

Young women's perceptions of Breast Cancer

A qualitative study exploring perceptions of breast cancer among first-degree relatives of breast cancer patients in Bulawayo Zimbabwe

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Abstract

Title: A qualitative study exploring perceptions of breast cancer among first degree relatives of breast cancer patients in Bulawayo Zimbabwe.

Introduction: Breast cancer (BC) is the leading cause of cancer death among females in Africa, where BC peaks 10-15 years earlier than in high-income countries, presenting in advanced and aggressive forms between the ages of 35-45. Cost of treatment is high and often self - detected tumors remain untreated resulting in low survival rates. There is low BC public awareness and low action taken by the government to address BC publicly in Zimbabwe. Young women with a family history of breast cancer are an “at risk” group for BC and exploring their perceptions on BC could contribute towards understanding and addressing their needs.

Objectives: To explore perceptions of BC among young women aged between 18- 35 years, who are first-degree relatives of BC patients in Bulawayo Zimbabwe.

Methods: Semi-structured interviews with 10 women, of 18 - 35years, from two health personnel who work for 2 separate non-profit cancer organizations in Bulawayo and informal discussions with 4 breast cancer patients.

Findings: Young women’s perceptions are strongly influenced by the experiences they had when witnessing their relative going through. They were aware of their BC risk and BSE as an early detection measure. They were able to correctly perform BSE but reported failure to practice BSE regularly (once a month) citing e.g. forgetfulness and worry of uncovering a tumor they could not afford to treat. The young women were missing information on vital risk factors and signs and symptoms of BC. Health professionals do not inform target groups like daughters and sisters of women affected by BC that they are at increased risk and should be screened regularly. The women (relatives) desired to learn more about the disease but noted little public media coverage on BC.

Conclusion: Although knowledge exists among young women with a family history of BC, there is still a need for target appropriate information about BC. There is also a need ensure that women receive affordable early diagnosis and adequate treatment of self-detected tumors.

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LIST OF ABBREVIATIONS

AIDS	ACQUIRED IMMUNODEFICIENCY SYNDROME
BC	BREAST CANCER
BSE	BREAST SELF EXAMINATION
CBE	CLINICAL BREAST EXAMINATION
HBM	HEALTH BELIEF MODEL
HIV	HUMAN IMMUNODEFICIENCY VIRUS
LEDC	LOW ECONOMICALLY DEVELOPED COUNTRIES
MEDC	MORE ECONOMICALLY DEVELOPED COUNTRIES
PPSTM	PATIENT/PROVIDER/SYSTEM/THEORETICAL MODEL
SDR	SOCIALLY DESIRABLE RESPONDING
WHO	WORLD HEALTH ORGANIZATION

1 Introduction

1.1 Background of the study

Breast cancer is the most common cancer among women worldwide, however medical advances have shown that one third of all cancers are preventable and a further one third of the cases, if diagnosed timely are potentially curable (Tiengo, 2011). In 2008 Approximately 45 % of breast cancer diagnosis and 60 % of breast cancer deaths occurred in middle to low-income countries (Jemal, 2006). Breast cancer statistics in Africa i.e. Nigeria, South Africa, Kenya etc, show that breast cancer has slowly surpassed cervical cancer as the most fatal cancer among women (Parkin et al, 2006). In Nigeria over a period of 8 years, breast cancer was reported to account for 56,6 % of all cancer diagnosis (Akpo et al, 2010). Furthermore breast cancer trends show that breast cancer incidence has been increasing in virtually all regions since 1973 (Curado et al, 2007).

Breast cancer in low to middle income countries has late presentation with poor treatment outcomes due to several factors such as unequal access to prompt high quality treatment, lack of screening facilities, or lack of awareness and knowledge of the disease (Opuku et al 2012, Anderson and Jakesz, 2008). In addition, breast cancer in low to medium income countries peaks 10-15 years earlier than in high income countries, presenting between the ages of 35-45 years as compared to 55- 65 years in high income countries (Akpo et al, 2010, Muguti, 1993).

Survival rates in high income countries such as USA and other regions have been favourable with some scholars citing 70 % whilst others cite 89 % survival rate per five years (Akpo et al, 2010, Sant et al, 2004), attributed to early detection by screening and by timely and effective treatment (Weir et al, 2003). In contrast however survival rates are much lower in low-middle income countries with survival rates in Ghana being less than 25 % and 10 % in Nigeria (Akpo et al, 2010, Opuku et al 2012).

According to Austoker (2004), the outcome of breast cancer survival after diagnosis and treatment depends on the stage of breast cancer at diagnosis. Consequently the earlier the breast cancer is diagnosed the better the survival rates. As such there is potential to reduce mortality from breast cancer by detecting breast cancer early. In the Nordic countries early screening for breast cancer reduced breast cancer mortality by 30 % over a period of 5 years (Hristova and Hakama, 1997). Research on knowledge, attitudes and practices of women on breast cancer and mammography at Mulago Hospital in Uganda, shows the main barrier to

women receiving any kind of screening such as mammography, as lack of information (Kiguli – Malwadde et al, 2010). Consequently if women are not made aware of ways to detect cancer, mortality will remain high. In spite of the rising incidence of breast cancer, and the success in high income countries in reducing mortality (Porter, 2008), research shows that women in most parts of Africa, i.e. Botswana, Uganda, Zambia, Nigeria have low knowledge of breast cancer, (Tiengo, 2012, Kiguli- Malwadde, et al 2010, Muthoni and Miller, 2010, Akpo, et al, 2010).

1.2 Zimbabwe Country Profile

Zimbabwe is a landlocked country in Southern Africa that has recently been surrounded by both political and economic turmoil. The population of Zimbabwe is approximately 12,9 million (Population census 2012). Zimbabwe's capital city is Harare and the second largest city is Bulawayo where this study was conducted. Females constitute 51.2% and males 48.8%. 68% of the population resides in the rural areas and population density is estimated to be 335 per square kilometre. Children under 15 years of age make up 45 % of the population. The projected annual growth rate is 3.7% and the average fertility rate is 4.5 per woman (Population census 2012).

The health parameters for the country are poor. The infant mortality rate is estimated at 68 per 1000 live births. Zimbabwe has been battling the HIV/AIDS epidemic, which according to the WHO has slashed the average life expectancy from 61 to 33 years on average since 1990 (Mothobi, 2010). However life expectancy has since seen a steady rise in the last couple of years and is up from 33 years to 52 years for men and from 34 years to 55 years for women (Mandere, 2009). Inflation, unemployment, poverty, shortage of medical personnel, shortage of medicine and medical resources have all left millions of Zimbabweans at the mercy of all kinds of disease and illness without sufficient health care (Mandere, 2009).

Whilst economic conditions have slightly improved in the health care sector, not everybody is able to afford medical care. Challenges continue to exist, especially for illnesses such as breast cancer, which are not as wide spread as HIV/AIDS. The main government hospitals are unable to provide subsidised drugs due to shortages and there are long waiting lists for radiotherapy treatment and drugs for chemotherapy and in most cases emergency surgery is dependent on the ability of patient's relatives to purchase drugs from private sellers (Mothobi, 2010).

1.3 Breast cancer in Zimbabwe

Reports state that more than 80 % of Zimbabwean women are not aware that they should be screened for breast cancer (Mothobi, 2010). Though breast cancer is the second most common cancer, deaths from breast cancer continue to be extremely high because women present themselves for treatment at late stages (Mothobi, 2010). Over 184,000 Zimbabwean women are diagnosed each year with breast cancer. Only 50% are diagnosed at the early stage of the disease where the cancer cells remain in the breast duct, or where the tumour measures less than 2 cm and the cancer is still confined to the breast (Mothobi, 2010). About 30 % of all women are projected to subsequently die from the disease (Mandere, 2009). In Harare the where most of the health services are centred the 5 year survival rate of breast cancer between the years of 1992 – 1997 was 58% (Chokunonga et al, 2000). Breast cancer is not a notifiable disease and registration of breast cancer cases is done by active methods; this figure may not be a true representation of all breast cancer cases in the capital.

The overall perception in Zimbabwe is that little has been done to set in place preventive measures and treatment for breast cancer (Zaba and Muzulu, 2013). In Zimbabwe most lumps are detected by the women themselves through breast self-examination, as other options are expensive or unavailable (Mothobi, 2010). Breast self-examination involves examining ones' own breasts using a specific palpation technique to detect any lumps in the breast tissue which may be cancerous. By proper breast self-examination, cancers can be detected at an early stage and can be cured by modern treatment (Mothobi, 2010). As mentioned earlier, 68% of the population live in rural areas where mammograms are unavailable and travelling costs to the city is often expensive and serves as a deterring factor towards seeking treatment. In urban areas unless one is on medical insurance the cost of mammograms range is \$40 going upwards and remains out of reach for some (Mothobi, 2010).

Recently the Vice President of Zimbabwe opened up a new breast cancer clinic in Harare's Parirenyatwa hospital. She spoke about how general lack of awareness and poor health seeking behaviour among the people of Zimbabwe irrespective of level of education and socio-economic status of the individual contributed to high levels of mortality from cancer (Zaba and Muzulu, 2013). She also addressed the high cost of breast cancer treatment and pointed out that the government would attempt to provide free screening facilities and also

provide cancer treatment at affordable prices in order to tackle the burden of breast cancer. Although the government is attempting to provide infrastructure, such as screening clinics, costs for both screening and treatment continue to be high. The government has also hinted at providing two facilities that will offer free cancer treatment, one in Harare and one in Bulawayo.

Currently there is only one public hospital that offers services for breast cancer at a discounted rate and other types of cancers for Bulawayo, Matebeland North and Matebeland South, resulting in long waiting lists for radiation therapy and people travelling long distances to receive treatment. In November 2012 however, the radiation machine had been out of order, and patients had to either wait till it was fixed or travel as far as Harare for radiation therapy for about 7 hours or more by road (Mothobi, 2010).

Chemotherapy is expensive and patients must purchase drugs privately and bring them to the doctor. Furthermore only a few drugs are available and patients have to wait long periods between each chemotherapy cycle to raise money for purchasing the drugs. Consequently some patients resort to other treatments such as traditional treatments that only worsen the plight of the affected women. In Zimbabwe, treatment for cancer including doctors' fees, surgery costs and treatment cycle costs are estimated between us\$4000 and us\$5000 in private hospitals, yet most civil servants earn a minimum salary of us\$300 a month, (Mothobi 2010; Zaba and Muzulu, 2013). In government hospitals treatment may cost half of what it costs in private hospitals, however drugs are always out of stock and they are quickly depleted due to high demand and low supply (Zaba and Muzulu, 2013).

Whilst issues with health care are apparent, reports state that lack of knowledge has been identified as the greatest obstacle, because most women are unaware that they have breast cancer due to lack of knowledge of breast cancer symptoms (Mothobi, 2010). The cancer association of Zimbabwe believe that cancer awareness in Zimbabwe is low due to shortage of resources to reach all the masses (Muthobi, 2010), with their cancer centres in Bulawayo and Mutare currently being non-functional due to lack of funds to keep the organisations running.

2. Literature Review

2.1 Introduction

The aim of a literature review is to critically analyse and carry out an in-depth evaluation of previous research. This chapter will examine available, relevant literature that addresses breast cancer and young women, with a focus on perceptions, family history and perceived risk of breast cancer among this age group.

2.2 Literature search

Breast cancer as a research topic has been extensively covered; a wide range of topics exists .g. barriers to care (Tiengo, 2011), knowledge attitudes and practice of screening, etc (Krombein, 2006). In order to avoid being too general it was vital to search for specific breast cancer issues relevant to this research. This literature review does not cover all the literature on breast cancer but instead only focuses on areas surrounding breast cancer perceptions in African women, young women and women with a family history of breast cancer. This literature review is also only limited to literature that was accessible to me, accordingly there may be other relevant literature omitted due to inaccessibility. A thorough search of literature using different databases such as pub med, Cochrane, Google scholar and Medline was carried out.

An initial literature search included key words such as “breast cancer”, “Africa” and “perceptions”, this produced several results that only covered African American women and nothing exclusively on African women. Consequently new searches with different key words were run such as “breast cancer perceptions”, “breast cancer perceptions developing countries”, “breast cancer developing countries” and” breast cancer family history”. From the aforementioned searches relevant articles were found that explored breast cancer in an African context and a few hits on breast cancer perceptions in Africa were also found. To source more literature, reference lists of relevant articles initially found was used to further acquire more literature relevant to the study.

2.3 Global Response to breast cancer

Breast cancer has been recognised as a serious public health concern mostly in More Economically Developed Countries (MEDC) (CanTreat, 2010) and one major strategy to try and reduce mortality from breast cancer is the introduction of effective screening programmes to detect the disease early, e.g. breast self examination, clinical breast

examination, mammography and creating awareness (Women's Health Queensland Wide 1999a: 10).

Under the Norwegian Breast Cancer Screening Programme, started in 1996 and government funded, all women in Norway aged 50-69 were invited for mammography screening every two years. After a 15-year follow up, the programme reduced mortality from breast cancer by 43% among the women in this age group from the year 1996 to 2009 (Hofvind, 2013). Before the introduction of this screening programme, a total of 4 out of 10 women were already receiving private mammograms and this had brought about a significant decline in BC mortality (Keilman, 2012).

As is the case with most screening measures, there are differing opinions on whether screening actually saves lives and why screening for breast cancer by mammograms should begin at the age of 50 and not 40 (Kopan, 2014). Some experts suggest that mammograms do not detect BC in women younger than 50 as there is no evidence of reduced mortality for women aged 40- 49 from the use of mammograms. This may be due to the difficulties in interpreting mammograms in premenopausal women, due to glandular breast tissue (Willacy, 2012). On the other hand some studies in the US have shown that mortality was decreased with screening beginning at the age of 40 (Mandelblatt et al, 2009).

More than 40% of the years of life lost to breast cancer are among women diagnosed in their 40s (Kopan, 2014), thus some experts suggest that all women below the age of 40 should also be invited to take part in annual screening because the breast cancer (BC) in women under the age of 40 is often aggressive and has faster growth rates between mammograms and clinical detectability (McLelland et al, 1990).

With all the controversy surrounding mammograms and the claims that it results in over diagnosis (Kopan, 2014) Breast self-examination (BSE) comes to the forefront. However, similarly, BSE is not recommended by most cancer associations in developed countries such as Canada, (PHAC,2005), Denmark (Gotzsche, 2006) as there is no evidence that it saves lives or enables women to detect breast cancer at earlier stages (Kosters and Gotzsche, 2003). In addition according to McLelland et al (2001), women do not perform BSE, and those who do, do not do it right and it sends the wrong message to women that they should detect their own breast cancers.

Based on an individual assessment of benefits and risks, the US still recommends BSE for women aged 20 and over. According to Baxter (2001), BSE creates more harm than good; women discover lumps that are not cancerous, resulting in unnecessary procedures that may deform or scar a woman's breast for life. Some scholars argue that for some women, BSE is the only way their tumors can be detected early and to downplay BSE is a gross reaction that needs re-evaluation (Weis, 2008). A more fitting way to handle this according to Child (2008), is to explain to women the pros and cons of BSE but still give them the option of using BSE.

This brings to light the dilemma of women in developing countries who rely solely on BSE to discover their tumors, cancerous or not. Other scholars argue that, recent studies that have shown BSE to be unhelpful (Thomas et al, 2002), have only considered developed countries or urbanized areas of developing countries, where routine primary healthcare is more available and breast cancer awareness and education are high and mammography is more routinely accessible (Shulman et al, 2010). As the debate still rages on about whether screening saves life, what is apparent is that improvements in treatment for BC and efficiency of health care systems contributes immensely towards reduced mortality and survival rates (Autier et al, 2011).

A lot has been done in developed countries to prevent breast cancer and to create awareness; initiatives still have to go global. Cancer is reported to be a bigger problem for developing countries than HIV (Johnson, 2006), but cancer still remains a low priority on the budgets of developing countries. Only 5% of global funding set aside by the WHO for cancer is spent in developing countries (Ngoma, 2006).

Many preventive measures remain inaccessible to many women in Less Economically Developed Countries (LEDC) who are most vulnerable to BC due to the nature of their breast cancer and high mortality rates (Porter, 2008). Regardless of the low incidence rates, women in LEDC's continue to die, mostly according to Shulman et al, (2010), due to a lack of awareness of the importance of early detection and treatment, a lack of availability for routine screening and diagnosis and poor access to primary care.

There are few facilities for cancer prevention and treatment in LEDC's (Ngoma, 2006). Cancer drugs are largely unavailable or extremely expensive, and access to diagnostics or

radiotherapy facilities, a main component of cancer treatment, is often limited to one or two hospitals in the country (Anderson and Jakesz, 2008).

Shulman et al, (2010) recognizes that though useful, breast cancer treatment and screening such as mammogram will continue to be unavailable to most women in LEDC's. Data indicate, however, that there were substantial improvements in survival in the USA even prior to these technological and diagnostic advances, possibly from an increased awareness of the threat of breast cancer and the importance of the practice of getting regular clinical breast examinations (Shulman et al, 2010). Consequently while the aim is to increase access to more advanced technology, survival can also be improved by creating awareness of breast cancer and the potential for being successfully treated through a fully functioning primary care system without economic or cultural barriers (Shulman et al, 2010).

Measures that reduced mortality prior to improved diagnostics and screening in the US can be attributed to a more general availability of health care, encompassing gynaecological health care and general physical examinations (Shulman et al, 2010). Cancer Associations began promoting BSE (American Cancer Society, 1950), and there were more effective breast education programmes, increased breast cancer awareness, detection of palpable tumours with BSE or CBE and better diagnostics (Jatoi et al, 2005).

Since incidence rates in LEDC's are not as high as incidence rates in MEDC, Porter (2008) suggests that the main focus should be on increasing survival rates. To do this, culturally and economically sound early detection measures and surgeries should be improved (Magrath and Litvak, 1993). Furthermore, education about breast cancer, promotion of breast cancer as a curable disease and not a death sentence, and improvement of health care surrounding breast health would boost survival rates as witnessed in the USA in the early 80's (Shulman,et al, 2010).

Shulman et al (2010) recommend that education efforts need to deal with issues that hinder women who are economically challenged and uneducated from seeking help. These issues according to Shulman (2010), could be because women are not aware what a lump in their breast could potentially mean, or are afraid of what people's reactions will be, the fear of being rejected by the community, fear of the loss of a breast, or fear that there is no cure for the disease.

Ngoma, (2006) recommends that in LEDC's breast cancer deserves the same treatment that HIV coverage has, because most of the issues surrounding breast cancer are very similar to

perceptions people have of HIV despite the curability of BC. Evidence shows that the impact of HIV response is higher where programs are integrated with other health and social welfare services and the same could be achieved for breast cancer (CanTreat, 2010).

In Malaysia, a programme through community public awareness campaigns and the training of health staff in clinical breast cancer examination managed to reduce late stage of breast cancer presentation from 77 % to 37 % in a period of four years from 1994 - 1998. They attribute the change mostly to the public awareness campaigns as the health personnel hardly stayed in the same place for long enough to impact late cancer presentation through frequent breast cancer examination (Devi et al, 2006).

2.4 Breast cancer knowledge and perceptions among African women

Research in the USA about breast cancer suggests that there is an abundance of material about breast cancer and yet misconceptions about breast cancer still remain (Thompson et al, 2005). Women continue to overestimate or underestimate their risk of having Breast Cancer, creating an overwhelming amount of anxiety that would otherwise be unnecessary (Hopwood, 2000). A lot of factors have been found to influence women's perceptions on breast cancer, such as perception of cancer as fatal (Powe, 1995), lack of awareness of breast cancer screening (Pham, 1992), lack of knowledge about the importance and practise of breast self-examination, clinical breast examination, and mammography as a means of early detection for breast cancer.(Rashidi and Rajaram,2000).

Several studies in Sub-Saharan Africa e.g Kenya, Uganda, Botswana and South Africa have been conducted to measure women's knowledge on breast cancer most of which have been knowledge, attitude and practise quantitative studies (Muthoni and Miller, 2010; Karen, 2011;Tiengo, 2012). Overall there still exists a research gap as there are very few studies that have investigated young women's perceptions with a family history of breast cancer in Africa (Dein, 2004). Much research on perceptions of breast cancer focuses on African American women residing in America or black women residing in England (Powe et al, 2004). Since there were few hits on young women's perceptions of breast cancer in Africa, most of the literature used in this research will be from studies conducted in Canada, America, and a few Asian countries. A few studies were found addressing perceptions of women in general, with no specific exclusion criteria in Botswana and Kenya. Although these past studies have a different target group from this research, the issues are still similar to the scope of this study and will be presented in our literature review.

The greater part of research on breast cancer has been analysed through the Health Belief Model, (Austin, McNally, & Stewart, 2002; Muthoni and Miller, 2010; Opuku et al, 2012).

The Health Belief Model (HBM) attempts to predict health-seeking behaviours of individuals. According to the health belief model there are six factors that influence adoption of health behaviours: (a) “perceived susceptibility,” or perceived personal risk of contracting a health condition; (b) “perceived seriousness,” or perceived personal harm of the condition in terms of physical, psychological, and social consequences; (c) “perceived benefits,” or perceived positive attributes of a particular action in reducing the threat of disease or illness; (d) “perceived barriers,” or aspects related to an action that may be inconvenient, time consuming, expensive, complicated, unpleasant, painful, or upsetting; (e) “cues to action,” or events that stimulate an individual to perform preventive health activities; and (f) “self-efficacy,” or feelings of confidence in one’s ability to perform a behavior (Rosenstock, Strecher, & Becker, 1988).

Available evidence indicates that the HBM has only a weak predictive power in most areas of health related behaviour. This is in part a result of poor construct definition, a lack of combinatorial rules and weaknesses in the predictive validity of the HBM’s core psychological components (Taylor et al, 2007). The health belief model also neglects social and cultural factors that also play a significant role in influencing health behaviours (Rajaram and Rashidi, 1998). Lastly the HBM attributes all failures to the patient and does not call into account the role played by medical staff in challenging women’s perceptions about breast cancer (Powe et al, 2005).

Other theories to explain health behaviours have been used as well such as the patient/provider/system theoretical model (PPSTM), (Powe et al, 2005). The PPSTM seeks to access the role played by a specific medical encounter in creating perceptions in patients. The role of the health system in modifying patient’s perceptions and consequently behaviours is left out of health research (Roter and Hall, 1991). Barriers existent within the health care system are believed to influence patient’s perceptions of breast cancer (Powe et al, 2005). For example Powe et al, (2005), explored to what extent educational pamphlets in primary care challenged existing misperceptions about breast cancer among African American women in America, results showed that out of 6 pamphlets available in most doctors waiting rooms only 2 directly challenged these breast cancer misperceptions. While it may be difficult to

change perceptions, there are ways to create culturally sensitive interventions without alienating women while still providing needed care (Lende and Lachiondo, 2008).

A study done in Kenya by Muthoni and Miller (2010), primarily on urban women and a few rural women without a history of breast cancer, outlined that most women are not aware of signs and symptoms and causes of the disease, nor do they have knowledge of the correct risk factors for breast cancer, which include age, lifestyle, environment, and genetics. This same study conducted in Kenya showed that women are acutely aware of their susceptibility to breast cancer, in spite of them having little or no knowledge about breast cancer, (Muthoni and Miller, 2010).

Furthermore, Muthoni and Miller (2010) in their study showed that, although Kenyan women are not sufficiently educated on breast cancer, certain experiences with breast cancer contributed significantly towards their perceptions and views of breast cancer. Those who had seen friends or relatives affected by breast cancer were naturally more aware of the disease than those who had no experience with breast cancer (Muthoni and Miller, 2010). Urban women heard and saw the publicity surrounding breast cancer month from television and radio stations, thus arousing curiosity on the subject of BC (Muthoni and Miller, 2010).

In Kenya, Nigeria, Ghana and Botswana women perceive breast cancer as an incurable disease; a diagnosis in breast cancer implies death (Peek et al, 2008). Peek et al believes perceptions on the fatality of BC are grounded in community's experience of breast cancer and what they have witnessed from other members of the community who have suffered from the illness and the outcome of the illness. Women in Kenya also shared similar scepticism, doubting that any type of treatment would save women from ultimate death (Muthoni and Miller, 2010). The severity of cancer according to them is much worse than AIDS, because AIDS has available treatment. These women perceive cancer to be unmanageable by drugs and they are not aware that any chemotherapy exists to treat breast cancer (Muthoni and Miller, 2010).

Furthermore in Kenya, women perceived breast cancer to be a spiritual illness, something that lies in God's hands, and God is the only person who can cure the disease. The women also believed it to be a curse that is created by the devil, and can only be treated by spiritual powers (Muthoni and Miller, 2010; Powe et al, 2011). Women have these perceptions because in their experience doctors are unable to cure breast cancer, because women present late, and usually die because the cancer is too advanced to treat (Opuku et al, 2012).

On the other hand, women in the North of Uganda perceived breast cancer to be an illness that can be cured and that this cure lay solely in the hands of the doctor. None of the participants in the study mentioned any possibility of death, including one patient who was receiving palliative care (Karen, 2011). In the same study the author acknowledges, contrary to many studies, that the spiritual dimension of breast cancer was not an issue or something that the women brought up in their discussions about breast cancer (Karen, 2011).

Overall there is no clear consensus on which group of women, young versus old, are most likely to have misperceptions of breast cancer risk as there has never been a unanimous definition of the term risk (Johnson, 2006). Research has suggested that women with lower levels of formal education and lower levels of economic income are likely to have more misperceptions about breast cancer (Carter et al, 2002). In addition the role that culture, and structural causes play in the development of these perceptions should not be overlooked (Lende and Lachiondo, 2008).

