

UNIVERSITY OF FORT HARE

FACULTY: SCIENCE AND AGRICULTURE

TOPIC: Patients' perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital, Buffalo City, Eastern Cape.

By

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DECLARATION

I Caroline Ntombekaya Matwele, student no 201213752 hereby declare that the work contained herein, is my own original work, that I am owner of the copy right thereof and that I have not previously in this entirety or in part submitted it for any qualification.

Signature.....

Date.....

ABSTRACT:

The aim of the study was to: explore and describe patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape, South Africa.

Reasons why patients diagnosed with breast cancer delay in the commencement of the treatment were to be elicited and strategies for curbing the problem were looked into. A qualitative approach was used, with an exploratory, descriptive and contextual design.

The purposive sampling technique was used. The sample comprised 15 participants, 14 Black Africans and 1 Coloured lady.

Data were collected using an interview guide from female patients diagnosed with breast cancer whose age ranged from 18-72 years. Interviews were recorded on a tape. Tesch's (1990) steps of qualitative data analysis guided the analysis process. The results revealed that being diagnosed with breast cancer is perceived as a traumatic and painful experience with negative emotional, social, physical impact and unbearable side effects of from the treatment. Fear of undergoing treatment emerged as a barrier for taking prompt treatment.

In exploring, one needs to use empathy, particularly that the researcher engaged in bringing to surface painful information. With the use of understanding and broad mindedness, participants opened up.

Recommendations were made regarding strategies for care.

DEDICATION

I would like to dedicate this study to my sister in-law, Mrs. Shunkie Mani who died from breast cancer. May her soul rest in peace!

I also dedicate this study to my late parents who believed in me since I was a little girl and knew that I would reach the stars.

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The Almighty, for giving me the strength, courage and power to finish this study.

A special word of appreciation and gratitude for realization of my dream goes to the following:

My dear loving husband Sangweni Matwele for listening, understanding and all the support he gave me.

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I am grateful to the authorities at the Department of Health for allowing me to conduct this study.

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CHAPTER 1

1.1 Introduction and background:

Breast cancer is the commonest malignancy amongst women world-wide (Yabro, Frogge & Goodman 2005:1023). It accounts for 32% of all cases of female cancers. As such, it is the leading cause of deaths in women between the ages of 20-59 years, and is the leading cause of cancer deaths in women (Cancer statistics SA, 2004). In estimation, records have shown that breast cancer has been the second leading cancer between 1986 and 1992, cervical cancer being the leading cancer between 1993 and 1995. Breast cancer seems to have overtaken cervical cancer and it is now the most common cancer in women (16, 6%). It is ranked first in Southern Africa compared to other types of cancers (Global Cancer Facts and Figures 2008:42). It is the commonest cancer in white (17, 9%), Asiatic women (24, 4%), the second commonest cancer in mixed races (18, 2%) and (13, 2) in Black women (Department of Health report: 2000). It is estimated that 226,870 new cases of invasive breast cancer have occurred among women in the United States during 2012 (Global Cancer Facts and Figures 2012:38).

The Australian institute of Health and Well Being and National Breast Cancer Centre believe that around 223 women will die of breast cancer in Western Australia. Breast cancer is lower in Gambia compared to other African countries (Zimbabwe, Uganda) but the incidence rate is higher in Southern Africa (Global Cancer Facts and Figures 2008:42).

In several sub-Saharan African countries, breast cancer has now become the most commonly diagnosed cancer in women, a shift from previous decades in which cervical cancer was the most commonly diagnosed cancer in many of these countries. (Global Cancer Facts and Figures 2008:42). This may be due to increases in the prevalence of risk factors for breast cancer such as early menarche, late child bearing, having fewer children, and obesity, which are associated with economic development and western behaviors. (Global Cancer Facts and Figures 2008:42). Based on data from the Uganda (Kampala) and Algeria (Setif) cancer registries, breast cancer incidence rates have nearly doubled over the past 20 years, though

the rates still remain about one-fifth of that in the US and several Western countries. (Global Cancer Facts and Figures 2008:42).

Oncology services (chemotherapy, radiation therapy and surgery) in South Africa, are situated in the main cities despite the fact that cancer patients are distributed in a scattered manner, over the large geographical area that the country occupies, this is not convenient for health care users as they travel long distances to get oncology services. In Primary Health care facilities in the Buffalo City Metropolitan Municipality (the area selected for this research), there are no trained oncology nurses who are responsible for screening women for breast cancer, conducting awareness campaigns and making follow up visits, to diagnosed women (Department of Health 2008:3). Diagnosed women are left alone unaccompanied and with no one to comfort them. There is no documented programme for oncology services at the Primary Health Care setting, yet early detection is said to be the best cure (Primary Health Care Supervision Manual (2009:79). Oncologists and Radiologists are very few and are allocated in tertiary hospitals which have been identified as the only hospitals where cancer patients can be treated and Frere Hospital is the only public hospital that offers oncology services in Amathole District (Department of Health 2008:3). This hospital serves all the sub districts i.e. Amahlathi, Mbashe, Mquma and Nkonkobe, all under Amathole District.

Despite the growing burden, cancer continues to receive low public health priority in Africa, largely because of limited resources and other pressing public health problems including communicable diseases such as HIV and AIDS, Malaria and Tuberculosis. This may also be due to lack of awareness of the magnitude of the current and future cancer burden among policy makers, general public and international , private or public health agencies interested in Global Health (Cancer Facts and Figures 2008:370). It is in the light of this background that the researcher explored the problems surrounding breast cancer. It is hoped that this study will help raise awareness amongst the general public, public or private health agencies interested in global health of the importance of early detection and providing support services to cancer patients. (Global cancer fact and figures 2008: 370)

1.2. Problem statement

Literature revealed that lack of awareness regarding breast cancer, fear of being diagnosed and misconceptions about breast cancer treatment were identified as barriers to presenting early for treatment and as such prompt treatment does not occur in women diagnosed with breast cancer. What compounds on the previously mentioned barriers is that oncology services are centralized, women have to travel long distances for diagnoses and treatment and get lost in the process.

Due to delayed response of women following diagnosis with breast cancer, such women present themselves late for treatment, at times at stages 3 and 4, that is, with observable symptoms (American Cancer Society, 2013:9). Though breast cancer is likely to be cured, it is still believed to be the number one killer in the world, compared to other types of female cancers. For the 41.6% and 36.1% of women showing up at advanced stages 3 and 4, nothing curative can be done but only palliative care. This brings about hopelessness to users, families and health care providers as their efforts cannot be successful. Breast cancer patients express doubts regarding breast cancer treatment. They show lack of knowledge and helplessness when it comes to treatment because these patients die young, leaving motherless children and frustrated relatives.

1.3. Definition of concepts used in the text

Patient

The term patient refers to a person of any age and either sex gender, as a total being-body and spirit, sick or well who needs help to complement his specific ability to accept optimal responsibility for his own health (Searle 2002:122).

In this study, the term patient will be used to refer to a person who is either admitted in a ward for diagnosis and treatment or a person who is receiving breast cancer treatment as an out- patient.

Breast Cancer

It is cancer that originates in the tissue of the breast usually the ducts and lobules. It occurs in both males and females although male breast cancer is very rare (Yabro et al 2005:1023). In this study, breast cancer is a disease that presents itself with a lump on the breast or else-where, a discharging nipple and or pain.

Treatment commencement

Treatment commencement is to begin on an act or programme that sets in motion some cause of events. (Oxford Advanced Learner's Dictionary 2010:1576). For the purpose of this study, treatment commencement means the therapeutic strategies that are conducted following screening and diagnosis for breast cancer patients.

Diagnosis

Diagnosis means taking the identification of, and discriminating between physical, psychological and social signs and symptoms in man (R2598 as amended 2001:10). In this study, diagnosis means the identification of a disease that is made after a series of tests have been done, which will lead to commencement of treatment.

1.4. Significance of the study

This study will contribute to the following:

Policies

After the completion of this study, there will be an increase of information on policies regarding oncology services in the Eastern Cape Province. It is hoped that early submission for cancer treatment will be embraced in the policy. If the recommendations of the study are adopted, this will lead to preventive strategies at schools and any targeted areas. Early commencement of treatment including education of the community will be put in place and implemented at Primary Health Care level.

Practice

An in-service program would be conducted for health practitioners on issues surrounding breast cancer.

Research

The study will contribute to a body of knowledge as awareness will be created regarding breast cancer. Results of this study will be made available to all stakeholders.

Patients

Patients will be made aware of presenting signs and will be able to present themselves early for prompt treatment.

1.5. Purpose of the study

The purpose of this study was to:

Elicit reasons for delayed commencement of treatment by women diagnosed with breast cancer and provide strategies for curbing the problem.

1.6. Research question

The research questions guiding this study were:

1. How do people diagnosed with breast cancer perceive the commencement of treatment?

2. How do patients diagnosed with breast cancer describe the delay in treatment commencement?
3. How can late commencement of treatment by women diagnosed with breast cancer be curbed?

1.7. Objectives of the study

To answer the research questions, the following objectives were put in place:

1. To explore the perceptions of women diagnosed with breast cancer regarding commencement of treatment.
2. To describe the reasons for the delay in commencing treatment by women diagnosed with breast cancer.
3. To elicit strategies that can be used to prevent delay in treatment commencement.

1.8 Research Methodology

1.8.1 Research Approach

A qualitative approach was used to conduct the study. The qualitative approach was chosen because patients were expected to describe their perceptions regarding treatment commencement after diagnosis with breast cancer. According to Brink, Van Der Walt and Van Rensburg (2009:113), qualitative research is done by researchers who wish to explore the meaning, or describe and promote understanding, of human experiences; qualitative methods are more appropriate and effective alternatives for this type of research.

1.8.2 Design

Polit and Beck (2008:765) define a research design as “the overall plan for addressing a research question, including specifications for enhancing the study’s integrity”. Brink (2009:92) in turn describes a research design as “a set of logical steps taken by the researcher to answer the research question”. It forms the blue print of the study and determines the methodology used by the researcher to obtain sources of information.

A descriptive and explorative design was used to carry out this research because the researcher wanted to explore and describe the perceptions of women diagnosed with breast cancer regarding treatment commencement.

1.8.3 Research setting

The study was conducted at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape. Buffalo City Metropolitan Municipality is situated relatively centrally in the Eastern Cape Province, which is bounded to the South-East by the long coastline along the Indian Ocean. Frere Hospital is a large 800 bed provincial government tertiary hospital situated in East London.

