

**CONTRIBUTION OF PSYCHOSOCIAL SUPPORT GROUP IN
IMPROVING QUALITY OF LIFE AMONG FEMALE BREAST CANCER
PATIENTS IN FARAJA, NAIROBI COUNTY-KENYA**

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Palliative Care)of Masinde Muliro University of Science and Technology

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DECLARATION

This Thesis is my original work and has not been presented for a degree or an award in any other university

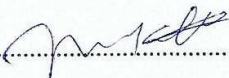
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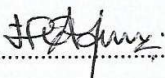
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DEDICATION

I dedicate this thesis to my family with love.

ABSTRACT

Breast Cancer is one of the devastating types of cancer common and most prevalent in women accounting for 23% of all cancers of women globally, Kenya reporting high incidences. After diagnosis, the quality of life (QOL) of women is highly affected, due to the emergence of physical, psychological, spiritual and social effects leading to changes in attitude and expectations towards life. Due to insufficient cancer facilities in Kenya and expenses of the available treatment modalities, majority of the patients can't afford treatment leading to undignified deaths. Psychosocial support group is affordable and has been found to improve QOL among breast cancer patients besides traditional medical procedures. In Kenya, some cancer centers have support groups with patients of different types of cancers, yet there is no research done. The purpose of this study was therefore to investigate the contribution of psychosocial support group in improving the QOL, among female breast cancer patients in Faraja Support Trust, Nairobi County that offers free psychosocial support group specifically for breast cancer patients. Analytical cross-sectional study design where both qualitative and quantitative methods of data collection was used. The study used a validated Quality of Life-Breast Cancer specific questionnaire for quantitative data collection and focus Group Discussion (FGD) for qualitative data. 70 female breast cancer patients participated in the study. Descriptive analysis was done for socio-demographic data and Paired T-test was performed to evaluate the Statistical difference in the variable means for those in the support group and nonsupport for their quality of life. The study results revealed that psychosocial support group was statistical significant in all the four domains of quality of life: with physical domain having a significant mean of 3.0 (95%CI=2.8-3.3) for those in support group contrary to 2.4 (95%CI=2.1-2.7) in non-support group ($p=0.0053$); Psychological well-being having a mean of 2.2 (95% CI = 2.1 – 2.3) for support group compared to a mean of 1.5 (95% CI = 2.1 – 2.3) for non-support group

($p=0.0001$); where social domain was 2.2 (95% CI = 2.1 – 2.3) for support group contrary to mean of 1.7 (95% CI = 1.5 – 2.0) for non-support group ($p=0.0004$) and spiritual domain with 4.2 (95%CI=4.1-4.3) in support group contrary to non-support group mean of 4.0 (95%CI= 3.8-4.1) with a $p=0.05$. The study therefore concluded that, psychosocial support group improved quality of life among female breast cancer patients and recommended that support groups may be integrated in the existing oncology service in all cancer centers across the country.

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LIST OF ABBREVIATIONS AND ACRONYMS

| | |
|--------------|--|
| Acc | Accessed |
| BC | Breast Cancer |
| <i>et al</i> | and others |
| EWB | Emotional Well-Being |
| FGD | Focused Group Discussion |
| FLIC | Functional Living Index-Cancer |
| FWB | Functional Well-being |
| HROQL | Health Related Quality of Life |
| KEMRI | Kenya Medical Research Institute |
| MOH | Ministry of Health |
| MOMS | Ministry of Medical Services |
| MOPHS | Ministry of Public Health Services |
| PCS | Physical Component Summary |
| PWB | Physical Well-being |
| QOL | Quality of Life |
| UICC | Union for International Cancer Control |
| WHA | World Health Assembly |
| WHO | World Health Organization |

CHAPTER ONE

INTRODUCTION

1.1 Overview

This chapter entails the description of the background of the study, statement of the problem, study objectives, research questions, scope of the study, conceptual framework, limitations of the study and operational definitions.

1.2 Background of the Study

Breast cancer is the most common cancer in women worldwide, with 1.7 million new cases diagnosed in 2012; it is the second most common cancer overall worldwide (Ferlay, *et al.*, 2013). Jemal, *et al.*, (2011) in their study indicated that it accounts for about 12% of all new cancer cases and 25% of all cancers in women.

Breast cancer incidence has increased by more than 20%, with mortality rate increasing by 14% globally (Bray, Ren, Masuyer, & Ferlay, 2013). Hayana & Newman who were cited by Mutebi (2014) reports the higher incidence/mortality rate in women on African continent as 1:2 as compared to 1:5 among white American which is attributed to late presentation and lack of follow up.

During breast cancer life journey from diagnosis to end-of-life stage, the life of the patient change as well as their perspectives on and appreciation of life affecting their QoL (Björneklett, Lindenmalm, Rosenblad, 2012a). Tehrani, Farajzadegan, Rajab, & Zamani (2011) commented that almost one third of

patients with cancer suffer from a known psychological problem needing proper intervention as well as socio-emotional supports in each stage of disease.

Boesen,*et al.*, (2011) further express that loss of each or both of the breasts would cause the patient to feel a defect in her body and would change her self-body-imaging. This causes a feeling of loss of not only self-confidence also feminine attraction, leading to anxiety, depression, despair, shame (embarrassment), fear of recurrence of the cancer and death.

Therefore, Lee,*et al.*, (2011) in search of methods to maintain quality of life expresses the importance of social support and defines it as availability of people whom the individual trusts and makes one feel cared for. Globally, studies have been in agreement that formation of psycho-social support groups are considered best approach to help patients cope better with psychosocial consequences of their disease and improve their QoL (Spiegel, Kraeme, Bloom,& Gottheil, 1989; ForsEgil, *et al.*, 2011; Lo, *et al.*, 2015). They provide an expressive forum of peers and have significant association with improved health related quality of life(Lee, Lee, Oh,& Kim, 2013).

According to Anderson, Ganz, Bower & Stanton (2011) women join groups in order to feel less isolated, to learn coping skills, and to obtain information. In as much as psychosocial support has been found to have beneficial effects on the quality of life for breast cancer patients, implementation is still a challenge (Montgomery & McCrone, 2010).

Grassi & Watson (2012) however, reported that in Africa psychosocial support group was still underway as few countries had national cancer plans, and in others, psychosocial support group was not specifically offered except within the context of more, general psychological support. Nevertheless, Selman,*et al.*, (2011) in their study done in South Africa and Uganda acknowledged that psychosocial support was the backbone of patients' quality of life which is the main aim of palliative care.

Kenya Network of cancer organization in their 2015 report, stated that the incidence of breast cancer in Kenya is estimated at 39,000 new cases of Cancer each year with more than 27,000 deaths per year with 60% being below 70years. Due to lack of cancer facilities in Kenya, Nairobi County receives majority of the patients who are referred for both diagnostic and treatment procedure that are only found in four hospitals within the county (MOH, 2013).

As confirmed by Korir, Okerosi, Ronoh, Mutuma,& Parkin, (2015) who said that cancer centers are not evenly distributed as most of them are found within Nairobi.

With the current situation in Kenya, patient may benefit more on psychosocial support however, in as much as psychosocial support group have been implemented in some sites(Nairobi Hospice, Texas Cancer Centre, Aga Khan) that are inclusive of all types of cancers for both men and women; no research has been done to investigate its contribution in improving QOL among breast cancer patients. This spurs the researcher to carry out the study.

1.3 Statement of the Problem

Due to lack of cancer awareness, low economic status, insufficient diagnostic equipments, qualified staff and poor infrastructure, patients seek medical care in late stages of cancer where chemotherapy and other treatment modalities to patients are of minimal help as compared to the need for psychosocial support (Mutuma & Korir, 2006).

Receiving a cancer diagnosis often triggers a strong emotional response. Garssen,*et al.*, (2013) express that although some people experience shock, anger, and disbelief, others may feel intense sadness, fear, and a sense of loss. While, Sharif,*et al.*, (2010) reported that loneliness and isolation are other common feelings because even the most supportive family members and friends cannot understand exactly how it feels to have cancer. Peers have proved to be a good source of information as they share with each other what their experience has been and expected drug side effects (MOPHS & MOMS, 2011).

Grady (2013) observes that many cancer patients die in a devastating state as they encounter few professionals or non to offer them psychosocial support that helps them to cope with the multidimensional effect experienced from the time of cancer diagnosis to end-of-life.

In Kenya, by the fact that Oncology services are majorly within Nairobi, access to care becomes expensive due to travel cost besides increased workload, machine breakdown or professionals having limited time counsel patients, in addition, a patient can take even a year on a waiting list for a procedure (Mutuma *et al.*, 2006).

These constraints have contributed to many clients dying in a very undignified state, with poor quality of life at the end-of-life stage (Ferlay, *et al.*, 2013).

Taking into consideration the current situation of breast cancer patients, its effect on patients' quality of life against many studies that focus on chemotherapy, pain relief, incidence rate (Korir, *et al.*, 2015; Wata, Osanjo, Oluka, & Guantai. 2013; MOH, 2013; Mwangi, Faith, Powell & Richard, 2013), yet none of these studies has been conducted on psychosocial support group for breast cancer patients in Kenya. It is against this background that the current researcher decided to carry out this study. This study therefore intended to investigate the contribution of psychosocial support group in improving quality of life among female patients with breast cancer.

1.4 Purpose of the Study

The study was guided by the following objectives:

1.4.1 Main Objective

The main objective of the study was to investigate the contribution of psychosocial support group in improving the quality of life among female patients with breast cancer attending services in Faraja within Nairobi County.

1.4.2 Specific objectives of the study

The study was guided by the following specific objectives:

- i. To determine the utilization of psychosocial support groups among breast cancer patients in Faraja.
- ii. To compare the health related quality of life (physical well-being, psychological well-being, social well-being and spiritual well-being) among those in support group and those not in support group.
- iii. To examine patients' perception about psychosocial support groups in relation to their quality of life

1.5 Research Questions

The study was guided by the following research question:

- i. What is the psychosocial support group utilization among breast cancer patients in Faraja support Trust?
- ii. What is the difference in the Health related quality of life among those patients attending support group and those not attending support groups?
- iii. What is the patients' feeling and perception about psychosocial support group in relation to their quality of life.

1.6 Justification of the study

World Health Assembly resolution on cancer prevention and control (WHA 58.22) adopted in May 2005 (WHO, 2007) and the Kenya's strategic plan on Cancer prevention and control recognizes psychosocial support care as one of the priority areas in improving the quality of life among cancer patients (MOH, 2013).

Quality of life is the fundamental outcome for all breast cancer patients, yet studies have shown that, majority of them barely report good quality of life (Castro, 2013). Almost one third of the patients with breast cancer suffer from a known psychological problem that affects their quality of life which needs proper intervention as well as socio-emotional support in each stage of the disease (Tehrani,*et al.*, 2011). In as much as studies have reported of medical procedures like chemotherapy, radiotherapy and surgery having a statistical significance in improving quality of life for patients with breast cancer, more specifically on the physical and mental sub-domains, it has no statistical significance on the psychological and social sub-domains (Efunkoya, Adebola, Omeje, Akhiwu,& Osunde, 2015, Tehrani,*et al.*, 2011). Besides, in Kenya, not all patients can access or afford these medical procedures due to the cost implications, inadequate equipment with few oncology personnel among others (Korir *et al.*, 2015). They end up having total pain that leads to undignified death (Saunders, 1978). Psychosocial support group has been found to be affordable and helps breast cancer patients to understand cancer trajectory from peers resulting to positive living with better quality of life (Björneklett *et al.*, 2012a). This has also been found to be a better approach to compliment other medical procedures (Castro, 2013); however, no research has been

done in relation to psychosocial support group and improving of the quality of life among female breast cancer patients in Kenya. This is the gap the present study seeks to fulfill.

1.7 Significance of the Study

The result for the present study may contribute to the body of knowledge for reference by other researchers to help justify psychosocial support group as evidence based practice in improving the quality of life among breast cancer patients; help nurses in providing quality care to female breast cancer patients, where replicable findings may be integrated in the already existing oncology nursing care to improve the quality of life for cancer patients.

The study results may also enable patients in rural areas to find a friendly environment with other peers from the affordable alternative method besides medical treatment in improving the quality of life for female breast cancer patients, with their caregivers giving them opportunity to learn and understand on how to assist and care for the cancer patients.

The finding may help policy makers at all levels from health facility level through County to Country as a whole to avail funding for the implementation of psychosocial support group in collaboration with other developing partners.

1.8 The Scope of the Study

This study was delimited to Breast cancer specific psychosocial support groups in the improvement of health related quality of life for female patients with breast cancer.

This was carried out in Faraja Support Trust within Nairobi County being the only facility with the type of support group within the County.

