina…………………………Ubushiku……………………………………(uleibimbamo).

ABA KWISHIBISHA NGA KULI UBWAFYA

1. Beauty Lilala Namushi, Cancer Diseases Hospital, P.O Box 51337, Lusaka. Cell: 0955832541.

2. Dr Marjorie K. Makukula, University of Zambia, School of Nursing Sciences, P.O Box 50110. Cell: 0977889430.

3. The Chairperson, University of Zambia Biomedical Research Ethics Committee, P.O Box 50110, Ridgeway, Lusaka, Telephone: 260-1-256067.
Appendix V: Pampili Ya Zibahanzo Ya Tumelelano: (Information Sheet-Silozi)

Toho Ya Taba: Patisiso Ya Lizibiso Ze Tokwahala Kwa Bakuli Ba Butuku Bwa Kansa Ya Mazwele Baba Kulela Mwa Sipatela Sa Butuku Bwa Kansa Mwa Lusaka

Makalelo

Beauty Lilala Namushi, mwana sikoo yali mwa sikolo sa Nursing Science fa sikolo sese pahami sa university of Zambia, u mi kupa kuunga kalululo mwa patisiso ye n’gozwi mwa toho ya taba ya mpampili ye. Patisiso ye ibata kuziba buino bwa bakuli ba butuku bwa kansa ya mazwele ni lizibiso ze batokwa. Ki patisiso ye butokwa kakuli ze ika patulula li katusa kumbweshafaza pabalelo ya bakuli ba butuku boo.

Mu sika iketela kale kuunga kalulo kappa kusa eza cwalo mwa patisiso ye, ni lakaza kumi taluseza mulelo ni mu koloko wa patisiso ye, butokwa bwa yona, ni ze muswanela kueza. Kuunga kalulo mwa patisiso ye haku hapelezwi kono ku itingile ku mina. Ni hamusaangi kalulo hakuna ni se sikana sika sesi maswe se si ka ezahala kumina ha muka taha kuto bata kalafo kappa tuso kwa katengo kafi kapa kafi ku mutu ufi kapa ufi.

Hamu lumela kuunga kalulo muka kupiwa ku saina/kunyatela pampili ya tumelelano inge kunani paki. Tumelelano ya kuunga kalulo haina ku mi tiseza lika ze butokwa mwa kupilo bwa mina mwa nako ye kuswani fela.

Mulelo Wa Patisiso/ Tuso

Ku fumaniwa ni butuku bwa kansa ki nto ye sabisa ye tiseza kuishonda, ku ikambusa ni kunahana hahulu mi bun’gata bwa bakuli ni bahabo bona ba ikutwanga bumaswe mwa mubili, mwa minahano ni mwa moyo hamoho ni kutoxwa kozo mwa mabasi abona (Anken, 2006; Motlagh et al, 2014). Bakuli babanca ba ipumananga inge ba palelwa kuziba mafelelezo abona mo aka bela, banze ba bilaela hahulu ni kunyolelwa sepo ni tuso. Kabak leo lizibiso ni lituto ze ama butuku bo li kakona kutusa ku katulusa mibili ni moyo wa bakuli kuli mane bakone kuyangwela kupilo bwa bona, ni kutoxomela hamoho cwalo ni ku latelela likalafo. Kahlo lipatisiso kappa tuto ye ika patulula lika zeo bakuli ba butuk bwa kansa ya mazwele ba swanela kuziba mwa nako ya makulano a bona. Lizibiso ze li toolwa kako nyatisisa kupilo bwa baba ka inga kalulo mwa patisiso ye.
Lizibiso ze ka zwa mwa patisiso ye lika itusiswa kwa ku baakanya mikwa ye ka itusiswa kwa ku tusa bakuli ba butuku bwa kansa ya mazwele. Kuziba lika zeo bakuli ba tokwa, ku katusa ku ziba masheleti kapa tuso ya makete ka bunolo ni ka bubebe ili nto ye ka tusa ku mbweshafaza bupilo bwa bakuli ni haba kula cwalo.