All the hospitals in Amathole, Chris Hani and Buffalo City refer their cancer patients to Frere hospital for diagnosis and treatment because it is the only public hospital that has been identified as a public tertiary institution that can render oncology treatment i.e. chemotherapy, radiation therapy and surgery.

1.8.4 Target Population

The population for this study comprised females diagnosed with breast cancer between the ages of 18 and 72 years at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape. The above mentioned age group was selected because breast cancer is more prevalent in this stated age group as revealed by statistics in the introduction. (Global cancer facts and figures 2008:42)

1.8.5 Sample and sampling

The sample for this study consisted only of women diagnosed with breast cancer between the ages of 18 and 72 years of all races. Purposive sampling method was used to get the information from breast cancer diagnosed women because they were the ones who suffered from breast cancer.

1.8.5.1 Sample size

For the purpose of quality, (explain) the researcher decided to interview 15 participants, although the researcher was aware of saturation. The researcher interviewed all the participants although there seemed to be no new information from participant number 10 saturation had occurred onwards.

1.8.5.2 Inclusion criteria

The sample included female patients diagnosed with breast cancer and they ranged from the ages of 18 and 72 years. The participants were women admitted in the oncology unit at Frere hospital or coming for treatment on an outpatient basis at the time of the study.

1.8.5.3 Exclusion criteria

Patients who were excluded were the ones outside the age range, at terminal stage as well as those who were not willing to participate.

1.8.6 Pilot Study

A pilot study was done to test the practical aspect of the research study. The researcher used an interview guide which would be used for the actual study. Three participants who met the inclusion criteria were interviewed but did not form part of the final sample. Data collected during this process was not included in the main study. A pilot study was done to test the feasibility of the instrument, to detect possible flaws in the methodology and also to sharpen the skills of the researcher (Brink 2012:175).

The pilot study assisted the researcher to identify problems with the design and to determine whether the sample was representative of the population or whether

sampling technique was effective (Burns & Grove, 2012:42). It also sharpened the researcher's interviewing skills.

1.8.7 Data collection

Before conducting data collection the researcher obtained consent from the participants. The researcher conducted interviews with participants who came to the breast clinic for follow up and for chemotherapy. During the interview sessions, the researcher probed where it was necessary so as to understand the experiences of the participants. Probing was done without compromising the rights of the participants. The researcher used a tape recorder to record the interviews. Data were transcribed verbatim from the tape. Field notes were also taken.

1.8.8 Data analysis

Data analysis was done concurrently with data collection. Data collection was continued until there was no more new information reported. The transcriptions together with field notes were sent to "an independent coder" for data analysis as suggested by Creswell (1994:158). Data analysis was done using content analysis technique, guided by Tesch's method of analysis as cited by Creswell (2009:185-190).

The coding process resulted in the emergence of themes. The researcher and the co-coder agreed on the categories, subcategories and the themes identified in the transcriptions. The researcher and the co-coder used a work protocol to ensure the use of the same steps in analysing the data. What is the work protocol?

1.9 Ethical considerations

The researcher has a professional responsibility to design research that upholds sound ethical principles and that protect human rights (Speziale & Carpenter 2007:57). The researcher requested ethical clearance for doing the study from the Ethics committee of the University of Fort Hare by submitting a proposal, ethical clearance was granted.

Permission to conduct the study was also requested from the epidemiology and research unit at the Department of Health, Bisho and from the Frere hospital management and it was granted.

Participants were also given the necessary information regarding the nature and duration of the study, taking into consideration benefits and risks involved in the study so that the participants can give an informed consent.

The information in question embraced attitudes, behavior and records. However, the participants' privacy was respected at all times. The researcher ensured privacy in the setting where data was collected. A side ward was arranged for data collection because the topic under study was very sensitive. Privacy of participants was protected by not using their real identity and by asking permission from them to share the information if there was a need. In other words anonymity and

confidentiality were observed in the study. On the basis of the right to privacy the research participants had the right to anonymity and the right to assume that the data collected will be kept confidential (Burns & Grove 2005:188).

All information related to participants was kept in complete confidence and was locked away; only one person was responsible for the safe keeping of data. No unauthorized person had access to the information except for the researcher. Participants were assured that the information would be used for the purpose of the study so as to improve the quality of patient care. Confidentiality was ensured by not reporting private data that identifies participants.

The right to protection from discomfort and harm is based on the ethical principle of beneficence that one should do good but above all, should not do harm (Burns & Grove 2005:190). The researcher continually re-assessed the participants during data collection to check whether the effects of the research were not causing more discomfort. The researcher was prepared to adapt the research plan or even discontinue should unexpected effects occur. An on-site counselor or oncology social worker was arranged to counsel the affected participants.

Informed consent was obtained from participants who were capable of giving such and according to Speziale & Carpenter (2007:63) informed consent means that “participants have adequate information regarding the research, are capable of comprehending the information, and have the power of choice enabling them to participate in research or decline participation”. Informed consent is required to ensure that participants comprehend the aim, nature and benefits of the proposed investigation. Participants were informed about the overall purpose of the research and its main features as well as risks, benefits of participation and social implications (Joubert & Ehrlich 2010:35). Consent was obtained from the participants and permission was granted, for using a tape recorder.

1.10 Trustworthiness

Authenticity of the study was ensured as follows:

For the purpose of the study, trustworthiness was ensured by using four concepts. These were:

Credibility, transferability, dependability and confirmability. These will be discussed in chapter 3.

1.11 Conceptual Framework

The Health Belief Model (HBM) was used as the conceptual framework to guide this study. The theory focuses on the degree of fear of illness related to the potential benefits of taking health action.

According to Burns & Grove (2005:121) a framework is “an abstract, logical structure that guides the development of the study and enables the researcher to link the

findings to nursing's body of knowledge". Brink (2012:26) explains that a conceptual frame work is developed through identifying and defining concepts and proposing relationships between these concepts. The conceptual framework for this study was presented by making use of related concepts in Becker's Health Belief Model.

The Health Belief Model was developed in the 1950's by a group of U.S. Public Health Service Social Psychologist who wanted to explain why people were participating in programs to prevent and detect diseases (Janz, Champion, & Strecher, 2002:45-66). The Health Belief Model states that a person's health and related behaviour depends on the person's perception of four critical areas: the severity of a potential disease, the person's susceptibility to that illness, and the benefits of taking a preventative action and the barriers to taking that action. In this study, five major concepts of the Health Belief Model were used, these were: perceived susceptibility, perceived severity, perceived barriers, perceived benefits and cues to action.

The model postulates that health seeking behaviour is influenced by a person's perception of a threat posed by a health problem and the value associated with actions and how they will comply with health care therapies. Below, is a description of concepts used:

Perceived susceptibility

It addresses the relationship between the person's beliefs and behaviour (Young, van Niekerk & Mogotlane 2003:20) For the purpose of the study, perceived susceptibility means the individual's assessment of her chances of getting breast cancer.

Perceived severity

Perceived severity is the individual's judgment as to the severity of breast cancer (Young, van Niekerk & Mogotlane 2003:20). Even when the individual recognises personal susceptibility, action will not occur unless the individual perceives the severity to be serious enough to have serious organic or social implications. In the study this was observed in participants who delayed seeking prompt treatment because signs were not serious enough to take action for example presence of a lump that was not painful or a discharging nipple and absence of a lump.

Perceived barriers

Perceived barriers are the individual's opinion as to what will stop her from commencing treatment. (Taylor, Bury, Camping, Carter, Garfield, Newbould & Rennie 2007:3). Barriers may include the distance from the patient's residential area to the site of treatment, costs of the proposed treatment and the patient's cultural beliefs. In this study distance also posed as a barrier as participants were from different districts in the Eastern Cape, for example Chris Hani, Amathole and Buffalo City.

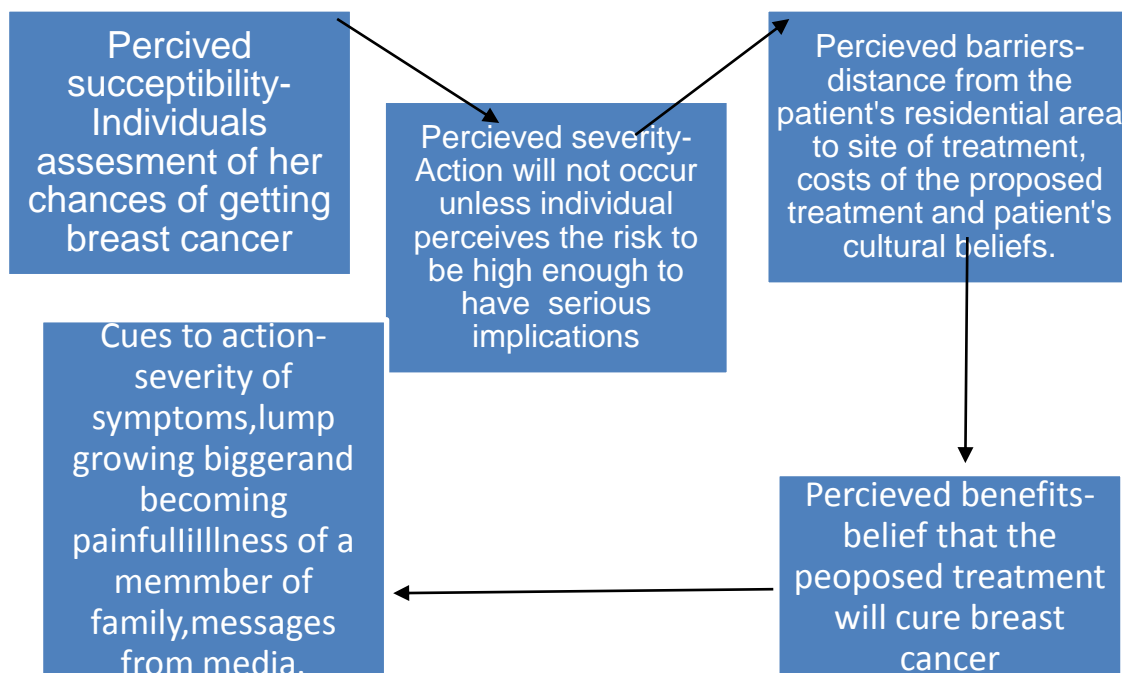
Perceived Benefits

Perceived benefits are an individual's conclusion as to whether the new behaviour is better than what she is already doing. Perceived benefits refer to the patient's belief that a given treatment will cure the illness or prevent it (Young, van Niekerk and Mogotlane 2003:20).