2.5 Breast cancer in young women

Young in breast cancer terms implies any women below the age of 40 (Komen, 2011). In the US, 5 % of all breast cancer cases occur in women under the age of 40 and this figure continues to increase (American Cancer Society, 2009). In LEDC breast cancer presents in much younger age groups, with an early peak of 35 – to 45 years, (Muguti, 1993; Opuku, et al, 2012,). A study done in Zimbabwe on experiences with breast cancer in Zimbabwe documented that 63 % of the women diagnosed with breast cancer in Zimbabwe were pre-menopausal (Muguti, 1993).

There was a very limited amount of literature on the perceptions of young women with a history of breast cancer in the family in Africa. From existing literature 2 studies were found in Nigeria measuring knowledge of BSE among young graduate women and young doctors and nurses at a teaching school (Okpu et al, 2012; Akpo et al, 2010). The literature reviewed in this section will be from existing general literature on young women and breast cancer as there is a limited amount of literature on the subject in Africa.

Cancer in young women is usually of a more aggressive nature and is less responsive to hormone therapies that are performed in order to prevent the cancer from returning (Graf & Geller 2003). Studies have shown that women diagnosed with breast cancer below the age of

35 had a poorer prognosis than older women and fell into a risk of dying from breast cancer regardless of stage at diagnosis (Johnson, 2006).

Most women with breast cancer, despite age difference, may have similar experiences and anxieties (Johnson 2006). Research has shown that younger women experienced heightened levels of depression and stress after the diagnosis of their disease, mostly attributable to the different biological and psychosocial needs of young women (Coyne and Borbasi, 2006). Specific issues identified in earlier research have related to the phase of life of younger women, which is premenopausal. The disruption of ovarian function from hormone treatments usually results in clinically induced menopause and infertility and are a cause for further anxiety and distress for women of child bearing age (Graf & Geller 2003; Knobf 2001).

Research shows that young women appear to suffer from greater psychological morbidity than older women after a breast cancer diagnosis (Coyne and Borbasi, 2006). Younger women due to the nature of treatment suffer a larger decline in quality of life, and mental health than older women. They still have careers to look forward to, and a diagnosis of breast cancer means a disruption in possible future plans (Johnson, 2006). They also face challenges in their ability to find suitable marriage partners and their ability to conceive and have children as they suffer from deteriorated sexual functioning (Coyne and Borbasi, 2006). Women who have undergone mastectomy suffer the most post treatment from body image insecurity and disruptions in their sexual life (Munoz, 2010).

In spite of the severe side effects that young women face post breast cancer diagnosis, Johnson (2006) reports that there is still a need for health professionals to be more in tune with the needs of young women diagnosed with breast cancer. A study done by Coyne and Borbasi (2006) shows that women wished that their family members were more included in decision making when it came to treatment as this would assist the family in helping the women through her journey. Furthermore these young women wished for child friendly wards and treatment plans that took childcare into consideration (Coyne and Borbasi, 2006).

2.5.1 Young women with history of breast cancer in family

Family history has been strongly linked to risk of developing breast cancer (Calle et al, 1993; Foxcroft et al. 2004; McCredie et al. 1998; Williams et al. 2001). When a female has a mother, sister or aunt with the disease, they are twice as likely as the general population to get diagnosed with the disease at some stage in their lives (Dite et al. 2003). Furthermore

according to Willimas et al, (2001) and Zeleniuch-Jaquotte and Shore (1999) the risk is even greater if the relative develops the cancer before age fifty. Women with a close relative who has suffered from breast cancer in the family often develop breast cancer at a younger age.

Studies in USA have shown that women with a close relative who has or had breast cancer in their family perceive themselves to be at a great risk of developing breast cancer because one or more of their family members has breast cancer (Evans et al.). Despite young women having a strong history of breast cancer in the family and perceived susceptibility to breast cancer, studies show that these women did not exhibit any significant differences in practising BSE compared to women with a lower risk of getting breast cancer. Furthermore they do not have routine mammograms more often than the rest of the population, either in denial or optimistic bias (Chalmers and Thomspson,1996).

However, other studies found that women in this high-risk group often underestimated their risk of getting breast cancer because they believe it is not in their hands or it just won't happen to them, as it only happens to older women (Hopwood, 2000). In Canada research shows that perceptions of women who have family history are usually influenced by the experience and outcome of the illness in the family. Usually illness in the family is an important mechanism to awaken an individual's awareness to personal breast health and in seeking risk assessment and advice on risk management or cancer prevention (Hopwood, 2000). Young women in this risk group also seem to fear inheriting breast cancer (Johnson, 2006).

Chalmers and Thomspson (1996) found that the emotional impact of the family members cancer and the women's sense of vulnerability played a huge role in determining how serious women perceive breast cancer to be. Women felt more vulnerable to breast cancer if the shared and lived experience of the breast cancer patient was difficult and if they have subsequently found it hard to resolve the emotional impact breast cancer had on them as a relative (Hopwood, 2000).

In response to the rising need of breast cancer awareness, the USA for example, has developed breast cancer genetic counselling services. These services seek to address women who are concerned with inherited risk, by assessing their personalized familial risk and interpreting it (Bowen, 1999). Research has shown that breast cancer risk counselling helps to reduce inaccuracies in risk assessment and helps with providing women who are concerned

with their personal breast health with known facts allowing them to make correct and informed choices in risk management and preventive measures (Hopwood, 2000).

In Australia, Johnson (2006) found that young women think the risk of breast cancer cannot be reduced or controlled. They believe that if it's meant to happen it will happen. This misconception is higher among women with a family history of breast cancer as they feel most vulnerable to getting breast cancer (Johnson, 2006). For the most part, BSE and Clinical Breast Examination (CBE) are the only methods available for young women to detect breast cancer at an early (Johnson, 2006). However in spite of this, younger women who perceive themselves to be at high risk of acquiring breast cancer are not reported to regularly practice breast self-examination (Bryan, 2001).

Furthermore Johnson (2006) reported that young women below the age of 40 in Australia are found to have insufficient amounts of information about breast health knowledge and education. Yet availability of sufficient breast information and education plays an important role in changing the perceptions of young women (Baum, et al, 2007). This highlights the importance to target these young women, by exploring their perceptions and knowledge, in order to provide them with valuable and appropriate information to help them combat the disease (Johnson, 2006).

3. Study Rationale

In Zimbabwe breast cancer has not been identified as a health priority as the country is still battling with contagious diseases such as HIV/ AIDS and cholera among other possible reasons (Anderson and Jakesz, 2008). Cancer statistics on breast cancer from Zimbabwe from 2004 show survival rates of 40, 2 %, among black ethnic women versus 61,9 % among Caucasian women in the same country (Chokunonga et al, 2006). Also in 1993, breast cancer in Zimbabwe presented itself in black women ten years earlier than in Caucasian women, at 35 – 45 years (Muguti, 1993). The black women presented at a late stage for seeking treatment with severe tumour burdens that take a more aggressive route and consequently reduce chances of survival (Muguti, 1993). These discrepancies in presentation could be due to unequal access to health care and treatment.

Older age, personal health history, family health history, certain genome changes, ethnicity (African American, Asian, and Latina), higher breast density, lack of physical activity, and excessive alcohol consumption are some of the risk factors associated with breast cancer worldwide (Woloshin et al, 1999; Johnson, 2007; Porter, 2008). Family history is known to account for 20- 30 % of all breast cancer cases worldwide (NCI, 2009), and having a first degree relative with breast cancer can double the risk of getting the disease (Imaginis, 2012).

However literature searches on family history as a risk for breast cancer in Sub- Saharan Africa did not yield any results (Palmer et al, 2009). In addition, breast cancer when diagnosed in younger women who have a family history of breast cancer is far more aggressive and deadly than when diagnosed in women who are 40 years and above and the disease is characterised with high-grade disease that is severe and spreads fast to the rest of the body (Johnson, 2006). Furthermore detection rates are lower in younger women because breast cancer has been affecting older women and because “breast tissue in younger women is commonly denser than in older women, resulting in mammography results which may be inconclusive” (Bottom et al., 2006). This underscores the importance of targeting young women who have this double risk and who are likely to suffer from this aggressive breast cancer.

In exploring perceptions of young women with a first-degree relative with breast cancer the study hopes to contribute towards building knowledge on what young women know and believe about breast cancer. It also seeks to identify the need for knowledge and awareness on breast cancer issues.

3.2 Objectives of the study

3.2.1 Main Objectives

To explore perceptions of breast cancer among young women aged between 18- 35 years, who are first-degree relatives of breast cancer patients in Bulawayo Zimbabwe. First-degree relatives in this study include young women who are nieces, daughters and sisters of women who have been diagnosed with breast cancer.

3.2.2 Specific Objectives

- a) Explore the experience of breast cancer relatives before and after their relative discovered the breast cancer.
- b) Identify if and how relatives of breast cancer patients perceive themselves to be at risk of breast cancer and the reasons why they believe they are or are not at risk.
- c) Examine what relatives of breast cancer patients know about causes, treatment, signs and symptoms of breast cancer.
- d) Assess what oral or written information was received and or sought by the relatives of breast cancer patients from health care facilities or from the cancer association.
- e) Investigate the role and function of the private local cancer institution in Bulawayo and find out what information if any is available on breast cancer and how it is used.

4 Methodology

This chapter will outline the methods used in this research, including the type of research, sample characteristics, sample selection, data collection, data analysis, and the reasoning and considerations behind the choices of these methodologies.

4.1 Theoretical Framework

A theoretical framework provides a direction through which a topic is to be examined and allows for researchers to situate their research in larger theoretical traditions. The selection of a theory should be developed during an analysis of related literature. For example if the study is in an area in which theory is well developed, the study may be used to challenge or expand existing theory (Marshall and Rossman, 1999). The researcher may borrow concepts used by previous researchers and also develop questions similar to those used in previous studies (Marshall and Rossman, 1999).

According to Reeves (2008) “Theories give researchers different “lenses” through which to look at complicated problems and social issues, focusing their attention on different aspects of the data and providing a framework within which to conduct their analysis”. Different theoretical frameworks focus on different aspects of a problem and can only present a partial view of reality. Therefore it is important to explore different types of frameworks and focus on one that best addresses the particular problem under scrutiny through an extensive study of previous literature in the field (Bordage, 2009).

The next section will explain what theories guided the planning, analyzing and interpretation of the study.

4.1.1 Theories in qualitative research

The aim of the research was to carefully, capture and describe how young women in Bulawayo experience the phenomenon of breast cancer through living with a person who has the illness. How they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others (Patton, 2002). The planning and designing of the study was shaped by phenomenological theoretical framework in order to capture a deeper understanding of the nature or meaning of the young women’s every day experiences with breast cancer.

Phenomenology is the study of how people describe events and how they experience them through perception, thought, memory, emotion and social activity (Patton, 2002). The main focus of phenomenology is to purely describe our experiences as they are given from the first person perspective, without focusing on either the biological or psychological origins of those experiences (Zahavi, 2003). Phenomenological analysis acknowledges that human beings do not exist only for themselves but also for others and that one's existence is not only defined by how they view themselves but also by how others view them (Zahavi, 2003).

In order to explain experiences, data can only be gathered by speaking to people who have experienced the phenomenon, or lived through the experience hence the use of in depth interviews (Gelling, 2011). Description consists of what they experienced and how they experienced it (Creswel, 2007). Furthermore phenomenology requires the researcher to set aside any preconceived judgments and to focus on what is real, based on the information collected from participants. The researcher has to be constantly aware of how his/her own perceptions may influence the data. Consequently the researcher has to constantly reflect and examine how their own standpoints and views may affect the data collection and analysis to avoid biasing the research.

Whilst the overarching theoretical framework was phenomenology other theories also inspired and guided the researcher. Constructivism was also used to a lesser extent in shaping and designing the research. Constructivism states; individuals construct their own knowledge through interacting with the environment, sometimes this knowledge changes as individuals confront new experiences that may contradict their past knowledge (Vygotsky, 1978). Constructivism supposes that all learning occurs in an individual's mind and it is a personal interpretation of experience implying that truth is subjective. It also supposes that all knowledge is closely tied to experience and the contexts of the particular experience regardless of when or how the learning takes place (Swan, 2005).

According to constructivists, we give meaning to the world we live in by reflecting on our experiences (Patton, 2007). Based on this premise the different experiences the young women have had with breast cancer through living with a relative diagnosed with the illness, allows them to have different interpretations of the phenomenon of breast cancer and what it means to them. Consequently the different experiences create different perceptions and knowledge of breast cancer. However simply experiencing a phenomenon is not a guarantee that one has

gained new knowledge, learning only happens when the individual reflects on the experience and processes it internally to actively make sense of the experience (Reich, 2013).

In addition to qualitative theories other theoretical perspectives and concepts that are used to analyze and understand health behaviours also influenced the researchers thinking and guided the researcher during analysis.

4.1.2 The Health Belief Model

The health belief model developed by M Rosenstock in 1966 has often been applied to breast cancer studies to examine potential predictors of breast cancer screening behaviours and in essence its main theme is that personal beliefs influence behaviour (Johnson, 2007; Hayden, 2009). The Health Belief Model (HBM) has been used to identify predictors of preventive health behaviours such as an individual's perceptions of the disease, an individual's perceptions of the preventive health behaviour, and modifying factors such as income, education, access to health services, number and type of provider encounters and certain cues to action (Fulton, 1988). Its main concept is that health behaviour is determined by personal beliefs or perceptions about a disease and the strategies that are present to reduce its occurrence (Hochbaum, 1958).

The initial HBM focused on four perceptions; perceived seriousness, perceived susceptibility, perceived benefits, and perceived barriers (Hayden, 2009). It was later expanded to include cues to action, motivating factors and self-efficacy.

Perceived seriousness deals with individuals' perceived seriousness or severity of the disease. The knowledge of how serious a disease is may be based on medical information, but it may also be a result of the beliefs that one has about the difficulties a disease would create or the changes the disease would make to their life in general (McCormick-Brown 1999).

Perceived susceptibility refers to an individual's perception of risk or the chances of contracting a health condition or disease (Witte, 1992). According to Hayden, (2009) the greater the perceived risk, the greater the chances of engaging in health behaviours that reduce the risk. When people believe they have a great risk of getting a disease, they practise preventive behaviours that may reduce the risk like screening or breast self-examination (Rose, 1995). As expected when people perceive themselves unsusceptible to a disease, they tend not to practise the specific health behaviour. In most cases increased perceived susceptibility is linked to increased preventive behaviours, however, some studies have

shown that though people realise their increased risk this rarely leads to preventive behaviours (Yep, 1993).

Perceived susceptibility combined with seriousness results in perceived threat, which in turn determines how a person processes health information and how motivated they become to engage in a particular behaviour (Witte, 1992). When people perceive a threat of developing a disease they are more likely to engage in more risk reducing behaviours (Mullens, et al, 2003), but this perception of threat does not always lead to changed behaviours.

Perceived benefits refer to the beliefs that people have of the positive outcomes that would result as a consequence of practising certain behaviour in response to a perceived threat. It is specific to an individual's belief about personal outcome, as such they may believe that- for example- mammograms may work for others but not for them (Champion, 2000). People tend to practise new health behaviours if they believe the new health behaviour will decrease their chances of developing a disease (Hayden, 2009). For example research has shown that the earlier breast cancer is detected the higher the odds of survival and that BSE done regularly can be a reliable way to detect breast cancer early. Despite this not all women perform BSE (Muthoni and Miller, 2010). An individual has to first believe that there is a benefit in adopting this behaviour for them to actually practise it (Graham, 2000).

Glasgow (2008) defines perceived barriers as "a person's estimation of the level of challenge of social, personal, environmental, and economic obstacles to a specified behaviour or their desired goal status on that behaviour." For a new behaviour to be adopted the benefits of the new behaviour have to outweigh the consequences of continuing the old behaviour. In the case of breast cancer, literature shows that breast cancer is perceived to be a serious threat that would likely motivate women to practise breast self-examination (Powe, et al 2005; Hopwood 200, Evans et al, 1993; Kösters and Götzsche, 2008). Regardless of the perceived high threat of breast cancer, the barriers to adapting breast cancer preventive measures appear to outweigh the threat of breast cancer itself (Champion, 1993; Ellingson and Yaber, 1997). Some of these barriers range from embarrassment, lack of confidence in performing breast self-examination and having to give up certain habits in order to perform breast self examination to procrastination and forgetfulness (Hayden, 2009).

Modifying factors are other variables that affect the four major constructs of the HBM, which include demographic, socio psychological and structural factors such as culture, education level, past experiences, skill, motivation etc. For example if someone's experience with

breast cancer has been that it is incurable then that person is very likely to have a higher perception of susceptibility due to past experiences. However if they have witnessed a loved one survive cancer and be successfully treated they may not perceive cancer as a serious illness because the illness was treated and cured without any major challenges (Hayden, 2009).

Cues to action or health motivators is another construct of the Health Belief Model, which refers to events, people or anything that may trigger people to change their behaviour e.g. illness of a family member, advice from others or mass media campaigns (Hayden, 2009). This construct of the HBM has been found to have a positive effect on behaviour change in relation to breast cancer. Often women who have relatives who have suffered from breast cancer are more aware of their breast health and engage in healthy behaviours more often than women who do not have a history of breast cancer in the family (Rees, 2004).

Self-efficacy is also a concept that was later added to the HBM by Champion, self efficacy represents the belief that one has the personal ability (confidence) to change risky health behaviours to achieve a favourable outcome. Change of behaviour is influenced by personal sense of control. Often when an individual feels they have the power to efficiently solve a problem they feel more inclined to do so and are committed to carrying out the particular behaviour (Schwazer and Fuchs, 1996). A substantial amount of research has been conducted to find out the relationship between the practise of BSE and self -efficacy and it has been found in some studies to be the strongest predictor of BSE (Jirojwong and Mcnellan, 2003;Avci, 2008,).

In summary cues to action, modifying factors and self-efficacy affect ones perception of susceptibility, seriousness benefits and barriers and consequently our beliefs (Hayden, 2009). The health belief model supposes that one must feel threatened by their current health life style and believe that change of a certain kind will result in a positive outcome, at an acceptable cost and the capability to implement that change (Stretcher and Rosenstock 1997).

4.2 Research Design

To explore the perceptions of first-degree relatives of breast cancer in Bulawayo an exploratory qualitative design was used. Qualitative methodology is suitable for this study because the goal of the study was to understand and explore the current situation of young women's perceptions on breast cancer. This research explores the perceptions of these young women and attempts to gain an understanding of the issue from the participant's views.

Qualitative methodology helps the researcher to uncover a deeper understanding of the participants lived experiences of the phenomenon being studied (Marshall and Rossman, 1990). It is a good option if the researcher aims to uncover the thoughts, perceptions, and feelings experienced by respondents (Grbich, 1990). Qualitative studies focus more on the depth and detail of data than the breadth of it, with an aim of understanding how people make sense of their lived experiences and attempt to explain the studied behaviour without including “judgements about whether what occurred was good or bad, appropriate or inappropriate, or any other interpretive judgements” (Patton, 2002).

Qualitative research seeks to explain a current situation in a specific setting for a specific group (Patton, 2002). According to Patton, (2002), “research takes place in real-world settings and the researcher does not attempt to manipulate the phenomenon of interest”. Qualitative studies can enhance our understanding of the complex and multi dimensional nature of breast cancer perceptions, and how these perceptions influence health behaviour. Qualitative studies are good in bringing out personal experiences, which makes the data rich, unique and perfect for analysis (Milligan et al, 2002). In qualitative enquiry the researcher has the potential to approach the field without prior constraints from predetermined categories of analysis, this creates a potential opportunity for depth, detail and openness whilst collecting data (Patton, 2002).

Furthermore, qualitative methods are good in testing out situations where little is known by facilitating the generation of hypothesis that can be potentially further tested by quantitative methods (Patton, 2002). Little is known about breast cancer in Bulawayo and in Zimbabwe as a whole, and a qualitative study exploring perceptions is possibly a good place to start before carrying out a more comprehensive study that can be generalised to the whole population. Qualitative methods generally seek to answer the why, what, how of a situation instead of the; how many or how much answered in quantitative studies (Patton, 2002).

The method for collecting data is appropriate as we seek to explore young women’s thoughts, feelings and opinions about breast cancer. The main philosophical assumption of all types of qualitative research is that it is about individuals interacting with their social worlds that construct reality (Sherman and Webb, 1988). Qualitative research is about understanding constructed meanings; how participants make sense of their world and the experiences they have in the world (Sherman and Webb, 1988). Consequently due to the deficit in research on

young women's perceptions regarding breast cancer, a qualitative research with its exploratory, descriptive and constructive nature is ideal for the study.

The research is based on data collected from semi – structured interviews, facilitated by an interview guide, with young women who have experienced living with a relative with breast cancer. It also includes informal conversations carried out with a few of the women who suffered from breast cancer and two health professionals who work with cancer organisations within the city of Bulawayo.

4.3 Study Site

The research was carried out in Zimbabwe's second largest urban city of Bulawayo. It has a population of 655 675 (UNSTATS, 2012) and is located in Matabeleland. Bulawayo has three main hospitals, one of which is private and services the more affluent citizens of Bulawayo. One of the 2 government hospitals houses the city's only radiology wing, which services not only residents of Matabeleland but also Midlands and Masvingo provinces which have populations of approximately 1, 622 476 and over 1 486 604 people respectively (UNSTATS, 2012). The 2 government hospitals both have a cancer wing, one which offers screening for cervical cancer and breast cancer and one offering radio therapy treatment.

In Zimbabwe only two hospitals have a radiology wing. As of January 2013, the radiotherapy machine in Bulawayo had been out of order for over 6 months. As a result cancer patients had to travel to Harare the capital city for treatment, which requires a total of 7 hrs travel by road for Bulawayo residents and even more time for those living outside Bulawayo.

The study site was chosen primarily because there has been very little research on breast cancer in the city of Bulawayo. Furthermore, since there are only two hospitals that offer subsidised screening for breast cancer and other cancers for over 3 million residents, the research could potentially draw attention to the barriers faced by residents in receiving treatment or screening for breast cancer. Mpilo hospital serves as the focal point for radiation therapy for all cancer patients in Bulawayo, Midlands and Masvingo provinces, implying that most breast cancer patients were referred to this hospital from several different areas and patients could all potentially be accessible to the researcher.

Last but not least the researcher was familiar with the area, culture and language which is also important because in a qualitative study the researcher is the only research instrument and the credibility of the study relies to a large extent on the “skill, competence and rigor of the person doing the field work”, (Patton, 2002).

Possible participants were also available from other towns that are close to Bulawayo, since Mpilo was the main referral point, but access to these areas would have been limited due to distance, time and financial constraints. Consequently the researcher had to recruit participants within Bulawayo. For most of the part, the research had to travel to the homes of the participants, some of which required 1 to 2 hours travel by road.

4.4 Study Population

The main study population for this study was young women aged between 18- 35 years who have a family history of breast cancer because evidence shows that “women with a family history of breast cancer (generally one or more first-degree relatives) constitute 6% to 12% of women under the age of 50 years. A woman with at least one first degree relative who has had breast cancer has at least twice the risk of a woman without such a family history for developing breast cancer (Neugut and Jacobson, 1995).

In total 10 low-middle income urban women below the ages of 35 were interviewed through semi-structured interviews, two health workers through semi-structured interviews and 4 women who had/have breast cancer through informal conversations. All 10 participated in semi-structured interviews ranging from one hour to 2 hours in length. The characteristics of the 10 young women who participated are presented in the table below; each participant was given a pseudonym for the purposes of characterization and confidentiality.

Participant / Age	Marital status	Education A	Employment S	Relationship
Linrose 22	Single	University	Student	Daughter
Ruth 18	Single	A level	Student	Daughter
Prim 22	Single mom	O level	Unemployed	Granddaughter
Norma 30	Single	University	White collar job	Daughter
Christine 25	Single	O level	Police officer	Niece
Mellissa 23	Married	O level	Unemployed	Daughter
Bomi 29	Single mom	O level	Unemployed	Daughter
Memory 18	Single	A level	Student	Daughter
Amanda 18	Single	A level	Student	Daughter
Patience 27	Married	A level	Teacher	Niece

One of the qualities of a qualitative study is the ability that one has to make adjustments as the study progresses (Patton, 2002). It became apparent as the study progressed that speaking to women who had suffered from breast cancer as well would be valuable towards providing a holistic picture about the perceptions of young women in relation to breast cancer.

4.5 Sampling Strategy

For qualitative research an appropriate sample size is one that adequately addresses the research question (Marshall, 1996). Consequently the study's research questions and characteristics of the study determine which and how many people to select because the aim

is not to describe the distribution but rather the process involved in the phenomenon (Johnson, 2006). Qualitative inquiries focus typically on “relatively small samples...selected purposefully” and they aim to produce a wealth of detailed data about a much smaller number of people and cases hence results cannot be generalisable (Patton, 2002).

A combination of purposive sampling and snowballing was used to identify participants for the study. In purposive sampling the researcher “selects individuals and sites for study because they can purposefully inform an understanding of the research problem and the central phenomenon in the study” (Creswell, 2007). Through purposive sampling the researcher was able to select information rich cases for in-depth study, which provided great insight on issues that were central to the purpose of the research.

4.6 Recruitment of first degree relatives of breast cancer patients

The method of recruiting participants used was snowballing and purposive sampling. The only link to these young females was affected first-degree relatives. After applying for ethical clearance from the hospital that would provide names of possible breast cancer patients, the head nurse in the radiotherapy ward was approached. She suggested that the researcher attend review days on Monday and Wednesday when patients with cancer had appointments. The following Monday the researcher went to the radio therapy ward and there waited for the key informant to refer breast cancer patients who were coming for reviews to the researcher. From then on the researcher would ask them about their family, and if they had a young woman between the ages of 18- 35 who would be willing to be interviewed. Five participants were recruited through this method.

