SELF-MANAGEMENT NEEDS AMONG PATIENTS SUFFERING FROM BREAST CANCER DURING TRANSITION FROM ACTIVE TO MAINTENANCE PHASES OF SYSTEMIC THERAPY AT KENYATTA NATIONAL HOSPITAL

ANN WANJIRU GITAHI

MASTER OF SCIENCE
(Nursing)

JOMO KENYATTA UNIVERSITY
OF
AGRICULTURE AND TECHNOLOGY

2024

Self-Management Needs among Patients Suffering from Breast Cancer during Transition from Active to Maintenance Phases of Systemic Therapy at Kenyatta National Hospital

Ann Wanjiru Gitahi

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Science in Nursing (Oncology and Palliative Care) of the Jomo Kenyatta University of Agriculture and Technology

2024

DECLARATION

This thesis is my original work and has not been presented for a degree in any other university

Signature……………………………………………….Date …………………………

Ann Wanjiru Gitahi

This thesis has been submitted for examination with our approval as the University Supervisors

Signature……………………………………………….Date …………………………

Dr. Drusilla Makworo, PhD
JKUAT, Kenya

Signature……………………………………………….Date …………………………

James Odero Ochieng, MScN
JKUAT, Kenya

DEDICATION

I dedicate this work to my family members (my husband, my children, siblings, and my parents) for their encouragement to see me walk this journey. Also, to patients suffering from breast cancer who helped with the data, I forever remain grateful.

ACKNOWLEDGEMENT

I acknowledge my supervisors Dr. Drusilla Makworo and James Odero Ochieng for the countless times I had to seek their support and the selfless dedication they had to my work. May our good Lord bless them abundantly. Secondly, I want to thank my Research Assistants, especially Margaret Kimani, Robert Makori, and Morris Muriithi from KNH cancer treatment Centre for their efforts and commitment during data collection. I also want to thank JKUAT School of Nursing, KNH/UoN ERC, and Kenyatta National Hospital for granting the necessary approvals and clearance for my study. I'm grateful to all my classmates for the moral support they accorded me.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF APPENDICES

ACRONYMS AND ABBREVIATIONS

CTC	Cancer Treatment Center
FGD	Focus group discussions.
IOM	Institute of Medicine
KNH	Kenyatta National Hospital
KNH/UoN ERC	Kenyatta National Hospital/University of Nairobi Ethical Review Committee
MOH	Ministry of Health
NHIF	National Health Insurance Fund.
SCNS – SF 34	Supportive Care Needs Survey – Short Form 34
SPSS	Statistical Package for Social Sciences
UON	University of Nairobi
WHO	World Health Organization

DEFINITION OF OPERATIONAL TERMS

Active phase	administration of chemotherapy, following specific interval to allow the immune system to reconstruct before the other dose depending on the kind of drugs used.
Breast cancer	It's an abnormal growth cell that normally lines the ducts and the lobules.
Cancer self-management	It's a conscious and active contribution by cancer patients during the period of regaining. Physical health, convalescence, and restoration to reduce undesirable effects, promote survival and health well-being following treatment.
Cancer	It is a disease where abnormal cells divide without control with ability to invade adjacent parts of the body and/or spread to the near and distant organs
Health system & information needs	The health system and information domain assess needs related to the treatment center and for information about the disease, diagnosis, treatment, and follow-up.
Maintenance phase	Administration of hormone therapy which block the effects of estrogen on the growth of breast cancer cells or biological therapy which modifies the immune response so that the cancer cells are injured, killed, or prevented from dividing.
Self – management	This is the engagement of patients, along with family members and healthcare providers, in dealing with medical, behavioral, and emotional aspects of their health condition.

Self-management needs	These are gaps and problems experienced by patients as individual in conjunction with family, community, and healthcare professionals, in managing symptoms, treatments, lifestyle changes & psychosocial, cultural, and spiritual consequences of health condition.
Systemic therapy	Refers to the administration of chemotherapy, biologic therapy, or hormonal therapy.

ABSTRACT

Self-management benefits all patients in the cancer care trajectory from diagnosis, treatment, survivorship to the end of life. The study aimed at assessing self-management needs among breast cancer patients during transition from active to maintenance phase of systemic therapy at Kenyatta National Hospital. The study utilized explanatory sequential mixed methods (Analytical cross-sectional and phenomenological research designs). Cochran (1977) formula was used to determine the number of respondents, which was (169) on systemic therapy only and met the inclusion criteria, sampling technique utilized was census. Respondents gave informed consent to participate. Quantitative data was collected using a questionnaire and Supportive Care Needs Survey-Short Form 34 tool (SCNS SF 34). Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 23.0) to derive descriptive and inferential statistics. Core factors behind interdependence between correlated variables were identified using Principal Component Analysis via Rotated Component Matrix. Findings are presented in the form of tables, bar graphs and charts as appropriate. Qualitative data were collected through Focus group discussions (FGD) among patients with breast cancer who had not participated in quantitative study. NVIVO software version was utilized in thematic data analysis. Qualitative data from 3 focus group discussions. Findings were used to complement and explain quantitative results. A total of 169 participants took part in the study, (99.4%, n=168) were female, Majority were married (68.26%, n=115) and were from rural (63.9%, n=108) set up and n=73 (43.2%, n=73) had secondary level education. Majority (81%, n=137) had information about self-management. In psychological needs domain, the outstanding aspects for which additional help was needed was concerns about the worries of close relatives (20%, n=34). In the informational need's domain, items that patients expressed needed additional support was member of staff whom you can share with about your condition and follow-up (74%, n=125) and information about sexual relationships (62% n=105) Patient centered factor identified was financial constrains (87%, n=147). The study concludes that breast cancer patients at KNH had knowledge on self-management. However, they experienced psychological and informational needs during transition period. In addition, qualitatively; Physical and psychological symptoms, (2) Lack of information (3) Financial constraints are among the themes were created to support factors affecting self-; management. The principal component analysis rotation sums of squared loadings collectively explain 55.3% of total variance observed in the study and three major themes psychological needs accounted for 20%, informational needs accounted for 12.3% and staff related at 10%of the total variance.