Cues to action:

Internal and external factors may contribute to a change in behaviour and the individual may decide to go for treatment (motivators). Motivating factors may include progression of the disease, the lump growing bigger, pain and discomfort or there may be a member in the family who has become sick. Messages from mass media, advice from others, reminders from health professionals and newspapers may also trigger response to change in behavior (Young, van Niekerk and Mogotlane, 2003:20). Theoretically, the framework helps the researcher to work within the borders of the framework.

FIGURE 1. Schematic presentation of the Health Belief Model (adapted from Jans & Becker 1984)



The Health Belief Model alleges that an individual will take action when seeing benefits. This is peculiar in Health promotion, it demands awareness creation to the community.

1.12 Overview of Chapter one

The background and introduction, problem statement, aims, objectives, research question and significance of the study were presented in this chapter. Focus was on

all the steps of the research process which require to be applied in a research report. The next chapter will focus on literature review.

CHAPTER 2: Literature review

2.1. Introduction

Literature review is defined as the review of other researchers' empirical experiences with related or similar problems of the study. The researcher critically and analytically reviewed experiences, findings, designs and methods used to understand them and to form conclusions (Brink 2012:54).

The purpose of literature review was to show how current findings fit into what is already known about the topic under study. Two main types of literature review were used for the purpose of this study. Data based literature which have been derived from previous research studies and theoretical literature which consist of conceptual frameworks that supported the selected research problem (Burns and Grove 2009:93).

Literature review focused on the following:

Scope of the problem, delayed presentation of patients with breast cancer and delayed diagnosis in patients with breast cancer. The researcher reviewed literature on breast cancer and commencement of treatment.

2.1.2 Scope of the problem

It is estimated that 226,870 new cases of invasive breast cancer have occurred among women in the United States during 2012 (Global Cancer Facts and Figures 2012:38). The Australian institute of Health and Well Being and National Breast Cancer Centre believe that around 223 women will die of breast cancer in Western Australia. Breast cancer is lower in Gambia compared to other African countries (Zimbabwe, Uganda) but the incidence rate is higher in Southern Africa (Global Cancer Facts and Figures 2008:42).

In several sub-Saharan African countries, breast cancer has now become the most commonly diagnosed cancer in women, a shift from previous decades in which cervical cancer was the most commonly diagnosed cancer in many of these countries. (Global Cancer Facts and Figures 2008:42). This may be due to increases in the prevalence of risk factors for breast cancer such as early menarche, late child

bearing, having fewer children, and obesity, which are associated with economic development and western behaviors.(Global Cancer Facts and Figures 2008:42). Based on data from the Uganda (Kampala) and Algeria (Setif) cancer registries, breast cancer incidence rates have nearly doubled over the past 20 years, though the rates still remain about one-fifth of that in the US and several Western countries. (Global Cancer Facts and Figures 2008:42).

2.1.3 Delayed presentation of patients with breast cancer for treatment

According to Rey, Bendiane, Viens, Bouhnik, Buk, Obadia, Peretti-Natel and OrsPaca (2009:318), womens' physical and socio demographic characteristics have an influence on delay to presentation. They suggest that health education messages are needed to convince symptomatic women to present quickly to a physician even if they do not have risk factors (2009:318).

In a study conducted by Mousa, Seifeldin, Hablas, Selbana, Solimen (2011:555) in Egypt, to investigate patterns of seeking medical care among Egyptian breast cancer patients, it was revealed that patients visiting general practitioners experience delays than those visiting surgical oncologists. The researchers linked the delay to who the patient consulted, not to patterns of seeking medical help.

Late presentation for treatment in women with breast cancer has been associated with negligence, economic status, literacy, delayed presentation of symptoms, time factor, difficulty in accessing health care, fears for treatment, general practitioners and fear of cancer (Macleod, Mitchelle and Romirez 2009:S 92-S 101).

2.1.4 Delayed diagnosis in patients with breast cancer

Some of the factors that are associated with delays in diagnosis in patients with breast cancer as investigated by Bright, Bargash, Donach, dela Barrera, Schneider and Formenti (2011:554) are related to health system factors. According to Bright et al (2011:554), the bulk of delays occur from the onset of the first symptom to first primary care consultation, from primary consultation and from that stage to confirmed diagnosis and a further delay from diagnosis to commencement of treatment. Macleod et al (2009: S 92) add that women diagnosed with breast cancer are more likely to delay if they have an atypical symptom, that is, one that does not include a breast lump. They further argued that fear of cancer is a contributor to delayed presentation. Karla, Claudia and Infante (2011:1096) disagree with the

above researchers when stating that delays are a result of interplay between the patient's socio cultural context, individual characteristics that influence symptom interpretation and decision making, interaction with social network and aspects of local health service. They concluded that future research on cancer delay should take into account the diverse dimensions involved.

Arma, Phil and Gurpreet (2010:158) in their study that examined patient's conceptions agreed that patients' beliefs about medication influence their behaviour and interactions with the medical system. The authors allege that patients' conceptions about treatment may play a role in delaying the initiation of treatment. Additionally, the authors say that fear, lack of knowledge and beliefs about medication influence the patients' decision to undergo treatment.

Findings in a study conducted by Masi and Gehlert (2009:413) reveal that concerns most frequently expressed by patients with breast cancer are mistrust of the medical establishments and federal governments, the effects of racism and lack of health insurance on quality care, impact of treatment on intimate relationships, negative effects of surgery, radiation therapy and chemotherapy. The researchers concluded that the breast cancer mortality gap is associated with the above factors and therefore logistical and information support needs to be provided and strategies to reduce breast cancer mortality gap should also be addressed. Stanley Anyawu, Ochama, Egwuomvu, Ihekwoaba (2011: 551) state that barriers to patient adherence to diagnostic and treatment recommendations include both patient barriers and system barriers.

Montello, Schitulli and Rosaria (2009:382) explain that the mode of breast cancer detection is significantly associated with diagnosis delay. Selected characteristics like socio-demographic, clinical, health system and related features appear to affect delay significantly. They concluded that further research is needed to investigate unclear aspects such as the consequences of diagnostic delay in terms of survival and the extent to which breast cancer therapeutic management may influence the latter association.

Bairati, Jobi, Fillion, Larochlla and Vincent (2007:323) disagree with the above researchers as they believe that determinants of delays for breast cancer diagnosis are associated with the interpretation of the first diagnostic procedure, type of final

diagnostic procedure, size of tumor and family income. They further argue that medical indication of the investigation to the breast is a strong determinant of diagnostic delay.

2.2 Conclusion

This chapter explored existing literature on breast cancer, commencement of treatment, delayed presentation of patients diagnosed with breast cancer, delayed diagnosis and perceptions of women diagnosed with breast cancer regarding treatment. The aim was to convey to the reader what is already known about the topic under study. The next chapter focused on research methodology.

CHAPTER 3 : RESEARCH METHODOLOGY

3.1. Introduction

Chapter 3 presents the following:

Research methods and designs, setting, population, sampling, sample size instrument, inclusion criteria, exclusion criteria, data collection so as to create clarity to the reader.

3.2 Research Approach

A qualitative approach was used, in which patients were expected to describe their perceptions regarding treatment commencement after diagnosis with breast cancer. It gave the participants an opportunity to express their perceptions and their views regarding treatment commencement after diagnosis with breast cancer. The qualitative approach was chosen because participants were allowed to express themselves in a manner which revealed their experiences with breast cancer.

According to Brink, Van Der Walt and Van Rensburg (2009:113), “qualitative research is done by researchers who wish to explore the meaning, or describe and promote understanding, of human experiences, qualitative methods are more appropriate and effective alternatives for this type of research. A semi-structured interview guide was used.

3.3 Research Design

Polit and Beck (2008:765) define a research design as “the overall plan for addressing a research question, including specifications for enhancing the study’s integrity”. Brink (2009:92) in turn describes a research design as “a set of logical steps taken by the researcher to answer the research question”. It forms the blue print of the study and determines the methodology used by the researcher to obtain sources of information.

Descriptive and explorative designs were used to carry out this research.

3.3.1 Descriptive

The design was descriptive because it described the perceptions of women diagnosed with breast cancer regarding treatment commencement. According to Brink (2006:10) descriptive designs are used in studies where more information is

required in a particular field. Participants were given an opportunity to express their views or concerns regarding breast cancer, their perception regarding commencement of treatment and perceived severity. The participants were allowed to express themselves in a manner which revealed the real situation.

3.3.2 Explorative

The study was exploratory because the researcher probed after response when necessary.

Probing was undertaken when picking up cues in the response of a participant. The explorative design was relevant for this study, which was meant to get in-depth information from the participants. Participants were allowed to express themselves in a manner that described the phenomenon.

3.4 Research setting

The study was conducted at Frere hospital in Buffalo City Metropolitan in the Eastern Cape and is situated relatively centrally in the Eastern Cape Province. Frere Hospital is a large 800 bed provincial government tertiary hospital situated in East London. All the hospitals in Amathole District and Chris Hani which are both rural and urban refer their cancer patients to Frere hospital for diagnosis and treatment because it is the only public hospital that has been identified as a tertiary institution that can render oncology treatment i.e. chemotherapy, radiation therapy and surgery. The most commonly used languages are isiXhosa and English. Most of the Afrikaans speaking people are also fluent in English.

3.5 Population

Brink (2012:131) defines the study population as the entire group of persons or objects that are of interest to the researcher. The population for this study comprised all the females diagnosed with breast cancer, at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape. The age range was 18 -72 years. Participants were mostly Black Africans and one Coloured lady. The above age group was selected because breast cancer is more prevalent in this age group.

3.6 Sampling method

Sampling is the process of selecting a group of people, events, behaviours or other elements with which to conduct a study as alleged by Burns Grove (2012:40). According to Brink (2009:124) sampling refers to the researcher's process of

selecting the sample from a population in order to obtain information regarding a phenomenon in a way that represents the population of interest. Purposive and convenience sampling was used for the study. The purposive sampling technique was used to get the information from participants who knew what the issue was about as they were the ones affected. The researcher wanted the information from the main source. Convenience sampling was used to select those prospective participants who were available.

3.6.1 Sample size:

For purposes of quality, the researcher decided to interview 15 participants, although the researcher was aware that saturation might occur earlier than that. The researcher believed that though participants raised the same points, they might be expressed differently requiring probing in some. Interviews were continued although there seemed to be no new information after the 10th participant.

3.7 Inclusion criteria

The sample included all female patients diagnosed with breast cancer and these were between the ages of 18 and 72 years.