After the first five participants were gathered, snowballing technique was used, as it is likely that cancer patients may know each other and thus assist in identifying respondents. Snow balling refers to a process of accumulation whereby participants are asked to pass the research information on to other people that they know who would be suitable for the study (Llewellyn et al.1999). Where respondents are few in number, snowball sampling takes advantage of the social networks of already identified respondents to identify more respondents (Atkinson and Flinch, 2004).

Snowball sampling provided an added advantage; not all the participants used the radiotherapy ward available in the city due to long waiting lists and the fact that the machine had been broken down since June 2012. Consequently the rest of the participants were

sourced using snow balling from other breast cancer patients who had shared hospital rooms with other patients, or those who had met during support group meetings. Using the two different types of sampling enabled the study to have a range of people that may not have been available using one sampling method.

4.7 Recruitment of women who had or have had breast cancer

After the interviews with the young women who were relatives of breast cancer patients, the researcher had an informal conversation with a few of the women who had breast cancer, depending on the location of the interview and the availability of these women. The researcher initiated the conversations and this was done primarily to show concern and respect to the older women and also find out how they have been coping with the illness. These women displayed a willingness to talk to the researcher and provided rich information and a new perspective from their younger daughters. In total 4 women were interviewed using informal conversations.

4.8 Recruitment of health workers

Two interviews were conducted with a breast cancer survivor from the Cancer Association of Zimbabwe and one professional nurse from Island Hospice, both non-profit organisations that offer assistance and support to cancer patients. The researcher approached Island Hospice and asked for permission to ask a few questions about their organisation, access was granted immediately and a nurse who volunteers with the organisation was assigned to me. The interview was conducted in English and tape recorded. It was a semi -structured interview, which lasted 45 minutes, with the nurse providing information about the services offered to breast cancer patients, as well as her opinions and perspectives about breast cancer.

The second interview was a formal, unrecorded interview with a volunteer from the cancer association of Zimbabwe who focuses on support groups for breast cancer patients and who is also a cancer survivor. The researcher met the volunteer at the radiotherapy wing at Mpilo Hospital after being referred to her by the head nurse at the radiology wing.

4.9 Data collection

4.9.1 Semi –structured interviews

‘A good interview is like a good conversation. Good conversation is a two-way affair. One person talks while the other listens, responds and encourages’ (Liamputtong and Ezzy (2005). In the interview, the person who did most of the talking was the interviewee. During the interview the researcher asked questions and talked a little about them self, but most of the time the researcher merely listened, and the focus of the observation was the experience of the interviewee. In depth interviews facilitate conversations with a purpose and interviewees were able to discuss a wide range of topics.

Semi-structured interviews were chosen as the method for data collection. In semi-structured interviews the researcher “has a list of questions or fairly specific topics to be covered often referred to as an interview guide” (Bryman, 2008). Questions asked during interviews did not follow a specific order and the respondent had a great leeway on how to respond. The researcher had the possibility to ask questions that are not included in the guide as the researcher picked up on what the respondent was saying. The interview guide provided areas in which the researcher was “free to explore, probe, and ask questions that will elucidate and illuminate that particular subject” (Patton, 2002). Semi- structured interviews allowed the researcher to carefully decide how best to use the limited time available in an interview setting.

The semi- structured interview allowed the researcher to explore topics in-depth, and was able to unearth some underlying issues that may be omitted by structured interviews. They also allowed for flexibility in interviews whilst pursuing topics of particular importance to different individuals, and adjusting questions for different participants or circumstances.

Once participants were identified and they had agreed to participate in the research, the researcher gave the participants an information letter and informed consent form, either in English or Ndebele, a day before the actual interview. This was done to provide the participants with ample time to reflect upon what was required of them and note down any questions they might have for the researcher.

Interviews were carried out at a place convenient for the participants, which was usually their home. They were conducted at a time suitable for the participants and they usually lasted as long as 45minutes to an hour. Interviews were carried out to explore perceptions and participants lived experiences with the illness. A themed interview guide with open-ended

questions was used as a base to begin the conversations, with occasional probing to follow up what has been said through direct questions. Different participants focused on different issues and this enabled the researcher to see all the social and cultural dimensions that different families faced. The interviews all had different structures depending on how the respondent understood events and issues. The advantage of using face-to-face interviews was the possibility for immediate follow up and clarification on some unclear issues.

Prior to beginning each interview, the researcher made polite conversation on general matters with respondents, to make them comfortable and introduce some familiarity between the researcher and the participant before talking about breast cancer. Issues discussed ranged from the weather, school, and challenges present in everyday life situations to anything that spontaneously came up. This appeared to create a more relaxed environment and may have possibly contributed greatly towards the amount of personal information revealed during each interview.

Right before each interview, the researcher would then enquire about the consent form, and if they had any questions or needed any further clarifications. Once the informed consent form was signed the researcher explained again verbally, the participants' rights and encouraged them to stop the interview whenever they felt uncomfortable.

Initially the researcher planned to carry out the interviews in English, but at the request of the Zimbabwe Medical Ethical Board, a separate themed interview guide was drafted in Ndebele, which is the mother language of most of the people living in Bulawayo. Most participants were comfortable using Ndebele, resulting in most of the interviews done in Ndebele and then later translated to English. The remainder of the interviews were conducted in English. The researcher was familiar with the Ndebele, and this facilitated the participants to respond freely in the local language with greater flow of conversation.

Interviews require attentiveness, and in addition to the tape recorder, the researcher took notes on certain body cues and body language displayed by the participants. Understanding the non-verbal communication made it easier for the researcher to respond appropriately to what was being said and avoid saying anything that might upset the respondent or change the flow of the conversation.

Although recruiting participants was a challenge, after the 7th interview, saturation was reached and no new information was introduced, in the last 3 interviews. A larger sample size may not have guaranteed any new information.

4.9.2 Informal Discussions

Four women who had suffered from breast cancer were also interviewed through informal conversations. This was done to include the breast cancer patient, and shed some light on other issues that initial respondents may have been unsure off. This was also a good way to explore the different perspectives held by the different groups of women about breast cancer. All the women displayed a willingness to talk about their illness. Notes were collected during all of the interviews.

In an informal interview most of the questions flow from the immediate context, the conversation flows in whatever direction appears to be appropriate at the particular setting (Patton, 2008). An advantage of using informal conversations is the opportunities it offers for flexibility and spontaneity in discussing issues. In most cases according to Patton, (2008) the respondent may not know during any particular conversation that data is being collected “in many cases participant observers do not take notes during such conversational interviews, instead writing down what they learnt later. In other cases it can be both appropriate and comfortable to take notes or even use a tape recorder”.

4.9.3 The interview guide

To facilitate the interview process an interview guide was used. An interview guide is a list of questions or themes that will be explored during an interview, and provides a systematic way of approaching the issues under study and ensures that similar lines of inquiry are pursued with each person interviewed (Patton, 2002). The researcher identified general topics that could possibly be discussed during the interview. The guide was not a questionnaire, it was a useful tool for the researcher to monitor that the interview was going in a direction that will produce relevant information that answers the research question. It was important to ensure that there was a certain order on the topic areas, so that the questions flow well during the actual interviews and to avoid asking leading questions.

The thematic interview guide was originally constructed in English, and then later translated to Ndebele. The translation was done in a way that would capture the original meaning in English, to ensure participants would have the same understanding of the questions being asked. Translators who specialise in translating documents from English to Ndebele did the

translation to achieve translations that were as true to meaning as possible. The researcher then went through the interview guide and ensured that the language used was comprehensible and relevant to the people to be interviewed.

Patton states that a good qualitative interview should be open ended, neutral, sensitive and clear to the interviewee. There are six types of questions that one should ask, those based on “behaviour or experience, on opinion or value, on feeling, on knowledge, and on sensory experience and those asking about demographic or background details” (Patton, 2008). The interview guide followed this design, dwelling first on questions that the interviewee can easily answer, e.g. their experience during their relative’s illness and then to more difficult and technical questions such as causes of the disease.

4.9.4 The audio recorder

An audio tape recorder is used in such studies to document and thereafter analyze the interviews (Kvale & Brinkmann, 2009). In the current study, a tape recorder was used to remember what was said during the interview and capture as much of the information as possible for use during analysis. All participants were informed about this in advance and were asked for permission. They were informed of their right to switch off the device at any point during the interview, or erase taped material afterwards. Participants were also assured that the tape recorder would only be used by the researcher for the purposes of the study and then deleted after. Most participants seemed to eventually forget about the presence of the tape recorder as the interviews progressed. One participant though, was uncomfortable with the use of a tape recorder, although no specific reasons were given; consequently the researcher took down notes during this particular interview and the audio recorder was not used.

4.10 Data Analysis

Data analysis is a continuous process, and occurs also during data collection. The first step is to familiarise with the material as a whole (Patton, 2002). It involves bringing order, interpretation and structure to the collected data (Marshall and Rossman, 1990).

4.10.1 Management of data

All data was kept in a secure location by the researcher. The names of those who participated in the research were only known to the researcher and were kept separate from the transcripts and the recorded material. There were no names mentioned during the interviews that were recorded to possibly link participants back to the interviews. After the interviews the

recorded material was transferred to the researchers laptop that had a password lock at all times. During and after transcription, the researchers' private laptop was used, and the data was kept safe always.

Participants were given pseudo names throughout and there is no direct way of linking any participant to their transcript for anyone but the researcher.

4.10.2 Transcription

All the interviews were tape recorded in either Ndebele or English. The transcribing was done verbatim by the researcher in a quiet place with no external influences that might interrupt the transcribing process and result in errors that may change the content of the data. Transcribing these personally provided the researcher with an opportunity to get immersed in the data from an early stage as the researcher had to transcribe as well, and experience that might generate some insights (Patton, 2002). Transcripts recorded in Ndebele, were first transcribed verbatim in Ndebele then later translated to English by the researcher.

Some interviews were transcribed in the field and this helped the researcher adjust the questions in the interview guide with the aim of improving the approach to other participants. However not much changes were made to the interview guide as each interview was unique in structure and content and each participant focused on matters they felt were important to them, it was therefore imperative for the researcher to use the interview guide to cross check that all issues had been addressed.

The researcher transcribed the 3 interviews recorded in English verbatim. The interview carried out with the health care worker was conducted in English and transcribed verbatim by the researcher.

4.10.3 Analysing Procedure

The first stage of data analysis involved familiarising myself with the content of the data. This was facilitated by the fact that I transcribed the interviews personally. However I went through all the data several times again and wrote down any findings that immediately jumped out at me as well as all my first impressions.

Data analysis was carried out using an inductive approach, through the process of open coding, guided by constructs from the health belief model. Open coding is an important first step to creation of theory which is a very open and general style of coding that consists of identifying themes, patterns and categories in ones data (Sarantakos 1998: 203).

Coding concepts were yielded which were later grouped and turned into themes that appeared throughout all of the interviews. Throughout the coding process terms used were borrowed as much as possible from participants own words. I focused on an individual case and identified themes that recurred in each interview, by highlighting occurring topics within the interview. During this process I shared some of the transcripts with fellow classmates, there was no violation of confidentiality during this process, as there were no names on the transcripts to link the participants back to the interview. They went through the transcripts and identified themes that I compared with my own to test my own findings and to check for any other emerging themes I may have over looked.

4.11 Credibility

All research has its strengths and limitations, which was also the case for this study. Assessing quality of qualitative research is often a discussion of how the strengths and limitations of the applied methods have affected validity, reliability and transferability of the findings. Credibility refers to conducting the research through the use of proper practise and sound methodology (Patton, 2002). Guba and Lincoln (1985), state that ensuring credibility is an important factor in establishing trustworthiness in a qualitative study. Looking at validity, Malterud, (2001), suggests that, “internal validity asks whether the study investigates what it is meant to, whereas external validity asks in what contexts the findings can be applied”.

Throughout this study, methodological and ethical concerns were constantly evaluated. One possible aspect that ensured that the study investigated what it intended to was through the use of data person triangulation. It ensures a completeness of findings, and a rich picture of the attitudes, needs or behaviour of those under study may be constructed based on the contributions of a range of people. An accurate picture of the phenomenon under study may come from a combination of different individuals’ perspectives (Malterud, 2001). Data was collected from three different sources i.e. young women with first-degree relatives, women who had or have suffered from breast cancer and health workers who offer services to cancer patients. The main themes uncovered with the young women were similar to those uncovered with their relatives who had suffered from breast cancer and perspectives from the health workers allowed for a complete picture of the phenomenon of breast cancer in this particular setting.

Trustworthiness is also based on response bias, what the informants are willing to share and how they share it (Lincoln & Guba, 1985). The participants in our study may have had their own reasons for participating, and may have shared information according to what they thought I would have liked to hear, and yet I would have interpreted this information as their genuine experiences and opinions of breast cancer. In our study some participants may have assumed our aim was to help breast cancer patients financially and may have possibly underscored the financial challenges they had faced with the hope of possible assistance. To address this, my first action was to explain my role as a research student working individually towards a master's degree, without any financial backing from a bigger organisation. This was explained in the information sheet and when introducing myself for the first time to the participants. In addition I mentioned that there would not be any immediate benefits from participating in this study.

A limitation that must be considered is the reliance on self-reported data. Attitudes and behaviours reported by the participants may not have been fully accurate. Participants may have engaged in socially desirable responding, which is an attempt by the respondent to give answers that will be viewed favourably by others (Paulhus, 1991). An attempt to reduce socially desirable responding (SDR) was to reassure the participants of their anonymity. This was done by informing them through the information sheet and before each interview that there would be no obvious link between their responses and their identity. Furthermore each interview was conducted in private, with just the participant and the researcher separate from their ill relative diagnosed with breast cancer. Some of the discussions during the interview revolved around the ill relative with breast cancer, participants at times disclosed information about their relative in hushed tones. Such action suggests that this information may not have surfaced had the relative been present in the room during the interview.

Each person approached for the purposes of participating in our study was given an opportunity to refuse to participate in the study. This ensured that all the participants interviewed were genuinely willing to participate in the study without any undue influence. Participants were encouraged to be frank from the onset of the interview. To encourage this frankness from participants I mentioned to them that I was not a professional but a student and I was also here to learn from them. This was done to encourage participants to open up and talk of their experiences without fear of losing credibility in front of the researcher.

Using different sources for recruiting the participants provided us with participants with varying backgrounds potentially giving a broader understanding of perceptions of first-degree relatives. Our study had young women of school going age, university students, stay at home mothers, and working women. Also there was a mixture of socio-economic status backgrounds. Although there was no deliberate step taken to measure the socio-economic status of the participants, participants openly spoke about their financial backgrounds, and sources of income.

The findings from this study are from a small sample in a specific geographical area collected in a specific time and are therefore cannot be generalised to a larger population. However, given the nature of qualitative research this was not the purpose. However, since a thick description of the context, the research setting, methods used and the study population was described in detail, some extent of transferability might be possible to other similar settings.

Data analysis was conducted mainly by the principle researcher, thus the findings are very much dependent on personal interpretations of the data. In attempt to reduce subjectivity, I worked together with a couple of my fellow students for parts of the process of analyzing the data. They analyzed some of the transcripts and coded them, followed by feedback and discussion on their interpretations of the data. The comments and discussions that ensued allowed me to challenge some of my assumptions and strengthen some of my arguments on the interpretations we found. Frequent debriefing sessions with my supervisor also highlighted some flaws in my research design and methods and also helped me to recognize my own biases prior to the commencement of data collection.

To encourage neutrality through the research process, I reflected on my data collection as it progressed. I reflected on the interviews I had conducted and how I could attempt to improve them and also on the patterns that were appearing in collected data. The subjectivity of the researcher was always present and will influence the results, which makes reflexivity important in the validation of the study (Patton, 2002).

4.12 Reflexivity

In qualitative research the researcher is deemed as the primary instrument of data collection and analysis, consequently in every step of the research process the position and perspective of the researcher will influence the research in some way or another. Thus the researcher has to continuously reflect on the ways he or she affects or influences the situation. One of the

ways a researcher may do this is by recognising the ways in which the researchers individual awareness of the topic affects the research, recognising the relationship dynamics between the researched group and the researcher and the ways in which meaning and interpretations are assigned to data (Johnson, 2003).

4.12.1 Preconceptions and Assumptions

My interest in breast cancer arose from my involvement in the master's programme in International Community health at the University Of Oslo. My previous background was in Development Studies; consequently many of the health issues that were brought up were new and very interesting to me. I have an interest however with working with vulnerable groups and it was always a possible plan to do research either on women, children or the elderly population as they are the backbone of the community and health issues impacting women also impact the development of a nation.

During the course work in the masters class, it came to my attention that breast cancer mortality was high in Africa, on reflection I realised that in my experience growing up in Africa I had never been taught about breast cancer nor had I met a woman suffering from breast cancer before, yet so many women were said to be dying from the illness. This eventually highly influenced my choice of research. I followed up by a thorough literature search on breast cancer in Southern Africa. It was apparent that there was a shortage of knowledge about breast cancer among most women in Africa both educated and uneducated and a huge research gap on breast cancer in Bulawayo.

I immediately formed my opinion about the state of breast cancer in Bulawayo as that of people having insufficient knowledge about the disease partly because I too had very little knowledge about the disease prior to my extensive research on the subject. Coming in to the research with this opinion may have affected several aspects of my research. Firstly it may have compromised how I phrased my questions and what kind of themes I chose to explore further, perhaps based on what I felt I had not known and therefore assumed other women did not know either. After realising this I made an attempt to let the questions be as explorative as possible and open to individual interpretation by the participants to avoid categorizing their views and perceptions. For example the first question in the interview guide was a general question,

“Please tell me about your mothers experience with breast cancer”

From this question participants shared their different stories and all the other themes in the theme guide built up from the information provided by the participants through probing.

Based on my own previous limited knowledge on the subject of breast cancer I may have had my own expectations of the results of the research. I expected the women in the study to have limited knowledge on the subject of breast cancer. The discussions I had with my supervisor on the results of my study allowed me to view the data as it was without judging the participants but instead to attempt as honestly as possible to present the views of my respondents as they had presented them to me. In qualitative research it is important for one to leave out individual preconceptions and assumptions and I attempted to do this by reminding myself of the importance of viewing each individual as different and having a unique experience.

I also reminded myself that I was not a part of this group, as I had never had a relative with breast cancer. Thus, though I was of the same age group as they were and had similar background in terms of culture, our situations were different and I should not have pre-determined assumptions. I presented myself as a student, and all the participants seemed to accept this with ease and this did not affect the interviews negatively. Perhaps the fact that I was of the same culture, race and ethnicity as the participants made it easier for the participants to open up and see me as one of them.

4.12.2 Cultural Barriers and Opportunities

I had been away from Zimbabwe for 5 years prior to carrying out this research. I have become more exposed to different cultures since I moved to Norway in 2008 and my views have changed quite a lot since then. However in spite of this I was still familiar with the culture. This definitely contributed towards making the data collection process smoother. I was aware of what was expected of me when arriving in people's homes. I greeted everyone politely with respect in my mother tongue; Ndebele and made small talk about the weather and shortage of water or sporadic electricity power cuts. This way people warmed up to me and may have found me "respectful" which is something that is prioritised in my culture, as someone should not appear boisterous.

It was also of utmost importance to check my appearance and how I presented myself to my participants so they would not prejudge me and withhold information based on my appearance. I made it a point to dress in modest dresses to avoid appearing inappropriate or flashy and influence the quality of the interview and the responses of the participants. I

avoided speaking English too often as people in some areas associate people who converse in English as snobbish and that might result them in not opening up, or answering untruthfully with hopes of impressing me.

I am still very much aware of the judgements that people have of people who come from abroad. Since Zimbabwe has been going through economical turmoil, people who live in countries in Europe are regarded as “rich”. Consequently perhaps some of the participants agreed to participate in the research in the hopes that there might be some economical benefits at the end of the research. However this was not made explicit in any of the conversations or interviews and most seemed just willing to participate in the study. Most families had faced economical challenges in sourcing funds for chemotherapy, and for some these challenges were ongoing. This was a dilemma of sorts for me, as I could not offer any assistance except to share information I had received from other breast cancer patients as to how they got help with chemotherapy drugs.

My shared identity with the participants i.e. language and identity, facilitated a more rapid and more complete acceptance of me by the participants, which facilitated a greater depth to data collected and this created a certain degree of conflict for me. It became increasingly difficult to establish myself as the researcher, as I caught myself answering some of the participant’s questions when I should not have been or leading the participants in my responses. I consequently had to exercise self-restraint before I responded inappropriately and consciously remind myself of my position in this setting, because the atmosphere resembled one of being around friends having a general discussion on certain issues and not a research project for a master thesis. For example participants would pose questions during the interview:

“I heard that if there’s family history of breast cancer, that’s all I know, how else do people get BC?”

This initially caught me off guard but I responded by informing her that I would have some information for her at the end of the interview that she could later read for herself without offending the participant and changing the flow of the interview.

4.12.3 Dealing with Dilemmas in the field

I recruited some of my participants via the government hospital. I feared that this would possibly affect the quality and depth of information they would supply. Some of the themes

to be explored required participants to talk about the hospital their relatives had received treatment from and the kind of information they received about breast cancer from the hospital. I worried some of the participants might have refused to disclose this information in fear of repercussions from the hospital. Nonetheless, I found that participants were extremely open and honest about their experiences regardless of how negative their encounters had been. Informing them that whatever they told me would never be linked back to them by anyone probably reassured them and encouraged them to be open without fear of future punishment from the hospital by refusing them treatment.

During my literature review and discussions with other peers it came to my attention that many African women believed that breast cancer was a supernatural occurrence and was a result of witchcraft. I consequently may have assumed that this was the case in this particular community and hoped to explore this in more detail. However most participants barely brought this up as a possible cause of breast cancer, and it was important for me as the researcher not to push participants to discuss issues they did not consider important in relation to breast cancer simply because I had expected them to be important. As such I had to be attentive and avoid guiding participants to incline to certain paradigms. Going over the transcripts, taking notes after each interview and reflecting on my research as a whole, allowed me to put such issues into focus and avoid unduly influencing participants.

Another dilemma I faced in the field was how to regulate the flow of information from participants. Some participants spoke at length about other insignificant matters whilst other participants revealed too little. For most of the time I allowed participants to talk in length about their experiences and feelings about breast cancer, but it was also important to guide the participants and avoid them spending a lot of time discussing other issues that were not directly relevant to the research. This was not a crisis in my opinion, but to keep issues in perspective, I would probe on a previous issue they had previously brought up, when participants paused for air to gently guide them back to the scope of the research if they had strayed too far. The real challenge was how to obtain information from those who spoke very little. I had already faced challenges in recruiting participants for the research and I felt that I had to get as much information as I could from the few participants I had. In the first interview of this kind I had not anticipated this challenge and I was not sure how to react or make of it. I avoided being forceful or appearing impatient with the participant, to avoid offending her. Eventually after going over the transcript, I realised that, perhaps as long as I

had asked and probed on relevant issues the information would still be sufficient for the research and the questions I was attempting to explore.

It was interesting to note how both cultural and structural barriers influenced people's perceptions. Whilst I came into the research expecting more structural barriers, i.e., lack of information about breast cancer and lack of services, it was also apparent on analysis that barriers need to be broken within the family structure as much as in the health system.

4.13 Ethical Considerations

For any study to be valid, it must be carried out ethically, to protect the participants from exploitation or any possible violations from researchers and research projects. In most cases participants are not aware of their rights and it is up to researchers to ensure that ethical guidelines are met whilst conducting research. Whilst most research is well intended there might be some adverse negative effects that could occur during the collection of data (Goodwin, 2006). Consequently it is important for the researcher to investigate whether any type of harm could occur whilst planning research and to ensure that mechanisms are instituted to remove or lessen the harm. It is, essential that the potential for harm to arise is evaluated and to ensure that researchers behave according to appropriate ethical standards; consider how their research might negatively affect participants; and to protect the researcher, supervisors/teachers, and the institution from being placed in situations in which individuals could make claims of inappropriate behaviour (Goodwin, 2006).

4.13.1 Ethical Clearance

Ethical clearance was granted from the Regional Ethical Committee in Norway and also from the Medical Research Council of Zimbabwe in November 2012. In order to do research in Bulawayo the researcher also had to get clearance from Mpilo Central Hospital, the initial participant recruitment site.

4.13.2 Informed consent

To ensure that participants were certain and aware of the expectations of the research project an information sheet typed in both Ndebele and English was provided to them as soon as possible research participants were identified. The information sheets remained in their possession until the researcher contacted them for the interviews. This allowed them ample time to reflect and decide if they are willing to participate or not. The information sheet included the main focus of the research project, the importance of the study for the participants and the larger community, the right to reject and/or withdraw from the research at any point without giving reasons and finally any possible risks and benefits from participating in the research. The data collection methods were also included to inform participants that the interviews would be collected using a tape recorder. After potential participants agreed to participate they were given an opportunity to clarify any ambiguities they may have had, however all the participants did not have any questions to clarify. It was important to ensure that during the recruitment participants were not unduly influenced or

coerced to participate. A written consent form was then provided for the participant to sign at the beginning of each interview.

At the onset of the interview and throughout the interview the researcher made it a point to verbally remind the participant that they were allowed to stop the interview if they felt so or delete some information they had disclosed, during the interviews the participants did not stop the interview or request for any information to be erased.

4.13.3 Confidentiality

Participants were reassured that private information and data identifying them would not be included in any documents; names and identifying information were changed for the thesis. The researcher also made sure that there would be no link between participants and the information they provided to avoid any information shared during the research being traced back to any participants. Names of the participants and the recorded material were only traceable to the researcher.

Furthermore the nature of sourcing respondents ensured that key informants at the hospital have no way of knowing who participated in the interview. A key informant provided only names of those with breast cancer and following correspondence with them and procedures taken to identify potential participants, was left to the researcher. This ensured confidentiality and assured respondents of remaining anonymous.

During the research the participants were not required to disclose personal information such as income or any sensitive information that was outside the scope of breast cancer and the purpose of the research.