The study recommends that the psychological and informational health system needs to be addressed.

CHAPTER ONE

INTRODUCTION

1.1 Background Information

Cancer is a large group of malignant diseases with abnormal cell proliferation. They lack controlled growth and cell division, and they have the ability to spread and involve other tissue (Hesketh, 2023).

Globally, breast cancer is leading with 11% of all cancer diagnosed and the second top cause of death among women in developed states. Breast cancer is the topmost cause of cancer related mortality among females, accounting for 15%. Records from various countries, Kenya included, indicate that in every four-cancers diagnosed globally one is a breast cancer and the highest number among women at 24.2% (WHO, 2018).

During active phase the patient is in close contact with the health care providers and most of the needs are likely to be identified and the necessary intervention given. However, in maintenance phase, care is enabled through the assistance of transitional coordinator led by a nurse and patients must cope with a wide range of physical signs, emotional/psychological, social, spiritual, and informational needs during transition.

Improved screening techniques, early detection and improved treatment modalities have decreased deaths related to cancer and enhanced survival rates of patients with breast cancer. This corresponds the rising number of female survivors with cancer of the breast enduring progressive consequences/morbidities related to breast cancer (Allemani, *et al.*, 2009).

Self-management denotes having confidential meetings with the patients, along with closest household members and providers, in handling the therapeutic, behavior, and emotional characteristics of their health state (Green, *et al.*, 2011). In relation to cancer, it’s a conscious and active contribution by cancer patient during the period of regaining physical health, convalescence, and restoration to reduce undesirable effects, promote survival and health well-being following treatment, which is still under-explored (Lawn *et al.,* 2012).According to Kim (2020) a substantial need for a constructive relationship with healthcare providers who, by respecting and communicating with them, would help empower them. Self-management is also defined as 'the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health, and well-being' and 'developing the skills needed to devise, implement, evaluate, and revise an individualized plan for lifestyle change (Orem,1991).

When demands on self-care exceed the ability to perform it results in a self-care deficit (Wei, 2016; McCorkle *et al.,* 2011). It has been revealed that the majority of survivors during active treatment phase experience difficulties in seeking additional knowledge and support (Foster, 2011, McCorkle *et al*., 2011 & Salvatore *et al*., 2016;). Moreover, studies based on SCNS-SF 34 among patients suffering from breast cancer have revealed that psychological needs were more perceived than other needs across the domain (Dwarswaard *et al*., 2016; Edib, 2016).

It is therefore important that they have access to the ideal self-management care services (Coulter, 2013; Gaspard, 2009; Given, 2012; Green, *et al.,* 2011; Makau-Barasa 2020; Matfin, 2009 & Parker,2016).

Studies have revealed that a transition appointment, treatment summary and information on continuation of care have helpful experience. Seamless transition promotes personal security for the period immediately after primary treatment, active participation on laid down plans, chance of going back to a place they are familiar and comfortable with and lastly an opportunity to screen for and address possible emotional symptoms they may be experiencing (Shea *et al.,* 2018; Wittal, 2018).Transition of patients occurs through an appointment diary that is built in clinical practice and it's done consistently. An appointment is done when the patient completes the active treatment and changing to a different therapy part of follow up care. Therefore, it's necessary that health care providers use anticipatory guidance to assess and address stressors in transition Period.

Studies indicate that patients wish to discuss their needs with the health care professionals and seek their guidance while trying new coping strategies, but professionals often perceive self-management as merely handing out written information and telling patients what to do. They also desire self-management be provided from a well conversant approachable health care providers who individualise patient care (Dwarswaard *et al.*, 2015). Therefore, this study aimed at describing the self-management needs among breast cancer patients during the transition period from active to maintenance phases of systemic therapy at the largest referral hospital in Kenya.

1.2 Statement of the Problem

Lung cancer and female breast cancer are the most commonly occurring cancers worldwide accounting respectively for 12.4% and 11.6% of total new cases. Further, breast cancer is among the cancers that can be screened routinely and have high rates of survival when detected and treated early (IARC 2016).

In Africa, female breast cancer is the most diagnosed cancer (11.7%) of total cancer cases. Mortality rates in sub-Saharan African regions have increased simultaneously and rank now in the world highest reflecting weak health infrastructure and subsequently poor survival outcomes (IARC 2016). Records from various countries, Kenya included, indicate that in every four-cancers diagnosed globally one is a breast cancer and the highest number among women at 24.2%. In Kenya breast cancer tops in yearly incidence with 5,985 new cases accounting for 12.5% of all new cases and 9.2 % in women alone (WHO,2018)

Patients with self-management challenges, especially with socioeconomic insecurity, may experience depression and emotional distress which leads to decreased motivation, prioritization skills and problem-solving skills. This eventually leads to negative emotions which affects self-confidence and self-efficacy.