1.9 Conceptual Framework

The QOL model for cancer patients as proposed by Ferrell (1996) was adopted which consists of four domains (figure 1 below) to include physical, psychological, social and spiritual well-being. Physical dimension infer that the patient can be able to continue with activities of daily living. Patients with breast cancer experience pain from the disease, drug side effects and other symptoms from other co-morbidities that interferes with activities of daily living. Psychological domain emphasizes a sense of control over the disease and its threat to life. Breast cancer patients may undergo surgery and the loose of part of the breast or the whole breast causing changes in the body image as a woman. This and other fears of cost, recurrence or death may cause severe distress affecting the psychological well-being. The Social well-being refers to an individual's ability to re-integrate and maintain meaningful relationships. Due to the disease myths and the body changes, the patients' relationship may be affected leading to social isolation and withdrawal among others. Whereas the spiritual domain requires that an individual maintains hope and an understanding of their disease. Breast cancer diagnosis makes a patient to have many questions to God of why me? Others may realize that all their hope is in God as they may not live for long. They are these domains that are thought to be influenced by Breast cancer specific support group where the peers share their life experience that may directly influence the disease perception and subsequent change in behaviour

and coping mechanism in a unique way causing effect on the quality of life of a patient.

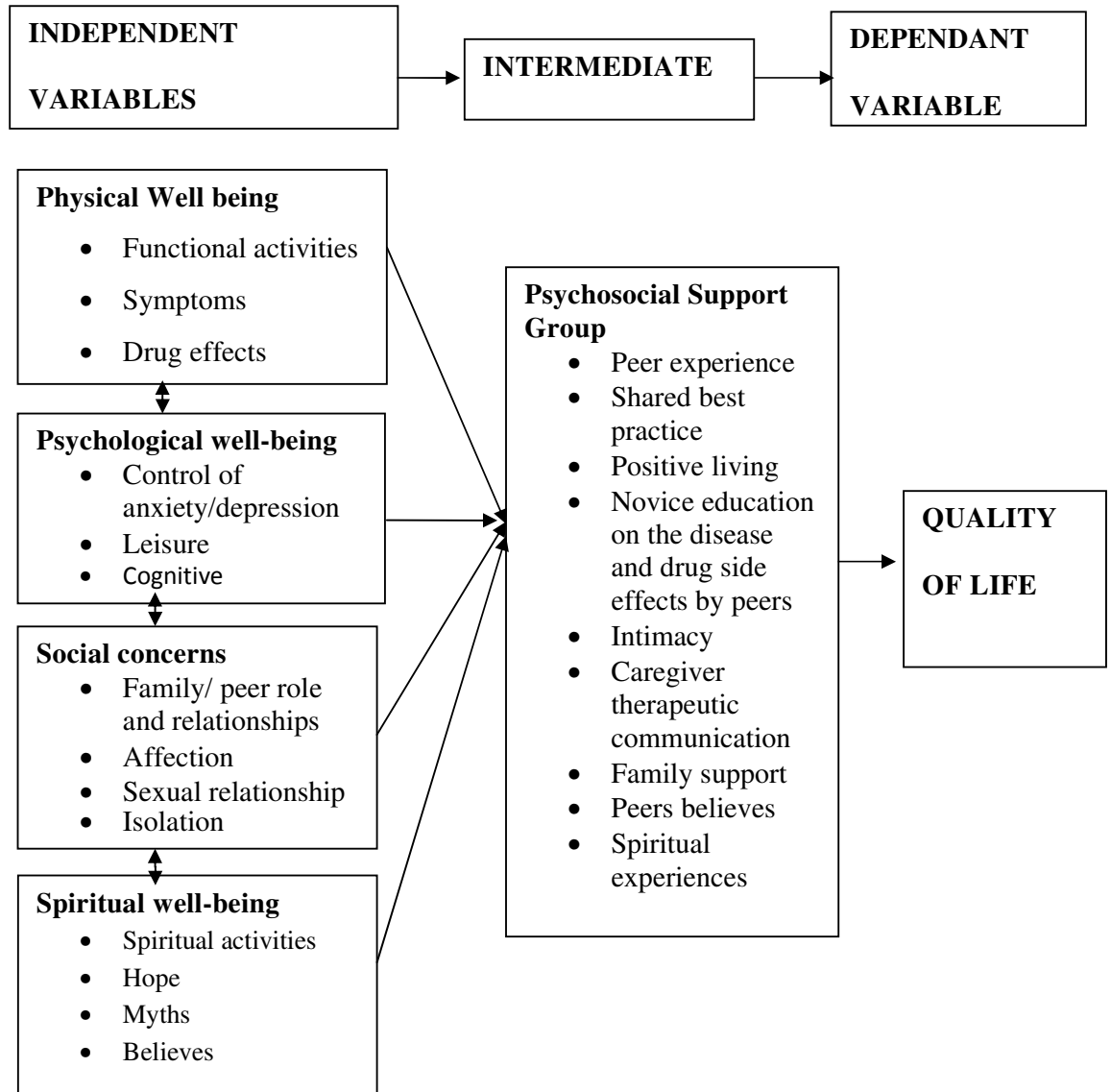


Figure 1.1 Conceptual frame work showing interaction among variables in breast cancer patients

□

1.10 Limitations

The limitations of the present study included study design which was cross sectional and result was only done one at a time.

Sampling technique that was mainly purposive and convenient sampling.

Limited choice for study area as Faraja was the only place with breast cancer specific support group.

The sample size that was small as they were the only patients that received services in Faraja.

1.11 Operational Definition of Terms

A malignant tumor is a group of cancer cells that can grow into (invade) surrounding tissues or spread (metastasize) to distant areas of the body”.

Breast Cancer is a malignant tumor that starts in the cells of the breast in this study will be specific to the female breast tissue.

Cancer Centres: these are health facilities with specialized professional and equipment for cancer diagnosis, treatment, rehabilitation and end-of-life care.

Domains of QOL: It will include the areas of well-being as defined by WHO in assessing QoL that will comprise of; Physical well-being, Spiritual Well-being, Psychological Well-being and Social Well-being

Hospice care is an approach which improves the quality of life of a terminally ill, chronically or seriously ill person. This achieved by attending to the emotional needs. The goal of the care is to help people who are dying have peace, comfort and dignity.

Palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family.

Psychosocial Support Group is a group of people in similar life situations who meet on a regular basis in a formal organized way to share their concerns as it is a safe place to exchange ideas about how to handle difficult issues.

Quality of life meant an individuals' perception of their own position in life within the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns while focusing on the health related four domains of physical, Psychological, Social and Spiritual.

Total Pain: it is a multidimensional nature of the palliative pain experience to include physical, psychological, social and spiritual domains.

CHAPTER TWO

LITERATURE REVIEW

2.1 Overview

The purpose of the study is to investigate psychosocial support in improving the quality of life among patients with breast cancer in cancer centers. This chapter presents the review of literature divided into four sections to include psychosocial support group utilization rate by patients and quality of life, psychosocial support group in improving quality of life among breast cancer patients lastly, patients feeling and perception about psychosocial support groups in relation to their quality of life.

2.2 Breast Cancer and Patients' Quality of Life

Whether surviving a longer or shorter time, all women with breast cancer and their families, are not only living with uncertainty about the future, the burden of treatment, and the threat of dying, but also dealing with the existential, emotional, social and psychological difficulties their situation brings (Mustafa, Carson-Stevens, Gillespie, & Edwards 2013).

The patients end up depressed because of the deterioration of daily activities of living, low self-esteem due to change in the body image, physical, spiritual and psychological pains, and in search of a listening ear and knowledge about the disease from a trustful person (Garssen *et al.*, 2013).

2.2.1. Psychosocial Support Group

Antonia (2014) defines support group as group of people in similar life situations who meet on a regular basis to share their concerns as it is a safe place to exchange ideas about how to handle difficult issues. Members can meet regularly in person, by telephone, or online. Consequently, Tehrani *et al.*, (2011) pointed out different approaches, methods and condition including educational or peer group to help patients defeat the fear of the unknown future and of death by sharing their experience.

Alagraa, Abujuber, Chandra,& Daughty, (2015) Quoting Palsson&Norberg 1995, Pistrang& Barker 1995, Levy &Schain 1988, Neuling&Winefield 1988, Northouse 1988, reported that informal social support and education from fellow patients, family members, and the health care team influenced adaptation to breast cancer. Formal support groups designed are based on the premise that patients with cancer benefit from contact with other cancer patients through mutual social support.

Union for International Cancer Control (UICC) (2011) states that support groups have measurable benefits in improving the coping and adaptation of members, reducing distress and levels of depression and enhancing self-esteem. They added that participants reported benefits such as hope, encouragement and reassurance; the opportunity to exchange information with peers and improve cancer-related knowledge; reinforcement of the normalcy of reactions and a sense of belonging.

In Africa, partners have made it possible in some African countries for the implementation, maintenance and funding of support groups, with HIV/AIDS support

groups being best practice in most African countries (Mutebi, 2014). However, in most regions psychosocial oncology is not specifically offered except in a much more general psychological support (Grass & Watson, 2012).

In East Africa, Uganda breast cancer women embraced support group idea and utilize it even to educate the community in the importance of early screening and giving testimony (Jack, Kirton,&Birakuraki, 2013) which has had great impact on improving QOL and positive living for the survivors.

In Kenya Wata, Osanjo, Margaret, & Guantai, (2013) acknowledges the longer survival period for patients diagnosed with incurable malignancies due to scientific advances. However, the myriad options for treatment have established a culture of cancer care that has not been matched with a similar availability of efficacious supportive care interventions aimed at relieving debilitating symptoms due to progressive disease (MOH, 2013).

Owing to the fact that Cancer care facilities are mostly within Nairobi (Korir,*et al.*, 2015) there is minimal psychosocial support intervention being implement due to increased work load by few available oncologists and counselors and lack of access to the services due to long distance from the patients' residence, lack of linkage and travel expenses among other factors.

The inadequate facilities are stipulated in the report by the Kenya Network for Cancer Organization (Acc. 28thAug. 2015) where only Ten facilities established palliative care among the twenty-six offering oncology care mostly offering medical

treatment which is expensive and most patients can't afford. Five (half) located within Nairobi County.

2.2.2 Quality of life among breast cancer patients

The World Health Organization (WHO) defines quality of life as “an individual perception of their own position in life within the context of the cultural and value system in which they live and in relation to their goals, expectations, standards and concerns” (WHO, 2004); this concept is consistent with the definition of health in the same organization, incorporating physical, psychological, level of independence, social relationships, environmental, and spiritual areas. This definition means that the quality of life is a subjective assessment and stresses that it can only be improved if incorporated into the cultural, social and environment life of that person (Castro, 2013).

UICC (2011) enumerates that understanding and responding to the full impact of cancer on emotional, mental and physical wellbeing will maximize the quality of life for patients, their families and careers. Castro (2013) observes that QOL is considered an essential outcome variable and is conceptualized according to a system of values, standards or perspectives that vary from person to person, from group to group and from place to place. So, the quality of life is the sense of well-being that can be experienced by people and represents the sum of objective and subjective personal feelings (Mowry & Wang, 2011).

In African context, QoL is understood as feeling at peace and having a sense of meaning in life rather than just being active or having physical comfort and spiritual

wellbeing as all is attached to community relationship (Selman, *et al.*, 2011). Greater social or emotional support was associated with better QOL in the study carried out by (Mowry *et al.*, 2011).

Because there is no single definition of QOL, the operational definition in this study that focuses on the four aspect of quality of life will be used. The researcher will use the Quality of Life Instrument-Breast Cancer Patient Version revised by the National Medical Center and Beckman Research Institute that contains a forty-six item ordinal scale that measures the Quality of Life of a breast cancer patient (Ferrell & Grant, 2003).

2.2.3 Psychosocial support groups and the quality of life for patients with breast cancer

MOH (2013) acknowledges the fundamental aspect of palliative care as a genuine commitment to whole-person care, including managing patients' physical, psychological, and spiritual distress, thereby seeking to preserve patients' quality of life in cancer journey.

Globally studies have shown that psychosocial therapies have a positive impact on emotional adjustment, HRQoL, psychological distress and coping skills among patients with breast cancer (Mowry,*et al.*, 2011; Jacobsen, 2012).

In Africa, Mutebi (2014) who cited Ferrell, (1996) pointed out that HRQOL may be determined by the health, professional and family environment. These factors may be further modified as a result of the disease and its treatment (Montazeri, 2008). QOL plays a very important role in breast cancer survivors and the overall physical,

psychosocial and spiritual considerations need to be addressed. Physical limitations, such as the impaired ability to return to work, and psychological distress and uncertainty over the future, have implications on the individual's QOL (Kwan,*et al.*, 2010).

Masika, Wettergren, Kohi,& Essen (2012) observed that patients do receive overwhelming volume of information from informal social support which is sometimes contradictory, plus physicians giving a lot of information due to limited time of consultation and fear of loss to follow up. This is contrary to achieving the goal of "Putting life into their days, not just days into their life" (Patt, 1996).

