

**UNIVERSITY OF LIMPOPO
(MEDUNSA CAMPUS)**

DEPARTMENT OF FAMILY MEDICINE AND PRIMARY HEALTH CARE

**THE KNOWLEDGE AND PRACTICE OF PATIENTS SUFFERING FROM
CANCER OF THE BREAST ABOUT THEIR DISEASE AT PRINCESS
MARINA HOSPITAL (PMH) GABORONE, BOTSWANA**

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department of family medicine at the university of Limpopo

Dated submitted

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DECLARATION

I, Mbuka Ongona, Deogratias hereby declare that the work on which this research is based, is original and that neither the whole or any part of it has been, is being or is to be submitted for another degree at this or any other university.

Signed:

Dated:

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ABSTRACT

Introduction

Inspired by the late presentation for care and consequently the diagnosis of breast cancer done at an advanced stage of the disease in majority of cases, this study aimed to explore the knowledge and practices related to breast cancer from patients presenting at Princess Marina Hospital (PMH) for care.

Methodology

The descriptive qualitative method using interviews (free attitude) was chosen to understand the trend of late presentation among participants, with following opening questions:

- 1. Can you please tell me all you know about the cancer of the breast?*
- 2. How have you been treating your breast condition (growth/wound/pain) before you decided to come to PMH?*

Sampling was purposeful with a sample of twelve. Out of eleven interviews done with breast cancer patients fulfilling the criteria of inclusion, ten were used in the final analysis. Interviews were recorded (audiotape), transcribed verbatim and translated. Emerging themes were identified and coded into different categories

Results

This study noted a poor knowledge and understanding of patients about cancer of the breast. The knowledge and practice of the common well established screening methods like self breast examination (SBE) was equally poor.

In majority, participants delayed going to the hospital as a result of the preceding(poor knowledge and understanding about Ca breast), as well as the influence of lays beliefs and advices received from the surrounding.

In some cases however advices from the surrounding resulted in timely medical consultation.

Unexpectedly, Poor clinical practice of health worker in some cases and decision maker's inadequate involvement on issue of cancer awareness were other important themes which emerged during analysis of the results.

Conclusions

Cancer awareness together with consistent use of early detection measures by adhering to screening methods should be taken seriously and done throughout the country for the benefit of all potential victims, to address the poor knowledge, misconceptions and inappropriate health seeking behavior encountered in case of breast cancer.

LIST OF ABBREVIATIONS

PMH: Princess Marina hospital
Ca: Cancer
MOH: Ministry of health
ENT: Ear, nose and throat
HC: Health center
GPH: Gaborone private hospital
NRH: Nyangabwe referral hospital
KSDH: Kanye seventh day Adventist hospital
BLH: Bamalethe Lutheran hospital
SLH: Scottisch livingstone hospital
DRMH: Deborah retrieves memorial hospital
CAB: The cancer association of Botswana
LCIS: Lobular carcinoma in situ
DCIS: Ductal carcinoma in situ
SBE: Self breast examination
BSE: Breast self examination
CBE: Clinical breast examination
BRCA: Breast cancer or breast cancer susceptibility
HRT: Hormone replacement therapy
FNA: Fine needle aspiration biopsy
MRI: Magnetic resonance imaging
REPC: Research, ethics and publications committee
KAP: knowledge attitude and practice

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Chapter 1

Introduction

In Botswana cancer of the breast (Ca breast) is one of malignant diseases on the increase. According to the recently established national registry which is undergoing improvement on data collection, available data compiled from 1986 to 2004, published in 2005, showed an increase in the occurrence of malignancy in the country, with Ca of breast reported to be the second malignancy in women at about 26.3% of cases after the leading being cancer of cervix (Ca cervix) with 30.7% of cases (MOH, 2005).

These percentages from national level supported a significant prevalence of Ca breast in Botswana which justified a particular attention to the condition. However, at local level at Princess Marina Hospital (PMH), in Gaborone the capital city of Botswana, the use of the out and in patients registry as well as patients records for the period of 2002 to 2003, noted about 10 % of cases of Ca breast of which about 90 % presented at PMH for care when the disease was significantly advanced, 'stage III and IV' (PMH oncology records, 2002).

1.1 Motivation and Aim

The researcher observed that a high proportion of patients suffering from cancer of the breast presented at PMH for care at an advanced stage of the disease and considering that the recently created national cancer registry reported a high national prevalence of the disease, the researcher decided to embark on a study on the knowledge and practices of patients suffering from Ca breast and late presentation at the hospital.

Interacting informally with patients suffering from Ca breast showed that, there was a potential of bringing about an understanding of the trend observed of late presentation at PMH. In view of the above the aim was to explore the knowledge and practices of patients suffering from Ca of breast so that an understanding of the reasons for late presentation at PMH for care would be extrapolated.

1.2 Study Setting

This study was conducted at the Department of Oncology at PMH in Gaborone Botswana. PMH is a referral hospital of about 500 beds located in Gaborone the capital city of Botswana. The hospital has the following specialties: internal medicine, paediatric, obstetric & gynaecology, general surgery, orthopaedics, ears nose & throat (ENT), out patient psychiatric care unit, ophthalmology, stomatology, accidents and emergency unit.

The department of oncology has only 20 beds for admission of patients from Gaborone and the southern part of Botswana, but it is not uncommon to admit patients from the entire country including the north part of Botswana despite the presence of another referral hospital there.

The flow of patients from all over the country resulted to inadequate room in the oncology department to accommodate all patients. Consequently the health centre (HC) formally used as a tuberculosis isolation ward became an extension of the oncology ward where stable patients coming from outside Gaborone are kept especially for course of radiotherapy which lasts for an average of six weeks. The HC has an additional 15 beds to accommodate cancer patients in need of cancer therapy in Gaborone.

The Oncology department runs an out patient clinic on a daily basis, providing chemotherapy to both out and in patients in PMH, however some patients who are in the HC, located at about 500 meters from PMH attend chemotherapy at PMH, while the majority of them are taken to Gaborone Private Hospital (GPH) for radiotherapy.

The study participants were identified from either the HC or the out patients department of oncology.

1.3 Health Care Facilities and Organizations

Health care in Botswana is provided by the public sector, the private sector and traditional practitioners. Alternative medicine is also available giving a wide range of choice to clients in need of health services.

PMH and Nyangabwe Referral Hospital (NRH) are currently the two referral hospitals of the public sector in the country serving respectively the southern and northern part of Botswana. They are located about 500 kilometres apart, and each has about 500 beds. Close to PMH are a number of district hospitals such as: Athlone Hospital in Lobatse, Kanye Seventh Day Adventist Hospital (KSDH) in Kanye, Bamalete Lutheran Hospital (BLH) in Ramotswa, Scottisch Livingstone Hospital (SLH) in Molepolole and Deborah Retrieve Memorial Hospital (DRMH) in Mochudi within a 100 kilometres distance from Gaborone.

Other hospitals around NRH in the north are also in the same vicinity and distance except Maun District Hospital which is more than 200 kilometers away.

Gaborone Private Hospital (GPH) is a private hospital operating at a referral level and located in Gaborone. It is the only facility providing radiotherapy in the entire country.

Services are more costly at GPH, a private institution than in other institutions in the public sector found in the country like PMH in Gaborone.

Nevertheless, in the case of Ca breast, patients from the public sector (entire country through NRH and PMH) are referred to GPH for radiotherapy as part of the management of cancer after surgical intervention or chemotherapy. These patients are sponsored by the government to the citizens of this country.

The cancer association of Botswana (CAB) established in 1998 is the only non governmental organization helping cancer patients but it is faced with lack of sponsorship. This limits activities such as awareness and support programs. According to the administrative secretary of the association, the above activities only started happening slowly since 2006 (personal communication with CAB).

Chapter 2

Literature Review

2.1 Introduction

This chapter is on literature on cancer of the breast (Ca breast). It will focus on the following aspects:

- General concept on cancer(definitions and types)
- Epidemiology of cancer of the breast world wide
- Cancer of the breast in the African continent and sub-Saharan Africa.
- Lay beliefs on breast cancer, screening awareness and adherence to screening methods
- Trends of stage at presentation and related issues
- Risk factors (endogenous hormone, heredity, social class, hormone therapy, diet/obesity)
- Assessment of breast problem and,
- Early detection of cancer of the breast, treatment, prognosis and preventive strategies

2.2 Methods of Literature Search

Pubmed was the engine used for literature search on internet, and whenever there were overwhelming references; limits to articles published last ten years, in English, done on humans with link to full text could be used to get acceptable number of articles to screen. Literature search was done by exploring internet sites, and consulting the resource centre at the department of family medicine for full text and relevant articles at the University of Limpopo (Medunsa Campus). Relevant books about the topic were also read.

Keys words and combination used for internet searches were as follows:

Cancer of the breast AND prevalence in population

Cancer of the breast AND prevalence in population AND risk factors

Cancer of the breast AND risk factors

Cancer of the breast AND histological findings

Patients with cancer of the breast AND knowledge of cancer of the breast AND practice

KAP AND breast cancer

2.3 Definitions and Types of Cancer

2.3.1 Definition of cancer

Cancer is any malignant tumor, carcinoma or sarcoma, arising from the abnormal and uncontrolled division of cells that then invade and destroy the surrounding tissues.

Additionally by the virtue of metastasis, cancer cells may spread via the bloodstream or lymphatic channel or across body cavities such as pleural and peritoneal space resulting in secondary tumors at sites distant from the original tumor (Elisabeth A & Martin MA, 1994).

Ca breast is an uncontrolled growth of malignant tissue that arises in the breast. It starts as a single cell in the breast followed by a doubling of this cell in size every 3 days in fast growing tumors while the same process can take up to 240 days in slow growing tumors, meaning that the tumor can take as short as 3 months to grow to 1 cm in size, in very fast growing tumors compared to as slow as 8 years in some slow growing tumors to reach the same size of 1 cm (Kessler E, 1994).

2.3.2 Type of breast cancer

Based on histopathology findings there are *non-infiltrating (in situ) carcinoma* and the *infiltrating breast malignancy*. Under the category of cancer in situ it has been reported that lobular carcinoma in situ (LCIS) develops predominantly in premenopausal women (mean age 45). It is usually an incidental finding as opposed to ductal carcinoma in situ (DCIS), which is the true precursor of invasive breast cancer. However the infiltrating ductal carcinoma also called *scirrhous carcinoma* is the most frequent adenocarcinoma of the breast from which a subtype is called Paget's disease of the breast presenting as an itching eczema or ulcerative lesion (Gonzalez AM & Moffat FL, 1998).

A similar high prevalence of the infiltrative / invasive ductal carcinoma of the breast has been reported in a retrospective histopathology study done in Nigeria based on a twelve years' record from 1993 to 2004. In that study 75.5% prevalence of infiltrative ductal carcinoma against 2.7% of prevalence for papillary carcinoma which is a DCIS was the outcome (Ekanem VJ & Aligbe JU, 2006).

2.4 Epidemiology of cancer of the breast world wide

Based on registry of 1993 to 1997 compiled in 2000, cancer of the breast was the most occurring malignancy in women and second most common tumor in women with more than one million of new cases of Ca breast diagnosed each year world wide (Bray F, Maccarron P & Parkin DM, 2004). According to the same authors, cancer of the breast accounted for about 375,000 deaths worldwide in the year 2000.

As far as mortality was concerned, Ca breast was the principal cause of death from cancer among women and was reported to be the second leading cause of deaths among women by year 2000 (Imaginis, 2004).

Bray F, Maccarron P and Parkin DM (2004) as well as Imaginis (2004) reported that the incidence of Ca breast increased world wide in the past two decades while the mortality was reported to decrease due to effective treatment currently available.

However according the same authors, the above trend was more evident in developed countries where early detection is done followed by appropriate available treatment as opposed to developing countries where the diagnosis was done late and there was lack of appropriate treatment.

Beyond the reported increased incidence of Ca breast linked to the aging process of about 1 case out of 2,212 women at age 30 to 1 out 10 women by age 80 in the western set up

(Imaginis, 2004), the chances of a women to develop Ca breast during their life time was rated at one out of ten women (Kessler E, 1994).

Considering the risk of developing Ca breast, different environmental factors and the range of socioeconomic differences were reported to support about 10 folds variations in the cancer incidence rate worldwide (Bray F, Maccarron P & Parkin DM, 2004).

The recorded Ca breast incidence rate based on geographical variation was 100 per 100.000 in the USA from the compiled registry of 1993 to 1997, being one of the highest rate, while Africa recorded a rate of 10 to 30 per 100 000 considered to be the lowest incidence rate world wide for the same period; In addition worldwide, Ca breast was the second common malignancy after the cancer of lung in both sexes. (Bray F, MacCarron P & Parkin DM, 2004).

2.5 Cancer of the breast on the African continent and sub Sahara Africa

Late diagnosis of Ca breast and lack of appropriate treatment was reported in developing countries (Bray F, Maccarron P & Parkin DM, 2004; Imaginis, 2004).

Accuracy of statistics are however needed to ascertain the existing cancer risk model presented by some authors(Imaginis, 2004) in the African context where the incidence of Ca breast was lower compared to the western world.

However, according to existing literature, Ca breast was reported to be the second commonest malignancy after Ca cervix in sub-Sahara African (Anim JT, 1993). In South Africa, the prevalence of Ca breast reported during years 1993 – 1995, found Ca breast to be the commonest malignancy. Ca cervix was the leading malignancy in women during pervious years (1986 -1992) regardless of racial differences.

Nevertheless considering racial differences, Ca breast appeared to be commonest malignancy in white women, while it was reported to be the second commonest malignancy in mixed races or black women (Vorobiof DA, Sitas F & Vorobiof G, 2001). It remained in each case that Ca breast is either first or second common malignancy among women.

2.6 Lay beliefs about breast cancer, screening awareness and adherence to screening methods.

It appeared from different studies that personal attitude towards diseases are culturally determined and vary around the world. The explanatory models often referred to as lay beliefs, for this particular case of cancer, was reported to determine the perception of the risk of developing cancer and subsequently having substantial effects on participation in screenings programme, decisions about treatments, doctor patients relationships and emotional response to the disease (Dein S, 2004). From this systematic review of studies done on black American in USA and Canada as well as published studies on women of different origin like Asia, Africa , Australia and UK, there was different explanatory models(lay beliefs) on breast cancer. Therefore eliciting the perceptions of patients was reported to be essential as well as the attempt to understand them and incorporate them in the treatment as that could enhance both doctors-patient relationship and improve compliance (Dein S, 2004).

In keeping with the above it was demonstrated in a study done on South Asian women by Bottorff JL *et al* (1998) , that on the basis of emerging four major beliefs (beliefs about a woman's calling ,beliefs about the cancer, beliefs about taking care of your breast and beliefs about accessing services) that religiously and culturally they had paramount reasons not to adhere to screening programmes. In fact from the above beliefs they were not encouraged to know that they are having a cancer since it would imply the possibility of putting a label of cancer to the family, therefore destroying family pride (Bottorff JL *et al* 1998).

Additionally by modesty they were taught that they were not supposed to be naked showing their breast to a stranger unless their own husband; therefore they were discouraged seeking breast examination while the language barrier was not the least in promoting the absence of use or participation to available screening facilities by that community (Bottorff JL *et al* 1998).

Although with different explanatory models in different part of the world, cancer awareness was present especially by the common fatality outcome, the knowledge of different screening methods and the actual practice of screening were discordant worldwide (Dein S, 2004).

Up to 92 % of the sample size of a cross sectional population based survey in Austria was aware of self breast examination (SBE) while only 31 % practiced it thoroughly (Janda M *et al* 2000). A similar trend of the gap between knowledge of breast examinations and the actual practice was shown among Japanese American women (Robins SG *et al* 2003) , Australian women(Budden L,1995), Iranians women (Haji-mahamoodi M *et al* 2002) and united Arab emirates women (Bener A *et al* 2001) .

Being employed was proved to be an independent predictor to the participation in the three screenings procedures: self breast examination (SBE), clinical breast examination (CBE) and mammography among United Arab Emirates women (Bener A, *et al* 2001).

2.7 Trends of stage at presentation and related issues

Advanced stage of Ca breast at presentation was not a new trend. Review of articles in the sub-Saharan region as well as studies done at the University of Benin in Nigeria reported a high proportion of late presentation of women suffering from Ca breast. Up to 78 % was the proportion of patients seen at a late stage of the disease (Anim JT, 1993; Chiedozi CL, 1995). Additionally cancer of the breast was found to be the most common cancer encountered after Ca cervix (Anim JT, 1993).

In South Africa about 77% of black women compared to 30% of non black women presented at stage III and IV of the disease, according to the national cancer registry covering the period of 1986 to 1992 which also noted that Ca cervix was the leading cause of cancer in women followed by Ca breast despite the fact that recorded figures are said to have underestimated the true incidence (Vorobiof DA, Sitas F & Vorobiof G, 2001).

Currently reasons for late presentation of the disease in America were, lack of education and knowledge on the perception of seriousness of breast symptoms as well as the perception on the pertinence of the associated risk factors, limited knowledge about the potential benefit of early detection in relation to the improvement of the survival in Ca breast patients (Gullatte MM, Philips JM & Gibsone LM, 2006).

The same authors noted additionally that advancing age, low socioeconomic status, fear of the diagnosis and consequences of cancer treatment, misconceptions about the etiology, denial and spirituality including faith were responsible for late presentation.

In the sub-Saharan region literature reviewed noted that lack of health education programmes in cancer especially about self breast examination and the lack of screening facilities such as mammography and hormone receptor assays were contributory to late presentation and poor prognosis (Anim JT, 1993).

Beyond the late presentation the overall poor prognosis was also associated to the lack of standard treatment such radiotherapy and chemotherapy in many African countries (Anim JT, 1993).

Ignorance, use of alternative medicine and the fear of surgery were equally found in Africa to justify late presentation (Ekanem VJ & Aligbe JU, 2006).

The cultural determinant of strong beliefs that witchcraft caused cancer was another variable recorded among the reasons of delayed presentation at hospital for care since priority was the reversal of sorcery, while same authors also reported the non- acceptance of the difficult concept of a painless lump to be a cancer with a fatal outcome in the eyes of rural women (Vorobiof DA, Sitas F & Vorobiof G, 2001).

Rural women as well as health workers participated in a knowledge attitude and practice (KAP) studies elsewhere with following findings:

Rural women lack appropriate information about breast cancer and consequently the early detection measures (Oluwatosin OA & Oladepo O, 2006); community dwelling women in Nigeria had extremely low level of awareness of cancer of the breast with minimal skill of self breast examination and clinical breast examination, while increased awareness was noted among those with some level of education (Okobia MN, Bunker CH, Okonofua FE & Osime U, 2006).

Health workers, in particular nurses were found to have a good knowledge about Ca breast in general and the value of self breast examination. However, there was poor practice of self breast examination among the participants (Bastani R *et al* 1994; Odusanya OO & Tayo OO, 2001).

2.8 Risks Factors

2.8.1 Hormone endogenous

Since there is no clear evidence regarding the causes of cancer of the breast, little can be done to prevent it. The better available option was the assessment of the risk in potential victims with particular attention given to women at higher risk as opposed to others as supported by some research works (Birken RA, 2004).

Female endogenous hormone production was however, reported to be an important determinant in the development of Ca breast (Kessler E, 1994; Eliassen AH, *et al* 2006).