Mukoloko Wa Patisiso

Hasamulao wa ku fiwa nako ya kubuza lipuzo ni ku saina pampili ya tumelelano, mu ka kupiwa ku alba lipuzo ze ama lizibiso ze mubata kufiwa ku amana ni butuku, likalafo ni mokusinganyakelwa kuli kona mo mu ka folela. Mu ka kupiwa hape kuli mubulele mo mu batela kuli lizibiso zeo li fitiswe ku mina ni mo ku swanela ku ezezwa kuli lizibiso zeo li fitiswe kwa bakuli baban’gwi.

Likozzi Ni Ze Sa Tabisi

Hakuna likozi ze liten’gi mwa patisiso ye. Ni hakuli cwalo mw asana mwa ikutwa bumaswe ka nako ye muka buziwa lipuzo kakuli lipuzo ni lipulelo zen’gwi lika mi hupulisa lika za kwa mulaho ze ne sika mi tabisa. Haiba muka ikutwa kuli ha mu sa tabela ku zwelapili ni lipuzo ni ka tuhela ni ku kupa lizazi lisili le luka zwelapili. Haiba muka ni lumeleza na Kamba baban’gwi baba sebeza mwa sipatela lu ka mi tiisa pilu ni ku mi ombaomba.

Tuso

Hakuna kuba ni tuso ya kapilipili ku mina baba kanga kalulo mwa patisiso ye kono tuto ye ka patululwa ki lipatisiso ze ika lu tusa ku utwisisa lizibiso ze ba tokwa bakuli ba butuku bwa kansa ya mazwele. Tuto ye ikatusa maluko aman’gata niba baakanyi ba milao ku bea mikwa ye ka tusa bakuli ba butuku bwa kansa ya mazwele.

Likunutu

Ze muka bulela kaufela ka nako yak u buziwa lipuzo ni ta ipulukela zona. Batu b aba ka ziba kuli mu ungile kalulo mwa patisiso ye ki ba sikwata sesi zamaisa patisiso ye feela. Ni haiba libizo la mina ha lina kuptutululwa lu ka mi biza fela aka nombolo ye lu ka mifa. Hakuna ze mu bulezi ze ama mabizo kappa bupilo bwa mina ze ka itusiswa ni sa kupi ku lumelwezwa ki mina pili.
Appendix VI: Pampili Ya Zibahazo Ya Tumelelano (Consent Form-Silozi)
Ni bulelezwi mulelo wa patisiso ye mi na utwisisa tuso, likozi ni likunutu za yona. Ni sa utwisisa hape kuli ni ani lumela kuunga kalulo mwa patisiso ye na kona ku sa zwelapili ni yona ni sa fi libaka lifi Kamba lifi kakuli ki nto yenzi eza ka tato feela yaka.

Na…………………………………………………………………………………………………………………(Libizo)
Na lumela kunga kalulo mwa ku alaba lipuzo.

Saina………………………………………Lizazi………………………………….(Yaanga kalulo).

BAKUZIBISA NJI KUNANI BUTATA

1. Beauty Lilala Namushi, Cancer Diseases Hospital, P.O Box 51337, Lusaka. Cell: 0955832541.
2. Dr Marjorie K. Makukula, University of Zambia, School of Nursing Sciences, P.O Box 50110. Cell: 0977889430.
3. The Chairperson, University of Zambia Biomedical Research Ethics Committee, P.O Box 50110, Ridgeway, Lusaka, Telephone: 260-1-256067.
Appendix VII: Ipeepa Ilya Kuzumina: (Information Sheet- Tonga)

Mutwe Wa Buvwuntauzi: Makani Atwaambo Twa Zhi Yandika Kuli Ba Malwazi Ba Kansa Wa Kunkolo Ku Cancer Diseases Hospital Mu Lusaka, Zambia

