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Exploring the perceptions women have about breast cancer in Bolobedu, Limpopo.

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A report on a study project presented to

The Department of Social Work

School of Human and Community Development

Faculty of Humanities

University of the Witwatersrand

In partial fulfilment of the requirements

For the degree Bachelor of Social Work

Supervisor: Dr. A. Warria

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DECLARATION

I Tsakane Tivani, am submitting this research report to fulfill the requirements for Bachelor of Arts in Social Work at the Department of Social Work (School of Human and Community Development) of the University of Witwatersrand, Johannesburg.

I declare that this research is my own work and has not been submitted for any other degree or examination at any other University.

Signature …… **Date ……..**

ACKNOWLEDGEMENTS

- I would like to thank the Almighty God for his grace upon my life. God has been the pillar of my life and gave me hope when I felt hopeless.
- I would like to thank my supervisor for the support and guidance. Dr. AjwangWarria has encouraged and inspired this research report to succeed. Dr. Warria, I thank you for your patience and guidance from the beginning and completion of this report.
- My thanks also go to my beloved husband Godfrey Tivani for urging and supporting me during this research process. I also would like to extend my gratitude to my mother and family for their love and prayers. I also express my acknowledgement to my brother Justice Baloyi for his encouragement and support.
- I also express my deepest appreciation to Banner for All Nations Church and Pastor Mpkhobi for granting me permission to conduct the study. I would also like to thank the Department of Social Work for providing me the opportunity to enhance my ability and knowledge.

ABSTRACT

Exploring the perceptions women have about breast cancer in Bolobedu, Limpopo.

Breast cancer is identified as one of the most serious disease women face all over the world. It has been described as having physical and emotional challenges for both women and their families (Henderson, 2011). The purpose of this study is to explore the perceptions women have about breast cancer in Bolobedu Area, Limpopo.

The study used a qualitative research approach. Since qualitative is concerned with meaning that participants attach to their life experience, the researcher used exploratory case studies. Using non-probability purposive sampling technique, the researcher interviewed ten participants and two key informants using two different semi-structured interview schedules. There was an interview schedule for participants and a different one for key-informants. During the face-to-face individual interviews, data was recorded with the participants consent and transcribed verbatim. The most important problem that emerged from thematic analysis of the discussion included lack of knowledge about breast cancer, symptoms and self-examination.

It is important for social workers to understand all the components that might exist with different individuals in various contexts in order to empower them. This study is likely to contribute to knowledge and social work practice with appropriate breast cancer intervention, especially in the rural areas in South Africa.

Keywords: breast cancer, women, rural area

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Table 4.1

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List of Acronyms

CANSA	Cancer Association of South Africa
HPS	Health Promotion Model
WHO	World Health Organization
BSE	Breast Self Examination

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CHAPTER ONE

OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND BACKGROUND OF THE STUDY

Breast cancer is the most common type of cancer among women all over the world. The life-time risk of women developing breast cancer ranges from 1 in 36 for all South Africans (The Cancer Association of South Africa, 2007). Knowledge and beliefs about breast cancer screening and practices differs according to women and context. This study is about exploring the perceptions of women about breast cancer in Bolobedu area, Limpopo. This chapter highlights the statement of the problem and rationale of the study, aim and objectives. It will provide general indication of the research design and methodology and theoretical framework. Definitions of key terms, ethical consideration and overview will also be provided in this chapter.

1.2 STATEMENT OF THE PROBLEM AND RATIONALE FOR THE STUDY

Breast cancer is one of the deadliest diseases that women face all over the world and yet there are still some women who still do not know how to conduct self-examination. In most cases this is due to the cultural beliefs that can deter their access to health professionals. Rural areas in South Africa are characterized by poverty and lack of quality health care resources and this can make diagnosis to be difficult. There are very few hospitals in the country that offers treatment for breast cancer and many women in rural areas might not afford transport to go to these hospitals. Some women only find out about breast cancer when they feel painful growth on their breast (Priestman, 2012).

It is reported that more than 3,000 women die each year from breast cancer in South Africa (The Cancer Association of South Africa (CANSA), 2007). This death rate can be reduced when women are aware of the importance of early detection of breast cancer. CANSA focuses on the issue of breast cancer during the month of October annually to raise awareness about the seriousness of the

disease, show the importance of early detection of cancer as this enables more effectiveness of treatment and a better chance of recovery (CANSA, 2007). Despite CANSA's efforts, Pillay (2002) conducted a study in urban and rural South African women and found that half of the women interviewed were unaware of breast cancer self-examination techniques. He also found that there is a need for health promotion programmes in light of early detection, especially in rural areas where there is inadequate health care resources. Lower awareness was also found in older women who were likely to consult traditional healers. Matatiele and Van den Heever (2008) conducted a study in Bloemfontein Universitas Hospital aimed at assessing the level of awareness among women presenting with newly diagnosed breast cancer. They found low breast cancer awareness and that the diagnosis was at stage two. Communication researchers Johnson and Meischke (1991) found that women with breast cancer may obtain information from a range of interpersonal providers, including hospital consultants, breast care nurses, general practitioners, ward and clinic nurses, family, friends and support groups.

Women with breast cancer have different needs for information throughout their breast cancer expedition as can be seen in a study by Cappiello, Cunningham, Tish Knobf, and Erdos, (2007). They found that women diagnosed with breast cancer sought information and support after treatment. The main aim of treatment is to kill as many cancer cells as possible (Priestman, 2012). It is important to note that treatment for breast cancer comes with sides' effects such as fatigue, nausea, vomiting, pain, sleep disturbances and lymphoedema (CANSA, 2007). However, Cappiello, et al. (2007) found that additional research is needed to optimize approaches to providing post-treatment care. Carter (1997) explored women's experiences with lymphoedema in the United States of America and found that more research is still needed to explore the effects of lymphoedema on body image, self-esteem and social support.

Remennick's (2006) study on Russian women immigrants to Israel looked at barriers experienced by women from traditional culture, both in their native countries as well as immigrants and minorities. Factors such as accessibility to health care or medical aid, denial and lack of knowledge about the disease can hinder early detection and treatment even in these multicultural societies, including in South Africa. According to Weis (2003), early and accurate diagnosis is important for optimizing the treatment of breast cancer. However, Ashing-Giwa et al., (2004) found that there

are socioeconomic and cultural barriers such as financial problems and long working hours that hinder some women to seek early health care.

Much research has been conducted on breast cancer in the medical field and there seems to be limited studies from the social work perspective. According to Reddy, Meyer, Shefer and Meyiwa (2014, p. 3), "In South Africa, for example, care concepts influenced by African, oriental, and occidental traditions exist alongside each other, sometimes at odds, sometimes in syncretic fusions" and it is imperative to understand perceptions of women residing in rural areas on breast cancer within the larger context of care and social work. Context-sensitive understanding of breast cancer is important as global trends and national policies and practice may frame local knowledge and perceptions and socio-cultural forces may create diverse understanding of the same issue. This study may contribute to the knowledge base of social workers on breast cancer especially in rural areas to inform appropriate interventions as it is the researcher's hope that women in rural areas can be empowered with knowledge that concerns their health and illness prevention and early diagnosis options (CANSA, 2007).

1.3 RESEARCH QUESTIONS

What are the perceptions of women in Bolobedu, Limpopo about breast cancer?

How aware are they about available resources and where to go for assistance?

1.4 AIM OF THE STUDY

The aim of the study is to explore the perceptions women have about breast cancer in Bolobedu, Limpopo.

1.5 OBJECTIVES OF THE STUDY

i) To explore the knowledge women have about breast cancer.

ii) To investigate the women's knowledge on where to go for diagnosis and treatment.

iii) To examine the role social workers can play in raising awareness about breast cancer.

1.6 RESEARCH METHODOLOGY

The research opted to utilize a qualitative research method together with a case study research design. The sampling strategy that was used is non-probability sampling. Since the sample is known to the researcher, the research used purposive sampling. Semi-structured interviews were conducted with ten participants based on the following criteria: women, attending Shawela Banner for All Nations Miracle Centre, aged 35-40 years, with Grade 12 education level (minimum), staying in Shawela Village and had to be available during data collection. Triangulation of data sources was applied and two key informants were interviewed based on their knowledge or experience about breast cancer. The key informants were the social worker and a CANSA official based in Bolubedu District. The data collected was analysed using thematic data analysis.

1.7 THEORETICAL FRAMEWORK: THE HEALTH PROMOTION MODEL (HPM)

Health promotion is an approach that brings about social change by improving health and wellbeing of individuals (Rootman, et,al. 2001). The overall goal of HPM is to enhance positive health and prevent ill health. This is important because one of the preventative measures include screening and treatment. The researcher aims to help women to be aware of the importance of early detection that would enable a better chance of recovery. So this means that women have to be aware of regular self-examination methods and consulting healthcare professionals for advice on proper screening tests if there is a family history of breast cancer.

One of the strengths of this model is its integral nature of which the social, behavioural and medical disciplines participates and offer a diverse health promotion. A multi-disciplinary team consists of different staff members with several different backgrounds who operate under different areas of expertise. These different team members respond to people who require help of more than one kind of professional (DiClemente, Crosby & Kegler, 2002). A multi-disciplinary team in this case can include social workers, Oncologists, dieticians, psychologists and so forth. Multi-disciplinary

team is able to deal with more complex problems better than when a professional is working alone. This strength is relevant to the second and third objectives of the research as it examined the role that health practitioners, traditional healers and social workers play in addressing breast cancer.

This model is also important in that it operate around vital principles that are also enshrined in the social work profession. One of the principles is that of empowerment that enables people to assume power over factors that can affect their health. This is supported by Lee (2001) in that social work intervention should always strive to empower the people that they work with. This is important because it will lead to self-reliance even after the worker is no longer involved. Self-reliance is the opposite of dependency. It enables people to take initiatives, make decisions, and it is based on a positive perception of one's potential and capabilities. The researcher hopes that the study will empower women with knowledge that will contribute to their wellbeing.

Another important principle is that of participation. Participative Health promotion initiative should involve people concerned in all phases of planning, implementation and evaluation (Schenck, Nel, & Louw, 2010). As people get together they share knowledge and skills and this could lead to empowerment. This principle is aligned with the strengths perspective as it assumes that people will always know the intervention needed to bring about necessary change in their lives (Zastrow, 2012). The researcher aims to use the suggestion from Seidman (1998) to help participants realize the strengths and resources available in themselves and their environment. Each person has and can rely on inner strengths to cope with stressful situations. Problems call for the use of strength to provide solutions.

Holistic Health promotion focuses on the physical, mental, social and spiritual health (WHO, 2005). It is important for the researcher to be aware of factors that can influence or hinder treatment such as the cultural and spiritual beliefs.Several studies have shown that women have unrealistic perceptions about the development of breast cancer. Inaccurate perceptions can have physical and emotional consequences about the disease and its treatment (Woloshin, Schwartz, Black & Welch, 1999).A woman who perceives that she is susceptible to breast cancer and that breast cancer is a serious disease would be more likely to perform regular breast examinations. The research aims to explore the perceptions women have about breast cancer and where they would go for diagnosis and treatment. HPS is relevant in exploring women's awareness about breast cancer and the

researcher will be help participants realize preventative measures including screening that are available to assist them know about their breast cancer status.

1.8 DEFINITION OF KEY TERMS

1.8.1 Breast cancer: Breast cancer is an uncontrollable growth of abnormal cells in the body. Cancer develops when the body's normal control mechanism stops to work. There is no definite source of what really causes it. Cancer and its treatment weaken the body's immune system as it affects blood cells that protect against disease and germs (Priestman, 2012).

1.8.2 Women: A woman is an adult female person. It is associated with gender identity. Women are usually born with genetic development that enables them to give birth (Beasley, 2005).

1.8.3 Rural area: A rural area is an open swath of land that has few homes and its population density is very low. It is mostly located outside towns and cities and characterized by sharing of beliefs and traditions. Subsistence farming is the source of living where some people live or work on farms and villages (National Geographic, 2011).

1.8.4 Social worker: A social worker is a qualified professional who is concerned with helping individuals, families, groups and communities to enhance their well-being. Social work is a service that is sanctioned by society to address the needs and problems by empowering them in order to improve the quality of life for everyone (Potgieter, 1998). A social worker must register with the South African Council for Social Service Professionals before they can start rendering their services (Sheafor & Horejsi, 2012).

1.9 ETHICAL CONSIDERATIONS

Research Ethics are important as they help guides the study processes. Approval to conduct the study was given by the Department of Social Work Ethics Committee before the researcher commenced with the study. The researcher adhered to the research ethic guidelines that are stipulated in Babbie and Mouton (2001). Participation in the study was voluntary; participants

were informed of the purpose of the research and signed informed consent and study and tape-recording of the data collection. The researcher used codes names to protect the identity of participants and data collected is stored in a computer protected password. This was done to ensure anonymity and confidentiality of information. Participants were told that they can withdraw from the research at any time without consequences. It is important for the researcher to do no harm, so arrangements for counselling were made with the social worker at the local clinic for participants who might have emotional burdens due to the study. Permission to conduct the research has been granted by Pastor Mokhobi from the Church.