In this regard the risk of developing Ca breast was increased among woman who had experienced menarche before 13 years of age with a relative risk of up to four fold compared to the risk of having menarche after 13 years. Additionally in keeping with endogenous hormone production “the *estrogen window theory*”; the number of days in the ovulating cycle before the first pregnancy, determined the life time risk of a women to develop Ca breast as well as a pregnancy after the age of 35 increased the risk of Ca

breast compared to nulliparous women (Kessler E, 1994; Bray F, MacCarron P, & Parkin DM, 2004).

2.8.2 Heredity

Among many risk factors associated with cancer of the breast, the family history of breast cancer in either maternal or paternal line increased the risk of developing cancer of breast. The risk enhanced when a first degree relative such as mother, sister or daughter had Ca breast (Kessler E, 1994; Cortesi L *et al* 2006).

The significance of first degree relative in the family history of Ca of breast supported the inheritance patterns of the disease which could be explained by either a genetic defect or environmental factors.

Breast cancer or breast cancer susceptibility (BRCA) is a tumor suppressor gene which is protective against the development of cancer of the breast or any other cancer; the defect on this gene or mutation is said to predispose the carriers to a lifetime risk of between 40-85% of developing breast cancer in females (Kotze MJ *et al* 2005).

According to the same authors these altered genes BRCA1/2 of high-penetrance mutations contributed to about 5-10% of inherited cancer in the families as opposed to the sporadic breast cancer which were reported to be as a consequence of environmental factors which could trigger multiple low-penetrance mutations representing 90 to 95 % of all cancers.

In keeping with genetic defects, the discovery of the mutant genes BCRA1 and BCRA2, was proof of genetic implications which predisposed carriers for breast cancer and ovarian cancer (Ca ovary), as demonstrated in this recent cohort study in terms of standardized incidence ratio comparing carriers of the defected gene to others with family history at risk of developing cancer of the breast (Cortesi L *et al* 2006).

However these defects in BRCA tumor suppressor gene responsible of familial breast cancer were reported to be present in South Africa although there are clinical limitations of screening through a routine DNA test (Kotze MJ *et al* 2005).

Kessler E, (1994) pointed out the environmental effects on the occurrence of Ca breast. An example to support that was Japanese women who had an increased incidence of Ca breast after immigrating to the USA as well as the case of Japanese living Japan who adopted a western lifestyle. The development of cancer in the breast was shown to be linked to social economic status of the patients.

In the measurement of social class by income and level of education the higher the social class the higher was the risk of developing Ca breast which was said to be counter balanced, by the lower mortality in this social class (Bray F, MacCarron P & Parkin DM, 2004).

The same trend was reported earlier by Kessler E,(1994) who explained the trend as a possible combination of operative factors such as early menarche, use of the pill, high fat diet, alcohol, late first pregnancy, fewer pregnancies, reluctance to breast feed as well as the role of hormone replacement therapy which were common in the higher / affluent social classes, while the lower social classes, however, were said to have lower incidence of Ca breast but with late presentation and higher mortality rate.

2.8.3 Hormone therapy (exogenous hormone)

The risk of developing cancer of the breast after use of exogenous hormones in different situations such as postmenopausal hormone replacement and oral contraceptive was still under debate with contradictory result such as a questionable significance of additional risk related to the use of estrogen in postmenopausal women (Kessler E, 1994).

However the same authors reported that the use of oral contraceptive pills was reported to be associated with an increased risk after prolonged use of about 10 years.

Recent studies supported the view that oral contraceptives and hormone replacement therapy resulted in an increased risk of breast cancer (Beral V, 2003). But the low risk of Ca breast observed with the use of oral contraceptives was persistent up to ten years after cessation of use, while patients on hormone replacement therapy were likely to have an earlier stage disease at presentation with low mortality (Bray F, MacCarron P & Parkin DM, 2004).

The debate on the increased risk of developing cancer of the breast while using exogenous hormone replacement therapy (HRT) was again raised, suggesting that there was minimal additional risks of developing Ca breast among the users of HRT, especially when combined replacement was used compared to estrogen alone , for periods greater than five years (Coombs NJ *et al* 2005).

A recommendation by these authors was that of taking a decision of use of HRT on an individual basis. Minimal risk was demonstrated that, careful use of exogenous hormones should be recommended especially beyond five years of use.

2.8.4 Diet and obesity

Dietary fat intake was long proved to be correlated with an incidence of Ca breast worldwide (Bray F, MacCarron P & Parkin DM, 2004). The occurrence of cancer in such a population depended on the type of fat; fish fat having negative correlation with cancer occurrence as compared to animal or vegetable fat which proofed to have positive correlation with Ca breast, the correlation being observed more in the age group of fifty and above (Sasaki S, Horacsek M & Kesteloot H,1993).

Studies assessing weight gain and the risk of developing Ca breast showed that there is an association between massive weight gain from the age 18 and the development of postmenopausal Ca breast (Magnusson C *et al* 1998; Eliassen AH *et al* 2006).

Eliassen AH *et al* (2006) in a cohort study showed that there is a higher relative risk of developing Ca breast in post menopausal period in women aged 18 who gained about 25 kg or more, as well as the gain of 10 kg or more from menopause increased the risk of developing Ca breast compared to menopausal women who maintained body weight or better who lost about 10 Kg from menopause.

Additional to the fat consumption and weight gain, daily alcohol consumption at a younger age before age 30 is said to be associated with increased risk of developing Ca breast as compared to late alcohol consumption (Kessler E, 1994).

2.9 Assessment of patient breast problem

Beyond the assessment of the clinical presenting problem which was summarized in: pain, lump, nipple discharge, skin changes (Kessler E, 1994), a full assessment of patient through a patient centered approach using a three stage assessment will help addressing concerns, fears, expectations of the patient as well as the understanding of the patient's context which is in keeping with the foundations of family medicine is recommended (De Villiers M, 2000).

Alarming signs and symptoms included a hard painless lump which was typical for malignancy and persistent pricking pain in the breast compared to a cyclic breast pain. However, any breast lump required a doctor's assessment and a biopsy, the same being reported for a frank nipple discharge which should be considered for cytology studies (Kessler E, 1994). The same author emphasized on the importance of considering on a serious note any changes on the breast skin such as dimpling, nipple retraction which required urgent investigation.

A full assessment is achieved by combining the above clinical warnings signs and symptoms, the patient's investigations, with patient's ideas, fears, expectations as well as the contextual assessment whereby family history is believed to be very important in terms of malignancy risk assessment of patient whenever malignancy is suspected .

In conclusion the clinical diagnosis of Ca breast should be based on family history, thorough physical examination and imaging (mammography, ultrasound), from which abnormal findings such as a lump warranted fine needle aspiration biopsy (FNA) or surgical biopsy (Gonzalez AM & Moffat FL, 1998).

Beyond mammography and ultrasound which are available in our facilities, many other investigations such as magnetic resonance imaging (MRI), Doppler flow, digital subtraction angiography of the breast, were reported to be of value in the diagnosis of Ca breast (Gonzalez AM & Moffat FL, 1998)

2.10 Early detection, treatment prognosis and preventive strategies

Early detection of Ca breast is crucial to the treatment success and the prognosis of the disease. This could only be done with a good breast screening program similar to the one recommended by the American Cancer Society (Kessler E, 1994; Imaginis, 2004) which was found to increase the incidence of Ca breast in the screened group in England and Australia (Wales), even if the decrease in mortality three years after the introduction of the screening program was in this case unlikely due to the screening program since during the same period there was a wide spread use of tamoxifen (Quinn M & Allen E, 1995).

It was however, expected from this follow up cross sectional study that with the existing fall in mortality the additional benefits from the screening program would be achieved in the future.

Corroborating the above, tamoxifen was reported to be modest in reducing mortality in postmenopausal women with a positive receptor node. It was also reported to support improvement in the disease management and responsible for the decline in mortality in the developed countries (Australia, UK and Finland) without screening or prior to the introduction of a screening program (Bray F, MacCarron P & Parkin DM, 2004).

The American cancer society recommended a screening program , including *breast self examination* (BSE)from age twenty and above, a *clinical breast examination* (CE) every three years from age twenty to forty and yearly beyond forty, and a *mammography* every one to two years from age forty to forty nine ;every years from age fifty. This screening program was said to allow detection of tiny pre invasive cancers curable with less mutilating surgery and better results (Kessler E, 1994).

According to the same authors (Kessler E, 1994), while BSE and CBE should be adhered to, the need for mammography should be assessed in a particular part of the world depending on the incidence of the Ca breast which is in rise where the influence of western culture is being felt.

Taking into account the uneven incidence of Ca breast in different part of the world, as reported by Bray F, MacCarron P and Parkin DM, (2004), there was need of assessing the indication of mammography in Africa where the incidence was reported to be low compared to USA. This consequent limitation of routine use of mammography screening in developing countries was due to financial constraints and lack of accurate data on the burden of the disease in those countries (Okobia MN *et al* 2006).

The current treatment of Ca Breast was reported to be based on a combination of surgical procedure(excision or mastectomy),radiotherapy, hormonal therapy and chemotherapy (Kessler E,1994).The expected and reasonable out come could be achieved by individualization of treatment variation in term of above combinations to each patient (Gonzalez AM & Moffat FL,1998).

In general the prognosis of Ca breast depends on the stage of the disease, which dictates the type of combination therapy to use, while the earlier the disease was detected the better the survival rate (Kessler E,1994).

However, the prognosis of Ca Breast in younger women was worse in women with positive lymph node and receptor positive despite the use of tamoxifen and adjuvant chemotherapy as compared to the elderly (Saghir NSE *et al* 2006).

Considering that the primary risk factors for Ca breast were reported not to be easily modifiable because they originated from prolonged endogenous hormonal exposure the only way to go was to implement breast screening programs and to improve the treatment of the disease (Bray F, MacCarron P, & Parkin DM, 2004). The same study advocated the promotion of breastfeeding and weighing the benefit and risk of using tamoxifen / raloxifen in high risk women with regard to cancer of endometrium and thrombo-embolic risk. The preventive strategy was also to be applied whenever a carrier of mutant BRCA1/2 was detected for a possible prophylactic mastectomy.

2.11 Conclusion

Cancer of the breast is one of the commonest malignancies among women worldwide and in Africa. However reported low incidence in Ca breast in developing countries (Africa) is possibly attributable to the lack and inaccurate data on the issue compared to western countries.

This low incidence of Ca breast in Africa may be changing in the near future due to improving data capturing system as well as the influence of western countries life style which is reported to influence the growth of Ca breast incidence in the developing countries.

The presence of endogenous and exogenous risks factors supports the etiological multifactorial nature of Ca breast which make it difficult to be hundred percent preventable, implying the use of early detection measures as acceptable step in the management of breast cancer.

Consequently, early detection remains the way forward for better outcome in term of prognosis and survival rate. However improvement of adherence to screening methods need understanding of lays beliefs on cancer from each particular patient since they (lays beliefs) dictate patient health seeking behavior and therefore may prevent the use of early useful tools for breast cancer detection .

Breast self examination (BSE), clinical breast examination (CBE) and mammography should be used as well as the up coming genetic screening for BRCA 1/2.

Considering financial constraints in developing countries BSE and CBE should be done religiously while rigorous risk assessment of patient (age, family history...), should guide the recommendation of mammography and genetic screening to patients who can afford those investigations for early detection. Nevertheless it is prudent to biopsy a breast lump for histological diagnosis of its nature and appropriate timely treatment.

Chapter 3

Methods

3.1 Aim of the Study

To explore the knowledge and practices about cancer of breast (Ca breast), among women suffering from the disease.

3.2 objectives

- To assess the level of knowledge about cancer of the breast amongst patients having the disease
- To evaluate practices related to cancer of the breast amongst those having the disease.
- To make recommendations potentially effective in early detection, diagnosis and treatment of Ca breast.

3.3 The study design

This research was a qualitative exploratory descriptive study which used free attitude interview (one to one) technique for data collection.

Considering the potential differences in knowledge and practice from individual participants this method of data collection was selected since interview in qualitative study uses open ended questions which allow for individual variation (Hoepfl M, 1997) from participants. In addition, Holman HR, (1993) reported that free attitude interview was used to collect data, since they gave participants a freedom of expression for their perceptions.

3.4 Participants and Sample

The study was conducted among patients suffering from cancer of the breast (Ca breast) attending at PMH. Patients admitted at the health centre (HC) and those attending the hospital for chemotherapy or radiotherapy constituted the study population. The majority of patients recruited from the HC were not inhabitants of Gaborone.

To obtain variation in location fewer participants were recruited from PMH therefore increasing the chance of having participants living in Gaborone.

Included in the sample of this study were patients in either of these locations (PMH or HC), with a stable disease and mentally sound while unstable patients in pain, depressed and not mentally sound, were excluded from the study. Variation was based on age, level of education, marital status and living in rural or urban area.

Sampling was purposive (Reid AJ, 1996) and a sample of twelve respondents; the number was felt to meet the degree for saturation. The researcher and assistant identified primary themes immediately after the interview or the day after and noted down the

findings to complement the field notes as well as to serve as a memory aid in the future to ensure saturation.

Continuous dissemination of the respondents' information contents (refer appendix D) was done at the health centre and at PMH followed by the identification of potential participants through the management of the respective facilities represented by matrons / sisters-in-charge. They selected articulate patients in either Setswana or English who were prepared and keen to share about the disease they were suffering from. The researcher was then informed about the potential participants who were willing to participate in the research so that an appointment was arranged for an interview.

Eleven interviews were conducted, however one was not included in the final analysis because it was the shortest interview and the respondent did not have much to share; another aspect in excluding this interview was the inability to validate the interview because her contact details were unclear. Consequently only ten interviews were analyzed.

Inclusion criteria:

- All patients (women) diagnosed with cancer of the breast and seen at PMH
- Stable and mentally sound patients with Ca breast.

Exclusion criteria:

- Unstable patient (with disturbing excruciating pain)
- Not mentally sound patient (confused) or
- Depressed patient

3.5 Exploratory Questions

The following were exploratory questions asked during this study:

- English version:

1. *Can you please tell me all you know about cancer of the breast?*
2. *How have you been treating your breast condition (growth/wound/pain) before you decided to come to PMH?*

- Setswana version:

1. *Kekopa gore o mpolelele sengwe le sengwe se o se itseng ka kankere ya lebele?*
2. *O ntse o alafisa seemo sa lebele (boruruga, ntho, kana botlhoko) la gago ka eng kana jang pele fa o tla ko sepateleng sa PMH?*

A pilot study was conducted with two hospital general assistants who had been treated for Ca breast at PMH to establish whether information would be adequate. This exercise gave a wide range of responses from these two ladies and the information was appropriate and informative.

3.6 Data Collection

The free attitude interview technique was the research instrument used for data collection. The respondents met with the researchers through an arrangement with the sister in charge of the health centre (HC) then appointments for the interviews were in the afternoon or during lunch time according to the patient's convenience.

Most interviews for participants recruited at the health centre took place at the television and counseling room of the health centre.

However, for patients recruited at PMH, one interview was conducted at PMH at the patient's request while she was still admitted at PMH and two other interviews were conducted at the HC; these two participants were not staying at the HC, but opted to be interviewed there.

The research assistant was fluent in both languages she conducted all the interviews except the first one which was done by the researcher.

The research assistant established rapport with each participant, made an effort to remain neutral and used reflective summaries as well as clarifications to facilitate the interview, all the interviews were audio taped. The researcher took field notes and observed the interview process. Data collection was done from August 2006 to January 2007.

3.7 Analysis

The English interviews were transcribed verbatim by the researcher while the interviews in SeTswana were transcribed verbatim than translated by a professional translator.

Content analysis was done through the inductive theory of data analysis (Hoepfl M, 1997; Pope C, Ziebland S & Mays N, 1999). Thematic analysis also known as coding was used in this case; similar sentences and words were regrouped separately from others under specific themes, than major from minor themes separated. However, on a subsequent stage of the analysis some modifications of themes were noted to be appropriate.

The researcher and the researcher assistant did the analysis while having a check of the process by the co-supervisor for final more appropriate theme to apply.

3.8 Reliability and Validity

The researcher participated at a workshop on qualitative research skills arranged by the Department of Family Medicine, Medunsa. The research assistant holds a Masters degree in nursing science, her dissertation was from a qualitative perspective and was skilled in the technique used in this study.

Begley CM, (1996) with regards to enhancing validity recommended the use of triangulation. In this study the following was done; all the interviews were audio taped, field notes were taken, thus using more than one source of data collection. Member checks were done with all the participants, the purpose being to give the participants an opportunity to confirm what they had said during the interviews. Reliability was enhanced by asking the same questions during the interview to all the participants. Translations of the Setswana interviews were done by a professional translator. Back

translation of the Setswana interviews were done by the research assistant who was fluent in English and Setswana.

3.9 Bias

This study being from a qualitative perspective the following biases were expected: Interviewer, selection, sampling and interpretation bias.

The interviewer was unknown to the respondents; she met them on the day of the interview. However, she did establish rapport with them but maintained neutrality throughout the process of interviewing.

Selection bias is inevitable from a qualitative perspective, the selection criteria excludes respondents who would have been included. Respondents were selected on the basis of, having experienced the phenomenon under investigation, and thus exclude those who are not eligible.

Sampling is also based on being articulate and knowledgeable about the subject under investigation. The small sample size also is not meant to generalize the results but is dependent on saturation of data.

Interpretation bias occurs from error arising from inference and speculation. In qualitative research it is minimized in the employing a devil's advocate and the reporting outliers identified in the text and reported as such.

3.10 Ethical Considerations

Permission to conduct the study was sought from the Departmental Research Committee of the Department of Family Medicine & PHC. Approval for the research was obtained from the Medunsa Campus Research and Ethics Committee (MCREC) MP14/2006, Limpopo (Medunsa Campus), the hospital management of Princess Marina Hospital (PMH) and the Ethics Committee of the Ministry of Health in Botswana.

Written consent was obtained from all the respondents prior to the commencement of the each interview. They were assured confidentiality and anonymity.

Chapter 4

Results

Introduction

This chapter will present the results obtained after analysis of collected data from ten out of eleven participants of this study. It will consist of emerging major themes as well as sub-themes for each participant. This will be immediately followed by the combined results. Reason for exclusion of one interview in the final analysis will be explained in the chapter on discussion.

Interview 1

Respondent profile

She was a 43 years old woman, single, mother of three children. Her education level was primary. She developed a breast lump in 2002; upon discovery of the breast lump she delayed to go to the hospital till 2004 when finally she decided to consult. During interview she spoke freely with a lot of humor sometimes speaking in SeTswana to emphasize what she meant.

Emerging themes and sub-themes:

4.1.1 Going to Hospital

This lady with hindsight realized that she should have consulted at the hospital at the first sign of developing a lump in the breast.

4.1.1.1 Urgency to consult when Lump/ wounds develops in the Breast

At the time of being diagnosed with Ca breast she realized that she should have consulted. These thoughts were contrary to her behavior when she had a lump. She was now advocating to other women about the importance of seeking medical care as soon as a breast lump has been identified; “...*When lumps develop or a wound on the breast you should run to the hospital.*”

4.1.2 Cancer can start anywhere

Apart from commonly known initial signs of breast cancer which develop in the breast, she believed that cancer of the breast can start anywhere else in the body, like on the leg.

“...*Yes on the leg because at times it starts with the legs...*”

4.1.3 Source of Information

She reported to have heard about breast cancer from the community as well as from the hospital teachings after she had been diagnosed.

4.1.3.1 Community Conversations and Hospital Teachings

She reported that she heard about breast cancer from discussions with other people in the community. *“...I heard from people as we were discussing...”*. Hospital teachings were also reported by the participant to have been another source of information on breast cancer. *“.....and also from the hospital teachings...”* she said.