4.13.4 Risks and benefits

The potential harm and benefits to participants as a consequence of participating in research need to be approached and potential benefits should outweigh the risk of harm (Kvale & Brinkmann, 2009).

Breast Cancer is a disease that is affecting women all over the world and is accompanied by high mortality in most African countries. Yet African countries command only 5 % of the world's economic resources and health care programs are already fully extended and frequently insufficient (Parkin, 1994). The results of this research may be distributed to local cancer organisations that may use the information collected in the results to expand and

develop programmes that will disseminate information about breast cancer with the needs of the women in mind, garner support to assist those who cannot afford treatment and to encourage people to immediately seek treatment once a lump is discovered. However it may take time before any concrete initiative is developed. Available breast cancer awareness information is only targeting a select number of women, thus a more comprehensive and widespread campaign that has potential to reach a large number of women is required.

The researcher may also be creating a potential hazard as participants may become aware of a disease they have no means to treat or afford the cost of screening programmes. Many participants mentioned how it was a daunting task to even consider discovering the disease as they were already struggling with the cost of their relatives illness, but further discussion with them, showed that some of them reasoned that the sooner you discover the illness perhaps the less money you would spend on treating the illness. As a result, this was beneficial to them, because they thought more on the issue and realised that it is better to discover the illness as soon as possible and get it treated.

The researcher was aware of the ethical dilemma that exists by failing to provide any correct or concrete information about breast cancer to the participants as some of them may not know much about the disease but be in real danger. Thus when all the interviews had been collected information about where to find breast cancer associations in the city was distributed to participants and also a small pamphlet on breast cancer causes, risks, signs and symptoms was distributed to the participant.

5. Findings

This chapter will identify the main findings of the research. Through the process of thematic analysis main themes were identified from the interviews that were undertaken.

5.1 Living the Cancer Experience

In order to understand young women's perceptions and how they eventually perceive their own risk we explored how the participant "lived" the cancer illness through their relative's cancer experience, because family dynamics have been proven to play a significant role in how second degree relatives create their own personal perceptions about breast cancer (Chalmers and Thompson, 1996). Through this theme we are able to understand the extent of involvement with the sick person during the illness and finally analyse how this experience shaped the perceptions of the participants in the study.

5.1.1 Sharing the cancer experience

Sharing the experience through the relative referred to the woman's emotional involvement with the experiences of the ill relative's breast cancer experience. The degree to which the participants were involved in the relative's illness strengthened or weakened this sharing experience and thus either increasing the impacts of breast cancer or alienating the participants from the breast cancer illness. Sharing the cancer experience depended on the relationship of the cancer patient and the young women. In this section, the relationships between the young women and the cancer patients will be presented as well as the role played by the participants during the relative's illness.

5.1.1.1 Exclusion of young women from the cancer experience of their relatives' illness

Most of the participants expressed how they felt left out of any discussions related to their ill relatives. None of the first-degree relatives interviewed reported being consulted or informed about how long the treatment plan their sick relative would take. Some viewed this lack of involvement negatively whilst others accepted this situation and felt their ill relatives had been protecting them from unwarranted stress and worry.

The fact that they never fully shared in this experience created a distance between them and the disease, as there was no real emotional involvement with the person suffering from the disease. Some of the younger women (18-24) felt they were being excluded from decision making due to their age, and the desire of their parents to protect them, consequently a large

part of their relatives experience with breast cancer was relatively unfelt and did not have a profound effect on them. Most of them were not even aware of the severity of the cancer or had simply never seen the affected breast until advanced stages.

“I just knew about it, but I think when I was at school, it is because maybe they did not want me to worry about it, so I did not know much about it until I saw her when I came back from school” Linrose, 22yrs

“I was pretty much on the sidelines... I was ok with it...My schoolwork was not affected” Ruth 18yrs

“Just when you are children, and you do not know what is going on, you are not really faced with any challenges. I never even got to see the breast” Prim, 22yrs

Of the 10 participants interviewed only one young woman, had lost her mother to breast cancer. The mother had had breast cancer for a long period of time, and the daughter had been the main caregiver when the mother was in critical condition. Only she had physically shared the experience of breast cancer with her mother. She only became the primary caregiver when the mothers' condition had deteriorated significantly and had not been involved in any decision-making about treatment or care giving before she was critically ill. She spoke about how when her mother was critically ill, she had to look for money from different sources to try and raise money for her mother to undergo a biopsy to check for cancer, something she was not responsible for before as her mother relied on her grandmother instead.

“..But by then we were also very young, we did not know much and my grandmother gave her advice..” Rose, 22

5.1.1.2 Nature of the relationship between the ill relative and the participants

To further understand how sharing the experience is important in shaping perceptions, we also have to explore the nature of the relationships between the participants and their relatives and how this affected living the experience of breast cancer through the relative's illness. Most of the participants were still considered relatively “young” by Zimbabwean standards during their relative's illness and some participants brought up the issue of their weak relationships with the ill relatives. Participants expressed how their parents were uncommunicative even prior to the breast cancer diagnosis and how this did not change during the illness. This created a barrier in the sense that the young women had limited options to what they shared with their relative during their illness.

“I just knew the basics, she got B.C., the financial stuff I didn’t know much about it, but since she was on medical aid, medical aid used to pay for all of us. But I think my sister was included more than I was, sometimes I think my mother likes her more than me. She’s more open with her than she is with me”. Rose 22yrs

“You know when you are a girl, you have no sister, and your mother is the closest woman to you. You want to have like, that sister to sister talk, like that mother daughter talk... you know ...it hurts that I couldn’t get through to her, like she used to block us out” Amanda 18yrs

According to a few of the participants they were only informed of the illness at the advanced stage of the breast cancer and even then, their ill relative relied on older family members for assistance. Most of the participants reported helping their ill relative with basic things around the house such as preparing meals and tending to the affected breast after chemotherapy and mastectomy.

“My mom has a problem with her hand ... So she would keep calling me to come and massage her hand, or come and massage her back” Amanda 18yrs

“We just ask her what she needs, because she already has pills that she got, that if she is vomiting then she drinks those. If the medicine is available, we give it to her, that’s the only thing we can assist her with” Christine 25yrs

The nature of these relationships and the limited involvement of the younger women in their mothers or sisters lives may be partly explained by the fact that some of the participants were students in boarding schools and it may have been difficult for them to be part of the experience. Four of the participants interviewed reported being at a boarding school at the time their mother was diagnosed whilst 2 others were not living together with the ill relative. Another participant did not see her mother’s affected breast until she took her to get a biopsy. When asked by the researcher why this was so her response was:

“ I had some kind of fear...just a bit...you know there’s this sore you can look at, you know you can look at it and put betadine (ointment used for wounds)...after 3 days it will be closing up .but that one was white , I think it was pus , it was white, some parts were black” Bomi 29yrs

5.1.2 Effects of the illness trajectory

The following section looks at the emotional and social adaptations that had to be made by the young women and their ill relatives as the illness path changed over time. Participants who witnessed their ill relative visibly decline in health during the course of their breast cancer illness were more affected by breast cancer than those whose relatives had no significant physical challenges and this possibly determined how intensely they personalised

their own breast cancer risk. Most of the participants described feeling positive about breast cancer and the disease outcome, because their relatives suffering from breast cancer had responded to treatment and had gone into complete remission and were still living, furthermore their health had not declined to the point where they had to depend on others for care. This success contributed to the positive attitude most young women had about breast cancer and consequently possibly relating to breast cancer with seemingly little emotional impacts.

“She has been strong, like really strong, even the days during chemo because when I was done with my O level exams she was still doing chemo, she was that kind of person who wanted to do her things by herself, no matter how sick she was, she wanted to wake up and do it herself, like no I want to do my own laundry, I want to clean my own...because at that time we didn’t have a maid, she did not want a maid anyway. I want to do my things, my way. So she was pretty strong” Amanda 18yrs.

“For me it was the same. Maybe because sometimes you see the person doing stuff for herself so it’s not... it’s just hard those times when you see that she is feeling pain here and there but when she is able to do stuff for herself it doesn’t bother you so much....” Norma 29

This was the general feeling most participants described, as they had all witnessed their ill relatives continue to do the things they did before the diagnosis and living with cancer was never really at the forefront of everyone’s mind. However, participants felt a heightened sense of worry during chemotherapy treatment as their relatives became sicker than before, participants described how they were “scared” by the chemotherapy:

“Because the first days after chemo, you would have thought she was about to die...you would have been looking at death in the eye, you could see the pain she was in, and you could tell the pain was severe and she would wake me up at night and tell me, “I think I am dying” Bomi 29yrs

“When she was doing her chemo, that’s when she was now sick. That’s when it got to me, it scared me” Ruth 18yrs

“I used to worry a lot, because sometimes she would be vomiting, and she wouldn’t want to eat, and she would be like what is the point of eating anyway. You know you get worried...so yes, I think that’s the part that used to scare me a lot” Amanda 18yrs

One participant whose mothers illness had poor prognosis due to late diagnosis, explained that maybe she would only be scared if her mother was now dying, because she had seen the

disease progressing from when it was a lump till it became a huge sore without affecting her mother's ability to function normally:

“I think when it gets to that point where she can't wake up or do stuff for herself that's when it will hit home. Plus the fact that since 2004 you know that this person is like this, the lump grew, burst. You watch everything, telling yourself that uhuh its just a process so, unlike other people , it starts 3 months, 4 months and the person is bed ridden, ...so for her it dragged out you will just be taking it as an every day event” Bomi 29yrs

The only participant whose mother had died displayed increased emotional frustration because her mother's illness required great emotional and social adjustments as she had witnessed her mother's suffering. Her mother had suffered a long and painful experience, which she lived with her as she vividly describes all the challenges she faced during this period:

“I had too much on my mind; I couldn't even sleep when I had left her at the hospital, I would wake up early in the morning, by 6 o'clock I would be at the hospital already. Sleep is hard to come by when someone is in that state...sometimes she would be so silent, you would be thinking is she dead ? You carry her to hospital and the hospital would only put drips, and you would just find it pointless to take her to the hospital” Rose 22yrs

The participant had lived the horrors of breast cancer and faced difficulties in resolving her mother's death resulting in a negative and painful cancer experience, making her live in fear of the disease.

5.2 Perceptions about breast cancer

The levels of breast cancer knowledge varied among different participants. Their knowledge was acquired from radio programs on breast cancer, breast cancer patients, the Internet, antenatal clinics and to a lesser extent their ill relative. The young women interviewed reported knowing about the nature and cause of the disease but they had little knowledge about the clinical progression of the disease. Breast cancer was referred to as “breast cancer” and not by the traditional name of “imvukuzane by all the participants. The traditional name denotes a ground mouse that burrows underground.

5.2.1 Causes of breast cancer

Generally participants seemed unsure about what the causes of breast cancer were, as the majority of the responses were punctuated with “I don’t know”. Breast cancer was understood to be something that “pops up”, cancer cells that have been corrupted in the body or something that spreads from one part of the body to the next, participants never gave reasons as to why these cells are corrupted.

*“I would lie to you. I only know that it’s something that just shows up only” Bomi
29yr*

“I would be lying because isn’t the cancer comes in different places, some people get it on their feet, others it comes here (pointing to stomach), others in the throat, others in the breast. It depends on, I’ve heard them say, its these cells in the body, right.. they will be being built, so it takes turns, new cells are made and old cells die, so I heard them say, some of the old cells do not die, instead it grows and becomes something that affects that particular area its situated.” Christine 25yrs

“I’ve never really thought of what causes it, I thought it was just a disease that pops up. I thought though, that if you have one type of cancer in your body...doesn’t it spread to form another type of cancer in another part of your body. I once thought about it but never took it seriously.” Amanda 18yrs

When asked about possible causes for their relative’s breast cancer some women mentioned that it could have been because of the family history. One young woman stated that her mother had very likely inherited breast cancer from her grandmother who had died from cervical cancer, but she did not know much else on what the risk factors for breast cancer were.

“I hear that it is genetic because my grandmother who gave birth to my mother died of cervical cancer is it cervical? It was in the stomach, so I am just assuming that it

was cervical. So since its genetic maybe it jumped on to her and it's yet to pass through generations, (laughs) but what causes it exactly. I don't know" Bomi 29yrs

Although some of the participants speculated that family history was a risk factor, they explained that they did not have knowledge of anyone in the family who had had it before so they did not understand why their relative had it. One young woman proposed that it could have been due to the environment and the type of food we eat, however she went on to guess some other possible causes and later stated that she did not believe that breast cancer could be inherited because her mother had not inherited breast cancer as she was unaware of anyone else with it in the family:

"I am not sure.... But I think it's like ... environment, and the type of food we eat. But I don't think it's the generation to generation, I think it's just the environment and our diet I don't know, sometimes it could be something you would have worn or the ink or maybe when you get a tattoo you can get cancer, so maybe her, I don't know, maybe it was something that she used to wear or the weather, when the sun is hot and all" Ruth 18yrs.

The majority of the young women believed that anyone could get breast cancer. Age was never mentioned when participants were asked why their relative had the disease. But when asked separately on age as a risk factor for breast cancer, participants gave varying responses demonstrated in the following quotations and others simply stated that they did not know:

"I think it depends with the genes and blood type and all, but I think from 16 to 18 going up" Ruth, 18yrs

"I read this other magazine and they said a baby had BC. So anyone at any age really (can get breast cancer)" Amanda, 18yrs

"Middle Ages from 20 to 48 that's what I think. I read about one lady who got breast cancer; she thought only older people got breast cancer and she thought it never happened to younger people. So there was an article attached to the story about breast cancer and they were saying anyone can get breast cancer especially from the 20s going up" Rose, 22yrs.

5.2.2 Breast cancer and witchcraft

Past empirical studies had reflected that some women from African cultures believed that breast cancer was caused by witchcraft (Muthoni and Miller, 2010). The researcher asked the participants what their views on the subject were. Contrary to past findings, this group of women all felt that witchcraft was not responsible for breast cancer. Whilst they did not rule out the existence of witchcraft they nonetheless stated that the two were not related.

According to the young women, some of the relatives who had been ill, had chosen to seek alternative treatment first from traditional healers and not medical treatment. Furthermore, participants had mentioned in their responses that these ill relatives feared that their illness was “manmade” but the young women interviewed strongly disagreed with this belief. One participant believed that witchcraft had nothing to do with breast cancer because if it was actually caused by witchcraft traditional healers would be able to treat this condition but this was not the case as her grandmother had been unable to cure her condition by traditional medicines

“I have no idea why or what causes BC, witchcraft is there for sure, but I doubt that cancer has anything to do with it, because otherwise, there would be medicine to treat it from Traditional Healers?” Prim 22yrs.

Another participant explained that since breast cancer is a global disease that affects all races, witchcraft is very likely not responsible for it:

“Back when we were growing up that’s what we were told, that when someone has cancer it was due to witchcraft.... with all these things that are happening, I think it’s things that just exist. Cause I was asking myself that if someone was bewitched, are white people bewitched too?” Bomi, 29yrs.

5.2.3 Breast cancer signs and symptoms

Most participants stated that they did not know the signs and symptoms of breast cancer and a few others mentioned a lump, swollen breasts, and discharge of pus from the nipples, and / or a bump / lump under the armpit. According to one other participant you could only tell you had breast cancer after testing at the hospital and the only time you could be able to tell before then, is when the breast develops a sore and becomes untreatable. Furthermore there was a consensus among the young women that any sign of a lump was a cue to go the hospital.

“With BC, if I find the lump I can go to the hospital and get the lump checked and if its cancer I am able to remove the lump” Bomi 29yrs

“You get swollen breasts, and you get pus from your nipples” Amanda 18yrs

5.2.4 Barriers to knowledge of breast cancer

Participants explained that there was a lack of available information about breast cancer and they had no one to ask. Most participants stated how they had never been personally addressed about breast cancer, neither at the hospital by doctors, by parents nor by breast

cancer support groups who pay home visits to breast cancer patients. One of the young woman expressed how the hospital never followed up on her ill relative when she failed to show up for scheduled treatment because she failed to raise funds for the required treatment. She also described how the lady who paid home visits only spoke to her mother and offered support to her but she as the daughter with a high risk of suffering from breast cancer, had been overlooked in the entire process.

“I think support and information about breast cancer was only given to her, we on the other hand at least not me, we didn’t. I once thought about it though, that why couldn’t they give information to us the family members of the ill person. I never got any information from the health official. But I never asked either. ” Rose 22yrs

“We didn’t get any information about breast cancer from the hospital at the hospital they spoke to my mom” Bomi 29 yrs

“They have never come and they never bother to ask what’s going on (with the chemo). They never even made a follow up to see why she is no longer coming. So we are now thinking, maybe she should go there and tell them she wasn’t able to raise money” Norma 29yrs

One participant said she would like to know more about the disease but had no idea who to ask. She was not taught at school, and what little knowledge she got about breast cancer she had incidentally come across on a radio show about breast cancer. This particular young woman had limited knowledge about signs and symptoms and causes and risk factors of breast cancer:

“I don’t know much [be]cause this was the first time I had ever seen it. I just heard them talking on the radio, I don’t know if what they were saying is true, but they were saying, when cells are created, old ones die, so when old ones refuse to die that’s how it starts.” Christine 25yrs

“No I haven’t, who would I have asked? I don’t know how she came to have it. ..I would love to learn how you get BC, I have a wish to tell others, so that I can help inform others how you get it and what they must or must not do” Norma 29 yrs

Another barrier to knowledge was the lack of communication within the family. Many participants said how breast cancer was never discussed within the family structure between the ill relatives and the young women participating in the study. One participant described how her mother was a breast cancer advocate who spoke extensively about the disease. Despite this she never spoke about it to her daughter at home:

“At home, we have never had a one on one conversation about breast cancer. But then at times you only hear her telling other women about it. With me personally, I don’t know maybe that’s just how I am....Asking her directly I don’t know... we are not too close” Rose , 22yrs

This was one of many who spoke about how “breast cancer” was never discussed at home. Some discussed possible reasons why the ill relative did not seek timely treatment and others discussed the issue during the illness, but once the ill relative recovered the issue of breast cancer was not talked about. One young woman mentioned how she never asked her sister too much about the disease at home to avoid violating her sisters privacy and stirring up emotions about her condition. She likened it to going to test for HIV, and explained that the choice for people to talk about the disease would depend on if the projected outcome would be positive or not:

“Sometimes it might be her private stuff she might not want to share. It’s the same as if you went to the new start center or something it’s your own decision to make, whether you are going to tell me or not, if the outcome is good then maybe you will tell me. It’s also difficult to ask someone about their condition, if someone is sick and you keep asking them what happened when it has been removed already.” Christine 25yrs

Participants mentioned how they did not feel the need to actively seek information about breast cancer. When participants were asked if they had sought information about breast cancer from any sources most participants had not because they had thought about it but never actually followed through with finding information about breast cancer. One participant felt that since her mothers’ illness trajectory went smoothly with the breast cancer responding to medication she did not need to find out any information about breast cancer as it “had already passed”:

“I just didn’t feel like it. She’s been through it. She’s been past it; she will complete her medication in the next 3 – 4 years.” Amanda 18yrs

However the only participant to have lost her mother had a different reason for not seeking information, which was how she was too burdened by her mother’s illness and she felt her own health at that moment was a lesser priority.

5.2.5 Early detection measures

The young women’s knowledge of early detection measures varied widely. Most of the women were able to identify the purpose and procedure for BSE. One woman explained how she examines her breasts everyday because she is breast-feeding and this is something they are encouraged to do at antenatal clinics. Another was able to voluntarily describe to the researcher how BSE is performed:

***“You raise your hand, and check, lay down and divide your breast into 4 , check this side, this side, underneath here , then you put your arms on the back of your head , then it will show you whilst your arms are raised if there is something out of place”
Bomi 29yrs***

All the participants who had knowledge about the procedure spoke about how they checked randomly when they remembered and sometimes many months would pass without performing the procedure at all.

“Sometimes when I’m from bathing.... Maybe almost every day or sometimes I totally forget about it and go for months without checking” Bomi 29 yrs

“I do it sometimes, but I don’t think I do it right. At school we were once given leaflets on instructions on how to do it” Ruth 18yrs.

The only other method of early detection mentioned by participants was a biopsy. This method according to them was the main procedure carried out by their ill relative to check for cancer cells. Excluding the biopsy none of the participants related clinical breast examination as an early detection method for breast cancer and none of the participants had ever had CBE performed on them. Participants also briefly mentioned a mammogram as a possible early detection measure and most did not mention it at all.

“She did a ...there’s this process, starts with a letter M, what is it called ...I know they check you using it, they were talking about in the news too saying women should go for monthly check ups for that mamo what what ” Amanda 18yrs

“I have a friend from central[referral hospital] who offered to take my mom for mammogram and she refused, so I know that it checks for breast cancer, but I don’t know how it’s done.” Bomi 29yrs

5.2.6 Attitudes towards the severity of breast cancer

There were two distinct perceptions expressed by the young women in this study, those who found breast cancer life threatening and serious and those who thought breast cancer was something that you could deal with easily as long as one carried a positive outlook towards it. These perceptions may have been based on the cancer experience of the young women’s relative. Young women whose relatives had experienced a smooth recovery facilitated by availability of funds and timely treatment found the severity of breast cancer less daunting. Whereas the young women who had witnessed their relative struggle with the disease either financially or physically had a less positive perception of the severity of breast cancer.

One participant felt that cancer was a serious disease because treatment was very pricy compared to HIV, because patients diagnosed with HIV receive free treatment and drugs. With cancer you may detect the lump timely but still die because you could not raise funds for treatment. According to the participant her mother required 432 US dollars for one round of chemotherapy injections of which she required 8 cycles, which would each, cost another 432 US dollars to purchase. This amount according to her is a figure they cannot afford and her mother has only since been able to receive one round of chemotherapy due to lack of funds to purchase the medicines. The participant explained how the only way they were able to purchase the first round was through well-wishers who donated to them through pleas at their place of worship.

“It’s a deadly disease because look, treatment is pricy, people can’t afford it. So when you compare this disease to HIV, you see that HIV, is not as scary as this disease, because at least you see they get ARV’S for free. And in this case you have to part with a lot of money of which in many cases you don’t even have the money. You could be in a situation like ours, where it’s just two of us and there’s no one else with money. And among your relatives there isn’t even one you can say this one is better than others who could afford to give us either 100 \$ or 200 \$, there isn’t anyone like that. So I think its bad..” Bomi, 29 yrs

Another young woman described a horrible ordeal faced by a woman she knew who eventually died from breast cancer. She described how this particular woman resorted to mutilating her arm to alleviate the pain. She also added that in her opinion, cutting the breast did not count for much because even when one has it, as long as the cancer has spread to the rest of the body death was inevitable. The participant also went further to mention how the lumps that her mother had had spread to both breasts and she was pessimistic about the survival of her mother.

“What I’ve eventually realised is whether you remove it or you don’t (the breast) as long as it has spread it will kill you. When they spoke at the hospital they said, first thing is it will go to the kidneys and to the lungs. If it eats up your kidneys and your lungs then you are hardly a person then if its on this side, the side were the heart is, eating inwards you just end up being....” Norma, 29yrs

Some felt that breast cancer was a serious disease because it was not curable; the only cure was losing a part of you, that is, a breast and in some cases both breasts. All participants emphasised that detecting the lump in the breast early before it spreads to the rest of the body was paramount to survival.

“If you are quick to detect it I think it’s curable, but if you keep it ...then you will be in trouble” Bomi 29yrs

“I think cancer is in curable, so the only way to prevent yourself from getting it is that, if you find it then you have to remove the entire breast before it spreads then it can be treated that way” Rose 22yrs

Several of the young women expressed concerns about the removal of the breast, resulting from a diagnosis of breast cancer. The young women revealed how witnessing their mothers with one breast came as a shock, and made them anxious and “lucky to have theirs” .One young lady explained that she would feel sorry for a woman who has one breast. Upon seeing her mother with one breast she thought it was an advantage that her mother was already old and she would not attract much attention to herself in public from having one breast.

“I was really shocked, she had come to visit me at school in October, I’m not sure if I had seen her or not, but the last time I had seen her she was fine then next time I see her she was bald and one breast was missing..” Rose, 22yrs

“You know being a woman and you have only one breast, it’s not nice, when you were born with two breasts now suddenly you have one breast. If you see my grandmother now when she is wearing a t shirt, you can see that one side, has no breast, so you seem different, at a different place, in another world where no one else is like that” Bom,i 29yrs.

Participants also felt that breast cancer and its outcomes all depended on one’s positivity and outlook in life. One young woman sighted how being positive reduced the burden of breast cancer, because her own mother had been positive and believed that she would recover, she did recover. She further explained how she had watched a television show where one woman had been given a prognosis of 6 months to live but because she chose to be “positive” she lived longer than 6 months. Positivity according to this participant was refusing to believe that the disease would kill her and cooperating with doctors, taking medication, and change of diet.

“You can get breast cancer but you can still survive, you just need to be strong....you need to be positive... Tell yourself that you can surpass it, you are going to live right, take your medicine....You know, go to the doctor”. Amanda, 18yrs

The participants explained that, prayer, and having experienced a cancer diagnosis in the past that had been successfully treated contributed to this confidence in recovery explained as positivity. Two participants interviewed had mothers who had both had reoccurring cancers

and had both recovered, and this fact according to them reduced any fear of breast cancer as a disease that kills since their mothers had recovered

5.2.7 Susceptibility to breast cancer

There was a unanimous agreement among study participants that anyone could get breast cancer. Several of the participants said they felt heightened levels of anxiety because they had relatives with breast cancer, and therefore felt they too would possibly suffer from it, regardless of the outcomes of their relative's illness. The two young women, who had previously suffered from breast illness in the form of benign tumours and swollen breasts, also had similar perceptions to susceptibility to those who did not have any past breast illness. However, these perceptions of susceptibility did not result in increased actions to prevent the severity of the disease. One participant who had lost her mother to breast cancer explicitly described how she was afraid she might have breast cancer because her breasts would swell at the bottom if they filled up with breast milk however she explained that she could not seek treatment at present because she feared that this swelling might possibly be breast cancer and she would be unable to afford the cost of treatment.