1.10 OVERVIEW OF THE RESEARCH REPORT

Chapter one contains a detailed summary of all essential concepts that are discussed in the study. These include the statement of the problem and rationale, aims, objectives, methodology, theoretical framework as well as ethical considerations. Chapter two provide literature review that supports the study. This involves evaluation of previous research related to the study. Chapter three discuss research methodology. It indicates the research design that was used, sampling technique, and research instrument, method of data collection and analysis as well as reflexivity. Chapter four presents the findings that emerged from data analysis. Chapter five provide summary of the findings as well as recommendations.

1.11 CONCLUSION

This chapter highlights the statement of the problem and rationale of the study, aim and objectives. It will provide general indication of the research design and methodology, ethical considerations as well as the overview of the research report. Definitions of key terms as well as theoretical framework are provided in this chapter.

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

Breast cancer has been described as having devastating consequences on the physical, emotional, sexual, self-esteem, psychological, just to name a few. The challenges that breast cancer women face are unique depending on the individual and the stage of cancer development. A woman's diagnosis of breast cancer not only impact on the individual diagnosed but on couples and family relationships. Helpers must be aware of the impact of breast cancer, different coping strategies and the effects of different treatment. This chapter presents a literature review that is relevant to the study that was conducted. It presents the overview of breast cancer and highlights the different needs that women diagnosed with breast cancer has. It further highlights the role that CANSA and social workers can play in raising awareness.

2.2 OVERVIEW OF BREAST CANCER

Breast cancer is one of the most serious and common diseases women (and some men) face all over the world. The cancer itself and the treatment come with numerous challenges and side effects. Breast cancer is an uncontrollable growth of abnormal cells in the body. Cancer develops when the body's normal control mechanism stops to work (Priestman, 2012). This means that cancer start when cells become abnormal and divide without control or order. According to Ross and Deverell (2004) when cell become uncontrollable, they form a cell called tumour and leaves the body dysfunctional. Most studies fail to provide a specific cause of breast cancer. They argue that abnormal cells develop in a person's body all the time (Ross & Deverell, 2004). When they develop, the body usually destroys them but sometimes the body fail and cancer develops. Several factors such as genetic background, diet, environment and lifestyle can contribute to cancer development (Priestman, 2012).

Sometimes doctors give diagnosis and offer little explanations of what the disease is and what causes it. Cancer is a malignant growth that when it is not stopped, can spread to other part of the

body through the blood stream (CANSA, 2007). Breast cancer mostly affects women. However, in a study that was conducted by Iredale, Brain, Williams, France and Gray (2006) breast cancer also affect men but it is very rare. Some of the symptoms of breast cancer include painless breast lump, lump under armpit, nipple discharge/bleeding, change in shape of breast, lumpiness in breast, pain in breast region, changes in size of breast, dimpling of breast skin, breast swelling, inversion/pulling in of nipple, bruising of breast and scaling/dry skin in nipple region. They found that the most common symptom in men's diagnosis is the presence of painful lump. They also found risk factors to include family history of breast cancer, previous breast cancer, smoking, oral contraceptives, older age, bumping or bruising breast, stress, excess weight, first child at late age, early onset of menses, late menopause and large breasts. According to Iredale,et, al. (2006) risk factors in men include age and obesity. The most common risk age was found to be 60 to 65 years. Survival rates of men with breast cancer are smaller to those of women with breast cancer. This is due to the fact that for men it is diagnosed at an advanced stage.

Survivors of breast cancer have a compromised immune system and this leaves their bodies unable to fight infections and the disease. This is due to the fact that cancer and its treatment can weaken the body's immune system because it affects the blood cells that protect the body against diseases and germ infections CANSA, 2007). Breast cancer diagnosis has different impact on people diagnosed and their families. Miles and Huberman (1994) found that there are devastating consequences on the physical, emotional, sexual, self-esteem and psychological. Some women struggle to cope with the diagnosis and the side effects of treatment. Potential problems were found to exist in most women seeking new dating relationships (Greendale, Petersen, Kahn & Bower, 1997).

2.3 PERCEPTIONS AND KNOWLEDGE OF WOMEN ABOUT BREAST CANCER

2.3.1 Perceptions

Bower, et. al. (2005) found that most research focused mostly on the negative impact of breast cancer. They have argued that there are negative and positive changes following breast cancer diagnosis. Some women live a full life and create meaning around their diagnosis. This helped

some women to prioritize their lives and plan for their families when they no longer around. Therefore the perception of vulnerability can be associated with enhance meaning. It is important for women to have realistic perceptions about breast cancer in order for them to be able to make good decisions about screening and treatment (Woloshin, et. al. 1999). Several studies have shown that women have unrealistic perceptions about the development of breast cancer. Inaccurate perceptions can have physical and emotional consequences about the disease and its treatment.

2.3.2 Knowledge of breast cancer

Most women in rural areas have little knowledge about breast cancer. Most women lack knowledge about breast cancer because there are no awareness programmes in rural areas. This is supported by Beck and Falkson (2001) that knowledge and support can help others to get through their battle of cancer. They acknowledge the gab that exists between urban and rural areas in terms of services. The problem is that CANSA services have not been accessible to most people in the rural areas. In rural areas there are financial problems where people stay far and need transport money to get to where services are. They argue that Cancer Association are mostly located in urban areas so people from rural areas have to travel to get treatment and this has an impact in adherence. Matatiele and Van den Heerver (2008) found that in a CANSA campaign that happened in Free State in 2006, groups from different places asked CANSA representatives to come and give presentations in their communities. This shows that CANSA still has a long way in reaching all the women in South Africa.

Some women lack knowledge about breast cancer because of the belief that they have about the use of western medicine. Some denies the existence of breast cancer and label it as witchcraft and ancestral punishment. Due to the apartheid, many rural areas relied on traditional healers as they had little or none medical resources (Pillay, 2002). So it is understandable that some still have little faith in western medicine. Some women prefer the inclusion traditional and western medicine. Iredale, et. al. (2006) found that there is still a lack of awareness about breast cancer in men. Many efforts have been put in place to help women support women with breast cancer. What they found was that many people still don’t believe that a man can be diagnosed with breast cancer. Men

would also like CANSA to raise awareness about breast cancer in men with emphasis on general information on symptoms and side effects of treatment. They would also like support through telephone help lines and same methods that are made available to women.

2.3.3 Breast cancer self-examination

It is important for women to do monthly breast self-examination (BSE) and regular clinical examination. Unlike to mammography and clinical breast examination, BSE is simple, inexpensive, low in technology, teaching is possible to both health professionals and women and more importantly raises awareness about breast cancer in women (Montazeri, et. al, 2008). However, this is a problem in most rural communities as they don't have knowledge about the disease. In a study that was conducted by Pillay (2002) in KwaZulu-Natal in the area of breast cancer screening and knowledge, most women were not aware that medical tests can detect breast cancer. There was lack of knowledge about mammography and early detection techniques. Women still don't know where to go in order to be tested and at what age they are considered to be at higher risk. This was not surprising as advanced health care facilities are not accessible in rural areas.

CANSA focus on women's health campaign in the month of October. The purpose of the campaign is to raise awareness about the disease and the importance of early detection. Early detection and prevention campaigns provide counseling, individuals are informed of health care centers and appropriate referrals are made for screening. According to Bower, et. al. (2005) found that advances in early detection and treatment have led to the increased rate of number of breast cancer survivors. They argue that many breast lumps are harmless but they should be checked. It is important for women to do regular clinical breast examination in order to detect lumps in the breast.

2.3.4 Breast cancer risk development

Pillay (2002) argues that there is still a need for women to be educated about breast cancer tests and how they influence risk reduction. This is supported by Matatiele and Van den Heerver (2008) in that the majority of South African women have limited knowledge when it comes to the risk of developing breast cancer. This mostly referred to older black women who are particularly poor and lacks knowledge of identifying breast cancer symptoms. They further found that there is lack of awareness when it comes to the development of breast cancer. This contributes to most women being diagnosed with invasive cancer that was diagnosed at a later stage. .

Iredale, et, al. (2006) found risk factors to include family history of breast cancer, previous breast cancer, smoking, oral contraceptives, older age, bumping or bruising breast, stress, excess weight, first child at late age, early onset of menses, late menopause and large breasts. According to Iredale, et. al. (2006) risk factors in men include age and obesity. The most common risk age was found to be 60 to 65 years. Survival rates of men with breast cancer are smaller to those of women with breast cancer. This is due to the fact that for men it is diagnosed at an advanced stage.

2.3.5 Breast cancer signs

According to Montazeri, et. al. (2008) most women have knowledge of breast cancer symptoms. Some of the source of information includes Radio, Television and health practitioners at clinics. Iredale, et. al. (2006) found symptoms of breast cancer to include painless breast lump, lump under armpit, nipple discharge/bleeding, change in shape of breast, lumpiness in breast, pain in breast region, changes in size of breast, dimpling of breast skin, breast swelling, inversion/pulling in of nipple, bruising of breast and scaling/dry skin in nipple region. They found that the most common symptom in men's diagnosis is the presence of painful lump.

2.4 THE IMPORTANCE OF EARLY DETECTION

It is important for women to recognize the importance of early detection of breast cancer. According to (Weis, 2003) early and accurate diagnosis is important for optimizing the treatment of breast cancer. He argues that accurate diagnosis is a required step in the management of breast

cancer. In women with breast cancer diagnosis can confirm the presence of the disease, reduce treatment delay and clarify the predictive and prognostic factors of the breast cancer. Physical examination should include assessment of the primary tumour and the regional lymph nodes. Mammography is useful in detecting early breast cancer, ruling out the multi-centricity of tumours in the breast, chest wall and skin. Early detection is very important for symptom free women from the age of 40. It is vital that they go for mammogram every year to detect lumps in the breast (CANSA, 2007).

2.5 THE GOAL OF TREATMENT AFTER EARLY OR LATE DETECTION

The treatment of cancer depends on the type of cancer that one has and the stage is at. The goal of treatment is to kill as many cancerous cells in the body (Priestman, 2012). Treatment in breast cancer is based on the stage of the disease; early breast cancer often allows breast conservation to be practiced. The majority of patients with breast cancer in developing countries have invasive cancer, which requires more thorough and aggressive treatment (Gluck, 2001). This is helpful in understanding the different treatment and side effects of participants that will be interviewed. There are three main treatment used to kill cancer cells which are surgery, chemotherapy and radiation therapy. According to Senbanjo, Ihekwaba and Ajaji (1990) surgical approach was found to be very important treatment of breast cancer for Nigerian women. More important is the fact that invasive breast cancer is a universal illness (Weis, 2003). The function of surgery is to reduce the tumour burden and obtain analytical information.

In the study that was conducted by Ashing-Giwa (2004) to compare the experiences of multiple ethnic groups in the United States. They found that Asian and Latinas were more likely to receive mastectomies. African Americans are least likely to receive therapy such as radiation and chemotherapy. The concern for all women includes overall health, physical concerns, cancer recurrence, psychological concerns and the body image and sexual concerns and lack of knowledge about cancer. Chemotherapy is one of the treatments that use chemicals to kill cancer cells, and surgical operation can be used to remove the growth or tumour (Priestman, 2012).

Radiation therapy is another form of treatment that uses x-rays to kill cancer cells. However, in some areas it is not easily accessible. This is supported by Adenipekun, Camtell, Oyesegun and Elumela (2002) that in developing countries, including Nigeria, radiation is often not easily accessible. Some women use tamoxifen which is still a form of chemotherapy. Advanced breast cancer poses enormous management problems because of extensive lesion which often result in difficult operative and postoperative problems such as flap wound infection and early recurrence of breast cancer (Weis, 2003). According to CANSA (1997) traditional healers play a significant role in the kind of treatment that people in rural areas use. Research shows that rural women prefer to consult traditional healers rather than medical doctors.

2.6NEEDS OF WOMEN WITH BREAST CANCER

2.6.1 Information needs of women diagnosed with breast cancer

A comprehensive literature review was conducted by Bilodeau and Degner (1996) to examine the information needs of women with breast cancer. Women with breast cancer have different needs for information throughout their breast cancer expedition. Kristjanson and Ashcroft (1994) state that information needs changes with diagnosis and it is different and depend on the individual. This is relevant with the researcher's social work value of individualization. Individualization refers to "starting where the person is and it requires an understanding of the specialness of each individual" (Potgieter, 1998, p. 42).This helps the researcher to bear in mind the different stages of cancer diagnosis and different information needs that will occur. Cappiello, et al. (2007) found that women continue to experience different physical and psychological symptoms and social issues and are in need of diverse information on persistent treatment effects, emotional distress and lifestyle changes and on support.

2.6.2 Information need on treatment effects

The findings by Cappiello, et al. (2007) indicate that women with breast cancer require information and support after treatment due to the treatment's side effects associated such as fatigue, nausea,

vomiting, pain, sleep disturbances and lymphoedema. The side effects of treatment can result in pain or fatigue which may persist for months or years after treatment ends Cappiello, et al. (2007) found that additional research is needed to optimize approaches to providing post-treatment care. The majority of women with no children or very young children had sought information about the impact of their treatment on the fertility and their ability to breast feed (Walsh, Manuel & Avis, 2005). Some women become distant and can't perform their sexual duties because of the side effects of treatment. Some of the side effects of chemotherapy include nausea, fatigue/tiredness, diarrhoea, and so on. Another study shows pre-menopausal women spoke about a number of gynaecological late-effects of treatment including irregular or painful periods, vaginal dryness, and loss of libido (Thewes, Butow, Girgi & Pendlebury, 2004).