4.1.4 Delayed going to Hospital

She had delayed going to the hospital for reasons she referred to as conflicting advices from close people to her as well as her own delaying tactics.

4.1.4.1 Delaying Tactics in seeking help

When the disease started in 2002, she was torn between going to and not going to hospital. She had a contribution in the delay as well because she thought that the lump was self-limiting. She apparently deliberately took the decision of not consulting appropriate medical doctor for about two years. *“... This disease started in 2002..., ...I was reluctant to go to the hospital in 2002, employing delaying tactics...,...in 2004 I went to a private doctor who suspected cancer but I told him it will get cured...”*, *“... it was big when I went to see Dr X in Orapa...”*

4.1.4.2 Conflicting Advices delayed help seeking

Conflicting advices from her partner and her mother also caused her to be confused as to the importance of seeking medical care. Her partner encouraged her to consult, while her mother was reluctant that she consults, this was yet another reason for the delay. *“My mother was against going to hospital and my boyfriend said I should go to the hospital but...,... the old lady (mother) said that in the past it was treated with fumes from a medicine put on the fire and it disappeared.”*

4.1.5 Transfer to Hospital

As the disease was progressing, she was at a remote rural area being attended at a local clinic. She finally agreed to be transferred although initially she refused to be transferred to Nyangabwe referral hospital (NRH) for appropriate treatment.

4.1.5.1 Referred for appropriate investigations and Treatment

After she was seen at her local clinic, the doctor suspected that the lump could be cancerous and recommended the transfer to another hospital for further investigation and

treatment. *“He told me he wanted to refer me to NRH...”, “... after removal of lump and confirmation of cancer, I was removed the whole breast ...”*

4.1.5.2 Fear of Breast Removal and Death

While her breast lump was getting bigger, her mother’s ideas and advice made her reluctant to go to the hospital as she believed, if she went to the hospital the breast would be removed and she would die. *“It was big; I told the doctor that I didn’t want to go to Nyangabwe referral hospital (NRH) because they would remove my breast...”*. She feared going to the hospital whenever she remembered what her mother had told her. *“She asked me if I want to go to the hospital so that my breast will be removed and I die...”*

4.1.5.3 Fear of Side Effects of received treatment

She appeared to be concerned and afraid about the side effects from the treatment which she could recall with technical details and pertinent side effects. *“...I was given chemo which turned my skin and nails to black and I had poor appetite as food was tasteless...,...my hair changed, even hair on my pubic area was off...”*

4.1.5.4 Hope for a Cure

Despite fearing of developing side effects she had hope for a cure. After undergoing the biopsy and mastectomy, while receiving radiotherapy she expressed hope of being cured. *“I hope I will be cured as I am being treated.”*

4.1.6 Advice to Women

After she had been treated she was advocating to other women to do regular breast self examination and seek medical care whenever a lump is felt in the breast.

4.1.6.1 Seek Help for Breast Lump

She pointed out that whenever anything abnormal develop on the breast be it ulcer or other thing, one should urgently consult medical doctors to know what is going on. *“When things develop in the breast you should run to the hospital, even when you develop a wound or lump you should go to see the doctor to find out what is wrong with you.”*

Breast cancer is prevalent, she expressed the importance of breast self examination. *“Women are advised to check themselves because cancer of the breast is increasing, widespread and common.”*

4.1.7. Conclusion

She acknowledged to have deliberately delayed to go to the hospital for further investigations and management. The delay appeared to be as a result of both a personal decision of not going to the hospital as well as partially supported by conflicting advices

from her mother. There was yet another voice she ignored that of her partner who insisted that she seeks medical care. Her knowledge about Ca breast was based on hospital teachings and discussions with other people. She finally realized it to be an urgent matter to consult when a lump or wound developed in the breast. However, she still had misconceptions about Ca breast signs initially. Later on after diagnosis of Ca breast she became an advocate for breast self examination and to seek medical advice when something untoward was happening in the breast.

She also had fears of mastectomy and death, side effects were her other concern from radiotherapy. All these were allayed as she benefited from both the mastectomy and radiotherapy.

Interview 2

Respondent profile

She was a 61 years old woman, single, and mother of three grown up children. Her education level was secondary and a retired nurse. Her initial symptom was a breast discharge noted in 1997, diagnosed as mammal dysplasia of breast (benign tumor) in 1999 after biopsy. The breast was silent till 2005, when during a routine mammogram a small lump was discovered, and eventually diagnosed as cancer. She appeared relaxed during the interview and she expressed self freely.

Emerging themes and sub themes:

4.2.1 Breast cancer starts differently

She was surprised when she was informed that she had breast cancer. Her knowledge of breast cancer was that it starts with a lump in the breast. In her case she had had a discharge from the breast, which was a real shock.

4.2.1.1 Breast Lump not always at onset of cancer

Her experience of breast cancer was different as she presented with a discharge as opposed to the usual lump as reported in many cases. *“Before I thought that for one to have Ca breast you must have a lump not a discharge, it seems it is not like that, you can have a lump, you might not have a lump but still can still have cancer of the breast without a lump.”* She later discovered that there were other symptoms either than a lump namely pain and a discharge from the breast as in her case. *“It can be a lump or it can be anything, there could be pain as well in the breast.”*

4.2.2 Inappropriate Doctor’s clinical practice

She was in agreement with other patients about how doctors neglect to examine patients’ breast during consultations. She described it as inappropriate and not meeting with patients’ expectations as her case was not taken seriously while the diagnosis was not made timely on mammogram.

4.2.2.1 Doctors do not examine the Breast

Her experience at the hands of these doctors was that they do not examine breasts; her expectations were that breast examination should be done routinely at every visit. *“Even if the breast is ok, basically you should go to the doctors; they have to make it a habit of examining your breast but it seems as if they don’t do it.”*

4.2.2.2 Did not take my Case Serious

She reported to have not been attended to properly for about two years without written notes, until one doctor after many decided to take the case seriously. “...*they always ignored me they did not even write on the out patient card, but there was only one doctor who wrote once...*”, “...*I just kept on asking doctors, they always ignored me, they did not even write on my out patient card...*”, “...*it took about two and half years before they did a biopsy...*”

4.2.2.3 Failed to Diagnose Ca breast on Mammogram

While revisiting an old mammogram, she was informed that the old film showed evidence of cancer while there was no lump in the breast. “*So when I came here they said there was nothing, but Professor X looked at it, he said it was cancer.*”

4.2.3 Good knowledge about the Diagnosis and Treatment

She was familiar with the process she went through for diagnosis and treatment. She recalled the diagnostic steps in particular with regards to the biopsy and management such as mastectomy and chemotherapy.

4.2.3.1 Biopsy is a confirmatory test.

She reported that taking a biopsy was an important investigation for the diagnosis of cancer. “*A biopsy will confirm if it is cancer or not...*”

4.2.3.2 Mastectomy and Chemotherapy are to follow biopsy.

She was aware that after the biopsy, the decision would be taken for removing the breast or giving chemotherapy “*Thereafter, they will tell you what to do; whether they will remove the breast or will give you chemo...*”

4.2.4 Traditional and Alternative Treatment use

This lady probably out of frustration with orthodox medicine resorted to alternative medicine which was said by some people to be a preventive remedy and effective if used before surgery.

4.2.4.1 Preventive Remedy

She reported to have been informed about the preventive potential of the alternative treatment by reading leaflets which advocated the use of herbs for prevention “...*from leaflet of course, most of them are said to be for prevention....*”

4.2.4.2 Effective before Surgery

She was approached by friends who said that she could have used traditional medicine if surgery was not yet done since traditional medicine does not work after surgery. *“Some people said they could have known before I had surgery they could have helped me with some herbs to treat the cancer.”*

4.2.4.3 Intermittent use of Herbs and Safe Food

Despite the fact that clarification was not made from what she meant by safe food, attending conferences made her aware of potential useful effects of herbs and safe food which she could not resist to try using from time to time *“..They were talking about safe food so I started buying it, but I did not use it very regularly...”*

4.2.5 Sources of Information

This participant reported that her sources of information about breast cancer were the print, electronic media and the community.

4.2.5.1 Print and Electronic Media

Among various sources of information on breast cancer she acknowledged that reading helped her with information about breast cancer *“...in fact some of this I read...”* Another source was the radio from which, from time to time she reported to have heard about breast cancer. *“Sometimes you listen from the radio...”*

4.2.5.2 Community

Listening to people was also to a lesser extent a valuable source breast cancer. *“... And from the people saying if you have cancer, you will die...”*

4.2.5.3 Cancer means Death in the Community

Listening to people in the community, the type of information on breast cancer was unfortunately reported by the participant to be inadequate and superficial since they either avoided talking about breast cancer considered as taboo, as they made a link between breast cancers with death. *“...if you have something on the breast , they never want to talk about it because they are afraid they are going to be told it is cancer and when they are told that it is cancer they know they are going to die...”*

4.2.6 Advice to Women

Despite the fact that she did not have any lump at the onset of the breast condition, she still considered that anyone should be able to do self breast examination (BSE) and should go to the hospital if she picks up a breast lump be it painful or not .

4.2.6.1 Breast Self Examination

She advocated doing BSE by every one, resulting to a medical consultation whenever a lump has been detected “*you have to do what is called self breast examination.*”

Despite the fact that she did not have any lump at onset of the breast condition, she still considered that anyone should be able to do self breast examination (BSE) and should go to the hospital if she picks up a breast lump be it painful or not. “*...you palpate your breast to check the lumps, if you find any lump you need to go and see a doctor...*”

4.2.7 Conclusion.

Participant appeared to have been surprised by being diagnosed with Ca breast after discharging breast symptom instead of breast lump. She Knew about Ca breast from reading, media and the community which believed, that Ca breast means death.

She knows breast self examination technique and made apparently enough effort to consult doctors in time, unfortunately she did not get expected attention from doctors whom she qualified to have had inappropriate conducts. She was familiar with the diagnosis and treatment process as well as she used intermittently alternative medicine based on information received through conferences attendance and reading effort. Doctor’s attendance did not meet her expectation as far as clinical practice was concerned.

Interview 3

Respondent Profile

She was a 45 years old women, married and mother of three children. Her education level was tertiary (an accountant); she developed breast lump in 2005.

She noticed that her breast was getting thick and bigger for the bra. She then decided at that point to go to the clinic where she was told that the lump in the breast was not normal and referred to a bigger hospital Nyangabwe referral hospital (NRH), where unfortunately because of lack of necessary tools and doctor going on leave, histology diagnosis and operation could not be done. She ended up being referred to Republic of South Africa (RSA) where mastectomy was done.

During interview she was open with free speech, happily talking to an old colleague (interviewer).

Emerging themes and sub-themes:

4.3.1 Source of information

This participant appeared to have heard about breast cancer from electronic media although she was not sure whether that was from the radio. However health facilities provided additional information and opportunity to share breast cancer information with other patients.

4.3.1.1 Media and health facilities

She reported with uncertainty the type of media from which she has heard that breast cancer starts with a lump in the breast. *“...I just heard over, I don’t know if it was from the radio or what that if you have a cancer of the breast you will feel the lump in the breast...”*. She recognized that she came to know the practice of BSE after her visit to PMH, was advised to practice that regularly *“...I even came at PMH to check the breast , it was 1993 they checked the breast and they said that you should always relax on your bed put your arms behind your had..., ...checking for the lump...”*

4.3.1.2 Discussion with other patients

Considering that cancer issue is not much discussed at home, being together with other patients at health facility like health center (HC) provided opportunity to discuss about breast cancer and to raise question related to the cause of cancer. *“...ah really because at home we never speak about the cancer of the breast , but when I am here in the ward with other patients, they are still worried ...,... we are all saying we do not know how it is , what causes it and how...”*

4.3.2 Delayed going to hospital

Despite having heard about breast cancer and being taught breast self examination (BSE), she delayed going to the hospital till she was faced with an obvious increase in breast size as noted by progressive unsuitable bra for the breast instead of the use of regular BSE which could have detected an earlier breast lump; Furthermore it appeared that for this participant the delay in going to the hospital might have been explained by the painless nature of the lump. However beyond her personal case, she reported the use of traditional medicine as explaining the delay for other patients she happens to talk to.

4.3.2.1 Irregular breast self examination (BSE)

Instead of doing regular BSE as recommended at the health facility, she only did BSE infrequently; consequently a breast lump which could have been picked up earlier was not resulting to the delay in consulting. *“... They checked the breast and they said you should always be checking for lump. So I kept on doing that but not that frequently...”*

4.3.2.2 Painless breast lump

She reported that the painless nature of the lump made it difficult to go to the hospital. *“... than I noticed this side it was hard and that side it was soft but it was not painful even if I tried to press hard...”, “...But it was hard, not painful that is why one can delay to go to the hospital...”*

4.3.2.3 Consultation at obvious increase in breast size

She decided to consult a health facility only when her breast has significantly increased in size to fit her bra. *“...I felt that it was hard as if I want to breastfeed and then I got the bra it was getting a bit thick as if the bra was small while on the other side the bra was just ok...”*

4.3.2.4 Initial traditional medicine use

Using the example of the patient who confessed what happened to her, the use of advocated traditional medicine allowed the condition to get worse by the time the patient decided to go to the hospital. *“...people like lady I met when we were getting chemo, she said she was advised by other people they were related that there was a traditional doctor who know how to do this things, so they went there and they started treating her with whatever stuff and the breast went bad, by the time the operation was done she could not even put on her bra...”*

4.3.3 Going to hospital

Participant decided to go to the hospital when she noticed a gross increase in size of the breast as well as an identifiable growing lump in the breast.

4.3.3.1 Lump in the breast

In presence of identifiable growing painless lump, she finally decided to go to the hospital “... *I felt there was a lump but it was not painful still and it was around September last year when I just got serious saying why is it that this lump is still growing ... let me just go to the clinic and check what is happening...*”

4.3.4 Inappropriate doctor’s clinical practice

Participant was unhappy that some doctors were disappointing with regard to incorporation of HIV screening while taking care of cancer patients. On that issue she concluded that some doctors were taking things easy, were obsessed by HIV screening and were losing focus on the presenting problem which in this case was breast lump.

4.3.4.1 They take things easy

She reported that some doctors just took things easy. “...*doctor sometimes, they take matters easy like the Nyangabwe doctor, he was just so taking it easy...*”

4.3.4.2 Obsessed by HIV screening

Some doctors were said to be obsessed by HIV screening, telling patient roughly to just go and do HIV test without explanation about doing so “...*he said ah, do you know your status? What status, HIV? I said, I did test when I was doing head surgery in 2002 and it was negative. He said no, no, no, go to room eleven and check your status for HIV...*”

4.3.4.3 Losing focus and Annoying

In consequence to the obsession of doing HIV screening which was offered in a rough way, doctors were said to lose focus and therefore annoy patients. “... *Agree now He was forgetting the lump ah I got annoyed, I went to a private doctor...*”

4.3.5 Treatment

This participant considered from personal experience that currently mastectomy is better than lumpectomy. However she wished there was a discovery of a pill which could be a better curative alternative to the operative management of breast cancer.

4.3.5.1 Mastectomy better than lumpectomy

Based on personal experience with a friend who had a relapse after lumpectomy she preferred mastectomy to lumpectomy. “...*so I compared the two because I had a friend who removed lump and after sometimes she went again for operation ...*” she said.

4.3.5.2 Cure by Pills could be better alternative to the operations

Despite favoring mastectomy to lumpectomy, she felt that if a tablet that could cure breast cancer could be discovered it would be better than operations. *“...what I can say is only to say you should just try to find out the cure rather than these operations because I think if there was a cure so that you are given a pill or what so that this thing disappear...”*

4.3.6 Advice to health professional

Participant directed her advice to health professional in regard to HIV screening which she would like to see offered to patients in a nice manner as well as the reason of doing the test properly explained to patients.

4.3.6.1 Nice manner in offering HIV screening test

She was condemning the approach used by government health professional when offering HIV testing compared to the acceptable way often encountered with private doctors. *“...the approach was not good; when I went to the private doctors they also said something about HIV but it was in a nice manner...”*

4.3.6.2. Rational (benefit) of HIV testing

She recommended that reason of doing HIV test while consulting for breast cancer should be explained to patients who in first instance are traumatized and need compassion, in the way private practitioner do it often. *“...showing me that when you do this operation you should know your status and all that...;... not just saying know your status you see...,...they should learn to talk to different patients...,...they should know that one is traumatized already...”*.

4.3.7 Conclusion

Participant was prompted to go to the hospital when she discovered a lump in the breast while the breast size was otherwise noted to be significantly increased. She was aware of SBE which unfortunately was not used regularly. Consequently she discovered the lump late. However she revealed that the initial use of traditional medicine by other patients contributed to delay in going to hospital. She was basically informed of Ca breast from media and health facilities. The contact with other patients brought other questions about breast cancer while the community was reported to avoid discussion about Ca breast. She also noted inappropriate doctor’s clinical practice; doctors are therefore advised to improve their communication skills.

Interview 4

Respondent Profile

She was a 45 years old woman, single, and mother of one child. She never went to school and developed a small painless lump in the breast by 2005. She decided to consult in 2006 when the lump was noted to grow bigger and became painful.

During the interview she talked freely expressing some how what might have gone wrong with her health seeking behavior due to her ignorance.

Emerging themes and sub-themes:

4.4.1 Delayed going to hospital

The ignorance of this participant was at most responsible for her delay in going to the hospital. She was not aware of breast cancer and the dangerous nature of breast lump in connection with breast cancer. The painless nature of the lump contributed in her case to the delay of going to the hospital.

4.4.1.1 Lack of breast cancer awareness

She only heard about breast cancer when she was diagnosed with the condition. *“...I heard from doctors when they told me that I had cancer of the breast...”*

4.4.1.2 Meaningless, mere and Painless breast lump

Unaware of the possible dangerous nature of a breast lump, being painless, she did not seek help for that believing it was just a simple lump. *“...there was a very small lump in my breast; it was painless so I never bothered about it...”*

She additionally said *“...even when it started affecting me I was baffled because I thought it was just a mere lump, nobody ever thought it was a cancer...”*

4.4.2 Going to hospital

She finally went to the hospital based on non conflicting advices she received from friends and relatives to whom the condition was disclosed.

4.4.2.1 Non conflicting advices promoted hospital help seeking

Although she delayed going to the hospital, decision to finally go to the hospital was made easy when all the people (friends/relatives) to whom she decided to disclose the condition advised her to do so. *“...a lot of people, my friends and relatives, I showed them the lump, they advised me to go to the hospital...”*

4.4.3 Traditional and spiritual treatment use

Participant recognized that there was a strong temptation for use of traditional and spiritual treatment; however she was convinced of the ineffectiveness of such a treatment for breast cancer.

4.4.3.1 Strong temptation of use

Despite non conflicting advices she received in favor of going to the hospital, temptation of seeing traditional healers was present although in her case she reported to have changed her mind in favor of western medication. *“...I wanted to see the traditional healers but then I decided to go to the hospital...”*

4.4.3.2 Ineffectiveness against breast cancer

She additionally expressed negative opinion on spiritual healers that she considered to be unable of providing a cure to cancer rather than a worsening of the condition.

“... I gave up on spiritual healers because they would give you something to bath with while on the other hand the lump continue to grow , they can not cure cancer...”

4.4.4 Desire of information about breast cancer

Having no problem of talking about her ignorance she expressed the need of being informed about breast cancer especially on issue pertaining to causes of breast cancer so that measure for further prevention could be taken.