Ikuli Pandulula

Beauty Lilala Namushi ngu siciko a ciko cipati ca university of Zambia mu cibeeba cha cikolo ca Nusing Sciences na I ciko ica kuiya ku lwazha bantu mucibaddela, uombo kuti mujane lubazu na kutoola lubazu mukuyandaula bwinguzi na ibuvwuntauzi bula muutwe waambwa kale kumatalikilo. Buvwuntauzi obu mbwa kulanganya bamalwazi baciswa bulwazi bwa kansa wa kunkolo, a makani a tika janwe mubuvwuntauzi alayandika kapatipika nkaambo ay雍ngwashambambamba kabotu bamalwazi abaciswa bulwazi bwa kansa. Kamutaninga sala kuti na mutuole lubazu na tamutitoole lubazu pee, nyanda kuti mpandulule imuzezo wa bavwuntauzi obu, inzila iyobeleshgwa musbuwuntauzi, mizeezo wa buvwuntauzi oobu, intienda akutali kwaaya kuunga kuangwa, ibubotu buungu bwajanana alimwi nchotuyanda kuzwa kuli ndinwe. Ikutoola ilubazu mubuwantauntazi oobu nkwa kulyaba buyo. Kunyina mulandu ngo mungu mwepegwa naa mwatoola lubazu, inga nobeni mwalisalila iku toola lubazu naa pee. Kuti naa tamuyandi kutoola lubazu takwe ibubitu bunga mwanyangwa pee mwakuunka kusilikwa kuchibaddela nikuba ilungwasho kuzwa kumbuunga ili oonse nakuba imuntu buyo. Kuti naa mwazumina kutoola lubazu muyo lombwa kusaina chipeepa icakuzumina kumbeele aa kamboni. Kuzumina kutoola lubazu kunyina ibubotu buya kuli bonya mpoona aowo.

Muzeezo Wabuvwuntauzi

Kujanwa a bulwazi bwa kansa chiletela ikuyowa kapati mumaumiaba malwazi a basikamukowa bakwe. Bantu ibajarwa ibulwazi obu bataliika iweendo ndo batazhi nko baya, iluzwide mizezo a kuyeeya kapati, alimwi kabayandisha ikuba abulangizhi akuyandisha ilugwasho. Ikuupa makani ajatikizya ibulwazi obu inga a gwashilizha bamalwazi munziwa yabu kale bwabo alimwi a mu mizeezo yabo kutegwa bachikonzye kujana ikwendelezha maumi aabo alimwi a kutoola lubazu luzwide mukusilikwa kwabo. Aboobo buvwuntauzi obu buya kujana twaambo twaalo balwazi ba kansa wa kunkolo ntobayandika kuzhiba ciindi no baciswa bulwazi oobu. Twaambo out tuya kuzhibwa mukwiinda mukulanga-langa itwaambo tuya kuzwa mumubandira wa bantu ibayotoola ilubazu mubunvwuntauzi obu. Itwaambo tubotu out tuya kubeleshegwa kubamba inzila zhibotu
mukubelesha kuupa malailile a alugwasho kuli bamalwazi ba kansa waku nkolo. Ikuzhiba zhintu zhiyandika kuli ba malwazi chiyakupa kuti imali apegwa mubusilisi bwa bulwazi obu, a zhimwi zhintu zhiyandisika mukugwashwa mumaumi a zha ntanze zhi kapaulwe kabotu kabotu kutegwa zhintu zhoonse zhikeendele antomwe, aboobo chiya kuleeta kusumpuka munzila zha kulanganya ba malwazi abo a kusumpula imaumi abo.

Inzila Ya Kubelezya

Mwa mana kulemba mupeepa elialimwi mwaba aciindi cakubuzya imibuzyo, muyakuingula iiibuzyo ikujatikizya itwaambo ntomuyanda kuzhiba kuti naa mwajanwa aa bulwazi obu, bwakusilikwa aa mbomunga mwapona na kukala mubuumi bweni mwakumanizya kusilikwa. Kwamana muya kubuzhigwa mbuli mbo muyanda itwaambo out kuti tuleetwe kuli ndinwe alimwi mbuli mbo muyanda kuti iinga kwajanwa nzila isumpukide iya kutoola twaambo out kuli ba malwazi.