“I am afraid (laughs) I’m really afraid, but there’s nothing I can do...I don’t know but I also feel something here... and going to the hospital they want money. Like now I’m breast feeding, if my breasts get to full of milk, it swells down here...I don’t know if this is normal” Rose 22yrs

Several participants echoed these sentiments of fear, and worry. Citing how they did not know whom it would strike next and thus they occasionally worried about this, also because you could have the illness and never know it and wind up “getting your breast cut”. A concern raised by participants was the fact that someone could suddenly just get breast cancer and this made it difficult for them to protect themselves, as they might not have breast cancer today but have it tomorrow. When asked about their own perceived susceptibility to breast cancer their responses were as follows;

“I would not say no, right now when I check myself I may not have it, right, but I can’t say I won’t get it.... When I googled they said people get it from 40 years going up, but due to changes in things they say you can find someone who is 30 yrs going down having it. So the fact that it’s something that just develops I couldn’t possibly say I’m safe because it can show up at anytime from anywhere and it can just show up” Bomi, 29yrs

“You are always in fear, thinking you might get it or who is going to get it, it could be my child. It kind of stresses you because you don’t know who will get it next. Cancer is a problem, cancer may kill you and you don’t even know it”. Prim, 22yrs

When asked about what they did about this fear some participants said they checked their breasts occasionally through BSE, only when they remembered and others checked regularly because they were breast feeding and it was a must to check your breasts for the child’s safety. One young woman expressed that she never wondered so much about it because she did not have enough information about breast cancer to know if she was susceptible to the disease or not. However another participant who also said she did not know if she would get it because she did not have sufficient information about the disease stated:

***“I can’t say, but even the bible says in the end of days there will be many diseases”
Christine, 25yrs***

Of the participants who said they did not think they would get breast cancer one of them had past experience with breast illness. The participant explained that though she had wondered about it in the past she did not feel susceptible to breast cancer mainly because breast cancer was genetic and before her mother she had not heard of the disease affecting anyone in the family before. She also spoke about how she never took time to reflect on her own breast health and as such she had never checked her breasts since she suffered from swelling breasts.

“I never heard of anyone who ever got it before my mom. At times I feel like maybe there’s a history and I might also get breast cancer, but it’s just a feeling I had some time ago, then it went away. I just felt like it won’t come to me, but I know I should get tested , for maybe symptoms, but I’ve never really gone out of my way to do it. I’m not really worried; I never think about it. I’m not scared”. Rose, 22yrs

5.2.8 Benefits of early detection measures

Although some participants perceived themselves at risk of breast cancer, they seldom practised or sought any early detection measures but the participants unanimously agreed that early detection saves lives. The young women suggested that an early detection would enable participants to avoid extreme treatment measures such as mastectomy and through early detection women would not need to use so much money during treatment as the cancer would still be small and easily treatable. Several participants spoke about how any suspicious changes in their breasts would be a cue to go to the hospital and get it checked immediately in case it is breast cancer.

“When something is starting...even at the hospital they say if it’s starting it’s not so difficult to treat. I’ve heard them say at the hospital she / he died because she/ he came late. But, if you stand up and go when it’s early I think they will help you. It’s just that you never know if it’s BC or not, and they can only tell you at the clinic, we have different beliefs, others don’t go to the clinic thinking they were bewitched. So if you treat it quickly it’s easier that way” Christine, 25 yrs

“If I find something small I should act on it before it affects many places, not just to sit on it. I need to see the nurses, and ask questions, because the nurses know better and will be able to assist you ... because if you discover it in time, it seems to be curable. But if you delay then it’s difficult.” Prim, 22yrs

“If you are quick to detect it I think it’s curable, but if you keep it ...then you will be in trouble, that’s what she was supposed to do, she should have removed it when it was still a lump. If you got to the hospital at the lump stage you can cure it easily, and I think the chemotherapy treatment will be cheaper too” Bomi, 29yrs

5.2.9 Barriers to breast cancer screening

The young women in this study had different justifications for not screening for breast cancer; several of the barriers identified were mostly fear of discovering an illness they could not afford to treat, lack of knowledge about screening procedures, and forgetfulness. A few of the participants identified financial constraints as a barrier to screening. One participant spoke about how her own breast health appeared insignificant during her mother’s illness and how it would be meaningless to uncover her own cancer when she would be unable to treat the cancer in light of the challenges she was already facing raising money to treat her mother’s illness.

“Sometimes I tell myself, what’s the point of checking when right now we can’t even raise 432 \$, how are we going to raise mine in addition too? You end up asking yourself such questions, what’s the point of knowing” Norma, 29 yrs

Another barrier to screening identified by the participants was the lack of knowledge about causes and risk factors of breast cancer. Several participants explained how although they knew the basics about breast cancer such as BSE, but they still had insufficient information about the disease and therefore could not make informed decisions about the choices to make regarding breast cancer. Participants felt that they knew “too little” about breast cancer to accurately act upon it, outside from their relative having suffered from the disease and their possible risk of suffering from the disease too.

“Maybe if I knew more about it, when I know the causes, how to treat it and how to prevent it and all, that’s when I will take it more seriously” Ruth, 18 yrs

Breast cancer according to them is not prioritised as a health threat and they could only really act upon it if there were increased attempts from the ministry of health to increase awareness about breast cancer. Due to this lack of awareness participants found it easy to lapse and forget to check their own breasts once the initial scare wore off.

“People do not care about cancer; they treat it as something small. I don’t think its small; if it was up to me it would be a big deal just the same way they prioritise HIV, in order for people to be more aware of it. If they don’t prioritise it people will just ignore it and think its just cancer. I never searched for information; I considered it to be something small. You know everyone is afraid of HIV; it should be like that for cancer as well. People need to be just as conscious of it because it’s not an easy illness its just like HIV, there is no easy illness” Norma 29yrs.

A few participants also expressed discomfort in having CBE performed by male doctors or male nurses at the hospital. According to the participants it is uncomfortable to have their breasts touched by an unknown male at the doctor’s office and instead preferred that it would be better to have a “boyfriend” who they are familiar with, discover the lump during perhaps sexual activity. Long queues and waiting periods at the doctor’s offices were also cited as deterrents to undergoing CBE.

“I am shy to open my breasts to someone else. And my doctor is male. I’m on medical aid with CIMAS and my doctor is male in Gweru and here the doctor that I see is also male. I really wouldn’t want to open up” Rose, 22yrs

I would rather, your boyfriend found the lump when feeling my breasts, than to go to the doctor to get him to feel your breasts? I don’t think so”. Christine, 25 yrs

Another barrier to screening was forgetfulness and procrastination. Some participants said they practised BSE but sometimes they forgot and would go for several months without examining their breasts for lumps and abnormalities. One participant described how once her mother recovered from her breast cancer, the worry and concern over breast cancer resided, as the conversations would hardly revolve around breast cancer in their home.

“Sometimes I totally forget about it and go for months without checking” Bomi, 29yrs

5.3 Communication and information about breast cancer

One of the aims of the research was to find out the information these young women had about breast cancer and where they got this information. The following theme deals with communication about breast cancer and the sources of information available to young women in Bulawayo.

5.3.1 Communication Dynamics on breast cancer within the family

The lack of communication present in families of those affected with breast cancer has been discussed briefly above as a barrier to breast cancer knowledge. Several participants described how breast cancer was not discussed much during the course of the illness within the home and even less after the relative had recovered from the illness. Some participants explained how they always had difficulties opening up to their parents about day to day issues, and the same remained true about breast cancer, and thus little was discussed about the subject with their affected mothers. One participant described how her mother did address other women about breast cancer but how she had never been directly addressed.

“We don’t really have that close, mother daughter type of relationship. We don’t go deep with any of our issues”, Amanda, 18yrs

“At home, we have never had a one on one conversation about breast cancer. When she was sick she spoke about it a lot. But then at times you only hear her telling other women about it. With me personally, I don’t know maybe that’s just how I am....asking her directly I don’t know... we are not to close” Rose, 22yrs.

A young woman expressed how the subject was not discussed with the ill relative due to the desire to give the ill relative privacy in the event that the ill relative was not comfortable discussing her illness openly. Other participants did not talk about breast cancer within the family to avoid “stressing” other family members by bringing the illness into focus or simply because they had no time and as such never spoke about it with other family members.

“My sister and I? No. I don’t know how she feels about her own breast health; I have never really asked her. I think we never really get time to sit down and talk about it, when I get home I go straight to bed, and my sister comes home with my dad from work, and they catch up in the lounge watching TV. I’m not really involved in the discussions that go around” Norma, 29 yrs

“I speak about it with my aunt, but talking to her about it ...You feel as though you are stressing her ...So yah we usually do not talk about it” Bomi, 29 yrs

Furthermore when breast cancer was conversed about within the family it was in the absence of the affected person, as described by a participant how they would debate on what made their grandmother delay in seeking treatment.

5.3.2 Communication dynamics outside the family

Participants expressed how they felt comfortable talking about breast cancer with friends and people outside the family. Participants spoke about how they discussed how to check for lumps using BSE with friends, and openly discussed the condition and illness of their relatives openly without fear of being judged or stigmatised. Participants felt that people outside the family were interested in learning more about breast cancer and they had been comfortable discussing breast cancer as well.

“I speak to my friends about breast cancer; you’ll find that they too, have had relatives with BC, who are now alright. So it’s not like every day but we do talk about it. Sometimes I would also take my friends to the hospital to see my mom” Ruth, 18yrs

“At school I actually do ... I would say my mom has B.C. Even at work, we were discussing something to do with cancer, and I was like well my mom had B.C, then they would start asking me, how she found out, what, what... People actually are interested in the whole thing” Norma, 29yrs

Participants in the study also spoke about how people did not treat them differently after their relative was diagnosed with breast cancer and they were particularly interested in sharing their experiences and information with anyone else that would find him or herself in a similar situation with a relative suffering from breast cancer. However in all the communication present the content centred on the events leading to the discovery of the illness and the ill relatives progress.

5.3.3 Communication with health personnel about breast cancer

When participants were asked what kind of communication they had with health personnel about breast cancer, the response was none, as already presented as a barrier to breast cancer knowledge. Participants mentioned that health personnel had not addressed them about breast cancer neither regarding their own breast health as a high-risk group or that of their relatives. This question was particularly relevant for participants who had been present during their relatives’ illness and had accompanied their relatives to the hospital or had been present at home during visits from the cancer support organisation. All the 10 participants interviewed explained that they had not been personally addressed by the health personnel from the Island Hospice that came to see their ill relatives and had not received any information about their own breast health from them

“We didn’t get any information from the hospital...At the hospital they spoke to my mom” Bomi, 29yrs

5.4 Sources of information for breast cancer

This section will explore the different sources of information available to young women about breast cancer. Most participants said they never received any information about breast cancer that was directly targeted for them, during or after their relatives illness and the only information they had about breast cancer during this time was information they had personally sought.

5.4.1 Breast cancer education from school and antenatal clinics

A couple of participants explained that they had been briefly taught about breast cancer at school, however they were uncertain if this was part of a breast cancer campaign or not. The “education” was in the form of fliers left in the classroom on how to perform a BSE and had been briefly taught about the symptoms for breast cancer such as feeling a lump or bump in the armpit. On the other hand, most participants including those who were still studying said they had never received any information from school about breast cancer.

Some participants also received information from clinics during antenatal visits. According to the participants pregnant women are shown how to carry out self-breast examinations in a one-day crash course with several other women. The participant explained how she only remembered bits and pieces of the information she got because they only had one lesson.

“I don’t remember much, see when you learn these things, you only learn once, just before I gave birth” Prim, 22yrs

“At the hospital, when you are pregnant, they tell you about it.... So we got this information when we were pregnant during antenatal clinics” Norma, 29yrs

5.4.2 Media as a source of information

Several participants reported having come across some form of information about breast cancer from media, such as magazines, newspapers and TV and radio broadcasts. However, apart from the participant who had come across her information about breast cancer from a local radio show by accident, the rest of the media sources are often broadcasting international news about breast cancer. Participants described having read about breast cancer from South African magazines and watched TV programmes from Digital Satellite Television, which broadcasts TV stations and shows from Europe and America.

“On TV they were saying like. ...What are those diseases that you can pass on from generation to generation and stuff” Amanda, 18yrs.

“I heard that if there’s family history of breast cancer, that’s all I know, how else do people get to know about BC... from reading magazines...I used to love YOU magazine and People magazine, of which You used to have lots of issues about that” Rose, 22yrs.

5.4.3 Internet as a source of information

Some of the other participants also reported searching the web for information about breast cancer. Google was used as a source of information; participants explained how they found information from the search engine. One participant says she was not looking for information specifically because of her own health but more so to find out how she could help her ill relative. Whilst looking for possible donors to contribute towards the cost of breast cancer she came across some relevant information about breast cancer. One other participant stumbled on information about breast cancer while searching the Internet to find out about a recommended diet for a cancer patient.

One participant however did search for signs and symptoms of breast cancer, as her mother’s illness had created some considerable interest in the subject.

“Yeah only on Google, I just found out about diet, what someone with cancer would need to eat. I googled it because there was now someone with cancer at home, so I felt I needed to know” Memory, 18yrs.

“I think I used to Google. I’ve googled signs and symptoms of breast cancer, how someone gets breast cancer, before I never had an interest in BC.” Rose, 22yrs.

5.5 Cancer associations in Bulawayo

The Island Hospice a cancer society is an organisation that offers palliative care and end of life care to cancer patients free of charge. The organisation relies solely on donations; as such sometimes there are no supplies and resources to reach out to all cancer patients. This organisation provides counselling and assists patients with cancer, information, painkillers and other smaller items to improve the quality of life for patients.

Most of the cancer patients interviewed had contact with this organisation except for the most critical patient who eventually died but needed palliative care the most. Most participants mentioned how the organisation sent out people to their homes to speak to the cancer patients. The organisation had supplied women with painkillers, breast prosthetics for those who had undergone mastectomies and advise on how to care for wounds and maintain a healthy diet.

According to the nurse interviewed for this study when someone is diagnosed with a life threatening illness everyone at home gets affected and so they look at everybody in the home including the relatives, with an aim to find out how the relatives are dealing with the illness, and the financial challenges the family may be facing in order to assist them with planning for the future in the event that the ill relative dies. Another service offered by the organisation is death awareness to remaining relatives to prepare them for the passing on of their loved one.

“We speak to everyone...breast cancer is hereditary, so we speak to the daughters your mom has breast cancer you may have it as well so what do you do? We encourage women to do mammography every year, to do palpitations on your breast, check your breasts on a monthly basis. So that’s how we involve the family” Nurse

When asked about how the organisation selected people to offer their services to, the nurse explained that the organisation liaises with doctors at the major hospitals in Bulawayo who know about the Island hospice who then refer cancer patients to the organisation. In addition to this collaboration, the nurse explained that the organisation is generally well known and people who need them seek out their services directly and the organisations also held meetings at churches and schools to create awareness.

In the nurse’s opinion breast cancer was the most prevalent cancer affecting women in Bulawayo, she felt that although the cancer incidence was not as high as other countries it was still a cause for concern in the city. The nurse felt that the people know about breast

cancer in Bulawayo but simply because people associated this illness with witchcraft they seek treatment at a late stage when the cancer is untreatable.

“...People seek treatment late because of that belief that cancer is associated with witchcraft, and procrastination, and fear of the unknown and patients who seek alternative treatment. As it is I am from seeing a patient who has covered the affected breast with mud.” Nurse

The organisation did not have any written material to give away available on hand in their offices for those interested in learning about the disease. The findings reported in this section were contradictory to some of the information collected from the relatives of those affected by breast cancer.

6. Discussion of findings

Young women with a family history of breast cancer are an “at risk” group for breast cancer in Bulawayo. Understanding the perceptions of this group of young women and how these perceptions are formed is an important step to facilitate future research and effective interventions for breast cancer care. People interpret their world and the reasons for their actions based on a variety of social and personal factors. These factors play an important role in bringing into existence the explanations for health and illness, and guide choices and activities undertaken by individuals and families in the process of deciding health behaviours. The bulk of the findings in my study are compared and contrasted to other studies that focus on family history of breast cancer unless otherwise mentioned.

6.1 Role of experience in creating perceptions

The experiences of cancer in the family influence women’s current and future choices regarding their personal breast health. The young women in the study became aware of their possible risk to breast cancer after their relative was diagnosed with the disease. The young women interviewed perceived themselves to be at risk of breast cancer, and this awareness was influenced by experiencing breast cancer through their first-degree relative. Before the diagnosis of their relative some participants said they had heard of breast cancer but had never considered its relevance to their own health. A diagnosis in the family created awareness and interest in the disease, which opened up for opportunities for the young women to learn new information about breast cancer. It also created recognition of increased family risk and an increased sense of vulnerability to breast cancer.

Participants all learnt about their possible risk of breast cancer from differing sources, but all agreed that the desire to seek information was triggered by the cancer diagnosis of their relative. The young women in this study identified the media and the Internet as their main source of information about their risk of breast cancer as well as for information about other questions they might have had about breast cancer.

Little qualitative research has been done that covers perceptions of young women with primary relatives with breast cancer in Africa, however research in America and Canada has shown that emotional closeness and experience of a relative’s illness play a significant role in the development of an individual’s risk perception (Walter et al, 2004). Chalmers and Thompson (1996) carried out research on perceptions of women of all ages with primary relatives with breast cancer in Canada. According to their research women with relatives

suffering from breast cancer go through 3 phases in the process of developing their risk perception, i.e. living the cancer experience, developing risk perception and putting risk in its place. The young women in our study created their risk perception in stages, depending on the impacts of the lived experience and their ability to accept that their relative has or had this illness. Participants, who had not shared an intense emotional attachment with their relative during their illness, or witnessed extreme suffering from their relative due to breast cancer, were able to cope with the anxieties that they developed from witnessing their relative's illness promptly.

They were able to immediately create their own assessment of their personal vulnerability to breast cancer separate from that of their relative's experience. Furthermore similar to findings from the study by Chalmers and Thompson (2004) prompt acceptance facilitated the young women in my study to come to terms with the risk of breast cancer through a thoughtful processing of breast cancer information and experience. Failure to cope and accept their relatives experience perhaps from witnessing a difficult illness would possibly result in a risk perception that is based on the young women's emotional interpretation of breast cancer information and experience. According to Chalmers and Thompson (2004) this type of risk personalization occurs when there is insufficient information available to inform women about risk factors and this further impedes on a woman's ability to deal with the risk of breast cancer.

Research has also reported that easily recalled events are generally considered more likely to happen, and thus exposure to a disease in the family has high potential to influence risk perceptions (Rees et al, 2004). Whilst having the knowledge that medical risk through heredity is a risk factor for breast cancer, research (Absetz et al, 2000) has shown that women who simply have experience of breast cancer through some other significant person also develop a personal risk perception towards breast cancer (Subramaniam, 2013). Experience of breast cancer in family or close friends has also often been associated with heightened risk perceptions (Absetz et al 2000), and yet personal experience with cancer may lead patients to have positive and realistic perceptions of breast cancer, depending on what they may have witnessed in the family.

6.2 Family Communication

When the issue of communication about breast cancer within the family was addressed with several of the young women, they reported that discussion of breast cancer within the family was limited and difficult. Despite the fact that both the women with breast cancer and those without breast cancer are aware of the potential inherited cancer risk, it appeared that discussion was limited about the possible risk to relatives, as well as the screening and treatment interventions available to family members. Research has often shown sharing of information about diagnosis and treatment about breast cancer is the best way to effectively stimulate and inform relatives about their cancer risk for their own future health and decision-making (Claes et al, 2002). Our findings are similar to several other studies that show that, breast cancer risk communication between affected women and their children or close relatives, in line with familial cancer risk, is often restricted (Nycum et al, 2009; Black et al, 2012;Cohn et al, 2009).

Whilst the importance of intrafamilial breast cancer risk communication has been emphasized in past research (Julian- Reiyner et al, 2000, Black et al, 2012), it still remains an area that has been identified to pose challenges to many women affected with breast cancer. One study identified that the daughters of breast cancer patients who talked to their mother about breast cancer performed breast self-examination more frequently than those who did not (Benedict et al, 1997).

Lack of breast cancer risk communication within the family, could be a potential barrier to the recognition of breast cancer risk for some families (Cohn et al, 2008). Studies have often addressed communication flowing or being initiated by the relative suffering from breast cancer or carrying the gene for breast cancer risk, BRCA1 or BRCA2 (Nycum et al, 2009; Claes et al, 2003; Wagner et al, 2003). Barriers to communication identified by this group of women ranged from not wanting to upset or alarm relatives, not being close to certain family members to avoiding emotional harm that could arise from informing a relative of the potential risk of inheriting the breast cancer gene (Cohn et al, 2008). A notable difference between my study and the previous mentioned study is that responses were sourced from relatives of those who had suffered from breast cancer. They identified similar barriers to the above group, such as attempting to avoid upsetting their ill relatives, not wanting to breach privacy of the ill relative, and that the ill woman should be allowed the liberty to disclose and talk about only what she desired without the pressure from other family members.

According to Roland and Williams, (2005), “health related life events occurring to family members are likely to affect the family as a whole, including its organization and communication process”. These life events could be a cancer death or a cancer diagnosis within the family. Qualitative studies further suggest that life events within the family, such as reoccurring cancers may contribute towards facilitating communication within the family about breast cancer risk (Crotser and Dickerson 2010; Loescher et al. 2009; Lapointe et al, 2012). In contrast to these findings, communication about breast cancer risk did not increase after the cancer diagnosis of the young women’s relatives within the family. Nor did it increase within the families of the 2 young women in my study who had developed benign lumps in their own breasts after the diagnosis of their mothers.

This could partly be because perhaps breast cancer affected women were unable to link family history into the origins of their illness and may have difficulty recognizing the need to encourage breast cancer awareness in their younger unaffected relatives (Cohn et al, 2008). Some of the young women spoke about how their relatives believed that their cancer was a result of a curse, and consequently never reflected on whether their children would also be at risk or not. This belief could have also possibly limited what ill relatives were willing to discuss with the younger women as they may have thought breast cancer was irrelevant to them. The younger women in my study also felt that perhaps there was absence of cancer communication within the family and communication directed to them, because their ill relatives felt they were too young and needed protecting, thus avoided exacerbating difficult times by introducing the topic of possible breast cancer risk.

Participants described open communication about breast cancer with their peers outside the family, but had difficulties discussing breast cancer with their older relative diagnosed with breast cancer. According to Kenen et al, (2003), different families have different communication patterns; some are not open about all topics whilst others encourage free expression and communication. Furthermore Kenen suggests that different age groups within the family have different norms and thus “family communication patterns should be viewed in terms of members’ perceptions of family norms rather than adherence to one agreed upon family norms. Interactions between family members trigger customary responses and attempts are made to bring members back in line if they are perceived as violating the script and threatening the stability of the family” (Kenen et al, 2003).

6.3 Illness Perceptions

An individual's awareness of their breast cancer risk maybe the first step towards early detection practises that could potentially reduce mortality among young women (Nycum et al, 2009). Perceptions of breast cancer and beliefs about the disease have a high potential to influence how an individual reacts to their own breast cancer risk status (Rees et al, 2001). Illness perceptions are influenced by various sources such as direct experience of the illness or experience of illness through family friends and the media (Rees et al, 2001). Illness perceptions are also largely influenced by experience and culture. The experiences of women with a family history of breast cancer are likely to have a strong impact on their representations of the disease, particularly beliefs about the consequences, cure and control of breast cancer (Rees et al, 2001; Nycum et al, 2009).

Most of the young women in our study generally reported positive experiences of survival, and they spoke about how their ill relatives had coped well with the disease. This gave the women a sense that breast cancer was not a death sentence as long as one detected the cancer early and adhered to treatment plans. Some of the respondents reported that their relatives had detected their breast cancer at a late stage, but had still managed to recover from it. Whilst our findings are similar to those of women in America and Europe in the same risk group (Wellichet al,1996 ; Chalmers and Thomspson, 1996), there is little research about women with a family history of breast cancer in Africa.

Witnessing the outcomes of the illness also allowed participants to reflect on the disease and make decisions about their personal future breast health. Our findings are similar to Payne (1990), who found that women's beliefs about the cause and control of breast cancer help women make the decision whether not to or to practice breast self-examination. For example in our study, young women who had witnessed their ill relatives seeking alternative medicine to cure breast cancer, unsuccessfully, were able to reason that medically proven risk factors were causes of the disease. Our findings are inline with Rees et al, (2004), who found that women at increased risk of breast cancer had a better understanding of the causes of breast cancer due to their experience of breast cancer within the family. However, the former group was comprised mainly of highly educated women, which was not the same in our study that had women of various educational levels.

For most young women in our study, the quality of life of their relative after the cancer diagnosis largely contributed to their perceptions of the severity of breast cancer. The fact that their relatives had remained able bodied after the diagnosis, contributed to the young women's perception of the importance of early detection. The young women believed that early detection was important because if a woman discovered their breast cancer early there would be less physical pain, less body image adjustments, such as having to lose a breast and also less money required for cancer treatment. A qualitative study on daughters of cancer patients also reported similar findings that daughters' perceptions of severity were influenced strongly by the ability of their relative to care for herself, ability to manage household tasks, and ability to work outside the home (Wellich et al, 1996).