3.8 Exclusion criteria

The sample excluded diagnosed breast cancer patients below the age of 18 years, those who were at a terminal stage, as well as those who were not willing to participate.

3.9 Research Instrument

A semi-structured interview guide was used to collect data from the participants. The guide consisted of two sections. Section A with demographic data which included age, race and marital status. Section B consisted of questions which focused on the perceptions of women diagnosed with breast cancer with regards to commencement of treatment.

The questions that were asked are in the appendices:

3.10 Data Collection

The participants gave the researcher consent for interviews and permission to record the interviews.

According to Burns & Grove (2009b:695) “data collection is a precise, systemic gathering of information relevant to the research purpose or the specific objectives, questions, of the study.”

An interview guide was used to conduct interviews. The researcher conducted interviews with participants who came to the breast clinic for follow up and chemotherapy.

Probing was guided by the responses of the participants which required clarification thus the probing questions were used. Probing was done without compromising the rights of the participants. The researcher tape recorded the interviews. Data were transcribed verbatim from the tape recorder. Field notes were also taken during interviews.

Trust and rapport was attained by using effective communication skills, empathy, congruence and genuine acceptance.

For the purpose of quality, the researcher decided to interview 15 participants, although the researcher was aware of saturation. The researcher interviewed all the participants although there seemed to be no new information from participant number 10. This was no waist because participants expressed their views differently but meaning the same thing.

3.11 Data Analysis

Data analysis gives meaning to data. Analysis of data involves analysis of words rather than numbers. A considerable amount of time was spent inspecting the data. Collected data were transcribed verbatim from the field notes and the tape recordings that were made during interviews as suggested by Andrew & Halcomb (2009:188).

The researcher spent time reading through the data in order to familiarise herself with them. Data generated by qualitative methods are voluminous. They require checking for the following:

Completeness, as there might be glaring holes in the data that can be filled by collecting additional information before data analysis is commenced. For this reason data were labelled with dates, places and interviewee identifying information. This made retrieval of information manageable (Patton, 2002:440).

Data analysis was done using content analysis technique, guided by Tesch’s method of analysis as cited by Creswell (2009:185-190).

The steps outlined below were followed:

Step1

- Getting a sense of the whole by reading through all the transcriptions carefully and jotting down ideas. The transcripts were read thoroughly with the aim of interpreting the responses of participants.

Step2

- The researcher picked up the most interesting interview and consider its contents.

Step3

- Topics were categorised as major, unique and “leftovers” topics were abbreviated as codes and codes were written next to the appropriate segments of the text, then the organizing scheme was tried again to see whether new categories and codes emerged.

Step4

- Appropriate and most descriptive wording for the topics that relate to each other was established in order to reduce the total list of categories.

Step5

- The researcher made decisions on abbreviations of each category and placed codes in alphabetic manner.

Step6

- Data belonging to each category were assembled in one place. Preliminary analysis was performed.

Field notes were expanded, transforming short hand to narrative elaborating on non-verbal observations made during interviews. All expanded notes were typed for analysis. Analysis included careful checking of all data collected as well as attentive listening and analyses of the audio tape. The qualitative feedback of participants was interpreted by identifying themes on responses to each question asked by the researcher. The transcriptions together with field notes were sent to an “independent coder” for analysis as suggested by Creswell (1994:158). The coding process resulted in emergence of themes. These were refined during the consensus discussion with the co-coder. The researcher and the co-coder agreed on categories, sub-categories and themes identified in the transcripts.

3.12 Ethical considerations

Brink (2012:32) states that a researcher is responsible for conducting research in an ethical manner. The researcher has a professional responsibility to design research that upholds sound ethical principles and protect human rights (Speziale & Carpenter 2007:57). In this study, the following ethical procedures were followed.

3.12.1 Getting ethical clearance from the Ethics Committee.

The researcher submitted a proposal and was granted ethical clearance for conducting the study by the Ethics committee of the University of Fort Hare. Ethical clearance was also granted by the ethics committee of East London Hospital Complex.

3.12.2 Permission to conduct the study was granted by the Epidemiology and Research Unit at the Department of Health, Bisho and from the Frere hospital management.

3.12.3 Protecting human rights

Rights to respect and dignity were upheld. Participants were treated with respect and dignity, addressed as Mrs. or Miss.

Right to information

Participants were given all the necessary information regarding the nature and duration of the study, taking into consideration benefits and risks involved in the study. This was important so that the participants could make informed decisions.

3.12.3 Rights to self determination

Autonomy as a right to self- determination was considered in this research, just as in clinical practice. Participants decided whether to or not to participate in the study as a result those who participated did so on their own free will. This showed autonomy.

3.12.4 Right to privacy and confidentiality

The study involved information about attitudes, behaviours and records. The participants' privacy was respected at all times. The researcher respected the privacy of the participants in the setting where data were collected by arranging a

side ward for data collection at J 2 where patients undergoing radiation therapy were admitted. The privacy of the participants was also protected by not using their real identity and by asking permission from them to share the information if there was a need. In other words, anonymity and confidentiality were important principles related to privacy.

Burns & Grove (2005:188) elaborate that on the basis of the right to privacy, the research participants have the right to anonymity and the right to assume that the data collected would be kept confidential. As such, all information related to participants was kept in complete confidence, only the researcher had access to the data and was responsible for the safe keeping of data

3.12.5 Right to protection from discomfort and harm.

The right to protection from discomfort and harm is based on the ethical principle of beneficence that one should do good, but above all should not do harm (Burns & Grove 2005:190). The researcher continually re-assessed the participants during data collection to check whether the effects of the research were not causing more discomfort. The researcher was prepared to adapt the research plan or even discontinue should unexpected effects occur. An on-site, oncology social worker from the cancer association was arranged to counsel the affected participants.

3.12.6 Informed consent

Informed consent implies that participants have been given adequate information regarding the research, are capable of comprehending the information and have the power of choice enabling them to participate in the research or decline participation (Speziale & Carpenter 2007:63). Information that is required to ensure that participants understand the aim, nature and the benefits of the proposed study should be given before participants give consent.

Informed consent from persons that were capable of giving such consent was obtained. Participants were informed about the overall purpose of the research and its main features as well as risks and benefits of participation. The participants were informed of that they have a right to withdraw from participation at any stage of the research if they do not feel comfortable.

3.13 Trustworthiness/authenticity of the study

Trustworthiness / Authenticity of the study refer to the extent to which the researcher fairly and faithfully shows a range of different realities (Brink 2006:118)

Trustworthiness / authenticity of the study was upheld as follows:

For the purpose of this study, four concepts were used to ensure trustworthiness. These are credibility, transferability, dependability and confirmability.

3.13.1 Credibility

The researcher ensured that the study measured or tested what was actually intended. The researcher made sure that there was prolonged engagement with the subject matter to ensure acquaintance with the data. Enough time was devoted to the study (Speziale&Carpenter2007:49).

Only one researcher was involved in the study and as such the study can be said to be credible due to consistence. The researcher continuously checked with the participants to ensure that they were in agreement with the captured data. An agreement was also made with the participants that the findings will be taken to them so that they could check whether they agree with the findings.

3.13.2 Transferability

Transferability refers to the probability that the study findings have meaning to others in similar situations (Speziale& Carpenter 2007:49).This was done by practically using people who were affected by breast cancer. The researcher enhanced the transferability of the study by safeguarding all data transcripts, analyzing data recording, using audio tape and engaging the independent coder in analysis and in consensus discussion.

3.13.3 Dependability

Dependability is the extent to which similar findings are obtained through repeated research (Babbie & Mouton 2009:278).That is, the techniques used must show that if the work were repeated in the same context with the same methods and same participants, similar results would be obtained. To ensure dependability, the researcher recorded thoroughly and reported the process of research in detail thereby enabling future research to repeat the work (Speziale& Carpenter 2007:49).

3.13.4 Confirmability

Confirmability is the extent at which the researcher admits to his/her own predispositions. It is the traditional concept of objectivity (De Vos et al 2005:347).

The researcher ensured that the findings are the results of the experiences and ideas of participants rather than the thoughts and ideas of the researcher. This was done by taking notes throughout the data collection process and accurately translating them to reflect data that were collected from the participant.

3.14 Pilot study

The purpose of a pilot study was to investigate the feasibility of the proposed study and to detect possible flaws in the data-collection, such as ambiguous instructions in wording, inadequate time limits and so on. Brink (2009:166) explains that the time and effort expended in conducting a pilot study will be well spent, as pitfalls and errors that may prove costly in the actual study can be identified and avoided.

A pilot study was also conducted to test the worthiness of the study and to identify problems early in the study. The pilot study was conducted at Frere Hospital. The researcher decided to use Frere Hospital because it was a convenient, financially cost effective and less time consuming location for participants as they are referred to this hospital for investigations, diagnosis, treatment and care.

The researcher used an interview guide. The questions focused on the views and experiences of the participants with regard to their perceptions of commencement of treatment. The probing questions depended upon the participants' responses. The participants for the pilot study did not participate in the actual study. The researcher followed all the steps of the research process up to the findings. By doing so the researcher had the opportunity to detect possible flaws in the interview guide. The pilot study assisted the researcher in mastering interviewing skills .It also assisted the researcher to identify problems with the design and to determine whether the sample was representative of the population or whether sampling technique was effective (Burns & Grove 2012:42).Through the pilot study the researcher was able to test the interview schedule and to measure how long each interview took. Each interview took 15-30 minutes depending on the participant's response to questions.

3.15 Conclusion

In this chapter, research methods, design, setting, data collection, data analysis and trustworthiness of the study were discussed. A qualitative research paradigm which was explorative, descriptive and contextual was used to explore and describe perceptions of women regarding commencement of treatment.

CHAPTER 4

4.1 Study results and interpretation

4.1.1 Introduction

This chapter discusses the research findings, which include the demographic data of the participants and the themes that emerged from data analysis.

4.1.2 Participants' demographic data

This study comprised a total of fifteen (15) participants. Fourteen were Black African females and one was Coloured coming from different areas of the Eastern Cape Province, which are Chris Hani, Mnquma, Mbashe, Nkonkobe and Buffalo City. The participants came to Frere Hospital for treatment. The age range of the interviewed participants was between 42 and 72. Two of them were 42 years old and others ranged from 49 to 72 years old. This implied that breast cancer was more prevalent in elderly women.

4.1.3 Themes that emerged from data analysis

Four main themes emerged from data analysis:

Reactions of women to being diagnosed with breast cancer, support system, effects of breast cancer and effects of treatment.