2.6.3 Information need on emotional effects

Emotional feeling that comes with diagnosis involves shock, sadness, anger, denial, and relief of not having to live with uncertainty (Barraclough, 1999). In a study conducted by (Thewes, Butow, Girgi& Pendlebury, 2004) many women spoke about their fears of the cancer returning, and worry about physical symptoms. Many women had learned ways of coping with these fears such as positive thinking and having support system helps to ease the fear. Cancer bring with it feelings of sadness and loss. This involves the loss of the breast, hair and the interruption of the person's life plans and goals. Miles and Huberman, (1994) found that emotional distress was experienced by women in many ways. This also includes feelings related to grief and loss and mother-child distress. Feelings of grief and loss, which were reported, were related to time lost from being with their children because of treatment burden and to being unable to do much for and with their children because of factors such as fatigue. Some mothers of very young children felt that they missed their child's babyhood because of the cancer. This is because some children get to be cared for by their relatives during most of their treatment. Research shows that younger women with breast cancer have more severe emotional distress than older women. In a study that was conducted in Australia, young women have more psychological needs than older women (Schover, 1994).

2.6.4 Information need on the physical body

Survivors of breast cancer may also experience a number of other psychosocial problems including impaired body image and sexual dysfunction (Schover, 1994). Breast cancer has an impact on the women's body image and self-worth. This is due to the loss of breast or hair that they experience. Self-worth is the overall evaluation of oneself. It involves attributes of both negative and positive personal impressions (Zastrow, 2012). For one to function well in society, one must have a positive self-concept. This notion is supported by Greendale, Petersen Kahn and Bower (1997) in that loss of a breast or poor breast appearance would be more upsetting to women whose youth gives them high hopes for physical beauty. Potential problems can be seen in most women seeking new dating relationships after breast cancer treatment. They continue to argue that potential infertility also may impact on a woman's self-concept as a sexual person.

2.6.5 Social needs of women with breast cancer

Thewes, Butow, Girgi & Pendlebury (2004) found that women seeked information on relationships. Seeking new dating relationships after breast cancer treatment was found to be more stressful for single women. This happens because of the physical changes occurred after the treatment. Many women lose their breast and hair. Research shows that married women with breast cancer are comfortable taking their clothes off compared to women in a new relationship (Schover, 1994). In a study conducted by Miles and Huberman (1994) most of the women specified that their partner initiated separation or termination and most women recognized the reasons why their partner left. Some of these reasons mainly included the partner's inability to cope. They also found that although mostly men initiated separation or divorce, some women also initiate divorce after the diagnosis. The reasons for women leaving their marriage included lack of emotional support from their partner and viewing their diagnosis as a drive to leave a relationship that was problematic and not meeting their needs. This reason is supported by Avis, Crawford, & Manuel (2004) when they found that for some couples, breast cancer can bring problems that existed prior to diagnosis, whereas for other couples, it strengthens their bond. If problems already exist within the family, the diagnosis might make matters worse. Some women experienced the social impact

of changing their alcohol consumption when going out to bars with friends. Some women resigned from their jobs as a direct consequence of their diagnosis. Practical problems such as social stigmatization, discrimination and financial difficulties have also been reported.

2.6.6 Information needs for family members

Bilodeau and Degner (1996) argue that few studies have focused specifically on the information needs and source preferences of family members of women with breast cancer. Family members of women with breast cancer also have substantial needs for information (Hilton, 1993). The information that is needed is helpful in supporting diagnosed members of the family. Both women with breast cancer and family members prefer verbal outline of information from health care professionals, especially around the time of diagnosis. Shaw et al. (1994) also explored the information needs of women and their significant others prior to breast biopsy. They found that the most vital information need identified by both women and their significant others was information concerning the diagnosis. Northouse et al. (1997) explored the information needs of spouses for women undergoing breast biopsy. They found that spouses wanted similar information to their wives, most men wanting information concerning the biopsy procedure, potential diagnoses, treatment options, prognoses and physical side of breast cancer. Husbands also wanted information on how best to support their wives. They also found that women with breast cancer and their partners indicated that information helped them cope with the cancer experience.

The diagnosis of breast cancer does not only affect women diagnosed but children too. Some children were having difficulty coping (Avis, Crawford & Manuel, 2004). Women reported that their children displayed emotional distress such as withdrawal and by avoiding cancer-related discussions. Children exhibited emotional distress by clinging to their mother or by showing signs of regression as a result of the cancer. Burnstein and Winer (2000) found that some children feared that their mother could die from cancer and fear of potentially inheriting the cancer. Mothers also expressed the fear of dying before their children were grown and the fear that their daughters' would inherit breast cancer. It is also important to acknowledge that for some women and children,

the diagnosis brought them closer than before. This is because they had accepted the diagnosis and want to make the last moments counts.

2.6.7 Medical needs

Women would like information from their medical practitioners. Sometimes doctors give diagnosis and offer little explanations of what the disease is and what causes it. Women needs to understand the diagnosis and its impact (CANSA, 2007). This includes information on what the disease is, stage of development and the treatment to use. This is supported by Delbanco (1992 as cited in Ross & Deverell, 2004) in his research to find out what cancer patients expect from their physicians. He found out that they wanted to be treated with respect and dignity. This is very important because it one of the social work core values that the researcher also applied. They want to understand how their disease will affect their lives and trust the competency of their caregivers. They want to know the effect it will have on their families, friends, finance, relationships, future and other things depending on the patient.

2.6.8 Information communication sources

Communication researchers Johnson and Meischke (1991) have identified two main types of information sources which are interpersonal and mass media sources. Interpersonal sources involve face-to-face contact and mainly compose of verbal forms of information (Johnson & Meischke 1991). Mass media sources involve print or electronic materials and comprise of written or audio-visual types of information. Women with breast cancer may obtain information from a range of interpersonal providers, including hospital consultants, breast care nurses, general practitioners, ward and clinic nurses, family and friends (Beaver & Luker, 1997) and support groups. Mass media information, on the other hand, may be obtained from brochures, women's

magazines and newspapers (Beaver & Luker 1997), medical books and journals, television, computer materials, seminars and presentations.

2.7 THE ROLE OF SOCIAL WORKERS IN RAISING AWARENESS

Social workers are increasingly working in joint efforts with other professionals in order to meet the needs of people they work with. Multi-strategy Health promotion initiatives would then involve social workers working with medical practitioners to educate women about the importance of early detection and counselling and support options (WHO, 2005). Social workers utilize a variety of skills and knowledge in their intervention with individuals they work with (Potgieter, 1998). Here are some of the interventions that can be performed by social workers to support women and their families fight cancer.

2.7.1 Raising awareness

Women with breast cancer have different needs for information throughout their breast cancer expedition. The information that is needed is helpful in supporting diagnosed members of the family. Both women with breast cancer and their family members prefer verbal outline of information from professionals, most especially around the time of diagnosis (Hilton, 1993). Social workers have a role to play in raising awareness about breast cancer. This can include working together with health practitioners and CANSA in providing information that can lead the fight against breast cancer. Breast cancer threatens a woman’s wellbeing in many ways. In addition to the physical challenges of a life-threatening illness, the psychological demands are also frightening. The course of breast cancer diagnosis, treatment, recovery, and long-term survival can contribute to psychological distress and increase the need for support. Each type of assistance might be useful in dealing with the specific challenges that cancer presents (Moyer, 1997). Information can include the importance of early detection and BSE. Early detection of breast cancer plays the leading role in reducing mortality rates and improving the patients' prognosis

(Montazeri, et. al (2008). The information must also consider language barriers. In most cases information fails to reach people due to the medical terms that people don't understand.

2.7.2 Counselling

The purpose of counselling is to encourage acceptance of the diagnosis, promote disclosure, provide information in understanding the illness, promote healthy life style, assist family members to deal with loss, and pre-testing and post-testing counselling (CANSA, 1997). Women who have been diagnosed sometimes faces challenge when it comes to disclosure to the family about the diagnosis. Social workers can help them to find a way to disclose to the rest of the family. This can also include working with the family to also accept the diagnosis and provide information that would help them to cope and support each other.

2.7.2.1 Emotional support

There are emotional consequences that come with breast cancer diagnosis. Social workers can help women to constructively express and gain control of troublesome feelings and emotions (Sheafor and Horejsi, 2012). Before the clients can gain control of their feelings, they have to acknowledge its existence. Emotional feeling that comes with diagnosis involves shock, sadness, anger, denial, and relief of not having to live with uncertainty (Barraclough, 1999). In a study conducted by (Thewes, Butow, Girgi & Pendlebury, 2004) many women spoke about their fears of the cancer returning, and worry about physical symptoms. Miles and Huberman, (1994) found that emotional distress was experienced by women in many ways. This also includes feelings related to grief and loss and mother-child distress. Feelings of grief and loss, which were reported, were related to time lost from being with their children because of treatment burden and to being unable to do much for and with their children because of factors such as fatigue.

2.7.2.2 Coping strategies

Pistrang and Barker (1995) argue that it is important to understand and intervene in the couple relationship of women with breast cancer. They highlight different reasons for intervention. The first reason is that a woman's relationship with her partner is important in her adaptation to illness. This is one of the reason social workers to assess all the systems that are involved in their life in order to intervene holistically. The second reason involves understanding that as much many couple relationships are supportive, some can be a source of stress (Manne, Taylor, Dougherty, & Kemeny, 1997). This notion is supported by psychodynamic model that focuses on the emotions and feelings such as fear, hatred and other negative experiences that can disrupt the normal functioning of an individual (Sheafor & Horejsi, 2012). Sometimes there can be underlying factors that need to be addressed in order to understand the individual's problems.

Thirdly, confession about disease-related worries and fears is an essential component of couple communication and care giving (Pistrang & Barker, 1995). In order for spouses and care givers to support and take care of diagnosed person, he or she must understand all the components. It is important for the researcher to also bear in mind all the components that might exist in the potential participants. The fourth reason is that for some couples, breast cancer can bring problems that existed prior to diagnosis, whereas for other couples, it strengthens their bond (Avis, Crawford, & Manuel, 2004). If problems already exist within the family, the diagnosis might make matters worse. This goes back to the underlying factors that might be contributing to the presenting problems (Payne, 2005).

The fifth reason is to understand that sexual problems arise with great frequency, and very much depend on the quality of the relationship (Avis, Crawford, & Manuel, 2004). Sexual behaviours have been noted to change after breast cancer diagnosis and this is due to women's changes in body image and in sexual functioning. Partners may also have sexual difficulties and behaviour changes after diagnosis, including loss of sexual drive.

According to Manne (1998) two thirds of couples and families cope well with the distress brought about by a diagnosis of cancer. Issues that are relevant and important to some couple relationships include adaptation to breast cancer treatment, partner support and communication, and problems related to sexuality. Henderson (2011) explored the coping strategies of African-American living with breast cancer. The study was guided by the Roy Adaptation Model of 1999 which view the

individual as adaptive and able to cope with any change in their environment. The study found that most commonly used coping strategies involved prayer, positive attitude, developing willingness to live and social support from family members. Social workers can help to explore the coping strategies and support those women and their families have.

2.7.3 Empowerment

The concept of empowerment is closely linked to the strengths perspective approach. The strengths perspective encourages the social worker to identify and build upon the client strengths (Sheafor&Horejsi, 2012). The assumption of this perspective is that every client has strengths. The strengths can be identified in the client's attribute, experiences and capabilities. The strengths can include ability or skills and desire to change. Since breast cancer diagnosis comes with anxiety, depression, loss and other challenges, social workers can empower participants to re-gain control of their lives. Social work intervention should always strive to empower the people that they work with (Lee, 2001). This is important because it will lead to self-reliance even after the worker is no longer involved. Self-reliance is the opposite of dependency. It enables people to take initiatives, make decisions, and it is based on a positive perception of one's potential and capabilities.

2.8 CONCLUSION

According to Hofstee (2006) a good literature review identifies and reviews what has gone before and is based on theory. Most studies fail to provide a specific cause of breast cancer. They argue that abnormal cells develop in a person's body all the time. The literature review shows that research has been conducted to explore the needs that come with breast cancer diagnosis. Literature review also shows that there is still lack of knowledge about self-examination, development of breast cancer and risk factors. There is a role that CANSA and social workers can play in

supporting and raising awareness about early detection and treatment. Although this study focuses on breast cancer in women, there is still a need for raising awareness about breast cancer in men.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter provide a description of the research methodology. This includes the research approach and design of the study. It highlights how the sample procedure and how it was selected, research instrument used for data collection and pre-test that was conducted prior to conducting

the actual research. Data analysis, reflexivity, ethical considerations, trustworthiness of the study and limitations of the study will also be discussed in this chapter.

3.2 RESEARCH APPROACH

The research is based on a qualitative approach. Qualitative research is based on the need to understand human interactions from the participants' perspective. The main aim of this approach is to describe and explain human behaviour. It is well suited to study attitudes and behaviour in their natural settings (Creswell, 2009). This research will focus on interpretative approach as it is aligned with qualitative method. Interpretative argues that social realities are constructed through meaning and these realities are studied through people's own natural contexts (Payne & Payne, 2004). Creswell (2009) argues that qualitative is useful in answering questions that are complex in nature, but that it helps with the description and understanding of the phenomenon from the participant's stand point. This is significant to this study as it aims to explore the perceptions of women about breast cancer.