The consensus in our study was that breast cancer was a disease of chance, but the young women felt more at risk, and anyone of any age could get the disease. However most participants said they would immediately seek treatment if any breast cancer symptoms presented themselves. Other studies exploring illness perceptions of women who are not first degree relatives of breast cancer patients, who also do not have breast cancer, in America and Europe (Katapodi, Facione, Humphreys, & Dodd, 2005), found that women's perceived risk evolved around the belief that women who have the disease are to blame because of bad lifestyle choices resulting in stigmatization towards women with breast cancer.

On the contrary women from studies done in Kenya and Botswana, who do not have experience with breast cancer believed that breast cancer is a disease that someone can inflict on someone else or a disease that is in Gods hands and therefore one cannot escape the illness if God has ordained it (Ongona and Tumbo, 2013, Muthoni and Miller 2007). This belief in fatalism has often prevented women from seeking preventive cancer screening (Powe & Finnie, 2003). When limited information exists about the causes of breast cancer, "healthy women may become more frightened by it and develop myths to try to explain it" (Anagnostopoulos and Spanea, 2005).

Perceptions of women in Africa without a family history of breast cancer have generally been affected by social and cultural construction of the disease as a death sentence (Muthoni and Miller, 2006; Tiengo, 2010). There are three sources of information that people draw upon for the development of illness perceptions, which is cultural information, social information and personal or family illness experience (Anagnostopoulos and Spanea, 2005). Experience with cancer may lead women to have more positive and realistic perceptions of breast cancer, in comparison with the perceived severe consequences of the disease and the poor treatment

efficacy women who have no experience with the disease may believe (Anagnostopoulos and Spanea, 2005).

Respondents in this study felt that people outside the family had been very supportive after the diagnosis of their mother or sister with breast cancer and did not feel that people treated them differently. Participants spoke about how they too had been open about the diagnosis to their friends and never felt the need to keep the illness a secret. Breast cancer has often been reported as a stigmatized illness, with women expressing how friends and family disappeared after diagnosis and how they often dealt with the illness in private and in isolation (Bloom and Kessler, 1994; Baron-Ephel et al, 2004; Muthoni and Miller, 2010). African women do not appear to be judged for having breast cancer because one does not have control of whether they get it or not. In Canada for instance, breast cancer patients were stigmatized for having cancer and causing cancer, unaffected women may come to blame the patient for getting breast cancer because she did not prevent or control it (Anagnostopoulos and Spanea, 2005)

6.4 Awareness of Familial Breast Cancer

Family history is the most prominent risk factor besides age for most women and therefore women who inherit the gene for breast cancer are at increased risk of developing breast cancer relative to the general population (Petrisek et al, 2000). Most of the participants in my study, demonstrated a high level of awareness of family history as a breast cancer-associated risk factor, but, were unable to identify other risk factors such as age, previous breast health, and lifestyle related factors.

Although they were aware of family history as a risk factor, they had a difficult time incorporating family history into their familial experience of breast cancer. Several young women spoke about how, although they knew about family history, their ill relative was the first person they knew who had suffered from the disease. The fact that these women could not identify other relatives in their families, who had also suffered from cancer, resulted in some women doubting the importance of family history. This raises concern for if individuals at possible risk for breast cancer are unable to fully link family history into their perception of their relative's disease etiology, then they may have difficulty recognizing the need for early detection measures.

In other parts of the world, familial breast cancer clinics have been established with the aim of providing risk assessment and risk management for those women who are deemed to have a significant family history. In the United Kingdom for example specialised family history clinics with clinicians have been set up for risk counselling and screening, women are referred to the clinics mostly from general practitioners with the majority of referrals being young women between 35 and 50 years old who are not covered by the national mammography programme (Evans et al, 1993). Unfortunately these types of services are unavailable to women who may have concerns of family history in Zimbabwe and may be interested in these services.

Our findings also show that health professionals representing the Island hospice in Bulawayo are aware of the importance of family history and breast cancer risk, and spoke about how they also addressed daughters and sisters of women diagnosed with breast cancer during their home visits to cancer patients. However, although health professionals are familiar with the importance of family history, respondents all mentioned that the health professionals had not addressed them after the diagnosis of their relatives with breast cancer on their own possible risk of breast cancer. Furthermore the respondents also spoke about how health professionals in the clinics where their relatives had been treated had also missed an opportunity to create breast cancer awareness by failure to address them after their relatives breast cancer diagnosis.

A study by Acheson et al, (2000), reported that health professionals in America underuse the importance of family history in guiding their patients on how to maintain good health yet this is a valuable tool to create awareness to the most at risk patients through encouraging frequent early detection measures (Guttmacher et al, 2004).

6.5 Awareness of Breast Self-Examination

Respondents in my study considered early detection measures to be beneficial economically, physically, and mentally. These findings were similar to Johnson (2006), in a study of young women perceptions in Australia, who found that young women without experience of breast cancer “had a confidence in the benefits of early detection as they believed that if it was caught early then it was possible for the woman to survive”.

In addition, a study in the South African township of Bonteheuwel found that 86% of 100 women felt that screening helped detect disease early (Krombein, 2006). However both studies were done in Caucasian populations where there is generally higher awareness of

breast cancer due to the fact that incidence is higher in white women (Tiengo, 2010). A further difference is that the former studies were done in women without a family history of breast cancer.

Respondents in my study were all familiar with the practise of BSE, mainly because their relatives diagnosed with breast cancer had self-detected their own lumps. The aim of BSE is often to detect palpable tumours and increase awareness of normal breast composition to ensure that women are aware of any changes in breast composition. BSE has been identified as the main detection tool in most developing countries where other early detection tools are inaccessible to the majority of the women because they are either too expensive or due to lack of awareness of the importance of early detection measures among women (Loh and Chew, 2011; Coates et al, 2001). Women at increased risk of breast cancer are faced with a number of difficult decisions about their personal risk, especially when there is limited information available to them. With the lack of clear advice on the best course of action, women may be strongly influenced by their own family experiences of breast cancer (Rees et al, 2001).

A comparative study between undergraduate young women in London and Harare showed that 36 % of young Zimbabwean women had not heard about breast cancer or BSE, compared to 3 % in Britain in the early 90s (Pitts, 1991). In my study 9 out of 10 of the participants interviewed were knowledgeable about BSE. Similarly (Mothobi, 2012), found in her study on the practise of BSE among women in Harare that women with a family history of breast cancer had knowledge and practiced breast self-examination correctly whereas the respondents who had no family history of breast cancer had poor self-examination practices.

The efficacy of breast self examination has been widely debated, as evidence has shown that breast self examination does not reduce mortality (Norman and Brian, 2005; Kusters and Gotzsche, 2003) and yet other scholars argue that those who downplay the importance of BSE have only considered developed countries or urbanised areas of developing countries where routine primary health care and mammography is more available (Weiss, 2008; Shulman et al, 2010). Breast cancer mortality can only be reduced if BSE is effectively performed (once a month) and is followed up by appropriate diagnostic measures (Baines, 1992). Several participants reported how they had witnessed their own relatives discovering the tumour early through self-detection, but failed to seek medical treatment till the cancer

was in its late stages. Therefore the actions taken by women after detecting the lump could potentially explain why BSE does not reduce mortality.

A study in Shanghai also showed that women, who practise BSE, often detected their tumours at an early stage when the tumours are smaller than in women who do not practise BSE (Thomas et al, 2002). Thus whilst BSE may not be recommended in most countries the option of other screening measures such as, CBE and Mammograms are not readily available to most women in Zimbabwe and BSE remains the most accessible early detection measure for most women. The challenge that remains is sourcing affordable diagnostic and treatment measures that ensure that women treat their breast cancer in the early stages. Often women reported that they delayed treatment because they could not afford the expensive biopsies for testing their tumours for breast cancer.

In conclusion although the respondents in my study perceived themselves to be at risk of breast cancer, they perceived breast cancer to be a threat to their health and felt confident in their ability to perform BSE. Despite this they failed to practise breast self-examination at least once a month. These findings are similar to (Friedman et al, 1994; Murray & McMillan, 1993; Stefanek & Wilcox, 1991). The former studies report that, women in general, those with and those without a family history of breast cancer, although aware of the threat of breast cancer and are confident in their ability to perform breast self-examination, did not in fact perform breast self-examination according to clinical recommendations. Contrary to my study, Lierman et al. (1991) found that women who have positive attitudes about BSE, have positive social influences, greater perception of the importance of early detection, and thought breast cancer would have less impact on their lives were more motivated to practice BSE.

6.6 Factors that influence the practice of early detection measures

The participants in my study perceived themselves susceptible to breast cancer due to the knowledge that family history was a strong risk factor for breast cancer. In spite of the perceived threat the women in my study had, they still did not practice breast self-examination once a month as clinically recommended. According to the health belief model women who perceive themselves to be at increased risk of developing breast cancer, and believe it to be a serious disease, will often engage in early detection practises. The type of health behaviour they may choose to practise depends on an assessment of perceived barriers

and perceived benefits of a particular behaviour (Norman and Brian, 2005). For example, women who believe that performing BSE has many benefits and few barriers are more likely to engage in regular BSE.

The young women in my study accepted that breast cancer could happen to any of them but at the same time feared discovering the disease and avoided actively seeking out the disease. The following section will look at some of the factors that influenced women to practice BSE, CBE and Mammograms (where available). Other forms of screening such as Mammograms are not available to the majority of Zimbabwean women, and BSE will be used in reference to screening.

Yang et al, (2010), suppose that the HBM does not sufficiently give an explanation for the inconsistent practice of BSE in women due to the fact that many studies have found that most women believe that the threat of breast cancer can be high and the benefit of BSE is great. Yet knowing that BSE is beneficial does not guarantee that women will perform the action because there are several other modifying factors that affect this process. Although respondents talked about how they would seek immediate treatment if they found a lump in their breast, most of the young women reported that they did not practice BSE as often as once a month. The following section will discuss some of the reasons that influenced the practice of BSE.

6.6.1 Worry as a barrier to action

Studies of women at elevated risk for breast cancer because of a family history of disease in first-degree relatives have found that those at higher risk due to family history, including those with a single affected first-degree relative, experience high levels of worry about their personal breast cancer risk (Anderson et al, 2003). Furthermore quantitative studies have reported that high levels of worry among women of all age groups with a family history of breast cancer in this risk group have been reported to be a barrier to action (Lerman et al, 1993; Kenen et al.2003).

Respondents in my study, who witnessed challenges during their relative's illness, and felt vulnerable to the disease, reported being afraid of the disease mostly because they did not know if it would strike and when it would strike. This lack of control and uncertainty about the onset of the disease created levels of worry in the young women. Consequently although participants had perceived susceptibility to breast cancer and believed they were at high risk,

their worry arose from feeling powerless against the disease and the feeling that breast cancer was elusive.

High levels of worry and fear have been found to stimulate cognitive mechanisms, including efforts to reduce immediate stress (Anderson et al, 2003). Efforts to reduce stress may include denial and efforts to avoid reminders of risk. Denial and avoidance of thinking about personal risk could reduce use of early detection measures (Anderson et al, 2003). A young woman in our study with past breast illness, and a mother who had recurring cancers, spoke about how she occasionally wondered about the disease, but did not feel vulnerable because her mother was the first person in their family to suffer from breast cancer and she did not feel the need to practise any early detection measures.

There has been an ongoing debate on whether worry inhibits or facilitates breast cancer screening (Hay et al, 2006). Evidence suggests that perceived high risk of breast cancer evokes increased worry (Lerman et al, 1993; Kenen et al.2003). Evidence also suggests that women who worry a little about breast cancer have higher screening habits than individuals who do not worry at all about breast cancer and those who have high levels of worry (Anderson et al, 2006). Consedine et al, (2004), suggests that because women's cancer fears and worries are diverse, it is important to clearly identify the elements of cancer and the screening process that women are most afraid of and how these anxieties relate to screening behaviour. Although research suggests that fear or anxiety regarding getting breast cancer may be a facilitator of screening (Consedine et al, 2004), it appears to be a deterrent in our study because the women would prefer to rather not actively perform BSE, in order to avoid thinking about breast cancer.

6.6.2 Financial Barriers

The situation of poverty in Zimbabwe is critical and creates obstacles difficult to overcome for families with breast cancer on a daily basis. Lack of funds plays a major role in determining women's access to health care, and determines who survives breast cancer (Muthobi, 2012). Financial constraint was described by some young women as a major obstacle to breast cancer care during the course of their relative's illness, unless one had health insurance to assist in paying for treatment and screening. The high cost of treatment was cited as a deterrent to performing BSE. Two participants who had relatives who had struggled sourcing money for diagnostics and chemotherapy spoke about how they worried about uncovering an illness they could not afford to treat due to the high cost of treatment of breast cancer. This could cause women who cannot afford the cost of treatment to delay

seeking medical treatment and present late for diagnosis, when the tumours are no longer treatable.

Poor socio- economic status has often been a major factor that promotes the late presentation of breast cancer (Christopher, 2008; Epstein et al, 1990). Farley and Farney (1989) also found that women of poor socio- economic status had lower 5-year survival rates compared to higher socio-economic status women. In most studies poor knowledge of breast cancer and low education is often associated with low socio-economic status (MacKinnon et al, 2007). In our study however, participants were aware of the importance of early detection measures.

6.6.3 Fear of mastectomy

For several of our participant's, a breast cancer diagnosis was almost always associated with a mastectomy and the loss of sexual attractiveness that comes with being a woman.

Witnessing a relative undergoing a mastectomy often produced emotional reactions, such as fear and anxiety as young women imagined the loss of their own breasts. A mastectomy is often the only available treatment for breast cancer before chemotherapy and radiotherapy, regardless of stage of diagnosis in Zimbabwe. 2 Studies in Kenya and Nigeria have identified that the fear of mastectomy has often been responsible for women seeking treatment at the advanced stages of their breast cancer (Ajekigbe, 1991; Muthoni and Miller, 2010).

Studies show that a diagnosis of breast cancer is often accompanied by important changes in the body image and self-image of a woman, which could affect their experience of sexuality (Cesnik et al, 2013). Younger women, who have undergone mastectomy, suffer the most post-treatment trauma from body image insecurity and disruptions to their sexual life (Munoz, 2010). Furthermore women who underwent mastectomy reported a greater decrease in libido and more pronounced difficulties in relation to their interest in sex and to achieving orgasm than those who had conservative surgery (Cesnik et al, 2013). Research also encourages the use of other treatment options such as lumpectomy, which produces survival rates similar to mastectomy without the depression that affects most women after a mastectomy (Ajekigbe, 1991). While most young women in America and Canada who have a genetic mutation for breast cancer opt to have preventive mastectomies, women in my study had challenges to accept life without a part of their body they considered integral to a woman's appearance.

6.6.4 Health Policy barriers

Respondents felt that there was an over emphasis on HIV, with little attention given to breast cancer. Participants felt that the lack of attention given to breast cancer by the health professionals influenced their personal breast health behaviour. Despite the limited amount of breast cancer communication, with and from health professionals, participants expressed a desire to learn more about the disease. In Botswana, a study on knowledge about breast cancer and reasons for late presentation by cancer patients showed similar results, that women felt that HIV overshadowed breast cancer and policy makers were more concerned about HIV awareness than cancer awareness (Ongona and Tumbo, 2013).

A study in London, among 25 health professionals found that only 14 of the respondents were comfortable with educating others about breast awareness and that there was a need to target health professionals in order to improve their confidence in educating women (English, 2003). Another study in Nigeria done among female health workers with 102 doctors (26%), 252 nurses (64.6%), and 37 Radiographers, Laboratory Scientists and Pharmacists (9,4 %) also displayed poor levels of knowledge of breast cancer screening (Akhigbe and Oumemu, 2009). This could partly explain the absence of communication among health professionals and the young women in our study.

Awareness campaigns have often been undertaken to increase public awareness of a particular health threat. In most countries a National Breast Cancer Awareness Month exists with a primary aim to encourage regular breast examination so that disease can be diagnosed at an early stage. In America Jacobsen and Jacobsen (2011) found empirical evidence that the National Breast Cancer Awareness Month campaign has been successful in promoting early detection of breast cancer. However their findings show that promotion and adoption of beneficial health behaviours will have their greatest impact when they target behaviours that have not yet been fully accepted by society as normal behaviours (Jacobsen and Jacobsen, 2011).

Increased awareness and knowledge do not necessarily result in enhanced use of early detection measures. Research has shown that often there exists a discrepancy between awareness, knowledge of breast cancer risk and detection tools and practise of breast screening measures (Ongona and Tumbo, 2013; Janda et al, 2000). Health practise is not solely determined only by knowledge and awareness, but possibly a combination of other

factors such as socioeconomic status cultural values, beliefs and practises (Subramaniam, 2013).

7. Conclusion

My study findings show that the perceptions of young women who have first-degree relatives who have been affected by breast cancer are strongly influenced by the experience they witnessed their relative going through. The nature of those relationships may have allowed them to share in the experience of breast cancer and then reflect on their personal breast health. The young women in our study were aware of their breast cancer risk, due to the hereditary risk factor. In addition they were aware of BSE as an early detection measure and stated that they were able to correctly perform BSE. Despite being sufficiently equipped to practise BSE they reported failure to practise BSE regularly. Furthermore participants had a knowledge gap about several other risk factors and signs and symptoms of breast cancer, which could result in them missing an important opportunity to detect breast cancer early.

Health professionals are failing to effectively target groups that are vulnerable to breast cancer in the community by missing the opportunity to provide effective information to the daughters, sisters and nieces of women affected by breast cancer.

The young women in this study all expressed a desire to know more about the illness and were all of the opinion that more information should be disseminated about breast cancer because this is not an illness that anyone should be ashamed of. Furthermore there are notable differences in the aetiology of breast cancer in the younger group of women in comparison to that of their older relatives who suffered from breast cancer. The younger women were more open to biomedical explanations towards the causes of breast cancer and were confident that early detection of breast cancer was an important step towards fighting the disease.

In conclusion knowledge and awareness of breast cancer and its early detection measures is secondary in the absence of improved and affordable breast cancer treatment and efficiency of health care systems.

7.1 Recommendations for practise

Several young women pointed out the absence of breast cancer communication and a desire to learn more about breast cancer. Breast cancer presents earlier in black women than in white women. It is thus of utmost importance to possibly incorporate breast cancer education into school curriculum or carry out specific school education programmes similar to those that address HIV that have previously been undertaken before in the country. This would at least ensure that young women are aware of basic knowledge of breast cancer and are able to identify the signs and symptoms of breast cancer from an early age.

Available private or non-profit services for the cancer community should attempt to fill in the gaps left by government health services and address young women during their visits to the homes of those affected by breast cancer. Granted funds for carrying out nationwide breast cancer campaigns may not be available, and therefore health workers should take advantage and create awareness and empower the few people they have access to because it is guaranteed to make a difference

Furthermore, the cancer associations in Zimbabwe could also attempt to focus on encouraging communication about breast cancer within homes. There appeared to be a lack of communication addressing the young women with first degree relatives of breast cancer, as such, if parents played their part in encouraging their children, e.g. to practise BSE, a small difference could still be made.

Lastly there maybe many barriers to accessing information about breast cancer, perhaps doctors may have no time to address relatives or young women are too busy to visit the health centre when they are not ill etc. As such the community could potentially benefit from a wider distribution of educational pamphlets, brochures or booklets about breast cancer. The availability of this information would potentially increase the chances of young women reading this information. Creating awareness, providing knowledge and creating opportunities for behavioral change would increase both uptake of breast screening and delayed diagnosis.

7.2 Recommendations for future research

This was a small study and there is an all-round need for research on breast cancer in Zimbabwe and especially in Matabeleland North and South regions to gain an even deeper understanding of the dynamics of breast cancer in this community. A quantitative study that can be generalizable to the entire population to possibly measure knowledge and screening habits of women of all ages in Bulawayo would facilitate a bigger picture of the knowledge of breast cancer and who needs to be targeted for education initiatives.

Furthermore an in-depth qualitative study that compares the knowledge and perceptions of women with experience of breast cancer (through friends and family) and women who do not have any experience of breast cancer could possibly show the role played by experience. This research would look at the role of experience in increasing knowledge and forming perceptions and to see if there are differences in knowledge and perceptions. This could assist in identifying the information needs of different age groups across the life span.

Due to the fact that there is a scarcity of research on breast cancer in this community it could also be helpful to investigate the management of breast cancer in government hospitals. A qualitative study that explores how breast cancer is managed from the perspective of both the health professionals and the women affected by breast cancer could illuminate barriers to treatment and possibly assist the health system in targeting areas that need improvement. Through the few discussions carried out with women who had suffered from breast cancer in this study it was clear that there were several underlying structural concerns that these women had. For example some participants complained of the lack of follow up from hospitals, poor communication with health personal and referrals to doctors they could not afford, for treatment. The same research could also investigate what services are available for screening, how they work and who they target. It was evident during the preliminary investigations of this study that there was absence of information of breast cancer services in Bulawayo.

A lot of research has been done in other countries to identify barriers to early detection. However no such study has yet been done in Zimbabwe. It is thus my opinion that such a study is necessary. A qualitative study with women who presented late for breast cancer treatment would best address this research to enable initiatives to be culturally sensitive to the unique needs of different women.

Lastly there is a need to research on suitable communication channels in Zimbabwe. Researchers could investigate using a quantitative study what type of communication is most effective in addressing health needs in Zimbabwe and then focus communication towards this preferred form of communication in order to save money and effectively target as many people as possible. For example the majority of Zimbabweans do not watch foreign digital satellite television, as such communication initiatives through television would not be successful in reaching the masses.

References

- Absetz, P. 2002. *Determinants and psychological implications of breast cancer risk perceptions in the course of mammography screening*. Publications of the National Public Health Institute. University of Helsinki.
- Acheson, L.S., Wiesner, G.L., Zyzanski, S.J., Goodwin, M.A., and Stange, K.C. (2000) *Family history-taking in community family practice: implications for genetic screening*. *Genet* vol 2:180-
- Ajekigbe, A.T. (1991). *Fear of mastectomy: the most common factor responsible for late presentation of carcinoma of the breast in Nigeria*. *Clin Oncol (R Coll Radiol)*. 378- 80
- Akhigbe, A.O., Omuemu, V.O. (2009). *Knowledge attitudes and practice of breast cancer screening among female health workers in a Nigerian urban city*. *BMC Cancer*, 9, 203-5
- American Cancer Society. (2013). *Breast Cancer Facts & Figures 2013-2014*. Atlanta American Cancer Society, Inc Retrieved from :
<http://www.cancer.org/acs/groups/content/@research/documents/document/acspc-040951.pdf> on 23 March 2013.
- Anagnostopoulos, F., Spanea, E. (2005) *Assessing illness representations of breast cancer: A comparison of patients with health and benign controls*. *J Psychosom Res*;58:327–334
- Anderson, B.O and Jakesz, R. (2008) *Breast cancer issues in developing countries: an overview of the Breast Health Global Initiative*. *World Journal of Surgery* 32, 2578–2585.
- Andersen, R., Smith, R., Meischke, H., Bowen, D., Urban, N. (2003). *Breast cancer worry and mammography use by women with and without a family history in a population-based sample*. *Cancer Epidemiology. Biomarkers Prev*; 12 pp. 314–320
- Annals of Oncology. (2010). *Scaling up cancer diagnosis and treatment in developing countries: what can we learn from the HIV/AIDS epidemic?* 21 (4): 680-682
- Atkinson, R., Flint, J. (2004). *Snow Balling*. The SAGE Encyclopedia of Social Science Research Methods. Lweis-Beck, M., Bryman, A and Futing Liao, T. (ed), London
- Austoker., J. (1994). *Cancer prevention in primary care, screening and self examination for breast cancer*. *Br. Med. J.*, 309, 168 – 174
- Baines, C.J. (1992). *Breast self-examination*. *Cancer*. 1;69(7 Suppl):1942–1946.
- Baum, F. (2002). *The New Public Health*. South Melbourne, Vic: Oxford University Press.
- Baxter, N. (2001). *Should women be routinely taught breast self-examination to screen for breast cancer?* *Preventive health care update; CMAJ* 2001; 164: 1837–1846
- Benedict, S., Coon, G., Hoomani, J., Holder, P., (1997). *Breast cancer detection by daughters of women with breast cancer*. *Cancer Practice*; 5 (4) pp. 213–219
- Black, L., McClellan, K.A., Avard, D., Knoppers, B.M. (2012). *Intrafamilial disclosure of risk for hereditary breast and ovarian cancer: Points to consider*. *Journal of Community Genetics*. Advanced online publication. doi: 10.1007/s12687-012-0132
- Bloom, J. R., and Kessler, L. (1994). *Emotional support following cancer: A test of the stigma and social activity hypotheses*. *Journal of Health and Social Behavior*, 35, 118-133.