In addition, Kenya MOPHS & MOMS (2011) states that palliative care should be provided not instead of traditional medical oncology care, but in collaboration with all appropriate active cancer treatment, from the moment of diagnosis or even before diagnosis through the remainder of the patient's disease trajectory.

2.3 Utilization of psychosocial support groups among breast cancer

Patients

Ursaval, Karayurt, & Iseri (2014) in implementing Roys' Model of adaptation states that an individual takes time to cope with self-concept and group identity as the diagnosis comes with denial, fear of death and stigma. This may contribute to not joining of a support group.

Uden-Kraan, *et al.*, (2011) reported that although peer-to-peer contact might empower patients in various ways few patients actually engage in support groups. They found out that only a minority (10% -65/679) of the patients engaged in

organized forms of peer support. Björneklett *et al.*, (2012a) in turn commented that cancer patients who actually accepted participation in the support groups were those who had a higher degree of distress; also female, younger, more highly educated and of a higher economic status. However, Björneklett, *et al.*,(2012b) reported of the great awareness by patients about the support groups.

Grass *et al.*, (2012) agreed with the issue of non-participation as much as psychosocial interventions was effective in improving patients' health related quality of life and reducing health systems costs, by reducing psychosocial complication. Consequently, Björneklett *et al.*, (2012a) observed that many patients preferred not to participate due to other engagements in their lives to which they assigned higher priority.

2.4 Patients' perception about psychosocial support group in relation to their quality of life

Breast cancer diagnosis has different implications on the unique feelings and experience of patients. Patient perceived perceptions of psychosocial support are increasingly important to understanding appropriate holistic patient-centred care (Alagraa,Abujabei, Chandra, & Doughty, 2015). Consequently, Krippendorff (1998) in his exceptional study on perception of women with breast cancer had observed that women often feel as though they do not receive the emotional support that they need from their personal relationships.

Ussher, Perz, Gilbert, Hawkins,& Wong, (2012) highlighted that though women may have many supportive individuals around them; they are often discouraged from

expressing feelings of fear, anxiety, and thoughts of death to others. This often leads to seeking additional support in the form of support groups. In an interview, a breast cancer patient related the comfort they receive by being able to speak to others who have similar concerns as a contributory factor to a feeling of acceptance (Mowry, *et al.*, 2011).

Consequently, some feel that there are still a number of barriers to attaining optimal psychosocial health care to include stigmatization, reduced awareness of available resources, or an inability to access them; lack of knowledge, skills, and information necessary to manage the disease and its treatment; poor communication between patients and their health care providers; poor communication among health care professionals; and physical and financial barriers (Chabner, Efstathiou, & Peterson, 2013).

UICC (2011) recognizes that in many cultures and society today cancer remains a taboo issue and people living with cancer are subject to stigma and discrimination that may stop them from seeking care. Whereas, Greenlee, *et al.*, (2014) pointed out those physiologic effects of some cancer treatments, such as impaired fertility, sexual dysfunction, hair loss and weight gain result to stigma and discrimination and in some cases can be the cause of partner rejection and depression.

In sub-Saharan Africa, patients often present with advanced disease. Limited health-care infrastructure exists, and few personnel are available for the care of patients. Surgeons are often central to cancer care in the region, since they can be the only physician a patient sees for diagnosis, treatment (including chemotherapy,

radiotherapy or surgery) as a result psychosocial support not being given priority or not known by patients (Kingham,*et al.*, 2015).

In Kenya, Mutebi (2014) in his study reports that, patients face unique challenges in coping with breast cancer due to the low-resource settings, and not only do they have to deal with the emotional impact of a cancer diagnosis being incurable and subsequent loss of hope, but also with the additional constraints of poverty, lack of access to care and dependence on their partners for financial support.

CHAPTER THREE

METHODOLOGY

3.1 Overview

This chapter described the methodology that was used. It dealt with the description of the research design, study area, study population, sample size determination, sampling technique, inclusion and exclusion criteria, data collection instruments, data quality control, data analyses, data presentation method, ethical considerations, study limitations and dissemination of results.

3.2 Research Design

Analytical cross sectional study design where both qualitative and quantitative methods of data collection was used. According to Polit & Hungler, (1999) defines analytical study design as a test done between groups of subjects to compare the magnitude of association between the exposure and outcome, while cross sectional is research done at a point in time. The researcher therefore presented the phenomena under investigation as they are. The independent variable considered in this study was Physical, Psychological, Social and Spiritual well-beings, Intermediate variable being psychosocial support group while the dependent variable was health related quality of life among female breast cancer patients. Analytical research design was considered appropriate for this study because it makes inferences about a large group of people from data drawn on a relatively small number of individuals from that group (Mugenda & Mugenda, 2003).

3.3 Study Area

The study was conducted in Faraja Support Trust, Nairobi County. The County is a large cosmopolitan centre located in the Central Highlands of Kenya. It stretches itself across 684 Km² of land and lies adjacent to the eastern edge of the Rift Valley and is situated 5450 ft (1661 metres) above the sea level. This County hosts Kenya's political, commercial and industrial capital. It borders Kiambu County to the North and West, Kajiado to the South and Machakos to the East (Appendix VII). It lies between longitudes 36° 45' East and latitudes 1° 18' South with a population of 3,138,369 (1,605,230 males and 1,533,139 females) as per the 2009 census (Korir *et al.*, 2014). Faraja is a non-profit making facility that was started by a breast cancer survivor who dedicated her services to make cancer known to people and offer free complementary and alternative cancer services to all patients. The researcher had the aim of only sampling the cancer center with breast cancer specific support group, within Nairobi County that could offer a more open forum. Only Faraja Support Trust was found to be having these support groups. It is located on the 1st Floor, Cancer Care Kenya Building, next door to MP Shah Hospital Chemotherapy department, on Shivachi Road, Parklands in Westland Nairobi and serves patients from the entire County (Appendix VII).

3.4 Study Population

The study population consisted of all female breast cancer patients from Nairobi County estimated at 1154 as per Nairobi Registry, however, Cancer statistics in Kenya was scanty and mainly hospital based with only a few cancer facilities contributing to the registry (Korir *et al.*, 2012). This could not give a true

approximation of the study population. Faraja Support Trust was among the facilities that contributed to the registry with their breast Cancer patients at the facility being 102 at the time of study. This numbers were therefore used to adjust calculated sample size.

3.5 Sampling Techniques and Sample size

3.5.1 Sampling Techniques

The researcher used mixed sampling technique where purposive sampling technique was used in choosing the Cancer care facility with breast cancer specific support group. Since little was known in Nairobi registry about those facilities having Breast cancer specific support group within the County, the researcher moved to all cancer centers within Nairobi County to verify those with the groups, In as much as Nairobi Hospice, Texas and Aga Khan had support groups, patients with all types of cancers both male and female attended the same support group, apart from Faraja that had breast cancer specific support group making it the only facility sampled. Convenient sampling method was then used to get study participants where by all breast cancer patients who came for services within one month and consented to the study were interviewed. This was due to the small number of active patients.

3.5.2 Sample Size Determination

Considering that the target population was not static, the researcher employed the formula by Fisher *et al.*, (Fishers & Geiselman, 1989) to give the approximate sample size.

$$n = \frac{z^2 pq}{d^2}$$

Where

z = standard normal deviate usually set at 1.96

n = desired sample size in an infinite population

p = sample proportion (not known) set at 0.5

$q = (1 - p) = 0.5$

d = the degree of accuracy set at 0.05.

Therefore, the minimum estimated sample size was

$$= \frac{1.96 \times 1.96 \times 0.5 \times 0.5}{0.05 \times 0.05} = \frac{0.9604}{0.0025} = 384.16 = 384$$

Since the estimate of the population size in Faraja was 102 (n_o), sample size was corrected as follows:

$$nf = \frac{n_o}{1 + \{(n_o-1)/N\}}$$

n_o = the desired sample size when the population is less than 10,000

nf = the desired sample size when the population is less than 10,000

N = the estimate of the population size (Mugenda, *et al.*, 2003. Pg 44)

$$nf = \frac{384}{1 + \{(384-1)/102\}} = 81$$

However, only 80% (70) of the total sample size were interviewed as some patients had passed on and others were ill and excluded from the study at the time of data collection.

3.6 Inclusion and Exclusion Criteria

3.6.1 Inclusion criteria

The researcher included;

- ▶ All female breast cancer patient attending services at Faraja from 1st to 28th June 2016.
- ▶ Those in support group meant only those who had attended at least three support group meetings while those in nonsupport group were only receiving standard care or other complementary treatments for at least three months and still active on care.

3.6.2 Exclusion Criteria

The following patients were excluded from the study;

- ▶ Critically ill patients or in severe pain
- ▶ Those with a mental disorder and couldn't concentrate or comprehend questions

- ▶ Those in denial stage, which mentioning the diagnosis provoked psychological pain even tearing.

3.7 Data Collection Instruments

For the purpose of data collection, this study used questionnaires and Focus Group Discussion (FGD) guide.

3.7.1 Questionnaire for Breast Cancer Patients

Questionnaire is a form distributed through the mail or filled out by the respondent under the supervision of the researcher or the interviewer (Mugenda,*et al.*, 2003).

The Quality of Life Instrument (CANCER PATIENT/CANCER SURVIVOR VERSION) is a forty-one-item ordinal scale that measures the Quality of Life of a cancer patient was adapted (Appendix II).

The participant was asked to read each question or be read for and decide if he/she agrees with the statement or disagrees. She was then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale. The scoring was based on a scale of 0 = worst outcome to 10 = best outcome. Several items had reverse anchors and therefore while coding these items, reverse of the scores was done. For example, if a subject circles "3" on such an item, $(10-3 = 7)$ thus it was recorded as score of 7. The items that were reversed were: 1-7, 9, 16-27, & 29-34 and 38. Subscales were created for analysis purposes by adding all of the items within a subscale and creating a mean score. The QOL instrument was based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This instrument was revised in cancer survivorship studies and included 41

items representing the four domains of quality of life including physical well-being, psychological well-being, social well-being and spiritual well-being. 70 questionnaires were distributed with 100% response rate.

3.7.2 Focus Group Discussion (FGD)

Stewart & Shamdasani (1990) defines FGD as in-depth, group interviews with a small number 6 to 10 of carefully selected people, who usually have similar characteristics (such as gender, age, ethnicity etc). FGDs were used as it was suitable for obtaining data on group perception towards psychosocial support group and their quality of life. It was also effective in bringing to the surface issues with health significance that was considered sensitive and/or controversial by some informants, yet vital for the study results. In this study, breast cancer was a very sensitive condition that had very strong impact on the psychological, social, physical and spiritual well-being. Two focus group discussion session were done with the help of Guiding questions were used during the FDG (See Appendix III for FGD guide).

3.8 Pilot Study

Pilot study was conducted among female breast Cancer patients attending psychosocial support meetings in Kenyatta National Hospital. A total of 10 patients from the target population (10% of the minimum population for the study sample) who met the inclusion criteria for the study were included in the pilot. They completed the preliminary survey and gave individual feedback about the content, wording, clarity and the estimated timing to complete it. After this pilot test, the survey tools were revised and edited based on the patients' observations (Jacobsen, 2012). Testing of validity and reliability was as follows;

3.8.1 Validity of the Research Instruments

Validity refers to the issue of whether an indicator (or set of indicators) that are derived to gauge a concept really measure that concept (Polit & Beck, 2010)

In order to ensure validity, the researcher with the assistance of supervisors and experts from the school of Nursing, Midwifery and Paramedical Sciences of Masinde Muliro University of Science and Technology, ensured that the data collecting instruments had questions that included all the elements of the subject. These questions were to fit into the conceptual framework of the study (pg. 8 No. 1.9). The researcher also ensured that the scope was wide enough and the intent of the questions clearly indicated. This was necessary so that the respondents do not omit any part of the responses through lack of certainty as to what the question requires.

3.8.2 Reliability of the Research Instruments

Mugenda, *et al.*, (2003) define reliability as a measure of the degree to which a research instrument yields consistent results or data after repeated trials. The QOL Breast Cancer instrument used in this study had been tested for reliability and internal consistency using Cronbach's alpha coefficient as a measure of agreement between items and subscales which had good overall reliability of $r=.93$. Subscale alphas ranged from $r=.71$ for spiritual well-being, $r=.77$ for physical, $r=.81$ for social, and $r=.89$ for psychological well-being.

For the additional questions, the researcher with the help of the supervisors critically assessed the consistency of the responses from the pilot questionnaire that demonstrated consistency in the answers that the participants gave.

3.9 Data Collection Procedure

The researcher obtained a letter of introduction from the school of Graduate studies which was used to procure study permit from the National council for research and Technology. Consent was sought from the principal's office of Faraja Support Trust upon which the date was fixed for the exercise. The researcher planned, selected and trained appropriate research assistants from the facilities who were known to the patients. The information was written and put on the notice board informing the staff and patients about the one-month data collection period from 1st to 28th June, culminating with a support group meeting which had been planned for 28th June 2016. On the agreed date of the support group meeting, the participants assembled at Faraja meeting hall that was their usual meeting place. The researcher then personally administered questionnaire to those who had not filled and explained on how to fill. Research assistant helped those participants who needed help on how to fill or rate responses. Once the questionnaire was fully completed, support group participants were divided into two groups to form FGD which was recorded and later transcribed.