The major themes were further classified into categories and sub categories in the table below and these are: emotional impact, practitioner responses, social impact, and family support, and social support, religion as a means of support, chemotherapy, radiation therapy and surgery and lack of knowledge regarding treatment.

MAIN THEMES	CATEGORIES	SUB-CATERGORIES
1.Reactions of women to being diagnosed with breast cancer	Emotional impact	Uncertainty associated with fear of unknown as manifested by being worried, scared, shocked; frustration confusion and crying.
		Fear of mutilation, losing a breast represents loss of belonging, loss of self-worth, loss of life as it used to be, feeling no longer whole.
		Fear of losing control, displayed by misunderstanding, not feeling like self, something is wrong and something unusual
		Fear of breast cancer as it is associated with pain and death.
		Fear of treatment
	Participants responses regarding practitioners	Fear of symptoms getting worse
		Misdiagnosis
		Failure to adequately examine patients.
		Delay in commencement of treatment.

	Social impact	Loss of body image
		Low self esteem
		Stigma
2.Support systems	Family support	Husband
		Children
		Relatives
	Social support	Employer
		Social worker
	Religion as a means of support	Prayer
		Believing
		Pastor
		God
3.Effects of treatment	Chemotherapy	Loss of appetite
		Nausea
		Vomiting
		Terrible
		Hair loss
		Hands and nails turn
		black
		Does not help
		Fear of death due to
		chemo therapy

4.Effects of breast cancer	Radiation therapy	Fear of being ironed
		Burning
		Fear of being wrinkled
		Does not help
	Surgery	Fear of pain
		Fear of operation,
		Fear of being cut
		Scared
	Lack of knowledge regarding treatment	Does not know how it is treated.
		Before coming here I did not know
4.Effects of breast cancer	Clinical factors	Worsening of symptoms - Blood stains
		Painful lump
		Bone pain
		Pus
		Pain on the breast
		Loss of weight
		Lump growing bigger
		Fluid turned into blood
		Fatigue
		Weakness
		Loss of appetite
	Emotional response	Not feeling like self
		Something is wrong
		Something unusual

		Fear of breast cancer
		Fear of treatment
		Fear of symptoms getting worse
		Fear of losing breast
		Fear of death
	Denial	Moving from one doctor to another
		Seen by many doctors
		Wanting a different doctor
		Going around
		Nothing was wrong
		Ignorance
		Hoping It's not cancer

4.2 Interpretation of data

4.2.1 Reaction of women diagnosed with breast cancer.

Most of the participants presented different behaviours, though there were some commonalities. The most common factors were emotional impact, social impact, practitioner response and support system.

4.2.1.1 Emotional Impact

It emerged from this study that the participants went through different emotions when they discovered a lump that could be a breast cancer and when they were told that they had breast cancer. Their emotions ranged from not feeling like self, something is wrong, something is unusual, fear of breast cancer, breast becoming rotten, fear of treatment, fear of symptoms getting worse, fear of losing breast but above all, fear of death. Some felt that it was confusing and they did not understand why they had cancer as they thought it affected old people.

Below are some of the responses:

One respondent said: *"When I noticed that there was something unusual, I was not feeling like myself I went to see a doctor." "I became worried because I was told that it's not curable, it kills." "I cried, I could not sleep." "I have never seen somebody with breast cancer at home, I have seen it in old people they have rotten breast and die I thought that my breast will also be rotten and I will die".*

Other respondents said:

"I was afraid, it is said that cancer kills, that is what is worrying me. Even when I was admitted at Tygerburg people said it is better to have another disease than cancer. "I was worried because I was told that it's not curable." "I did not, understand I was confused, I thought it affects old people as my two aunts were old when they had cancer". "I was frustrated, I cried all the time and I started losing weight because all I could think about was dying." "I was scared it's said cancer kills, it's not curable. It was not nice, I felt hot, I did not sleep and I was thinking about my mother, I am a bread winner at home."

Macleod, Mitchelle and Ramirez (2009: S 92-S 101) argues that” fears of treatment and fear of cancer contributes to late presentation for treatment in women diagnosed with breast cancer”.

4.2.1.2 Participants responses regarding practitioners

Some of the participants verbalised that they noticed a lump that was indicative of breast cancer but some medical practitioners did not notice immediately that it was breast cancer. It also emerged that participants would continuously see a medical practitioner for years only to be referred to a specialist for investigations after several years.

Others claim that doctors were not sure whether they had cancer or not, or after investigations doctors were not certain about results of investigations and had to repeat tests. Even the ones who visited the clinic with discharging nipples were not referred immediately. They were told to stop breast feeding whilst others were told that the lump is caused by a blocked milk duct.

Some participants were reluctant to state exactly when they first saw signs that indicated they had breast cancer because they delayed seeking medical help. It also emerged from others that the delay was a result of the medical system especially for those participants who were seeing general practitioners. They state that they were treated symptomatically for some time and referred for specialized care at a later stage.

One participant stated that she first noticed pus from her nipple in 1995 after giving birth and was told to stop breast feeding. From 1995 to 1997 she went for check-up every month until she was discharged in 1998. In 2001 the lump got bigger and painful she later developed tonsillitis and was treated for this for some time but the discharge on the breast progressed now from pus to blood and it was only in 2008 that she was referred to Frere hospital for investigations. Even though participants discovered the lumps themselves and timeously, they still delayed seeking medical help due to incorrect advice until symptoms were worse as shown by the statements below:

”In 2001 yhoos the lump got bigger now and I could feel the pain after that I suffered from tonsils now and again”. “In 2008 my pyjamas were no longer damp now but wet

and I could see what was coming out of the breast was dirty now, the breast started becoming painful .“I noticed that the lump was now growing bigger and I went back to the clinic and the sisters said it is not what you think it is.” “I went to see my doctor, he said he does not know whether its cancer, I asked him how can it be cancer, because I have been seeing him for a long time and I have been referred to hospital on several occasions.” ”In 2009 doctors did not know what was the cause of pain, in 2010 they did not know what was wrong, in 2012 they thought it was cancer but it was not cancer and then in 2012 there was no problem and I stayed away. “I noticed the lump on my breast in 2008 but when I was told that I was going to be operated I refused and I came back in 2010 when I developed pain on my leg, I was told that my cancer has affected my bones.”

The above notion has been supported by Karla Unger-Saldana, Claudia & Infante Castarelo (2011:1096-1104) who state that patients postpone seeking medical attention until they feel that the lump is growing bigger.

According to an investigation by Bright et al (2011:554) the bulk of delays occur from the onset of the first symptom to first primary care consultation, from primary consultation and from that stage to confirmed diagnosis. This is seen above from the participant that was first consulted in 2008 and the final diagnosis was confirmed in 2012. Macleod et al(2009:S 92) adds that women diagnosed with breast cancer are more likely to delay if they have an atypical symptom, that is one that does not include a breast lump.

According to one of the statements above one participant delayed treatment commencement because doctors did not know the cause of pain in the participant's breast. This is supported by Berati, Fillion, Laroche & Vincent (2007:323-331) who allege that determinants of a diagnostic delay of more than 5 weeks were the medical indication for the breast investigation and the scheduling of the complementary diagnostic procedures.

4.2.1.3 Social Impact

In this study, it emerged that the loss of a breast resulted in loss of body image or a breast getting rotten and this resulted in low self-esteem. Some participants verbalised that if one had one breast one would not look nice. It also emerged in this study that in black communities, breast cancer was something that one needed not

to talk about because there was still a lot of stigma attached to it. One participant stated that “if you tell people that you were diagnosed with breast cancer they look at you differently.”

“I thought that my breast will be rotten and I will die”. “I was afraid that I will have one breast”. “I was afraid that I will not look nice” “if you tell people that you have breast cancer they will say yhuu” “My husband said it’s an old people’s disease.

4.2.2 Support System

Breast cancer is a dreadful disease and undergoing treatment is quite as traumatic as being diagnosed and women who are diagnosed with breast cancer need to get all the support they can get so that they can be able to cope with the disease, this may range from family support, social support and religion as a means of support.

4.2.2.1 Family support

From the interviews, it came to the fore that support from relatives led to willingness to engage in treatment, taking initiative and willingness to survive. Participants who were supported by their families verbalised that continuing with treatment was easy because they had all the support that they needed. Participants who were married were supported by their husbands, one verbalised that the lump was confirmed by her husband. One participant felt that in order for her to start treatment she needed to go to her children so that they could be able to spend time with her.

Although participants knew that support from family friends and relatives was important, however, some did not tell their relatives that they had breast cancer because they did not want them to worry.

“I want to go to my children in Cape Town so that they can see me whenever they want”. “I asked my husband to feel the lump”. “My husband said I must go to see a doctor”. “I never told my mother that I had breast cancer until this day”. “I did not tell my family that I was going to be operated”. “My sister is diabetic I did not want to worry her”. “I called my sister and I told her over the telephone but I had to sit down with my mother.” “My husband was still alive and was so supportive” “I told my sisters that I have a lump on my breast, I don’t know whether it is cancer and they said that I must go to a clinic”

4.2.2.2 Social support

It emerged in this study that the social workers from the Cancer Association played a big role in assisting participants to make a decision concerning commencing treatment. The support from other breast cancer sufferers who had undergone treatment helped some participants in taking a decision. One participant verbalised that her employer played a big role in supporting her from discovering of a lump up to commencement of treatment and if it were not for her she would have died. She said:

“What helped me was the support of my employer”. “If it were not for the support of my employer, I would have died.”

Another said: *“There is a social worker that was called to advise me.” “I was also supported by a woman from Transkei who told me she had both breasts removed”.*

4.2.2.3 Religion as a means of support

The church as a support system played an important role in survival and perseverance of participants as they believed that God is above all and if you believe in Him one can beat breast cancer. Participants believed that if they attached themselves to God they would beat breast cancer and can be cured. They also believed that breast cancer could be cured if an operation can be performed spiritually and one would be cured. Prayer also played a very important role in their lives as it assisted some in accepting being diagnosed with breast cancer. In contrast, some participants believed that breast cancer was made by God and there is nothing that they can do about it.

Below are verbatim quotes from participants

“I believe that the church can help me.” “As a Christian I believe that God is above all, nothing goes beyond Him. I believe that He is powerful, nothing goes beyond God, and I believe he can change my situation.” “I was operated spiritually” “I believed that I was healed” “I have that hope that God will help me.” “I that the church can help me, I went to my Pastor and I told him I was going to be operated, my Pastor performed my operation spiritually and when I took the operated I knew that I was healed.” “It was created by God there is nothing that I can do about it” “As I have been praying I find peace and learn to accept it”

4.3 Effects of treatment

Breast cancer treatment has unpleasant side effects which results in fears with regards to treatment.