- Bottom, K., O'Leary, M., Sheaffer, J., Phillips, M., Shu, X., & Arun, B. (2006). *Breast Cancer*. Cancer epidemiology in older adolescents and young adults 15 to 29 years of age; 112-21. 0 06-5767
- Bordage, G. (2009), Conceptual frameworks to illuminate and magnify. *Medical Education*, 43: 312–319. doi: 10.1111/j.1365-2923.2009.03295.x
- Bowen, D., McTierman, A., Burke, W., Powers, D., Pruski, J., Durfy, S., Galow, J., Malone, K. (1999). *Participation in breast cancer risk counseling among women with a family history*. *Cancer Epidemiol. Biomark. Prev.*, 8: 581–585,
- Bradley, C.J., Given, C.W., Roberts, C. (2002). *Race, socioeconomic status, and breast cancer treatment and survival*. *J Natl Cancer Inst*; 94: 490–496.
- Bryman, A. (2008). *Social Research Methods*. 3RD ed. New York. Oxford University.
- Calle, E. E., Martin, L. M., Thun, M. J., Miracle, H. L. and Clark W. Heath, J. (1993) *Family history, age and risk of fatal breast cancer*. *American Journal of Epidemiology*. 138(9): 675-681.
- CanTreat International. (2010). *Scaling up cancer diagnosis and treatment in developing countries: What can we learn from the HIV/AIDS epidemic?* *Ann Oncol*: 21:680-682. Retrieved from: <http://jco.ascopubs.org/content/29/22/3097.full.pdf+html> on 23 September 2013
- Carter, J., Park, E.R., Moadel, A., Cleary, S.D., Morgan, C. (2002). *Cancer knowledge, attitudes, beliefs, and practices (KABP) of disadvantage women in the South Bronx* *J. Cancer Educ.*, 17, pp. 142–149
- Cesnik, V.M., Vieira, E, M., Giami, A., Almeida, A.M., Daniela, B., Santos., M. (2013). *The sexual life of women with breast cancer: meanings attributed to the diagnosis and its impact on sexuality*. *Estudos de Psicologia (Campinas)*, 30(2), 187-197. Retrieved January 23 2014, from : http://www.scielo.br/scielo.php?pid=S0103-166X2013000200005&script=sci_arttext
- Chalmers, K., Thomson, K., Degner, L.F. (1996). *Information, support, and communication needs of women with a family history of breast cancer*. *Cancer Nursing*, 19(3), 204-213.
- Champion, V. (1993). *Instrument for breast cancer screening behaviours*. *Nursing research*: 42, 139 -143.
- Chokunonga, E., Borok., M.Z., Chirenje., Z.M et al. (2011). *Cancer survival in Harare, Zimbabwe, 1993 -1997*. Retrieved from : <http://survcan.iarc.fr/survivalchap31.php> on 27 August 2013.
- Christopher, M. (2008). *Breast cancer diagnosis comes late for women in gentrifying neighbourhoods*. *Biomedicine*; 2008
- Claes, E., Evers-Kiebooms, G., Boogaerts, A., Decruye-naere, M., Denayer, L., and Legius, E. (2003). *Communication with close and distant relatives in the context of genetic testing for hereditary breast and ovarian cancer in cancer patients*. *Am J Med Genet* 116A:11–19.
- Coyne E, Borbasi S (2006) *Holding it all together: breast cancer and its impact on life for younger women*. *Contemp Nurse* 23:157–169.
- Coyne E, Borbasi S. (2009). *Living the experience of breast cancer treatment: The younger women's perspective*. *Australian Journal of Advanced Nursing* ; 26: 6–13

- Consedine, N.S., Magai, C., Neugut, A.I., (2004). *The contribution of emotional characteristics to breast cancer screening among women from six ethnic groups*. *Prev Med*;38:64 – 77
- Creswell, J. W. (2007). *Qualitative inquiry and research method: Choosing among five approaches* (2nd. ed.). Thousand Oaks, CA: Sage.
- Crotser, C.B., Dickerson, S.S.(2010) *Women receiving news of a family BRCA1/2 mutation: messages of fear and empowerment*. *J Nurs scholars* 2010; 42: 367–378.
- Curado, M.P., Edwards, B., Shin, H.R., et al., (2007). eds. *Cancer incidence in five continents*. Vol. IX. Lyon, France: International Agency for Research on Cancer, ARC scientific publications no. 160
- Devi, B,C,R., Tang,T,S., Corbex, M. (2007). *Reducing by half the percentage of late-stage presentation for breast and cervix cancer over 4 years: a pilot study of clinical down staging in Sarawak, Malaysia*. *Ann Oncol* 2007;18:1172-1176.
- Dein, S. (2004). *Explanatory models of and attitudes towards cancer in different cultures*. *Lancet Oncol*;5:119–124.
- Dite, G. S., Jenkins, M. A., Southey, M. C., Hocking, J. S., Giles, G. G., McCredie, M. R. E., Venter, D. J. and Hopper, J. L. (2003) *Familial risks, early-onset breast cancer, and BRCA1 and BRCA2 germ line mutations*. *Journal of the National Cancer Institute*. 95(6): 448-457.
- Ellingson, L.A., Yarber, W.L.(1997). *Breast Self Examination, the health belief model, and sexual orientation in women* .*Journal of Sex Education and Therapy*; 22; 19-24
- English, J. (2003). *Importance of breast awareness in identification of breast cancer*. *Nurs Times* ;99:18–9.
- Epstein, S,A., Lin,T,H., Audrain, J., Stefanek, M., Rimer, B., Lerman, C. (1997). *Excessive breast self examination among first degree relatives of newly diagnosed breast cancer patients*.*Psychosomatics*, 38 (3) , pp. 253–261
- Evans, D,G., Burnell, L.D., Hopwood,P., and Howell, A.(1993). *Perception of risk in women with a family history of breast cancer*. *British Journal of Cancer*.;67:612–614.
- Ezzy, D. (2002a) *Qualitative Analysis : Practice and Innovation*.Crows Nest, N.S.W.: Allen & Unwin.
- Farley, T.A., Flannery, J.T. (1989) . *Late stage diagnosis of breast cancer in women of lower socio-economic status: public health implications*. *Am J Public Health*1989; 79: 1508-12.
- Fulton,M., Thompson.M, Elton,R.A., Brown,S., Wood.D.A.and Oliver,M.F. (1988) *Cigarette smoking, social class and nutrient intake. Relevance to coronary heart disease*. *European Journal of Clinical Nutrition*, 42, 797-803.
- Foxcroft, L. M., Evans, E. B. and Porter, A. J. (2004) *The diagnosis of breast cancer in women younger than 40*.*The Breast*.13(4): 297-306.
- Friedman, L. C., Helson, D. V., Webb, J. A., Hoffman, L. P., Baer, P. E. (1994). *Dispositional optimism, self-efficacy, and health beliefs as predictors of breast self-examination*. *American Journal of Preventive Medicine*, 10 (3), 130-135
- Gelling, L .(2011). *Review: strategies to engage clinical staff in subject recruitment*. *Journal of Research in Nursing*. 16(4), 333-334.

- Goodwin, D. (2006). *Ethical issues*. In C. Pope & N. Mays (Eds.), *Qualitative Research in Health Care* (3rd ed., pp. 53-62). Massachusetts, USA: Blackwell Publishing.
- Gotzsche, P.C, Nielsen, M.(2006). *Screening for breast cancer with mammography*. Cochrane Database Syst Rev: 3: CD001877.
- Graham, H. (ed) (2000) *Understanding Health Inequalities*. Buckingham: Open University Press
- Graf, M.C., Geller, P.A. (2003). *Treating hot flushes in breast cancer survivors: a review of alternative treatments to hormone replacement therapy*. Clin J Oncol Nurs ; 7(6):637-40.
- Gribich, C. F. (1999). *Qualitative Research in Health: An Introduction*. St Leonards,N.S.W.: Allen & Unwin.
- Grunfeld,E.A., Ramirez,A.J., Hunter,M,S., Richards,M,A. (2002). *Women's knowledge and beliefs regarding breast cancer*. Br J Cancer ; 86: 1373–1378
- Guttmacher, A.E., Collins, F.S., and Carmona, R,H. (2004).*The family history — more important than ever*. N. Engl. J. Med ;351:2333–2336.
- Guvenc, I., Guvenc, G., Tastan, S., Akyuz, A. (2012). *Identifying Women`s Knowledge about Risk Factors of Breast Cancer and Reasons for Having Mammography*. Asian Pacific Journal of Cancer Prevention, 13; 4191-4197. doi:http://dx.doi.org/10.7314/APJCP.2012.13.8.4191
- Hailey BJ, et al. (2000). *Breast cancer attitudes, knowledge and screening behavior in women with and without a family history of breast cancer*. Health Care Women Inter;21:701-15.
- Haristova.L., and Hakama.M. (2007) *Effect of screening for cancer in the nordic countries on deaths, costs and quality of life up to the year 2017*.Acta Oncol; 36(suppl 9):1–60
- Hay, J.L., Buckley,T,R., J.S., Ostroff.J.S., (2005). *The role of cancer worry in cancer screening: a theoretical and empirical review of the literature*. Psychooncology; 14, pp. 517–534
- Hochbaum, G. M.(1958). *Public participation in medical screening programs: A socio-psychological study* (Public health service publication no 572).Washington DC, gVT printing office.
- Hopwood, P. (2000) *Breast cancer risk perception: What do we know and understand?* Breast Cancer Res 2:387–391.
- Hofvind,S, Ursin,G, Tretli, S. et al.(2013). *Breast cancer mortality in participants of the Norwegian Breast Cancer Screening Program*. Cancer ;119:3106-3112.
- Huerta, E. and Grey, N,. (2007). *Cancer control opportunities in low-middle income countries*. CA Cancer J Clin 57:72-74
- Im, Karen, (2011)*The Different Perceptions of Breast Cancer in Post-Conflict Northern Uganda* . Independent Study Project (ISP) Collection. Paper 1205.
http://digitalcollections.sit.edu/isp_collection/1205
- Imaginis. (2012). *Risk factors for breast cancer*. Retrieved from :
<http://www.imaginis.com/breast-cancer-screening-prevention/what-are-the-risk-factors-for-breast-cancer> on 27 August 2012.
- Jacobsen, G.D, Jacobsen ,K,H. (2011). *Health awareness campaigns and diagnosis rates: evidence from National Breast Cancer Awareness Month*. J Health Econ, 30, 55-6.
- Janda, M., Obermair, A., Haidinger, G., Waldhoer, T., Vutuc, C. (2000). *Austrian*

women's attitudes toward and knowledge of breast self-examination. *J Cancer Educ*;15(2):91–94. PMID:10879898

Jatoi, I., Anderson, W.F., Rao, S.R., Devesa, S.S. (2005). *Breast cancer trends among black and white women in the United States*. *J Clin Oncol* ; 23: 7836–41

Jemal, A., Bray, F., Center, M.M., Ferlay, J., Ward, E. and Forman D. (2006). *Global cancer statistics*. *CA Cancer J Clin*. 2011; 61:69–90.

Johnson, N. (2007). *Young Women's Perceptions of breast cancer*. La Trobe University. Bendigo, Australia

Jones, B. (2013). *Health Belief Model*. Jones and Barlett Publishing. Retrieved from

Julian-Reynier, C., Mancini, J., Mouret-Fourme, E., Gauthier-Villars, M., Bonadona, V., Berthet, P., et al. (2011). *Cancer risk management strategies and perceptions of unaffected women 5 years after predictive genetic testing for BRCA1/2 mutations*. *Eur J Hum Genet*;19:500–6.

Katapodi, M.C., Dodd, J. M., Facione, N.C., Humphreys, J.C., Lee, A. K. (2010). *Why some women have an optimistic or a pessimistic bias about their breast cancer risk: Experiences, heuristics, and knowledge of risk factors*. *Cancer Nursing*. 2010;33(1):64-73.

Keilman, T. (2012). *An effective tool for battling Breast Cancer*. Retrieved from: http://www.forskningsradet.no/prognettmammografi/Nyheter/An_effective_tool_for_battling_breast_cancer/1253976490376/p1226994052823 on 7 May 2013

Kenen, R., Arden-Jones, A., & Eeles, R. (2004). *We are talking, but are they listening? Communication patterns in families with a history of breast/ovarian cancer (HBOC)*. *Psycho-Oncology*.

Kiguli-Malwadde, L. E., Mubuuke, A. G., Businge, F., Kawooya, G. M., Nakatudde, R., Byanyima, K. R., and Muyinda, Z., (2010) *Current knowledge, attitudes and practices of women on breast cancer and mammography at Mulago Hospital*. *Pan African Medical Journal* 3, 9.

Knobf, M. T. (2001). *The menopausal symptom experience in young-midlife women with breast cancer*. *Cancer Nursing*, 24, 201-210.

Komen, S., (2011). *Young women and breast cancer*. Retrieved from: http://www5.komen.org/uploadedfiles/Content_Binaries/806-352a.pdf on 23 June 2012.

Kopans, D., B. (2014). *Arguments against mammography screening continue to be based on faulty science*. *Oncologist* ;19:107-112.

Kösters, J.P., and Götzsche, P.C. (2003). *Regular self-examination or clinical examination for early detection of breast cancer*. *Cochrane Database Syst Rev*; CD003373.

Krombein, I.W. (2006) *Breast cancer-early detection and screening in South African women from the Bonteheuwel Township in the Western Cape: knowledge, attitude and practices*. *SA Fam Pract*. 2006;48: 5:14-19

Kvale, S. B., & Brinkmann, S. (2009). *Interviews: Learning the Craft of Qualitative Research Interviewing*. London: Sage Publications

Lapointe, J., Cote, C., Bouchard, K., Godard, B., Simard, J., Dorval, M. (2013). *Life events may contribute to family communication about cancer risk following BRCA1/2 testing*. *J Genet Counsel*; 22, 249–257

- Lende, D. H., and Lachiondo, A. (2009). *Embodiment and breast cancer among African American women*. *Qualitative Health Research*, 19, 216-228.
- Lerman, C., Seay, J., Balshem, A., Audrain, J. (1995). *Interest in genetic testing among first-degree relatives of breast cancer patients*. *Am J Med Genet* ;57:385–392.
- Lewis, T. (2006) *Seeking health information on the internet: Lifestyle choice or bad attack of cyberchondria*. *Media, Culture and Society*. 28(4): 521-539.
- Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods*. Oxford: Oxford University Press
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. California: Sage Publications.
- Loh, S.Y, Chew, S.L. (2011). *Awareness and practice of breast self examination among Malaysian women with breast cancer*. *Asian Pacific J Cancer Prev*, 12, 199–202
- MacKinnon, J.A., Duncan, R.C., Huang, Y., Lee, D.J., Fleming, L.E., Voti, L., Rudolph, M., Wilkinson, J.D. (2007). *Detecting an association between socioeconomic status and late stage breast cancer using spatial analysis and area-based measures*. *Cancer Epidemiol Biomarkers Prev*: 16(4):756-762
- Malterud, K. (2001). *Qualitative research: standards, challenges, and guidelines*. *The Lancet*, 358(9280), 483-488. doi: 10.1016/s0140-6736(01)05627
- Mandere, W., (2009), *Know More About Breast Cancer*. Breast Cancer Alleviation. 1st edition
- Mandelblatt, J.S.; Cronin, K.A.; Bailey, S. et al., (2009). *Breast Cancer Working Group of the Cancer Intervention and Surveillance Modeling Network. Effects of mammography screening under different screening schedules: Model estimates of potential benefits and harms*. *Ann Intern Med* ;151:738-747.
- Marshall, C. and Rossman, G. B. (1999) *Designing qualitative research*. Thousand Oaks, Calif: Sage Publications.
- Mbuka-Ongona, D., Tumbo, J. (2013) *Knowledge about breast cancer and reasons for late presentation by cancer patients seen at Princess Marina Hospital, Gaborone, Botswana*. *African Journal of Primary Health Care & Family Medicine*, North America. Retrieved on 23 January 2014. From: <http://www.phcfm.org/index.php/phcfm/article/view/465>
- McCredie, M. R. E., Dite, G. S., Giles, G. and Hopper, J. L. (1998) *Breast cancer in Australian women under the age of 40*. *Cancer, Causes and Control*. 9: 189-198.
- Meissner, H.I., Potosky, A.L., and Convisser, R. (1992). *How sources of health information relate to knowledge and use of cancer screening exams*. *J Community Health*. 17(3):153–65
- Milligan R, Wingrove BK, Richards L, Rodan M, Monroe-Lord L, Jackson V, et al.(2002). *Perceptions about prenatal care: Views of urban vulnerable groups*. *BMC Public Health*.
- Mothobi, N.M. (2010). *The relationship between knowledge of breast self examination and practises regarding breast self examination among women ages 25-49 years at Mbare Family services clinic in Hre Zimbabwe*. University of Zimbabwe. Retrieved from: <http://ir.uz.ac.zw/jspui/handle/10646/1102?mode=full> on 20 September 2013
- Muguti G.I.(1993) *Experience with breast cancer in Zimbabwe*. *J R Coll Surg Edinb*; 38: 75–78.
- Mukupo, F.C and Mubita-Ngoma, C.A. (2007). *Breast cancer knowledge and breast self examination practice among rural and urban women in Zambia*. *Africa Journal of Nursing and Midwifery*; 9:1: 50-58.

- Mullens, A.B., McCaul, S.C., Erickson, A.K., Sandgren, A.K.(2004). *Coping after cancer: Risk perceptions, worry and behaviors among colorectal cancer survivors*. *Psycho-Oncology* 13: 367–376
- Munoz, M. (2010). *Quality of life during treatment in young women with breast cancer*. *Breast Cancer Res. Treat.* Vol. 123. Suppl. 1.P. 75–77.
- Muthoni, A and Miller, A,N.(2010). *An exploration of rural and urban Kenyan women's knowledge and attitudes regarding breast cancer and breast cancer early detection measures*. *Health care for women international*, 31:9, 801-816.
- National Cancer Institute. (2005). *Theory at a Glance*. Washington, DC: National Institutes of Health.
- Neugut, A.I. and Jacobson, J.S. (1995) *The limitations of breast cancer screening for first degree relatives of breast cancer patients*. *American Journal of Public Health*,85, 832–4.
- Ngoma T. (2006). *World Health Organization cancer priorities in developing countries*. *Ann Oncol* 17 Supplement 8. viii9-viii14.
- Norman, P., Brain, K. (2005), *An application of an extended health belief model of the prediction of breast self-examination among women with a family history of breast cancer*. *Br J Health Psychol*2005, 10:1-16.
- Nycum, G., Avar, D., Knoppers, B.M. (2009). *Factors influencing intrafamilial communication of hereditary breast and ovarian cancer genetic information*. *Eur J Hum Genet*; 17: 872–880; doi: 10.1038/ejhg.2009.33
- Opoku, S,Y., Benwell, M., Yarney.B. (2012).*Knowledge, attitudes, beliefs, behaviour and breast cancer screening practices in Ghana, West Africa*. *The Pan African Medical Journal*;11:28
- Palmer, J,R, Boggs DA., Adams-Campbell. L.L., Rosenberg,L. (2009). *Family history of cancer and risk of breast cancer in the Black Women's Health Study*.*Cancer Causes Control* 2,20:1733-1737
- Parkin, D. M. (1994). *Cancer in developing countries. Trends in Cancer Incidence and Mortality Cancer Surveys*; 19:20, 519 – 555.
- Paulhus, D, L.(1991). *Measurement and control of response bias*. In J.P.Robinson, P,R,Shaver, & L,S,Wrightsmen (Eds), *Measures of personality and social attitudes*(pp.17-59).San Diego,CA:Academic Press.
- Patton, M. Q. (2002). *Qualitative Research and Evaluation Methods* .3rd ed. Newbury Park, CA: Sage Publications, Inc.
- Payne (1990). Rees, G., Fry, A. and Cull, A. (2001a). *A family history of breast cancer: women's experiences from a theoretical perspective*. *Social Science and Medicine*, 52, 1433–1440.
- Peek, M.E., Sayaa, J.V., Markwardt, R.(2008). *Fear, fatalism and breast cancer screening in low income African-American women: The role of clinicians and the health care system*. *J Gen Intern Med* ;23(11):1847–53.
- Petrisek, A., Campbell, S., Laliberte, L. (2000). *Family history of breast cancer. Impact on the disease experience*. *Cancer Pract.* 2000; 8:135.-42

- Pham, C.T., McPhee, S.J. (1992). *Knowledge, attitudes, and practices of breast and cervical cancer screening among Vietnamese women*. J Cancer Educ. Winter;7(4):305-10. PubMed
- Pitts, M., McMaster, J., Wilson, P. (1991). *An investigation of preconditions necessary for the introduction of a campaign to promote breast self-examination amongst Zimbabwean women*. Journal of Community and Applied Social Psychology, 1, 33–41.
- Powe, B. (1995). *Cancer fatalism among elderly Caucasians and African Americans*. Oncology Nursing Forum; 22(9):1355-1359
- Porter P. (2008). “*Westernizing*” women’s risks? *Breast cancer in lower-income countries*. New English Journal of Medicine ; 358: 213–16.
- Powe, B., Daniels, E., Finnine, R., Thompson, A. (2005). *Perceptions about breast cancer among African American women: do selected educational materials challenge them?* Patient Education and Counseling. 56 (2):197-204
- Rajaram, S.S., and Rashidi, A. (1998). *Minority women and breast cancer screening: The role of cultural explanatory models*. Preventive Medicine 27, 757-64
- Rees, G., Fry, A. Cull, A. (2001a). *A family history of breast cancer: women’s experiences from a theoretical perspective*. Social Science and Medicine, 52, 1433–1440.
- Rees, G., Fry, A., Cull, A., Sutton, S. (2004). *Illness perceptions and distress in women at increased risk of breast cancer*. Psychology and Health, 19, 749–765
- Rolland, J. S., Williams, J. K. (2005). *Toward a biopsychosocial model for 21st-century genetics*. Family Process, 44(1), 3–24.
- Roter, D. L. and Hall, J.A. (1992) *Doctors talking with patients/Patients talking with doctors: Improving communication in medical visits*. Auburn House, Westport, CT.
- Sant, M., Allemani, C., Berrino, F., et al (2004). *Breast carcinoma survival in Europe and the United States*. Cancer, 100, 715-22.
- Sarantakos, S. (1998). *Social Research*. South Yarra: Macmillan Education Australia
- Shenton, A. K. (2004). *Strategies for ensuring trustworthiness in qualitative research projects*. Education for Information, 22, 63–75
- Sherman, R.R., and Webb, R.B. (1988). *Qualitative Research In Education: Explorations in ethnography series*. Taylor & Francis. London
- Shulman, L.N., Willett, W., Sievers, A., Knaul, F.M. (2010). *Breast cancer in developing countries: opportunities for improved survival*. J Oncol :595167.
- Stefanek, Helzlsouer, Wilcox and Houn (1995). Rees, G., Fry, A. and Cull, A. (2001a). *A family history of breast cancer: women’s experiences from a theoretical perspective*. Social Science and Medicine, 52, 1433–1440.
- Stretcher, V.J., Rosenstock, M. (1997). *The Health Belief Model*. K. Glanz, F.M. Lewis, B.K. Rimer (Eds.), Health behavior and health education: theory, research, and practice, Jossey-Bass, San Francisco, CA ;pp. 41–59

- Subramanian, P., Ositadimma, O.N., Mohd, M.A., Aishah T.N., Ahmad, N. (2013). *Breast Cancer Knowledge and Screening Behaviour among Women with a Positive Family History: A Cross Sectional Study*. Asian Pac J Cancer Prev ;14(11):6783-90.
- Taylor, D., Bury, M., Campling, N., Carter, S., Garfied, S., Newbould, J., Rennie T.(2007). *A review of the use of the health belief model (HBM), the theory of reasoned action (TRA), the theory of planned behavior (TPB) and the transtheoretical model (TTM) to study and predict health related behaviour change*. London, UK: National Institute for Clinical Excellence.
- Thomas, D.B., Gao, D.L., Ray, R.M., et al. (2002). *Randomized trial of breast self-examination in Shanghai: Final results*. J Natl Cancer Inst; 94:1445–1457.
- Tiengo, J.G. (2011). *Knowledge, attitude and practice of breast cancer examination among women attending a health facility in Gaborone, Botswana*. Gender and behaviour.9:1
- Walter, F.M., Emery, J., Braithwaite, D., Marteau, T.M. (2004). *Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research*. Ann Fam Med ;2:583-94
- Weir, H.K., Thun, M.J., Hankey, B.F, Ries., L.A., Howe, H.L., Wingo, P.A., Jemal, A., Ward, E., Anderson, R.N and Edwards, B.K. (2003). *Annual report to the nation on the status of cancer, 1975 - 2000 featuring the uses of surveillance data for cancer prevention and control*. J Natl Cancer Inst 95,1276 - 1299
- Weiss, N. S., (2003) *Breast cancer mortality in relation to clinical breast examination and breast self-examination*. US National Library of Medicine Breast Journal 2, S86 – 9.
- Wellisch, D.K., Gritz, E.R., Schain, W., Wang, H.J.,. Siau, J. (1992). *Psychological functioning of daughters of breast cancer patients Part II characterizing the distressed daughter of the breast cancer patient Psychosomatics*, 33 (1992), pp. 171–179
- Williams, T., Clarke, V. A. and Savage, S. (2002) *Women's perceptions of familial aspects of breast cancer*. Health Education Journal. 102(2): 50-59.
- Witte, K., Cameron, J., McKeon, J., Berkowitz., (1996). *Predicting risk behaviors: development and validation of a diagnostic scale*. J Health Commun, 1 (4) , pp. 317–341
- Woloshin, S., Schwartz, L.M., Black, W.C., & Welch, H.G. (1999). *Women's perceptions of breast cancer risk: How you ask matters*. Medical Decision Making, 19, 221–229
- Yang RJ, Huang LH, Hsieh YS, et al (2010). *Motivations and reasons for women attending a breast self-examination training program: A qualitative study*. BMC Womens Health, 10,23
- Yep, G. A.(1993). *HIV prevention among Asian American college students. Does the health belief model work ?* Journal of American College Health; 41,(5):199-205
- Zaba, F., and Muzulu, P. (2013). *Cancer fight hamstrung by steep costs*. Zimbabwe Independent. Retrieved from; <http://www.theindependent.co.zw/2013/11/01/cancer-fight-hamstrung-steep-costs/>. On 27 January 2014
- Zahavi, D. (2003). *Phenomenology and metaphysics*. Metaphysics, Facticity, Interpretation. Contributions to Phenomenology. Kluwer Academic Publishers. Dordrecht-Boston: 3-22
- Zeleniuch-Jaquotte, A. and Shore, R. E. (1999) *Epidemiology In Breast Cancer*. ed. Daniel F. Roses. New York: Churchill Livingstone.