Greenstein, Roberts and Sitas (2003) state that qualitative research attempts to view the world through the eyes of the people being studies. It places emphasis on many aspects of social, historical and physical context for understanding the social world. This is also supported by De Vos, Strydom, Fouche and Delport (2005) that conducting qualitative research allows the researcher to gain a first-hand, holistic understanding of the phenomena of interest by utilising a flexible strategy of formulating a problem, and collecting data. This is the challenge with qualitative as reliability maybe jeopardised as inconsistency in obtaining results might occur due to the use of different data collection methods. This is also highlighted by Terre Blanche andDurrheim, (1999) who argued that as the research progresses to data analysis, the structure will be limited and this will prove difficulties if attempts are made to replicate the study in the future or in another setting.

The researcher is used as the primary instrument for collecting and analysing data (Creswell, 2009). This is very helpful and can make the research to be cheap. This is supported by De Vos, et.al (2005) that using qualitative enables the researcher to gain in-depth or thick descriptions of

actions and events as they occur. This is supported by Creswell (2009) that qualitative approach is useful in collecting data in the site where participants experience the problem. He further state that the focus of research is on the meaning that participant have about the problem. Women in this village might have their own meaning that they attach to breast cancer. The interpretation of meaning will come from what the researcher hears and understand.

3.3 RESEARCH DESIGN

Research design is a plan that outlines how the researcher will conduct the research. This consists of the research question, the method used to collect data and the analytic techniques used to enable data to answer the question (Babbie& Mouton, 2001). According to De Vos, et al. (2005) since qualitative is concerned with meaning that participants attach to their life experience, it is important to use case study research design. A case study "involves an exploration of a bounded system (bounded by time, context and/or a place), or a single or multiple cases, over a period of time through detailed, in-depth data collection involving multiple sources of information" (Creswell, 2009, p. 73). Case study will be used because of its exploration of phenomenon within its context and in-depth study of a particular situation from one or more individuals. This is the advantage of using a case study as it looks at a problem through different lenses (Baxter & Jack, 2008).

Stake (1995) and Yin (2003) align case study to constructivist paradigm. This is important because through the collaboration between the researcher and participants, the researcher is able to get a better understanding of the participants' view of reality. The researcher will use exploratory case study (Stake, 1995). Yin (2003) point out that when the research is exploratory; it aims to gain new insight into a certain phenomenon and it is used to explore situations that have no clear or single set of outcomes.

3.4 POPULATION AND SAMPLING

Population refers to the individuals in the universe who possess the same characteristics (De Vaus, 2001). The population in this study refers to all women living in Shawela Village in Bolubedu District (Limpopo Province). Sampling means the selection of a small sample from a large population which is done so that research tasks can be manageable as studying large group might not always be feasible and/ or possible(Monette, Sullivan, DeJong & Hilton, 2014). Even though the sample might be small, the focus is on the quality of information that the researcher will get from participants.

The sampling strategy that was used is non-probability sampling. Non-probability is useful when the researcher has no intention to generalize the results to a larger population (Maxwell, 2012). This is supported by Neuman (2000) that qualitative is less concerned with representativeness. However, sometimes a representative sample of locations and time is required to make generalisation of other research sites. Since the sample is known to the researcher, the research will use purposive sampling. Purposive sampling involves judgment about a specific case with a purpose (Maxwell, 2012).Furthermore, it is argued that the researcher can also use purposive sampling for the hard to reach participants. For some participants, breasts might be a sensitive area to talk about.

Permission to conduct the research was granted by Pastor M.R Mokgobi. The permission letter can be seen in Appendix F. The researcher did a presentation during the church service's announcements slot at Shawela Banner for All Nations Miracle Centre (a church that a majority of community members in Shawela village attend). During the presentation, the researcher will explain what the study is all about, the sampling criteria and the ethical considerations governing the research. The researcher then invited women fitting the selection criteria to contact her after the church service (outside the church hall).

Ten participants were selected for the study based on the following criteria: women, attending Shawela Banner for All Nations Miracle Centre, aged 35-40 years, with Grade 12 education level (minimum) and staying in Shawela Village. They should also be available during the data collection period. In order to adhere to ethics, participants were given consent forms so that they agree and participate in the study. According to Guba and Lincoln (1989) one method to ensure credibility is through the use of triangulation. Triangulation of data sources was applied and two

key informants were also interviewed and selected based on their knowledge or experience about breast cancer. The key informants were the social worker and a CANSA official based in Bolubedu District. The advantage of using triangulation of data sources is that it helps to verify participants' experiences and viewpoints. This involved asking different questions and using different sources.

3.5 RESEARCH INSTRUMENT

Semi-structured interviews schedule was used to collect data. It involves a clear list of issues to be addressed and questions to be answered (De Vaus, 2001). This involved the use of open-ended questions so that the participants provide broader explanations, elaboration and clarification about the topic discussed. It provided the opportunity for participants to answer as they wish and allowed for new responses to be generated. The use of open-ended questions also granted the researcher the opportunity to ask for clarity where it was needed. This is why it was important to ask questions that involves what, how and where. The researcher explained to participants to ask for clarity if there were questions that they did not understand. This helped to get accurate answers and avoid participants going astray.

The interview schedule was prepared by the researcher based on previous literature reviewed. There were two different interview schedules for the participants and key informants. The interview schedules were in Sepedi and Tsonga as these are the languages mainly spoken in the area. The interviews was transcribed verbatim then translated to English**.** The reason for using this instrument is that it is flexible and if clarity is needed, there can be follow-up questions. This helped participants to feel at ease as there was flow of conversation and made participants feel less interrogated. This is further supported by (Robson, 2000) that semi-structured questions are predetermined and can be modified in light of what the researcher see as appropriate and can add or omit some wording.

3.5.1 Pre-testing research instrument

To enhance the reliability of the research instrument, a researcher is expected to conduct a pre-test prior the actual research (Maxwell, 2012). The pre-test involved the same questions that were used in the actual research and it helped to evaluate if the questions will produce good results or if some editing is needed to some questions. The pre-test was done with a woman who meets the same criteria for sampling that the potential participants met. The data collected during the pre-test did not form part data of the study. Since the data collected during pre-test was insufficient, the researcher explored more on issues so that participants can provide rich data.

3.6 DATA COLLECTION

Data was collected using individual in-depth interview. Individual face-to-face interviews were used in the study, because it provide in-depth enquiry into the perceptions of women about breast cancer (Creswell, 2009). In-depth interviews are flexible and allows for rich descriptions of the phenomenon being studied. The researcher is used as the primary instrument and must be present with participants physically and psychologically. This enabled participants to give detailed description and for the researcher to observe the non-verbal communication. Observing the non-verbal behaviour created the opportunity for the researcher to make accurate assessment of the feelings behind the participants' answers as they shared their perceptions about breast cancer (Legard, keegan and Ward, 2003).

Data was collected as soon as the researcher obtained Ethics clearance by the Ethics Committee. Permission to conduct the research has been granted by Pastor Mokhobi. The interviews were conducted in the church offices when there was no service. The chosen venue was neutral and allowed for privacy and comfort sharing. This is supported by Legard, Keegan and Ward (2003) in that the place of interview has to be quite, private and physically comfortable.

The languages that were used during all interviews include Sepedi and Tsonga as these are the languages mainly spoken in the area, and back translated to English. The interviews lasted between 30-45 minutes and no additional interviews were done for the saturation of data. The interviews were audio recorded with permission from participants. This helped to ensure credibility of the data that was collected.

The interviews were transcribed verbatim then translated to English. Permission was requested to tape record the interviews and data will be stored in a password protected computer. Only the supervisor and the researcher will have access to the password. The data will be destroyed two years after any publication arising from the study or six years if no publication animate from the study. In case of any emotional distress, participants were advised to contact Ms. Katekani Precious Valoyi a social worker at Maphalle Clinic on 071 184 7291 for supportive counselling free of charge.

3.7 DATA ANALYSIS

The researcher used thematic data analysis to interpret data that was collected. Data refers to the information that is used for the purpose of description of something studied (De Vaus, 2001). According to Starks and Trinidad (2007) data analysis is a step that guides how the findings will be analyzed. Data analysis brings order and reduces raw information. The researcher followed the six-steps that Creswell (2009) highlights.

The first step involved organizing data. This was done through transcribing the interviews by putting it into words. According to Patton (2002) organizing data begins with inventory of what one has. This was helpful in identifying the gabs and if more additional data was still needed. The researcher made backup copies of all the data collected. Patton (2002) recommends that one master copy be kept for secure. The second step involved reading the data that was gathered in the first step. This means reading the transcripts in details several times. This was done to make sense of the data before attempting to break into different parts. This also involved looking at concepts that emerged based on the perceptions, treatment and knowledge about breast cancer.

The third step involved coding which means analyzing statements that are clustered in to meaning that represent the phenomenon of interest. Babbie (2007) identifies three types of coding data. The first one is code notes that explains the codes used in data analysis. For example, the researcher used codes such as P-01 which represented participant number one. The second code is the theoretical notes. The researcher reflected on the experiences of research. This is supported by Egan (2007) as he defines reflection as expressing of the thoughts and feelings that one had

undergone in a certain process or activity and it is the process where one asks oneself what the experience mean to them.

The third code is called operational notes. This involved providing detailed notes that might be for transferability. For example, the researcher is expected to provide motivation on the benefit of this research. The fourth step involved looking at the information about the participants in a particular setting. This involves noting regularities in the people being studied. The researcher searched for what Babbie (2007) calls the internal convergence and external divergence. This involved identifying meanings, putting it into categories and assigning codes (Grinnell &Unrau, 2005, p. 410 as cited in De Vos, 2011). The fifth step involved deciding on the themes that emerged from the information about participants. The sixth step involves reporting and presentation of the themes and attaching meanings to them.

3.8 REFLEXIVITY

Reflexivity is about keeping field notes that would highlight the experiences that the researcher has undergone (Bogdan &Biklen, 2007). It is about the thoughts and feelings of the researcher during the research process. This is important as it helped to eliminate the biases that might have occurred. Bogdan and Biklen (2007) provide a list of materials that should be included in the field notes. The first one is the reflection on analysis. I reflected on the learning outcomes. This involved writing the themes and thoughts that emerged when analyzing data. While analysing data, I was concerned about the lack of knowledge that is still prevalent in rural communities. I also felt sympathy for women who still perceived cancer to be witchcraft as this hindered early detection and chance of recovery.

The second thing is to reflect on the method used to collect data. The method used and all the processes were well documented with all the challenges encountered (De Vos, et al. 2011). Sometimes I felt like the questions were too much. What I liked about the interview was that it got women to think about their breast cancer status. I am also a woman and this brought subjective feelings. Some of the feelings that I had might have accidentally transferred to the participants. As these occur, it was well documented so that I can be aware of all those feelings so that they don’t

impinge on the study. I am fearful of breast cancer. Some of the perceptions aroused anxieties about the disease.

Thirdly, I must reflect on my own values to those of the participants. I believe that breast cancer is a disease like any other, so when other participants said that it was caused by witchcraft, I felt like it was a distorted perception. This was important to note because it is the reality that these women live with. I reflected on this because other people's beliefs must be respected. Lastly, I reflected about my own thoughts and feelings about the study and research site. Going into this study, I was enthusiastic and anxious at the same time. I am a very emotional person and almost cried when some participants kept re-scheduling the interview. The feeling elicited by the study during data collection was discussed with the research supervisor as they happened.

3.9 ETHICAL CONSIDERATIONS

Ethics are very important in research. The researcher adhered to the research ethic guidelines that are stipulated by Babbie and Mouton (2001). The following ethical considerations were be addressed:

3.9.1 Avoidance of harm

Babbie (2007) argues that the most important ethical rule in research is bringing no harm to participants. The researcher has an obligation to protect participants and should eliminate any physical discomfort that might occur (Creswell, 2009). Participants were informed of the potential harm that might occur, especially emotional distress. It is highly unlikely that the researcher can harm participant physically that is the reason the focus is more on emotional distress. Participants who required emotional distress counselling were referred to the social worker at the local clinic.

3.9.2 Voluntary participation

Babbie and Mouton (2001) argues that participation in research should be voluntary. No participant were forced or bribed to participate in the research. No other means or deception was used to make participants partake in the study. Participants were told that they can withdraw from the research at any point without any negative consequences. Participants were told about the purpose of the study and the anticipated emotional distress. The researcher took it upon herself to have information on where to refer women who might want to go for breast check-up and brochures on how to perform breast examination to check for breast cancer.

3.9.3 Informed consent

Informed consent relies on adequate information about the research. The information includes the purpose of research, expected duration, advantages and disadvantages and all relevant information that participant must know. All relevant information was included in the consent form that participants were requested to sign. Withholding information would have caused an ethical dilemma of deception and dishonesty. Autonomy or self-determination is fundamental to informed consent. This is aligned with voluntary participation and enabling participants to make their own decisions about the research. Permission was obtained from the participants to tape-record the interviews. This allowed the researcher to focus on the proceedings and then later transcribe for analysis (Smith, et al. 1995, p. 17 as cited in De Vos, et al. 2011). Participants were also requested to sign informed consent forms to take part in the study.