Intenda Aku Talivwa Kabotu

Kunyina intenda zhili zhoonse nazhili jazhyo zhiliiko mubuvwuntauzhi oobu. Nokuba boobo inga moyo wapya muchamba ciindi no mubuzigwa buzigwa imibuyo antela inzila yakumuyezya zyakainda inga zya muupa kupya moyo. Kuti moyo wapya alimwi tamuyandi kuzumanana inga ndaleka a kumupa ciindi ciimbi cakumubuzya buzya alimwi. Mwazumina kuzumanana njakumulaya mebo lwangu na kulomba imulayi ubeleka aka baddela kuti amulaye nguwe.

Ibubotu

Kunyina ibubotu buboola kuli ndinwe lwenu lyini mwatoola ilubazu mpona awo, pele ibwinguzi buya kutoola aambele ikunvwisisisha itwaambo tuyandika kuzwa kuli bamalwazi iba kansa waku nkolo. Twaambo out tuya kupa lungwasha kutubunga tulanganya makani aya aa babaambi ba nzila kuti babambe zhitu ziya kubeleshegwa ikubamba inzila ibeleka kabotu ikutoola twaambo alugwasho kuli bamalwazi ba kansa wakunkolo.
Maseseke

Itwaambo twenu tUYA kuba maseseke kuli ndime. I bantu baya kuzhiba kuti andinwe muli baabo ibatoola lubazu mba baabo bali mukabunga ikabuvwuntauzi aa zhi peepa zhabuvwuntauzi zhiya kuyobolwa mumaseseke. Akaambo kakuti tatuyandi kuti muzhibike kubantu muya kupegwa inambala iya kubelesha kutali izhina lyanu alimwi itwaambo tujatisha bube bwenu tatukatupi ibantu bambi kakunyina kuzimizhigwa kuzwa kuli ndinye.
Appendix VIII: Peepa Ilya Sikuzumina Kutoola Lubazu (Consent form-Tonga)

Imuzeego wabuvwuntauzi obu bwapandululwa kale kuli ndime alimwi ndaunywa imuzeego, ibubotu iutenda aa kutalinvwa kabotu a maseseka a buvwuntauzi, alimwi ndanvwisisisha kuti: naa ndatoola ilubazu mubuvwuntauzi obu, inga ndachileka akati kati na kufumbwa ciindi kakunyina a bupanduluzhi naa ikutoola lubazu mubuvwuntauzi nkwa kulyaba buyo naa ikulipaa buyo.

Mebo…………………………………………………………………………………………… (Mazhina)

Ndazumina kutoola lubazu mukwingula imibuzho kusai na…………………………………….

Buzuba…………………………………………………………………………………………(Sikutoola Lubazu).

IBA KUZYIBYA KUTI NA KULI PENZI

1. Beauty Lilala Namushi, Cancer Diseases Hospital, P.O Box 51337, Lusaka. Cell: 0955832541.

2. Dr Marjorie K. Makukula, University of Zambia, School of Nursing Sciences, P.O Box 50110. Cell: 0977889430.

3. The Chairperson, University of Zambia Biomedical Research Ethics Committee, P.O Box 50110, Ridgeway, Lusaka, Telephone: 260-1-256067.
Appendix IX: informed consent Nyanja

Zo onjetzela 1

Mutu Wa Phunziro: Zinthu zimene odwala khansa ya m’mabere afunika kuziba kuchipatala ca Khansa mu Lusaka muno mziko la Zambia.

A Beauty Lilala Namushi omwe ali ni apunzi pasukula lalikulu la University of Zambia m’cigawo ca ma phunziro ya unamwino kapena kuti unesi akupempha inu kuti mungatengeko mbali mukufufuza za mutu wa phunziro liri pa mwamba apa. Kufufuza kumeneku niko funikira cifukwa kuzathandiza aku cipatala ca khansa kupeza njira zabwino zotangatiramo anthu odwala matenda ya khansa. Ine ndifuna kuti kutengamo mbali kapena kusimuzatengamo mbali. Ngati mwasanka kuti simuzatengamo mbali pamene muyembekeza kutenyatidwa inu simuza taikidwa thandizo kucokera ku bungwe kapena munthu alionse. Ngati mwabvomera kutenga mbali mukufufuza muza pempedwa kuti musayine pepala lo bvomekeza pamoso pa mboni. Ku bvomera kwanu siku thantanza kuti inu muza landira malipilo pamene apo.