4.4.4.1 Causes of the condition for further prevention

Her need of information on breast cancer was directed towards the knowledge of causes of breast cancer so that such condition could be prevented.

“...actually I want to know its causes so that we prevent such diseases...”

4.4.5 Advice to women

Early presentation to the hospital has the potential of better out come of breast cancer.

4.4.5.1 Benefice of early presentation

In retrospect she realized that there was a potential of better outcome such as cure on early presentation for consultation. Women should therefore consider early presentation to stand a chance for better out come.

“... and I realized that if I could have gone earlier to the hospital I could have been cured before it is too late...” she reported.

4.4.6 Conclusion

The participant appeared to have no idea on the possible dangerous nature of a breast lump as she was not aware of a condition such as breast cancer until she was diagnosed with the disease that she still desiring to know the causes. She consequently delayed to go to the hospital when breast lump was noticed. However her going to the hospital was as a result of non conflicting advices from relatives and friends who advised her to do so. She recognized that going to the hospital earlier could have promoted cure from the disease. Consequently in retrospect she advised women to seek help earlier to stand better chance for cure. However temptation to see traditional doctors was present as well as spiritual healers that she considered to be ineffective in treating the breast cancer.

Interview 5

Respondent Profile

She was a 37 years old women, single, and mother of six children. Her education level was primary. She noticed an inconsistent sharp pain in the breast while she was breastfeeding in 2005. Later on she noticed a breast lump which she thought was milk collection but which grew bigger by the time the baby was weaned off. Eventually she went to the hospital to seek help.

During interview, she freely spoke about her ignorance and consequent delay in going to hospital.

Emerging themes and sub- themes:

4.5.1 Delayed going to hospital

This participant associated the delay with the lack of awareness of a condition such as breast cancer, its early signs, such as breast lump which did not mean anything dangerous to her. Instead since she was breastfeeding, she thought the lump in the breast was just a milk collection. In addition living in the remote area like a cattle post did not facilitate the move to the hospital.

4.5.1.1 Lack of breast cancer awareness and living in cattle post (remote area)

Participant reported to have heard about other type of cancer but not that of the breast possibly because she was living in remote area (cattle post) lacking information about breast cancer. *"...I really not heard anything about this type of cancer, the only types I ever heard of were the cancer of oesophagus, cervical cancer as well as cancer of the bone, may be this was due to the fact that I spent most of the time in the cattle post..."*

She also considered that living in the cattle post did not promote going to the hospital *"...when I first developed lump in the breast I was in the cattle post and I took a very long time before going to the hospital...,...when I went to the hospital the lump had already grown too big ..."*

4.5.1.2 Meaningless, mere breast lump

Considering a breast lump to be just a mere lump, not aware that such a lump could be as dangerous as a breast cancer did not either stimulate participant to seek medical attention *"...I just thought it was a mere lump and it never occurred to me that it was a dangerous disease..."* she said.

4.5.1.3 Misleading possible milk collection in the breast.

Considering that she was breastfeeding, changes in the breast were thought to be milk collection but not at any time thought to be cancer. The changes became worrisome when

after weaning off the child, lumpy change was still growing big instead of reducing in size.

“...when I touched my breast I realized and thought that the milk in my breast has formed a lump; after weaning off, I realized that the lump inside my breast is large but still did not know that it was a cancer ...”

4.5.2 Going to hospital

When she finally decided to talk about her breast condition to her relatives, she was advised to seek help in the hospital so that the lump could be removed.

4.5.2.1 Non conflicting advices promoted hospital help seeking

She reported that the relatives were informed about the breast conditions and they advised her to go to the hospital. *“... I told my relatives that I have a lump in the breast..., ... they advised me to go to the hospital so that lump could be removed...”*

4.5.3 Treatment

Participant was advised mastectomy instead of lumpectomy that she was asking for, because it appeared that she presented to the hospital after quiet a long time allowing disease to progress.

4.5.3.1 Mastectomy advised as better than lumpectomy

She reported that she wanted lumpectomy but was advised by doctors to go for mastectomy since she had stayed longer with the lump. *“...I then asked them why they do not just remove the lump instead of the whole organ and they told me that because I stayed long with the lump, it would be helpful to remove the whole breast...”*

4.5.4 Traditional treatment

Participant considered traditional treatment to lack required expertise and therefore ineffective in the treatment of breast cancer.

4.5.4.1 Lack of required expertise

From the fact that traditional doctors rely only on information given to them by patients she believed they lack required expertise compare to medical doctors who do investigations like X-Rays. *“...they do not have the expertise that the medical doctors have..., can not perform X rays to see what the patient is suffering from ...,...the medical doctors do tests and X rays to diagnose what the patient is suffering from...”*

4.5.4.2 ineffective against breast cancer

Since traditional doctors lack required expertise that medical doctors have and the fact that traditional healers depend on the information that patients give them, she had no trust they can cure cancer of the breast. *“...I do not think traditional healers can cure breast cancer...”*

4.5.5 Desire of information about breast cancer

Being concerned by seeing many patients suffering from breast cancer like herself in Botswana, she expressed the need of knowing much about the causes of the condition

4.5.5.1 Current high prevalence

She noticed that in health facilities, cases of breast cancer were many among women in Botswana. *“...when I came to Princess Marina Hospital, I realized that many women suffered from this disease...”*

4.5.5.2 Causes of the condition

In connection with the high prevalence of the disease among women in Botswana, she was wondering what could be the cause of the breast cancer. *“...and I wondered what the real cause of breast cancer is ...”*

4.5.6 Advice to women

Based on her experience she advised women to seek medical advices instead of going to traditional healers.

4.5.6.1 Medical consultation better than traditional healers

“..The only way is to go to the hospital not the traditional healer...”, “... I say this from personal experience...”, “... I went to the hospital and I was helped...” she said.

4.5.7 Conclusion

Out of many reasons like the lack of awareness on breast cancer as well as the potential dangerous nature of a breast lump, the confusion of changes during breastfeeding and the onset of breast cancer, as well as her location, she appeared to have delayed to go to the hospital. Eventually when relatives were informed that she was having a breast lump, they advised her to go to the hospital where mastectomy was advised and done. She expressed desire of knowing the causes of breast cancer, while not supporting traditional treatment judged to be ineffective in treating cancer.

From personnel experience she advised women to consult doctors, not traditional healers.

Interview 6

Respondent Profile

She was a 52 years old woman, single, and mother of seven children. She never went to school. Breast lump developed in her breast in 2005. She discussed the discovery of breast lump with children who advised her to go to the hospital.

During interview she spoke freely and was grateful for children's advices.

Emerging themes and sub-themes:

4.6.1 Delayed going to hospital

This participant reported that situation like having a meaningless painless breast lump like in her case as well as the initial use of traditional treatment before consulting medical doctor in case of other people with breast cancer were potentially responsible for late presentation at the hospital and poor outcome.

4.6.1.1 Meaningless, painless breast lump

Having a lump in the breast did not carry any particular meaning to her so could have delayed appropriate action. "*... I realized that I had a small lump in my breast, I wondered what the lump was for...*"

Similarly she made an observation that painless lump does not motivate people to go for consultation resulting in the delay. "*...The fact that the lump is painless usually makes people to delay without seeking help from the hospital ...*" she said.

4.6.1.2 Initial traditional medicine use

She observed that other people present late to the hospital due to the trend of consulting traditional healer before going to hospital followed with unnecessary blame to doctors about the out come. "*...people have this tendency of going to the hospital while it is already late and they start criticizing medical doctors ...*", "*... this delay is caused by consulting traditional healers first instead of going to the hospital ...*"

4.6.2 Going to the hospital

Non conflicting advices received from her children who appeared to know something about breast cancer apparently minimized the possible delay and consequently she went to the hospital.

4.6.2.1 Non conflicting advices from children promoted help seeking

After deciding to disclose the breast lump finding to her children who made the link between breast lump and breast cancer according to what they hear from radio, they advised her to go to the hospital. She was so grateful to her children for the appropriate

advice. *“...then I cold my children and told them that I have developed a lump in the breast. First born told me that they always hear over the radio about the breast cancer and that the lump is a sign of this disease, they advised me to go to the clinic...”, “... if it wasn’t for their advices and encouragement I might have sought help from the traditional healers...”*

4.6.3 Hospital delay in the diagnosis process

She reported that after deciding to go to the hospital, in her case the delay in the diagnosis might have taken place during the diagnosis process because of a break down of the testing machine.

4.6.3.1 Out of order machine delayed diagnosis

This participant presented to the hospital for care as advised by children, however she could not be tested for long since the machine was out of order. *“... On the set date I went to Gaborone but then was told that the machine used to test the lump in the breast was out of order...”*

4.6.4 Treatment

She consented to mastectomy supported by the possible relapse from the remaining of breast tissue in case of lumpectomy as per media teaching; however she expressed concern about the side effect of the treatment she was receiving.

4.6.4.1 Mastectomy better than lumpectomy

Considering that she could benefit from lumpectomy in view of the size of the lump, at diagnosis, the radio teaching convissed her for mastectomy instead of lumpectomy when it was confirmed that she was having breast cancer *“...I decided that they would remove the whole breast because I always hear from the radio that the remaining part of the breast could be dangerous...”*

4.6.4.2 Uncertainty on treatment side effect

Although she felt cured she was still having concern about the side effect of medication. *“...although I do not know the consequences and side effects of the treatment I get from the hospital, I feel cured...”*

4.6.5 Traditional treatment

She had strong conviction that traditional treatment will never cure a breast cancer instead it will only allow the condition to get worse.

4.6.5.1 Worsening of condition instead of cure.

She said “... *Traditional healing is not good because their herbs would not cure the disease...*”, “... *after a while the disease would be severe...*”

4.6.6 Source of information

Participant said to have heard about breast cancer through the radio especially on the issue of breast lump and breast self examination.

4.6.6.1 Media program on BSE and breast cancer

She heard about breast cancer on the radio. “... *I heard over the radio ...*”

The same media broadcasted program on breast self examination in the detection of the breast lump. “...*that women should self examine their breast and if they feel a lump in the breast they should know that it is breast cancer ...*”

4.6.7 Risk factors for Ca breast

She was concern about the cause of breast cancer and had misconceptions about possible causes for development of breast cancer. She additionally was unclear about the role of contraception and number of breastfeeding in the development of breast cancer.

4.6.7.1 Number of children breastfed (multiparity)

Multiple or recurrent breastfeeding normally protective from breast cancer was suspected by the participant to be the possible cause of her breast cancer. “...*because I have many children may be breast cancer can be caused by breastfeeding*”

Misconceptions were clarified at the end of interview.

4.6.7.2 Use of contraception

She was wondering whether the use of contraceptives could curry the risk of developing breast cancer. “... *I thought of contraceptives and wondered how they can affect the breast.....*”

Risk with contraceptives being only with hormonal tablets, but not with tubo-ligation she underwent.

4.6.8 Advice to women

Based on her own experience she is ready to advice any women with breast cancer sign to go to the hospital.

4.6.8.1 Women with Ca breast sign to go to hospital.

She was prepared to encourage anyone she will see with breast cancer sign to go to the hospital. “...*If I could see someone having signs of this disease I would encourage her to go to the hospital ...*”

4.6.9 Conclusion

Despite her poor knowledge on early sign of breast cancer which could delay seeking help at the hospital, she did not appear to have delayed seeking help. In her case instead of presenting late at the hospital, it appeared that the diagnosis process was the one which took long due brake down of testing machine.

The disclosure of breast abnormality earlier to her children who have heard about breast cancer on the media was helpful since children advised her on what to do, therefore preventing her from delaying. Based on her personal experience she pointed out reason why according to her patients delay going to the hospital, like assumption that breast lump is nothing to worry about especially that it is painless, and the fact that many other people go to traditional doctors first before running to the hospital.

She also considered that there is no cure for cancer with traditional treatment since the disease was noted to get worse on traditional treatment.

Risk factors were misunderstood on which way they would influence the development of breast cancer. Her source of information was media which talked about BSE, and on a note of advice, she appeared prepared to encourage women with breast cancer sing to go to the hospital.

Interview 7

Respondent Profile

She was a 38 years woman, single and never had a child. Her education level was tertiary. She discovered that she was having a breast lump in 2003. However participant acknowledged to have delayed going to the hospital because of the painless, inconsistency nature of the lump in her case. She was a cancer awareness activist who during interview appeared to be talking freely and at length on many issues of breast cancer.

Emerging themes and sub-themes:

4.7.1 Breast cancer starts differently

She shared the feeling of other participants who noticed that cancer of breast started or presented in different ways; it could start by a lump or a breast discharge.

4.7.1.1 Breast lump or discharging breast.

This participant reported that breast cancer could start or present by either of the two signs. “... *You can either have a lump or some fluid coming from your breast ...*” In her case she had a lump. “... *All I knew was that I had a lump...*”

4.7.2 Risk factors for Ca breast

This participant talked about some risk factors she believed could influence the development of breast cancer like family history of breast cancer, some eating habits and risky behavior.

4.7.2.1 Family history of breast cancer is a risk for cancer

She reported that a family history of cancer could put one at risk of being affected. “...*I guess they are various causes, a life history of cancer in the family...*”

4.7.2.2 Some eating habits and risky behavior could promote cancer

Helped by intensive reading on breast cancer and issue related to it, after being diagnosed with the condition, she noticed that some food habits could be avoided to prevent the development of breast cancer.

“...*I also realized that eating habits are very important...*”, “... *there are leaflets which say that people should not eat much of animal protein...*”, “... *animal are these days being injected and those substances, these additives are some of those things which*

cause disease to us ...”, “...it is also applied to vegetables if we are using fertilizer...”, “... we should use organic vegetables...”

She also noted that some behavior were said to be risky like smoking in relation to cancer “...even if you are a smoker or second hand smoker it also affects you...”

4.7.3 Good knowledge about the Diagnosis process

She appeared to be familiar with the diagnosis process as she was listing procedures that are commonly used such as mammogram, fine needle aspirate and biopsy.

4.7.3.1 Mammogram and fine needle test

Mammography and fine needle test were reported to reveal breast cancer. “...*but how do you find out!!! There are many test for breast cancer, there is mammogram test which is done at PMH and GPH...*”, “... *and there is fine needle test...*”

4.7.3.2 Ambiguous value of Biopsy.

She reported that the biopsy was done after the previous test (mammogram and fine needle test) and would determine the spread of the disease. “...*from there that is when they get the result from those test, that is when they do the biopsy..*”, “...*after the biopsy that is when they will know the extent of you illness, how far it has gone ...*”

It is however to note that the spread of the disease would be known by biopsy only if the biopsy was carried out on lymph nodes or else by a mastectomy (excision biopsy) with removal of lymph node; normally axillaries would tell the extend of the disease as clarify to the participant at the end of the interview.

4.7.4 Inappropriate doctor’s clinical practice

She was one of the participants who found that the doctor-patient relationship during medical care was far from being friendly and looked rather intimidating with threats than giving room to a negotiating management plan. Doctors were said not to have compassion to patients and condemning them.

4.7.4.1 No negotiation with patients over treatment

Doctors were viewed as imposing treatment without alternative to patients. “...*there, I have problem with doctors because it is like we patients, they just tell us no this is your condition and we just have to do this and when you ask is there any alternative way of treating this condition ? They will say no no no no, it is too late you have to do like this you have to do like this...*”

4.7.4.2 Use of Threat to obtain consent for operations

Doctors were said to use open threat to get consent for operations like in her case for mastectomy “...they said ok , if you don't undergo this operation we are just going to give you chemotherapy and radiotherapy may be you may survive for two and half months then you will be gone . Ah you know that was so scaring...”

4.7.4.3 Condemnation without compassion

Participant appeared concerned about the lack of understanding and support from doctors for desperate patients who were trying by all means to stay alive when choosing to use available herbs. “...then he said you are stupid, how can you take herbs? You know your condition and you are still on chemo, you have to finish first...”, “... I said ah fine he meant well, I think sometime the way we are told as patient you have to understand that we are also under stress, we want to live so you can try by all means and do whatever will make you to live ...”

4.7.5 Treatment

With regard to the treatment of breast cancer, she was significantly positive for the use of alternative medicine which was believed to have boosting effect to the immune system. She also believed to some instance that alternative medicine was more effective than the standard chemotherapy in reducing bodily symptoms like arm lymphoedema treated successfully by hydrotherapy in her case.

Based on personal experience she articulated that despite the use of chemotherapy and radiotherapy there is no guarantee that the western medicine always work.

4.7.5.1 Alternative medicine helps modern medication

She reported to have noticed the boosting protective property of alternative medicine (herbs) that she started using before the operation and during the beginning of chemotherapy. “...I started using herbs and I was operated, that is why you even saw my hair (showing photograph), it didn't even fall off when I was taking chemotherapy, it was because of this herbs I was taking; so alternative medication helps modern medication ...”

In support to the positive effect of alternative medicine, the use of hydrotherapy was even found to be effective where modern tablets failed to provide satisfactory result with regard to the swelling of upper limb after the operation. “...I said but I don't know if I can take that, there have to be a way, that is when I had gone to find out about the hydro therapist people, I went and did that and when I went to the hospital my hand had gone down...”

4.7.5.2 Death despite using chemotherapy and radiotherapy.

Based on her own experience and observation from her friend who apparently relied totally on radio / chemotherapy, she noticed that you can still be sick even if you use that

regimen for first, second or third time and eventually you will die. *“...I thought it was simple after doing those treatment it will be complete but what I realized is that you can do radiotherapy and chemotherapy and you can still remain like that and you can do it the second time, the third time, because one of my friend did it first time, second time, third time and she was gone...”*

4.7.6 Desire of additional Ca breast information

Her desire on knowing much about breast cancer started with the discovery of lump in the breast. By doing so she became passionate of searching information about breast cancer and its alternative treatment.

4.7.6.1 About Ca breast after a breast lump discovery

Since she knew that breast lump could cause cancer, as soon as she discovered breast lump, she started actively looking for more information about breast cancer. *“...I only knew that lump can cause breast cancer, but immediately after I have discovered that I had lump, I went all the way to find more information about the breast cancer...”*

4.7.6.2. About alternative treatment versus western way of treatment

While looking for information about breast cancer and having read about the use of alternative medicine, she was motivated to ask for alternative treatment as opposed to the only modern treatment (mastectomy), she was given as only option to undergo.

“...I got the book from one of the patient ...”, “... it showed modern medication and alternative medication so that is why I was asking the doctors; is there any alternative way of treating, and they said no it is just to be removed ...”

4.7.7 Delayed going to hospital

Apparently the inconsistent, no disturbing and painless nature of breast lump made patient to delay going to the hospital, while in addition conflicting advices from the surrounding were also not of the nature to facilitate decision to go to the hospital.

4.7.7.1 Painless lump delayed seeking help

She reported in her case that the lump was mainly not painful making it difficult like for other people to consult early, resulting in a diagnosis at an advance stage. *“...I had a lump...”, “... because you don’t feel any pain...”, “...I should think that is the reason why most of time many patients are diagnosed at an advanced stage...”*

4.7.7.2 Conflicting advices delayed decision to seek help

She reported mixed advices in favor or against the operation or alternative medication from friends, relatives to whom the breast condition was disclosed. These mixed advices might have delayed decision of going to the hospital. *“...I told people whom I am close*

with , whom I am staying with at home close friend and some of my church me... ” she said.

“...the advices were mixed, some were saying go for operation some were saying no you should not go for operation...”, “...one of my friends wanted me to have alternative medication...” she reported.