According to Lorig and Holman (2003), self-management requires six self-management skills in the patient: decision making, action planning, development of a patient– provider partnership, self-tailoring, resource utilization and problem solving. However, between 25% and 80% of patients received contradictory information on their diseases and their management.

In regard to Self- management needs among individual clients and locally, no study was found and especially in the framework of transitions from active to maintenance phase of systemic therapy in breast cancer patients. Most research has been focusing on the transition from diagnosis to survivorship. No study was found addressing primary treatment especially the period from active phase to maintenance phases of treatment (Kantsiper *et al.,* 2009). Provision of self-management care expands accessibility to much needed information, rendering support in the direction of wellness in behavioral fluctuations allowing support from the peers. Loh, (2013), stated that "focused, systematic, and increased provision of self-management care can have positive impacts on overall self-management outcome even when the health system resource is inadequate.

According to Kim (2020), Self-management among patients with Breast cancer after treatment should focus on training Self-Management skills, enhancing the survivor-provider relationship, and building survivor self-confidence. These aspects missed among the patients seeking treatment at KNH.

Therefore, the main purpose of this study is to explore the self- management needs among breast cancer patients during transition from active treatment to maintenance phases of systemic therapy administration.

1.3 Justification of the Study

According to the America cancer society as quoted by Allemani *et al.,* (2009) improved screening facilities and enhanced treatment modalities have decreased the death rate and improved survival rates of breast cancer patients. This consequently leads to increased figures of breast cancer women with long term comorbidities which is termed as “chronic condition” hence an impact on care provision.

Well facilitated system adjustment to transition will lessen nervousness, depression, and doubt due to prior knowledge of what one expects and plan accordingly. Improved patients’ self-efficacy to self-care improves their knowledge and capability of aiming to their intention. Also, direct practices of healthcare incomes taking an enhanced thoughtful action towards achieving of their intended purpose of care have also been found to be beneficial (Anderson,2011).

Therefore, self-management benefits all patients in the cancer care trajectory points from diagnosis, treatment, end of life and survivorship. Many studies done have focused on self-management in transition from primary diagnosis to survivorship care. However, limited information exists on transition after active phase of treatment to continuation phase.

Self- management remains vital in assessing the needs which keep on changing, planning of survivor care plans, implementing the interventions that are related to specific needs and evaluating self -management needs during the process of transition. This study seeks to highlight self-management as a key component of chronic care models. Its findings would be used to support development towards quality improvement of cancer patients care implementation not only to breast cancer patients but also to other cancer patients. An insight on self-management practices is vital in ensuring quality of care to cancer patients even after leaving the hospital to their families and community at large.

1.4 Research Questions

1. What is the definition of self-management concept in relation to systemic therapy among patients with breast cancer?
2. What are the psychological needs among patients with breast cancer during transition from active to maintenance phase of systemic therapy at KNH?

3. What are the informational and health system needs among patients with breast cancer during transition from active to maintenance phase of systemic therapy at KNH?
4. What are the patient-centered factors affecting self-management among patients with breast cancer during transition period from active to maintenance phase of systemic therapy at KNH?

1.5 Objectives of the Study

1.5.1 Main Objective

To assess self-management needs among patients with breast cancer during transition from active to maintenance phase of systemic therapy at Kenyatta National Hospital

1.5.2 Specific Objectives

1. To define self-management concept in relation to systemic therapy among patients with breast cancer at KNH.
2. To assess psychological needs among patients with breast cancer during transition phase from active to maintenance phase of systemic therapy at KNH.
3. To assess informational and health system needs among patients with breast cancer during transition phase from active to maintenance phase of systemic therapy at KNH.
4. To determine patient-centred factors affecting self-management among patients with breast cancer during transition phase from active to maintenance phase of systemic therapy at KNH.

1.6 Theoretical Framework

According to Dorothea Orem’s theory of self-care deficit, nurse’ s role is to guide, support and teach persons to come up and practice abilities related to self-care aiming at the best level possible of quality of care. Though the nurse may be the overall coordinator of care in these situations, other individuals and disciplines are also involved. In her theory she describes user related concepts as: self-care, self-care agency, therapeutic self-care demand and self-care deficit (Orem DE 1991 & Wagnild, 1987).

This study adopts self-care deficit concept where Dorothea Orem states that self-care is the practice of activities that an individual initiates and performs on their own behalf in maintaining life, health and wellbeing while self-care agency is individual influence to involve in self-care and competence in responsibility the self -care (self- care agent) and call for therapeutic self -care in respect to well-being shortfall to those health changes that bring about the necessity for action to stop more complications or overcome existing deviation from health.

In this regard to breast cancer as a chronic condition which results to health changes and even permanent health deviations, self-care that's performed by oneself for oneself enabling consistent, controlled, effective and purposive action will be therapeutic in sustaining life and health in recovering from disease and coping with their effects. Therefore, this study used Dorothea Orem's self-care deficit model.

1.7 Conceptual Framework

The conceptual framework (**figure 1**) shows the study variables that have an influence in effective self-management needs.