Colinga ca phunziro

Muntu kupezeka na matenda ya khansa kumvesa mantha ndaponso kuza mwambo mukalidwe ndi maganizo ndaponso odwala yemweyo pamodzi ndi banja lase ama bvutisidwa kutupi, mumaganizo, kumuzimu kuikila po nama bvuto ena apa banja (Ankem, 2006, Motlagh et al, 2014). Anthu omwe apezeka na matenda ya khansa amankala na cikaiko ca zatsologolo lao ndipo ama bvutika mumaganizo nakufunisisa chiyembekezo na thandizo. Kupatsa cidziwitso ca matenda ya khansa kwa anthu obvutika kunzathandize odwala ku thupi ndaponso mumaganizo kunzekera kuti agwepo kumwa mankwala naku zisamalila. Comwe co phunziro lizaonetsa zinthu zomwe odwala matenda ya khansa ya mabere afunika kuziba. Zinthu izi zizaziwika pambuyo po kambisana ndi anthu osiyanasiyana omwe azatenga mbali mu phunziro limeneli. Zotulika zo funikira zomwe zizachoka mukufufuza uku zizathandiza kuti tipeze njila zoyenera kulingana ndi makalidwe watu ndaponso kupeleka thandizo kwa anthu odwala khansa ya m’mabere. Kuziba
zofuna za odwala kuthandiso kuti ndalama ndi zinthu zonso zofunikira zipelekedwe munjila yo yenela. koteru kuti odwala azakhala naumo yo yobwino/oyenera

**Njila zo sebenzesa**

Pambuyo po sayina pepelablo bvomela kuti muzatengamo mbali mu phunziro ndiponso kufunsa mafunso, inu muza pumpedwa kuti mukambe zinthu zamene mufuna kuziba pakudwala kwanu, mainkwala na za tsogolo lanu chifukwa ca matenda ya khansa. Pambuyo muza pumpedwa kuti mukambe njila yamene mufuna kuti isebenzesedwe paku uza inu za matenda yamu ndiponso momwe tingapezere njila zoyenera zo gwililamo nchito imenei.

**Ubwimo wace**

Kulibe pindu yokuza inu yomwe muza landila cifukwa cotengamo mbali mu ma phunziro aya koma zothuluka za phunziro zizathandiza ife kuti tidziwe zofuna za anthu odwala khansa zothuluka zimenezi zizathandiza asogoleri kupeza njila zoyenera ndiponso zomwe ziyendelana na m’kalidwe watu popeleka cidziwiso kwa odwala khansa pamodzi ndi thandizo.

**Cisinsi**

Zone zomwe inu muzandiuza kupyolela mu phunziro ili, ine sindi zanena kwa munthu aliyense, koma cabe kwa akulu akulu omwe apezeka mu bungwe loyanganila za phunziro ili. Na onso aza sunga cisinsi. Cifukwa cosunga cisinsi inu simuzaziwika pa dzina lanu koma pa Nambala yomwe muzapasidwa. Zone zomwe muzakamba zo kuzo inu sizizapasidwa kwawina aliyenso kopanda cilolezo colembedwa kucokera kwa inu.
Appendix X: Consent form Nyanja
Zo onjela II: Cilolezo (Nyanja/Chewa)

Colinga ca phunziro cina masulidwa kwaine ndipo ndina mvetsetsa. Ubwino wace,mabvuto ndiponso cisinsi
cace.Ndi dziwanso kuti ngati na bvomela kutenga mbali mu maphunziro, ninga siye panthawi ili yonse popanda kupatsa cifunkwa ndidziwanso kuti ndiku cita izi mozi peleka.