3.10 Data Analysis

Data was entered and coded for the categorical data (nominal and ordinal) created. In cleaning of data, if more than 20% of the domain information/data in the QOL-Breast Cancer instrument missed from an assessment, it was discarded. Only those domains with a minimum of 80% of the items answered were analyzed. If more than two items missed from the domain, the domain score was not calculated (with exception of question 3, where it was only calculated if ≤ 1 item is missing).

Descriptive statistics that is; the mean, standard deviation and percentages; were used to analyze demographic characteristics of the sample. Two sided T test was performed to evaluate the statistical difference between the variable means of those in support group and those in non-support group on their quality of life. Statistical analyses were set at 0.05 error margin with 95% confidence intervals (CIs). Data analyses were conducted using the SPSS version17.0 (SPSS Inc., Chicago, USA). A p-value less than 0.05 were considered statistically significant.

Qualitative data obtained from the FGD was analyzed using a deductive approach where the recorded data was transcribed as per the study guide questions that addressed the four domains and way forward.

3.11 Ethical Considerations

The study involved human respondents and therefore, certain ethical issues were considered. This included: Privacy, Confidentiality, Safety, Autonomy, Justice, Beneficence and non-maleficence.

The researcher adhered to ethical and legal guidelines for the conduct of research and ensured human rights are safeguarded. An approval was sought to conduct the study from the Institution and Research Ethical Committee (IREC) of Masinde Muliro University of Science and Technology. Selection of the participants was based on ethical principle of justice that enhances fair treatment of subjects where all patients with breast cancer attending services at Faraja Support Trust had a chance of being selected. The respondents were ensured of confidentiality and that no information given would be shared with unauthorized person but be used for the purpose of the

study only. The respondents' participation was voluntary with no coercion and their consent sought to conform to the principle of respect of persons. The respondents had a right to stop answering the questionnaire without any negative consequences. Questions asked were put in consideration of patients' dignity, integrity, and vulnerability during interviews and focused group discussions. The researcher intended to utilize the findings collaboratively to benefit the study population. The principle of Justice was applied where all the study population had an equal chance to participate in the study. The researcher sought permission from the Ministry of Health Nairobi county and subsequent administrations within the study area (See appendices IV, V & VI for approval documents).

3.12 Dissemination of Results

The study reports were first given to the university's School of Graduate Study board and Research and Ethics committee. A soft copy of the findings was also sent to Faraja Support Trust to be availed for all breast cancer patients and management from whom were encouraged to read and comment on them. In addition, the researcher also plans to meet them face-to-face for feedback. After the comments, the article was then published by the International Journal for Innovative Research and Advanced Studies (IJIRAS) on an open access where it was subjected to peer review in order to meet international standards. The full soft copy of the study will also be availed to the University's library to be uploaded to the website for future referencing. These findings will be presented to the national and international conferences in order to share the new knowledge and enhance the implementation process of the study recommendations.

Six hard-copies were printed and distributed as follows; a copy for the researcher, a copy to the research and ethics committee, Masinde Muliro University of Science and Technology- to the faculty School of Nursing and midwifery and Paramedical Sciences, a copy to the MMUST Library, a copy to the research supervisor, a copy to Nairobi County research committee and a copy to the head of department, Clinical Nursing.

CHAPTER FOUR

PRESENTATION OF THE RESULTS

4.1 Overview

This chapter presents the study results on: Socio-demographic data, Prevalence of utilization of psychosocial support group, comparison of the QOL among those in support group and those not in the support group and perception of Breast cancer (BC) patients about the psychosocial support group.

4.2 Socio-demographics

The purpose of the study was to investigate the contribution of psychosocial support group in improving the quality of life among female breast cancer patients attending services in Faraja within Nairobi County. A total of 70 female breast cancer patients consented and participated in the study. This was only 80% of the intended sample size as 10 of the legible participants had declined the survey reporting that they were very weak and could not manage responding to the questionnaire while others had passed on. Being that there was no data about those in the support group or those in non-support group, a question was asked that helped identify those in these groups. Among them, a total of 54 (77.1%) respondents were in the support group while 16 (22.8%) were in the non-support group.

The study sought to establish the demographic information of the respondents including their age, level of education, household income and number of people in the household. Table 4.1 below shows the demographic characteristics of

respondents. Half of those in support group were aged between 30-49, as compared to 6 (37.5%) in non-support group whom majority were older and aged between 50–69 years (43.8%). Results also showed that more than three-quarters (76.9%) of the support group respondents had attained tertiary/higher education in contrast to 68.8% in the non-support groups falling in the same category. Household income was comparable for the majority of support group (64.8%) and non-support group (62.5%) and was at least Ksh. 10,000 and above. While three-quarters (77.8%) of those in the support group reported household membership of at least three members and more, 100% of respondents in the non-support group had similar number of household members.

Table 4.1: Socio-demographic characteristics of respondents

| Variables | Categories | Support Group | | Non-support group | |
|------------------------------------|---------------------------|---------------|--------------|-------------------|--------------|
| | | N | % | N | % |
| Age group in years | 20 – 29 | 2 | 3.7 | 1 | 6.2 |
| | 30 – 49 | 27 | 50.0 | 6 | 37.5 |
| | 50 – 69 | 25 | 46.3 | 7 | 43.8 |
| | >=70 | 0 | 0.0 | 2 | 12.5 |
| | Total | 54 | 100.0 | 16 | 100.0 |
| Level of Education | Primary | 2 | 3.7 | 5 | 31.2 |
| | Secondary | 12 | 19.4 | 0 | 0.0 |
| | Tertiary/Higher Education | 40 | 76.9 | 11 | 68.8 |
| | Total | 54 | 100.0 | 16 | 100.0 |
| Household income per month in KSh. | <5,000 | 10 | 18.5 | 6 | 37.5 |
| | 5,000 – 9000 | 9 | 16.7 | 0 | 0.0 |
| | >=10,000 | 35 | 64.8 | 10 | 62.5 |
| | Total | 54 | 100.0 | 16 | 100.0 |
| Number of household members | 1 | 6 | 11.1 | 0 | 0.0 |
| | 2 | 6 | 11.1 | 0 | 0.0 |
| | >=3 | 42 | 77.8 | 16 | 100.0 |
| | Total | 54 | 100.0 | 16 | 100.0 |

4.3 Year of diagnosis, types and number of treatments received

Among support group respondents, half of them were diagnosed between 2010-2014 (50%) followed by 2015 – 2016 (46.3%) as illustrated in table 4.2 below. More than half (56.2%) of those in non-support group were diagnosed between 2015 – 2016. A multiple response question was asked for the type of treatment received and the findings revealed that, Chemotherapy was the most common treatment received by those in support group (34.2%) and non-support group (37.2%). Opioids and alternative medicine were less frequently received by the support group with each attributing to 9% and 5.8% for the support group and 7% and 2.3% for the non-support group respectively.

Table 4.2: Year of diagnosis and types and number of treatments received

| Variables | Categories | Support Group | | Non-support group | |
|----------------------------|----------------------|---------------|--------------|-------------------|--------------|
| | | N | % | N | % |
| Year when diagnosed | 2000 – 2004 | 2 | 3.7 | 2 | 12.5 |
| | 2005 – 2009 | 0 | 0.0 | 0 | 0.0 |
| | 2010 – 2014 | 27 | 50.0 | 5 | 31.3 |
| | >=2015 | 25 | 46.3 | 9 | 56.2 |
| | Total | 54 | 100.0 | 16 | 100.0 |
| Type of treatment received | Radiotherapy | 40 | 25.8 | 13 | 30.2 |
| | Chemotherapy | 53 | 34.2 | 16 | 37.2 |
| | Surgery | 39 | 25.2 | 10 | 23.3 |
| | Opioids | 14 | 9.0 | 3 | 7.0 |
| | Alternative medicine | 9 | 5.8 | 1 | 2.3 |
| | Total | 155 | 100 | 43 | 100.0 |

4.4 Support group and other forms of Social support

As is illustrated in table 4.3 below, 98.1% of support group respondents were interested and benefited from a support group unlike those in the non-support group that less than two-thirds (62.5%) expressed the same interest or benefit. In the latter group, 83.3% who were not interested in a support group were receiving other forms of social support. The commonsocial support type was found to be support from family and friends (66.7%).

Table 4.3: Support group and other forms of social support

| Variables | Categories | Support Group | | Non-support group | |
|---|-----------------------------------|---------------|--------------|-------------------|--------------|
| | | N | % | N | % |
| Interested and benefiting from a support group | Yes | 53 | 98.1 | 10 | 62.5 |
| | No | 1 | 1.9 | 6 | 37.5 |
| | Total | 54 | 100.0 | 16 | 100.0 |
| Not interested but receiving social support elsewhere | Yes | 1 | 100.0 | 5 | 83.3 |
| | No | 0 | 0.0 | 1 | 16.7 |
| | Total | 1 | 100.0 | 6 | 100.0 |
| Other forms of Social Support received by those who reported not interested in the support group. | Family and friends | 1 | 100.0 | 4 | 66.7 |
| | Religious guidance and counseling | - | - | 2 | 33.3 |
| | Total | 1 | 100.0 | 6 | 100.0 |

4.5 High and low household's income by physical, psychosocial, social and spiritual well-being dimensions

A two-sided t-test was performed to test the general effect of household income on the four domains as illustrated in Table 4.4 below. A total of 70 participants reported to it to assess the general impact. The findings showed that there was a significant difference between the means of high household income (KSh. 20,000 and above) and low household income (Less than KSh. 20,000) using the four domains: physical, psychosocial, social and spiritual well-being as outcomes. Households with higher income had a higher mean outcome in psychosocial well-being of 2.2 (95% CI = 2.1 – 2.4) compared to a mean of 2.0 (95% CI = 1.8 – 2.1) of the low income group (p = 0.018); similarly, the former group did well in the social domain where they scored a mean of 2.3 (95% CI = 2.1 – 2.5) versus a mean of 1.9 (95% CI = 1.7 – 2.1) for the low income group (p = 0.0145). There were no significant associations between income for the two groups and physical or spiritual well-being.

Table 4.4: General effect of households' income on the physical, psychosocial, social and spiritual well-being

| Dimensions | Group | N | Mean | SD | df | t-test | 95% CI | P value |
|--------------------------|----------------------|----|------|-----|----|--------|-----------|---------|
| Physical | Income \geq 20,000 | 31 | 3.1 | 0.8 | 68 | 2.1 | 2.8 – 3.4 | 0.38 |
| | Income < 20,000 | 39 | 2.7 | 0.9 | | | 2.4 - 3.0 | |
| Psychological well-being | Income \geq 20,000 | 31 | 2.2 | 0.4 | 68 | 2.4 | 2.1 – 2.4 | 0.018 |
| | Income < 20,000 | 39 | 2.0 | 0.5 | | | 1.8 – 2.1 | |
| Social | Income \geq 20,000 | 31 | 2.3 | 0.6 | 68 | 2.5 | 2.1 – 2.5 | 0.0145 |
| | Income < 20,000 | 39 | 1.9 | 0.7 | | | 1.7 – 2.1 | |
| Spiritual | Income \geq 20,000 | 31 | 4.1 | 0.5 | 68 | 0.4 | 3.9 – 4.3 | 0.7 |
| | Income < 20,000 | 39 | 4.1 | 0.3 | | | 4.0 – 4.3 | |

4.6 Survival years after diagnosis and the four domains of physical, psychosocial, social and spiritual well-being.

A general analysis was made between all respondents who were tested at least two years and those tested less than two years prior to the study. Those tested at least 2 years or more experienced less social problems as confirmed by a mean of 2.2 (95% CI = 2.0 – 2.5) in contrast to a mean of 1.9 (95% CI = 1.6 – 2.1) of those who had taken less than two years after being tested (p = 0.0257). No significant relationship was reported for the physical, psychosocial and spiritual well-being, suggesting that none of the two groups was better than the other in the three domains analyzed.