The researcher's constructs were that the dependent variable and confounding factors impact greatly on the effective self-management needs.

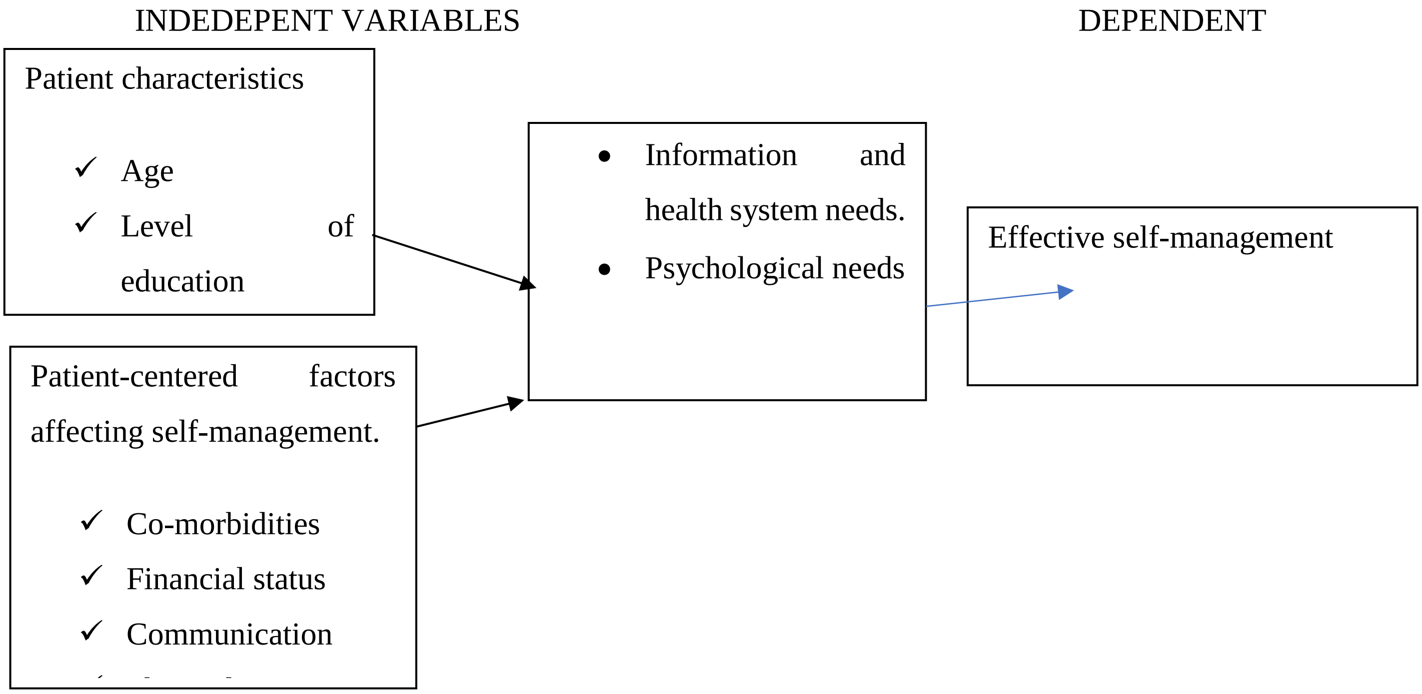


Figure 1.1: Conceptual Framework (Gitahi, 2024)

1.8 Limitations

1. The study explored only two domains of self-management and given that self-management has five domains, my study might not have captured all the aspects of self-management.
2. Respondents in the focused group discussion signed an individual consent but the social demographic was not captured during the discussion.
3. Patients were recruited from public hospitals where they may have different education levels and socio-economic status as compared to private hospital settings.

CHAPTER TWO

LITERATURE REVIEW

2.1 Epidemiology of Breast Cancer

Breast cancer records the highest number of cancers diagnosed among women at 24.2%, one in every four-cancer diagnosed globally one has breast cancer. Moreover, it's the topmost cause of cancer related mortality among females, accounting to 15.0% (WHO, 2018). This malignancy poses the greatest challenge in the victim's survivorship since they do not return to a pre-cancer diagnosis state after completion of active treatment (Wei *et al*., 2016).

According to Merab (2016) about 40,610 females and 460 males were predicted to die of breast cancer in 2017 and it was reported to have additional and hostile effects among Black women, who are reported to comprise 22.9% of all cancers in women.

In Kenya breast cancer is the top cancer in incidence with 5,985 new cases accounting for 12.5% of all new cancer cases and 9.2 % in women alone as cited by Globocan (2018). In Kenya, breast cancer accounts for 9.2 % of all cancer deaths making it the third top cause of all deaths in the country and commonest basis of cancer related mortality among females (WHO, 2018).

2.2 Self-Management

Self-management denotes the appointment of patients, along with close members of the family and clinical team members, in handling the therapeutic, behavior, and emotional characteristics of their health. Its significance to patients depends on the illness phase of their long-term illness and related concerns (Green *et al*., 2011). According to Green, *et al*., (2011) & McCorkle *et al*., (2011), self-management emphasis on illness needs, motivating incomes and living with a long-term illness.

Self-management is one among the essential elements identified in the Chronic Care model (Clark, 2012). According to Lipiäinen *et al.*, (2013) these identified basics mechanisms as well as the extents which are presently inadequate addressed, need to be researched further so as to reveal and address the recognized gaps.