3.9.4 Privacy and confidentiality

The participants' names were protected by using code names. Confidentiality means safeguarding information disclosed or communicated by the person requesting service or receiving to the practitioner or agency. Such practitioner will not reveal the person's information to others without their consent or under certain circumstances with the purpose of helping that person (Dhai & McQuoid-Mason, 2011). Confidentiality is based on trust and honesty and was essential for building trust between the researcher and participants for effective data collection process.

According to Babbie and Mouton (2001) confidentiality implies the way the information is handled. The records of the research will be kept in a computer protected password and only accessible to the researcher and supervisor.

3.9.5 Anonymity

The protection of participants' identities is very important in research (Rubin & Babbie, 2010). Participants were protected using codes names. Anonymity was guaranteed as the researcher was the one who knows the participants in the study. Permission to conduct the research has been granted by Pastor Mokhobi. Anonymity was also guaranteed when the researcher did not mention participants' names when writing the research report. The researcher did not reveal identifying details of participants to anyone.

3. 10 TRUSTWORTHINESS OF THE STUDY

The researcher must understand the trustworthiness of their research. For the researcher to access the trustworthiness of the research it must be achieved through four elements namely credibility, transferability, conformability and dependability (Maxwell, 2012). Credibility corresponds to internal validity. It is concerned with the logic of the research design. To prove credibility of the study, the researcher piloted the study using semi-structured interviews, audio-record the interviews, transcribing it and providing a literature review identifying the gabs and rationale for engaging in this study (Creswell, 2009).

Transferability is concerned with demonstrating that the results of the study can be applied to other situations and population (De Vaus, 2001). The context where the research takes place is important. According to Shenton (2004) researchers must be able to determine how they can be confident in transferring their results to other situations. This involves providing thick description whereby the researcher gathers as much data as possible. The researcher must also provide full description of contextual factors that can impose on the findings. Shenton argues that transferability can be ensured by providing the reader with additional information that must be

considered before any attempts of transferability are made. For example, the study used ten participants, semi-structured interviews were used to collect data and the length of the sessions was 30-45 minutes.

Conformability is concerned with the finding from the data collected (Maxwell, 2012). According to Shenton (2004) researchers spent long period of time with participants and unintended personal biases might occur. That is the reason conformability is concerned with the objectivity of the study. The researcher used quotations from the participants' statements as evidence. The researcher also used triangulation of data sources to ensure conformability. Two key informants were interviewed based on their knowledge of breast cancer in order to enhance validity and reliability. The researcher kept reflective field notes in order to document the processes of the study.

Dependability is concerned with the method being used (Creswell, 2009). A reliable measure would then show the same results every time it is used. In order to address the issue of dependability, the researcher must document the processes of the study in details. This includes reporting on the research design and how it was used. The researcher must also keep a reflective appraisal of the study (Shenton, 2004). This is significant in ensuring that the study can be replicable in a similar context.

3.11 LIMITATIONS OF THE STUDY

The limitation of the study is that it only considered women's perception about breast cancer and not men. This can be a disadvantage to the men as they can also contract breast cancer (Sharon et al., 2002). Another limitation is that the researcher hails from Shawela village and thus the participants might either give socially desirable answers or shy away from answering questions. The researcher reassured them of confidentiality and she will also keep a reflective journal throughout the study.

3.12 CONCLUSION

This chapter aimed at highlighting the methodology process that took place in the study. The research will be based on a qualitative approach and used exploratory case study design. Semi-

structured interviews were used for data collection on participants who were purposefully selected. Triangulation of data sources was applied and two key informants were also interviewed based on their knowledge or experience about breast cancer. The chapter also shows how thematic analysis was used to organise and analyse data that was collected. The findings are presented in the next chapter. Ethical considerations that were adhered to are presented in the chapter. Lastly, the chapter presented limitations connected to the study and how trustworthiness was achieved.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

This chapter will first show a description of the demographic of participants. It also presents data analysis and discusses the research findings. The research findings were established using thematic content analysis. The findings are aligned with the research objectives that directed the study. The discussion reports on the findings that are drawn from major themes and sub-themes that emerged from analyzing data. The themes are presented through the use of participants' quotes and in relation to the literature which has been reviewed.

4.2 AIM AND OBJECTIVES OF THE STUDY

The findings are based on the aim and objectives of the study. The aim of the study was to explore the perceptions women have about breast cancer in Bolobedu, Limpopo. In order to achieve this aim, the following objectives have been formulated:

i) To explore the knowledge women have about breast cancer.

ii) To investigate the women's knowledge on where to go for diagnosis and treatment.

iii) To examine the role social workers can play in raising awareness about breast cancer.

4.3 DEMOGRAPHIC INFORMATION OF THE STUDY PARTICIPANTS.

Table 4.1: Demographic Information of Participants

Participants	**Age**	**Home language**	**Occupation**	**Education level**
1	35	Tsonga	None	Grade 12
2	40	Tsonga	None	Grade 12
3	40	Tsonga	Self-employed	Diploma
4	35	Sepedi	None	Grade 12
5	38	Tsonga	None	Grade 12
6	40	Tsonga	Self-employed	BA Degree
7	40	Sepedi	None	Grade 12
8	38	Tsonga	None	NQF Level 4
9	35	Sepedi	None	Grade 12

10	36	Sepedi	Self-employed	Grade 12

The number of participants who took part in the study is 10. The participants were selected from Shawela Banner for All Nations Miracle Centre which is based in Shawela Village in Bolobedu. The demographics are presented in table 4.1 below. All the participants who were interviewed are residence of Shawela Village and with Grade 12 education level (minimum). Participants demographic characteristics are obtain from the participants who were available and agreed to be interviewed. All participants were females from different ethnic groups and between the ages of 35 and 40.

4.4FEEDBACK FROM KEY INFORMANTS

In this study two key informants were interviewed, a social worker and nurse. Key informants have worked with the community for 4 and 10 years and have worked with women who have been diagnosed with breast cancer. Key informants have shared their knowledge and experiences of working with women in the community.

During the interview with key informants they reported that there is still a lack of knowledge about breast cancer. This is due to the traditional beliefs and lack of resources to detect and diagnose breast cancer at local clinics. Most women in the village still prefer traditional medicine and not western medicine. Key informants mentioned that the challenge with this is that breast cancer gets diagnosed at a later stage when treatment will no longer be effective. The lack of resources is also a challenge as women have to be referred to the hospital for diagnosis and treatment. Most women end up going for alternative medicine as they cannot afford transport money to go to the hospital. Key informants went on to say that the lack of resources is also a challenge when it comes to reaching women in order to raise awareness.

The only time women can be reached is when they bring children to the clinic for immunization. Key informants acknowledge that the role of social workers can be helpful in eliminating ignorance and negative attitudes about western medicine. This might also involve working with

traditional healers and examine their role and involvement in women's health issues. They both see the solution as having resources so that early detection can occur for the effectiveness of treatment.

4.5 KEY THEMES

4.2 Major themes and subthemes

THEMES	**SUBTHEMES**	
Women's knowledge about breast cancer	i	Knowledge of breast cancer
	ii	Knowledge on self-examination
	iii	Knowledge on risk development
	iv	Knowledge on signs
Women's knowledge of where to go for diagnosis and treatment	i	Clinics
	ii	Doctors
	iii	Traditional healers
The role of social workers	i	Raising Awareness
	ii	Support

4.6 DISCUSSIONS OF KEY THEMES

During data collection a number of themes and sub-themes occurred as shown in table 4.2 above. Each theme is discussed in relation to the objectives of the study. The themes were linked to the

literature review in chapter two and the data collected from interviews and verbatim quotations will be used to support the discussions.

4.6.1WOMEN'S KNOWLEDGE ABOUT BREAST CANCER

The first theme is associated with the knowledge that women have about breast cancer. The theme emanates from the first objective which paid attention to exploring the kind of knowledge women have in order to understand their perceptions of breast cancer. During the interviews participants were asked to share their perceptions about breast cancer. There seems to be lack of knowledge on self-examination, who is at risk and the signs to help detect breast cancer.

4.6.1.1 Knowledge of breast cancer

The interview shows that there is a little knowledge of what breast cancer is. There were different perceptions that came out of the interviews which include death sentence, disease of the breast. Most participants know it as a disease that can only affects woman. Only one participant knew of breast cancer to affect both men and women. For some participants, there was a belief that breast cancer is a "white disease" only affecting Europeans and not African and black people. This was validated by the key informant who recounted that most women still believe in traditional and not western medicine. Some of these varying perceptions are emphasized by the quotations from study participants below:

"*Breast cancer is a disease that affects both men and women. It is a lump that develops inside the breast ...*" **(Participant 5).**

"*Breast cancer is a dangerous disease and when you are diagnosed with it, it means you are closer to the door of death. So you can start preparing for your journey to the afterlife ...*" **(Participant 3**).

*"Sometimes they would associate breast cancer with being a white disease and not a black disease ..."***(Key informant 1).**

This finding is supported by Beck and Falkson (2001) in that most women in rural areas have little knowledge about breast cancer. Most women lack knowledge about breast cancer because there are no awareness programmes in rural areas. They acknowledge that it is due to the differences that exists between urban and rural areas in terms of services. However, Priestman (2012) dispute the findings and argue that breast cancer is an uncontrollable growth of abnormal cells in the body. Cancer develops when the body's normal control mechanism stops to work (Priestman, 2012). This means that cancer start when cells become abnormal and divide without control or order. According to Ross and Deverell (2004) when cell become uncontrollable, they form a cell called tumour and leaves the body dysfunctional.

4.6.1.2 Knowledge on self-examination

The majority of participants did not know how to conduct self-examination. This is due to the lack of awareness in the community about breast cancer. Some participants have heard from the local clinic on how to conduct breast self-examination and radio and television. However, they are still not able to do it themselves due to the channels of communication used to convey the information. This can be illustrated in the quotations below.

*"I don't know how to conduct self-examination. I heard about it one day at the clinic when the nurse was explaining to us. I think you wait for your menstruation and you raise one hand at a time as you feel the breast" (***Participant 5).**

"The challenge with hearing things from TV is that sometimes they use English and it is not easy to most people to hear and understand. So we end up losing important information that can help us. It is not often that they speak about breast cancer on radio and even on TV there are channels about health issues but it is in English..." **(Participant 3)**

"*Most women don't know how to conduct breast self-examination. This is due to the lack of resources to enable us to reach the majority of the population ...*" **(Key informant 1).**

This findings support Pillay (2002), Woloshin, et. al. (1999), Weis (2003), statement that in most rural communities don't have knowledge to conduct a monthly self-examination. However, their findings also indicated that elder women were less likely to know how to conduct self-examination. Montazeri, et. al (2008) found that BSE is simple, inexpensive, low in technology, teaching is possible to both health professionals and women and more importantly raises awareness about breast cancer in women. However, this is a problem in most rural communities as they don't have knowledge about the disease. In a study that was conducted by Pillay (2002) in KwaZulu-Natal in the area of breast cancer screening and knowledge, most women were not aware that medical tests can detect breast cancer. There was lack of knowledge about mammography and early detection techniques. Women still don't know where to go in order to be tested and at what age they are considered to be at higher risk. This was not surprising as advanced health care facilities are not accessible in rural areas.

4.6.1.3 Knowledge on risk development

The findings also found that most women don't know about the risk development of breast cancer. There were some who knew that one can develop breast cancer when there is a history of breast cancer in the family. History in the family and age were the only factors that were identified by participants. This is illustrated by the quotations below:

"*I don't know what causes cancer or why it develops. But I would like to believe that it develops like any other chronic disease …"***(Participant 1).**

"*Hey, I don't know but I think a person is at risk of getting breast cancer when she is old. When you are an elderly person, it seems like you are most likely to develop many disease because the immune system gets weak. So growing up comes with health deterioration that leaves the body vulnerable to diseases …"***(Participant 3).**

"*I think one can get cancer when there are family members who have cancer. I know of someone who has cancer and both her mother and grandmother died from it ...*" **(Participant 6).**

This is supported by Matatiele and Van den Heerver (2008) in that the majority of South African women have limited knowledge when it comes to the risk of developing breast cancer. This mostly referred to older black women who are particularly poor and lacks knowledge of identifying breast cancer symptoms. They further found that there is lack of awareness when it comes to the development of breast cancer. Iredale, et. al. (2006) also found risk factors to include family history of breast cancer.

4.6.1.4 Knowledge on signs

Most women reported to have some knowledge about the signs of breast cancer. However, they all have a common knowledge of one sign of which the breast have to have a growth inside and be very painful. Some also spoke of weight loss, removal of the breast and dizziness. Most signs that were identified were acquired through information sources such as radio and television. This is illustrated with the quotations below:

"*Hah, I don't know but if it was me who wanted to find out about the signs, I would look at weight loss and pain around the breast but other than that I don't know"* **(Participant 3).**

"*I would say that it is a growth around the breast because the breast will be hard when you touch it. It will also be painful …*" **(Participant 8).**

"*One of the signs that I have seen from my cousin is the swelling under her arm. Her breast was removed but the whole area was so hard and very painful …*" **(Participant 9).**

This finding support previous research of Schover (1994) as he identified other signs of breast cancer to include lump in the breast, loss of hair and breast. This contributes to the loss of physical beauty and their desire to seek new relationships. However, CANSA (2007) dispute that all lumps are painful. They argue that not all breast lumps are painful. There are harmless lumps that require clinical breast examination. They emphasise that not all women will show signs of breast cancer. There are symptoms free women especially from the age of 40.This is also supported by Iredale, et, al. (2006) as they also found symptoms of breast cancer to include painless breast lump.