Table 4.5: Survival years after diagnosis and the four domains of physical, psychosocial, social and spiritual well-being

| Dimensions | Group | N | Mean | SD | Df | t-test | 95% CI | P value |
|---------------------------------|----------------------|----------|-------------|-----------|-----------|---------------|---------------|----------------|
| Physical | < 2 years | 34 | 2.8 | 0.9 | 68 | 0.9 | 2.5 – 3.1 | 0.189 |
| | >= 2 years | 36 | 3.0 | 0.7 | | | 2.7 – 3.2 | |
| Psychological well-being | < 2 years | 34 | 2.1 | 0.5 | 68 | 0.6 | 1.9 – 2.3 | 0.547 |
| | >= 2 years | 36 | 2.1 | 0.3 | | | 2.0 – 2.2 | |
| Social | < 2 years | 34 | 1.9 | 0.7 | 68 | 2.3 | 1.6 – 2.1 | 0.025 |
| | >= 2 years | 36 | 2.2 | 0.6 | | | 2.0 – 2.5 | |
| Spiritual | < 2 years | 34 | 4.2 | 0.4 | 68 | 1.3 | 4.0 – 4.2 | 0.214 |
| | >= 2 years | 36 | 4.1 | 0.4 | | | 3.9 – 4.2 | |

4.7 Chemotherapy and other forms of treatments (Radiotherapy, surgery, Opioids) on physical, psychological, social and spiritual well-being

Participants both in the support group and non-support group received different forms of treatment. A general analysis revealed that the participants who were not on chemotherapy had better QOL as indicated by the mean of 3.0 (95% CI = 2.8 – 3.2), those on chemotherapy had a marginally statistically significant lower mean of 2.5 (95% CI= 2.1 – 2.9) at a p value of 0.05 with regard to physical dimension on quality of life. This implies that patients on chemotherapy were worse off regarding their status on fatigue, appetite, pain, sleep changes, weight loss and overall physical health. Generally, there was no significant difference between the two groups with respect to psychological, social or spiritual well-being and chemotherapy treatment.

Table 4.6: Chemotherapy and other forms of treatments (Radiotherapy, Surgery, Opioids) in relation to physical, psychosocial, social and spiritual well-being

| Dimensions | Group | N | Mean | SD | df | t-test | 95% CI | P value |
|--------------------------|-----------------|----|------|-----|----|--------|-----------|---------|
| Physical | Chemotherapy | 14 | 2.5 | 0.7 | 68 | 1.9 | 2.1 – 2.9 | 0.05 |
| | Other treatment | 56 | 3.0 | 0.8 | | | 2.8 – 3.2 | |
| Psychological well-being | Chemotherapy | 14 | 1.9 | 0.4 | 68 | 1.6 | 1.7 – 2.1 | 0.1065 |
| | Other treatment | 56 | 2.1 | 0.5 | | | 2.0 – 2.3 | |
| Social | Chemotherapy | 14 | 1.9 | 0.7 | 68 | 0.7 | 1.6 -2.3 | 0.4738 |
| | Other treatment | 56 | 2.0 | 0.6 | | | 1.9 – 2.3 | |
| Spiritual | Chemotherapy | 14 | 4.3 | 0.6 | 68 | 1.5 | 3.9 – 4.6 | 0.3011 |
| | Other treatment | 56 | 4.1 | 0.3 | | | 4.0 – 4.2 | |

4.8 Surgery and other forms of treatments(Radiotherapy, Chemotherapy, Opioids) in relation to physical, psychosocial well-being, social and spiritual well-being dimensions

Generally, participants who had received other breast cancer treatment who had a mean of 2.1 (95% CI = 2.0 – 2.2), those who had surgery had a marginally statistically significant higher mean of 2.6 (95% CI = 2.1 – 3.0) at a p value of 0.0570 with regard to psychological well-being dimension on quality of life. We can conclude that, the quality of life with regard to psychological well-being was better for those who had undergone surgery than those who were on other treatment in the following items evaluated: coping with disease, coping with treatment, happiness, control of situation, life satisfaction, level of concentration, usefulness, appearance changes, changes in self- concept, distress level at initial diagnosis, cancer chemotherapy, cancer radiation, cancer surgery, completion of treatment, level of anxiety, level of depression, fear of the future tests, fear of second cancer, fear of recurrence, fear of metastasis and normality.

Table 4.7: Surgery and other forms of treatments in relation to physical, psychosocial well-being, social and spiritual well-being dimensions

| Dimensions | Group | N | Mean | SD | df | t-test | 95% CI | P value |
|---------------------------------|------------------------|----------|-------------|-----------|-----------|---------------|---------------|----------------|
| Physical | Surgery | 3 | 3.6 | 1.6 | 68 | 1.5 | -0.4 – 7.5 | 0.5104 |
| | Other treatment | 67 | 2.9 | 0.8 | | | 2.7 – 3.0 | |
| Psychological well-being | Surgery | 3 | 2.6 | 0.2 | 68 | 1.9 | 2.1 – 3.0 | 0.0570 |
| | Other treatment | 67 | 2.1 | 0.4 | | | 2.0 – 2.2 | |
| Social | Surgery | 3 | 2.1 | 0.5 | 68 | 0.2 | 1.0 – 3.3 | 0.8296 |
| | Other treatment | 67 | 2.1 | 0.7 | | | 1.9 – 2.2 | |
| Spiritual | Surgery | 3 | 4.0 | 0.2 | 68 | 0.4 | 3.6 – 4.5 | 0.721 |

| | | | | | | | | |
|--|------------------------|----|-----|-----|--|--|-----------|---|
| | Other treatment | 67 | 4.1 | 0.4 | | | 4.0 – 4.2 | 7 |
|--|------------------------|----|-----|-----|--|--|-----------|---|

4.9 Comparison between means of support and non-support group in relation to the physical, psychosocial, social and spiritual well-being dimensions

A two-sided t-test was performed to compare significant difference between the means of the support and non-support group with respect to the four domains, namely: physical, psychosocial well-being, social and spiritual in order to test if one group was better than the other with respect to the four domains. Results show that the mean physical domain of the support group was 3.0 (95% CI = 2.8 – 3.3) compared to a mean physical domain of 2.3 (95% CI = 2.1 – 2.7) for the non-support group (p=0.0053). This suggest that the former group did not have a lot of problems with fatigue, appetite, pain, slept changes, weight loss, vaginal dryness, menstrual changes and overall physical health.

Findings on psychological well-being shows that support group had a mean of 2.2 (95% CI = 2.1 – 2.3) compared to a mean of 1.5 (95% CI = 2.1 – 2.3) for the non-support group (p=0.0001). The psychological well-being examined support groups performance in the following items: coping with disease, coping with treatment, happiness, control of situation, life satisfaction, level of concentration, usefulness, appearance changes, changes in self- concept, distress level at initial diagnosis, cancer chemotherapy, cancer radiation, cancer surgery, completion of treatment, level of anxiety, level of depression, fear of the future tests, fear of second cancer, fear of recurrence, fear of metastasis and normality. The mean difference between the two groups was statistically significant implying that the support group was

doing well on the psychological well-being domain in contrast to the non-support group.

Further comparison of mean of the support group and non-support group on social domain revealed statistically significant differences in means of 2.2 (95% CI = 2.1 – 2.3) for the support group compared to a mean social domain of 1.7 (95% CI = 1.5 – 2.0) for non-support and overall p value of 0.0004. Nine items that were included under this domain included: family distress, level of support from others, health care versus relationships, sexuality versus illness, effect on employment, effect on daily activities of living, feeling of isolation, concern for inheritance and financial burden. Generally, the study participants in the support group did not experience a lot of problems with regard to the social domain unlike their counterparts in the non-support group. Therefore, the social life of study participants in the support group had significantly improved.

Finally, the two groups were evaluated on their spiritual well-being by comparing the means of the two groups. Statistically significant results were observed on the support group with a mean of 4.2 (95% CI = 4.1 – 4.3) while that of non-support group was 4.0 (95% CI = 3.8 – 4.1) with $p = 0.05$. Seven items covered under spiritual well-being were participation in religious and spiritual activities, positive changes, uncertainties, purpose of being and feeling of hope. Thus, being a member of the support group improved their spiritual well-being.

Table 4.8: Comparison between means of support and non-support group by physical, psychosocial well-being, social and spiritual well-being dimensions

| Dimensions | Group | N | Mean | SD | df | t-test | 95% CI | P value |
|---------------------------------|--------------------------|----------|-------------|-----------|-----------|---------------|---------------|----------------|
| Physical | Support group | 54 | 3.0 | 0.8 | 68 | 2.9 | 2.8 – 3.3 | 0.0053 |
| | Non-Support group | 16 | 2.4 | 0.6 | | | 2.1 – 2.7 | |
| Psychological well-being | Support group | 54 | 2.2 | 0.4 | 68 | 4.1 | 2.1 – 2.3 | 0.0001 |
| | Non-Support group | 16 | 1.7 | 0.4 | | | 1.5 – 2.0 | |
| Social | Support group | 54 | 2.2 | 0.6 | 68 | 3.7 | 2.1 – 2.3 | 0.0004 |
| | Non-Support group | 16 | 1.5 | 0.4 | | | 1.5 – 2.0 | |
| Spiritual | Support group | 54 | 4.2 | 0.4 | 68 | 2.0 | 4.1 – 4.3 | 0.05 |
| | Non-Support group | 16 | 4.0 | 0.3 | | | 3.8 – 4.1 | |

4.10 Qualitative Data Analysis from Focus Group Discussion (FGD) For Breast Cancer Patients in the Support Group



FGD was done in two groups of 10 and 12 among support group members. Being that the guide had the framework with which questions addressed the four domains; of Physical, psychological, social, spiritual domains and the way forward, the findings were merged under each domain with the respondents identified by a unique letter

4.10.1 Physical Well-Being

Researcher: In your journey of this sickness, you may have experienced pain, fatigue, nausea, reduced body functioning and other physical effects either from the disease or treatment. Kindly share how group meetings have contributed in coping with the above symptoms?

Patient X: When I was getting my chemo session, I was becoming worse every single day, I almost gave up thinking chemo was killing me instead of helping me. I

never wanted to be in the company of anybody, until “Shosh” (nickname of one of the breast cancer survivor) talked to me about the side effects that makes one feel worse thereafter introduced me to this support group. Through the sharing I came to understand that fatigue, nausea, “chemo-brain” (forgetfulness), and loss of appetite were some of the side effects of the drug and this made me to learn how to adhere to the treatment.

Patient H: It is true, chemo-brain is so bad that even you are holding something, you will forget and start searching for it and people may not understand you. But since I started coming with my sister who is caring for me, she now understands me that this happens and they need to bear with me and remind me when necessary.

Patient k: I kept on blaming myself when I could not do what I used to do. But this group made me to come up with my normal ‘normals’ (learning to make the abnormal normal) for example fatigue is my normal, with or without fatigue, life must continue.

Patient M: It is you who decides who to become.

Patient Y: you are right, but I have come to learn from this group that we are a special group needing special attention due to our low immunity. My people get it very hard because, I used to be sick very often until the doctor told me that I had infection in my blood. I was then advised to drink mineral water or boiled water and maintain hygiene. Avoid crowded places as I could get cross infection. It is really wise that through coming with our caretakers, they understand the need of all these not taking it negatively as though we do not like to be social or too special.

Patient W: The sharing enables one to know the expected side effects following ‘Chemo’ or ‘Radio’ and know the steps to take if it happens or how to prevent or seek medical attention for instance diarrhea, fatigue, nausea and hair loss.

Patient O;When I got this cancer and they said I had to go on chemo, I thought, "I'm not going to be able to do anything; I'm going to be sick and I'm not going to get around." I went to the support group and some of them were on chemo, and they were getting along and some were going to their jobs and they weren't getting sick. I saw that and thought, "I can do it, too." And I did. I managed, even with getting sick sometimes.

4.10.2 Spiritual Well-Being

Researcher: Thank you for the above, would you now share on how has this support group influenced your spiritual life?

Patient A: Seeing many people having survived breast cancer like ‘Shoshi’ here, it gives us courage to have a sense of purpose in our lives.

Patient L: in as much as we know that Cancer has no cure yet, we believe that God can do miracles through the many testimonies of the people on how they have been and how they are now.

Patient J: It is true, this reminds me the fact that God is able and always trust in Him for my tomorrow. We know that this treatment is only to slow the disease down but has no cure and the cure can only come from God.

Patient H: this support group has made me to know the power of meditation and prayer.

4.10.3 Social Well-Being

Researcher: What about impact on your social life?

Patient P: This disease makes one loss old friends because, when they know that you have cancer the next thing is death, therefore one just want to laugh at you may be you have become so poor due to the expenses of treatment or to just wait for what next in your life and never again free with you. They see you as a beggar. So this forum creates new friends who understand you better.

Patient D: Yes, even most people are just sympathizers and they feel very guilt when you meet them. They do not know what to tell you, thinking that you are going to die so the only word you can get from them is 'POLE'. I don't like this word (Very sad expression on her face of dislike). But here we find a home.

Patient S: The support group is the best place to be as it makes you have a sense of belonging. These are the friends that you can share all your experience of fears and expect to get a sincere hearing ear and some clue to your questions.

Patient R: Other than meeting here, we also do visit each other and even help each other when very sick and contribute when one of us has died. We also go through bereavement together as we have built bonds to help us in grieving.

Patient K: We help each other too on our Whatsapp page that people help to answer concerns to help one know how to deal with a problem faced while at home. Also our public facebook enables us reach out to make who are able to read from our page.

Patient T: We are like one family and we help the newly diagnosed to understand the disease process.

4.10.4 Psychological Well-Being

Researcher: Do what extend do you think the group has impacted on your psychological well-being?

Patient Z: In sharing one knows what to expect at different phases of the disease especially during ‘chemo’, ‘radio’ and surgery and the possible outcomes that makes you develop some coping mechanisms though not that easy as the effect is too much.

Patient Q: However, your anxiety level may reduce or increase depending on how your body will perceive the information given by the group.

Patient G: It is true that anxiety may increase but not as much as you do not know and never have heard about it.

Patient E: Sometimes you can be distressed of those treatment procedures and worse still when you see your friends dying, though good still is a lot of sharing when it happens

Patient F: support group is really a strengthening forum and a home to be to reduce fears of the unknown.

4.10.5 Way Forward

Researcher: What could be your way forward as pertaining breast cancer specific support group?

Patient G: This is the best approach to assisting cancer patients and should be used by all cancers centers in all Counties. Being that Faraja is the only place with Breast cancer specific support group we travel from far, but if it is spread, we shall minimize the cost of travelling and saving time

Patient W: Health policies should be amended to include cancer care that will help this practice to be rolled up in all Counties.

Patient C: Many places have mixed support group which is not a good forum for open sharing since one may not be free if a different gender is present in a discussion. We have some specific issues to share in specific groups

Patient B: This idea by health professionals that 'there is nothing to be done go home for home care' should be stopped, for now we know that there is something that one can do. Support groups not expensive yet it really helps one have hope.

Patient V: It is sad that some doctors get very happy when they know that you have cancer because that is money for them. They make sure even if they know cheaper options they will never tell you, worse still when they know that you have insurance, they make sure they have drained it to Zero and leave you there to die. Could we be able to have some regulations in pricing for cancer drug and procedures?

Researcher then thanked the participants for their free and active participation.

CHAPTER FIVE

INTERPRETATION AND DISCUSSION OF THE RESULTS

5.1 Overview

This chapter presents the interpretation and discussion of the results divided into four sections to include psychosocial support group utilization rate by patients and quality of life, psychosocial support group in improving quality of life among breast cancer patients and patients' perception about psychosocial support groups in relation to their quality of life.

5.2 Discussion of Findings

5.2.1 Utilization of psychosocial support groups

The study revealed that majority 77.1% of the female breast cancer patients who sought services at Faraja Support Trust were in the psychosocial support group as compared to 22.9% who were not in the support group. This is contrary to the results from other studies that reported low attendance of the support group. Krizek, Robert, Ragan, Ferrara & Lord (1999) reported that although support groups were offered to many patients who had received a diagnosis of cancer, only 35% participated as majority choose not to participate. Later supported by Uden-Kraan *et al.*, (2011) who remarked that in as much as patients were aware of the support group meetings, few patients actually attend.

The higher proportion of patients attending support group in the present study was attributed to their level of education where 76.9% of the support group respondents had attained tertiary/higher education in contrast to 68.8% in the non-support groups in the same category (see Table 4.1 above). These are people with good exposure and knowledge on the importance of sharing with the peers. The findings were justified by the study done by Bui, Last, Bradley, Law, Maier and Smith (2002) who reported that level of education was a significant predictor for attending support group among breast cancer patients.

Their exposure was clearly seen when during FGD sessions a participant K, reported of having a private Whatsapp page and public Facebook page for their communication that promoted sharing, education and sensitization of group members and the public.

On exploring age as a factor for attendance of support group, findings showed that younger clients aged 30-49 were the majority (50%) in support group, as opposed to the older clients aged 50-69 being the majority 43.8% in the non-support (Table 4.1). Sio, *et al.*, (2014) in their study indicated that age was significantly related to psychosocial well-being in breast cancer survivors and survivors younger than 50 years were more likely to choose aggressive therapies or complementary treatments as compared to their older counterpart. In addition, elderly breast cancer survivors reported of having less social support network mechanisms than young women (Sammarco, 2003). Other studies also conclude that young breast cancer patients prefer attending support groups because they are more stressed and find encouragement in support groups (Tehrani *et al.*, 2011).

Attending of the support group called too for the client to incur money on transport. The study revealed that most 64.9% of those in the supportgroup had a household income of Ksh. 10,000 and above (Table 4.1). However, Venas News (2016) answering the question of how one can survive in Kenya with an income of Ksh. 10,000 reports that this is hectic. Relating to the number of persons per household where majority 26(37.1%) had a total number of 4 and above (Table 4.1), medical bills and upkeep in Nairobi, business minded community among others, patient V during the Focused group discussion felt sad and expressed that;

“It is sad that some doctors get very happy when they know that you have cancer because that is money for them. They make sure even if they know cheaper options they will never tell you, worse still when they know that you have insurance card, they make sure they have drained it to Zero and leave you there to die”

In relation to the above, Uden-Kraan *et al.*, (2011) in their study concluded that breast Cancer patients who actually accepted to participate in the support groups are those who had a higher degree of distress; also female, younger, more highly educated and of a higher economic status. Therefore, for the health professionals to increase Support group participation, each individual should be assessed and counseled accordingly to be able to understand the need of attending the support group.

The study also revealed that 62.5% of the nonsupport group patients expressed interest to attend support group as they only had personal barriers (Table 4.3). During face to face interview, they reported of having challenges either, due to distance,

financial constraints, or duty demands which made them to seek other forms of social support where, 83.3% of those who were not interested in a support group were receiving other forms of social support (Table 4.3). The common social support type was found to be support from family and friends (66.7%). These findings were similar to the study done by Krizel, *et al.*, (1999) who reported of respondent not feeling a need for support, pointing to a good natural support system explaining that those in non-support group indicated actual or potential discomfort in being with and listening to other patients with poorer prognoses. The Alive strong report of 2007 by Neal, Beckjord, Rechis, Schaeffer, Berno, & Duchover on Cancer stigma and silence around the World indicated that once diagnosed, stigma will negatively affect medical decision making, and the provision of supportive care becomes a significant source of stress and can increase suffering. It is therefore recommended that other interventions of social support be used for individual patients.

5.2.2 Support group involvement and Health related quality of life

The results of health related quality of life (HRQOL) for those in support group and those in nonsupport group were tested using different factors for statistical difference. On general review on how income could impact on the HRQOL, it was shown that, the general participants who had the household income of $\geq 20,000$ had a better HRQOL as compared to their counterparts who had less with statistical significance in two domains of Psychological $p=0.018$ and social $p=0.0145$ (Table 4.4). These findings were confirmed by previous studies that linked high socioeconomic status to many aspects of better care of patients such as the prompt treatment and having less worry about financial constraint [Al-Naggar *et al.*, (2011);

Kwan *et al.*, (2010)]. However, further research is needed to investigate on the financial constraints and quality of life among breast cancer patient.

The study also showed that those diagnosed at least 2 years or more experienced less social problems as confirmed by a mean of 2.2 (95% CI = 2.0 – 2.5) in contrast to a mean of 1.9 (95% CI = 1.6 – 2.1) of those who had taken less than two years after diagnosis ($p = 0.0257$). This was clearly observed in patients during the FGD where those who had survived atleast two years and above were freer to self-expression than those diagnosed two years and below. Tehrani *et al.*, (2011) in their study had related findings and reported that during the initial stages of cancer diagnosis, many patients experience denial, social Stigma, distress and isolation which improve with time through group sharing. Similarly, Chou, Lee-lin & Kuang (2016) in their study reported that breast cancer patients experience high levels of psychological distress and depression, particularly immediately after diagnosis and treatment, therefore they need psychosocial support. Patients and families are therefore supposed to be assisted to go through stigma, distress and depression. Fewer studies have been conducted in this area of duration since diagnosis and the patients' quality of life hence there is need for further researches.

Support group and quality of life

Considering the impact of support group on the quality of life among breast cancer patients, the study results indicated that support group had statistical significance in all the four domains (Physical, Psychological, Social and Spiritual) of quality of life. The physical domain of those in support group was better as they did not have a lot of problems with fatigue, appetite, pain, slept changes, weight loss, vaginal dryness,

menstrual changes and overall physical health with a variable mean of 3.0 (95%CI=2.8-3.3) as compared to 2.3 (95%CI=2.1-2.7) for non-support group (p=0.0053). Clark (2005) in his study reported that social support would benefit a person's general health and immune systems, regardless of whether or not they have a lot of stress as it acts like a buffer to stress. He added that lack of social support in most cases, predicts the deterioration of physical and mental health among the victim. Therefore, the support group helps improve the general physical health of patients with breast cancer.

On psychological Wellbeing, the study demonstrated that the mean difference between the two groups was statistically significant (p=0.0001) implying that there was a positive psychological well-being outcome with a much higher mean score of 2.2 (95%CI= 2.1-2.3) for those in the support group contrary to 1.9 (95%CI=1.5-2.0) for non-support group. Those in support group were better in coping with disease, coping with treatment, happiness, control of situation, life satisfaction, level of concentration, usefulness, appearance changes, changes in self- concept, distress level at initial diagnosis, cancer chemotherapy, cancer radiation, cancer surgery, completion of treatment, level of anxiety, level of depression, fear of the future tests, fear of second cancer, fear of recurrence, fear of metastasis and normality contrary to their counterpart. This is in relation to many studies that have indicated of breast cancer patients suffering high distress levels and being a member of support group helps them improve their psychological well-being [Yan *et al.*, (2016); (Björneklett *et al.*, (2012), McCloskey-Lint., (2007)].

Looking at the social domain, the present study demonstrated a remarkable effect of the support group on the domain where there was a statistically significant differences in means of 2.2 (95% CI = 2.1 – 2.3) for those in the support group as compared to 1.7 (95% CI = 1.5 – 2.0) for non-support with an overall p value of 0.0004. Nine items that were included under this domain included: family distress, level of support from others, health care versus relationships, sexuality versus illness, effect on employment, effect on activities of daily living, feeling of isolation, concern for passing on of the disease to the daughters and financial burden. This implies that the participants in the support group did not experience a lot of problems with regard to the social domain unlike their counterparts in the non-support group. Therefore, the social life of study participants in the support group had significantly improved.

This was in agreement with the findings from others studies that reported of psychosocial support group providing an expressive forum for peers and had significant association with improved health related quality of life (Tehrani *et al.*, 2011). Another studies also reported of women joining the groups in order to feel less isolated, learn coping skills, and obtain information [Lee, *et al.*, (2013), Anderson, *et al.*, (2011)]. Study participants having reported of visiting each other and its benefits, confirmed the finding that visiting individuals in similar conditions creates a sense of belonging and sympathy in patients and provides information about how to cope with the disease (Poole, *et al.*, 2001).

Dunn, Steging, Occhipinti,& Wilson,(1999) reported that being visited by peer groups reduced levels of anxiety among cancerous women. They further reported that, patients felt that visiting volunteers with experiences of breast cancer made

them feel less lonely and be more hopeful for their future and thus felt more reassured about their own personal and feminine reactions. Docherty (2004) concluded that the presence of peer support groups paves the way of patients for coping with cancer through increasing the understanding about the normal process of the disease and providing emotional support and a sense of belonging. Breast cancer patients are more sympathetic to similar patients and do not feel uncomfortable or different at their presence (Tehrani *et al.*, 2011). In fact, seeing similar patients with complete remission gives current patients a pleasant feeling as expressed by Patient M during a FGD and added:

'This disease makes one loss old friends because, when they know that you have cancer the next thing is death, therefore one just want to laugh at you may be you have become so poor due to the expenses of treatment or to just wait for what next in your life and never again free with you. So this forum creates new friends who understand you better.'

Patient C added by saying; *'Yes, even most people are just sympathizers and they feel very quilt when you meet them. They do not know what to tell you, thinking that you are going to die so the only word you can get from them is 'POLE'. I don't like this word (Very sad expression on her face of dislike). But here we get a home.'*

Patient S said:

'The support group is the best place to be as it makes one have a sense of belonging. These are the friends that you can share all your experience of

fears and expect to get a sincere hearing ear and some clue to your questions'.

Contrary, Helgeson, Cohen, Schulz, & Yasko (2001) found that there was no significant difference between the QOL of patients in the support group and those not in the support group as there was reported decrease in their mental health and performance 6 months after the intervention and some relatively strong negative impacts were created in the peer support group. This contrary result may have been as a result of short duration of intervention and more studies recommended. However, patient Q had similar insight saying that during a support group meeting, one's anxiety level may reduce or increase depending on how one perceives the information given by the group.

Finally, concerning the spiritual domain, the present study revealed that, there was a statistical significance on the spiritual well-being of those in the support group with the mean of 4.2 as compared to 4.0 among those in non-support group. Seven items covered under spiritual well-being were participation in religious and spiritual activities, positive changes, purpose of being and feeling of hope. Thus, being a member of the support group improved their spiritual well-being. Other studies had similar findings and reported that high level of spiritual well-being was more related with enjoyment in life, and higher levels of meaning and peace, even in the midst of cancer-related symptoms such as fatigue or pain (Puchalski, 2012). It had also been indicated in another study that spiritual well-being in cancer patients was associated with lower levels of depression, better quality of life near death, and protection against end-of-life despair and desire for hastened death (Puchalski, Ferrell,

O'Donnell, Bruera,&Yennurajalingam, 2011). Cancer patients felt that their spirituality helped them find hope, gratitude, and positivity in their cancer experience, and also a source of strength that enabled them to cope, find meaning in their lives, and make sense of the cancer experience as they recover from treatment (Puchalski, 2012). During FGD, patient W said that cancer was a blessing and opportunity to see life in a different, perhaps more meaningful way. While Patient J added and said:

It is true that God can do miracles; this reminds me the fact that God is able and always trust in Him for my tomorrow. We know that this treatment is only to slow the disease down but has no cure and the cure can only come from God.

Religious beliefs of patients, as the cornerstone of the approaches for coping with the disease, play a pivotal role in struggling with the disease. Taleghani, Brahrami, Loripoor,& Yousfi (2014) reported that cancer increases people's awareness of religious aspects and moves them towards exploration of spiritual implications of life. They also added that religious beliefs are considered as an important source of support for facing and coping with the disease particularly in patients with breast cancer.

Similarly, Nairn,& Merluzzi (2004) expressed that patients who believed in God, cope and are able to adapt themselves with the disease. They added that feeling alone while faced with the disease and having reliance upon one's own energy cause anxiety and feeling of loneliness. Believing in a more powerful and supreme power assists patient in coping with the disease and give them opportunity to convey a part

and/or all responsibility to cope with the disease to that supreme power (Taleghani, Bahrami, Loripoor, & Yousefi 2012). Thus, all the mental pressures exerted on the patient will be lowered and their feeling of loneliness for coping with the disease will be decreased (Naim *et al.*, 2004). Similarly, Gall,& Cornblat (2002) found that cancer patients who felt the presence of God in their lives have more positive attitude toward life. Moreover, in subjects who survived cancer for a longer time, this positive attitude was accompanied by a sense of emotional health.

Therefore, the findings of this study is in agreement that psychosocial support group plays a very important role in improving HRQOL among female breast cancer patients and the overall physical, psychological, social and spiritual considerations need to be addressed.

5.2.3 Patients' Perception on Psychosocial Support Groups

The Focus group discussion data provided an opportunity to assess the feeling and perception of breast cancer patients in the support group about the group. This was to enhance the understanding of the findings from the quantitative data analyzed above. Focused group discussion was taped and transcript for the qualitative analysis.

Examination of the FGD transcripts from women about physical functioning which was regarded as adaptive responses revealed that the predominant theme addressed the utility of the information received during sharing

'When I was getting my chemo session, I was becoming worse every single day, I almost gave up thinking chemo was killing me instead of helping me. Through the sharing I came to understand that fatigue, nausea, "chemo-

brain” (forgetfulness), and loss of appetite were some of the side effects of the drug and this made me to learn how to adhere to the treatment.’

This was then supported by patient Z who said;

‘It is true, chemo-brain is so bad that you may be holding something, then you forget and start searching for it and people may not understand you. But since I started coming with my sister who is caring for me, she now understands that this happens and they need to bear with me and remind me when necessary’.

There was also feeling of self-acceptance where the abnormal signs were accepted and taken as normal to live with it as it is unique to me

‘I kept on blaming myself when I could not do what I used to do. But this group made me to come up with my normal ‘normals’ (learning to make the abnormal normal) for example fatigue is my normal, with or without fatigue, life must continue. Losing one breast is my normal, Chemo brain is my normal’

Furthermore, the women perceived that the information gained from support group participation enhanced their awareness of the expected side effects

‘The sharing enables one to know the expected side effects following ‘Chemo’ or ‘Radio’ and know the steps to take if it happens or how to

prevent or seek medical attention for instance diarrhea, fatigue, nausea and hair loss.'

Women explained that learning about other women's experiences during their participation helped them to deal with their own treatment side effects:

'When I got this cancer and they said I had to go on chemo, I thought, I'm not going to be able to do anything; I'm going to be sick and I'm not going to get around.' I went to the support group and some of them were on chemo, and they were getting along and some were going to their jobs and they weren't getting sick. I saw that and thought, "I can do it, too." And I did. I managed, even with getting sick sometimes. Moreover, the women indicated that the presence of unpleasant treatment-related symptoms, such as chemotherapy-induced nausea, was less distressing once they understood the cause of symptoms and realized that these symptoms would be time-limited: Sometimes I'm feeling really bad. But then I think about it and realize that the reason I'm nauseated or tired or whatever is because the chemo is acting And then, instead of hating the way I feel, I'm thankful because I know that the chemo is fighting the cancer.

These findings are in conjunction with findings by Alagraa, *et al.*, (2014) who noted that breast cancer diagnosis has different implications on the unique feelings and experience of patients. Patients' perceptions of psychosocial support are increasingly important to understanding appropriate holistic patient-centered care. Ussher, *et al.*, (2012) highlighted that though women may have many supportive individuals around

them; they are often discouraged from expressing feelings of fear, anxiety, and thoughts of death to others. Cavallo (2014) commented that women with breast cancer feel that they do not receive the emotional support that they need from their personal relationships and feel abandoned. This often leads to seeking additional support in the form of support groups (Alagraa *et al.*, 2014).

This was confirmed by a patient during the FGD who expressed the feeling that support group was very ideal for their psychosocial support in terms of finding a home and empathetic friends, an educational forum that enables them understand how to deal with their cancer journey and a place to alleviate their fears. They perceived psychosocial support group as a beneficial place to be.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

6.1 Overview

This chapter presents conclusions and recommendations drawn from the study findings. It will systematically focus on objectives, starting from utilization of support groups in Faraja, comparison of quality of life among those in support groups and those not in support groups and finally patients' perceptions towards support groups and their quality of life.

6.2 Conclusion

The main objective of the study was to investigate the contribution of psychosocial support group in improving the quality of life among female patients with breast cancer attending services in Faraja within Nairobi County. Attempts have been made to answer the research questions as contained in the specific objectives. The first objective was to determine the utilization of psychosocial support groups among breast cancer patients in Faraja. The study revealed that there was high utilization of the support group by the breast cancer patients in the study area where a total of 54

(77.1%) respondents were in the support group while 16 (22.8%) were in the non-support group. The study revealed that the level of education influences participation in the support group as evidenced by three-quarters (76.9%) of the support group respondents had attained tertiary/higher education in contrast to 68.8% in the non-support groups falling in the same category. It was also revealed that the longer the patient stays with breast cancer the more the chance of attending the support group as evidenced by half of those in the support group were diagnosed between 2010-2014 (50%) while 56.2% of those in the support group were newly diagnosed between 2015 – 2016.

The second objective was to compare the health related quality of life (physical, psychological, social and spiritual well-being) among those in support group and those not in support group.

The study revealed that psychosocial support group improves the quality of life for female breast cancer patients as supported by the results showing that there was statistical significant difference among all the four domain of physical, psychological, social and spiritual well-being contrary to their counterpart in the non-support group. The physical domain of the support group was 3.0 (95% CI = 2.8 – 3.3) compared to a mean physical domain of 2.3 (95% CI = 2.1 – 2.7) for the non-support group ($p=0.0053$). With psychological well-being having a mean of 2.2 (95% CI = 2.1 – 2.3) for those in the support group as compared to a mean of 1.5 (95% CI = 2.1 – 2.3) for the non-support group ($p=0.0001$). The comparison of mean of the support group and non-support group on social domain revealed statistically significant differences in means of 2.2 (95% CI = 2.1 – 2.3) for the support group compared to a mean social domain of 1.7 (95% CI = 1.5 – 2.0) for non-support and

overall p value of 0.0004. Finally, the two groups were evaluated on their spiritual well-being by comparing the means of the two groups. Statistically significant results were observed on the support group with a mean of 4.2 (95% CI = 4.1 – 4.3) while that of non-support group was 4.0 (95% CI = 3.8 – 4.1) with $p = 0.05$.

The third objective was to examine patients' perception about psychosocial support groups in relation to their quality of life. This was clearly expressed in the FGD where the patients felt that support group was very ideal for their psychosocial support in terms of finding a home and empathetic friends, an educational forum that enabled them understand how to deal with their cancer journey and a place to alleviate their fears. They perceived psychosocial support group as a beneficial place to be.

6.3 Recommendations

Based on the findings the study, the following recommendations were made:

- Support groups to be integrated in the existing oncology service in all cancer centers across the country to help improve the quality of life among breast cancer patients preferably a support group to include only one type of cancer for a more open forum.
- The government policy on psychosocial support should be implemented and strengthened to include psychosocial support groups, advocacy and sensitization.

- Further research be undertaken in different study areas preferably in rural or public cancer centers setups with a larger sample to allow for generalization of results.

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APPENDICES

APPENDIX I: INFORMED CONSENT FORM

Dear Participants

I am Sr. Elizabeth NasambuWafula Iam currently involved in a research project in partial fulfillment of the requirement for the Master's Degree in Advanced Nursing Practice -Oncology of Masinde Muliro University. Iam asking you to participate in a study on Contribution of Psychosocial support group in improving Quality of life among Female Breast cancer patients in Faraja, Nairobi county. Iam going to give you information about the research and invite you to participate in it. Your response is important because; I need information only you, a person diagnosed with breast cancer can provide. You do not need to decide right now whether or not you will participate in the research. Before you decide, take at least 5 minutes, you can talk to anyone you feel comfortable with about the research of this form. If you have any questions now or later, you are free to ask them from me or another researcher on our team.

What is the purpose of this Research? Quality of life is all what we want for any of our client in the cancer center and beyond. The purpose of this study is to investigate how psychosocial support group improve the quality of life among breast cancer patients. I believe you can help by telling us about yourself. We want to learn more about it as a way of improving others quality of life.

Why have you been asked to participate? You are being asked to participate in this research because your hospital is offering breast cancer specific support group that is our area of interest, and you are one of the clients who have attended there services for. Your experience is valuable to us and can contribute to our understanding of psychosocial support in improving quality of life.

Do you have to participate? Your decision to be a part of this study is entirely up to you. You may decide whether to or not to be part of this research. Should you choose not to participate, your relationship with your doctors and nurses will not change. If you do choose to participate, you may stop participating at any time without

consequence. You will also have a chance to review your survey and you may change your answers before it is submitted.

What will the research be like? This research will involve filling of questions only once which will not take more than 10minutes to complete. The questionnaire will be provided and collected by the researcher. You may answer the questions or it can be read out to you and you can say loud the answer you want the researcher to write. If you do not want to answer any of the questions included in the study, you may skip and move to the next question. The information recorded is private, your name or any other identifying piece of information are not being included on the forms, only a number will identify you, and no one else except myself and other researchers on my team will have access to your survey questionnaire.

What are the risks of Participating? There is a chance that you may feel uncomfortable answering some survey questions. However, we do not want that to happen. If you do not wish to answer a question for any reason, you may skip it and move on to the next.

What are the benefits of participating? There will be no direct benefit to you as a result of this study. However, we hope that the information you provide us with will help us better understand psychosocial support group and improving of quality of life among breast cancer patients.

How will your information be kept? We will not be sharing any information which could identify you with anyone outside the research team. Any information collected will have an ID number instead of your name.

Will you get to see the result of the study? Faraja Support trust will receive a copy of the summary of the research findings from all participants. This will be availed to everybody. I hope to publish the result in order to make my research available to the public. Remember we will not share any information which can identify you with anyone outside of the research team.

What if you have a question? If you have any question, you can ask them now or later. If you wish to ask a question later, you may contact me on my phone number below or Masinde Muliro University School of Graduate studies. This proposal has been reviewed and approved by MMUST Institutional Research and Ethics Board-IRB, which is a group of people whose job is to make sure that you are protected from harm. If you wish to find more about IRB contact them on email rel@mmust.ac.ke

Researcher: Sr. Elizabeth Nasambu Wafula 0722589199

Participant Declaration

I have read and understood the preceding pages of this Information Informed Consent form. The research procedures mentioned above have been explained to me and all of my questions have been answered to my satisfaction. I have been informed that I can withdraw from the study at any time without penalty and that, if I choose to do so, any data collected as a result of my participation will be destroyed. The potential discomforts that I might experience because I have participated in the study have been explained to me. I also understand the potential benefits of being a part of this study.

I know that I may ask now, or at any time in the future, any questions I have about the study. I have been assured that the records, transcripts, and tapes related to this study will be kept confidential to the limits of the law. I have also been assured that no information will be released or printed or made public that would disclose my personal identity unless I give permission for that to happen.

I hereby consent to participate: _____ Date: _____

Signature of Participant:

I hereby consent to having our focused group discussion recorded

Signature of Participant: _____ Date: _____

Signature of Principal Investigator: _____

Researchers Declaration

I have carefully explained to the participant the nature of the above research study. I hereby certify that to the best of my knowledge the participants signing this consent form understands the nature, demands, risks and benefits involved in participating in this study.

Investigators' Signature

Printed name of investigator

Date

APPENDIX II: QUESTIONNAIRE

Title: Psychosocial Support Group in Improving Health related Quality of Life

Among Female Breast Cancer Patients in Faraja, Nairobi County, Kenya

SECTION 1 Demographics/Socio-demographics

Please fill in blank or circle answer

Date: _____ Serial number (Participate, leave blank): _____

1. How old are you?
 - a. Below 20 year
 - b. 20 to 29 years
 - c. 30 to 49 years
 - d. 50 to 69 years
 - e. 70 and above
2. What level of education have you completed?
 - a. Primary
 - b. Secondary
 - c. Certificate /Diploma course
 - d. Bachelors degree
 - e. Masters degree and above
3. What is your total household income?
 - a. Less than Ksh. 5000 per month
 - b. Ksh. 5000 to 9,000 per month
 - c. Ksh. 10,000 to 19,000 per month
 - d. Ksh. 20,000 to 29,000 per month
 - e. Ksh. 30,000 and above
4. How many people are you in the household including yourself?
 - a. 1 person
 - b. 2 people
 - c. 3 people
 - d. 4 people
 - e. 5 and above
5. When were you first diagnosed with Breast cancer? _____

6. What treatment have you undergone for cancer? *This question may have multiple answers check all that apply.*
 - a. None
 - b. Radiation therapy
 - c. Chemotherapy
 - d. Surgery
 - e. Opioids
 - f. Alternative medicine
7. Are you in a support group for breast cancer patients? if so how many meeting have you ever attended _____ (*Tick yes if 3 meetings and above*)
 - a. Yes
 - b. No

SECTION II: Quality of Life Scale/BREAST CANCER PATIENT

The Quality of Life Instrument (CANCER PATIENT/CANCER SURVIVOR VERSION) is a forty-one-item ordinal scale that measures the Quality of Life of a cancer patient was used.

Directions: The patient is asked to read each question and decide if he/she agrees with the statement or disagrees. The patient is then asked to circle a number to indicate the degree to which he/she agrees or disagrees with the statement according to the word anchors on each end of the scale. The scoring was based on a scale of 0 = worst outcome to 10 = best outcome. Several items have reverse anchors and therefore when coding the items, reverse of the scores of those items was needed. For example, if a subject circles "3" on such an item, $(10-3 = 7)$ thus you would record a score of 7. The items that were reversed were: 1-7, 9, 16-27, & 29-34 and 38. Subscales were created for analysis purposes by adding all of the items within a subscale and creating a mean score. The QOL instrument is based on previous versions of the QOL instrument by researchers at the City of Hope National Medical Center (Grant, Padilla, and Ferrell). This instrument was revised in cancer

survivorship studies and includes 41 items representing the four domains of quality of life including physical well-being, psychological well-being, social well-being and spiritual well-being. Psychometric analysis was performed on 686 respondents including measures of reliability and validity. Two measures of reliability included re-test and internal consistency. In order to perform test re-test reliability, a randomly selected sample of 150 subjects who completed the initial QOL survey were asked to repeat this tool approximately two weeks later. 110 of the 150 subjects responded for an overall response of 73%. Of the 110 respondents, only those with complete data sets on all variables were used (N=70). The overall QOL-CS tool test re-test reliability was .89 with subscales of physical $r=.88$, psychological $r=.88$, social $r=.81$, spiritual $r=.90$.

a. Physical Dimension

To what extent are the following a problem for you:

1. Fatigue

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

2. Appetite changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

3. Aches or pain

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

4. Sleep changes

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

5. Weight gain

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

6. Vaginal dryness/menopausal symptoms

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

7. Menstrual changes or fertility

no problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

8. Rate your overall physical health

Extremely 0 1 2 3 4 5 6 7 8 9 10 excellent
poor

B. Psychological Well-being Items

9. How difficult is it for you to cope today as a result of your disease?

not at all 0 1 2 3 4 5 6 7 8 9 10 very difficult difficult

10. How difficult is it for you to cope today as a result of your treatment?

not at all 0 1 2 3 4 5 6 7 8 9 10 very difficult difficult

11. How good is your quality of life?

Extremely 0 1 2 3 4 5 6 7 8 9 10 excellent poor

12. How much happiness do you feel?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

13. Do you feel like you are in control of situations in your life?

not at all 0 1 2 3 4 5 6 7 8 9 10 completely

14. How satisfying is your life?

Not at all 0 1 2 3 4 5 6 7 8 9 10 completely

15. How is your present ability to concentrate or to remember things?

Extremely 0 1 2 3 4 5 6 7 8 9 10 excellent poor

16. How useful do you feel?

Not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

17. Has your illness or treatment caused changes in your appearance?

Not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

18. Has your illness or treatment caused changes in yourself concept (the way you see yourself)?

Not at all 0 1 2 3 4 5 6 7 8 9 10 extremely

How distressing were the following aspects of your illness and treatment?

19. Initial diagnosis

Not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing distressing

20. Cancer chemotherapy

Not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing distressing

21. Cancer radiation

Not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing distressing

22. Cancer surgery

Not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing distressing

23. Completion of treatment

Not at all 0 1 2 3 4 5 6 7 8 9 10 very distressing distressing

24. How much anxiety do you have?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

25. How much depression do you have?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

To what extent are you fearful of:

26. Future diagnostic tests

No fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

27. A second cancer

No fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

28. Recurrence of cancer

No fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

29. Spreading (metastasis) of your cancer

No fear 0 1 2 3 4 5 6 7 8 9 10 extreme fear

30. To what degree do you feel your life is back to normal?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

C. Social Concerns

31. How distressing has your illness been for your family?

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

32. Is the amount of support you receive from others sufficient to meet your needs?

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

33. Is your continuing health care interfering with your personal relationships?

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

34. Is your sexuality impacted by your illness?

Not at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

35. To what degree has your illness and treatment interfered with your employment?

No problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

36. To what degree has your illness and treatment interfered with your activities at home?

No problem 0 1 2 3 4 5 6 7 8 9 10 severe problem

37. How much isolation do you feel is caused by your illness?

None 0 1 2 3 4 5 6 7 8 9 10 a great deal

38. How much concern do you have for your daughter(s) or other close female relatives regarding breast cancer?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

39. How much financial burden have you incurred as a result of your illness and treatment?

None 0 1 2 3 4 5 6 7 8 9 10 a great deal

D. Spiritual Well-being

40. How important to you is your participation in religious activities such as praying, going to church or temple?

Not at all 0 1 2 3 4 5 6 7 8 9 10 very important important

41. How important to you are other spiritual activities such as meditation or praying?

Not at all 0 1 2 3 4 5 6 7 8 9 10 very important
important

42. How much has your spiritual life changed as a result of cancer diagnosis?

Less 0 1 2 3 4 5 6 7 8 9 10 more important important

43. How much uncertainty do you feel about your future?

Not at all 0 1 2 3 4 5 6 7 8 9 10 very uncertain uncertain

44. To what extent has your illness made positive changes in your life?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

45. Do you sense a purpose/mission for your life or a reason for being alive?

None at all 0 1 2 3 4 5 6 7 8 9 10 a great deal

46. How hopeful do you feel?

not at all 0 1 2 3 4 5 6 7 8 9 10 very hopeful

THANK YOU FOR YOUR TIME AND PARTICIPATION.

**APPENDIX III: QUESTIONS FOR FOCUS GROUP DISCUSSION OF
BREAST CANCER PATIENTS**

1. In your journey of this sickness, you may have experienced pain, fatigue, nausea, reduced body functioning and other physical effects either from the disease or treatment. Kindly share how group meetings have influenced to the above .
2. How has this support group influenced your spiritual life?
3. How has this illness impacted on your social life?
4. To what extend do you think the group has impacted on your psychological well-being?
5. What could be your recommendation as pertaining breast cancer specific support group?

APPENDIX IV: ETHICAL APPROVAL TO CONDUCT RESEARCH



MASINDE MULIRO UNIVERSITY OF SCIENCE AND TECHNOLOGY

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Kakamega
50100
Kenya

Institutional Ethics Review Committee (IERC)

MMU/COR: 403009(28)

7th April, 2016

Sr. Elizabeth N. Wafula
Registration No. HNR/G/24/14
Masinde Muliro University of Science and Technology
P. O. Box 190-50100
KAKAMEGA

Dear Wafula,

RE: ETHICAL APPROVAL TO CONDUCT RESEARCH

The IERC received your proposal titled "*Role of Psychosocial Support Group in Improving Quality of Life among Female Breast Cancer Patients in Hospice Nairobi County Kenya*" for review. Having reviewed your work, the committee has given ethical clearance for you to conduct research as proposed.

On behalf of IERC and the University Senate, my congratulations. We wish you success in your research endeavour.

Yours faithfully

Dr. Gordon Nguka
Ag. Chairman, Institutional Ethics Review Committee

Copy to:

- The Secretary, National Bio-Ethics Committee
- Vice Chancellor
- DVC (PR&I)
- DVC (A & E)



**NATIONAL COMMISSION FOR SCIENCE,
TECHNOLOGY AND INNOVATION**

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Date:

NACOSTI/P/16/23315/11550

27th June, 2016

Elizabeth Nasambu Wafula
Masinde Muliro University of
Science and Technology
P.O. Box 190-50100
KAKAMEGA.

RE: RESEARCH AUTHORIZATION

Following your application for authority to carry out research on *“Psychosocial support group in improving quality of life among female breast cancer patients in Hospice Nairobi County Kenya,”* I am pleased to inform you that you have been authorized to undertake research in **Nairobi County** for the period ending **27th June, 2017**.

You are advised to report to **the County Commissioner, the County Director of Education and the County Coordinator of Health, Nairobi County** before embarking on the research project.

On completion of the research, you are expected to submit **two hard copies and one soft copy in pdf** of the research report/thesis to our office.

**BONIFACE WANYAMA
FOR: DIRECTOR-GENERAL/CEO**

Copy to:

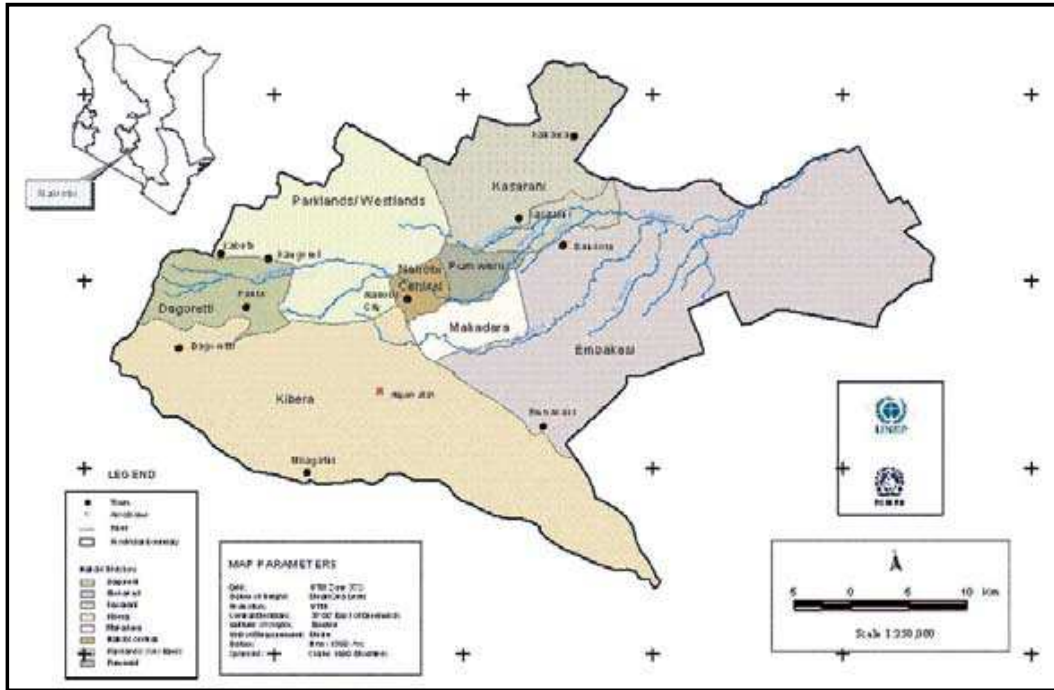
The County Commissioner
Nairobi County.

**COUNTY COMMISSIONER
NAIROBI COUNTY
P. O. Box 30124-00100, NBI
TEL: 341666**

The County Director of Education
Nairobi County.



APPENDIX VI: MAP OF NAIROBI COUNTY



(Source. Google map)