Nursing self-care deficit theory established by Orem (1995) forms the conceptual structure of chronic conditions. When demands on self-care exceed self-care, the ability to performance is compromised leading to self-care deficit hence need for a nursing system of care. Self-management is one way that individuals can cope with these many new and different demands due to chronic illness.

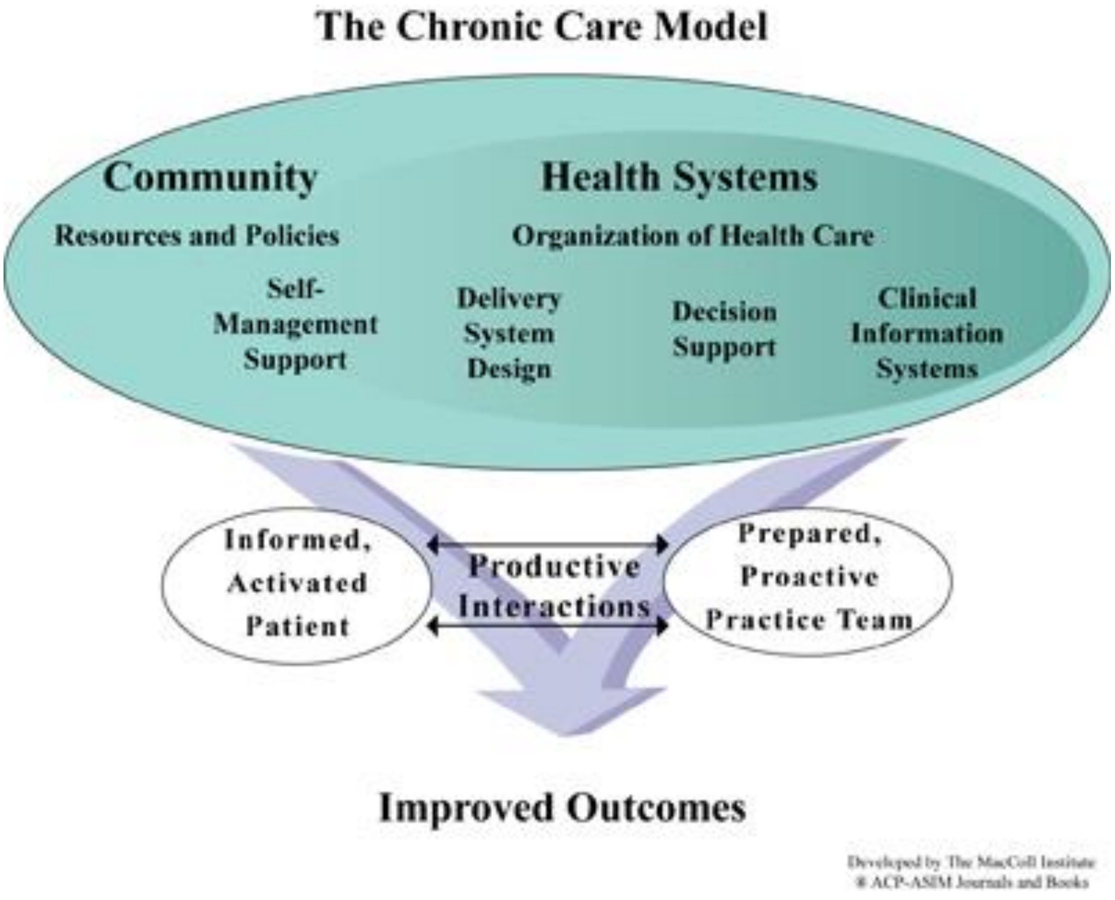


Figure 2.1: Chronic Care Model

Source: (http://www.improvingchroniccare.org/change/model/components.html)

Cancer self-management interventions can improve health related outcomes and quality of life across the cancer trajectory, from prevention to survivorship (McCorkle *et al.*, 2011; Salvatore *et al.*, 2016)

Figure 2.2: Integration of Care for Cancer Survivors

Source: (The COSA Model of Survivorship Care)

Improved screening services and enhanced treatment modalities have decreased the mortality and improved survivors among breast cancer patients. This agrees to the raising number of women living with breast cancer related morbidities. Patients with long term need of care are termed to have ‘chronic illness ‘which has implication on care provision meaning that the cancer is within the framework of chronic illness rather than acute (Loh, 2013).

Foster and Fenlon (2011) reported that majority of survivors following active treatment found ways to self -manage most of their difficulties encountered by being hands-on in looking out additional knowledge and support, dealing with warning sign, anticipation and judgments, careful forecasting activities and making wider networks with others with alike practices, as well as confidence to do these things.

Self-management support is mainly from family member's health care team, colleagues and sometimes from social media like internet. Social network can be treasured to support self-management by providing information and empowering people to pursue and share information with others they might not otherwise come into contact with (Foster, 2009).

Education, support, and good network referral system should be considered paramount as self-management intervention on acute, and effects of cancer and treatment related especially in transitioning and when the treatment intensity is reducing and during the initial stages of cancer treatment. During the transition from intense cancer treatment phase, frequent interaction with the health care providers and follow-up care on survivorship needs assessment should be done continuously. Components involved include risk calculation, treatment summary, and survivorship care plan.