Appendix

APPENDIX A: English Interview Guide

Themes and probes

Theme: Relatives experience with breast cancer in the family

- Please tell me about your experience
- Coping strategies – the patient
- Coping strategies - the relative (how are you doing, yourself? Living with the patient)
- Challenges
- Appreciation,/ positive aspects
- Patient – discovering the disease

Theme: Breast cancer relative's attitude towards Breast Cancer

- Relatives need while ill / on treatment
- Who was / have been helping her? How?
- Possible reasons relatives got cancer
- Other reasons other people get breast cancer
- What kind of support have you been giving to your relative?
- Can you think of reasons why this happened to your relative?
- Do you talk about your relative's condition with friends and other relatives?
- What kind of people do you think get breast cancer? Tell me more.

Theme: Social support services available for relatives of breast cancer patients

- Please tell me about how people outside the close family treated you and your relative. Support from cancer organisations or churches etc.
- Please tell me how this made you feel.
- Did you seek any help? What influenced your decision to either seek or not seek any support?

Theme: Role of experience in creating desire to know more about breast cancer

Please tell me how this experience has affected your view of breast cancer?

- Did you look/ ask health care givers for any information about breast cancer after your relative was diagnosed?
- What kind of information did you get? Did this information help you, how?
- If you did not get any information after you asked, how did this make you feel?

- Please tell me about your inspiration to look for information?

Theme: Level of knowledge

- Had you heard about breast cancer before your relative was diagnosed? (Severity of disease).
- In your opinion please tell me how one can tell that they have breast cancer before going to the hospital?(Signs and symptoms)
- Please tell me what you know about checking for breast cancer in the hospital
- In your opinion how is breast cancer treated? (Factors that may reduce mortality).

Theme: Perceived risk of breast cancer relative

- Have you ever thought of getting any breast check ups?
- Please tell me more about your decision to either get breast checks / not to get checks
- What age groups do you think get breast cancer?
- Do you feel that breast cancer is something you should worry about in your own life?
- Prompt to find out if respondent knows she is at risk because her sibling has breast cancer
- From where did you get this information?

Theme: Available knowledge on breast cancer

- Please tell me what kind of information you received about breast cancer if any? From who and from where and when.
- Show me information you have if any.

Closed ended questions at the end of the interview

- Do you think there is a relationship with Breast Cancer and Breast-feeding?
- Do you think it's contagious?
- Whose hands is the outcome of breast cancer in?
- Do you think it can be cured?
- Do you think the stage at which you find out you have the disease affects the outcome of your disease?

APPENDIX B: Ndebele Interview guide

Indikimba : okuhlangana leihlobo ngemvukazane yebele emulini

- Ngicela ungitshela nglwazi lwakho ngaokho osukubonile
- Indlela zokuphila ngazo – isigulane
- Indlela zokuphila ngazo – isihlobo (wena ngokwakho wenzanjani ? uhlala lesigulane)
- Ubunzima ohlangna labo ?
- Impumela ezinhle
- Isigulane – ukubakwazi ngomkhuhlane kwakhe

Indikimba: Izihlobo ziphatha njani umkhuhlane wemvukuzane yebele

- Ngubani owayencedisa/ obekade encedisa njalo njani ?
- Izizatho eingenza izihlobo zihlaselwe yimvukuzane
- Ezinye izizatho ezenza abanya abantu bahlaselwe ngumkhuhlane wemvukuzane yebele
- Yiziphi indlela zokuphathisa/ ukusekela ozenzela isihlobo sakho ?
- Yiziphi izizatho ongacabangela ukuthi kungani lokhu kwenzakala esihlobeni sakho
- Uyakhuluma yini ngesimo sesihlobo sakho labangane kumbe lezinye izihlobo ?
- Ucabanga ukuthi ngabantu abanjani abahlaselwa yimvukuzane yebele ? ngicela ungichasisele mbijana impendulo yakho.

Indikimba : lokhu osuhlangane lakho kudlale indima bani ekunikeni intshukuntshu ngomkhuhlane wemvukuzane yamabele

- Lokhu osuhlangane lakho kwakunika umbono bani mayelana lomkhuhlane wemvukuzane wamabele ?
- Wake wadinga kumbe ukubuza abantu bezempila kahle ngodletshwana oluqoqela umkhuhlane wemvukuzane ngemva kokuhlowa kwesihlobo sakho
- Wazuza udletshana bani ? udletshana lolu lwakuncedisa yini ? njalo njani ?
- Ngicela ungitshela ukuthi yini eyakwenza ukuthi ube lothando lokudingisisa ngodletshana ?
- Indikimba:ulwazi lwezi bonakaliso lezito ezingenza umuntu angafi ngemva kokuhlaselwa ngumkhuhlane wemvukuzane
- Wawuke wezwa ngomkhuhlane wemvukuzane ohlasela amabele ngemva kokuthi isihlobo sakho sihloliwe ? (ububi bomkhuhlane)

- Ngombono wakho ngicela ungitshela ukuthi umuntu engabakwazi ukuthi selomkhuhlane ohlasela amabele engaka hambisi sibhedlela (izibonakaliso lezishengiselo)
- Ngicela ungitshela ngokwaziyo mayelana lokuhlolwa kwemvukuzane esibhedlela
- Ngombono wakho umkhuhlane wemvukuzane ohlasela amabele uyelatshwa njani (izinto ezingehlisa ukufa)

Indikimba : ukubona ukutho kungaba lethuba lokuhlaselwa ngumkhuhlane wemvukuzane

- Sowake wacabanga ukuthi uyehlwa amabele yini ?
- Ngicela ungitshela ngabanzi ngesinqumo sakho sokuthi uyehlolwa amabele kumbe ukungahlolwa
- Ngabantu abalemnyaka engaki ocabangala ukuthi bengaba lomkhuhlane wemvukuzane yamabele ?
- Uzwa engani umkhuhlane wemvukuzane ehlasela amabele ungaba ngumkhuhlane okumele uzikhathaze ngawo empilweni yakho ?
- Buza ngabanzi ukuthi umabuzwa uyazi yini ukuthi usengozini yokuba lomkhuhlane wemvukuzane njengoba udadewabo elawo.
- Waluthola ngaphi ulwazi lolu

Indikimba: ukuba khona kolwazi lwemvukuzane ehlaselam amabele

- Ngicela ungitshela ukuthi wathola udletshana bani mayelana ngomkhuhlane ohlasela amabele uma wathola. Wawuthola kubani njalo ngaphi njalo nini ?
- Ngicela ungitshengise udletshana olalo nxa ulalo.

Imibuzo edinga impendulo kayebo kumbe hatshi

- Ucabanga ukuthi kungabe kulobudlelwano na phakathi komkhuhlane wemvukuzane yebele lokumunyisa ?
- Ucabanga ukuthi uyathelwana na lowu umkhuhlane ?
- Impumela yomkhuhlane wemvukuzane yebele usezandleni zikabani ?
- Ucabanga ukuthi uyelapheka na
- Ucabanga ukuthi isibanga obona ngaso kumbe onanzelela ngaso ukuthi usulomkhuhlane ingahlasele impumela yomkhuhlane wakho na ?

APPENDIX C: Ndebele Consent Form

Ukuzwisisa imibono lemicabango yabomama abayizihobo zase duze kulabo abalomkhuhlane wemvukuzane webele ngomkhuhlane wemvukuzane webele

Obambe lumsebenzi : Valerie Nkala

Inombolo Zocingo: 0772135878

Okumele ubekwazi ngalo umsebenzi :

- Sikunika imvumelano leyo ukuze ubale ukuthi umsebenzi lowu umayelana lani, okungaba yingozi lokungaba lempumela enhle
- Isiqokoqela salomsebenzi yikuzuzwa ulwazi olunganceda izigulani eminyakeni ebuyayo.
- Asingeke sithembise ukuthi umsebenzi lowu ungakusiza wena ngokwakho.
- Ulelungelo lokwala ukuncedisa kulo umsebenzi kumbe ukuvuma khathesi ubusutshintsha umcabango phambili uyekele ukuphathisa
- Ungakhetha ukungaqhubekeli phambili lalomsebenzi Uzaqhubeka ngithola ithuba lokweletshwa njengenjayelo
- Uyakhuthazwa ukuthi ubale incwadi leyi uzwisise ubuze imbuzo lapho ofisa khona
- Awubanjwa ngamandla ukuba uphathise kulo msebenzi.

Injongo

- Injongo yomsebenzi lo yikuzama ukuzwisisa ukuthi izihlobo ezingo mama zalabo abake bahlaselwa ngumkhuhlwane wemvukuzane yamabele. Ngalo umsebenzi sizama ukubona ukuthi izihlobo lezi zazi okunganani ngalo mkhuhlane, lokuthi babona engani bangawuzuzwa yini.

Indlela yokuyenza lowu msebenzi

- Ungavuma ukukhuluma lathi ngalolu udaba sizaxoxa okwehola elilodwa endaweni ekhethwe nguwe lalo oyabe ephethe lowumsebenzi. ngizabuza umbuzo omfitshane ubusuphendula kabanzi nxa ufisa. Ngiyabe ngingakubuzi okuyimfihlo kuwe. Indletshana eqondane lalomsebenzi yiwo wodwa esiyabe siwufuna.

Ingozi

- Lowu msebenzi ungaba lengozi yokukukhumbuzwa ubuhlungu osuke wabuzwa obubangelwe yilo mkhuhlane isihlobo sakho sigula, ngaphandle kwalokhu okula enye ingozi engakwehlela.

Okuhle

- Umsebenzi lowu uzaphathisa ukuzwisa ngomkhuhlane wemvukuzane kubomama abangaphansi kweminyaka engamatshumi amathathu lanhlanu ukuze sithole indlela ezifaneleyo zokuvikela omama kuwo. Angeke ngithembise ukuthi lowu msebenzi uzakuphathisa wena ngokwakho.

Ilungelo lemfihlo yakho

- Konke ozangitshela khona kuzoba sezandleni zami kuphela. Esizakukhuluma lapha akusoze kuntshintshe lutho ngokuthola uncedo esibhedlela kwakho. Ibizo lakho lizabe lifihliwe njalo akakho ozaba kwazi ukuthi nguwe obusipha impendulo lezi. Konke ongitshela khona ngizakusebenzisa ukubhala ugwalo lwami lwesikolo Uma ulemibuzo ulemvumo yokubuza njalo ngiyakukhuthaza ukuthi ubuze imbizo.

Ilungelo lokuncedisa

- Ulemvumo yokwala ukuphathisa kulomsebenzi, kukuwe awubanjwa ngamandla. uma ukhetha ukungaxoxi lathi uzaqhubeka uthola uncedo olufaneleyo ezibhedlela zonke koBulawayo. Njalo ulelungelo lokuthi uma ubuke wavuma ukuphathisa

- Ngiyavuma ukurekhodwa

Yes

No

Name of Research Participant (*please print*)

Date

Signature of Participant or legally authorized representative

Time

APPENDIX D: English Consent form

Exploring perceptions of breast cancer among first degree relatives of breast cancer patients in Bulawayo Zimbabwe

Principal Investigator : Valerie Nkala [postgrad]

Phone number: 0772135878

What you should know about this research study:

- We give you this consent so that you may read about the purpose, risks, and benefits of this research study.
- Routine care is based upon the best known treatment and is provided with the main goal of helping the individual patient. The main goal of research studies is to gain knowledge that may help future patients.
- We cannot promise that this research will benefit you. Just like regular care, this research can have side effects that can be serious or minor.
- You have the right to refuse to take part, or agree to take part now and change your mind later.
- Whatever you decide, it will not affect your regular care.
- Please review this consent form carefully. Ask any questions before you make a decision.
- Your participation is voluntary.

PURPOSE

- You are being asked to participate in a research study of breast cancer patients. The purpose of the study is to find out perceptions of young women who are first degree relatives of breast cancer patients in Bulawayo. You were selected as a possible participant in this study because you are a sister / daughter of a breast cancer patient, you will be one of 20 possible participants in Bulawayo.

PROCEDURES AND DURATION

- If you agree to participate in this study you will be required to have an hour-long interview with the researcher in a private setting. I will ask a few guiding

questions and the participant is free to explain at length. The researcher will not be collecting any personal information from the participants; only information that is directly related to the research will be collected.

RISKS AND DISCOMFORTS

- I am aware that this is a sensitive issue and some of you may have lost loved ones to breast cancer, appropriately you are free to stop the interview as desired and proceed at a later stage if you are willing too.

BENEFITS AND/OR COMPENSATION

- This research may help to increase the knowledge around young women and breast cancer and help to provide appropriate education and services for young women. Your participation in this study will help add to the research on breast cancer among young women in breast cancer risk groups. There are no direct benefits to you for participating, however this study may alert you to evaluate your own breast health and of those closest to you.

CONFIDENTIALITY

- If you indicate your willingness to participate in this study by signing this document, we plan to disclose this information in a masters thesis to be published by the University of Oslo in 2013 . Any information that is obtained in connection with this study that can be identified with you will remain confidential and will be disclosed only with your permission.

ADDITIONAL COSTS

- You will not be required to incur any costs and all the costs will be borne by the researcher.

IN THE EVENT OF INJURY

- In the event of injury resulting from your participation in this study, treatment shall be offered by the study.
- In the event of injury, contact Valerie Nkala on 00772135878

VOLUNTARY PARTICIPATION

- Participation in this study is voluntary. If you decide not to participate in this study, your decision will not affect your future relations with the University of Oslo , its personnel, and associated hospitals . If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.

OFFER TO ANSWER QUESTIONS

- Before you sign this form, please ask any questions on any aspect of this study that is unclear to you. You may take as much time as necessary to think it over.

AUTHORIZATION

- You are making a decision whether or not to participate in this study. Your signature indicates that you have read and understood the information provided above, have had all your questions answered, and have decided to participate.

Name of Research Participant (please print)

Date

Signature of Participant or legally authorized representative

Time

Signature of Witness
Conse

Signature of Staff Obtaining

YOU WILL BE GIVEN A COPY OF THIS CONSENT FORM TO KEEP.

- If you have any questions concerning this study or consent form beyond those answered by the investigator, including questions about the research, your rights as a research participant
- or research-related injuries; or if you feel that you have been treated unfairly and would like to talk to someone other than a member of the research team,

X

please feel free to contact the Medical Research Council of Zimbabwe on telephone 791792 or 791193.

Audio, Video Recording and Photography

- A tape recorder will be used to collect information, unless you are not comfortable with this, then a different method will be agreed upon. Afterwards interviews will be transcribed verbatim. No one (other than the researcher) will have access to the interview tape or verbatim transcript.

Statement of Consent to be photographed, Audiotaped or Videotaped.

- I understand that audio recordings will be taken during the study. (Mark either “Yes” or “No”)

- I agree to **being audio recorded**

Yes

No

Name of Research Participant (*please print*)

Date

Signature of Participant or legally authorized representative

Time

Name of Staff Obtaining Consent (*please print*)

Signature
Date

APPENDIX E: English Information sheet

Researcher : Valerie Nkala

Supervisor : Ane Haaland

Co.-supervisor: Ida Rashid Khan Bukholm

The research aims at exploring perceptions about breast cancer from female relatives who have had contact or experienced breast cancer from a first-degree relative. The research also hopes to explore how participants view breast cancer, what they understand about it, who gets breast cancer and whether or not they think they are at risk.

If you agree to participate in this study you will be required to have an hour-long interview with the researcher in a private setting. I will ask a few guiding questions and the participant is free to explain at length. The researcher will not be collecting any personal information from the participants; only information that is directly related to the research will be collected.

The interviews will be approximately an hour long, but you have the right to stop the interview when desired. A tape recorder will be used to collect information, unless you are not comfortable with this, then a different method will be agreed upon. Interviews will be carried out at a location agreed upon by you and the researcher at a time suitable most suitable for you.

This research may help to increase the knowledge around young women and breast cancer and help to provide appropriate education and services for young women. Your participation in this study will help add to the research on breast cancer among young women in breast cancer risk groups.

I am aware that this is a sensitive issue and some of you may have lost loved ones to breast cancer, appropriately you are free to stop the interview as desired and proceed at a later stage if you are willing too. There are no direct benefits to you for participating, however this study may alert you to evaluate your own breast health and of those closest to you.

The data collected from you will be accessible only to this researcher and kept in a safe place. No staff or other individuals will be able to know your thoughts and opinions on how you experience life. It will therefore have no consequences for the health care you receive. I am interested in you telling me your story, and I respect what you know. You will remain anonymous and if for any reason you desire to withdraw from the study you are free to do so without fear of any consequences. The data

collected from this thesis will be used in my master's dissertation and may appear in other journals or publications. If you have any questions or requests to me about the research and you part in it, I encourage you to ask me at any time before, throughout or after the interview.

If you have any questions please contact:

Valerie Nkala

Principal Investigator

valerienkala@yahoo.com

Ane Haaland

Main Supervisor

[*ane.haaland@gmail.co*](mailto:ane.haaland@gmail.com)

APPENDIX F: Ndebele information sheet

Injongo yomsebenzi lo yikuzama ukuzwisisa ukuthi izihlobo ezingo mama zalabo abake bahlaselwa ngumkhuhlwane wemvukuzane yamabele. Ngalo umsebenzi sizama ukubona ukuthi izihlobo lezi zazi okunganani ngalo mkhuhlane, lokuthi babona engani bangawuzuza yini.

Ungavuma ukukhuluma lath ngalolu udaba sizaxoxa okwehola elilodwa endaweni ekhethwe nguwe lalo oyabe ephethe lowumsebenzi. Ngizabuza umbuzo omfitshane ubusuphendula kabanzi nxa ufisa. Ngiyabe ngingakubuzi okuyimfihlo kuwe. Indletshana eqondane lalomsebenzi yiwo wodwa esiyabe siwufuna.

Uma sixoxa ulemvumo yokungimisa uma ufisa. Sizasebenzisa umtshina wokurekhoda uma sixoxa lapha, uma ulesisfiso sokungawusebenzisi lowu mtshina sizazama ukudinga ezinye indlela zokuthi sigcine indaba esixoxa ngayo. Wena uyanelisa ukukhetha lapho esizaxoxela khona ngkufaneleyo okuhambelana lawe.

Umsebenzi lowu uzaphathisa ukuzwisa ngomkhuhlwane wemvukuzane kubomama abangaphansi kweminyaka engamatshumi amathathu lanhlanu ukuze sithole indlela ezifaneleyo zokuvikela omama kuwo.

Konke ozangitshela khona kuzoba sezandleni zami kuphela. Esizakukhuluma lapha akusoze kuntshintshe lutho ngokuthola uncedo esibhedlela kwakho. Ibizo lakho lizabe lifihliwe njalo akakho ozaba kwazi ukuthi nguwe obusipha impendulo lezi. Konke ongitshela khona ngizakusebenzisa ukubhala ugwalo lwami lwesikolo Uma ulemibuzo ulemvumo yokubuza njalo ngiyakukhuthaza ukuthi ubuze imbizo.

Nxa kukhona ongakuzwisisanga ungakhuluma lo

Valerie Nkala

Principal Investigator

valerienkala@yahoo.com

Ane Haaland

Main Supervisor

ane.haaland@gmail.com

APPENDIX G: Ethical Approval



Region:	Saksbehandler:	Telefon:	Vår dato:	Vår referanse:
REK sør-øst	Hege Holde	22845514	07.11.2012	2012/1587/REK
			Deres dato:	Deres referanse:
			25.09.2012	

Vår referanse må oppgis ved alle henvendelser

Ane Haaland
Universitetet i Oslo

2012/1587 B Exploring perceptions and beliefs of breast cancer among young women in Bulawayo Zimbabwe

Vi viser til søknad om forhåndsgodkjenning av ovennevnte forskningsprosjekt. Søknaden ble behandlet av Regional komité for medisinsk og helsefaglig forskningsetikk i møtet 17.10.2012.

Forskningsansvarlig: Universitetet i Oslo

Prosjektleder: Ane Haaland

Prosjektomtale

Brystkreft er den hyppigste kreftform hos kvinner i den vestlige delen av verden, nå også blant kvinner i utviklingsland. Dette representerer et skifte fra forrige tiår (1990 - 2000), da den vanligste årsaken til kreft død var livmorhalskreft. Studiens hensikt er å undersøke oppfatninger av brystkreft blant unge kvinner i alderen mellom 18 - 35 år, som er førstegenerasjonslektninger av brystkreftpasienter i Bulawayo Zimbabwe.

Målet med studien er å:

a) utforske opplevelsen av brystkreft slektningen har før og etter det ble oppdaget sykdom

b) vurdere hvilken hjelp og / - eller sosial støtte de fikk

c) undersøke om / - hvordan slektninger av brystkreft pasienter oppfatter seg selv å være i faresonen for brystkreft og hvorfor de tror de er / - ikke er i faresonen

d) vurdere betydningen av muntlig / skriftlig informasjon

f) utforske hva slektninger vet om årsaker, behandling, tegn og symptomer på brystkreft

g) undersøke hvilken rolle det lokale sykehuset i Bulawayo har og finne ut hvilken informasjon som ble gitt og hvordan denne blir formidlet.

Utvalget består av inntil 20 kvinner. Kvinnene skal intervjues, og antall informanter avgjøres når datagrunnlaget mettes. Intervjuguiden er vedlagt. Det angis at om tiden strekker til skal det gjennomføres fokusgruppeintervjuer. Det skal primært gjøres lydopptak av intervjuene. Der kvinnen motsetter seg dette vil andre metoder benyttes. Data vil bli oppbevart forsvarlig og vil bli slettet ved prosjektets slutt.

Besøksadresse:

Nydalen allé 37 B, 0484
Oslo

Telefon: 22845511

E-post: post@helseforskning.etikkom.no

Web: <http://helseforskning.etikkom.no/>

All post og e-post som inngår i saksbehandlingen, bes adressert til REK sør-øst og ikke til enkelte personer

Kindly address all mail and e-mails to the Regional Ethics Committee, REK sør-øst, not to individual staff

Komiteens vurdering

Komiteen vurderer prosjektet til å falle utenfor helseforskningslovens virkeområde. Formålet med dette prosjektet er å undersøke opplevelser og erfaringer slektninger av brystkreftpasienter har, vurdere hvilken hjelp/støtte de syke fikk og finne ut hvilken kunnskap slektninger har om årsaker og symptomer på brystkreft. Det skal undersøkes hvilken rolle det lokale sykehuset har og hvordan informasjon ble formidlet og hvilken betydning den har. Ingen av disse formålene faller inn under helseforskningslovens formål som er å fremskaffe ny kunnskap om helse og sykdom.

For å gjennomføre prosjekter av denne typen trengs det ingen særskilt godkjenning fra REK. Det er institusjonens ansvar å sørge for på vanlig måte at tiltaket følger gjeldende reguleringer for behandling av helseopplysninger.

Vedtak

Prosjektet faller utenfor komiteens mandat, jf. helseforskningsloven § 2. Prosjektet kan gjennomføres uten godkjenning av REK.

Komiteens vedtak kan påklages til Den nasjonale forskningsetiske komité for medisin og helsefag, jf. helseforskningsloven § 10, 3 ledd og forvaltningsloven § 28. En eventuell klage sendes til REK sør-øst B. Klagefristen er tre uker fra mottak av dette brevet, jf. forvaltningsloven § 29.

Komiteens avgjørelse var enstemmig

Vi ber om at alle henvendelser sendes inn via vår saksportal: <http://helseforskning.etikkom.no> eller på e-post til: post@helseforskning.etikkom.no.

Vennligst oppgi vårt referansennummer i korrespondansen.

Med vennlig hilsen

Stein Opjordsmoen Ilnér

Dr. med.

Overlege, professor

Hege Holde Andersson
komitésekretær

Kopi til: l.m.low@medisin.uio.no

Universitetet i Oslo, universitetsdirektor@uio.no

Telefax: (263) - 4 - 790715
E-mail: mrcz@mrcz.org.zw
Website: www.mrcz.org.zw



Julian Tongogara / Mazoe Street
P. O. Box CY 573
Causeway
Harare

APPROVAL LETTER

Ref: MRCZ/B/408

03 December, 2012

Valery Nkala
University of Oslo
Institute of Health and Society
Department of Community Health
P.O Box 1130 Blindern, 0318
Oslo

RE: Exploring perceptions and beliefs of breast cancer among first degree relatives of breast cancer patients in Bulawayo, Zimbabwe

Thank you for the above titled proposal that you submitted to the Medical Research Council of Zimbabwe (MRCZ) for review. Please be advised that the Medical Research Council of Zimbabwe has **reviewed** and **approved** your application to conduct the above titled study. This is based on the following documents that were submitted to the MRCZ for review.

- a) Research proposal and summary
 - b) Informed Consent Form (English and Ndebele)
 - **APPROVAL NUMBER** : MRCZ/B/408
- This number should be used on all correspondence, consent forms and documents as appropriate.
- **APPROVAL DATE** : 03 December 2012
 - **TYPE OF MEETING** : Expedited
 - **EXPIRATION DATE** : 02 December 2013

After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the MRCZ website or our website should be submitted three months before the expiration date for continuing review.

- **SERIOUS ADVERSE EVENT REPORTING:** All serious problems having to do with subject safety must be reported to the Institutional Ethical Review Committee (IERC) as well as the MRCZ within 3 working days using standard forms obtainable from the MRCZ website: www.mrcz.org.zw
- **MODIFICATIONS:** Prior MRCZ and IERC approval using standard forms obtainable from the MRCZ website is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY:** On termination of a study, a report has to be submitted to the MRCZ using standard forms obtainable from the MRCZ website.
- **QUESTIONS:** Please contact the MRCZ on Telephone No. (04) 791792, 791193 or by e-mail on mrcz@mrcz.org.zw

Other:

- Please be reminded to send in copies of your final research results for our records as well as for the Health Research Database
- You are also encouraged to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours Faithfully

MRCZ SECRETARIAT
FOR CHAIRPERSON
MEDICAL RESEARCH COUNCIL OF ZIMBABWE



PROMOTING THE ETHICAL CONDUCT OF HEALTH RESEARCH