4.6.3 WOMEN'S KNOWLEDGE OF WHERE TO GO FOR DIAGNOSIS AND TREATMENT

The second theme is associated with the second objective of the study. This aimed to explore their knowledge about where they can help detect and treat breast cancer. During the interviews participants were asked to share their knowledge of where they would go for diagnosis and treatment should they be diagnosed with breast cancer. Amongst the places clinics, doctors and traditional healers were identified.

4.6.2.1 Clinics

The clinic was seen by participant as the first option that they would consider going to for the diagnosis and treatment. Some of them only heard about breast cancer when they went to the clinic. Local clinics were chosen because they are closer to their homes and the services are free of charge. Some women chose the clinic because they are poor and cannot afford to go anywhere else. Most of them acknowledge that had they had other means, they would go elsewhere. They spoke of the services at the clinic as being poor and without proper medication. Sometimes they would go to the clinic and they would come back empty handed as they would be told that there is no treatment. This is illustrated by the quotations below;

"*In this village, there is only one clinic where a person can go. Sometimes people don't prefer to go to the clinic for check-ups because the service in the clinic is bad. You find that some Nurses*

are rude and this discourages people from going there. Sometimes they don't attend to you and you would spend the whole day there. Sometimes when you old, Nurses don't explain fully about the diagnosis and you are not given any information ..." **(Participant 3).**

"*I would go to the clinic for check-up. I will not be able to afford to go anywhere, so I feel like that is my only option but if I had a choice, I would go elsewhere ...*" **(Participant 8).**

This finding supports Beaver and Luker (1997) in that women with breast cancer may obtain information about diagnosis from a range of interpersonal providers, including hospital consultants, breast care nurses, general practitioners and clinic nurses. The information that is needed is helpful in supporting diagnosed members of the family. Weis (2003) found that early and accurate diagnosis is important for optimizing the treatment of breast cancer. He argues that accurate diagnosis is a required step in the management of breast cancer as the diagnosis can confirm the presence of the disease, reduce treatment delay and clarify the predictive and prognostic factors of the breast cancer. The challenge with clinic in rural areas is that there are no resources to diagnose and women have to be referred to hospitals or breast clinics (CANSA, 2007).

4.6.2.2 Doctors

The majority of participants would prefer to go to the doctor for diagnosis and treatment. They acknowledge having the same challenge of affordability. Doctors are expensive for the majority of women who comes from poor background. However, they also agree that the service at the doctors' rooms is better than that of the public clinics. The doctor would also explain the diagnosis and make follow up appointments for further prognosis. The challenge that was also found at the doctor is that they also don't diagnose and treat breast cancer. This is due to the lack of equipment for clinical examination. This means that they also refer to the hospitals and breast clinics. This poses more money problems as they have to pay at the doctor and travel to the hospital. This is illustrated with the quotations below:

"*The other place where a person can check is at a doctor or to the hospital. What I like about doctors is that one get a chance to ask questions and get clarity about the diagnosis. The challenge is that most people live in poverty and cannot afford to go to the doctor or hospital ...*" **(Participant 3).**

"*I would prefer to go to the doctor for treatment. The challenge is that I cannot afford a doctor and let alone transport money ..."***(Participant 5).**

"Doctors can explain the diagnosis and provide information. That is why they are the best option for me ..." **(Participant 7).**

This finding support Okobia, Bunker, Okanofua and Osime (2006) there is indication of positive medical help-seeking behaviour as majority of participants prefer visiting the doctor as the best approach to breast cancer care. However, Ross and Deverell found that sometimes doctors give diagnosis and offer little explanations of what the disease is and what causes it. This is supported by Delbanco (1992 as cited in Ross & Deverell, 2004) in his research he found that cancer patients want to understand how their disease will affect their lives and want to trust the competency of their caregivers. They preferred doctors because they would offer explanation of the effect the disease will have on their families, friends, finance, relationships, future and other things depending on the patient.

4.6.2.3 Traditional healers

Only two participants reported to have consulted traditional healers about their health before considering the hospital or clinic. This is because they adopted their family's belief in traditional healers when seeking treatment. The key informant highlighted traditional healers as very important role players in the community health issues. This community in particular would prefer traditional healers than western medicine. These participants perceived the outcome of their illness as being completely in their ancestor's hands hence they consult traditional healers. This is illustrated with the quotations below:

"*My family has always consulted traditional healers and I did the same. I always believed that when illness falls upon me, it is because ancestors were not happy with something that I had done. So I consult traditional healers before I can consider going to the clinic …"***(Participant 4)**.

"*This is a rural area where some people still believe in traditional healing. So when they have cancer, they are more likely to associate it with witchcraft. This is the challenge that we face because when they eventually come to the clinic, it is too late. Breast cancer is more likely to be diagnosed at a later stage due to the beliefs that people have in this community. Traditional healers play a significant role in the kind of treatment that people in rural areas use …*" **(Key informant 1**).

According to CANSA (1997) traditional healers play a significant role in the kind of treatment that people in rural areas use. Research shows that rural women prefer to consult traditional healers rather than medical doctors. Due to the apartheid, many rural areas relied on traditional healers as they had little or none medical resources (Pillay, 2002). So it is understandable that some still have little faith in western medicine. Some women prefer the inclusion traditional and western medicine. Pillay (2002) argues that there is danger of women with cancer to refuse medical treatment in favor of traditional medicine.

Several recent studies suggest that women have unrealistic

4.6.3 THE ROLE OF SOCIAL WORKERS

During the interviews, women, were asked to explain the role that social workers can play in relation to breast cancer. This third theme is associated with the third objective of the study. It aimed to also explore the kind of information that they would like know. Raising awareness and support were amongst the answers provided.

4.6.3.1 Raising awareness

A partial explanation for the lack of awareness about breast is found to be due to lack of resources and awareness about the disease. Raising awareness about breast for both social workers and public health can be crucial in early detection and treatment. Most participants said that the role of social workers can be significant in helping women accept and deal with the diagnosis. One participant pointed out that it would be important to get door to door information about breast cancer. Participants reported that social workers can provide information that could be useful in the diagnosis. Most participants also pointed out that language is a barrier in understanding health issues. Health practitioners use medical terms that people don't understand. One participant said that most people in rural area are not educated and would prefer information in their home languages. Most participants would like social workers to link them with resources that would enable them to get to the hospitals. This is illustrated with participant's quotations below:

"I would like information to be communicated to me in concerning the development of breast cancer to be communicated in Tsonga. Sometimes nurses and doctors use medical terms that people don't understand and we end up being confused …"(**Participant 5).**

*"As social workers, my role could involve working together with health practitioners to raise awareness and educate women about self-examination and giving information about breast cancer.... Information can be key to eliminating ignorance and it is important for that information to be conveyed in the language that people understand …"***(Key informant 2).**

*"Social workers have significant role to play in this community. Through counseling they could help eliminate ignorance and negative attitudes people have about white medicine. It is difficult to reach women in this community due to their lack of trust in us. Working together with social workers could help raise awareness about the importance of early detection and taking the right treatment …"***(Key informant 1).**

This finding support Beck and Falkson (2001) Shaw, et, al. (1994), Northouse, et. al. 1997, Manne, 1998's notion that it is important to have awareness programmes that will educate people about breast cancer, health promotion and provide support services to patients and families. Women with breast cancer have different needs for information throughout their breast cancer expedition. The

most important information that women and their significant other identified was information concerning the diagnosis. The health promotion model is also important in bringing social change by improving health and wellbeing of individuals (Rootman, et,al. 2001). The overall goal of health promotion is to enhance positive health and prevent ill health. This is important because one of the preventative measures include screening and treatment. It could be useful in helping women to be aware of the importance of early detection that would enable a better chance of recovery. So this means that women have to be aware of regular self-examination methods and consulting healthcare professionals for advice on proper screening tests. One of the strengths of this model is its integral nature of which the social, behavioural and medical disciplines participates and offer a diverse health promotion.

4.6.3.2 Support

Most women find support from their families. In order for spouses and care givers to support and take care of diagnosed person, he or she must understand all the components. As much as partners provide emotional and social support, this study shows that there is a need for formal support services from social workers.

"*Social workers are very helpful in getting us in touch with our feelings. I think you call it counselling. The physical illness can affect the emotions where one keeps thinking about the disease and have sleepless nights. So the kind of support that I would like from them would be to consult them when I am diagnosed. It is good to talk to a professional who understand what you are going through. I believe that disease is not only about the physical but also the emotional wellness is important. Another support could be for the social workers to link us with resources that would help us fight the disease. For example, at the clinics we don't have resources to diagnose breast cancer, so they can help us also with money for transport to go to the hospitals …"***(Participant 3).**

This finding is supported by Manne, Taylor, Dougherty, & Kemeny (1997) in that as much many couple relationships are supportive; sometimes people need to speak to an outsider who can be objective. Beck and Falkson (2001) found that knowledge and support can help others to get through their battle of cancer. Supportive services can be offered telephonically, at clinics, hospitals and through community home-based care. Barraclough (1999) found that emotional support was very important in dealing with cancer diagnosis.

4.7 CONCLUSION

This chapter gave the demographic information of participants in the study. The research findings were aligned with the objectives and supported by the use of literature review in chapter two. The chapter also presented the themes and sub-themes that came to the fore during the study. Quotations from participants were used to illustrate the findings. The next chapter will highlight the summary of the main findings of the research study. Recommendations will also be made for for women in rural areas, social workers and future studies.

CHAPTER FIVE

MAIN FINDINGS, RECOMMENDATIONS AND CONCLUSIONS

5.1 INTRODUCTION

This chapter summarises the main findings of the study. Recommendations for women and social workers and future studies will be made based on the findings. Final conclusion will also be provided in this chapter.

5.2 SUMMARY OF FINDINGS

The findings have been summarised according to the objective.

5.2.1 To explore the knowledge women have about breast cancer

The overall aim of the study was to explore the perceptions women have about breast cancer in Bolobedu, Limpopo. The main findings of the study clearly indicate that there is still lack of knowledge about breast cancer. There are various reasons why women lack knowledge about breast cancer. Most women lack knowledge about breast cancer because there are no awareness programmes in rural areas. This is supported by Beck and Falkson (2001) in that there are differences that exists between urban and rural areas in terms of services. The source of knowledge

of breast cancer for the majority of participants was through mass media. According to the key informants, women in the community are diagnosed with breast cancer at a later stage of the disease. This reflects their lack of knowledge regarding early symptoms of the disease which is very important for effective treatment. This is supported by Weis (2003) in that early and accurate diagnosis is important for optimizing the treatment of breast cancer. The majority of women knew of breast lump as the presenting symptom of breast cancer. Family history of breast cancer was the most frequent cited risk factor. This is supported by Matatiele and Van den Heerver (2008) in that the majority of South African women have limited knowledge when it comes to the risk of developing breast cancer.

5.2.2 To investigate the women's knowledge on where to go for diagnosis and treatment

The findings revealed that the local clinic was seen by some participant as the first option that they would consider going to for the diagnosis and treatment. Some of them only heard about breast cancer when they went to the clinic. Local clinics were chosen because they are closer to their homes and the services are free of charge. Some women chose the clinic because they are poor and cannot afford to go anywhere else. This is supported by Beaver and Luker (1997) in that clinic nurses can provide information about diagnosis. The challenge with clinic in rural areas is that there are no resources to diagnose and women have to be referred to hospitals or breast clinics. The majority of participants would prefer to go to the doctor for diagnosis and treatment. This was due to the service at the doctors' rooms as it was considered to be better than that of the public clinics. The challenge that was also found at the doctor is that they also don't diagnose and treat breast cancer. This is due to the lack of equipment for clinical examination. This is supported by Delbanco (1992 as cited in Ross & Deverell, 2004) in that cancer patients preferred doctors because they would offer explanation of the effect the disease will have on their families, friends, finance, relationships, future and other things depending on the patient. There were participants who reported to have consulted traditional healers about their health before considering the hospital or clinic. This is due to the cultural beliefs of the disease being on ancestor's hands and language barrier. Key informant highlighted traditional healers as very important role players in the community health issues. This community in particular would prefer traditional healers than

western medicine. This is supported by CANSA (1997) in that traditional healers play a significant role in the kind of treatment that people in rural areas use.

5.2.3 To examine the role social workers can play in raising awareness about breast cancer

A partial explanation for the lack of knowledge about breast cancer was due to the lack of awareness programmes about breast. This was is found to be due to lack of resources and awareness about the disease. The findings revealed that most participants saw the role of social workers as significant in helping women accept and deal with the diagnosis. Participants reported that social workers can provide information that could be useful in the diagnosis. Most participants also pointed out that language is a barrier in understanding health issues. Health practitioners use medical terms that people don't understand. This is supported by Hilton (1993) information that is needed is helpful in supporting diagnosed members of the family. Participant reported that most people in rural area are not educated and would prefer information in their home languages. Most participants would like social workers to link them with resources that would enable them to get to the hospitals. As much as partners provide emotional and social support, this study shows that there is a need for formal support services from social workers. Barraclough (1999) found that emotional support was very important in dealing with cancer diagnosis. This finding is supported by Manne, Taylor, Dougherty, & Kemeny (1997) in that as much many couple relationships are supportive; sometimes people need to speak to an outsider who can be objective. Supportive services were suggested to include door to door visits in order to also include the elderly who struggles to walk to the clinics.