According to Salvatore *et al.,* (2016) after initial treatment design for cancer has completed, majority of survivors are expected to cope with the permanent and short-lived body changes and psychosocial problems like fatigue, pain, in ability to function, anxiety, depression, reduced quality of life and other concerns. An intervention would help patients achieve optimal status of health in terms of physical, psychosocial and health care behavior.

2.3 Self Managements Needs

Cancer patients have important number of care needs across a variety of domains. Greatest recognized relates to treatment and care received from clinical oncology team and provision of health information (Morrison *et al.,* 2011). Other surveys outline needs across this range and variety of needs, as outlined by brief assessment of adult cancer patients' perceived needs by Boyes (2009), reported needs across psychological, health information, Physical and daily living, patient care &support, and sexuality.

2.3.1 Psychological Support Needs

The psychological domain address needs to be associated with feelings and coping mechanism of the patient. Study done in Mexico by Villarreal-Garza, *et al.,* (2017), assessing fertility concerns among breast cancer patients identified Several phenomena related to psychological aspects of care to include reduction on the fertility Concerns, continuously change of in body image, loss of employment after treatment, influence on family relations and social links, and unmet emotional support and informational needs. To overcome all these needs physicians should be well fitted with adequate information and skills.

Almost half of the breast cancer survivors reported unmet needs which influence their quality of life. Some of the psychological concerns expressed includes fear of the future, disease recurrence, emotions of losses, concerns about change of body image and self-concept which relates to role adjustment and family responsibility (Allen *et al.,* 2009) & Green, 2011).

According to Green (2011), documented that maladaptive psychological response such as anxiety neurosis, depressive symptoms and maladaptive disorders are common if the emotional distress following intensive treatment therapy is not adequately addressed on due time.

According to Hubbeling *et al.,* (2018), available resources should be distributed equally to enable reconstruction to be more broadly accessible. Special programs to offer support and additional information materials should be put in place to take care of some of the challenges that survivors undergo especially on financial constraints. On return to their duties and day care programs at cancer centers should be available and family/patient means of transport and housing should be provided to lessen suffering connected to physical separation from children and elder family members during treatment (Faller *et al.,* 2017).

Reduction in overall performance and quality of life is affected greatly by emotional distress which is considered as the sixth vital sign among cancer patients. As a result, reduced adherence to treatment plan which increases the mortality cases in cancer patients is experienced (Linden *et al.,* 2012). Fafouti *et al*., (2010) in his study reported that breast cancer patients are a highly vulnerable group, and they require mental health professions for follow up from diagnosis through the course of therapy.

Moreover, studies based on SCNS-SF 34 among patients suffering from breast cancer have revealed that psychological needs were more perceived than other needs across the domain (Dwarswaard *et al*., 2016; Edib, 2016).

2.3.2 Information Needs

Information is paramount to patients because it helps them to understand their cancer, make decisions and cope with treatment (Smith *et al.,*2010). New patients' needs widespread information related to sickness treatment, process, undesirable effects, and outcome of the illness. Over time information needs transition from diagnosis experienced patients and maintenance phases (Chen, *et al.,* 2009 & Halket, *et al.,* 2012).

Matsuyama *et al.,* (2013) reported that the majority of patients want information including bad news for side effects disease and chances of poor prognosis, therefore continuous provision of information will help patients cope well with any eventuality. Survey on commonest, important, and unmet need of cancer outpatients, revealed that more needs were rated among breast cancer patients than other and in terms of gender females experienced more needs than their male counterparts. According to Morrison *et al.,* (2011); Wei *et al.,* (2016) most of breast cancer patients needed additional information related to their disease treatment and prognosis but oncology team thought that previously had provided adequate and enough material they need and the oncology nurses encounter difficulties in aiding in sieving the information gathered from the internet. Patients need information provided to be more positive and encouraging but providers deliver information on efficacy and safety of chemotherapy.

Information needs may differ greatly between age groups though women need additional information as it’s identified as major barrier to access medical attention. Providing survivors with adequate informational materials focusing on their information needs is important and it should be a common goal to all in patients care. For the countries with limited resources patient-physician communication and printed reading material remains the only trusted sources of information to the patients (Villarreal-Garza *et al.,* 2017). Provision of self-management care expands accessibility to much needed information, rendering support in the direction of wellness in behavioral fluctuations allowing support from the peers. Loh, (2013), stated that “focused, systematic, and increased provision of self-management care can have positive impacts on overall self-management outcome even when the health system resource is inadequate.

According to Faller et al., (2017) education and support over long- term to patients of breast cancer especially unmet information needs can be easily addressed by ensuring free availability of information booklets in national and regional languages.

According to Sharma, (2021), study found that, improving information among patient upkeep opportunities is vital on complete self-management because it helps them to reflect their responsibility in self-management grounded on what they know, their role and offer an appropriate setting for message delivery to close family members and health practitioners.