4.3.1 Chemotherapy

Participants had different perceptions regarding the various forms of treatment i.e. chemotherapy, radiation therapy and surgery. They had fears based on what they had heard from people who had undergone therapy. They revealed that chemotherapy caused loss of appetite, nausea, vomiting, hair loss, hands and nails were turned black. It is terrible and it does not help. One participant thought that she would die because of chemotherapy.

Below are verbatim quotes from participants:

"I thought I will be sick and die because of chemo". "It was terrible." "I had nausea and vomiting." "It was very strong I nearly stopped, I had no appetite, it was painful but I continued, I thought it was the demons that wanted me to stop". "Although my hands and nails turned black I continued with treatment." "It swept all my hair away." "It was terrible I had to carry a container all the time." "In the beginning it went well then it was terrible, I could not eat, I had nausea." People told me that I cannot come for chemo alone because I will not be okay after chemo" "I felt vomiting, I could not eat anything that had fat, when you are on chemo you have to eat lots of vegetables and you must eat early because you will vomit". "I lost my complexion when I was on chemo but now that I'm done my complexion is back to normal, I am back to being that beautiful lady." "Chemo was very helpful I could see that it relieves the pain."

4.3.2 Radiation therapy

Radiation therapy was a nightmare for most, they got scared because they believed they were going to be ironed or burned. This is because of the myth that when you undergo radiation you get ironed. One participant even verbalized that she was advised not to undergo radiation therapy as she was going to be burned.

Below are their responses when asked about radiation therapy:

"I was scared I thought that I will be ironed like clothes, I was expecting a big iron and that scares me, but it was just a machine that was far away." People said I

would be ironed like clothes". "I was told that I was going to be burned" "I was taken to that thing that burns, I was waiting for a big iron". "I was scared I was going to be wrinkled "I was afraid, people said I must not agree to be burned, I was shaking because I was waiting for fire to come out of the machine but there was no fire".

Arma, Phil and Gurpreet (2010:158) agreed that patient's belief about medication influence their behavior and inter-actions with the medical system.

4.3.3 Surgery

Some participants had fear of undergoing surgery. They were not aware that surgery is a treatment modality, all they knew was that they were going to be cut and they associated cutting with pain and this resulted in some running away when told that they will undergo surgery only to come back with metastatic breast cancer or when signs were evident to an extent that one just wanted to be treated without delay.

Below are their responses.

"I am scared of an operation. "I was scared of being cut" "I was scared of pain". "I had courage, I thought that a breast is nothing compared to my life". "I told them not to cut my breast they must remove the lump, because the problem was on the lump not the breast". "I said cut, cut I was not even sure what I was saying" "I was told I was going to be operated, what was it like, what am I going to do." "They said they were going to cut my breast and I was afraid I was not going to look nice" "I was told that the only way to cure it was to remove it and I said they must do it because I've had this thing for a very long time."

The above is supported by Masi and Gehlert (2009:413) who state that concerns most frequently expressed by patients with breast cancer were negative effects of surgery, radiation therapy and chemotherapy.

4.3.4 Lack of knowledge regarding treatment

During the interviews it also emerged that most participants lacked knowledge regarding breast cancer treatment. Below are verbatim quotes from participants:

They responded to the question, how you think it can be treated as such:

"I don't know" "I don't know what I know is that it kills".

"Before coming here I didn't know". "I don't know there was no pain."

“I don’t know what I know is that it can be cured by isiXhosa”.

Arma et al (2010:158) alleged that patients’ conceptions about treatment may play a role in delaying the initiation of treatment. Additionally they say that fear, lack of knowledge and beliefs about medication influence the patient’s decision to undergo treatment.

4.4 Effects of breast cancer

Breast cancer is a health concern in South Africa. Failure to recognise clinical signs may lead to disease progression and death which can be prevented with early detection and early commencement of treatment. Below are some of the participant’s verbatim quotes:

“I was afraid, it is said that cancer kills, that is what is worrying me. Even when I was admitted at Tygerburg people said it is better to have another disease than cancer. I was worried because I was told that it’s not curable.”

According to Macleod et al (2009: S 92) fear of cancer is associated with late presentation in patients with breast cancer.

4.4.1 Clinical Factors

Almost all the participants discovered the lump on their own and knew that they had to consult a clinic or doctor. An observation which was made during interviews was that almost all the participants who delayed seeking medical help had a lump that was not painful, while others just had a discharging nipple which they did not take as a serious sign, leading to no action. All the participants presented themselves late for treatment and only went for treatment when symptoms got worse. For example, a lump growing bigger, fluid coming from the nipple turning into blood or becoming dirty, fatigue or weakness, loss of appetite or painful bones.

Participants said the following about this:

“The lump was growing bigger” “What I noticed and became suspicious was if I was wearing a yellow blouse I would see blood stains”. “I started experiencing headache, weakness tiredness, dry throat and I thought that I have diabetes” “The pain was so terrible by now”. “It was not painful, but when it started growing it became painful” “My pyjamas were no longer damp now they were wet”. “There were no signs but I

noticed spots on my night dress every morning, but the spots were weak as if I was bleeding.” “I did not experience pain except for the pain on my shoulder and I thought it was caused by driving” “My breast was painful and I went to see my doctor and was given pain tablets”. “There was something coming out of my breast.”

The above notion has been supported by Karla Unger-Saldana, Claudia & Infante Castarelo (2011:1096-1104) who state that patients postpone seeking medical attention until they feel that the lump is growing bigger.

4.4.1.1 Emotional response

Identification of symptoms by participants had devastating effects for most participants as they responded with different emotions ranging from fear, loss of self-esteem related with loss of body image, fear of being diagnosed with breast cancer, fear of the devastating effect of treatment but above all fear of death.

“I am scared of an operation. “ “I was afraid, it is said that cancer kills, that is what is worrying me.” “I was told that it’s not curable.” “What I know is that it kills”.

“I am scared of an operation. “ “I was scared of being cut” “They said they were going to cut my breast and I was afraid I was not going to look nice”. “I thought that my breast was going to rot”.

4.4.2 Denial

Denial emerged as one of the factors that contributed to late presentation for treatment by some participants. Despite the fact that participants discovered the lump on their own, some delayed showing the lump to their doctors while others verbalised that they have been going around looking for other opinions. Some hoped that if seen by a different doctor they will be told that it is not cancer. Some participants shifted the blame for not taking initiative to being diagnosed late, while others associated symptoms with other disorders.

One participant knew that she had breast cancer but because she was in denial moved from one doctor to another and from hospital to hospital. The fact that there was no pain in some of the participants resulted in ignorance and failure to take action as shown in the statements below:

“As a person that goes around I went to this place called the health haven.” “I have been going around.” “I told him I wanted a different doctor.” “The first doctor was in Queenstown and others and others”. “I ignored the lump because there was no pain.” “I am sure it is because there were no serious signs” “it was on and off one

day you will see something then it will disappear". "I stayed away because the doctors said there was nothing." "I stayed away because there was no pain." "I went from doctor to doctor" "I was told that it is not cancer".

4.5 SUMMARY

This chapter presented the findings of the study. These were presented in a thematic manner. It was quite clear from the participant's responses that breast cancer is a very painful and traumatic experience. Most participants went through the same ordeal that included fear, denial and lack of knowledge regarding treatment. What emerged was the participant's perception of breast cancer treatment, lack of knowledge about the different types of treatment, the need for extensive education and intensification of the support system. The next chapter presents the discussion, limitations of the study, conclusion and recommendations.

CHAPTER 5: DISCUSSIONS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSIONS

5.1 Introduction

In the previous chapters, the researcher explained the purpose for this study, presented the research methodology and data analysis methods used in this study and study results. This chapter discussed the findings of the study in relation to reviewed literature, limitations of the study, conclusion and recommendations.

5.2 Discussion of perceptions

The perceptions of participants regarding commencement of treatment varied from participant to participant depending on the form of treatment the participant was started on. In this chapter, the perceptions of participants will be discussed according to the different types of treatment modalities.

5.2.1 Perceptions regarding chemotherapy

There is still a myth that chemotherapy does not help breast cancer. Participants were scared to undergo this type of treatment because they believed it was going to make them sick and die. Some of the factors that contributed to this fear were experiences of other patients who had undergone the procedure who, instead of encouraging them, scared them away. However there were some participants who felt that chemotherapy took away the pains, whilst others felt that they need to endure in order for them to get well.

5.2.2 Perceptions regarding the traditional route

Some participants verbalised that they were advised to take the traditional route instead of chemotherapy because they were told that breast cancer can be cured by traditional medicine, although but none of the participants admitted to taking the traditional route. Arma, Phil and Gurpreet (2010:158) explain that patient's beliefs about medication influence their behaviour.

5.2.3 Perceptions regarding radiation therapy

It also emerged from this study that participants still refer to radiation therapy as ironing or burning and the thought of being ironed or burned was frightening to most participants. They thought that a big iron was going to be used and were scared that they will be wrinkled if ironed, while others waited to see fire coming out of the radiation machine only to be relieved when told to get up and go. This is supported by Masi and Gehlert (2009:413) who state that concerns most frequently expressed by patients with breast cancer were negative effects of surgery, radiation therapy and chemotherapy. Most patients revealed that they lied on the radiation bed waiting for the fire to come out. Once again, it is clear that the perceptions of participants were influenced by others especially while sitting in the waiting room. Other patients told others that they would be ironed or burned. Participants that were positive about the effects of radiation therapy were the ones who had seen a radiation machine before commencing treatment.

5.2.4 Perceptions regarding surgery

Surgery was not regarded as a form of therapy by some of the participants. Surgery was interpreted as cutting of a breast which was associated with pain. It was also revealed that participants associated surgery with hospitalisation and were scared of being hospitalised. Some participants felt that they needed to undergo surgery irrespective of what was being said by others, one said "I'd rather lose my breast than lose my life"

From the above, it was evident that participant's perceptions regarding commencement of treatment were influenced by other patients who had undergone treatment who instead of giving them positive information, they gave them negative information which was frightening.