Ine…………………………………………………………………… (Dzina)

Nabvomela Kuyanka mafunso mu pepala ili

Posayina………………………………………………… Tsiku……………………………………

BO ZIBISA NGA KULIBVUTO

1. Beauty Lilala Namushi, Cancer Diseases Hospital, P.O Box 51337, Lusaka. Cell: 0955832541.
2. Dr Marjorie K. Makukula, University of Zambia, School of Nursing Sciences, P.O Box 50110. Cell: 0977889430.
3. The Chairperson, University of Zambia Biomedical Research Ethics Committee, P.O Box 50110, Ridgeway, Lusaka, Telephone: 260-1-256067.
Appendix XI: Interview Schedule

THE UNIVERSITY OF ZAMBIA
SCHOOL OF NURSING SCIENCES

SEMI STRUCTURE INTERVIEW SCHEDULE FOR PATIENTS

TITLE: INFORMATION NEEDS OF BREAST CANCER PATIENTS AT CANCER DISEASES HOSPITAL IN LUSAKA, ZAMBIA

Place of interview: .................................................................

Date of interview: .................................................................

Time started: ....................... Time ended: .................

Name of interviewer: ......................

Name of interviewee (optional): ...........................................

Instructions for the interviewer

1) Introduce yourself to the participant.
2) Explain the purpose of the participant.
3) Assure the participant of confidentiality.
4) Obtain an informed consent.
5) If the participant decline to take part, do not force them.
6) Do not write names on the interview schedule.
7) Thank the Participant at the end of each interview.
SECTION A: DEMOGRAPHIC DATA

1. Age at last birthday
   a. Less than 20
   b. 20-29
   c. 30-39
   d. 40-49
   e. 50-59
   f. 60-69
   g. 70 and above

2. Marital Status
   a. Married
   b. Single
   c. Divorced
   d. Widowed

3. Educational Level
   a. No education
   b. Primary
   c. Secondary
   d. College
   e. University

4. Occupation
   a. Formal employment
   b. Informal Employment
   c. Unemployed
   d. Self employed

5. Religious Denomination .................
SECTION B: MEDICAL RELATED DATA

6. How long have you been living with breast cancer?
   a. 1-4 years
   b. 5-9 years
   c. 10 and above

7. Tumor Stage at Diagnosis
   a. 0
   b. I
   c. II
   d. III
   e. IV

8. Current stage ..........................

9. Are you on cancer Treatment?
   a. Yes
   b. No

10. What type of treatment?
    a. Chemotherapy
    b. Radiotherapy
    c. Chemo radiation
    d. Hormonal

10. Co-morbidities
    a. No previous illness
    b. Hypertension
    c. DM and HTN
    d. Renal disease
    e. Others. Specify: ..........................
SECTION C: ANXIETY RATING SCALE

0 = Not present, 1 = Mild, 2 = Moderate, 3 = Severe, 4 = Very severe

|   | Description                                                                 | 0 | 1 | 2 | 3 | 4 |
|---|----------------------------------------------------------------------------|---|---|---|---|---|
| 12| **Anxious mood** *(Worries, anticipation of the worst, fearful anticipation, irritability)* |   |   |   |   |   |
| 13| **Tension** *(Feelings of tension, fatigability, startle response, moved to tears easily, trembling, feelings of restlessness, inability to relax).* |   |   |   |   |   |
| 14| **Fears** *(Of dark, of strangers, of being left alone, of animals, of crowds).* |   |   |   |   |   |
| 15| **Insomnia** *(Difficulty in falling asleep, broken sleep, unsatisfying sleep and fatigue on waking, dreams, nightmares, night terrors)* |   |   |   |   |   |
| 16| **Intellectual** *(Difficulty in concentration, poor memory)* |   |   |   |   |   |
| 17| **Depressed mood** *(Loss of interest, lack of pleasure in hobbies, depression, early waking, diurnal swing).* |   |   |   |   |   |
| 18| **Somatic (muscular)** *(Pains and aches, twitching, stiffness, myoclonic jerks, grinding of teeth, unsteady voice, increased muscular tone)* |   |   |   |   |   |
| 19| **Somatic (sensory)** *(Tinnitus, blurring of vision, hot and cold flushes, feelings of weakness, pricking sensation).* |   |   |   |   |   |
| 20| **Cardiovascular symptoms** *(Tachycardia, palpitations, pain in chest, throbbing of vessels, fainting feelings, missing beat).* |   |   |   |   |   |
| 21| **Respiratory symptoms** *(Pressure or constriction in chest, choking feelings, sighing, dyspnea).* |   |   |   |   |   |
| 22| **Gastrointestinal symptoms** *(Difficulty in swallowing, wind abdominal pain, burning sensations, abdominal fullness, nausea, vomiting, borborygmi, looseness of bowels, loss of weight, constipation).* |   |   |   |   |   |
| 23| **Genitourinary symptoms** *(Frequency of micturition, urgency of micturition, amenorrhea, menorrhagia, development of frigidity).* |   |   |   |   |   |
| 24| **Autonomic symptoms** *(Dry mouth, flushing, pallor, tendency to sweat, giddiness, tension headache, raising of hair).* |   |   |   |   |   |
25. **Behavior at interview** (Fidgeting, restlessness or pacing, tremor of hands, furrowed brow, strained face, sighing or rapid respiration, facial pallor, swallowing)