2.4 Factors Affecting Self-Management

2.4.1 Patient Centered Factors

2.4.1.1 Effective Communication

McCorkle *et al.,* (2011) identified limitation to self-management being failure to have common language between professionals and disciplines that is reasonable by patients and families. Other than that, there is no standardized way of delivering messages to patients and their relatives on self-care. Patients and family's expectations to achieve self-management themselves have outpaced the development of effective self-management interventions. Lack of common language that is usable across the professions and disciplines and which is understandable by patients and families; Lack of understanding of cancer and its trajectory example failure to understand cancer staging which later affected the prognosis and care after (Green *et al.,* 2011)

2.4.1.2 Care Coordination and Standardized Approach

Failure to have a common set of actions to teach patient and families how to take care of self-Several studies have highlighted the differences in the type, intensity of follow up care received by patients comparing type and quality of care. Outcome of care was better for patients followed in multi – disciplinary team approach. Studies have suggested care coordination as a strategy for improving self-management in individuals with cancer (Lovell *et al.,* 2016; McConigley *et al.,* 2011).

2.5 Patient Reported Outcome

Fear, worry and endurance of the treatment side effects were reported to be among the biggest challenges towards effective self-management. Also, the patients were most concerned about symptoms and recovery after the chemotherapy (Chou *et al.,* 2016)

2.6 Summary of Literature Review

Programs have been implemented to monitor the self-management care across the cancer trajectory continuum among breast cancer patients. This leads to close monitoring of all breast cancer patients hence it is easy to maintain statistics related to the disease and disease outcome. Locally incidence of breast cancer is on the rise which can be attributed to the improved screening and early detection measures, this implies that the number of survivors receiving treatment is also increasing. Few studies have been done focusing on care posttreatment and follow up though locally no study was found addressing self-management either during treatment, transition and even post treatment. Therefore, this study aims at assessing self-management needs among breast cancer patients exploring the satisfaction of the intensive phase of systemic therapy as they transit to maintenance phase of treatment.

CHAPTER THREE:

MATERIALS AND METHODS

3.1 Introduction

This chapter involved the data collection process and method. It provides methodology and design, data collection tools, sampling, population, and data analysis on self-management among patients with breast cancer on systemic therapy at KNH. Ethical considerations are also provided.

3.2 Study Design

The study utilized explanatory sequential mixed methods (Analytical cross-sectional and phenomenological research designs). Quantitative component was concerned with understanding of self-management and assessment of self-management needs. Subsequently, qualitative explored the patient centered factors affecting self-management based on the quantitative findings.

3.3 Study Area

The study was carried out at the largest public referral hospital in Kenya, Kenyatta National Hospital Cancer Treatment Center (CTC). Kenyatta National Hospital is the oldest and largest hospital in Kenya and serves as a public, tertiary, referral hospital for the Ministry of Health. It is also the teaching hospital of the University of Nairobi's College of Health Science. The Cancer Treatment Center is an established department that provides all modalities of cancer treatment to patients diagnosed with the condition in the hospital. It's also the only facility with comprehensive breast cancer treatment with services affordable to most of the population (Makau-Barasa 2020). The hospital is located in the area to the immediate west of Upper Hill in Nairobi which is the capital and largest city of Kenya. Its location is about 3.5 kilometers (2 miles) west of the city's central business district. The hospital complex measures 45.7 acres (18.5 ha) (Merab, 2016).

KNH was purposively selected due to its large catchment being a National referral hospital from across the country and even within eastern Africa countries and that was the only public hospital offering most cancer treatment modalities including chemotherapy.

3.4 Study Population

The study included adult patients with breast cancer at Kenyatta National Hospital cancer treatment Centre who were on systemic therapy for breast cancer. According to cancer treatment center health information department statistics (2018). The number was 40 to 45 patients weekly, so in a month were approximately two hundred patients.

3.5 Inclusion and Exclusion Criteria

3.5.1 Inclusion Criteria

The study comprised:

1. All patients who attended KNH-CTC were diagnosed with breast cancer on systemic therapy during their routine clinic visits.
2. Patients with breast cancer on systemic therapy above 18 years of age who can communicate in either Kiswahili or English.
3. Recruitment was also done to all despite their stage of disease on systemic therapy.

3.5.2 Exclusion Criteria

1. Physically (seriously ill patients) and mentally incapable of completing the questionnaire.
2. Those receiving end of life care, due to their limited capacity to provide information to fill the questionnaire.

3.6 Sampling

3.6.1 Sample Size Determination

There are no studies in Kenya conducted on self-management in either of the treatment phases of chemotherapy, therefore the proportion(p) was assumed to be 0.5. The sample size (n) was determined by Cochran (1977) formula as follows:

$$n = \frac{Z^2 p(1-p)}{e^2}$$

In this study, p was assumed to be 0.5, Z 1.96 corresponding to 95% confidence interval and margin of error(d) was allowed to be 7.5%. Therefore, using the above equation, the sample size was.

$$n = \frac{1.96^2 0.5(1-0.5)}{0.075^2}$$

$$n = 169$$

Therefore, the optimal sample size for our study was one hundred and sixty-nine (169) patients with breast cancer.

3.6.2 Sampling techniques

The total number of patients with breast cancer on systemic therapy in Kenyatta National Hospital at the time of study was two hundred and fifteen (215). The researcher decided to include all the patients into the study since they were accessible (Census). A total of one hundred and sixty-nine (169) were included in the qualitative study. They were recruited consecutively as the participants went in for their clinic reviews.