5.3 Discussion of the extent of knowledge regarding cancer and its treatment.

The researcher identified lack of knowledge with regard to the various forms of cancer treatment and a need for educating patients who have undergone therapy to pass positive information to others in order to encourage them to present themselves early for treatment. Arma, Phil and Gurpreet (2010:158) in their study examining patient's conceptions agree that patient's beliefs about medication influence their behaviour and interactions with the medical system. The authors concur that patient's conceptions about treatment may play a role in delaying the initiation of treatment. The above researchers believed that fear, lack of knowledge and beliefs about medication influence the patient's decision to undergo treatment.

It was revealed in this study that most participants displayed knowledge about signs and symptoms of breast cancer, for example, a lump whether it is on the breast or elsewhere, discharging nipple and pain. Some knew that as soon as one discovers a lump on the breast one must visit a doctor, but the ones who did not present the above symptoms tended to ignore them and did not go to a doctor. Participants stated different reasons for delays in seeking treatment, ranging from absence of symptoms to the fact that there was no pain. Thus public education initiative should focus on encouraging women to see a doctor for evaluation of symptoms so as to decrease delay. Macleod, Mitchell, Burgess, Macdonald and Romirez (2009:S92-S101) allege that women diagnosed with breast cancer are more likely to delay if they had an atypical symptom, that is one that did not include a breast lump. The researcher argues that fear of cancer is a contributor to delayed presentation.

Almost all participants discovered the lump on their own but delayed in commencing treatment. Some participants describe the delay as being caused by a delay in diagnosis by medical practitioners especially in clients who were seen by private practitioners, symptoms were treated rather than being referred for further investigations. This statement is supported by Bright, Bargash, Donach, dela Barrera, Schneider and Formenti (2011:554) who state that some of the factors that are associated with delay in diagnosis in patients with breast cancer are related to health system factors.

In this study, some participants delayed commencement of treatment because as soon as they were diagnosed and told that they will undergo surgery they decided to stay away as they were not in pain and only came back when they started feeling pain or the lump got bigger. This notion has been supported by Karla Unger-Saldana, Claudia & Infante Castarelo (2011:1096-1104) who state that patients postpone seeking medical attention until they feel that the lump is growing bigger.

It also emerged from the study that some participants delayed treatment commencement because they had to come back for further tests as doctors were not sure whether they had breast cancer or not. This is supported by Berati, Fillion, Laroche & Vincent (2007:323-331) who allege that determinants of a diagnostic delay of more than 5 weeks were the medical indication for the breast investigation and the scheduling of the complementary diagnostic procedures. While some mentioned the above reasons, other participants were in denial such that they moved from one doctor to another and every time, it was confirmed that they have breast cancer. Late presentation for treatment in women with breast cancer has been associated with negligence, economic status, literacy, and delayed presentation of symptoms, time factor, and difficulty in accessing health care, fears of treatment, general practitioners and fear of cancer.

The researcher concluded that the health system is not the only one to be blamed for delayed commencement in treatment, but health care users are also to be blamed as they are the ones that are experiencing symptoms. Anyanwu et.al (2011:551-553) concur that barriers to patient adherence to diagnostic and treatment recommendations included both patient and system barriers.

In this study, fear had appeared to be the major cause of delay in commencement of treatment. Participants were afraid of being told that they had breast cancer, they hoped that it was just a lump not breast cancer as they associated breast cancer with death. Despite the fear of death, they still did not consider presenting selves early for treatment because treatments on its own poses a threat to some as they thought that they would be sick and could die due to the treatment.

The researcher concluded that knowledge deficit, fear, denial and health system factors directly contribute to how patients diagnosed with breast cancer feel about treatment commencement and why they present themselves late for treatment.

Macdonald et al (2009:S91-S102) allege that mis-diagnosis, failure to adequately examine patients is a contributor to delayed presentation.

5.4 Application of the conceptual framework on the findings of the study

Concept	Description of the concept	Application to findings
Perceived susceptibility	Individual's assessment of her chances of getting breast cancer	Some participants did not think that they could be diagnosed with breast cancer. They thought that it was a disease that affect old people, some participants verbalised that they were very young to have breast cancer
Perceived severity	Perceived severity is the individual's judgment as to the severity of breast cancer. Even when the individual recognizes personal susceptibility, action will not occur unless the individual perceives the severity to be high enough to have serious organic or social implications.	Participants delayed seeking prompt treatment because signs were not serious enough to take action for example presence of a lump that was not painful or a discharging nipple and absence of a lump.
Perceived barriers	Perceived barriers are	In this study,

	<p>the individual's opinion as to what will stop her from commencing treatment. Barriers may include the distance from the patient's residential area to the site of treatment, costs of the proposed treatment and the patient's cultural beliefs.</p>	<p>distance also posed as a barrier as participants were from different districts in the Eastern Cape, for example Chris Hani, Amathole and Buffalo City. Some participants believed that breast cancer can be cured using traditional medicine and they believed that it cannot be cured by chemotherapy or radiation therapy.</p>
Perceived Benefits	<p>Perceived benefits are the individual's conclusion as to whether the new behaviour is better than what she is already doing. Perceived benefits refer to the patient's belief that a given treatment will cure the illness or prevent it.</p>	<p>In this study participants believed that chemotherapy takes pain away and some were willing to engage in treatment because they were going to be free from pain, some weighed risks against the benefits and felt</p>

		that even though chemotherapy had unbearable side effect they had to continue because they wanted to be cured.
Cues to action	Internal and external factors may contribute to a change in behaviour and the individual may decide to go for treatment. Motivating factors may include progression of the disease, a lump growing bigger, pain and discomfort or there may be a member at the family that has become sick. Messages from mass media may also trigger response to change in behaviour.	Change of behaviour in most participants was triggered by progression of the disease for example lump growing bigger, discharge from the nipple turning into blood pain and discomfort.

5.5 Implications for practice

It is envisaged that after sharing the findings of the study with relevant stakeholders and implementation of recommendations, clients will be more aware of signs and symptoms of breast cancer, when to consult a doctor, as a result late presentation for treatment will be curbed. Additionally, medical practitioners and primary health care nurses will know when to refer clients to specialised care for diagnosis and treatment.

5.6 Implications for Research

The Department of Health is urged to encourage nurses within the Eastern Cape Province to conduct research not only on breast cancer, but on cancer in general and release funds to conduct research.

5.7 Limitations of the study

The limitations that should be noted for this study and are listed below:

- The researcher assumed that the population lives in Buffalo City Metropolitan whilst some come from different Districts including O.R.Tambo and Chris Hani.
- Time was also a limitation as some participants were in a hurry to go back to their respective places as soon as they are seen by doctors which made it difficult to interview some as they were in a hurry to get back.
- The study focused only on clients that were admitted for radiation therapy at Frere Hospital or coming for treatment and follow-up on an outpatient basis at the Breast Clinic.
- Patients that were in the community as well as those that are admitted in private hospitals around East London were not involved in the study.

5.8 Recommendations

Community Nursing Practice

- Out-reach programs and awareness campaigns regarding the various forms of breast cancer treatment need to be intensified, putting more emphasis on surgery as a form of treatment for breast cancer, chemotherapy as well as radiation therapy.
- Public education initiative to focus on encouraging women to see a doctor promptly for evaluation of symptoms in order to decrease delays.
- Health care users need to be educated to take initiative regarding their own health and not wait too long to be referred for specialised care, so as to avoid delays in diagnosis and treatment of breast cancer.
- Breast cancer survivors need to be actively involved in education programs in order to encourage others to come early for diagnosis and prompt treatment.
- Formulation of support groups would also assist with health education.

In-service programme:

- Intense in-service training programmes for primary health care nurses to obtain a minimum standard of core skills including the ability to screen and refer patients with suspected lumps timeously for diagnosis and prompt treatment.
- Training of more oncology specialist nurses at primary health care level to assist in screening for breast cancer so that it can be detected early.

Research

The Department of Health to encourage nurses to conduct research not only on breast cancer but on cancer at large and release funds for those projects.

5.9 Conclusion

The study explored and described the perceptions of women diagnosed with breast cancer, regarding treatment commencement at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province. Responses from participants were congruent with allegations from previous studies

Information regarding prevalence or incidence of breast cancer or any other type of cancer is lacking at primary health care level and in District Hospitals as there are no indicators for breast cancer on the information system. The Department of Health needs to put in place a system that will monitor the reporting of breast cancer as it is an emerging health priority because it is ranked first compared to other types of cancer in Southern Africa.

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APPENDIX A

Letter of application to the University of Fort Hare research ethics committee

26 Beaumont Road

King Williams' Town

5600

The Committee

University of Fort Hare research ethics committee

University of Fort Hare

Alice

REQUEST FOR APPROVAL TO CONDUCT A RESEARCH STUDY

I am Matwele Caroline Ntombekaya, currently registered as a Masters student in the Nursing Science Department (M.cur.) at the University of Fort Hare, East London campus. The requirement to complete this degree is to conduct a research study in the relevant area of practice. The research study that I have proposed to do is:

Patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province. The main purpose of the study is to explore and describe the perceptions of patients diagnosed with breast cancer, regarding treatment commencement at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province.

Significance of this study is that it will add to the body of knowledge in oncology research.

Hoping that this request will receive your favourable consideration

Thanking you in advance

Yours Faithfully

Caroline Ntombekaya Matwele



University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE

Certificate Reference Number: MAG02 1SMAT01

Project title: **Patient's perceptions regarding commencement of treatment, following diagnosis with breast cancer at Frere Hospital Buffalo City Metropolitan Municipality in the Eastern Cape Province.**

Nature of Project: Masters

Principal Researcher: Caroline Ntombekaya Matwele

Supervisor: Mrs N Magadla

Co-supervisor:

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document

- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
 - Any unethical principal or practices are revealed or suspected
 - Relevant information has been withheld or misrepresented
 - Regulatory changes of whatsoever nature so require
 - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.

The Ethics Committee wished you well in your research.

Yours sincerely



Professor Gideon de Wet
Dean of Research

25 July 2013

APPENDIX C

Letter to the Eastern Cape department of health

26 Beaumont Road

King Williams' Town

5600

The Manager

Epidemiology and Research surveillance unit

King Williams' Town

5600

Dear sir/ madam

I, Caroline Ntombekaya Matwele, a Master's student at the University of Fort Hare hereby request permission to conduct a research study on patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province. The aim of the study is to explore and describe the perceptions of women diagnosed with breast cancer, regarding treatment commencement at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province.

The objectives of the study are to:

(1) Explore perceptions of women diagnosed with breast cancer regarding commencement of treatment. (2) Identify how patients diagnosed with breast cancer describe the delay in treatment commencement. Identify and describe strategies that can be used to prevent delay in treatment commencement. Ethical clearance has been granted by the University of Fort Hare's research committee.