5.3 RECOMMENDATIONS

Based on the findings, the following recommendations for women in rural areas, social workers and future studies have been made.

5.3.1 Recommendations for churches in rural areas

Churches in rural area can play a role in helping women with breast cancer status. Interventions can be done through the church.

5.3.2 Recommendations for social workers

The level of awareness of women regarding breast cancer is not adequate and health education programmes for this subject should be introduced in rural areas. Social workers can work in collaboration with traditional healers to raise awareness. Social workers to also work with women in the area to help explain the diagnosis. The researcher stresses the need for social work advocacy for more affordable and accessible health care services.

5.3.3 Recommendations for future studies

There is still a need for more research to explore the role that government can play in ensuring affordable and accessible health care services. Western intervention has become a challenge when applied in rural communities, there is a need to explore multidimensional approach in helping women realize their breast cancer status.

5.4 CONCLUSION

The purpose of this research was about exploring the perceptions women have about breast cancer. This chapter reported on the findings in relation to the literature review. It reported on women's knowledge of breast cancer. There were various reasons that were highlighted as the cause of lack of knowledge about the disease. Knowledge on where to go for diagnosis was also reported. The role of social workers was explored in relation to raising awareness about breast cancer. Recommendations were made to women, social workers and future studies.

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APPENDIX A: PARTICIPANT INFORMATION SHEET

Good day,

My name is Tsakane and I am a fourth year student registered for the degree of Bachelor of Social Work at the University of Witwatersrand. As part of the requirements for the degree, I am conducting research to explore the perceptions women have about breast cancer. It is hoped that the information may enhance social workers' understanding of the perceptions women have in order to improve awareness campaigns and support services.

I therefore wish to invite you to participate in my study. Your participation is entirely voluntary and refusal to participate will not be held against you in any way. If you agree to take part, I shall arrange to interview you at the time and place that is suitable for you. The interview will last approximately 30-45 minutes. You may withdraw from the study at any time and you may also refuse to answer any questions that you feel uncomfortable with answering. You are guaranteed confidentiality and your personal information will be safe-guarded in a password protected computer**.** In case of any emotional distress, you may contact Ms Katekani Precious Valoyi a social worker at Maphalle Clinic on 071 184 7291 for supportive counselling free of charge.

With your permission, the interview will be tape-recorded. No one other than my supervisor will have access to the tapes. The tapes will be destroyed two years after any publication arising from the study or six years if no publication emanate from the study.

Please feel free to ask any questions regarding the study. I shall answer them to the best of my ability. I may be contacted on 072 196 8728 or e-mail at 0108430v@students.wits.ac.za, or my supervisor Dr. Warria on 011 717 4472 or e-mail atAjwang.Warria@wits.ac.za. An abstract will be available should you wish to receive the summary of the research.

Thank you for taking time to consider participating in the study.

Yours sincerely

Tsakane Tivani (Student Social Worker).

University of the Witwatersrand

APPENDIX B: CONSENT FORM FOR PARTICIPANTS AND RECORDING

TITLE OF RESEARCH: Exploring the perceptions women have about breast cancer in Bolobedu, Limpopo.

I hereby consent to participate in the research project. The purpose, aim and procedures of the study have been explained to me. I understand that my participation is voluntary and that I may refuse to answer any particular items or withdraw from the study at any time without any negative consequences. I understand that my responses will be kept confidential. Details of a supportive counsellor have been provided in case of emotional distress that may arise from the study participation.

I hereby consent to tape-recording of the interview. I understand that my confidentiality will be maintained at all times and the tapes will be destroyed two years after any publication arising from the study or six years after completion of the study if there are no publications.

Name: ……

Date: ……

Signature: ……

APPENDIX C: INTERVIEW SCHEDULE FOR PARTICIPANTS

Demographic information:

Age: ……

Occupation: ……

Objective 1: To explore the knowledge women have about breast cancer.

i) What is your perception about breast cancer?

ii) Who is at risk of breast cancer?

iii) How can a person get breast cancer?

iv) What are the signs that would show that one has breast cancer?

v) How does one go about conducting self-examination for breast cancer?

vi) How often are women supposed to check for breast cancer?

Objective 2: To investigate knowledge on where to go to for diagnosis and treatment.

i) Where can one go to for breast cancer check-up and or diagnosis?

ii) If one is diagnosed with breast cancer, what should they do?

iii) Where can one go to after breast cancer diagnosis?

Objective 3: To examine the role social workers can play in raising awareness about breast cancer.

i) What kind of information do you think would be important for other women in this village to know in relation to breast cancer?

ii) How would you like this information to be communicated to you?

iii) What role(s) can social workers play in relation to breast cancer? Explore: support during/ after diagnosis, information on treatment etc.

Is there anything that you would like to add that I did not ask?

☺Thank you for participating in the study.

APPENDIX D: INTERVIEW SCHEDULE – KEY INFORMANTS

Demographic information:

Occupation: ……..

Time spent working in this community: ……..

i) Briefly tell me about your role in this community.

ii) From your experience, what do women in this community know about breast cancer?

iii) What are some knowledge gaps that you have observed in your work?

iv) How can these gaps be addressed?

v) What role can social workers play in this community, with regards to breast cancer?

vi) How do you communicate with women about their health?

vii) What resources are available to help women know about their breast cancer status?

Is there anything that you would like to add that I did not ask?

☺Thank you for participating in the study.

APPENDIX E (I)

TRANSCRIPT FOR THE MAIN PARTICIPANT

Identifying code: P 03

Age: 40

Language: Tsonga

Education level: Diploma

Occupation: Self-employed

Researcher: Thank you for participating in the study. Can you please tell me about your perception of breast cancer?

P 03: Thank you. My perception about breast cancer is that it is a dangerous disease and when you are diagnosed with it, it means you are closer to the door of death. So you can start preparing for your journey to the afterlife. I compare this disease with HIV/AIDS because both of them are severe and dangerous.

Researcher: Do you mean that when you are diagnosed with breast cancer, you will die?

P 03: Yes it means I will die. If you can look carefully, as I already mentioned that I compare it with HIV/AIDS. People with breast cancer seems like they lost their will to live as they will start

to prepare for their death. If you hear rumours of the diagnosis, you might hear after a month that the person had died.

Researcher: Do you know anyone who had been diagnosed with the disease?

P 03: No, I don't know anyone or heard of anyone who has been diagnosed in this village. This is due to secrecy. People in this village are very secretive so it is not easy to hear of anyone. However, from what I know from Television is that when people are diagnosed with breast cancer, it is the end.

Researcher: Do you know who is at risk of getting breast cancer?

P 03: Hey, I don't know but I think a person is at risk of getting breast cancer when she is old. When you are an elderly person, it seems like you are most likely to develop many disease because the immune system gets weak. So growing up comes with health deterioration that leaves the body vulnerable to diseases.

Researcher: Do you know how one can get breast cancer?

P 03: No, I don't know how one can get breast cancer. What I use to hear is that when there is a history of breast cancer in the family, it makes their children to be more at risk of getting the disease. In other words, it could be hereditary where can inherit it. I don't know of any other way that one can get it.

Researcher: Do you know of the signs that show that a person has breast cancer?

P 03: Hah, I don't know but if it was me who wanted to find out about the signs, I would look at weight loss and pain around the breast but other than that I don't know.

Researcher: Haven't you ever heard or witnessed any signs of breast cancer?

P 03: No I have never heard of anyone but I know of this disease from Television and hear about it from the radio. So it is very difficult to know about the signs as most of them are not very clear on TV. But I know of breast cancer and its existence. However, I don't really know the details of the disease.

Researcher: Do you know how to conduct self-examination in order to check for breast cancer?

P 03:I don't know how to conduct self-examination. I heard from the radio that it is good to go to the clinic to check if one has breast cancer even when there is no pain around the breast. There are other symptoms that do not show but it does not mean that they are not there. So it is good to always go for check-ups especially for those who are older.

Researcher: Can you tell me about your inability to conduct self-examination? I mean could it be because you lack knowledge or what?

P 03: Yes it is due to lack of information. When you don't have information there is nothing that you can do. The challenge with hearing things from TV is that sometimes they use English and it is not easy to most people to hear and understand. So we end up losing important information that can help us. It is not often that they speak about breast cancer on radio and even on TV there are channels about health issues but it is in English.

Researcher: How often can one check if they have breast cancer?

P 03:I think a person can check at any time. A person does not have to wait for 3 or 4 months without going to the clinic for check-up. As women we are vulnerable to breast cancer so it is easy for us to get it. If it was possible, I would say that a person must go for check-up every month. Going for a check-up at the clinic is very convenient as it is free so people must always go for check-up. It is better to find out early rather than later when you are dying because one failed to go for check-up.

Researcher: Do you know the importance of early detection?

P 03: Yes I know of the importance of early detection. When you don't go for check-up, you will detect the disease at a later stage where it is not curable. But when the person had found out early it would have been treated and to get help from doctors. So when people don't go for check-up, they are signing their own death sentence. The more a person wait, the disease is also busy destroying the immune system and leaves the body prone to other diseases. So it is very important to detect the disease early.

Researcher: Where can one go to check for breast cancer diagnosis?

P 03: In this village, there is only one clinic where a person can go. Sometimes people don't prefer to go to the clinic for check-ups because the service in the clinic is bad. You find that some Nurses are rude and this discourages people from going there. Sometimes they don't attend to you and you would spend the whole day there. Sometimes when you old, Nurses don't explain fully about the diagnosis and you are not given any information. The other place where a person can check is at a doctor or to the hospital. What I like about doctors is that one get a chance to ask questions and get clarity about the diagnosis. The challenge is that most people live in poverty and cannot afford to go to the doctor or hospital.

Researcher: If you can be diagnosed of breast cancer, what would you do?

P 03: Hmm, it would be very difficult. If I were to be diagnosed, I would not know what to do. However, I would follow the instructions that I will get from the Nurse. I will try by all means to adhere to the treatment that I will be given. I think it would be easier to follow instructions. What I realised is that most people don't adhere to treatment and when they don't get healed, they turn to blame the Nurses. So it is good to follow instructions and adhere to the treatment until the end.

Researcher: Do you know which treatment to use when one is diagnosed of breast cancer?

P 03:I don't know but from what I heard is that they might remove the breast where they found the lump. So this makes the disease to disappear but one will have one breast left. If it spread to the other breast, it will also be removed but they only remove a breast that is infected with the disease. This is the reason I said that when one is diagnosed, one must start preparing to die. This is a deadly disease where one loses part of their body. The problem is that this will affect my self-esteem. As a respected woman in this community, I am part of the School Government Body at the school and also in the church committee. As a person who constantly stands in front of people, it might affect my role as a speaker. I feel like people will be staring at my breast and miss the information that I am sending. My moral will be broken and my self-esteem will be very low. Especially if the knowledge that we one is diagnosed with breast cancer, their breast will be removed. So everyone will know and pose their judgment. Even in the church where they preach love for fellow women, they are also human and judgemental. So when one of my breasts is

removed, I would also remove myself from all the committees that I'm involved in. This will also affect my appearance as a woman as Clothes will no longer suit me the way they use to. Just imagine wearing a nice dress but with one breast it would be awkward. I know that doctors have a bra that one can wear but still I will not be comfortable.

Researcher: What kind of support would you like to have from your family if you were to be diagnosed with breast cancer?

P 03:I would like my family to be by my side throughout the journey. I would like them to help me and encourage me to take the treatment. It would be helpful for them to remind me to take my medication and assuring me that they are with me. I want to be included in family activities and not be isolated just because I am ill. I would want to be treated normally and not like a dying person. I would want them to change the diet to more healthy food such as fruits and vegetables. My family should also research or try to find out more about the disease in order to help me.

Researcher: What kind of support would you like from social workers?

P 03: Social workers are very helpful in getting us in touch with our feelings. I think you call it counselling. The physical illness can affect the emotions where one keeps thinking about the disease and have sleepless nights. So the kind of support that I would like from them would be to consult them when I am diagnosed. It is good to talk to a professional who understand what you are going through. I believe that disease is not only about the physical but also the emotional wellness is important. Another support could be for the social workers to link us with resources that would help us fight the disease. For example, at the clinics we don't have resources to diagnose breast cancer, so they can help us also with money for transport to go to the hospitals. The challenge is that we also don't have a social worker in this village and we have to travel long distance to the next village to access one. One has to get a taxi and pay in order to see a social worker. It would be easier to have a social worker in the village to help us.

Researcher: What kind of information about breast cancer would you like in this village?

P 03:I would like people to be told about breast cancer. As women we can meet and educate each other about health issues. Women have stokvels and could use it and invite someone who knows

about breast cancer to come and educate us. I would like all women to know how one can develop breast cancer, to conduct self-examination and the importance of early detection. As you were asking questions, I realised that there is still more information that I don't know about this disease, so it would be helpful to have someone to educate us. For women who are not included in stokvels, they can get information from the pamphlets that we will collect. But when we have meetings where we invite speakers, we will include all women to benefit from the information provided. Women can bring a pen and paper to write all the information to take home to other families or relatives. Another way that we can get information could be door to door exposure. People with information can visits homes and raise awareness about this disease at home so that they can also accommodate older persons who are no longer able to walk. I would also like to see pictures of the severity of the disease because it will help people to take it seriously. They must also leave pamphlets that are written in our own language so that we can understand the information. So when there is information that I forgot, I can consult the booklet or pamphlet.