4.7.8. Concern about a high Ca breast prevalence and poor cancer awareness

She considered that breast cancer is very prevalent while the awareness on the condition is poor in this HIV era throughout the country.

4.7.8.1 Ca breast is prevalent

Cases of cancer breast were acknowledged to be many. *“...many people are affected by cancer...”*

4.7.1.2 Poor Ca breast awareness compared to HIV campaign

She reported to have noticed unfortunately that despite high prevalence of Ca breast, not much was being done to increase cancer awareness compared to resources which were mobilized to fight HIV. *“...and it seems people are much concern about HIV and cancer awareness they are not much concern about it...”*

4.7.9 Advice to decision maker

The decision maker were reminded of possible beneficial effect of cancer awareness countrywide if such activities were taken seriously

7.7.9.1 Countrywide awareness activities is beneficial

She believed that decision maker should get involved in promoting cancer awareness throughout the country, instead of being confine at Gaborone.

“...this awareness walk, it seems to be just in Gaborone and in some other places it is not being done; if only a lot was being done it would really help people...”

4.7.10. Conclusion

This participant had significant information about cancer of breast as far as symptom, risk factors and diagnosis were concerned. Her current knowledge on Ca breast was driven by the discovery of breast lump, only sign she knew that time about breast cancer. However despite the knowledge that breast lump is a sign of breast cancer, she acknowledged that she stayed for long time before going to the hospital because of the inconsistent, painless nature of breast lump and conflicting advices received.

She appeared to believe in the alternative medicine as possible solution on the treatment of breast cancer complementing the actual modern treatment, since from her point of view standard treatment of chemotherapy, radiotherapy after surgical one was not always

effective. Lastly she observed that in this era of HIV, helpful cancer awareness is unfortunately not looked after. All health promotion activities are directed to the fight against HIV.

Interview 8

Respondent Profile

She was a 56 years old woman, married, and mother of six children. Her education level was primary. She experienced pricking pain under her breast nipple for long time since 1995 and only noticed breast lump in 2005. Suspicion of cancer was made by her family member to whom breast condition was disclosed. Beyond the help of family member, media information as well as painful symptom of the lump motivated her to consult doctors. During the interview she was speaking freely relating with confidence her experience as well as the ignorance on cancer issue before her decision to go to the hospital.

Emerging themes and sub-themes:

4.8.1 Ca breast starts differently

She reported that breast cancer could start with a breast lump or with pricking pain like in her own case or it could start by breast cracks and bleeding.

4.8.1.1 Pricking pain followed by breast lump

In her case she experienced for a long time a pricking pain before she could pick up a small lump in the breast. *“...what I have noticed about breast cancer is a small lump, but at first I noticed repeated sting...”*

4.8.1.2 Breast cracks and bleeding

When developing breast cancer she reported in addition that a time the breast could crack and start bleeding. *“...sometimes breast cracks and bleeds...”*

4.8.2 Source of information

She has heard from the radio and from family members that breast lump could be a cancer even if she thought that living in the cattle post would have impaired the quality of information she knew about breast cancer since while in cattle post they did not listen all the time to radio.

4.8.2.1 Media and family member

Participant appeared to have been informed about the possible cancer nature of her breast condition through radio and after discussion with relatives. *“...I heard on the radio when they were speaking about cancer that if it is cancer you will feel that lump...”*, *“...then I went to tell my family...”*, *“... Some told me that auntie; this thing must be a cancer...”*

4.8.2.2 limited access to media when in cattle post

She however reported that when in cattle post it was not always possible to listen to radio, therefore possibly missing some information on breast cancer.

“... We mostly hear from the radio when you people or whoever speaks; now I sometimes spend a lot of time staying in the cattle post and at times not listening to the radio at all...”

4.8.3 Going to hospital

Although initially undecided with pricking breast pain she delayed going to the hospital, however upon the discovery of breast lump and helped by advices from the relatives she ended up going to the hospital.

4.8.3.1 Non conflicting advices promoted help seeking

Despite different choices for the hospital to consult, her relatives were involved and influenced both the hospital help seeking decision and the choice of the hospital to consult. *“...I have a nephew here who said, we can go to Gaborone auntie...,... the other one said, no auntie let's go to Orapa...; the other one said ...in Gaborone you will be able to get medical attention quickly...”*

4.8.4 Diagnosis

During the diagnosis process for breast cancer, this participant was offered screening test for HIV.

4.8.4.1 Offer of HIV test not unusual

Participant reported that while consulting for breast condition she was offered HIV testing which she accepted. *“... He asked me if I tested for AIDS, I said no, I have not tested, then he asked me if he could do the test and I said yes you can do anything on me; he did the test and told me that your blood is okay...”*

4.8.5 Traditional treatment

This participant expressed a negative opinion on traditional treatment, regarded as ineffective in treating breast cancer, even if elders were saying that breast cancer could be cured traditionally.

4.8.5.1 Ineffectiveness in treating breast cancer

Based on the experience of a lady she knew who used traditional medicine before coming to the hospital and eventually passed away she did not believe that traditional doctors would help in her case.

“...a traditional doctor tells you stories, like this other lady last time who said she had three years struggling with cancer. she had been going to traditional doctors then she was eventually advised by someone to go to the hospital, she didn't last long she was buried...”, “...so I just thought if I can go to the traditional doctor , I am going to end up dead...”

She however reported that old ladies claimed that in the past the disease was being treated traditionally although not supported by the personal experience previously related. *“... I heard from our mothers...”, “... so they only treated it the setswana way, and the big lump would be uprooted and would fall off as they kept steaming the breast ...”*

4.8.6. Desire of information on breast cancer

Like other participants she wanted to know the cause of breast cancer so that some preventive measures could be applied in consequence.

4.8.6.1 Causes of breast cancer for prevention

“...I just want to hear from you how we should prevent breast cancer what we should do to prevent it...”, “...I want to hear from you ...” she said.

4.8.7 Conclusion

This was a participant who experienced pricking pain in the breast for long before she could notice a lump. Helped by information on cancer of breast from the radio broadcasting program, she disclosed breast condition to the relatives who advised her to go to the hospital. Although she went to the hospital she considered that there was a delay in doing so since she had been experiencing breast pain for years while in cattle post before discovering the lump. She desired information about breast cancer especially about causes for possible prevention. She did not have problem screening for HIV while pursuing the diagnosis of possible breast cancer and finally considered traditional treatment as ineffective in treating breast cancer.

Interview 9

Respondent Profile

She was a 57 years old female, single and mother of three children. She never went to school. She noticed a breast lump in 2005, and then consulted the doctors immediately since she was aware that breast cancer could be a possibility. During interview she was open to talk and was comfortable about the steps taken for the care of her breast condition.

Emerging themes and sub-themes

4.9.1 Going to hospital

This participant decided to go to the hospital when she discovered a lump in her breast. She immediately went to consult since she was aware of breast cancer, its early signs, and her daughter in law was in support of seeing doctors.

4.9.1.1 Breast cancer awareness stimulated consultation

Based on what she knew about breast cancer, she did not hesitate to go to the hospital. *“...I then decided to see the doctors immediately because I had already heard about breast cancer...”*

4.9.1.2 Breast lump discovery motivated urgent consultation

Upon discovery of a lump in the breast she immediately decided to consult a doctor. *“...My breast developed a small lump...”, “...I then decided to see the doctors immediately...”*

4.9.1.3 Non conflicting advices facilitated help seeking

In addition to the above reasons, friends and relatives like her daughter in law who also suspected cancer, advised her to go to the hospital. *“...I told my daughter in law; she is the one who encouraged me to go the hospital because she too suspected that it was breast cancer...”*

4.9.2 Source of information

Participant reported to have heard about breast cancer from the teaching session at health facilities as well as from the community.

4.9.2.1 Health facilities during teaching sessions

She reported to have heard about breast cancer in the clinic during teaching sessions when her aunties were affected with breast cancer. “...*I heard about cancer of the breast at the clinic...*”, “...*we were taught in the clinic since it affected my aunties...*”

4.9.2.2 Community (family member)

As part of the surrounding community, she actually witnessed the disease from her aunties who suffered from breast cancer. “...*I have three aunts who were affected by breast cancer ...*”

4.9.3 Risk factors of breast cancer

She considered that having relatives who suffered from breast cancer put her at risk of developing breast cancer.

4.9.3.1 Cancer of breast runs in families

Having relative suffering from cancer made the participant to accept her vulnerability to cancer of the breast. “...*I had three aunties who were affected by cancer of the breast...*”, “... *now I think this is the same thing which is affecting me because these people are my relatives, how could I escape...*”

4.9.4 Breast cancer and HIV co morbidity

As much as she was affected by breast cancer, she reported that she was HIV positive diagnosed earlier than breast cancer and was on highly active antiretroviral treatment (HAART).

4.9.4.1 Positive HIV status

Participant freely came forward by disclosing her prior positive status for HIV before her breast cancer was diagnosed as well as the fact that she was taking HAART. “...*This breast cancer came after I was infected by HIV, which was diagnosed in 2003...*”

4.9.5 Advices to women

She advised women to take on a serious note any breast symptom.

4.9.5.1 Breast symptom require particular attention

She was warning women on the need of medical consultation as serious step to take in presence of any breast symptom “... *I would like women not to take anything that affect their breast for granted...*”

4.9.6. Conclusion

This participant heard about breast cancer from hospital teachings and through the community based experience of having family members suffering from breast cancer.

She decided to go the hospital because she was aware of breast cancer, as well as because her relatives (in law) advised her to do so after the disclosure of the on going breast condition (breast lump).

She had no problem in disclosing her positive HIV status discovered before she was diagnosed with breast cancer. She had strong feeling about breast cancer being a hereditary disease and finally advised women not to take for granted any breast symptoms for which they should always urgently consult medical doctors.

Interview 10

Respondent Profile

She was a 31 years old women, married, and mother of one child. Her education level was secondary. Breast lump was discovered in 2005 by the mother in low during pregnancy while doing a traditional antenatal massage. Breast lump was apparently missed in the normal antenatal clinic but she eventually reported the findings to doctors. During interview she was calm, undermining what she knew about breast cancer.

Emerging themes and sub-themes

4.10.1 Going to the hospital

After the discovery of breast lump during a traditional massage done by her mother in law who thought it was milk collection, she decided to go to the hospital since she was aware of breast cancer therefore of a possible cure if breast cancer was detected earlier as opposed to the diagnosis on a late stage.

4.10.1.1 Better prognosis and possible cure with early detection

She knew that if detected earlier, there would be better prognosis or possible cure, and decided to go to hospital. *“... if detected at an early stage it can be treated and the person can live, however if it is detected very late one can not be cured, but at early stage it is curable...”*

4.10.2 Source of information

She reported to have known about breast cancer by readings and from doctors.

4.10.2.1 Reading (print), health facilities and community provided Ca breast information

What she knew about breast cancer resulted from teachings at health facilities by health professional, personal readings and interaction in the community *“... I read from the books and I also hear from my doctors and others who usually advised me on this condition...”*

4.10.3 Risk factors of Breast Cancer

Participant was aware of the possible relation between early menstruation, family history of breast cancer and the development of breast cancer. She also made a possible link between breast cancer and some eating habits while talking of food allergies.

4.10.3.1 Heredity or early menstruation is a risk for breast cancer

Having a relative with breast cancer or starting menstruation early was reported to predispose to breast cancer. “...*Cancer of the breast can be hereditary, if you had a relative who suffered from breast cancer...*”, “...*or when you start menstruation at an early age ...*”

4.10.3.2 Some eating habits may predispose to cancer

She had inaccurate information about the relation between breast cancer and food habits while suspecting that even food allergy could cause breast cancer. “...*if you are allergic to certain food...*”, “... *but from book that I read there are no specifications on type of food to eat...*”

4.10.4 Delayed going to hospital

Although she did not delay going to the hospital, she was able to share with us reasons why people are diagnosed at an advanced stage of the disease.

4.10.4.1 Waiting for long before medical check

From general observation participant’s feelings were that people present late to the hospital for medical check up while we should have medical check up regularly. “...*the thing is we wait until it is late; but we must always ask the medical personnel to check us ...*”

4.10.4.2 Conflicting advices may delay help seeking

She received a lot of conflicting advices for the right step to take when faced with her breast condition, which could delay the move to the hospital.

“...*people advised me to take traditional herbs, to go for prayers at church, a lot of advices ...*”

Fortunately she went straight to the hospital based on her own awareness on breast cancer.

4.10.5 Diagnosis

The diagnosis was challenging in the situation like hers of pregnancy. The biopsy was the answer, while the traditional massage carried comparable value to self breast examination in detecting breast lump.

4.10.5.1 Challenging breast lump nature in pregnancy

She reported from personal experience the difficulty encountered by health professional and traditional care giver in coming into agreement on the nature of breast lump in

presence of pregnancy, whether milk collection or cancer, as well as the consequent management. *“...my mother in law thought it was milk...”, “... after some time I showed the lump to the doctors at Ramotswa hospital, they suggested that I should have an operation immediately after delivery...”, “... I went then to a different clinic beside the hospital and the doctor told me it was milk ...”, “...I felt he was wasting my time so went back to Ramotswa, the doctor said it was a lump and removed it...”*

4.10.5.2 Helpful traditional antenatal care

Traditional antenatal care using massage was helpful in detecting a breast lump when regular medical check up did not. *“... I was 5 months and since we go through medical check up, I was told there was no lump in my breast. My mother in law administered antenatal care and as she was massaging me she felt that there was something below the breast...”*

It is to note however that in a routine antenatal clinic breast examination is almost not done.

4.10.6 Treatment

Participant's preference was mastectomy. She was however amused with a high prevalence of the disease when she was coming for treatment and expressed her compassion for patient with advanced incurable disease.

4.10.6.1 Mastectomy preferred to lumpectomy

Considering possibility of recurrence in breast cancer, she preferred mastectomy to other conservative breast surgery *“...they asked me whether to remove it or not and then I said remove it because I do not know what would happen in years to come. I heard it can recur...”*

4.10.6.2 Amusing high breast cancer prevalence

Thinking that she was the only one suffering from the disease she was amused to see many other patients suffering from the same condition. *“.. I thought I was the only one but was shocked to see other people with the same condition at the hospital, they were many...”*

4.10.6.3 Compassion for incurable patients

She reported to have been sad and at the same time comforted to see that she was not the only one suffering from breast cancer; but compare to others she felt cured therefore having pity for other patients. *“... It is really comforting ...”, “... I am better because I am cured; I feel pity for them...”*

4.10.7 Advice to women

She felt that regular hospital check up as well as the use of support group would help to respectively detect the condition earlier and motivate patient to persevere on treatment while having trust in God

4.10.7.1 Regular hospital check-up regardless of age

“...I would like to say that we should encourage parents and guardians to go to the hospital more often because cancer affects every female be it girl or women...” She said.

4.10.7.2 Perseverance in treatment and trust in God

She encouraged relatives and other patients to support each other in the line of perseverance in treatment while having trust in God.

“...We advised each other and encouraged each other to go through the unwanted medication...”, *“...some wanted to quit and we encouraged them to trust in God and they would be cured ...”*

4.10.8 Conclusion

This participant experienced the difficulty that medical professional go through before coming up with the diagnosis as far as the nature of breast lump is concern. Diagnosis of a breast lump during pregnancy was not easy with regard to the possibility of milk collection. She reported discordant opinion among doctors and laypeople (women);

Unlike other participants, she immediately went to the hospital without delay although she noticed that conflicting advices could have laid to a late presentation at the hospital, in favor of traditional treatment or prayers.

She was aware of some risk factors linked with breast cancer, like heredity, early menses, as well as the role of eating habits although this last one was not well elaborated.

Participant was surprised to see that many women suffered from breast cancer and felt pity for those with advanced disease considering that she was healed (on full remission).She finally advised women to do regular breast check up regardless of the age. For those on treatment she advised perseverance and use of support group in case of difficulty with side effects of medication.

Combined Themes

The following is a presentation of combined results of the ten interviews:

a) Going to hospital was differently motivated

This theme was shared and experienced by all the participants considering the fact that regardless of what they decided to do immediately or later after discovering something abnormal in their breast, they ended up going to the hospital for their breast condition.

Participant with breast cancer awareness before the onset of the breast condition decided to go to the hospital in consideration to some concepts, practice or physical findings in relation to breast cancer expressed in the following sub themes:

- Breast cancer awareness stimulated consultation
- Urgency to consult when Lump/ wounds develops in the Breast
- Breast lump discovery motivated urgent consultation
- Better prognosis and possible cure with early detection

However participant not aware of breast cancer prior to the onset of breast condition basically went to the hospital helped by non conflicting advices from the surrounding (relatives, friends, and children or in law....) who happened to have heard about breast cancer and therefore advocating for medical consultation.

b) The majority of participants delayed going to Hospital

Except from two participants who reported to have gone immediately to the hospital upon discovery of their breast condition, almost all the participants were found to have delayed going to the hospital.

The lack of awareness, poor knowledge on early warning signs of Ca breast, and misconception about the treatment and out come appeared to have delayed going to the hospital as illustrated in the following sub-themes :

- Lack of breast cancer awareness and living in cattle post (remote area)
- Painless lump delayed seeking help
- Meaningless, mere and Painless breast lump
- Misleading possible milk collection in the breast
- Fear of breast removal and death

Some participant however appeared to have neglected the use important screening tool like BSE, while being influenced against appropriate health seeking behavior by the surrounding, resulting in the delay of medical care as illustrated in the following sub-themes:

- Irregular breast self examination (BSE)
- Conflicting advices delayed decision to seek help
- Waiting for long before medical check
- Delaying Tactics in seeking help
- Initial traditional medicine use

- Consultation at obvious increase in breast size

c) The experiences of diagnosis and treatment were different among patients

Different feelings and opinions were expressed by number of participants about the diagnosis, treatment or both.

In majority they had good knowledge about diagnosis and treatment based on personnel experience while some participants reported challenges encountered during the process as found in the following sub-themes:

- Mammogram and fine needle test
- Biopsy is a confirmatory test
- Mastectomy and Chemotherapy are to follow biopsy
- Offer of HIV test not unusual
- Hospital delay in the diagnosis process
- Out of order machine delayed diagnosis
- Helpful traditional antenatal care
- Challenging breast lump nature during pregnancy

Four participants expressed either their preferences for mastectomy or the fact that they were advised in that regard:

- Mastectomy preferred to lumpectomy
- Mastectomy better than lumpectomy
- Mastectomy advised as better than lumpectomy

Concerns about the current therapy in term of side effects, treatment out come, as well as the compassion for other while wishing that there was other ways of treating breast cancer was reported by four participants:

- Uncertainty on treatment side effect
- Death despite using chemotherapy and radiotherapy.
- Compassion for incurable patients
- Cure by Pills could be better alternative to the operations
- Alternative medicine helps modern medication

d) Knowledge regarding risk factor for Ca breast was good for some patients

About four participants appeared to know risk factors that might contribute to the development of breast cancer. Although sometime participants had unclear concepts of cause to effects, it appeared from the participants that following subheading had details on risk factors that contribute in Breast cancer development:

- Heredity or early menstruation is a risk for breast cancer
- Family history of breast cancer is a risk for cancer
- Cancer of breast runs in families
- Some eating habits may predispose to cancer
- Number of children breastfed (multiparity)
- Use of contraception

However there was confusion and unclear statement about the link between multiparity and breast cancer as well as the type of contraception which could contribute to development of breast cancer. Clarifications were given at the end of interview

e) Cancer of the breast started differently

Three participants appeared to have been shocked to see that they were finally diagnosed with breast cancer without having breast lump at onset of symptoms as expected. They experienced other symptoms than the commonly reported breast lump by the majority of participants. Details are in the following sub-themes:

- Breast Lump not always at onset of cancer
- Breast cracks and bleeding
- Pricking pain followed by breast lump
- Breast lump or discharging breast.

f) Inappropriate doctors' clinical practice created poor doctors-patients relationship and left patient's expectation for care unmet

Criticism on doctor's clinical practices was unexpected finding in this study. Three participants appeared to have been disappointed or annoyed by the way doctors handled their cases to the point of losing focus to the primary presenting problem, obsessed by HIV testing, not being compassionate, using threat to obtain consent and not allowing negotiation with the client. Objections on doctors' practice were elaborated in following sub-themes:

- They take things easy
- Doctors do not examine the Breast
- Did not take my Case Serious
- Losing focus and Annoying
- Obsessed by HIV screening
- Failed to Diagnose Ca breast on Mammogram
- Use of Threat to obtain consent for operations
- Condemnation without compassion
- No negotiation with patients over treatment

g) Source of information were numerous but inaccurate for the majority

About more than half of the participants have not heard about breast cancer before the diagnosis was made. However three participants had reasonable to accurate information on breast cancer as a result of previous exposure to issue related to breast cancer and active effort to know more about the condition since the time they were affected. Two other participants only knew about breast cancer when they were diagnosed with the condition. In majority information on breast cancer was full with misconception. Following sub-themes have more details:

- Reading(print),health facilities and community provided Ca breast information
- Print and Electronic Media
- Media and health facilities during teaching sessions
- Media program on BSE and breast cancer
- Discussion with other patients
- Community (family member)
- Community Conversations and Hospital Teachings

A frequent common example of misconceptions noted from the community source was:

- Cancer means deaths in the community

h) There is particular need of information about the causes of Ca breast among participants

Despite the fact that majority of participants reported to have heard about breast cancer from different sources, three participants voiced up the desire of more information about breast cancer and in particular about the causes and the way forward for prevention, considering the current high prevalence of breast cancer among women.

Following sub themes got more details:

- Current high prevalence
- Causes of the condition
- Causes of the condition for further prevention

i) Traditional and spiritual treatments are ineffective against breast cancer despite a present temptation for use

Four participants expressed themselves on the issue regarding traditional and spiritual treatment use in case of breast cancer. According to these participants, none of traditional or spiritual treatment was effective in treating breast cancer, while making rather the condition to get worse due to lack of expertise by traditional and spiritual healers, as reported in the following sub-themes:

- Ineffectiveness in treating breast cancer
- Worsening of condition instead of cure.
- Lack of required expertise

However the temptation for use was reported by one participant who said to have used in her case at least an alternative medicine irregularly.

Another participant however reported that based on elders' practice, preventive and possibly curative action of traditional treatment was supported if used before surgical procedure on the breast.

All these different views and opinions about this type of treatment were elaborated under following sub-themes:

- Strong temptation for use

- Preventive remedy
- effective before surgery
- intermittent use of herbs and safe food

j) Advices on breast health seeking behavior and breast care to women, health professional or decision maker.

Majority of participants (seven) came up with advices to women, health professional, decision maker or both.

About five from above participants advised women to seek medical advice for breast lump and to do breast check up regardless of age while avoiding traditional treatment and persevering on treatment despite side effects as supported in the following sub-themes:

- Breast Self Examination
- Seek Help for Breast Lump
- Breast symptoms require particular attention
- Benefice of early presentation
- Women with Ca breast sign to go to hospital
- Regular hospital check-up regardless of age
- Perseverance in treatment and trust in God

(This could help early and urgent handling of the breast condition.)

In this era where HIV is highly prevalent and coexist with an increasingly high prevalence of breast cancer, some participants expressed the hope of seeing decision maker promoting Ca breast awareness activities which was said to be currently poor compare to HIV campaign throughout the country. This was elaborated in the next sub themes:

- Breast cancer and HIV co morbidity
- Positive HIV status
- Ca breast is prevalent
- Poor Ca breast awareness compared to HIV campaign
- Concern about a high Ca breast prevalence and poor cancer awareness
- Countrywide awareness activities is beneficial

(This would increase the number of people who know about breast cancer that could be indirectly used to positively advise patient to go to the hospital in time)

One participant wished that Health professionals could learn good manner in particular when offering HIV screening to patient by explaining to patients during the process the benefit of doing so to desperate patients of Ca breast. Following sub-themes got more details:

- Nice manner in offering HIV screening test
- Rational (benefit) of HIV testing

(This will help the handling of HIV positive patients with a good clinical practice with regard to the current reality of co existing morbidity between HIV and breast cancer.)

Chapter 5

Discussion

5.1 Discussion of Methods

5.1.1 Purpose of study and objectives

The purpose of this study was to explore the knowledge and practices of women suffering from breast cancer about their disease. Patients' knowledge and practices were indeed explored in this study.

It is however noted that many previous studies explored knowledge, practices and attitudes of different healthy women, as well as did the comparison between the knowledge and practices on breast cancer among different group of healthy health workers.

However, only few authors (Bruera E *et al* 2002; Fargerlin A *et al* 2006) explored specific aspect related to knowledge and practices of breast cancer from the actual patients. These were on issue like knowledge about treatment and patients' perceptions as opposed to the wide approach of knowledge and practices that we adopted. Nevertheless the findings of this study were similar to those quoted in the literature, although in majority those studies were done on healthy participants.

The objectives of the study were to assess the level of knowledge and practices of participants about the breast cancer as well as to suggest recommendations potentially effective for early detection, diagnosis and treatment of Ca breast. It appeared that the level of knowledge and the practice of participants on breast cancer was in majority of cases poor and blurred with misconceptions as reflected in the chapter dealing with results.

5.1.2 Study Design

This study was a descriptive qualitative research. The researcher felt that the method was appropriate for this study in exploring participant's knowledge and experiences about the breast cancer that they are suffering from and being treated for.

This corresponds to Pope C and Mays N (1995) report that qualitative methods such as interviews can be used to provide a description, an understanding of a situation or behavior. In fact having interview with patients helped us the researcher to assess the level of knowledge and practices they had experienced. It also helped in hypothesizing on the reasons for diagnosis done at an advanced stage of the disease which in fact was the motivation for doing this study.

5.1.3 Study Population and Sample

A purposeful sample of ten participants was enough to assess the level of knowledge and practices of participants about breast cancer. In keeping with the purposeful sampling

method , *information rich participants* as described by Patton MQ(1987) and Hoepfl MC(1997), were selected.

Our participants were patients suffering from breast cancer presenting to PMH in Gaborone for care. Included were resident of Gaborone as well as referral cases from the entire country mainly because, the required radiotherapy was only available in Gaborone. The maximum variation recommended by same authors in case purposeful sample was achieved by including in the sample size younger and older participants, rural and urban residents ,as well as participant who had some level of education versus those who had not attended school at all, although this last category constituted the majority of participant due to the nature of the cancer ; prevalence in middle or advanced age.

5.1.4. Exploratory Questions

Two open ended exploratory questions were used to enquire in a complementary way about the knowledge and practices. Patients responded to the questions with a variety of themes some time overlapping and calling for number of probing questions and clarifications as well as reflective summaries from the researcher assistant who was conducting the interviews.

5.1.5 Data Collection

Interviews were done for data collection. Although places for interview were convenient to participants, we wished interviews were done at their homes to realize a proper natural setting as opposed to an experimental one as advised by Pope C and Mays N (1995).

In our case all interviews were done in health center (HC) except for one done in Princess Marina Hospital (PMH) on participant's demand as she was having her mastectomy wound taken care of in the hospital.

It is however noted that two patients living in Gaborone, estimated that at their home the environment and set up would not be conducive for a proper quality interview both for privacy and recording quality, therefore wished to be interviewed at HC.

The remaining other participants preferred to be interviewed at health center where they have been "admitted" to stay for about six to eight weeks for a course of radiotherapy and these were in majority patients who came from the surrounding or far from Gaborone, having no place to stay in Gaborone .

Eight interviews were done in Setswana while three were done in English.

After the researcher had conducted one interview in English as per protocol , while the research assistant was writing down field notes, it was decided that the researcher write down field notes while the research assistant fluent in both languages carried out interviews to reduce inter observer variation .

The quality of interviews improved with time and in keeping with the recommendation of some authors (Lofland J & Lofland LH, 1984), notes were jotted down during and soon after each interview with additional discussion and summary on the interview process. Based on that, primary themes were detected by the researcher and the researcher assistant immediately or the day after and written down to complement the field notes and served as memory aid in the future. This exercise helped to decide on saturation as new themes were no longer picked up during the immediate analysis following the end of

each interview and subsequent one. At that point the researcher and researcher assistant decided to stop conducting further interviews considering that the number of interview were enough for the study. To complement the field notes all interviews were audio taped with acceptable recording quality.

Participants were informed of the process of interview, they responded freely to the exploratory questions although there was some times overlap on answers to the two questions. Participant answers in majority were in both cases (knowledge and practices) experienced based. It is however to note that one interview was discarded because it was difficult to get member check and had poor information. The length of interview varied from about twenty minutes for shortest to forty-five minutes for the longest.

5.1.6 Analysis

All interviews were transcribed verbatim as recommended by Pope C, Ziebland S and Mays N (1999). Interviews done in English were transcribed by the researcher while the setswana ones were transcribed verbatim and translated by a hired professional. Going forward and backward for better understanding of what participants were saying happened to both the researcher and the hired professional transcriber.

The recommended content analysis (Pope C, Ziebland S & Mays N, 1999) using analytic induction helped to identify emerging themes from raw data resulting in coding, “open coding” (Strauss A & Corbin J,1990). Gradually similar words, phrases or events which were grouped into the same category were modified or changed on subsequent stages of analysis as reported by Hoepfl MC (1997).

5.1.7 Reliability and Validity

In conformity to this study protocol, to achieve reliability and validity of the data we used more than one source of data (Patton MQ, 1987). Field notes were taken, interview were audio taped than transcribed as well as emerging themes were presented to participants for member check (Lincoln YS & Guba EG,1985) as part of triangulation .

Themes were similar with little differences among the researcher, researcher assistant and co supervisor Nomsa malete. This realized the concept of inter rater reliability (Pope C, Ziebland S & Mays N, 1999) used in quantitative study.

5.1.8 Bias

The observer or interviewer bias which can not be abolished or fully controlled in any qualitative study (Greenhalgh T & Taylor R, 1997) was a reality in this study which was a qualitative. In fact as supported by these authors, despite the type of data collection used, the interviewer perception on the issue surrounding breast cancer might have influenced the process of interview and data collection. To attempt minimizing this bias effort were made by trying to be as neutral as possible and following cues as much as possible, as well as clarifications through reflexives summaries to the participants, or probing questions as recommended by free attitude interview.

This observer bias was kept in mind since the researcher is a doctor and the researcher assistant is a nurse, all working in the same hospital.

Together with the preceding, sampling and selection bias are integrant part of the data collection in qualitative study, especially when using a purposeful sampling which seeks for information rich persons.

however in our case to get information reach persons was not difficult since ninety percent of patients were being treated for advanced stage of disease, therefore they were easy to target as part of the sample .

But in keeping with maximum variation effort was made to get survival younger and old patients, resident of Gaborone and surrounding/remote areas, as well as cases of different level of education.

Interpretation and information bias was a challenge in this study. Some participants (three) preferred to be interviewed in English which was not their first language. The possibility of this type of bias was noticed some time when they were using Setswana words in trying to explain what they meant in response to clarifications questions. To reduce this bias, after the first interview conducted by the researcher, it was decided to let the researcher assistant conduct all other interviews be it in English or Setswana contrary to what was done previously since she was fluent in both languages .

5.1.9 Ethical Considerations

To ensure that the research was ethically accepted, we got approval from the MEDUNSA ethical committee, as well as the Princess marina hospital (PMH) ethical committee and the approval from the research committee at the ministry of health in Gaborone.

Informed consent being a requirement to any research (Lewis J & Hallenberg D, 1995), participants needed to be informed about the research before actually signing the consent form.

To ascertain the validity of the informed consent which was signed by the participants, two sisters in charge(one in PMH oncology ward, the other in HC) initially discussed the participant's information sheet with all potential participants followed by a check of understanding about the research before the actual form was signed by the participants.

Except for one patient who needed permission from her boyfriend before she could actually sign the consent, all participants did not hesitate to give consent of participating to the study after going through the participant's information briefing with the sister in charge followed by a check of understanding done by the researcher and his assistant for further clarity, just before the actual signature. Interview for that participant was rescheduled to a later date.

Participants were assured of confidentiality by the private use of all data gathered and more important was the assurance that no name was going to be used in the write up of the research report.

5.1.10 limitations of the study

One of the important weakness of this study is that the research was carried out by a researcher during his learning process of a qualitative study methodology as well as the use of interviews technique for data collection which required to be rigorous and preferably done by experienced interviewer to reduce possible bias .

However to increase the quality of data collection the researcher participated in a qualitative research workshop organized at Medunsa , and had opportunity to practice as well as discuss the interview skills of the research assistant (after a pilot interview done with two hospital general assistants who had been treated for Ca breast at PMH),with the co-supervisor.

Consequently the co-supervisor after listening to the first interview done by the researcher assistant, recommended that research assistant remain consistent in the next interviews and eventually data collected were rich of information for the study.

The other limitation of this study was the possibility of transferability of this study to another set up considering that PMH and the HC are particular environments to be replicated some where else. This is in part a weakness due to the nature of qualitative research under which each set up is seen as being unique and makes it difficult to reproduce same result of the same phenomenon in different set up, even in the population of same cultural back ground. Therefore the existence of local conditions will make it impossible to generalize (Cronbach LJ, 1975) the findings to all breast cancer patients. According to Cronbach LJ (1975), when giving proper weight to local conditions any generalization is a working hypothesis, not a conclusion.

Would the researcher had a full understanding of Setswana which was used for many of participants, the field notes which were helpful in analyzing data in this study could have been richer ; nevertheless the body language, flow of speech, tone as well as the general impression of the interaction during interview when discussed immediately (between the researcher and researcher assistant) after the interview and jotted down on the field notes helped to cover missing details by the researcher .

5.1.10 Discussion of Results

The following were major findings of this study:

Poor knowledge and understanding of patients about breast cancer, Poor knowledge and practice of common well established screening methods with consequent delay in seeking help for breast condition, and Inappropriate doctors' clinical practices responsible of a poor doctors-patients relationship and unmet expectations when seeking for help.

These major findings related to the poor knowledge and practices on breast cancer and the common well established screenings methods were not very different from the findings in the literature (Rashidi A & Rajaram SS, 2000; Bener A *et al* 2001; Haji-Mahamoodi M *et al* 2002; Marinho LA *et al* 2003; Okobia MN *et al* 2006; Oluwatusin OA & Oladepo O, 2006).

However, *health seeking behavior for breast cancer and health beliefs on breast cancer (misconceptions)*, as well as *awareness of breast cancer* were also discussed as all were thought to play a role in the late presentation and the diagnosis of the disease at an advanced stage.

Poor knowledge and understanding about breast cancer with consequent delay in seeking help for breast condition

Although participants of this study ended up going to the hospital, few are those who went to the hospital because they knew concept like early warning signs, the urgency to consult, the issue of better prognosis with early detection or based on the findings from a regular practice of self breast examination .

This lack of knowledge on vital issues about breast cancer and its early detection measures viewed as major factor of the delay in going to the hospital observed in this study was also reported by Oluwatosin OA and Oladepo O (2006), and expressed differently by participants to this study.

In fact a number of participants said that they were not aware of breast cancer until they were diagnosed with the condition. In support to this lack of knowledge a wide range of misconceptions on breast condition and its management were expressed by the majority of participants.

One participant said she decided not to consult believing it(breast condition) will cure, while others despite noticing a painless lump in the breast ,said painless nature of lumps made it difficult to consult. Another participant reported the possibility of using traditional treatment and spiritual healers first as advised by some relatives.

In keeping with traditional treatment, the recognition of uselessness of traditional treatment in cancer management by only few participants reflected the poor knowledge on the issue in the majority of participants.

The poor knowledge described by Oluwatosin OA and Oladepo O (2006) on the issue such as early warning signs of breast cancer which was hypothesized to have contributed in the delay of going to the hospital was also found in this study where many participants had painless breast lump in the beginning of breast condition and reported to have been surprised that breast lump could be as dangerous as a cancer.

However in contrast to the majority of participants with poor knowledge of early warning signs, only two participants to this study reported to have been aware of the benefit of early consultation at the beginning of breast symptoms. They said in substance that, better prognosis was with early detection and early presentation for treatment.

Based on the poor knowledge and numerous misconceptions described as a results from this study, it could be hypothesised that the presentation on a later or advanced stage of the disease could be attributed to poor knowledge of breast cancer issue and its early detection measures of the warning signs as reported by Oluwatosin OA and Oladepo O(2006), and in particular to our set up, a possible ineffectiveness of BSE program and malfunctioning of screening tool such as mammogram, as opposed to lack of educational program on BSE and screening tools such as mammogram reported by Anim JT(1993). Similarly to the poor knowledge described by Oluwatosin OA and Oladepo O (2006) on the issue such as early warning signs of breast cancer which was hypothesized to have contributed in the delay of going to the hospital, this study found that many participants had painless breast lump in the beginning of breast condition and reported to have been surprised that breast lump could be as dangerous as a cancer.

With regard to the risk of developing breast cancer, only two of our participants reported the importance of appropriate food habits like a significant reduction of animal fat and protein.

An increased dietary fat intake was found to correlate with breast cancer mortality in the study of Sasaki S, Horacek M and Kesteloot H (1993). As much as evidence is suggestive of the role of food habits, in particular that of fat intake in the development of breast cancer, there is need of such education in the community.

In this regard a diet aiming to control weight gain after menopause, representing the characteristic of many of our participants, should be advised since this weight gain of about 10 kg from the onset of menopause has been shown to correlate with an increase risk in postmenopausal breast cancer (Elliassen AH *et al*, 2006) .

The familial trend of breast cancer was equally known by only few participants of this study. Those participants revealed that they were somehow expecting to develop same condition like that of their relatives; That awareness on the heredity nature of breast cancer as reported by Kessler E(1994) and Cortesi L *et al* (2006), was only known by two participants to the study. The dissemination of such awareness (heredity nature of breast cancer) in the general population would have a potential of alerting female with relatives suffering from breast cancer of the appropriate health seeking behavior in case of any warning signs of breast cancer.

Such awareness should be done during health promotion in response to the overall poor knowledge on breast cancer demonstrated by the majority of participants to this study in form of community oriented health promotion.

Poor knowledge and practice of common well established screening methods with consequent delay in seeking help for breast condition

The ignorance of breast self examination (BSE) and its value in the detection of early small lump, found among our participants was an additional proof of lack of knowledge on vital skills (tool) helping in early detection of signs of breast cancer .

Despite the fact that the majority of our patients only noticed a big lump in the breast close to the time of diagnosis, only few participants were aware of BSE. Two participants acknowledged irregular use of the technique which could have been useful for early detection.

Okobia MN *et al* (2006) found similar poor knowledge in breast cancer, and lack of practice of BSE and CBE among community dwelling women in Nigeria. Similar findings were reported by Oluwatosin OA and Oladepo O (2006), in a study done in rural Nigeria.

Marinho LA, Costa-Gurgel MS, Cecatti JG and Osis MJ (2003) also reported that women attending health centers sampled in Brazil had inadequate knowledge and practice of breast self examination. There was consequently poor knowledge about BSE, a useful screening tool, as well as poor clinical practice from health professional with regard to CBE as reported by few of our participants.

However knowing BSE and CBE did not seem to be correlated with the practice. In this regard, one of our participants reported to have been aware of BSE but did not do it regularly while another participant complained that the doctors did not even examine her

breast. It then appeared that adherence to the screening tools by both patients and health professional was an issue of concern.

A similar finding was reported by Odusanya OO and Tayo OO (2001) who noted in their study that nurses were knowledgeable about breast cancer issues while only few had a breast examination done the past three years.

It was observed that CBE and BSE appeared to be less adhered to by both patients and clinician like in our set up. Additionally on the issue screening methods, many other studies reported a big gap between knowing breast health screening methods and adhering or practicing it, in particular the practice of BSE (Budden L, 1995; Janda M *et al* 2000; Bener A *et al* 2001; Haji-mahamoodi M *et al* 2002; Robins SG *et al* 2003).

Similarly Bottorff JL (1998), found that although most women could recite the recommended breast health practice and the importance of early detection, there was an underlying reluctance to participate in these practices due to lay beliefs about breast cancer.

To address this reluctance in adhering to these screening methods which constituted the gap between knowledge and practice, Dein S (2006) suggested that lay beliefs of breast cancer for each individual patient be discussed. Therefore the incorporation of this lay belief (explanatory model) in the care was believed by Dein S (2006) to carry a high potential of influencing the participation on the screening methods.

In our resource-limited setting with sometimes available but malfunctioning diagnostic devices, effort in mastering BSE skills and practicing it should be almost the corner stone of early measures for breast lump detection despite the difficulty in term of accuracy of findings in the breast during pregnancy and breastfeeding as reported by two of our participants. This could also help in early detection in cases like that reported by a participant who said she could not do the test because the machine was out of order and she was told to check on a later date when mammography equipment would be functioning.

Having experienced the diagnosis process and the treatment, it appeared that the diagnosis of breast cancer in our set up was definitively done through a biopsy which is an international gold standard procedure, even if the cost effective BSE was not optimally used by participants to help early diagnosis. Mammogram which was another screening tool available could not apparently be used by many participants since not always functional as reported by two participants.

The suboptimal use of screening methods noted in this study as reported by few participants who could have benefited from screening methods was however noted in other studies like in a follow up survey done in San Diego among Japanese American women by Robins SG *et al* (2003) who reported that after breast cancer education, while there was high adherence to mammography, there was lower than optimal adherence to CBE and monthly BSE.

This could be discouraging in the effort of campaigning for breast cancer awareness in our set up where BSE and CBE could be easily offered as opposed to mammogram, but based on different explanatory models described by Dein S (2006), which recognized different health seeking behavior based on cultural differences, there is no choice than to promote cancer awareness along with screening methods like BSE and CBE; these methods being all the time available compared to mammogram which is technically and financially constraining in our set up of developing world.

The inappropriate doctors' clinical practices responsible of poor doctors-patients relationship and unmet expectations when seeking for help.

In some cases doctors' practices in caring for patients with breast cancer were reported to be poor and discouraging not meeting patients' expectations. Some participant ended up changing medical doctor or demanded for transfer to different facilities in Botswana, or abroad like in RSA for better care. These negatives perceptions from some of participants to doctors' practices constituted unexpected findings of this study. Three of participants were concerned by the fact that even if some doctors were empathic to patients some other had totally unacceptable clinical practice and attitude which did not promote doctor-patients relationship.

Health professional were in this regard reported by one participant to be irresponsible by not doing CBE to patients, which should have been a routine practice. Not Offering screening for breast cancer was also reported by Bener A *et al* (2001) supporting the need for more commitment from health professional to play their role in the care of breast cancer among potential victims.

In addition doctors were accused of taking matters easy, using open threat to obtain consent for operation, not giving choice to the patient as far as the treatment was concerned, especially the use of alternative medicine and they were even loosing focus obsessed by HIV screening.

The above described doctor's malpractice requires an improvement in doctor patient communication skills as well as patient education to ensure that women are able to make an informed decision about their breast cancer treatment as recommended by Fagerlin A *et al* (2006) and Oskay-Ozcelik G *et al* (2007), as the only way of enhancing doctor-patients relationship.

As part of doctors malpractice, the reported missed breast cancer diagnosis in early stage on mammography cloud be addressed by continue medical education as well as getting radiologist specialized opinion in doubtful cases for the good benefit of the patient which some how responded to the application of the networking principle of family medicine (Whittaker D, 2000) .

Taking a long time before deciding on the nature of a suspicious breast lump destroyed trust from patient to doctors like in the case of a participant who stayed long before a biopsy could be decided and done. In fact from the light of what was encountered in this study, diagnosing a breast cancer from a breast lump was not easy task during the period of physiological changes like breastfeeding and pregnancy since breast lump and physiological glandular activities made the breast clinical findings confusing. In such a case the biopsy remained the answer.

Health seeking behavior in case of breast cancer

Victim of ignorance and misconceptions for early symptoms on breast cancer, majority of participants did not go earlier to the hospital for medical consultation unless advised by relatives, friends or if traditional medicine didn't seem to work or finally if the condition was getting worse. The health seeking behavior was therefore in majority inappropriate.

Since majority of the participants said to have discussed the issues about their breast condition for the first time people close to them, it appeared of paramount that community in general receive the right critical information about breast cancer so that it can advise potential new cases on the right step to take faced with breast symptoms.

In this study the painless nature of breast lump made it difficult for participant to consult like in the study of Virobiof DA, Sitas F and virobiof G (2001) done in south Africa. However while struggling to find solution to their obvious breast lump, only few participants to our study reported the temptation of traditional medicine use beside the medical consultation. Nevertheless, in trying to address the issue of quality of life one participant decided to use alternative medicine which fortunately for her case was successful therefore making her an advocate for the use of alternative treatment for breast cancer.

With regard to the use of complementary/alternative medicine (CAM) as advocated in this study by one participant, it appeared important to enquire about such use among patients since Shen J *et al* (2002) noted that CAM use was a common practice in the majority of patients with advanced stage of breast cancer, this characteristic being similar to that of the breast cancer population in our set up (majority with advanced cancer); Therefore clarification on the possibility of CAM use among our patients should be kept in mind for possible interaction with medication especially when CAM are ingested.

Majority of participant decided to go to hospital advised by relatives, friends, children, and in laws. Of note even those who knew something about breast cancer received support from the surrounding in the decision of going to the hospital.

Despite the fact that among the participants some received advice against seeking help from the hospital, it remained in this study that for the majority of participants, the level of cancer awareness in their surrounding ultimately helped the victim to seek medical help. In support to the preceding are participants who despite the delay in going to the hospital ended up taking the advices from the surrounding who suspected breast cancer and consequently went to the hospital to seek for help.

The trend in disclosing the breast condition to close people found in this study was equally not new, since even in an Asian community living in Canada, Bottorff JL *et al* (1998) established that women were often reluctant to seek medical advice without the sanctioning and encouragement of important family members or close friends.

From the preceding we can hypothesize that any advice received from the people around the patient had a potential of affecting health seeking behavior. Therefore an active dissemination of information on cancer across generations would put future potential victims in a position of either stand greater chance of knowing the appropriate health seeking behavior through cancer awareness campaign or by being surrounded by people aware of breast cancer who could advise potential victim to go to the hospital in time. In addition, in our set up health facilities should continue providing appropriate information for potential breast cancer patients in the clinics or via media as reported by some participants; that will help improving health seeking behavior.

Health beliefs regarding breast cancer

Doing this study helped to have an insight on what participants and their surroundings were thinking about breast cancer which eventually dictated their health seeking behavior.

In this study only few participants expressed themselves about traditional and spiritual treatment reporting that they were useless in treating breast cancer as opposed to the finding of Virobiof DA, Sitas F and virobiof G (2001) done in South Africa where many patients were reported to have used traditional medicine as first step of treatment. This trend of traditional medicine use before going to the hospital was only reported by one participant of this study.

Similarly to the findings of Dein S (2006) on the traditional healers explanatory model, Virobiof DA, Sitas F and virobiof G (2001) reported that in south Africa many patients with cancer believed that breast cancer was caused by witchcraft therefore first priority was to reverse the sorcery before presenting to the hospital for treatment with modern medicine methods; Patients sought help first from traditional healer, as a way of dealing with the cause of the disease.

In this study many participants did not believe that a painless breast lump could be as dangerous as breast cancer therefore were reluctant to consult medical doctor. Same believes were reported by Virobiof DA, Sitas F and virobiof G (2001) who found that in South Africa, many rural women found it difficult to accept the concept that a painless breast lump could be a cancer therefore potentially fatal.

The above believes about breast cancer discouraging early presentation to the hospital found in this study were also reported among Asian women who were reported to say, it was better to forget about any breast lump since if you go to the hospital, the doctors would give you a treatment and that would be the end of your life (Bottorff JL *et al* 1998). In keeping with this, one participant to this study ultimately believed that going to the hospital will result in breast removal and death. Consequently she took long to go to the hospital.

Dein S (2004) reported that culturally different groups would be exhibiting preferably a certain type of misconceptions than other culturally different group even if in this study different misconceptions were noted in an apparently same culture people.

According to the same authors, in Africa there was a prominent role of traditional healers' explanatory model which incriminated magic, bad blood, infections by germs, incest and adultery as the cause of cancer, which in general dictated health seeking behavior in Africa as opposed to the other part of the world like USA, Asia, Australia, and UK where perceptions on cancer showed that misconceptions correlated with the level of education while the fatalistic attitudes, God's will, karma, as well as lack of knowledge that a breast lump can be serious even if not painful.

The painless nature of the lump reported in other part of the world and in Africa among our participants as discouraging them from seeking medical care, was a testimony of possible similarity in different set up or culture as far as misconceptions on breast cancer were concerned, regardless of where the victim is coming from.

Beyond the question of believes, a participant pointed out the issue of quality of life after going through the combination of therapy made mastectomy as well as radiotherapy and chemotherapy, in term of recurrences and lymphoedema. Kirsty S *et al* (2006)

reported that association of decreased quality of life in women after the above combination therapy. Some participants of this study feared the actual recurrences and development of lymphoedema. In a form of counseling after interview the question was dealt with. Clarification was given for radical treatment's side effects resulting in lymphoedema and the benefice early presentation in the reduction of recurrences was discussed.

Breast cancer awareness from the participants.

As reported by the majority of participants and supported by the poor knowledge on the issue of breast cancer found in this study there was a lot to be done to promote breast cancer awareness which will improve breast cancer knowledge.

Considering different source of information reported in this study by participants, in our set up health facilities should continue providing appropriate information for potential breast cancer patients in the clinics or via media as reported by some others participants. However personal reading as source of information reported by few participants would be only effective with an improved level of education.

To ensure wide spreads of information on breast cancer and knowledge on critical skills like BSE, the level of education of the population need to be actually improved since a positive correlation was reported by Okobia MN, Bunker CH, Okonofua FE and Osime U (2006) in a study done in Africa, between the level of education and knowledge of critical skills like BSE.

Since majority of our participants were not able to read, therefore could not have used this route of information delivery, this route of health promotion can be use only for younger generation in a long term strategy of transmitting information about breast cancer.

Contrary to the level of education and reading as a way of promoting breast cancer information, Oluwatosin OA and Oladepo O (2006) found that the leading source of information on breast cancer among rural women were elders, neighbors and friends while only few women acknowledged to have heard about breast cancer from health facilities .

Consequently targeting the communities with health promotion from both the public health sector and the use of health facilities education program would be in our case the right way to go in term of cancer awareness.

It is therefore important to focus on the right information to deliver in the community since in this study the decision to go to the hospital was based on both personal and community (relatives, friends, elders) awareness about critical information on breast cancer. In consequence, majority of participants ended up consulting a medical doctors upon disclosure of the breast condition to relatives, depending on whether participants were advised to do so or not by relatives or else they consulted only when breast symptom had been progressing for a long period of time .

The desire of information on breast cancer, especially about the cause and preventive measures expressed by participants during interviews were in support of the need of promoting health education on the issue related to breast cancer. This promotion has the potential of addressing the lack of awareness on breast cancer which did not raise in time

the alarm on early warning sign of the condition in the majority of participants to this study.

However the earlier warning sign of breast cancer varied among participants. Although majority of participants had a breast lump, some had breast discharges (bloody, serous fluid) or pricking pain, thickness of the breast. As a result even if Kessler E (1994) who reported that breast lump must taken seriously for possible breast cancer, also said that only one out of ten lumps would be cancerous, other symptoms like persistent pain, pricking sensation ,or new pain as opposed to cyclic pain , should also be taken seriously for medical check up.

This is in consideration to the fact that some participants were finally diagnosed with breast cancer from the initial symptoms of breast discharge and breast pain, as opposed to the statement of some authors like Haji-mahamoodi M *et al* (2002), who did not consider pain as a sign of cancer.

Instead of focalizing on breast lump, other symptoms like breast discharge especially bloody discharge which usually could be sign of papilloma(Kessler E, 1994), should also guarantee medical check up.

Thickness of breasts (skin) or ulceration (Kessler E, 1994) as experienced by a few participants should also guarantee immediate medical check up as few participants to this study, experienced those at the onset of the breast condition which ended up being diagnosed breast cancer.

There is therefore no hundred percent single symptom that would be seen as typical of cancer although breast lump has been emphasized by Kessler E (1994) ; anything of the above four symptoms should guarantee a medical check up for early detection.

However, on the issue related to cancer awareness, and initially expressed desire of information about breast cancer, genuine concern were acknowledged at the end of interview, relevant information about current treatment, limited additional options and the unfortunate side effect discussed.

The description by a participant of breast cancer as a sad reality in Botswana with and increasing number of patients was in keeping with the increasing incidence of breast cancer worldwide reported by Bray F, Maccarron P, & Parkin DM (2004) and Imaginis (2004).The Same authors reported that breast cancer was the second leading cause of death as far as malignancy was concerned in women. In our set up however we need accurate data on mortality to ascertain that.

The trend for future treatment based on hormonal receptor testing and use of monoclonal antibodies (Romond EH *et al* 2005) was brought to the knowledge of participants who expressed the need of such information during interview, as well as other issues like risk factor factors and clarification of some misconceptions noted during interview.

Participants were encouraged and advised for those who did not expressed themselves in that regard to be the advocate of any person (friends /relatives) who would happen to have any breast problem to have it checked in the hospital so that in case of cancer the diagnosis would be made earlier .

In this era of HIV, one participant was concerned that for a life threatening condition like breast cancer, not much was being done in line with cancer awareness, while big campaign against HIV was on going. She considered campaigning against HIV without doing something against breast cancer unfair. This was a call for the decision makers to

improve health promotion on breast cancer awareness even at this moment that health care attention seemed to be drowned by HIV care.

In conclusion poor knowledge about warning signs of breast cancer as well as misconceptions about it due to well known lay beliefs which basically constituted the explanatory models of the cancer as understood by patients, appeared to be major cause of the delay in going to the hospital and therefore late presentation .

Considering that change in health seeking behavior can not happen without addressing lay beliefs, and the fact that decision of going to the hospital was made by consulting surrounding who in majority would be seeking care based on lay beliefs, it is fundamental to address lay beliefs. An attempt to understand them, and, incorporate them in the treatment will enhance doctor-patients relationship and improve compliance as recommended by Dein S (2004). This would improve possible adherence to screening methods, if effort is done to enquire from the community or patient possible cultural reasons that would make them uncomfortable adhering to the screenings and address the issue. Doctors' communications skills need to be improved while decision maker should show more involvement in campaigning for breast cancer to reach the entire community on the issue of breast cancer awareness.

Chapter 6

Conclusions and Recommendations

6.1 Conclusions

This study showed that the knowledge and understanding of patients about cancer of the breast was poor.

The knowledge and practice with regard to Common well established screening methods such as SBE was also found to be poor.

There was a delay in going to seek medical care as a consequence of:

- poor knowledge , practice and understanding of breast cancer ,
- inadequate utilization of screening methods,
- As well as the influence of lays beliefs and advices received from the surrounding which at time was advocating for traditional treatment than medical consult.

Unexpectedly, participants' unmet expectations were translated by inappropriate doctors' clinical practice qualified as not emotionally supportive, with poor communication skills and sometime with poor clinical skills when dealing with patients suffering from breast cancer.

Finally, breast cancer incidence was increasing in contrast to cancer awareness activities reported to be poor in this era where HIV was reported to receive all the attention of the decision maker.

6.2 Recommendations

Considering the above conclusions following are the recommendations:

In view of massive misconceptions about breast cancer, cancer awareness is the way to go through media and health facilities on regular schedule of activities to clear misconceptions in the communities, therefore stimulating the change in health seeking behavior which will be beneficial in term of early detection, good management out come and prognosis.

Considering that in majority of case health seeking behavior depended on advices received from relatives or friends, cancer awareness should target patients and healthy people in the community in particular by teaching the regular use of basic BSE which is known to detect breast lump, a common earlier sign of breast cancer as found in this study population.

However any other symptoms like breast discharge, pain or breast unusual appearance should be reported for medical opinion regardless of age.

The use of mammogram is to be advised whenever the country health system resources allow that as a screening tool for appropriate age.

It is recommended that trainings in communication skills for health professional be considered especially for those dealing with cancer patient in this era of HIV where all effort seem to be deviated to the fight against HIV.

While fighting HIV/ AIDS, it will be appreciated if the decision maker are reminded that potential victim for breast cancer deserve attention in term of community sensitization (cancer awareness), which will address lay beliefs about breast cancer, so that community is educated on possible earlier sign of breast cancer as well as the appropriate health seeking behavior when faced with any early breast symptom.

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Appendix A: research protocol

Study problem

Princess Marina Hospital (PMH) is the national referral hospital where cancer of the breast is one of the common malignancies seen and treated in Gaborone Botswana.

Work is currently being done to have an updated national statistics on cancer of the breast (Ca breast); however in the department of oncology, patients with Ca breast who were treated in the past years (2002- 2003) represent about 7-10 percent (7-10%) of all patients treated with malignancy in the department and unfortunately the majority (about 90%)¹ of these patients with Ca breast come for treatment at a very late stage of the disease (stage III to IV), which by the end of the day confines the treatment to a basically short term palliative therapy without any long term remission expectation in term of five years survival rate. In our set up, Ca breast is currently the third cancer in the ranking after Kaposi Sarcoma (KS) and Ca cervix.

Initially, cancer of the breast was the second leading cause of death in women after cancer of the lung (1), but currently available statistics (2, 3), report that Ca breast is the leading cause of death in women with malignancy followed by Ca cervix.

Since late presentation entails late diagnosis and less effective treatment, this study seeks to explore the knowledge and practices of patients suffering from cancer of the breast so that by understanding the drive of their health seeking behaviour, we can contribute in the care of potential victim of cancer of breast with recommendations and suggestions aiming to address possible wrong concepts and practices which will be picked up during different interview in our context, Botswana.

Literature review

Literature reviewed confirms that cancer of the breast is currently the leading cause of mortality in women with malignancy (2, 3). In the past however, cancer of the lung has always been leading in statistics (1) followed by cancer of the cervix (2).

The incidence of cancer of the breast increases with age thus one out of two thousand two hundred and twelve women (1:1212) will develop Ca breast by the age of thirty while one out of two hundred thirty five (1:235) will develop cancer of the breast by the age of forty (1). This cancer risk model may be higher or lower on individual basis depending on several factors such as genetics, family history of cancer, age of menstruation and others not yet identified (1).

In some of the sub-Saharan African countries (3), statistics confirm that the leading cause of deaths among female patients with malignancy is Ca breast.

On the same issue of national cancer registry, despite the inadequacy reported by some authors (3) concerning the sub-Sahara African cancer registers, the existing register in some of those countries are providing almost the same trend in patients with cancer of the breast. Cancer of the breast is known to be prevalent in the age group of forty and above in women as reported in other studies (1, 2, 4).

¹ Out and in patients registry records, department of oncology / Princess Marina Hospital

The trend is that patients with Ca breast present to health care facility in the late stages of the disease (stage III, IV). (2, 4)

Late presentation for medical care is explained by many factors such as lack of knowledge in cancer of breast, socio economic conditions of the patient, access to diagnostics resources, patients beliefs as well as trends to seek traditional healers services before presentation to a western type of health facility, deficient knowledge in personal screening program or lack of practice of the personal screening method despite the knowledge of the screening method as well as less offer of clinical screening by health professional. (2, 4, 8).

Similar findings were substantiated by other authors; in that regard, consultation with traditional healers for cultural reasons and lack of personal screening methods practices were found to be the cause of late presentation(5,6).

Early detection of cancer of the breast makes a big difference in terms of five year survival rate of patients (2, 7) .However five years after the diagnosis, the survival rate is said to decline while ten years later, survival depend on the stage of the disease; early stage of detection being associated with high survival rate than late stage (1).

Age parameter is also to be considered in the prognosis of the cancer.

In fact when cancer of the breast develops or is discovered in a forty to fifty year old woman the prognosis in terms of five year survival is better compared to its development in a younger woman where the cancer is known to be very aggressive (1)

Another important factor to consider in terms of survival rate of patients suffering from cancer of the breast is the stage of the disease (1); efforts are therefore needed for detection of cancer of the breast on an early stage, which entails improvement of the survival rate of patients who will be presenting for care in PMH.

Indeed if patients who present currently in stage III and IV can be detected earlier (stage I and II) and started on treatment on due time , this will improve their five years survival rate from 50%of cases(stage III) and 16% of cases(stage IV) to 98% and 88% of cases, if they are started on treatment respectively on stage I and stage II of the disease.

Failure of getting literature on Ca of the breast reporting on the knowledge and health seeking behavior in our set up Botswana(PMH), as well as the need of knowing prominent motivations which entails late presentation to health facility , we thought it would be useful to know the reasons justifying the trend noted in our patients in comparison to the findings of the above literature review done on different set up than ours.

Purpose of study

To explore the knowledge and practices of women suffering from cancer of the breast about their disease.

Objectives

- To assess the level of knowledge and practices about cancer of the breast.
- To suggest recommendations potentially effective for early detection, diagnosis and treatment of Ca breast.

Research question

What is the knowledge and practice of patients suffering from Ca breast about their disease?

Methods

Study Design

This will be a descriptive qualitative study using free attitude interview (one-to-one) technique for data collection.

Study Population / Sampling

All women who have been diagnosed with Ca breast, currently on treatment (chemo/radiotherapy) at PMH and health center. Variation will be by; age, level of education, marital status and living in rural or urban area. Sampling will be purposive (9) and a sample of 8 to 10 respondents will constitute the sample or until saturation of the data has been reached.

Identification of the respondents:

Continuous dissemination of the respondents' information contents (refer appendices) will be done in health center² and the oncology OPD followed by the identification of potential respondents through the management of the respective facilities represented by matrons / sisters in charge. They will be asked to select fluent patients in either setswana or English who are in preference found to talk freely among others. I will then be put in contact with those patients willing to participate in the research so that appointment is set up for interview.

Inclusion criteria:

- All patients (women) with diagnosed cancer of the breast and seen at PMH
- Stable and mentally sound patients with Ca breast.

Exclusion criteria:

- Unstable patient (with disturbing excruciating pain)
- Not mentally sound patient(confused) or
- Depressed patient

Data Collection

² Kind of extension of oncology department where stable patients on treatment from outside Gaborone are kept.

Exploratory Questions

- 1. Can you please tell me all you know about the cancer of the breast?**
- 2. How have you been treating your breast condition (growth/wound/pain) before you decided to come to PMH?**

Note: A Setswana version of both questions (see appendices)

Respondents will be explained about the aim and objectives of the study and requested to sign the consent (refer to appendices). The interviews will be conducted in the language of preference of the respondent i.e. SeTswana or English. The researcher will do most of the English interviews while the setswana one will be conducted by a research assistant (A) who is proficient in both languages. All the interviews will be audio taped and field notes will be taken by the researcher. Ideally data should be collected in a natural setting (10) whenever possible but in this study it will be somewhat difficult to accomplish this. The Patients in the hospital come from far and wide and that makes it not possible to comply with being in a natural setting. However we will arrange a suitable room where interviews will be conducted with privacy.

Reliability, validity and bias

To meet validity and reliability in this study we are going to:

- Audio tape interviews
- Use more than one method of data collection called triangulation (9, 12) (in this case, audio taping interview, notes fields, having a research diary) as well as possible use of member check (9) where transcribed data are verified by the respondent.
- The following are potential areas of Bias:
 - Interviewer bias
 - Sampling bias and selection bias
 - Interpretation bias and language bias

To minimize the above areas of biases, effort will be done to practice good interview technique (follow cues and avoid additional questions; researcher to practice with researcher's assistant on normal subject not trained in medical field, audio tape interviews to be used for self awareness and improvement on missed cues, before true collection of data), sampling will be purposeful, questions will be translated in sestswana Principal researcher(myself) and research assistant will be involved in interpreting and analyzing the transcribed document.

Whenever necessary, in case of doubt we can seek opinion of an independent researcher for consistent finding between researchers although the concept of inter rater reliability is contested (13).

Analysis

The content analysis will be done under the inductive theory of data analysis (11, 13).

Practically English interviews will be translated by the researcher, while the seTswana interview will be done by the researcher's assistant. (In case of extreme need we can hire professional for transcription).

Thematic analysis also known as coding (annotating or marking up the themes, coloring) will be first step.

Themes will then be regrouped in categories (refined) using cut past technique, followed by a comprehensive write up of different categories and integration of all.

ETHICAL CONSIDERATIONS

Participants will be asked to sign a written consent, and confidentiality of the gathered information will be assured.

Permission to conduct the study will be sought from the Departmental Research Committee Family Medicine. Approval of the research will be obtained from REPC University of Limpopo (Medunsa Campus).

The hospital (PMH) ethical committee will also be consulted for approval and will forward it to the Ministry (National level).

TIME FRAME

After approval from the REPC, collection of data and transcription work will be done during about four months followed by data analysis and write up of dissertation for about 6 months

BUDGET/FUND

To follow (currently could be personally founded but contact is being made to get some sponsor)

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Appendix B: Opening questions○ English version :

1. Can you please tell me all you know about the cancer of the breast?
2. How have you been treating your breast condition (growth/wound/pain) before you decided to come to PMH?

○ Seswana version :

1. kekopa gore o mpolelele sengwe le sengwe se o se itseng ka kankere ya lebele?
2. O ntse o alafisa seemo sa lebele (boruruga, ntho,kana botlhoko) la gago ka eng kana jang pele fa o tla ko sepateleng sa PMH?

Appendix C: Consent form

Informed consent form to the participants (patients)

1.English version:

I, Miss/ Mrs/ participant n°do hereby agree/disagree to participate in the study being undertaken by Dr Mbuka Ongona Deogratias, about the knowledge and practices of patients suffering from cancer of breast at PMH / Gaborone. The purpose of the study has been explained to me and I understand that this study is purely for research purposes.

I also understand that I reserve my right to withdraw / discontinue my participation at any time if I may decide to do so.

Please circle the appropriate statement:

1. consent given
2. consent not given

Date.....

Researcher (name/signature).....

Date.....

Participant (name/signature).....

Date.....

Witness (name/signature).....

2.Setswana version:

Tletla ya go tsenelela dipatlisiso

Nna ke le, nomore..... Ke dumalana/ gake dumalane le go tsaya karolo mo dipatlisisong tsa kankere ya lebele tse di dirwang ke ngaka Mbuka ongona Deogratias mo sepateleng sa Princess Marina.

Ke tlhaloseditswe maikaelelo a dipatlisiso tse ebile ke tlhalogantse.Ke tlhaloganya gape gore ke na le tshwanelo ya go tswa mo dipatlisisong tse fa ke batla lefa ntswa ke ne kedisimolotse.

Tshwaya se o batlang go se dira:

1. ke dumalana le go tsaya karolo mo dipatlisisong
2. gake dumalane le go tsaya karolo mo dipatlisisong

kgwedi/letsatsi.....

Leina le setlanyo sa mmatlisisi.....

Kgwedi / letsatsi.....

Leina le setlanyo sa yo o arabang dipotso.....

Kwedi/letsatsi.....

Mosupi ke.....

Appendix D: participant's information

1.English version:

Participants' information

Dear patients and participants

Re: A STUDY OF THE KNOWLEDGE AND PRACTICES OF PATIENTS
SUFFERING FROM CANCER OF THE BREAST AT PMH / GABORONE

Thank you for your time to listen to my research assistant and myself today.

My name is Dr Mbuka Ongona, currently working at PMH/Gaborone.

We (my assistant and I) would like to inform you that it has been noticed that patients with cancer of the breast present at Princess Marina Hospital at a very advanced stage of the disease. Therefore knowing and understanding the reason as to why people present at an advanced stage of the disease at Princess Marina Hospital, will be helpful in planning how to take care of other patients.

In relation to the above, we are conducting a research on patients suffering from cancer of the breast. This will help me fulfilling the requirement of MMed family medicine degree in which I am currently involved with the University of Limpopo in South Africa.

However we (researcher assistant and me) believe that the outcome of that research will help in understanding the current trend of the late presentation for care and will also help in advising other citizens and non citizens on what type of health seeking behavior would be helpful for early detection, diagnosis and treatment of cancer of the breast.

The patients willing to participate in this research will be given an appointment to come and share with us (researcher and assistant) information that is highly personal and sensitive about the cancer of the breast during an interview of about 30 to 50 minutes. This interview will be audio taped to allow revisiting of information and accurate use of it. Be assured that your current care is not going to be affected by your decision of refusing or accepting to participate in the study.

We wish as much as possible that honest and detailed information is given to us from the participant ,since it will help us come up with suggestions about early detection of cancer of the breast among our relatives and friends.

Since we hope that you will be wiling to participate in this research, we would like once more to assure you of complete anonymity and confidentiality of any shared information.

Do you have any questions?

Thank you

For your right contact:

Shanaz El-halabi;

HRDC (health research and development committee)

Ministry of health

Tel: 3914467

* For information about the study contact: Dr mbuka ongona; PMH/GABORONE tel: 3953221 ext: 481

2. Setswana version:
Se o tlhokang go se itse

Go motsaakarolo mo dipatlisisong,

THITO KGANG: DIPATLISISO MABAPI LE KITSO GA MMOGO LE
 TLHOKOMELO YA BALWETSI BA BANANG LE KANKERE
 YA LEBELE MO PRINCESS MARINA HOSPITAL MO
 GABORONE.

Ke lebogela theetso ya gago gompieno.

Leina lame ke ngaka Mbuka Ongona, ke bereka mo sepateleng sa Princess Marina mo Gaborone. Nna le mothusi wame re eletsa go go itsise gore go lemogilwe fa balwetsi ba kankere ya lebele ba tla kwa sepateleng e setse e aname.

Jaanong go itse le go tlhaloganya mabaka a gore balwetse ba kankere ya lebele ke eng batla mo sepateleng sa Princess Marina e se tse e a name le mmele go tla thusa go dira dithulaganyo go tlhokomela balwetse ba bangwe.

ka mabaka a a fa godimo re dira dipatlisiso mo balwetsing ba ba nang le kankere ya lebele jaaka wena, re dumela gore maduo a dipatlisiso tse a tla thusa mo go tlhaloganyeng seemo se re mo go sone, sa ditshupo tsa tlhokomelo le go thusa mo go gakololeng baagedi le ba e seng baagedi ka boitsholo kana ditselana tse di ka thusang mo go lemogeng balwetse le kalafi ya kankere ya lebele ka bofefo.

Dipatlisiso tse gape di tla nthusa mo dithutong tsa me ke le moithuti wa botsogo ba lelwapa kwa mmadikolo wa Limpopo ko South Africa.

Maikaelelo a loeto lwa me gompieno ke go batla go itse gore a o tla tsaya karolo mo dipatlisisong le gore fa gontse jalo re dumalane ka nako e e go siametseng gore re buisane. Fa o dumela go tsaya karolo, puisanyo ya rona e ka tsaya metsotso ele masome a mararo go ya ko go e e masome matlhano. Puisanyo e tlaa gatisiwa ka sekapamantswe gore re kgone go tsaya mafoko a rona ka boammaaruri jotle le go netefatsa se o se buileng fa re kwala. Ga rena ape maikaelelo a go go anamisa gope ka sekapamantswe se. Go tsaya karolo kana go se tseye karolo mo puisanyong e ga gona go ama tlhokomelo ya gago mo sepatela ka gope. Mafoko a o tlaa buang ke tla a somarela thata ka gore a tlaabo a bua ka ga gago. Dipuisanyo tsa teng di ka nna metsotso e le masome a mararo go ya ko go a matlhano.

Re kopa ka tsweetswee fa le ka re thusa ka botlalo ka kitso e e tletseng, ka gore e ka re thusa , go tswa ka megopolo, le ditsetlana tse di ka thusang go lemoga ka bofefo ka kankere ya lebele mo masakeng le ditsala

Ka ke solofela fa o tla rata go tsaya karolo mo dipatlisisong tse , kego tshepisa gore ga ke ke ke boleme leina la gago, puisanyo ya gago le nna ke tla e babalela fela thata .

A o na le dipotso?

Re aleboga.

* Ona le tetla ya ko itshwaraganya le:

Shanaz El-halabi; HRDC (health research and development committee)

Ministry of health, Tel: 3914467

* Go itse ka thuto e ikgolaganye le: Dr Mbuka ongona; PMH/Gaborone tel:3953221 ext: 481

Appendix E: demographic data form

- **English version**

1. Patient's number
(code):.....
2. Address:
3. Telephone number if any:.....
4. Age (years):.....
5. Marital status:
6. Age at onset (breast
symptom):.....
7. Family history of cancer
(breast):.....
-
8. Level of education:
 - a. None
 - b. Primary
 - c. Secondary
 - d. University
9. Age at menarche:.....
10. Number of children/parity.....
11. Use or not of hormonal contraception:
 - a. Pills..... What type.....
 - b. Injection..... what type.....
 - c. Others.....

- **Setswana version**

- 1: Nomore ya molwetse.....
- 2: Aterese.....
- 3.: Mogala fa o le teng.....
- 4: Dingwaga.....
- 5: A otserwe
- 6: O ne ole ngwaga tse kae fa o lwala lebele.....
- 7: A go nale mongwe wa losika yoo lwateng lebele.....
- 8: O badileng bokae ko sekolong
 - a. sepe
 - b. thuto e potlana
 - c. thuto e kgolwane
 - d. thuto ya mmadikole
- 1.9: O bone setswalo ole dingwaga dikae
- 1.10: O nale bana ba le kae
- 1.11: Tiriso ya tsa boiphemelo pelegi
 - a. pilisi.....mohuta ofe.....
 - b. mokento.....mohuta ofe.....

Appendix F: REPC clearance certificate

UNIVERSITY OF LIMPOPO

Medunsa Campus

**RESEARCH, ETHICS & PUBLICATIONS COMMITTEE****FACULTY OF MEDICINE****CLEARANCE CERTIFICATE**

P O Medunsa
Medunsa
0204
SOUTH AFRICA

Tel: 012 - 521 4000
Fax: 012 - 560 0086

MEETING: 02/2006**PROJECT NUMBER:** MP 14/2006

PROJECT: **Title:** Knowledge and practice of patients suffering from cancer of the breast about their disease at Princess Marina Hospital (PMH) in Gaborone / Botswana

Researcher: Dr D Mbuka Ongona
Supervisor: Dr J Tumbo
Co-supervisor: Ms N Malete
Hospital Superintendent: Dr KIS Malefho
Department: Family Medicine & Primary Health Care
Degree: M Med (Fam Med)

DATE CONSIDERED: March 02, 2006**DECISION OF COMMITTEE:**

REPC approved the project.

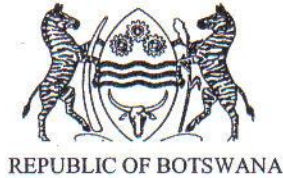
DATE: March 06, 2006

PROF GA OGUNBANJO
CHAIRMAN (RESEARCH) REPC OF FBM

- | | |
|-----------------|---|
| Note: i) | Should any departure be contemplated from the research procedure as approved, the researcher(s) must re-submit the protocol to the committee. |
| ii) | The budget for the research will be considered separately from the protocol. PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES. |

Appendix G: PMH clearance

Princess Marina Hospital
P.O. Box 258
Gaborone Botswana



Tel: 3953221
Fax: 3973776
Email: ygureja@gov.bw

INSTITUTIONAL RESEARCH AND ETHICS COMMITTEE

Our Ref: PMH2/11B/I

Date: 02 July 2005

Dr. Ongona Mbuka
Principal Investigator
Gaborone

Re Your Protocol: Knowledge & Practice of Patients Suffering from Cancer of Breast at PMH Botswana

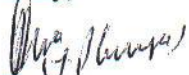
I am pleased to communicate Ethics Committee's final approval of the above protocol. The approval is effective from the date of this letter provided you comply with the list of conditions given below.

Committee expects you to: –

1. Have formal approval from the HRDU of the Ministry of Health
2. Resubmission for re-approval of the protocol if there is expected or unexpected change at any time of the study.
3. A copy of the report at the completion of the study
4. A regular update on its progress.

On behalf of the Committee, I wish you success in this important endeavour.

Yours truly,


Y.P. Gureja
Chairman,
c.c. Medical Superintendent
PMH.

Appendix H: MOH clearance

TELEPHONE: 3632000
 FAX: 3914467
 TELEGRAMS: RABONGAKA
 TELEX: 2818 CARE BD



MINISTRY OF HEALTH
 PRIVATE BAG 0038
 GABORONE
 BOTSWANA

REPUBLIC OF BOTSWANA
 MINISTRY OF HEALTH

REFERENCE No: PPM&E 13/18 PS Vol I (20) May 8, 2006

Dr Mbuka
 Princess Marina Hospital
 Box 258
 Gaborone

Research Permit: "Knowledge and Practice of Patients suffering from Cancer of Breasts about their disease at Princess Marina Hospital, Botswana"

Your application for a research permit for the above stated research protocol refers.

The application form, protocol and consent form have been reviewed and found to be ethically and scientifically appropriate. **Permission is therefore granted to conduct the above-mentioned study.** This approval is valid for a period of 1 year, effective May 8, 2006.

This permit does not however give you authority to collect data from Princess Marina Hospital without prior approval from the management of the hospital. Similarly, consent should also be sought from all the participants prior to undertaking data collection.

The research should be conducted as outlined in the approved proposal. Any changes to the approved proposal will need to be resubmitted to the Health Research Unit in the Ministry of Health.

Furthermore, you are requested to submit at least one hardcopy and an electronic copy of the report to the Health Research Unit, Ministry of Health within 3 months of completion of the study. Copies should also be sent to relevant authorities.

Approval is for academic fulfillment only.

Thank you,

S. El-Halabi

For Permanent Secretary Ministry of Health