|   | Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important |
|---|---------------|--------------------|----------------------|---------------|---------------------|
| 26 | Diagnosis and the stage |                     |                      |               |                     |
| 27 | The cause of breast cancer |                   |                      |               |                     |
| 28 | How the cancer behaves in my body |               |                      |               |                     |
| 30 | Which other organs are affected or if the cancer is anywhere else in my body |           |                      |               |                     |
| 31 | If the breast cancer will be cured |             |                      |               |                     |
| 32 | How the illness will affect my life over the next few months |           |                      |               |                     |
| 33 | How my illness will affect my life in future |              |                      |               |                     |

**SECTION D: BREAST CANCER INFORMATION NEEDS QUESTIONNAIRE**

Please read each of the following sentences tick in the space that best describes how important it is for you to have this information.

To help me with my illness it is important for me to know.

1. **Disease Process**
2. Investigative tests that are done

|   |   | Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important |
|---|---|---------------|--------------------|----------------------|---------------|---------------------|
| 34 | Why my Doctor suggests certain tests done (e.g. FBC, creatinine, X-ray, Ultra sound, Mammogram) |   |   |   |   |   |
| 35 | What I need to do before the tests |   |   |   |   |   |
| 36 | How tests are done |   |   |   |   |   |
| 37 | How I will feel during and after the tests |   |   |   |   |   |
| 38 | What the results of the tests mean |   |   |   |   |   |

3. Treatment Modalities

|   |   | Not Important | Slightly Important | Moderately Important | Very important | Extremely Important |
|---|---|---------------|--------------------|----------------------|---------------|---------------------|
| 39 | The types of treatment available |   |   |   |   |   |
| 40 | How the treatments works against the cancer |   |   |   |   |   |
| 41 | Why the doctor suggests this treatment plan for me |   |   |   |   |   |
|   | The modalities which will be used to deliver the treatment |
|---|----------------------------------------------------------|
| 42 | What I need to do to prepare for treatment               |
| 43 | How long I will be receiving treatment                   |
| 44 | The possible side effects of my treatment                |
| 45 | How I will deal with my side effects                     |
| 46 | What side effects I should report to the Doctor / nurse  |
| 47 | If there are ways to prevent side effects                |
| 48 | How I will feel after my treatment                       |
| 49 | If I am prone to infection after my treatment            |
| 50 | Who to talk to if I have questions during treatment      |
| 51 | If the treatment will alter the way I look               |
| 52 | Who to talk to when I hear about treatments other than Surgery, chemotherapy, radiotherapy or Hormonal therapy |
### 4. Physical Needs

|   |   | Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important |
|---|---|---------------|--------------------|----------------------|----------------|---------------------|
| 54 | How to care for my skin after the skin reactions |   |                     |                      |                |                     |
| 55 | How long my skin will take to heal |   |                     |                      |                |                     |
| 56 | If I can wear a brassier |   |                     |                      |                |                     |
| 57 | If there are special arm exercises to do |   |                     |                      |                |                     |
| 58 | If can take a bath or shower |   |                     |                      |                |                     |
| 59 | If I can apply anything on my body |   |                     |                      |                |                     |
| 60 | Where I can get help if I have problems feeling unattractive as I did before |   |                     |                      |                |                     |
| 61 | If I can continue with my usual hobbies and sports |   |                     |                      |                |                     |
| 62 | If I can continue my usual social activities |   |                     |                      |                |                     |
| 63 | Where my family can go if they need help |   |                     |                      |                |                     |
| 64 | If there are groups where I can talk with other people with cancer |   |                     |                      |                |                     |
### 5. Psychosocial Needs

|   | Not Important | Slightly Important | Moderately Important | Very Important | Extremely Important |
|---|---------------|--------------------|----------------------|----------------|---------------------|
| 66 | If the cancer will come back |                     |                      |                |                     |
| 67 | How to tell if the cancer comes back |                     |                      |                |                     |
| 68 | What to do if I become concerned about dying |                     |                      |                |                     |