Researcher: Is there anything that I might have left out that you feel is important in relation to breast cancer?

P 03:I would like you to tell me or help with information to know where to get information. I would like women to be helped with knowledge of this disease and what to do when they don't have money. These questions helped me to realise what I know and don't know about breast cancer and I would like for all women to be asked these questions.

Researcher: Thank you so much for what you have just said. I have with me pamphlets that can help provide information about breast cancer. I would it will be helpful and you can share the information with other women in the village as you suggested.

APPENDIX E (II)

TRANSCRIPT FOR MAIN PARTICIPANT

Identifying code: P 05

Age: 38

Language: Tsonga

Education level: Grade 12

Occupation: None

Researcher: Hello and welcome. Can you please tell me what your perception about breast cancer is?

P 05: Breast cancer is a disease that affects women and men. It is a lump that develops inside woman breast. I don't know much about it but for me it is a disease like any other disease. One would have a painful growth inside the breast and that is how I know that it could be breast cancer.

Researcher: How do you know about breast cancer?

P 05: I heard about breast cancer from Television and the clinic. There was a time in one of the soapies where one lady had breast cancer. When watching the TV that is where I saw that this is a life threatening disease that should not be ignored.

Researcher:Do you know anyone who had been diagnosed with breast cancer?

P 05: Mmmmmm..... No. I don't know anyone personally except for what I saw on TV. I think I would know if a relative was the one diagnosed. It is not easy for people to talk about their health status especially when a person is really diagnosed. This is a small community and people like to gossip, so I would also like my diagnosis to be a secret.

Researcher: Do you know who is at risk of getting breast cancer?

P 05:I think everyone is at risk of getting breast cancer is either a woman or man particularly between the ages of 40 and above. I think a person can inherit it form the family if there is a history of the disease.

Researcher: Are saying that since you are under 40, you are not at risk of developing cancer?

P 05: Ah.... exactly. I mean.....I am too young to die. (Smiling) from what I saw on TV, people who were diagnosed with cancer had 3 months maximum to live.

Researcher: Do you how a person can get breast cancer?

P 05: I don't know much about that, what I know is that everyone can get cancer. I just know about the family history as the contributing factor. Other than that, I have no idea how one can develop breast cancer. Like... if it was lung cancer, I would say it is caused by excessive smoking. But I don't know what causes the growth to develop.

Researcher: What are the signs that will show that one has a breast cancer?

P 05: Some people get to lose weight, feel pains inside their breast, some become dizzy at some point, I think there are different kinds of symptoms but those I mentioned are the one I heard about.

Researcher: Do you know how one can conduct self-examination?

P 05: I don't know how to conduct self-examination. I heard about it one day at the clinic when the nurse was explaining to us. I think you wait for your menstruation and you raise one hand at a time as you feel the breast. Yah women can examine themselves by checking their breast each month after their period. That's how they can feel that lump inside their breast. Oh...yah, I think

the nurse said that you can use your right hand to examine your left breast and use your left hand to examine your right breast by doing a sort of massage on both breast. If there is something hard you can feel it. It is going to be painful when you touch it. That's how you will fell the different in your breast when you are in periods or after.

Researcher: How often are you supposed to check breast cancer?

P 05: I think every six months you can go for check-up. Yes.... yes (nodding her head). Every six you can go for check-up to find out if you have breast cancer or not. The doctor will take you to..... (trying to remember). I think it is called mammogram. I have never seen it but I think it is a machine to test for breast cancer.

Researcher: Where can one go to check for breast cancer?

P 05: You can go the local clinic, hospital, and the doctor who deal with this kind of disease, they will check you if you have the disease or not. I would prefer to go to the doctor for treatment. The challenge is that I cannot afford a doctor and let alone transport money.

Researcher: If you were to be diagnosed with breast cancer what will you do?

P 05: I could go into fasting prayer until God hear my prayers. I think I will also ask the doctor how far my cancer is, after telling me the stage, I will take it from there. I can collect as much information about it before I panic. I could find out which steps to take, what kind of treatment I must get. So I will take it from there. The doctor will tell me which medication should I use or what kind of treatment should I get to cure my cancer. What I know is that cancer is curable if it is found at an early stage.

Researcher: Where would you go to seek for treatment?

P 05: Obviously I would go to the clinic. But I will do it together with prayers and hope for miracle from God.

Researcher: so you know about the importance of early detection.

P 05: Yes (with confidence). This I know with every disease that when it is discovered at an early stage, it can be curable. The problem is that I don't know much about the signs of breast cancer. So I could not be able to recognise then until it is too late.

Researcher: What kind of information do you think will be important for woman in your village?

P 05: Firstly, I would like to know what breast cancer is and how it develops. So I would like all the information about it and its treatment. Information should also include how to conduct self-examination and how often it should be done. Woman should must have the knowledge of conducting breast self-examination. It could help them to detect the growth early. Women must go to the local clinics and ask about this disease, ask their doctors how one could get this cancer. How one could live with this disease and how can they get treatment after examination. I would also like to know how one can move on with her life after been diagnosed with breast cancer. All in all I would like information about the impact it will have on me and my family. I heard also that one can lose their breast. So I would like to know the impact it will have on my physical appearance.

Researcher: How would you like the information to be communicated to the women in the village?

P 05: I would like information to be communicated to me in Tsonga. Sometimes nurses and doctors use medical terms that people don't understand and we end up being confused. The challenge that we have in this community is access to information. Maybe it could be helpful if the government can send mobile clinics to our village; have meetings with the community and inform people about breast cancer. Some information's we get from the newspaper but it is useless because most women are not educated. Some of them don't have radios; some don't know how to read pamphlets on the wall at the clinic. I think if the doctors and nurses can be sent to our communities to teach people about this disease, give them more information, how this disease start, how should the disease be stopped, how can the disease be cured if they find out that they have cancer.

Researcher: what kind of support would you like to get from your family if you were to be diagnosed with breast cancer?

P 05: You know I ..... I think I can get through anything as long as I have the support of my family. I would like all kind of support from them. I would like them to help me to accept the diagnosis by being there for me. If it means that we have to change the diet that we eat, they must be able to do so to accommodate me. I would prefer that they treat me as normal like before. I will not like to be treated like an egg that can break at any point.

Researcher: What role do you think social workers can play?

P 05: when a person is diagnosed, so many feelings come rushing down at the same time. Social workers can provide emotional support through counselling. They can supply information to most people about this disease. Let's say that I just found out that I have breast cancer and I don't know how to handle it, they can help me to accept it. We can also explore coping options that can help me and my family. After finding out about that disease social workers can sit us down and give us information about this disease, how to handle it, how to live your life with the disease, how to take your treatment so that one can have more knowledge about the disease and not live in fear. I would like social workers to also advocate for us to get access to resources and information. What I realised is that people get diagnosed at a later stage because they don't have access to information. However, I would like information to reach women even before they get diagnosed. This can be helpful for when they get diagnosed, they will know what to do.

Researcher: Is there anything that you would like to add that I might have left out?

P 05: I would like to know how this research will benefit us in this community.

Researcher: I am hoping that this study helps you to assess your knowledge about breast cancer. This study may contribute to the knowledge base of social workers on breast cancer especially in rural areas to inform appropriate interventions. I also hope that women in rural areas can be empowered with knowledge that concerns their health and illness prevention and early diagnosis options. As you can see, I have a pamphlet for you that can contribute to your knowledge about breast cancer information and services.

APPENDIX E (III)

TRANSCRIPT FOR KEY INFORMANT

Identifying details: Key informant 2

Occupation: Nurse

Time spent working in the community: 10 years

Researcher: What is your role in this community?

Key informant: I am a professional Nurse. As a nurse my role involves wellness of my patients. Most of the services offered here are based on prevention measures. Due to the lack of resources, we can only offer primary care services. As part of prevention, my role involves raising awareness about preventing diseases and adhering to treatment.

Researcher: Based on your experience, what do women in this community know about breast cancer?

Key informant: Women in this community know very little about breast cancer. This is a rural area where some people still believe in traditional healing. So when they have cancer, they are more likely to associate it with witchcraft. This is the challenge that we face because when they eventually come to the clinic, it is too late. Breast cancer is more likely to be diagnosed at a later stage due to the beliefs that people have in this community. When they bring children for immunisation that is the only opportunity that we get to educate them about their wellness. We

would urge and encourage them to do regular screening and teach them how to conduct self-examination. So I would really really say that there is still a lack of knowledge when it comes to breast cancer. I feel helpless that some still after all our efforts, still don't know how to conduct self-examination despite being taught at the clinics. Most clinics also don't have resources to detect breast cancer. Referral to hospital comes with a challenge of transport money.

Researcher: **What are some knowledge gabs that you observed in your work?**

Key informant: Breast cancer is one of the most serious disease women faces all over. As already mentioned that most people still associate breast cancer with witchcraft, this is what most people know about breast cancer. So they would seek treatment elsewhere instead of coming to the clinic. Sometimes they would associate breast cancer with being a white disease and not a black disease. Sometimes it does not matter how much awareness we raise, we still cannot remove the beliefs that people have.

Researcher: How can these gabs be addressed?

Key informant: Traditional healers play a significant role in the kind of treatment that people in rural areas use. It might be helpful to engage with them and work with them in sending accurate information about breast cancer. The lack of resources in rural area is also a problem. Here at the clinic are not able to diagnose breast cancer and have to refer women to the hospital. This is challenging because most come from poor families where they cannot afford transport money to go there. Having equipment to regular clinical breast examination might help in making women know about breast cancer. It could also be helpful to have CANSA offices in our local hospitals. If we cannot have offices, we could have their members visiting the community twice a year to help raise awareness about breast cancer.

Researcher: What role can social workers play in this community with regard to breast cancer?

Key informant: Social workers have significant role to play in this community. Through counseling they could help eliminate ignorance and negative attitudes people have about white medicine. It is difficult to reach women in this community due to their lack of trust in us. Working

together with social workers could help raise awareness about the importance of early detection and taking the right treatment.

Researcher: How do you communicate with women about their health?

Key informant: We communicate with women about their health when they visit the clinic. Due to lack of resources and shortage of staff members, we are not able to go to the community. This is a concern because I believe that more people could benefit if we visit the community and give them information about their health.

Researcher: What resources are available to help women know about their breast cancer status?

Key informant: We do not have resources to help us with clinical breast examination and we do not have mammograms. When we suspect that a woman have breast cancer, we refer them to the hospital for a diagnosis. We only teach them to be able to do monthly self-examination and encourage that they go to the hospital for a special x-ray that detect lumps in the breast.

Researcher: Is there anything that you would like to add in this study?

Key informant: Women need to make good decisions about screening and prevention and I can only hope that the study helps to raise awareness about breast cancer.

Researcher: I hope so too. Thank you so much for participating in the study.

APPENDIX F: PERMISSION LETT

Shawela Banner for All Nations Miracle Church

P.O. BOX 549
Modjadjiskloof
0835
South Africa

Shawela Banner
For all Nations
Miracles Centre

Assistant Pastor: Mokhobi M.R.
Cell No.: 082 953 6001
E-mail: mokhobirm@gmail.com

RE: GRANTED PERMISSION TO CONDUCT A RESEARCH: TSAKANE TIVANE

1. The above matter refers.
2. Tsakane Tivane, **student number: 0108430v** has been granted permission by the church council of the above-named church to conduct her research within the mothers department.
3. Her research is based on the topic: **To explore the perceptions of women about breast cancer.**

Banking always on your co-operation

Yours sincerely

Mokhobi M.R (Mr)

Assistant Pastor

Signature: ..... **Date:** 18/07/2016

Shawela Banner For All Nations
Miracles Center, Mopani District
2016 -07- 18
Molotoni Area, Assistant Pastor
P.O. Box 549 Modjadjiskloof 0835

APPENDIX G: CLEARANCE CERTIFICATE

SOCIAL WORK
THE SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT (SHCD)

DEPARTMENTAL HUMAN RESEARCH ETHICS COMMITTEE (SOCIAL WORK) CLEARANCE CERTIFICATE

PROTOCOL NUMBER: SW/2/16/8/12

ROJECT TITLE: Exploring the perceptions women have about breast cancer in Bolobedu, Limpopo

RESEARCHER/S: Ms T J Tivani (0108430V)

SCHOOL/DEPARTMENT: SHCD Social Work

DATE CONSIDERED: 12 August 2016

DECISION OF THE COMMITTEE: Approved

EXPIRY DATE: 30 November 2017

DATE: 19/8/16 **CHAIRPERSON:** K Peters

Cc: Supervisor: Dr Ajwang' Warria

DECLARATION OF RESEARCHER(S)

To be completed in **DUPLICATE** and **ONE COPY** returned to the Administrative Assistant, Room 8, Department of Social Work, Umthombo Building Basement.

I/We fully understand the conditions under which I am/we are authorised to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the committee. **For Masters and PhD an annual progress report is required.**

Rnani T-J
SIGNATURE

25/10/2016
DATE

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES