ASSOCIATION BETWEEN UNMET SUPPORTIVE CARE NEEDS AND QUALITY OF LIFE AMONG PATIENTS WITH BREAST CANCER AT KENYATTA NATIONAL HOSPITAL, KENYA

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A DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF THE DEGREE OF MASTER OF SCIENCE IN NURSING (ONCOLOGY NURSING) OF THE UNIVERSITY OF NAIROBI (UON)

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DECLARATION

I, Adong Lucy Ruth declare that this thesis titled "Association between unmet supportive care needs and quality of life among patients with breast cancer at Kenyatta National Hospital, Kenya" is my original work and has not been submitted for the purpose of obtaining a degree or any other academic award in any institution of higher learning or elsewhere.

Signature ....

Date...07|12|2020...

CERTIFICATE OF APPROVAL

We the undersigned certify that this thesis has been submitted for examination with our approval as internal supervisors of school of Nursing, University of Nairobi.

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DEDICATION

This piece of work is dedicated to: the loving memory of my late husband Ogwang P.S Daniel (RIP) who inspired scientific thinking in my life, motivated me always to take to finish that which I have started.

My children; Blessing Ogwang, Promise Noki, Gracious Akello, Estreasure Comfort and Daniella Bernice Genrwot who have altruistically missed my company without grumbling to allow me pursue a noble course, Master of Science in Nursing (Oncology).

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LIST OF ABBREVIATIONS

CTC: Cancer Treatment Centre

EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30

ERC: Ethics and Research Committee

ESMO: European Society for Medical Oncology

IARC: International Agency for Research in Cancer

KNH: Kenyatta National Hospital

LMICs**:** Low and Middle-Income Countries

NCCN: National Comprehensive Cancer Network

NCCS: National Cancer Control Strategy

NCI: National Cancer Institute

PWBC: Patients with Breast Cancer

QOL**:** Quality of life

SCNF: Supportive Care Needs Framework

SCNS-SF: Supportive Care Needs Survey-Short Form Questionnaire

SPSS**:** Statistical Package for Social Sciences.

UoN**:** University of Nairobi

WHO: World Health Organization

OPERATIONAL DEFINITION OF TERMS

Cancer: Uncontrolled proliferation of abnormal cells in the body which is capable of metastasizing to neighbouring tissues.

Care needs: The requirement of some actions and or resources in care that is essential to attain ideal wellbeing and quality of life by patients with breast cancer.

Supportive care: The provision of services (physical, health system and information, sexuality, psychological, and patient care and support) to cancer patients, their immediate families and caregivers to enable them deal with the effects of the disease and its treatment and to improve their quality of life.

Multidisciplinary team approach: Is a patient care model that comprises of experts from different disciplines to establish shared patient care goals for a more holistic approach to patient care.

Unmet needs: Is the gap between breast cancer patient's experience of services and the tangible services required.

Quality of life: : is subjectively defined as a complete appraisal of life by patients with breast cancer and being satisfied with their present level of functioning compared with what the patients recognize to be real.

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ABSTRACT

Background: Breast cancer patients need support in the management of cancer symptoms, therapy-related adverse effects, educational, psychosocial, spiritual and sexual needs in all aspects of their lives. Provision of supportive care is not always of high significance in developing countries mainly dependent on existing resources. Patients who have cancer of the breast and have more unsatisfied supportive care needs, right from the early phases of treatment, have a poorer quality of life (QOL) and general state of health. This, in the long run, may increase family and community burden, healthcare utilization and expenses. Broad objective: In Kenya, there is no data on the researches which have assessed the Supportive Care Needs (SCNs) and quality of life of patients with breast cancer (PWBC). Hence, this study examined the association between unmet SCNs and QOL among patients with breast cancer receiving care at Kenyatta National Referral Hospital (KNH) of Kenya. Study design and site: The research adopted a descriptive cross-sectional study design using structured questionnaires to collect data at the Cancer Treatment Centre (CTC) of KNH and took eight weeks. Participants and method: The study involved sixty-six (66) participants who have breast cancer, recruited by purposive sampling. The study obtained ethical clearance from the University of Nairobi (UON), and KNH, Ethics and Research Committee (ERC) and participants were consented to participate. The analysis was done using correlation analysis and multivariate linear regression. **Results**: The study enrolled a total of 66 participants who were all breast cancer patients receiving care at CTC of KNH. Most of the respondents were female 95.5% (n=63), aged between 45-54 years 45.5% (n=30), attained at least secondary education 65.2% (n=39), and were married 75.8% (n=50). Most of the participants were Christians 84.9% (n=56), housewives 33.3% (n=22), earned a monthly income of between 5000 - 29,999 Kenya Shillings 57.6% (n=38) and resided in rural areas 75.8% (n=50). In terms of the patient clinical factors, most of the respondents had been diagnosed between 6 months – 1 year ago, 43.9% (n=29). More than half of the patients were undergoing single therapy 54.5% (n=36). The study established that the unmet psychological needs were the most prevalent 75.2% (mean = 73.1; SD = 63.4) among breast cancer patients. The study also found negative correlations between the overall QOL and unmet needs in all the five domains, which imply that more unmet SCNs predicted poorer QOL of breast cancer (BC) patients at KNH. The regression analysis revealed that the overall QOL was predicted by unmet sexuality needs. **Conclusion:** Based on the findings of this study, it can be concluded that; The most prevalent unmet needs of breast cancer patients were found in the psychological domain followed by unmet needs in health systems information domain. There was a correlation between unmet supportive care needs and quality of life. More unmet supportive care needs predicted a poorer quality of life of breast cancer patients. **Recommendations**; Kenyatta national hospital should put particular emphasis on training and recruiting more psychosocial counsellors, Onco-psychologists and oncology nurse specialists besides the existing multidisciplinary team to address the psychological, health system information and sexual needs of patients with breast cancer hence improving their QOL. Further studies should be conducted in Kenya to determine effective methods in managing the supportive care needs of breast cancer patients using bigger study sample sizes.

CHAPTER ONE

1.0 INTRODUCTION

1.1 Background

Breast cancer is the most predominant type of tumor among females globally, with rising occurrences in developing countries. Breast cancer is associated with immense suffering, posing a significant burden on the economic and health status of the individual, family and society (Tompkins et al., 2016). Out of the 18.1 million cases of cancer diagnosed universally in 2018, 2.1 million (11.6%) were females with BC (Ferlay et al., 2019).

It has also been estimated that 47,887 cancer incidences were reported every year with 32,987 death rate. This represents approximately a rise of up to 45% of new cases in comparison with the earlier report that indicated 37,000 incidences yearly with an annual death rate of 28,500 in 2012 (Bray et al., 2018).

In Sub-Saharan Africa, Kenya registers the greatest risk of developing breast cancer (Joko-Fru et al., 2020) and in East Africa, it records the highest number of ill health and death associated with cancer attributing to 40% of the total annual mortality (Atieno et al., 2018). In Kenya, the 3rd topmost cause of death after the infectious and cardiovascular diseases is cancer; and the 3rd foremost of all cancer deaths after cancer of the oesophagus and cervix is breast cancer (Bray et al., 2018).

Cancer and its management pose a tremendous burden on both the patients and the family. The impact of cancer includes physical, social, psychological, and sexuality (Kim et al., 2007; Thorne et al., 2013). Also, breast cancer therapies which include chemotherapy, radiotherapy and surgery are associated with physical, emotional, and economic impacts. These impacts may be mitigated through support systems which could range from family, health care professionals (HCPs) and community. Therefore, it is essential to comprehend how support systems pacify the impact of cancer of the breast and related therapies (Tompkins et al., 2016; Gysels M, Higginson IJ, Rajasekaran M, Davies E, 2004).

From diagnosis to the last phases of adjuvant therapy are changeover periods of deprived adjustments and low QOL among PWBC (Montazeri et al., 2008; Rummans et al., 2006). This period requires extensive supportive care to both patients and caregivers. Caregivers' difficulties are intently related to patients' wellbeing (Milbury et al., 2013) and unresolved problems of caregivers affect both the outcome of health of the patients and their QOL undesirably (Hodgkinson, Butow, Hunt, Wyse, et al., 2007)

Patients diagnosed with BC receiving therapy in both high and low-income countries may have unsatisfied psychological, physical, informational and social supportive care needs throughout treatment. However, in underdeveloped countries, supportive care is usually given a low priority (Cardoso et al., 2013).

Visibly, not every breast cancer patient has identical supportive care needs; they vary with regards to disease stage, patient's age, social and cultural background of the patient, or patient's perceptions and may also alter at the time of treatment. These unmet needs may cause an unfavorable impact on the patients QOL (Fiszer et al., 2014)**.**

Recognizing and appreciating the full effect of unsatisfied needs on QOL of BC patients is central and very significant throughout their continuum of care. Hence incorporating suitable and effectual supportive care interventions into the already offered programs of breast cancer treatment is a vital element of a multidisciplinary and interdisciplinary advancement to the cancer care, extending survival and improving QOL of breast cancer patients (Epplein et al., 2011; NCI, n.d.)

From the general point of view, during cancer therapy, supportive care is crucial. It ought to be on hand, inexpensive, and reachable to every PWBC and their immediate family members. Nevertheless, supportive care needs in several instances are unmet probabl**y** as a result of less prioritization of supportive care by health care facilities with inadequate resources (Cardoso et al., 2013; Ganz et al., 2013).

The benefits of supportive care cannot be overemphasized yet poorly understood, especially in LMIC. Supportive care creates an integral portion of breast cancer treatment; therefore, extra efforts are essential to assess the care needs of BC patients and deliver the most excellent care in a multifaceted locale.

1.2 Problem Statement

Supportive care is a necessary intervention that ensures and improves the QOL of breast cancer patients by encompassing various portions of supportive care services (like educational, psychological support, physical (symptom control), spiritual support, social support, rehabilitation and bereavement support); this undertaking calls for multidisciplinary collaboration and coordination. Most of the breast cancer patients' needs are not constant, and they keep changing with time reliant on the disease progress, therapy and care offered. Unfortunately, these needs are persistently unmet. Even in the healthcare facilities, the support provided is varied and not comprehensive in any one single setting; probably due to less prioritization of supportive care by health care facilities with inadequate resources.

In Kenya, approximately half of the population of patients with BC are below the age of 50 years; and the majority of these patients are mothers, employees, or even small business proprietors (NCCS, 2017). This age group requires a lot of attention and support to deal with the symptoms of cancer, side effects of therapy, and the demands levied on them by the families and society. However, in Kenya, there has been no evidence of any study done to determine the SCNs of patients with cancer of the breast and how it impacts on their QOL. Still, most of the studies are mainly from western nations. Therefore, it was necessary for this study to examine the association between unmet supportive care needs and quality of life among PWBC receiving treatment at the Cancer Treatment Centre of KNH.

CHAPTER TWO

2.0 LITERATURE REVIEW

2.1 Introduction

Breast cancer is the commonest cause of morbidity and mortality among women with cancer which interferes significantly with their QOL; and over a million of these women, succumb to the disease annually (Williams et al., 2018).

Women who have cancer of the breast have the 5-year comparative survival rate slightly over 80% in high-income countries for those aged 55-64 years old (Katanoda & Matsuda, 2014). Majority of women with breast cancer go through physical and psychological intricacies in the 1st year after diagnosis and therapy; and years later due to treatment and disease complications (Ganz et al., 2013; Tomich & Helgeson, 2002).

Even if survival rates are increasing, patients with breast cancer are most likely to suffer from social, physical, psychological and sexuality concerns during and after therapy. Panic of relapse is one of the greatest irresistible fears, repeatedly generated by physical symptoms leading to psychological suffering (E. E. J. Pauwels et al., 2013; Richards et al., 2011), exhaustion, low energy and early menopause are frequently mentioned physical symptoms. Alterations in sexual function, reduced libido, altered physical appearance and body image worries can lead to caring and relationship concerns (Hui et al., 2013).

Accepting the loss and worry about the future are also vital worries. Towards the final phases of therapy, breast cancer patients feel deserted and helpless, detached from the evident security and safety of the hospital and healthcare professionals (HCPs). There are also reported issues of loss of opportunities and life roles (Glaser et al., 2013; Pennery & Mallet, 2000). Breast cancer patients mainly undergo emotional, physical and psychosocial turbulences and unsatisfied needs mostly in the periods following therapy unlike the periods during cancer care. Supportive care is a vital safeguard constituent of patients with cancer for the recovery of emotional stability, physical strength, cognitive function, social adjustment, body image and prospect perception (Amatya et al., 2014; C. H. Kroenke et al., 2013).

Refining QOL of patients with breast cancer necessitates tackling their unsatisfied needs. The needs assessment provides a straight forward evaluation of support preference and gaps in the delivery of health care services to patients. Understanding the insight of patients who have cancer of the breast and their unmet care needs sheds light on where actions and sharing of resources are essential in the healthcare institutions to support the patients and overcome their challenges (Carlson et al., 2012).

Besides the administration of anticancer therapies, a healthcare setting should pay attention towards recognizing the unfulfilled SCNs of patients with breast cancer which offers the chance to augment the QOL of these patients; and in the long run would lessen the usage and cost of healthcare (Akechi et al., 2011; Butow et al., 2012).

2.2 Supportive care needs

Supportive care is providing services that could enable BC patients, family members, together with their caregivers to deal with the ailment and its therapy during treatment to support the patient to make the utmost use of therapeutic benefits. This supportive care enables patients with breast cancer to deal with the impact of cancer from diagnosis to post-therapy periods (Au, 2012; Gysels M, Higginson IJ, Rajasekaran M, Davies E, 2004).

Patients with breast cancer from the rural setup have minimal contact with cancer support groups and mental health services. They encounter minimal positive individual attitudes and societal norms about the usage of healthcare resources as a purpose of residing in small rural societies compared to their counterparts from the urban areas (Andrykowski & Burris, 2010). Therefore, it is also of concern to look critically into the SCNs of breast cancer patients residing in the rural locale.

Unmet needs denoted the dissimilarity between the experiences of services of breast cancer patients and desired tangible benefits. A sizeable number of patients who have BC experience substantial unmet needs during their cancer course, with psychological needs being predominant and sexuality needs being the least. Unmet needs vary among patients residing in rural and those in urban areas, and this probably could have consequences for supportive care interventions (Carr & Wolfe, 1976; Edib et al., 2016). Specifically, the want to move long distances from home for treatment leads to interference with family and work demands hence raising a feeling of division and dislocation (Butow et al., 2012; Ann Bettencourt et al., 2007).

A deeper and broader understanding of the unsatisfied care needs of BC patients empowers healthcare deliverers to come up with a proven and customized actions. The significance of exploring the supportive care needs and their related influences on the QOL of BC patients in due course is influenced by how appropriately it informs the progress and achievement of interventions of a healthcare institution. Issues related to the patient's unmet needs can give proof for decision-making on resource healthcare allocation and ought not to be overlooked (Wang et al., 2018).

2.2.1 Physical Needs

Physical wellbeing is defined as the extent to which BC and its treatment affect the performance of a range of daily living activities. Pain-related to cancer has been associated with reduced performance status and poor QOL (Costa et al., 2017). Impaired Physical Health-Related QOL is characterized by the difference between an individual’s actual level of functioning and their excellent standard (Cella, 1994).

Predominantly, patients who have cancer of the breast have strong desires in their physical strength and how to handle pain amidst the numerous kinds of physical needs; which possibly could be the outcome of cancer therapy and ought to be watched on a timely basis to typify the point of unmet needs. Several works of literature agree with the suggestion that body weakness and physical pain are serious needs amidst patients who have cancer of the breast for the entire treatment and survivorship period (Berger et al., 2012). 14%–100% of patients who have cancer of the breast experience pain which is related to depression with the most significant consequence on their QOL and survival (K. Kroenke et al., 2010).

Continuous experience of symptoms related to treatment toxicity, ill-health, and related unmet needs could considerably affect QOL of PWBC and their positive shift from early to durable survivorship (K. K.F. Cheng et al., 2014) Therefore timely and suitable symptom management and physical rehabilitation are of greatest priority relying on the healthcare setting needs once the primary line of breast cancer therapy is complete (Edib et al., 2016; ESMO, 2015)

Well-established healthcare delivery systems found mainly in nations with high income enable a patient identification and resolution of problems associated with healthcare. Many physical symptoms require professional support of high quality. Programs of muscle stretching, physiotherapy, aquatic exercises, core stability exercises, muscle strength, and physical activity are likely to reduce fatigue hence improving the total QOL of breast cancer survivors (Karis Kin Fong Cheng et al., 2014; Garcia & Thomson, 2014).

2.2.2 Psychosocial needs

A breast cancer diagnosis is heartbreaking, therefore accepting the diagnosis, informing family members, planning for therapy and managing side effects may contribute to psychological pain and ill health in these patients (Maguire et al., 2015).

The most prevalent psychological syndromes amidst patient with breast cancer are depression, mood disorders, anxiety, and sexual dysfunction. It has been realized that immediately from diagnosis to periods following the initial therapy of cancer of the breast is long and extremely stressful, leading to psychological instability and depression; which is the most occurring comorbidities amidst breast cancer survivors, lessening their QOL and may lead to an escalation of healthcare cost (Hodgkinson, Butow, Hunt, Pendlebury, et al., 2007; Okediji et al., 2017).

Depressive symptoms range from 8 to 60% and anxiety disorders range from 12 to 60% among breast cancer patients in LMICs founded on reports from various studies from Korea, Turkey, the Czech Republic, Portugal, Spain, Croatia and India (Cardoso et al., 2013).

Psychosocial interventions and exercise lessen the psychological ill-health related to cancer for better daily functioning, QOL and assist patients with cancer of the breast in going through a smooth shift from treatment to recovery (Duijts et al., 2011; Tehrani et al., 2011).

Therefore, providers of healthcare services in LMICs should be trained on how to conduct a proper assessment, referral, and therapy of breast cancer psychosocial issues. This will ensure the best establishment of a multidisciplinary and interdisciplinary method to BC supportive care in addressing distress related psychosocial concerns, recognized to interfere with therapy adherence and recovery, worsen fears and subjective experiences of tiredness, insomnia, pain (Doumit et al., 2010; Riba et al., 2019) and may also affect the progression and survival of cancer patients (Rowlands et al., 2015; Urbaniec et al., 2011).

Social support is vital for the patient as part of cancer care. This encompasses the interaction with people sharing the allied experience of the effect of the disease on individual relationships. Social support is intensely related to the psychosocial domains of cancer care. Psychological care is very central for breast cancer patients with increased risk of developing depression and anxiety, necessitating applicable referral systems and access to inexpensive psychological specialists are required for the right psychosocial care (Macleduff et al., 2004; Tabrizi & Alizadeh, 2018).

In respect to this, supporting mental and physical health is an essential part of all associated healthcare programs (Williams et al., 2018). It is a collective goal among medical and healthcare communities to assist patients with breast cancer to attain the greatest imaginable QOL (Somjai & Chaipoom, 2006).

However, in Kenyan healthcare institutions, interventions for psychosocial support for patients with cancer are not yet well known. Consequently, constant patient physical reintegration and psychological care can contribute to reduced continual sufferings and aid them to adjust the course during and periods following the durable treatment path to improve their QOL.

2.2.3 Spiritual Needs

Spirituality is that part of humanity that depicts on how people look for and articulate experience, purpose and meaning on their attachment to self, life, others, sacred and to the moment rooted in matters like the meaning, control, identity and associations (Puchalski & Ferrell, B. (2011).

Understanding the spiritual themes including beliefs, community coping, transformation and practices that are active in patients' cancer experience is essential because most patients with cancer experience one or more spiritual concerns (Stefanek et al., 2005).

Patients with breast cancer search for comfort in the spiritual beliefs to confront cancer diagnosis and its challenges, which at times are related to positive psychological outcomes. Reduced levels of pain and social isolation, nervousness, anger and healthier coping in breast cancer patients are associated with religious and spiritual coping (Morgan et al., 2006; Puchalski, 2012).

Participation in reflection, yoga, and psycho-spiritual therapy is believed to lessen a series of physical symptoms (Kinney et al., 2003). Study results by (Berger et al., 2015) disclosed that cancer patients were in a position to bear the severe physical manifestations of the disease if they described the greater level of peace and meaning in their lives compared to those with lesser scores on peace and purpose.

Achievement of hope and positive state of mood, good wellbeing; the reduced level of hostility, nervousness, and social isolation, general wellbeing, and QOL are associated with improved spiritual wellbeing (Cotton et al., 1999; Wildes et al., 2009).

Patients experiencing existential benefits of the spiritual viewpoint are likely to have enhanced QOL, the zeal to live and cope with the disease. An incorporated holistic spiritual program for patients who survived breast cancer can support members to experience reduced distress, better QOL, a higher sense of wellness and deeper meaning of reason and life purpose (Kinney et al., 2003).

Implementation of spiritual programs may empower breast cancer patients to reexamine their goals in life, priorities, bases of meaning and life purpose, lessen emotional reactivity, and promote an appreciation for life and leads to better psychological adjustment to cancer following the critical phases of the illness and subsequent therapy. Spiritual group intervention is found to improve patients' hope, life satisfaction, and happiness, therefore, increasing their mental strength (Fallah et al., 2011).

In high-income countries (HICs), more excellent scores of spirituality are linked with greater perceived quality of life and contentment with the relationship between clinician and patient. Assessed independently from religious practice spirituality has been correlated with QOL, signifying that over-all pastoral counselling outside spiritual practice could be of help to breast cancer patients and looked at as a fraction of the support (Purnell & Andersen, 2009; Wildes et al., 2009).

2.2.4 Informational needs

Educational, supportive care may provide crucial information on cancer of the breast to allow better comprehension about the ailment, choice of therapy and the test results. While there are no provided procedures on family and patient education for supporting BC care, numerous study findings provide information on educational approaches and the significance of ethnically suitable communications (Jibaja-Weiss et al., 2006; Knoerl et al., 2011).

Patient education can be offered in a range of methods such as verbal, in print or video subject depending on the choice of a patient and practicability in particular countries. Providing printed information and internet-based interactive content to educated women can be the appropriate and effectual mode of delivering psycho-educational approaches and reach many people (Kreps & Sivaram, 2008; Tercyak et al., 2012).

Giving patient information improves adherence, management of pain, as well as providing satisfaction. This education throughout therapy ought to cover acknowledgement and management of treatment for particular organ-based toxicities and the effects on the health of women like infertility, early menopausal symptoms, sexual health and body image concerns (Chou & Lin, 2011; Ell et al., 2009).

Educational messages on possible psychosocial complications associated with treatment and the likely interferences to their usual social roles should be provided to breast cancer patients, including families and partners as suitable. Education of BC patients and their families in LMICs is a critical factor to the recovery of a patient and enhanced QOL. When breast cancer patients and family members understand what to expect, and the experienced disease manifestations are common and in many cases will resolve, can be reassuring and hasten recovery. Patients with breast cancer who underwent educational information and support described lesser nervousness, depression and marital difficulties (Odigie et al., 2009; E. Pauwels et al., 2012).

Several relatives or family caregivers of breast cancer patients frequently have unsatisfied educational needs hence experience more distress and depression compared to their relative or patient with breast cancer (Schmid-Büchi et al., 2011; Girgis et al., 2013).

Partners of BC patients should be involved in patient education with the express permission of the patient as culturally appropriate; this is because the majority of partners who received educational information indicated reduced anxiety, depression and marital distress (E. Pauwels et al., 2012).

Studies by (Binkley et al., 2012; Cheville & Tchou, 2007) found out that, symptoms that occur after cancer therapy were worse and took a longer time than expected with a feeling that they were not given practical information during treatment and were not introduced to suitable rehabilitation programs. Provision of information to cancer survivors is critical, and educational approaches are helpful and positively influence QOL of survivors (Tucholka et al., 2018).

Educational programs can aid to get rid of social and cultural traditions as well as assist in the management of social issues in helping families comprehend the influence of diagnosis and therapy of BC in family life and at the workplace. An in-depth understanding of traditional and cultural family intricacies, encompassing gender roles, and the type of social support offered in the diverse cultures is a component of the artistic capability of a health practitioner. The choice of a patient for a gender specific health practitioner ought to be valued and contained. Patients might choose for peer support as of their people of ethnic background. Audiotape, peer modelling videotapes, printed materials, telephone support and counselling must be included in patient and family education and delivered by health care specialists in a culturally sensitive manner (Kreps & Sivaram, 2008; Singh-Carlson et al., 2013).

2.2.5 Sexuality needs.

The health issues allied to breast cancer therapy comprise of change in body image, sexual health and untimely menopause. Body image and fertility ought to be considered during the treatment planning of patients. Sexual dysfunction and early menopausal symptoms can be an issue for mutually pre and post menopausal women as the consequence of systemic therapy for cancer (Munshi et al., 2010; Ruddy et al., 2011).

At the start of treatment, body image, sexual health, and other related reproductive health issues should be shared with patients. It is reported that over one-year post therapy was a considerable predictor of greater attention in a sexual health plan. In Nigeria, 38.3% of the 61.7% married patients who underwent mastectomy testified marital separation initiated by their spouses (Odigie et al., 2009). Therefore, particular propositions and behavioural sexual treatments can make significant progress in sexuality even if the stress on body changes could reduce gradually (Hill et al., 2011; Taylor et al., 2011).

For young patients who have breast cancer who are much concerned with fertility preservation, careful choice of chemotherapy regimens that do not interfere with DNA can be considered. Due to the significant number of diagnosis at a tender age, fertility is an upcoming BC care concern. Choices for female fertility preservation may consist of fertility clinics and cryopreservation of embryos or eggs (King et al., 2012; Lee et al., 2006; Niemasik et al., 2012).

2.3 Quality of Life

Definition of QOL differs from individual to individual and from study to study. As a concept, QOL has been both subjective and varied. QOL is subjectively defined as a complete appraisal of life and being satisfied with the present functioning level compared with what the breast cancer patients recognize to be real (Safaee et al., 2008).

The concept of QOL, especially concerning its dimensions, namely physical, psychosocial and spiritual is essential, considered subjective and depends on a person's judgment (Lavdaniti et al., 2019).

In patients who have breast cancer, QOL has received growing consideration as a result of the increasing cancer incidences, important women's roles in the community and better survival rates. The period after confirmation and therapy of cancer has a significant impact on QOL of breast cancer patients. Individuals who survive breast cancer for five or more years have been reported to have either similar or advanced quality of life compared to the overall population (Dorval et al., 1998).

Although QOL is critical and needs to be integrated into the care of cancer, many underdeveloped nations with increasing new cases of breast cancer have not prioritized it (Vanderpuye et al., 2017). When QOL among people who have breast cancer is understood, it can offer evidence regarding portions of supportive care essential and which requires improvement hence alleviating suffering.

2.4 Gaps in the Literature Review.

During the literature review, several gaps were identified. Most of the literature review on breast cancer patients' care support did not prioritize care needs assessment as a primary objective hence the information gathered might not be as comprehensive as it would have been if the primary purpose were assessing needs.

There is also not much literature providing proof on the influence of spirituality-based interventions on the diverse cultures. However, studies have shown the importance of religiousness in the QOL of patients with cancer (Jafari et al., 2013). This indicates the need to look at the influence of spirituality-based interventions in patients who have BC. Nevertheless, no proof exists on the outcome of spiritual therapy as far as spiritual health, and its relation to QOL of life is a concern.

All reviewed works of literature were restricted to English-language only yet there could have been some informative literature about SCNs of patients who have cancer of the breast published in other languages.

Several reviewed studies had the main focus on female breast cancer despite the title of the research using the word "patient and not women". Not much is evident about cancer of the breast in men; therefore, it should not be assumed that supportive care needs are similar in both men and women.

2.5 Theoretical Framework

This study adopted the SCNs Framework, which has been used in assessing the SCNs among cancer patients. Gray et al. (2002) stated that the Supportive Care Needs Framework (SCNF) was developed to guide healthcare professionals to ensure cancer patients' needs are met encompassing all the aspects of care and alongside the ailment continuum. Every domain of care is believed to differ across a continuum with varying points of priority, relying on the exclusive needs of the patient. According to (Kerr et al., 2004), each of the domain of the need of SCNF is predisposed by various external factors such as socioeconomic, culture, age, education, family, gender, social support, and personality.

The SCNF is widely used in oncology and views SCNs from a subjective and multidimensional perspective. In this study, the SCNs are viewed as independent, QOL as dependent on the unique perspective of the SCNs.

In this research, the five domains (physical and daily living, health system and information, psychological, sexuality needs, and patient care and support) of supportive needs were utilized as independent variables (Boyes et al., 2009).

2.6 Conceptual Framework (Boyes et al., 2009)

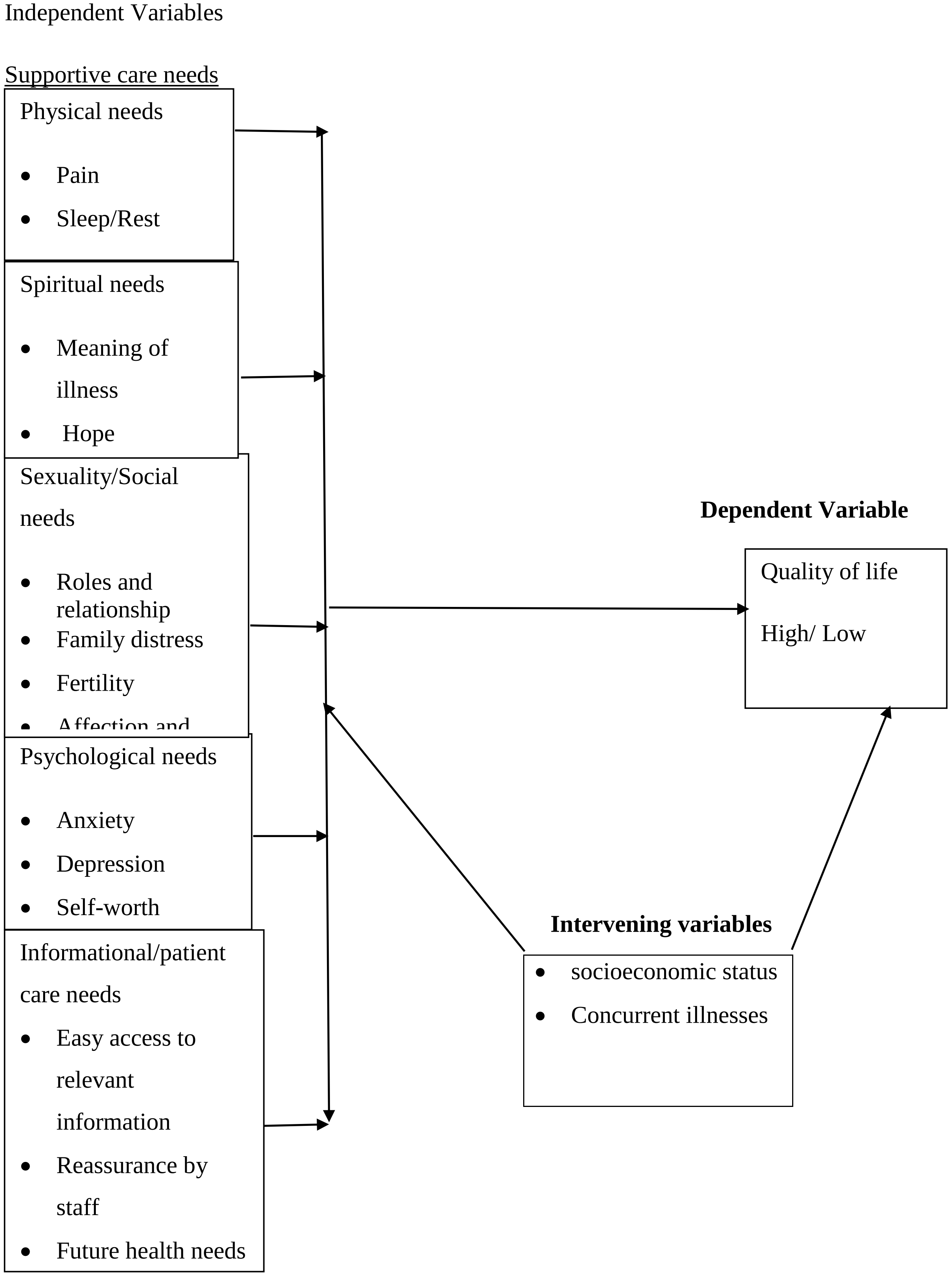

Figure 1: Conceptual Framework

2.7 Justification of the Study

Recognizing and appreciating the full effect of unsatisfied needs on QOL of BC patients is central and very significant throughout their continuum of care. (Epplein et al., 2011; NCI, n.d.). The findings from this study is expected to enrich health care providers with information as a basis to recognize the breast cancer patients with unsatisfied needs, shed more light on the areas of care which need more support and influence more research into specific care needs of the patients. It should also encourage the inclusion of supportive care services and needs in the nursing training curriculum.

2.8 Research Questions

i. What was the prevalence of unmet supportive care needs of patients with breast cancer at KNH?
ii. Were supportive care needs predictive of quality of life of patients with breast cancer at KNH?

2.9 Hypothesis

H_0: There is no difference in the quality of life between breast cancer patients who have unmet supportive care needs and those with met supportive care needs.

H_a: Breast cancer patients with met supportive care needs have a better quality of life than those with unmet supportive care needs.

2.10 Objectives

2.10.1 Broad Objective

Examined the association between unmet supportive care needs and quality of life among patients with breast cancer receiving treatment at KNH.

2.10.2 Specific Objectives

i. Determined the prevalence of unmet supportive care needs of patients with breast cancer on care at KNH.
ii. Determined if supportive care needs were predictive of the quality of life of patients with breast cancer on care at KNH.

CHAPTER THREE

3.0 METHODOLOGY

3.1 Introduction

Data and methods used to answer the objectives that were set by the study are presented in this chapter. It discusses the study design, area and population, the sample size calculation and the statistical techniques used for data management and analysis.

3.2 Study Design and Area

The study adopted a descriptive cross-sectional design to determine the SCNs of patients with breast cancer; in eight weeks of data collection. The study was conducted at Cancer Treatment Centre (CTC) of Kenyatta National Hospital, Nairobi, Kenya. This study area was chosen because currently, it is the largest referral and teaching hospital of the University of Nairobi (UON), College of Health Sciences in Kenya, and receives the largest number of cancer patients in the country. The Hospital was started in 1901 with a bed capacity of 40, and currently, it has a bed capacity of 2,000. It attends to a yearly average of 70,000 inpatients and 500,000 outpatients. KNH is located directly to the west of Upper Hill in Nairobi, and approximately 2.5 KM West of the central business area of Nairobi city. CTC is situated on the first floor of KNH and provides both outpatient and inpatient care to both new and revisiting cancer patients.

3.3 Study population

The study population comprised of BC patients receiving care at CTC of KNH during the data collection period. On average, the total number of cancer patients seen at CTC is approximately 4238 out of which 441 are patients with breast cancer per year (KNH, Medical Records and Information 2018). It has 25 specialized nurses and six oncologists and medical specialists who are consulted in case of comorbidities.\

3.4 Determination of Sample size

The sample size was determined by using Yamane Tore formula, which is a standard formula for a cross-sectional study for known population size. The Yamane formula according to Yamane Tore, 1967 is shown below

$$n = \frac{N}{[(1 + N(e)^2]}$$

Where: - n is the sample size of the adjusted population

N is the population size

e is an acceptable level of error taking alpha as 0.05.

Based on the statistical information from the hospital health records, the number of patients with breast cancer seen at the CTC is 441 in the year 2018 from January to December. The approximate number of patients diagnosed with breast cancer per month in 2018 is 36 patients. Replacing this number into the above formula, a sample size of 66 is got as shown below.

Calculation of sample size: $n = 36/1+36(0.05)^2$

$n = 36/1+36(0.0025)$

$n = 36/1+0.09$

$n = 36/1.09$

n = 33 X 2 =66(sample size for 2months)

3.5 Sampling Procedure

Recruitment of study participants was done using purposive sampling. Every eligible patient suffering from breast cancer receiving care at the cancer treatment centre, KNH, who consented to take part in the study, was interviewed. This process was repeated until the required number was achieved.

3.6 Recruitment and consenting Procedures

3.6.1 Inclusion criteria

1. All patients aged 18 years and above suffering from breast cancer irrespective of disease stage receiving care at CTC of KNH

2. All patients who had breast cancer and had no history of psychiatric disorders or occurrence of stressful conditions like the death of a close relative over the past three months
3. Patients who had breast cancer with the capability to speak English or Swahili and accepted to consent to participate in the study.

3.6.2 Exclusion criteria

1. All patients who had breast cancer but below 18years of age
2. Patients who had breast cancer and were not able to speak English or Swahili, and those who refused to consent to take part in the study.
3. All patients who had breast cancer and had a history of psychiatric disorders or occurrence of stressful diseases like the death of a close relative over the past three months

3.6.3 Consenting Procedure

The information sheet containing study information and the consent form was translated into Kiswahili (see Appendix IIA-D). Suitable participants were taken through the contents in the information sheet including the purpose of the study, procedures employed, voluntary study participation, probable benefits and risks, and participants' choice to withdraw at any time from the study without any consequences. The eligible research participants were allowed to seek clarifications on whatever aspects of the study that were unclear to them. Both verbal and written approval was sought from the appropriate participants before the beginning of interviews.

3.7 Data collection procedure, research tool, reliability and validity

Structured questionnaires were used to collect data (see Appendix I). They consisted of the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC QLQ-C30), the socio-demographic and disease characteristics of participants, and the Supportive Care Needs Survey-Short Form Questionnaire (SCNS-SF34). The SCNS-SF34 is a 34 item of supportive care needs questionnaire with five domains. The domains include physical and daily living, health system and information, psychological, patient care and support, and sexuality needs. SCNS-SF34 was validated in Australia, where it had an adequate internal consistency ($\alpha = 0.70$) and general construct validity of 72.1% with the total scores (Boyes et al., 2009). EORTC QLQ-C30 is a 30-item questionnaire consisting of five functional subscales (role, cognitive, emotional, physical, and social subscale); three symptom scales (nausea, vomiting and pain); Global Health (GH) Status and QOL scale. The frequently stated symptoms by cancer patients such as dyspnea, loss of appetite, insomnia, diarrhoea and constipation are determined by use of remaining single 5-items. EORTC QLQ-C30 was validated and had adequate internal reliability ($\alpha > 0.70$) and general construct validity ($r > 0.40$) with the total scores (Fayers & Bottomley, 2002). The tools are designed to assess the patients' personal experience in each of the domains and subscales. Eligible participants were ascribed to a quiet and confided area within the facility where the questionnaires were then administered. All the questionnaires were collected and reviewed daily for completeness and accuracy.

3.8 Pre-testing

A pre-test of the study tool was undertaken at Oncology ward GFD, KNH by the researcher; 10% of the sample size was used in the pretesting to determine the validity of the tool, identify areas of problem, reduce errors of measurement, reduce response burden, determine whether or not respondents were interpreting questions correctly, and ensure that the arrangement of items did not influence the way the respondent's answered. The study tool was therefore found valid and reliable.

3.9 Quality Assurance procedures

The C30 (EORTC QLQ-C30) and the SCNS-SF34 questionnaires were developed and validated with the internal consistency of 0.7 and above. A pre-test of these study tools was undertaken by the researcher assisted by the research assistants to determine the validity of the instrument. Eligible participants were ascribed to a quiet and confided area within the facility where the questionnaire was administered. All the questionnaires were collected and reviewed daily for completeness and accuracy.

3.10 Ethical considerations

Ethical clearance was sought from the UON/KNH ERC. Authorization to collect data was gained from the relevant authorities of Kenyatta National Hospital. The purpose, risks, and study benefits were explained to the respondents by the principal investigator and research assistants before obtaining verbal and written permission from the participants. Participation was voluntary, and all those who took part were told that they would pull out at any point from the study if they wished so with no consequence. Confidentiality was guaranteed to maintain the secrecy of the participants, and data collected was stored and protected in files with password.

3.11 Data management and analysis

The collected data was uploaded into a computerized database by the use of Kobo Collect. Later on, the data was exported to version 26.0 of the Statistical Package for the Social Sciences (SPSS) for analysis. Demographic variables, EORTC QLQ-C30 and SCNS-SF34 scores were analyzed using descriptive statistics. The relationship between independent and dependent variables were evaluated using spearman's rank correlation and multivariate linear regression. Data presentation was prepared in the form of frequency tables, pie charts and bar graphs.

3.12 Data Dissemination Plan

On completion, the study results were disseminated to;

1. The staff and the KNH management through the KNH research unit.
2. The KNH-UoN ERC
3. The school of Nursing Sciences (SONS)
4. The University of Nairobi Library
5. Shared with the public and other health care professionals through Presentations in professional conferences.
6. Published in peer review journals

CHAPTER FOUR

4.0 RESULTS

4.1 Introduction

This chapter presents the study results and is divided into descriptive statistics showing the socio-demographic and clinical characteristics of the study, the prevalence of unmet SCNs, and the relationship between the unmet supportive care needs and the quality of life of the respondents. The findings are presented using charts, graphs, and narratives for interpretation. All the 66 questionnaires disseminated to study respondents remotely and some physically were utterly filled and reimbursed, hence making the study record 100% response rate. All the respondents were Kenyan nationals.

4.2 Socio-demographic and clinical characteristics

This subsection shows the distribution of the socio-demographic and clinical characteristics of the respondents. The study enrolled a total of 66 participants who were all breast cancer patients receiving care at CTC of KNH.

4.2.1 Distribution of Age of respondents

Figure 2 shows that 45.5% (n=30) of participants were aged between 45-54 years. 30.3% (n=20) were aged between 25-44years. Those aged between 55years and above were 24.2% (n=16). The data indicates that most of the participants were aged between 45-54 years, 45.5% (n=30) while a few were aged between 55 years and above, 24.2% (n=16); indicating that all the study respondents were of age to respond to the questionnaires.

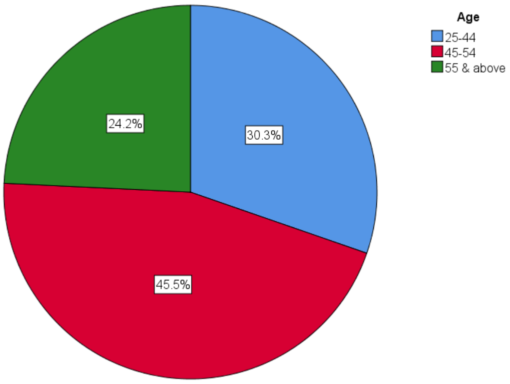

Figure 2: Age of respondents

4.2.2 Distribution of gender of respondents

In terms of the gender of the respondents, females were 95.5% (n=63) and only 4.5% (3) being male (Figure 3). The finding shows that female respondents were majority while only n=3 (4.5%) were male.

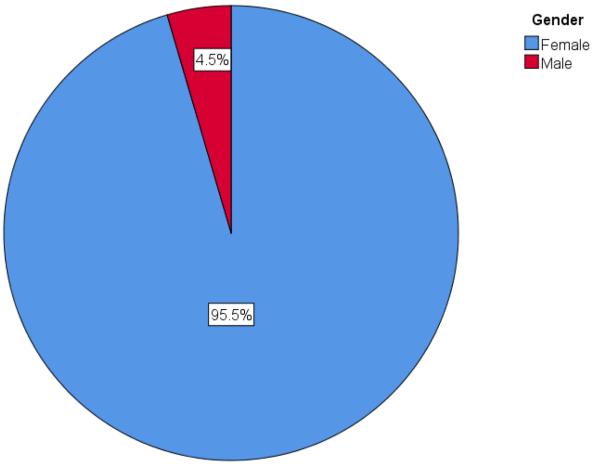

Figure 3: Gender of respondents

4.2.3 Distribution of education level of respondents

The distribution of respondents by level of education shows that 59.1% (n=39) reached secondary level of education, 34.8% (n=23) stopped at primary level and those who attained tertiary level of education were 6.1% (n=4). This finding indicates that the majority of the participants had reached secondary level of education while only a few attained tertiary education (Figure 4).

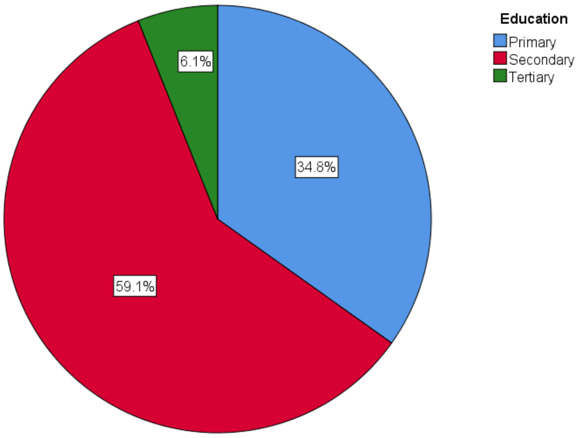

Figure 4: Education level of respondents

4.2.4 Distribution of the occupation of respondents

Figure 5 shows that most of the respondents were housewives 33.3% (n=22), followed by casual workers and self-employed 19.7% (n=13) each, 16.7% (n=11) had a background of formal employment, 7.6% (n=7) were peasant farmers while only 1.5% (n=1) was retired.

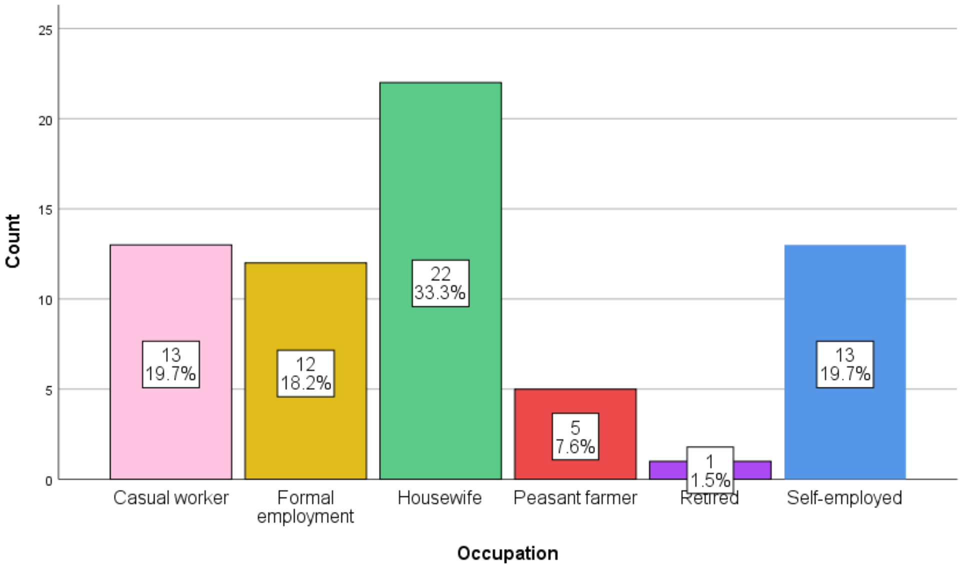

Figure 5: Occupation of respondents

4.2.5 Distribution of the marital status of the study respondents

In table1, the highest number of respondents in this study were married 75.8% (n=50) followed by 13.6% (n=9) who were single, and only 10.6%(n=7) were either widowed or separated.

Table 1: Marital status of the study respondents

MARITAL STATUS	FREQUENCY	PERCENTAGE (%)
Single	9	13.6
Married	50	75.8
Widowed/widower/separated	7	10.6
Total	66	100

4.2.6 Distribution of the religion of the study respondents

The Christian respondents were the majority in this study, with a percentage of 84.9% (n=56), followed by Islam with 12.1% (n=8) and 3% (n=2) indicated that they had no religion.

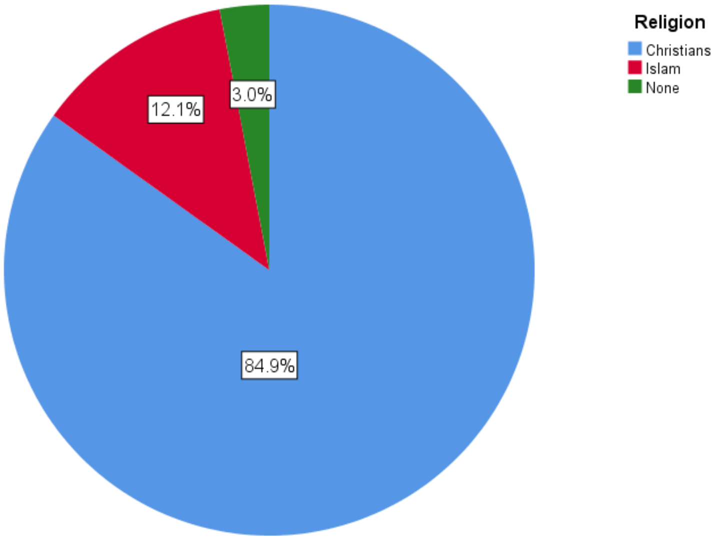

Figure 6: Religion of the respondents

4.2.7 Distribution of the monthly income of the study respondents

Most of the respondents earned a monthly income of between 5000 - 29,999 Ksh 57.6% (n=38). Those who earned less than 5,000 Ksh were 39.4% (n=26) and very few earned 30,000 Ksh and above 3.0% (n=2) in the study.

Table 2: Monthly income status of the study respondents

MONTHLY INCOME (KSHS)	FREQUENCY	PERCENTAGE (%)
Less than 5,000	26	39.4
5000 - 29,999	38	57.6
30,000 & above	2	3.0
Total	66	100

4.2.8 Place of residence of the study respondents

The majority of the respondents were residing in rural areas 75.8% (n=50), 13.6% (n=9) were from peri- urban areas and those from Urban setting were 10.6% (n=7).

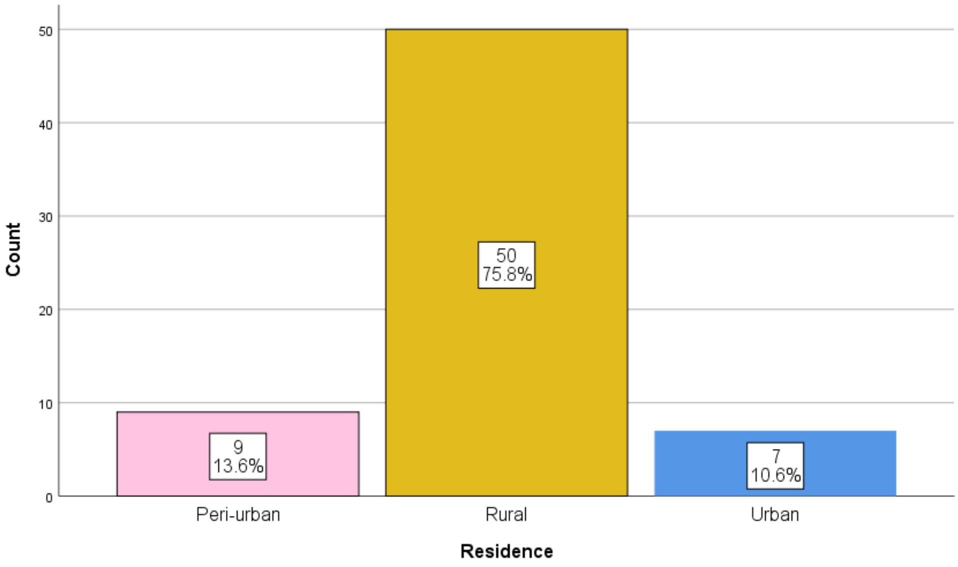

Figure 7: Place of residence of the study respondents

4.2.9 Time since diagnosis of the study respondents

In terms of the patient clinical factors, most of the patients had been diagnosed between 6 months – 1 year ago 59.1% (n=39), those who were diagnosed more than 1 year were 24.2% (n=16) and only 16.7% (n=11) were diagnosed less than 6months.

Table 3: Time since diagnosis of the study respondents

TIME SINCE DIAGNOSIS	FREQUENCY	PERCENTAGE (%)
Less than 6 months	11	16.7
6 months – 1 year	39	59.1
More than 1 year	16	24.2
Total	66	100

4.2.10 Time since initial therapy of the study respondents

In this study findings, 43.9% (n=29) of the respondents reported that they were on treatment for a period between 6 months - 1 year, 33.3% (n=22) were on treatment for less than 6 months and 22.8% (n=15) had been on treatment for more than 1 year.

Table 4: Time since initial therapy of the study respondents

TIME SINCE INITIAL THERAPY	FREQUENCY	PERCENTAGE (%)
Less than 6 months	22	33.3
6 months – 1 year	29	43.9
More than 1 year	15	22.8
Total	66	100

4.2.11 Distribution by type of therapy received by the study respondents

In terms of distribution by type of therapy received, more than half of the participants were undergoing single therapy 54.5% (n=36), and they were the majority, and 45.5% (n=30) were on combined therapies.

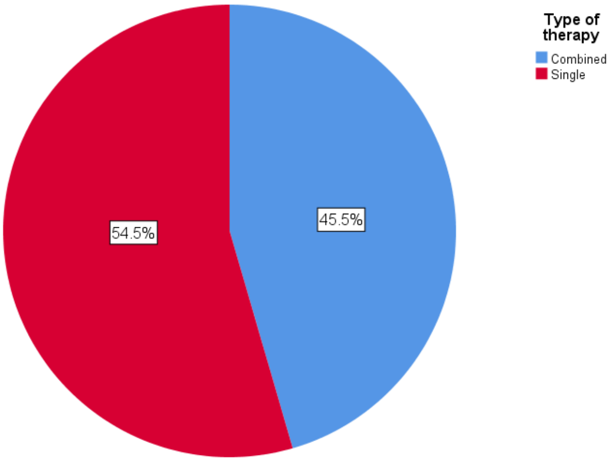

Figure 8: Type of therapy

4.3 Prevalence of unmet supportive care needs

The research findings under the prevalence of unmet needs revealed that, in the psychological domain, the most prevalent unmet needs were “fears about cancer spreading” at 98.5% (n=65) followed by “anxiety” and “worry that the results of treatment are beyond your control” each at 86.4% (n=57); uncertainty about the future, feelings about death and dying, and feeling down or depressed ranking third highest each 81.8% (n=54). Health system and information needs ranked 2nd highest with the most prevalent unmet needs being; being adequately informed about the benefits and side-effects of treatments before you choose to have them 81.8% (n=54), being given explanations of those tests for which you would like explanations 78.8% (n=52) and having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it 78.5% (n=51). Under patient care and support domains, the most prevalent unmet needs were reassurance by medical staff that the way you feel is normal 77.3% (n=51) followed by hospital staff acknowledging and showing sensitivity to your feelings and emotional needs 71.2% (n=47). The most prevalent need under the physical domain was lack of energy or feeling tired at 68.2% (n=45) while under the sexuality domain, changes in the sexual relationship of the patients were the most prevalent unmet need at 65.2% (n=43) followed by changes in sexual feelings 59.1% (n=39) and being given information about sexual relationships 57.6% (n=38).

4.4 Unmet supportive care needs domain score of PWBC (n = 66)

The results in Table 5 indicates that 75.2% (mean = 73.1; SD = 63.4) of the respondents had unmet SCNs in the psychological domain and it ranked highest. On the other hand, slightly more than half of the patients 52.4% (mean = 44.6; SD = 27.5) reported that they had unmet SCNs in the physical and daily living domain which ranked least.

Table 5: Unmet Supportive care needs domain score of PWBC

Rank	**Domain**	**%**	**Mean (SD)**
1	Psychological	75.2	73.1 (63.4)
2	Health systems and information	66.6	60.7 (41.9)
3	Patient care and support	62.4	60.1 (50.7)
4	Sexuality	60.6	59.7 (46.4)
5	Physical and daily living	52.4	44.6 (27.5)

4.5 Relationship between unmet SCNs and quality of life

Table 6 shows the correlations of unmet SCNs with QOL. We found negative correlations between the overall QOL and physical, psychological, sexuality, patient care and health system information domains (r=-0.014, *p=0.913;* r=-0.164, *p=0.188;* r=-0.21, *p*=0.91; r=-0.098, *p=0.433;* r=-0.025, *p=0.026*). However, they were all insignificant at 0.05% level of significance (p>0.05). These correlations imply that more unmet needs under all domains predict poorer QOL of BC patients at KNH. Regarding the functional scales, unmet supportive needs across all the domains significantly predicted higher functional scores, which implies that patients with more unmet needs had an unhealthy level of functioning. Under the symptom scales, unmet needs in the sexuality, health system information and psychological domains predicted more symptoms. The physical and patient care unmet needs predicted fewer symptoms, but the results were not significant.

Table 6: Spearman's correlation between SCNs domains and QOL

	Functional scales	Symptom scales	Overall QOL
Physical	0.334*	-0.055	-0.014
Psychological	0.570*	0.116	-0.164
Sexuality	0.367*	0.391*	-0.21
Patient care	0.297*	-0.018	-0.098
Health System Information	0.072	0.107	-0.025
*significant at 0.05 level of significance			

4.6 Multivariate linear regression to study the relationship between unmet needs and quality of life.

The results in table 7 indicate that unmet supportive care needs (sexuality domain) predicted lower overall quality of life (β=-0.056, p = 0.069). Also, the unmet supportive care needs in the sexuality and health information system domains predicted more symptoms for patients. The health system information domain also predicted lower functional QOL (β=-0. 162, p = 0.026). In the functional, symptom and overall quality of life domains, 41.5%, 14.7% and 3.6% (Adjusted R2 - Table 7) were explained by the unmet supportive care needs, respectively. In the functional scales, the strongest predictor was the unmet psychological needs (***Standardized Beta*** = 0.525), while in the symptom scales, the strongest was the sexuality unmet needs. The overall quality of life was predicted by sexuality unmet needs according to the results of this study.

Table 7: Multivariate linear regression for studying the relationship between SCNs and QOL

Quality of Life	**Unstandardized B**	**Standardized B**	**p-value**	**R2**	**Adjusted R2**
Functional					
Unmet supportive care needs					
Psychological	0.300	0.525	0.000*	0.460	0.415
Sexuality	0.131	0.214	0.033*		
Patient care	0.288	0.325	0.012*		
Health system Information	-0.162	-0.290	0.026*		
Symptoms					
Unmet supportive care needs					
Sexuality	0.305	0.388	0.001*	0.173	0.147
Health system Information	0.143	0.200	0.088		
Global Health Status					
Unmet supportive care needs					
Sexuality	-0.056	-0.225	0.069	0.051	0.036
* significant at the 0.05 level					

CHAPTER FIVE

5.0 DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 DISCUSSION

5.1.1 Introduction

This study determined the unmet supportive care needs and established the association between these needs and quality of life among breast cancer patients at Kenyatta national hospital. This is the first study to address the SCNs and its relationship with QOL among patients with breast cancer in KNH, Kenya. This chapter includes a discussion of significant findings and relates these results to the of previous studies; which eventually answered the research questions; i) what was the prevalence of unmet supportive care needs of PWBC at KNH? ii) Were SCNs predictive of quality of life of BC patients at KNH? The first section highlights the Socio-demographic characteristics of the study respondents. Discussion on the prevalence of the unmet SCNs of the respondents is in section two. In the third section, is a discussion of the findings regarding the relationship between supportive care needs and QOL of the respondents followed by conclusions and recommendations.

5.1.2 Socio-demographic characteristics of respondents

Majority of the respondents in this study were aged between 45-54 years, and a more significant percentage were female. These study findings is in disagreement with the study findings by (Joko-Fru et al., 2020) which revealed that the highest breast cancer incidence in sub-Saharan Africa was between the age of 50 years and above; also contrasting with research results by (UICC, n.d.) which established that the peak incidence of BC was between the age of 45 years and below. Another study by (NCCS, 2017) also found a contradicting result that in Kenya, the highest number of BC occurrence were below the age of 50years. However, in all these study results, the most significant incidence of BC are found in premenopausal women. This could probably be associated with reproductive risk factors like high estrogen levels in premenopausal women and marked reduction in estrogen concentration and declined fertility in postmenopausal women. There were also very few men with breast cancer in this study with varying age groups. It also concurs with the statistics from the American Cancer Society (ACS, n.d.) which discovered that historically, there are fewer men who develop breast cancer and this could be attributed to the fact that men have lower estrogen levels, they develop fewer breast milk ducts and lobules which predisposes to BC. However, men who might develop symptoms may also decide to ignore them because of the perceived stigma and fear of emasculation, hence get diagnosed at a later stage. Therefore men should be health educated on early breast cancer detection by performing breast self-examination and sensitized on the importance of seeking health care early when symptoms appear.

5.1.3 Prevalence of unmet supportive care needs

The BC patients at KNH reported psychological needs as the most frequent unmet needs followed by health systems and information needs, patient care and support needs, sexuality needs and physical needs being least. The most frequently reported unmet needs under the psychological domain of unmet SCNs were "fears about cancer spreading", followed by "anxiety", "worry that the results of treatment are beyond your control", feelings about death and dying and uncertainty about the future. These study results are compatible with the other studies which revealed that psychological needs were the most prevalent unmet needs among cancer patients (Brédart et al., 2013; A. Molassiotis et al., 2014).

A breast cancer diagnosis is heartbreaking, therefore accepting the diagnosis, informing family members, planning for therapy and managing side effects may contribute to psychological pain and ill health in these patients (Maguire et al., 2015). Therefore, there is need to train healthcare service providers at KNH to conduct a proper assessment, referral, and therapy of breast cancer patients' psychosocial needs. This will ensure the best formation of a multidisciplinary team in addressing psychosocial concerns, recognized to affect therapy adherence and recovery, worsen fears and anxiety, and intensify feelings of dying.

On the contrary, study findings by (Tucholka et al., 2018)) found that health systems and information needs were the most prevalent among BC patients. However, care needs amidst cancer patients are not static and may alter over time. Some scholars found out that there is an alteration in the trend of perceived care needs, from informational needs to psychological needs among cancer patients, quoting that advances in the delivery of information have led to the said change over the years (Fong & Cheah, 2016). This finding implies that a lot should be done to address the psychological needs of PWBC to harmonize the trend to favour the patients as well. Secondly, conflicting results could also arise due to patients characteristics, calculation of needs and assessment methods which vary widely across different countries and cultures leading to different results in other settings (Effendy et al., 2015; Alex Molassiotis et al., 2011).

(Hediya Putri et al., 2018) found out that physical needs were the most prevalent unmet needs among gynaecological cancer patients. The finding contradicts the results of this study where physical needs scored least. This could probably be as a result of KNH having a navigation program with more focus on physical navigation. This finding points out the significance of well-established navigation programs among cancer patients.

5.1.4 The relationship between unmet needs and QOL of respondents

The core findings of this study, therefore, revealed that unmet SCNs predicted a lower QOL among BC patients at KNH. Patients who stated more unmet needs also reported poorer overall QOL and an unhealthy level of functioning. This finding is consistent with the results of the previous studies by (Costa et al., 2017; Jibaja-Weiss et al., 2006; Okediji et al., 2017; Smith et al., 2013; So et al., 2014) who also found a relationship between unmet supportive care needs and QOL of cancer patients.

The highest predictor of the functional domain was the unmet psychological needs. A similar study by (Edib et al., 2016; Akechi et al., 2011) also discovered that unmet psychological needs led to the development of psychological syndromes which is the most occurring comorbidities among BC patients lessening their QOL. Therefore, interventions targeting psychological domain should be emphasised to reduce the psychological ill-health related to cancer for better daily functioning, QOL and assist PWBC go through a smooth shift from treatment to recovery.

Despite the fact that the highest predictor of the functional domain was the unmet psychological needs, unmet sexual needs were the most pertinent and strongest predictors for the symptom domains and global health status in both sexes in this research. The study findings are in conformity with the study results by (Odigie et al., 2009) which revealed that sexuality needs are the most important in predicting QOL of PWBC among married couples; he further explained that in Nigeria, 38.3% of the married patients who underwent mastectomy were divorced. The same results were found by (Hediya Putri et al., 2018). This could have been attributed by effects of cancer and its treatments which is extremely stressful, leading to psychological and sexual instability primarily affecting the married couples more than the un-married or other categories of relationships. Therefore, particular propositions and behavioural sexual treatments can promote significant progress in sexuality, even if the stress on body changes could reduce gradually.

The study findings are also in agreement with other studies that found that lack of enough treatment to address cancer and its side effects resulted in a low QOL of the patients (Bayram et al., 2014; Cramarossa et al., 2013; Hediya Putri et al., 2018). And it is also consistent with a study finding by (Hwang & Park, 2006) whereby sexuality needs were more likely to be expressed among married patients for support.

However, this finding was in contrast to study findings by (Afiyanti et al., 2016) who found that sexuality-related issues are looked at as a taboo, hence hindering the patients from openly voicing their sexuality needs considering the various cultural backgrounds among continents around the globe. (Afiyanti et al., 2016) also revealed that cancer patients might relax and take it for granted that sexual needs services are rarely offered in most health facilities and the different communities.

Sexuality concerns regarding symptom domain and global health status were strongly expressed among patients with breast cancer in KNH, probably as a result of the convenience of self-reported questionnaires used compared to if the in-depth interview approach was employed. However, further studies could be carried out to establish factors that have prompted PWBC in Kenya to be quite open with their sexuality needs compared with findings from other African communities. Besides, this finding makes intuitive sense, since married breast cancer patients have partners in whom they have confided and have desires to confront more frequently their sexuality needs, hence intensifying their needs.

5.2 Conclusion

Based on the findings of this study, it can be concluded that;

1) The most prevalent unmet needs of breast cancer patients were found in the psychological domain, followed by unmet needs in health systems information domain.
2) There was a correlation between unmet supportive care needs and quality of life. More unmet supportive care needs predicted a poorer quality of life of breast cancer patients.

5.3 Recommendations

Kenyatta national hospital should put particular emphasis on training and recruiting more psychosocial counsellors, onco-psychologists and oncology nurse specialists besides the existing multidisciplinary team to address the psychological, health system information and sexual needs of patients with breast cancer hence improving their QOL. Further studies should be conducted in Kenya to determine effective methods in managing the supportive care needs of breast cancer patients using bigger study sample sizes.

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APPENDICES

APPENDIX IA: QUESTIONNAIRE (ENGLISH VERSION)

Assessment of Supportive Care Needs and quality of life of Patients with Breast Cancer Receiving Treatment at Cancer Treatment Centre in Kenyatta National Hospital

Date……………………………………Serial Number……………….

Section 1.0 Socio- Demographic Data

Q 1.1 How old are you?

1. 18-24 years [ ] 2. 25-34 years [ ] 3. 35-44 years [ ]

4. 45-54 years [ ] 5. 55-64 years [ ] 6. 65 years and above [ ]

Q 1.2 What is your gender?

1. Male [ ] 2. Female [ ]

Q 1.3 What is your level of education?

1. None [ ] 2. Primary-not completed [ ] 3. Primary- completed [ ]

4. Secondary-not completed [ ] 5. Secondary- completed [ ]

6. Tertiary [ ] 7. Other [ ] (Specify) ……………………

Q 1.4 What is your occupation?

1. Housewife [ ] 2. Peasant farmer [ ] 3. Casual worker [ ] 4. Self-employed [ ]

5. Formal employment [ ] 6. Other [ ] (Specify)……………………

Q 1.5 What is your marital status?

1. Single [ ] 2. Married [ ] 3. Widowed [ ] 4. Separated [ ] 5. Divorced [ ]

6. Other [ ] (Specify)……………………

Q 1.6 What is your religion?

1. None [ ] 2. Protestant [ ] 3. Catholic [ ] 4. Islam [ ]

5. Other [ ] (Specify)……………………

Q 1.7 What is your average monthly income (In Kshs)/?

1. Less than 5,000 [ ]   2. 5,000-9,999 [ ]   3. 10,000-19,999 [ ]   4. 20,000-29,999 [ ]

5. 30,000-39,999 [ ]   6. 40,000-49,999 [ ]   7. More than 50,000 [ ]

Q 1.8 Where do you reside?

1. Urban [ ]   2. Periurban [ ]   3. Rural [ ]

Section 2.0 Clinical Characteristics

Q 2.1 When were you diagnosed with breast cancer?

1. Less than one month ago [ ]   2. One month ago [ ]   3. Two months ago [ ]

4. Three months ago [ ]   5. Four months ago [ ]   6. Five months ago [ ]

7. Six months ago [ ]   **8.** Other [ ] (Specify)……………………

Q 2.2 when did you start receiving treatment?

1. Less than one month ago [ ]   2. One month ago [ ]   3. Three months ago [ ]

4. Six months ago [ ]   5. One year ago [ ]   6. Other/ [ ] (Specify)……………………

Q 2.3 Have you received any treatment for the breast cancer?

1. Yes [ ]   2. No [ ]

Q 2.4 If yes, what type of treatment did you receive?

1. Chemotherapy [ ]   2. Surgery [ ]   3. Radiotherapy [ ]   4. Surgery and Chemotherapy [ ]

5. Chemotherapy and Radiotherapy [ ]   6. Other? [ ] (Specify)……………………

Q 2.5 Are you currently suffering from any other illness other than cancer?

1. Yes [ ]   2. No [ ]

Section 3.0 Supportive Care Needs Survey Short Form 34 (SCNS-SF34)

Instructions

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Put a circle around the number which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

NO NEED	1. Not applicable-This was not a problem for me as a result of having cancer 2. Satisfied-I did need help with this, but my need for help was satisfied at the time.
SOME NEEDS	3. Low need-This item caused me concern or discomfort. I had little need for additional help. 4. Moderate need – This item caused me concern or discomfort. I had some need for additional help. 5. High need - This item caused me concern or discomfort. I had a strong need for additional help**.**

For example

In the last month, what was your level of need for help with:

Being informed about things you can do to help yourself to get well	1	2	3	●	5

If you put the circle where we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

Now please complete the survey on the next 2 pages

In the last month, what was your level of need for help with:					
1.Pain	1	2	3	4	5
2. Lack of energy/tiredness	1	2	3	4	5
3. Feeling unwell a lot of the time	1	2	3	4	5
4.Work around the home	1	2	3	4	5
5.Not being able to do the things you used to do	1	2	3	4	5
6.Anxiety	1	2	3	4	5
7.Feeling down or depressed	1	2	3	4	5
8.Feelings of sadness	1	2	3	4	5
9.Fears about the cancer spreading	1	2	3	4	5
10.Worry that the results of treatment are beyond your control	1	2	3	4	5
11.Uncertainty about the future	1	2	3	4	5
12.Learning to feel in control of your situation	1	2	3	4	5
13.Keeping a positive outlook	1	2	3	4	5
14.Feelings about death and dying	1	2	3	4	5
15.Changes in sexual feelings	1	2	3	4	5
16.Changes in your sexual relationships	1	2	3	4	5
17.Concerns about the worries of those close to you	1	2	3	4	5
18.More choice about which cancer specialists you see	1	2	3	4	5
19.More choice about which hospital you attend	1	2	3	4	5
20.Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21.Hospital staff attending promptly to your physical needs	1	2	3	4	5
22.Hospital staff acknowledging, and showing sensitivity to your feelings, and emotional needs	1	2	3	4	5
23. Being given written information about the important aspects of your care	1	2	3	4	5
24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25. Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5

27. Being informed about your test results as soon as feasible	1	2	3	4	5
28. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29. Being informed about things you can do to help yourself to get well	1	2	3	4	5
30. Having access to professional counselling (eg, psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31. Being given information about sexual relationships	1	2	3	4	5
32. Being treated like a person not just another case	1	2	3	4	5
33. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

Thank you for completing this surve

Section 4.0. The European Organization for Research and Treatment of Cancer Quality of Life Questionnaire C30 (EORTC QLQ-C30)

	Not at All	A Little	Quite a Bit	Very Much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag?	1	2	3	4
2. Do you have any trouble taking a long walk?	1	2	3	4
3. Do you have any trouble taking a short walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4
During the past week				
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain**?**	1	2	3	4
10. Did you need to rest**?**	1	2	3	4
11. Have you had trouble sleeping**?**	1	2	3	4
12. Have you felt weak**?**	1	2	3	4
13. Have you lacked appetite**?**				
14. Have you felt nauseated**?**	1	2	3	4
15. Have you vomited**?**	1	2	3	4
16. Have you been constipated**?**	1	2	3	4
During the past week:				
17. Have you had diarrhoea**?**	1	2	3	4
18. Were you tired**?**	1	2	3	4
19. Did pain interfere with your daily activities**?**	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching?	1	2	3	4

21. Did you feel tense**?**	1	2	3	4
22. Did you worry**?**	1	2	3	4
23. Did you feel irritable**?**	1	2	3	4
24. Did you feel depressed**?**	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life**?**	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities**?**	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties**?**	1	2	3	4

For the following questions please circle the number between 1 and 7 that best applies to you

29. How would you rate your overall health during the past week?

1 2 3 4 5 6 7

Very poor Excellent

30. How would you rate your overall quality of life during the past week?

1 2 3 4 5 6 7

Very poor Excellent

APPENDIX IB: (KISWAHILLI VERSION)

KIAMBATISHO I: DODOSO

Tathmini ya mahitaji ya huduma ya kusaidia wanawake wenye saratani ya matiti kupokea matibabu katika kituo cha matibabu ya kansa katika hospitali ya Taifa ya Kenyatta

Tarehe…………………………… Namba tambulishi……………….

Section 1.0 Takwimu za kijamii na demografia

Q 1.1 Una umri gani?

1. 18-24 miaka [ ] 2. 25-34 miaka [ ] 3. 35-44 miaka [ ]

4. 45-54 miaka [ ] 5. 55-64 miaka [ ] 6. 65 miaka na juu [ ]

Q 1.2 Jinsia yako ni nini?

1. Kiume [ ] 2. Kike [ ]

Q 1.3 Kiwango chako cha elimu ni nini?

1. Hakuna [ ] 2. Msingi-sio kukamilika [ ] 3. Msingi umekamilika [ ]

4. Timirishi-haijakamilika [ ] 5. Ya pili iliyokamilika [ ]

6. Elimu ya juu [ ] 7. Nyingine [ ] Taja……………………

Q 1.4 Je, kazi yako ni ipi?

1. Mke wa nyumbani [ ] 2. Mkulima wadogowadogo [ ] 3. Mfanyakazi wa kawaida [ ]

4. Kujiajiri [ ] 5. Ajira rasmi [ ]

6. Nyingine [ ] Taja……………………

Q 1.5 Je, hali yako ya ndoa ni ipi?

1. Bado ndoa [ ] 2. Ndoa [ ] 3. Mjane [ ] 4. Kutengwa [ ]

5. Talaka [ ] 6. Nyingine [ ] Taja……………………

Q 1.6 Dini yenu ni ipi?

1. Hakuna [ ] 2. Kiprotestanti [ ] 3. Katoliki [ ] 4. Kiislamu [ ]

5. Nyingine [ ] Taja……………………

Q 1.7 Nini wastani wa mapato yako ya kila mwezi (katika shilingi)?

1. Chini ya 5,000 [ ] 2. 5,000-9,999 [ ] 3. 10,000-19,999 [ ] 4. 20,000-29,999 [ ]

5. 30,000-39,999 [ ] 6. 40,000-49,999 [ ] 7. Zaidi ya 50,000[ ]

Q 1.8 Wapi kukaa?

……………………………………………

Section 2.0 Tabia za kliniki

Q 2.1 Ni wakati gani wewe kukutwa na saratani ya matiti?

1. Chini ya mwezi mmoja uliopita [ ] 2. Mwezi mmoja uliopita [ ] 3. Miezi miwili iliyopita [ ]

4. Miezi mitatu iliyopita [ ] 5. Miezi minne iliyopita [ ]

6. Miezi mitano iliyopita [ ] 7. Miezi sita iliyopita [ ]

8. Nyingine [ ] (Taja)……………………

Q 2.2 lini ulianza kupokea matibabu?

1. Chini ya mwezi mmoja uliopita [ ] 2. Mwezi mmoja uliopita [ ] 4. Miezi mitatu iliyopita [ ]

5. Miezi sita iliyopita [ ] 6. Mwaka mmoja uliopita [ ] 7. Nyingine [ ] (Taja)…………….

Q 2.3 Umepokea matibabu yoyote kwa saratani ya matiti?

1. Ndiyo [ ] 2. La [ ]

Q 2.4 Kama ndiyo, ni aina gani ya matibabu Je, wewe kupokea?

1. Tibakemikali [ ] 2. Upasuaji [ ] 3. Radiotherapy [ ] 4. Upasuaji na tibakemikali [ ]

5. Tibakemikali na radiotherapy [ ]

6. Nyingine [ ] (Taja)……………………

Q 2.5 Je, Kwa sasa unaugua ugonjwa mwingine wowote isipokuwa saratani?

1. Ndiyo [ ]   2. La [ ]

Section 3.0 Utunzaji wa kusaidia unahitaji Fomu fupi ya utafiti 34 (SCNS-SF34)

Maelekezo

Ili kutusaidia kupanga huduma bora zaidi kwa watu ambao wamepatikana na kansa, tuna nia ya kama au mahitaji ambayo unaweza kuwa wanakabiliwa kutokana na kuwa na kansa wamekutana. Kwa kila kipengele kwenye kurasa zifuatazo, zinaonyesha kama unahitaji msaada na suala hili katika mwezi uliopita kama matokeo ya kuwa na kansa. Weka duara karibu na namba ambayo inaelezea vyema kama unahitaji msaada na hii katika mwezi uliopita. Kuna majibu 5 yanayowezekana. kuchagua:

HAKUNA HAJA	1. Haiwezi kutumika-hii haikuwa tatizo kwangu kama matokeo ya kuwa na kansa 2. Kuridhika-mimi ninahitaji msaada kwa hili, lakini haja yangu ya msaada alikuwa kuridhika wakati huo.
BAADHI YA MAHITAJI	3. Mahitaji ya chini-kipengee hiki kimesababishwa na wasiwasi au usumbufu. Nilikuwa na haja ndogo ya msaada wa ziada 4. Mahitaji ya wastani-kipengee hiki kimesababishwa na wasiwasi au usumbufu. Nilikuwa na haja fulani ya msaada wa ziada. 5. Mahitaji makubwa-kipengee hiki kimesababishwa na wasiwasi au usumbufu. Nilikuwa na haja kubwa ya msaada wa ziada.

Kwa mfano

Katika mwezi uliopita, ni kiwango chako cha haja ya msaada na:

Kuwa taarifa kuhusu mambo unaweza kufanya ili kujisaidia ili kupata vizuri	1	2	3	●	5

Kama kuweka mduara ambapo tuna, ina maana kwamba si kupokea maelezo mengi kama wewe alitaka kuhusu mambo unaweza kufanya ili kujisaidia mwenyewe kupata vizuri, na hivyo zinahitajika baadhi ya habari zaidi.

Sasa Tafadhali kamilisha utafiti katika kurasa 2 zinazofuata.

Katika mwezi uliopita, ni kiwango chako cha haja ya msaada na:					
1. Maumivu	1	2	3	4	5
2. Ukosefu wa nishati/uchovu	1	2	3	4	5
3. Kuhisi kutokuwa na wakati mwingi	1	2	3	4	5
4. Kazi karibu na nyumba	1	2	3	4	5
5. Si kuwa na uwezo wa kufanya mambo ambayo umetumia kufanya	1	2	3	4	5
6. Wasiwasi	1	2	3	4	5
7. Kuhisi chini au huzuni	1	2	3	4	5
8. Hisia za huzuni	1	2	3	4	5
9. Hofu kuhusu saratani ya kueneza	1	2	3	4	5
10. Wasiwasi kwamba matokeo ya matibabu ni zaidi ya udhibiti wako	1	2	3	4	5
11. Wasiwasi kuhusu siku zijazo	1	2	3	4	5
12. Kujifunza kuhisi katika kudhibiti hali yako	1	2	3	4	5
13. Kuweka mtazamo mzuri	1	2	3	4	5
14. Hisia kuhusu kifo na kufa	1	2	3	4	5
15. Mabadiliko katika hisia za kimapenzi	1	2	3	4	5
16. Mabadiliko katika mahusiano yako ya ngono	1	2	3	4	5
17. Wasiwasi kuhusu wasiwasi wa wale walio karibu nawe	1	2	3	4	5
18. Zaidi ya uchaguzi kuhusu ni wataalamu wa kansa unaweza kuona	1	2	3	4	5
19. Chaguo zaidi kuhusu ni hospitali gani unayohudhuria	1	2	3	4	5
20. Uhakikisho na wafanyakazi wa afya kwamba njia unayojisikia ni ya kawaida	1	2	3	4	5
21. Wafanyakazi wa hospitali wakihudhuria haraka kwa mahitaji yako ya kimwili	1	2	3	4	5
22.Wafanyakazi wa hospitali kukubali, na kuonyesha unyeti kwa hisia zako, na mahitaji ya kihisia	1	2	3	4	5
23. Kupewa habari zilizoandikwa kuhusu vipengele muhimu vya utunzaji wako	1	2	3	4	5

24. Kupewa habari (zilizoandikwa, michoro, michoro) kuhusu vipengele vya kusimamia ugonjwa wako na madhara nyumbani	1	2	3	4	5
25. Kupewa maelezo ya majaribio hayo ambayo ungependa maelezo	1	2	3	4	5
26. Kuwa na taarifa za kutosha kuhusu faida na madhara ya matibabu kabla ya kuchagua kuwa na	1	2	3	4	5
27. Kuwa na taarifa kuhusu matokeo ya mtihani mara tu iwezekanavyo	1	2	3	4	5
28. Kuwa taarifa kuhusu kansa ambayo ni chini ya udhibiti au kupungua (kwamba ni, msamaha)	1	2	3	4	5
29. Kuwa taarifa kuhusu mambo unaweza kufanya ili kujisaidia ili kupata vizuri	1	2	3	4	5
30. Kupata ushauri wa kitaalamu (kwa mfano, mwanasaikolojia, mfanyakazi wa jamii, mshauri, muuguzi mtaalamu) kama wewe, familia au marafiki haja yake	1	2	3	4	5
31. Kupewa habari kuhusu mahusiano ya kingono	1	2	3	4	5
32. Kuwa kutibiwa kama mtu si tu kesi nyingine	1	2	3	4	5
33. Kuwa kutibiwa katika hospitali au kliniki ambayo ni kama mazuri kimwili iwezekanavyo	1	2	3	4	5
34. Kuwa na mwanachama mmoja wa wafanyakazi wa hospitali ambaye unaweza kuzungumza juu ya nyanja zote za hali yako, matibabu na kufuatilia	1	2	3	4	5

Asanteni kwa kukamilisha utafiti huu

Section 4.0 Shirika la Ulaya kwa ajili ya utafiti na matibabu ya ubora wa kansa ya C30 ya maisha Dodoso (EORTC QLQ-C30).

	Sivyo hata kidogo	Kidogo	Wastani	Nyingi sana
1. Je, una shida kufanya shughuli strenuous, kama kubeba mfuko nzito ya ununuzi	1	2	3	4
2. Je, una shida yoyote kuchukua kutembea kwa muda mrefu?	1	2	3	4
3. Je, una shida yoyote kuchukua kutembea fupi nje ya nyumba?	1	2	3	4
4. Je, unahitaji kukaa kitandani au kiti wakati wa mchana?	1	2	3	4
5. Je, unahitaji msaada kwa kula, dressing, kuosha mwenyewe au kutumia choo?	1	2	3	4
Katika wiki iliyopita:				
6. Je, ulikuwa mdogo katika kutenda ama kazi zako za kila siku?	1	2	3	4
7. Je, ulikuwa mdogo katika kutafuta Hobby au shughuli nyingine za wakati wa burudani?	1	2	3	4
8. Je, wewe una pumzi?	1	2	3	4
9. Je, una maumivu?	1	2	3	4
10. Je, unahitaji kupumzika?	1	2	3	4
11. Una shida ya kulala?	1	2	3	4
12. Je, umehisi dhaifu?	1	2	3	4
13. Je, wewe akipungukiwa na hamu?				
14. Je, umehisi kwa ana?	1	2	3	4
15. Je, akamtapika?	1	2	3	4
16. Je, umewahi kuwa na nguvu?	1	2	3	4
Katika wiki iliyopita:				
17. Una kuhara?	1	2	3	4
18. Je, ulikuwa nimechoka?	1	2	3	4
19. Je, maumivu ya kuingilia kati na shughuli yako ya kila siku?	1	2	3	4

20. Je, una ugumu katika kuzingatia mambo, kama kusoma gazeti au kuangalia	1	2	3	4
21. Je, unajisikia kuwa na wasiwasi?	1	2	3	4
22. Je, una wasiwasi?	1	2	3	4
23. Je, unajisikia hasira?	1	2	3	4
24. Je, unajisikia kuwa na huzuni?	1	2	3	4
25. Je, una ugumu kukumbuka mambo?	1	2	3	4
26. Je, hali yako ya kimwili au matibabu waliingilia na maisha yako ya familia?	1	2	3	4
27. Je, hali yako ya kimwili au waliingilia matibabu na shughuli zako za kijamii?	1	2	3	4
28. Je, hali yako ya kimwili au tiba ya kimatibabu imesababisha matatizo ya kifedha?	1	2	3	4

Kwa maswali yafuatayo Tafadhali weka nambari kati ya 1 na 7 ambayo inatumika zaidi kwako

29. Je, unaweza kupima afya yako kwa jumla katika wiki iliyopita?

1 2 3 4 5 6 7

Maskini Sana bora

30. Je, ungependa kiwango chako cha maisha kwa jumla katika wiki iliyopita?

APPENDIX IIA: CONSENT EXPLANATION (ENGLISH VERSION)

I. Purpose

My name is Adong Lucy Ruth, a postgraduate student at the University of Nairobi. I am inviting you to participate in a study I am conducting in this unit. The purpose of this study is to obtain your experience as a breast cancer patient in the treatment being offered in this hospital. This study is being conducted in this unit with permission from the management of the hospital. I am requesting you to participate in this study since you are one of the patients receiving care in cancer treatment centre.

II. Procedure

If you agree to participate in the study, then you will be required to respond to questions in an interview which will take approximately 30 minutes.

III. Risks

There is no physical harm that will be inflicted on you during this process since it does not involve an invasive procedure but there are minimal risks to you for participating in this study. There is a possibility that some of the questions you will be asked may make you uncomfortable. Should this happen feel free to inform the interviewer and the interview will be temporarily stopped. A counselling session will be held in such cases to support you as a patient as need be.

IV. Benefits

This study may not benefit you directly but your participation and the findings from this study will provide important information that will be used to improve care for cancer patients.

V. Voluntary Participation and Withdrawal

Your participation in the study is completely voluntary. You are free to decline participating in the study or withdraw from the interviews at any point. Your decision will not lead to any form of victimization or bias in the subsequent medical care in this hospital.

VI. Confidentiality

Some questions may involve providing personal information but the information provided will be kept confidential and anonymous. Your personal particulars will not be included in the questionnaire or any written reports from this study. Information collected will be saved in password protected files and computers.

VII. Contact Persons

Should you have any questions or concerns about the content of this study or your rights as a participant in this study, feel free to contact the researcher, Adong Lucy Ruth, School of Nursing Sciences, University of Nairobi, mobile 0742375516; email – lucyruth84@gmail.com. The lead supervisor Dr. Kirui Angeline, School of Nursing Sciences, University of Nairobi, mobile 0720440665. You may also contact the Chairperson of Ethics and Research Committee, KNH/UON through the following address: University of Nairobi, College of Health Sciences, P. O. Box 19676-00202 Nairobi or Tel no. +2542726300 Ext 44102.

APPENDIX IIB: CONSENT FORM (ENGLISH VERSION)

I. Confirmation of consent

I confirm that I have read the consent information and received an explanation on the purpose and benefits of the study. I have had a chance to ask all questions regarding the study. I hereby voluntarily agree to participate.

Name: …………………………………………………

Sign: ………………………………….. Date: ………………………

Researcher …………………………. ……………………

Sign: ………………………………….. Date: ………………………

II. Contact Persons

Should you have any questions or concerns about the content of this study or your rights as a participant in this study, feel free to contact the researcher, Adong Lucy Ruth, School of Nursing Sciences, University of Nairobi, mobile 0742375516; email – lucyruth84@gmail.com. The lead supervisor Dr. Kirui Angeline, School of Nursing Sciences, University of Nairobi, mobile 0720440665. You may also contact the Chairperson of Ethics and Research Committee, KNH/UON through the following address: University of Nairobi, College of Health Sciences, P. O. Box 19676-00202 Nairobi or Tel no. +2542726300 Ext 44102.

APPENDIX IIC: CONSENT EXPLANATION (SWAHILI II VERSION)

I. Lengo

Kwa majina naitwa, Adong Lucy Ruth, mwanafunzi katika chuo kikuu cha Nairobi.

Nakualika kushiriki katika utafiti ninaoufanya katika kliniki hiki. Lengo kuu la kufanya utafiti huu ni kupata kufahamu munayoyapitia kama wagonjwa wanaougua Saratani wahudumiwapo katika kliniki hiki. Utafiti huu umeidhinishwa na wasimamizi wa hospitali hii. Ukiwa mmoja wa wagonjwa wanaohudumiwa katika kliniki hiki, nakuomba uweze kushiriki katika utafiti huu.

II. Mikakati itakayofuatwa

Ukikubali kushiriki katika utafiti huu, utahitajika kujibu maswali utakayoulizwa katika mahojiano utakayokuwa nayo na mtafiti ambayo yatachukua muda wa dakika ishirini na tano.

III. Madhara yanayokusudiwa

Hakuna madhara yoyote utakayoyapata katika zoezi hili lakini huenda baadhi ya maswali utakayoulizwa yakakukera kidogo. Hili likitendeka kuwa huru kumjulisha anayekuhoji ili asimamishe hayo mahojiano na aweze kulishughulikia jambo hilo

IV. Faida ya utafiti

Utafiti huu huenda usikufaidi kibinafsi lakini kushiriki kwako huenda kukaibua matokeo yatakayosaidia kuimarisha huduma munayopata katika kliniki hiki.

V. Kushiriki kwa hiari na Kujiondoa katika mahojiano

Kushiriki kwako katika utafiti huu ni kwa hiari yako. Uko huru kukataa kushiriki ama kujiondoa katika mahojiano utakayoshiriki na mtafiti wakati wowote. Uamuzi wako hautashawishi kwa vyovyote vile huduma utakayoendelea kupata katika hospitali hii.

VI. Usiri wa Mahojiano

Baadhi ya maswali utakayoulizwa yatahusisha utoaji wa maelezo kuhusu nafsi yako lakini majibu yote utakayoyatoa yatabakia kuwa siri na jina lako halitafichuliwa. Maelezo kuhusu nafsi yako hayatajumuishwa katika ripoti itakayoandikwa kutokana na utafiti huu. Maelezo haya yatafichwa katika tarakilishi zilizobanwa ambapo hakuna yeyote anayeweza kuyafikia.

VII. Mawasiliano na Wahusika

Ikiwa utakuwa na maswali ama jambo lolote ungependelea kujua kuhusiana na haki zako kama mshiriki katika utafiti huu, jisikie huru kuwasiliana na mtafiti, Adong Lucy Ruth, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0742375516; barua pepe – lucyruth84@gmail.com. Ama mwadhiri msimamizi wa mtafiti Dr. Kirui Angeline, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0720440665 . Waweza pia kuwasiliana na mwenyekiti wa kamati inayochanganuza maswala ya utafiti ya hospitali ya Kenyatta na Chuo Kikuu cha Nairobi kupitia sanduku la posta 19676-00202 Nairobi ama nambari ya simu +2542726300 Ext 44102.

APPENDIX IID: CONSENT FORM (SWAHILI VERSION)

I. Dhibitisho la Idhini

Mimi nadhibitisha ya kwamba nimeyasoma maelezo yaliyopo kuhusu utafiti huu na nimefafanuliwa zaidi kuhusu lengo na umuhimu wa utafiti huu. Nimepewa fursa ya kuuliza maswali kuhusiana na utafiti huu na nimeridhishwa. Nimeamua kwa hiari yangu kuidhinisha kushiriki kwangu katika utafiti huu.

Jina: …………………………………………………

Sahihi: ………………………………….. Tarehe: ………………………

Mtafiti ………………………. ……………………

Sahihi: ………………………………….. Tarehe: ………………………

II. Mawasiliano na Wahusika

Ikiwa bado utakuwa na maswali ama jambo lolote ungependelea kujua kuhusiana na haki zako kama mshiriki katika utafiti huu, jisikie huru kuwasiliana na mtafiti, Adong Lucy Ruth, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0742375516; barua pepe – lucyruth84@gmail.com. Ama mwadhiri msimamizi wa mtafiti Dr. Kirui Angeline, Shule ya Uuguzi, Chuo Kikuu cha Nairobi, namba za rununu 0720440665. Waweza pia kuwasiliana na mwenyekiti wa kamati inayochanganuza maswala ya utafiti ya hospitali ya Kenyatta na Chuo Kikuu cha Nairobi kupitia sanduku la posta 19676-00202 Nairobi ama nambari ya simu +2542726300 Ext 44102.

APPENDIX III: APPLICATION LETTER TO KNH/UON ERC

Adong Lucy Ruth,

School of Nursing Sciences,

College of Health Sciences,

The University of Nairobi.

1^{ts} August 2020.

The Chairperson,

KNH-UoN ERC,

P. O. BOX 19676-00202,

Nairobi.

Dear Sir/Madam,

RE: REQUEST FOR CLEARANCE TO CONDUCT RESEARCH

I am a second year post graduate student at the School of Nursing Sciences, University of Nairobi. I am writing to request your committee to kindly consider and approve my revised research proposal titled "**The association between supportive care needs and quality of life among patients with breast cancer at Kenyatta National Hospital, Kenya**".

Your kind consideration of the same will be highly appreciated.

Thank you.

Yours Faithfully

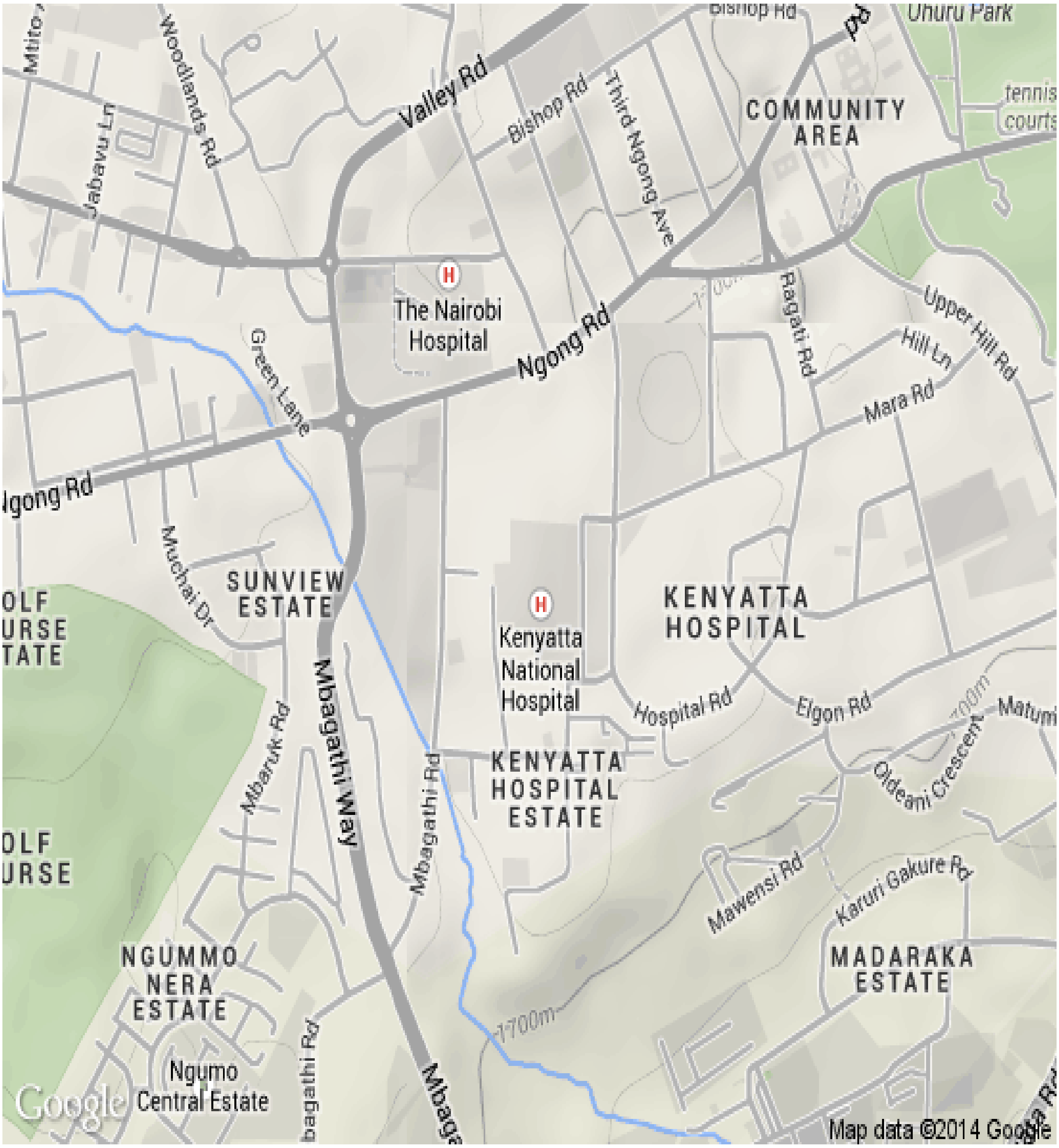
ADONG LUCY RUTH

H56/12682/2018

APPENDIX IV: PREVIEW OF STUDY AREA; KENYATTA NATIONAL HOSPITAL

Kenyatta National Hospital is the largest National and Referral Hospital in Kenya. It is the pinnacle of the referral system in the health sector in Kenya. It is located in the upper hill area, which is about 2.5 kilometres to the west of the Central Business District, in Nairobi City.

The hospital covers an area of about 45 hectares.



UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
Tel:(254-020) 2726300 Ext 44355

KNH-UON ERC
Email: uonknh_erc@uonbi.ac.ke
Website: http://www.erc.uonbi.ac.ke
Facebook: https://www.facebook.com/uonknh.erc
Twitter: @UONKNH_ERC https://twitter.com/UONKNH_ERC

KENYATTA NATIONAL HOSPITAL
P O BOX 20723 Code 00202
Tel: 726300-9
Fax: 725272
Telegrams: MEDSUP, Nairobi

Ref: KNH-ERC/A/267

17th August 2020

Lucy Ruth Adong
Reg.No.H56/12682/2018
School of Nursing Sciences
College of Health Sciences
University of Nairobi

Dear Lucy

RESEARCH PROPOSAL – THE ASSOCIATION BETWEEN SUPPORTIVE CARE NEEDS AND QUALITY OF LIFE AMONG PATIENTS WITH BREAST CANCER AT KENYATTA NATIONAL HOSPITAL, KENYA (P68/02/2020)

This is to inform you that the KNH- UoN Ethics & Research Committee (KNH- UoN ERC) has reviewed and **approved** your above research proposal. The approval period is 17th August 2020 – 16th August 2021.

This approval is subject to compliance with the following requirements:

a. Only approved documents (informed consents, study instruments, advertising materials etc) will be used.
b. All changes (amendments, deviations, violations etc.) are submitted for review and approval by KNH-UoN ERC before implementation.
c. Death and life threatening problems and serious adverse events (SAEs) or unexpected adverse events whether related or unrelated to the study must be reported to the KNH-UoN ERC within 72 hours of notification.
d. Any changes, anticipated or otherwise that may increase the risks or affect safety or welfare of study participants and others or affect the integrity of the research must be reported to KNH- UoN ERC within 72 hours.
e. Clearance for export of biological specimens must be obtained from KNH- UoN ERC for each batch of shipment.
f. Submission of a request for renewal of approval at least 60 days prior to expiry of the approval period. (*Attach a comprehensive progress report to support the renewal*).
g. Submission of an *executive summary* report within 90 days upon completion of the study.
This information will form part of the data base that will be consulted in future when processing related research studies so as to minimize chances of study duplication and/ or plagiarism.

For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY, KNH-UoN ERC

c.c. The Principal, College of Health Sciences, UoN
The Senior Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
The Director, School of Nursing Sciences, UoN
Supervisors: Dr. Angeline C. Kirui(UoN), Dr. Irene Mageto(UoN)

KNH/R&P/FORM/01

KENYATTA NATIONAL HOSPITAL
P.O. Box 20723-00202 Nairobi

Tel.: 2726300/2726450/2726565
Research & Programs: Ext. 44705
Fax: 2725272
Email: knhresearch@gmail.com

Study Registration Certificate

1. Name of the Principal Investigator/Researcher
ADONG LUCY RUTH

2. Email address: lucyruth84@gmail.com Tel No. ~~02~~ +256786519420

3. Contact person (if different from PI) —

4. Email address: — Tel No.

5. Study Title
THE ASSOCIATION BETWEEN SUPPORTIVE CARE NEEDS AND QUALITY OF LIFE AMONG PATIENTS WITH BREAST CANCER AT KENYATTA NATIONAL HOSPITAL KENYA.

6. Department where the study will be conducted CANCER TREATMENT CENTRE
(Please attach copy of Abstract)

7. Endorsed by Research Coordinator of the KNH Department where the study will be conducted.
Name: Robert Makori Signature Date 31/8/20

8. Endorsed by KNH Head of Department where study will be conducted.
Name: DR C. NYONGESA Signature Date 31/8/2020

9. KNH UoN Ethics Research Committee approved study number ______
(Please attach copy of ERC approval)

10. I ADONG' LUCY RUTH commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Medical Research.
for Signature Date 31st August 2020

11. Study Registration number (Dept/Number/Year) CTC / 86 / 2020
(To be completed by Medical Research Department)

12. Research and Program Stamp ______

All studies conducted at Kenyatta National Hospital <u>must</u> be registered with the Department of Research and Programs and investigators <u>must commit</u> to share results with the hospital.

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