### SECTION E

1. What are the barriers to accessing information by breast cancer patients at CDH?

   I. ................................................................. .................................................................

   II. ................................................................. .................................................................

   III. ................................................................. .................................................................

   IV. ................................................................. .................................................................

   V. ................................................................. .................................................................

2. Recommendations

   ..........................................................................................................................................................

   ..........................................................................................................................................................

   ..........................................................................................................................................................

   .............................................................................................................................................................
Appendix XII: Application letter for Authority

THE UNIVERSITY OF ZAMBIA
SCHOOL OF NURSING SCIENCES
Office of the Assistant Dean Postgraduate

19th June 2017

Ms Beauty Namushi
School of Nursing Sciences
UNZA
LUSAKA

Dear Ms Namushi,

RE: GRADUATE PROPOSAL PRESENTATION FORUM

Following the presentation of your dissertation entitled “Information needs of breast cancer patients at cancer diseases hospital, Lusaka” your supervisor has confirmed that the necessary corrections to your research proposal have been done.

You can proceed and present to the Research Ethics.

Yours faithfully,

[Signature]

Yolan Banda (Mr.)
ASSISTANT DEAN POSTGRADUATE

Cc: Dean, School of Nursing Sciences
Appendix XIII: Ethical Clearance

THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarcc@unza.zm
Assurance No. FWA 00000338
IRB00061131 of IORG00000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

23rd August, 2017.

Your Ref: 008-07-17.

Ms. Beauty Namushi,
University of Zambia,
School of Nursing Sciences,
P.O. Box 50110,
Lusaka.

Dear Ms. Namushi,

RE: RESUBMITTED RESEARCH PROPOSAL: “INFORMATION NEEDS OF BREAST CANCER PATIENTS AT CANCER DISEASES HOSPITAL, LUSAKA, ZAMBIA” (REF. NO. 008-07-17)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee on 17th August, 2017. The proposal is approved.

CONDITIONS:

- This approval is based strictly on your submitted proposal. Should there be need for you to modify or change the study design or methodology, you will need to seek clearance from the Research Ethics Committee.
- If you have need for further clarification please consult this office. Please note that it is mandatory that you submit a detailed progress report of your study to this Committee every six months and a final copy of your report at the end of the study.
- Any serious adverse events must be reported at once to this Committee.
- Please note that when your approval expires you may need to request for renewal. The request should be accompanied by a Progress Report (Progress Report Forms can be obtained from the Secretariat).
- Apply in writing to National Health Research Authority for permission before you embark on the study.
- Ensure that a final copy of the results is submitted to this Committee.

Yours sincerely,

[Signature]

Dr. S.H. Nsala
VICE-CHAIRPERSON

Date of approval: 23rd August, 2017. Date of expiry: 22nd August, 2018.
Appendix XIV: Permission from CDH

6th July, 2017.

Dr. Marjorie Makukula
The University of Zambia
School of Nursing Sciences
Box 50110
Lusaka.

Dear Dr. Makukula,

RE: APPROVAL TO CONDUCT RESEARCH - BEAUTY ULALA NAMUSHI (COMPUTER NO. 201513093)

Reference is made to the above.

I wish to inform you that CDH has no objection to your request to conduct research at our institution, entitled: "Information Needs of Breast Cancer Patients at Cancer Diseases Hospital, Lusaka." However, the Hospital would appreciate being availed a copy of the research report for the library for use by other students and staff.

Kindly request the student to come with a copy of this letter during the research.

Yours sincerely,

Dr. Lewis Banda
Senior Medical Superintendent