Your assistance in this regard will be highly appreciated.

Yours Faithfully

Caroline Ntombekaya Matwele

APPENDIX D PERMISSION TO CONDUCT RESEARCH

From:

To: 0406530865

22/08/2013 15:42

#204 P.001/001



Eastern Cape Department of Health

Enquiries: Zonwabele Merile

Tel No: 040 608 0830

Date: 22nd August 2013

e-mail address: zonwabele.merile@impilo.ecprov.gov.za

Fax No: 043 642 1409

Dear Ms CN Matwele

Re: Patients's perception regarding commencement of treatment, following diagnosis with breast cancer at Frere Hospital, Buffalo City Metropolitan Municipality, Eastern Cape Province

The Department of Health would like to inform you that your application for conducting a research on the abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it after having a written approval from the Department of Health in writing.
2. You are advised to ensure, observe and respect the rights and culture of your research participants and maintain confidentiality of their identities and shall remove or not collect any information which can be used to link the participants.
3. The Department of Health expects you to provide a progress on your study every 3 months (from date you received this letter) in writing.
4. At the end of your study, you will be expected to send a full written report with your findings and implementable recommendations to the Epidemiological Research & Surveillance Management. You may be invited to the department to come and present your research findings with your implementable recommendations.
5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with the Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

DEPUTY DIRECTOR: EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT



APPENDIX E

Letter of permission to the East London Hospital Complex ethics committee

26 Beaumont Road

King Williams' Town

5600

Research Ethics Committee

E.L.Hospital Complex

Health Resource Centre

East London

5200

Dear sir/ madam

I Caroline Ntombekaya Matwele, a Master's student at the University of Fort Hare hereby request permission to conduct a research study on patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province. The aim of the study is to explore and describe the perceptions of women diagnosed with breast cancer, regarding treatment commencement at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province.

The objectives of the study are to: explore perceptions of women diagnosed with breast cancer regarding commencement of treatment. Identify how patients diagnosed with breast cancer describe the delay in treatment commencement. Identify and describe strategies that can be used to prevent delay in treatment commencement. Ethical clearance has been granted by the University of Fort Hare's ethics committee and approval to conduct the study granted by the Department of Health .Your assistance in this regard will be highly appreciated.

Yours Faithfully

Caroline Ntombekaya Matwele

APPENDIX F REPLY FROM ETHICS COMMITTEE EAST LONDON COMPLEX

Ethics Committee: E. L HOSPITAL COMPLEX

Postal Address :

C/o East London Health Resource Centre
PO Box 12882
Amalinda
5252

Telephone : 043 –709 2032

Physical Address :

Cheltenham Road
East London
5201 South Africa

Fax no.: 043 – 7092386

27th September 2013

Caroline Ntombekaya Matwele
East London Hospital Complex
Amalinda
East London
5200

Dear


Re: request to conduct research on patient's perception regarding commencement of treatment following diagnosis with breast cancer

We acknowledge receipt of the above mentioned proposal.

Having gone through your proposal, the committee has no ethical problems noted.

Please be advised that the committee has granted you the consent to do the research.

Yours sincerely



**Dr P Alexander – Chairman Region C Ethics Committee
Ophthalmologist EL Hospital Complex**

APPENDIX G

Letter of permission to the Hospital Manager Frere Hospital

26 Beaumont Road

King Williams' Town

5600

The Hospital Manager

Frere Hospital

East London

Dear sir/ madam

I Caroline Ntombekaya Matwele, a Master's student at the University of Fort Hare hereby request permission to conduct a research study on patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province. The aim of the study is to explore and describe the perceptions of women diagnosed with breast cancer, regarding treatment commencement at Frere hospital in Buffalo City Metropolitan Municipality in the Eastern Cape Province.

The objectives of the study are to: explore perceptions of women diagnosed with breast cancer regarding commencement of treatment. Identify how patients diagnosed with breast cancer describe the delay in treatment commencement. Identify and describe strategies that can be used to prevent delay in treatment commencement. Ethical clearance has been granted by the ethics committees of the University of Forte and East London complex and permission by the Department of Health.

Your co -operation will be highly appreciated.

Yours Faithfully

Caroline Ntombekaya Matwele

APPENDIX H REPLY FROM FRERE HOSPITAL



Province of the
EASTERN CAPE
HEALTH

EAST LONDON HOSPITAL COMPLEX
Frere Hospital, Amalinda, Private Bag/Ingxowa Eyodwa X 9047, East London, 5200
South Africa • Tel: (043) 709 2135 • Fax: (043) 709 2443 • Website: www.eccdh.gov.za

INTERNAL MEMORANDUM

To:	Ms. C. N. Matwele, Student, UFH
From:	Dr. J. Thomas; Acting Director Clinical Governance, ELHC
CC:	Mrs. J. Scholl; Acting Hospital Manager, Frere Hospital Mrs. T. Mguli; Deputy Director Nursing services, Frere Prof. B. Pokharel; Head of Radiation Oncology, Frere
Subject:	Research Request: Patient's Perceptions regarding Commencement of Treatment Following Diagnosis with Breast Cancer.
Date:	1 October 2013

Your correspondence of 6 August 2013 refers. Your request to access Frere Hospital has been approved.

It is requested that a copy of the completed analysis be submitted to this office for record purposes.

You can liaise with the following persons to coordinate the research:

1. Mrs. T. Mguli, Tel: (043) 709 2781
2. Prof. B. Pokharel, Tel: (043) 709 2429

Regards,

Dr. J. Thomas

Acting Clinical Governance Director: ELHC

Nmp/cjr

United in achieving quality health care for all

24 hour call centre: 0800 0323 64
Website: www.eccdh.gov.za



Ikamva eliqagambikyo!

APPENDIX I: CONSENT FORM

NAME OF APPLICANT

Ethics Human 2011

<<Approved

>>

OFFICE USE ONLY

Ref:

Date:



University of Fort Hare
Together in Excellence

Ethics Research Confidentiality and Consent Form

Please note:

This form is to be completed by the researcher(s) as well as by the interviewee before the commencement of the research. Copies of the signed form must be filed and kept on record

I Caroline Ntombekaya Matwele a masters student at the University of Fort Hare , is asking people from the hospital/ sample / group to answer some questions, which I hope will benefit your community and possibly other communities in the future.

I am conducting research regarding Patient's perceptions regarding commencement of treatment, following diagnosis with breast cancer. I am interested in finding out more about your perceptions regarding commencement of treatment following diagnosis with breast cancer. I am carrying out this research as a fulfillment for a master's degree. Recommendations from the study will assist in formulating policies regarding Oncology units in Buffalo City.

Please understand that you are not being forced to take part in this study and the choice whether to participate or not is yours alone. However, I would really appreciate it if you do share your thoughts with me. If you choose not take part in answering these questions, you will not be affected in any way. If you agree to participate, you may stop me at any time and tell me that you don't want to go on with the interview. If you do this there will also be no penalties and you will NOT be prejudiced in ANY way. Confidentiality will be observed professionally.

I will not be recording your name anywhere on the questionnaire and no one will be able to link you to the answers you give. Only the researchers will have access to the unlinked information. The information will remain confidential and there will be no "come-backs" from the answers you give.

The interview will last around (30) minutes (*this is to be tested through a pilot*). I will be asking you a questions and ask that you are as open and honest as possible in answering these questions. Some questions may be of a personal and/or sensitive nature. I will be asking some questions that you may not have thought about before, and which also involve thinking about the past or the future. I know that you cannot be absolutely certain about the answers to these questions but I ask that you try to think about these questions. When it comes to answering questions there are no right and wrong answers. When we ask questions about the future I am

Document approved by UREC: 11 August 2011, V01

APPENDIX J Semi-structured interview guide

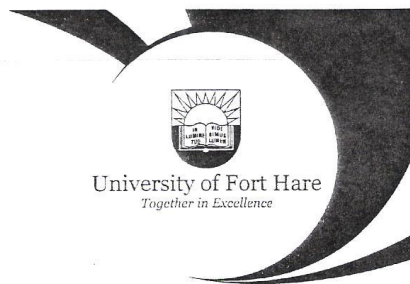
Note: The questions can be changed or adapted to meet the respondent's intelligence, level of understanding, or beliefs.

1. How old are you?
2. How old were you when you had your first period?
3. How many children do you have and how old were you when you gave birth to your first child?
4. Is there history of cancer in the family?
5. I would like to know when you first noticed signs that indicated breast cancer?
6. Explain what comes to mind when you think about breast cancer, the disease?
7. Please share with me your idea of what goes on inside the body with breast cancer?
8. Based on what you think is going on, how do you think it should be treated?
9. Explain your concerns/ feelings about treatment of breast cancer?
10. Can you please share with me what was the cause of the delay in seeking help?

Compiled By: C.N. Matwele

SCHOOL OF HEALTH SCIENCES

P.O. Box 1054
East London 5200
Tel: +27 (043) 7047475 | Fax: 0866282026
Date : 01/10/2013

**REGARDING: Co-coding of analyzed data.**

This is to confirm that I co-coded analyzed data for MCur Student Caroline Matwele. Student No: 201213752.

The processes that I embarked on are as follows:

I read her proposal and methodology chapter to understand the approach and the design of choice for the study so as to understand the objectives and the questions the participants had to answer

I thereafter read how she delineated the meaning units from the data transcripts. I examined the analyzed data to understand how segments of meaning units were clustered. I then made suggestions with regard to how she and her supervisors could modify categorization of some information so as to come up with the final themes, categories and sub-categories where applicable.

I do have experience in qualitative data analysis and have been utilized by Nursing Science Department to co-code analyzed qualitative data for several studies.

D.Murray

D Murray

Signature

22/4/2014

Date

APPENDIX L Editor's proof reading certificate

EDITOR'S DECLARATION

I Dr Ketiwe Ndhlovu, confirm that I edited Caroline Ntombekaya Matwele (Student Number: 201213752)'s MA thesis entitled: **An investigation on patient's perceptions regarding commencement of treatment following diagnosis with breast cancer at Frere Hospital, in Buffalo City Metropolitan Municipality, in the Eastern Cape Province.**

The following changes were recommended: eliminating repetition, grammatical errors, paragraphing and writing proper conclusions. It is up to the candidate to effect these changes, as she remains the author of this thesis.



05/ 05/ 2014

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Editor's Signature

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Date



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Candidate's Signature

05/05/14

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Date