For the focus group discussion, a group was constituted every week on Wednesday during their revisit appointment with all the patients who didn’t participate in the quantitative data collection who met the inclusion criteria. Three focus group discussions were conducted, and each comprised of 8-10 participants who were purposefully selected and then were supplied with information regarding study purpose and data collection process as well as informed consent was obtained to participate in the study, after which an audio-recorded focus group discussion was conducted. To ensure homogeneity in the group age was considered, above 50 years were grouped together, and less than 49 years were grouped together because they were still within the childbearing age.

3.7 Data Collection Tools

3.7.1 Quantitative Tools

Structured questionnaire consisted of socio-demographic data, Patient centered factors affecting seamless transition from active to maintenance phase during systemic therapy (Appendix I) assessment of self-management needs (Appendix III) and (Appendix X)

The SCNS-SF 34 is a standardized instrument for assessing cancer patients' perceived needs across a range of several domains including psychological, information, patient care & support, physical & daily living, and sexuality needs. The appropriateness of the tool lies in its ability to identify or assess the perceived support care needs of cancer patients. It has a five-factor structure consisting of: health system and information (10 items), psychological (10 items), physical and daily living (5 items), patient care and support (5 items), sexuality needs (3 items).

The participants who were cancer patients were asked to identify their need within the recent month which needed help using the five answer choices. Five scale was measured using the Likert-type items: 1=Not applicable, 2=Satisfied, 3=Low need, 4=Moderate need, and 5=High need. Used to rate the patient level of needs in the past month. Standardized Likert summated score was used to score SCNS-SF 34 according to supportive care needs survey scoring manual.

The score has a possible value ranging from 0-100, with the higher score indicating high level of self -care deficit. The sub-dimension scores were attained by addition of each item points. A high score meant that the perceived need is high which equal to support needed, low score means perceived needs are low hence patient able to take care of self or minimal assistance. For the sake of this study, Support Care Needs Survey –Short Form (SCNS-SF 34) was adapted partially to assess the perceived self-management needs in particular informational needs and psychological needs.

Informational needs include: Being given information on aspects concerning illness and side effects, explanations of the test results, adequately informed on benefits and side effects of treatment, informed about results feasibly, informed about cancer in control, informed on ways to help get well, having access to professional counselor, information about sexual relationships, being treated like a person, hospital or clinic pleasant, member of staff whom you can share with your condition, and follow-up .

Psychological needs include Feeling down or depressed, feeling of sadness, fears about the cancer spreading, worry that the result are beyond self-control, Uncertainty about the future, feeling in control of self-feelings, keeping a positive outlook, feeling about death, and dying and Concerns about the worries of close relatives (Boyes, 2009).

Permission from the head of the Center of Healthcare Research and Psycho-Oncology of New South Wales Cancer Council, who created the SCNS-SF 34, was sought and an approval granted, see attached **(Appendix IX).** Internal reliability of items within each factor was assessed using Cronbach alpha with the coefficient criteria set at 0.7. According to Boyes, (2009) the 34 items SCNS achieved high internal consistency reporting Cronbach’s alpha coefficients for factors ranging from 0.86 to 0.96. Ideally Cronbach’s alpha of 0.7 or above is reflected to be indication of internal consistency of a scale.

3.6.2 Qualitative Tools

A focus group discussion guide was developed and generated to explore further patients’ experiences on the patient centered factors affecting self-care management based on quantitative data collected (**Appendix X).** Participants were recruited using purposive sampling and they all gave informed consent to participate in the study. Focus groups discussion were conducted every Wednesday for three consecutive weeks as the patients came for their clinic review. Patients who didn't participate in the quantitative data collection and were meeting the inclusion criteria were included in the FGDs. The participants had already completed the active phase of treatment and were now doing their maintenance phase. To ascertain different viewpoints of the breast cancer patients, group one consisted breast cancer women with an advanced age (50 years and above), group two and three consisted of young women with breast cancer within their reproductive age (18-49 years). We stopped recruiting new participants where the data appeared to have reached saturation with no new themes or information within themes emerged. Three focused group discussions were conducted, and each session had 6-8 participants aged 18-50 years.

3.7.3 Data Collection Procedure

Participants were recruited to fill in the questionnaire and SCNS-SF34 tool from KNH Cancer Treatment Center based on their registration on appointment diary. Recruitment was done consecutively as they went in for their clinic reviews until the desired sample size was attained. Those with confirmed breast cancer diagnosis on systemic therapy transiting from active to maintenance phase were requested to participate in the study after signing informed consent. For the participants who had difficulties in understanding the English, a Kiswahili version was given translated.

3.7.4 Training of Data Enumerators

Training of two research assistants on research process, research tools and collection procedure was done before the data collection. Research assistants were nurses working at KNH in the navigation department who had been involved in patient's management and care during systemic therapy. The researcher together with the research assistants recruited the participants through providing written study information and informed consent. Consenting patients were asked to complete the tool. Self-administered questionnaire and SCNS-SF tool were administered by the research assistants to the participants who had consented for the study for a period of one month. All the questionnaires filled in were checked for completeness and accuracy. Assessment for understanding what self-management concept was done using one item asking "have you ever heard about self-management? If yes, they proceeded to tick against a statement which best suited their understanding of self-management. To gather information on patient centered factors affecting seamless transition a 5-point Likert type of response format ("strongly disagree", "Disagree"," Average", "Agree", "strongly agree")

Qualitative study (focus group discussions) was based on quantitative data findings and socio- demographic data based on age ensured homogeneity of the groups.

3.7.5 Qualitative Tools

3.7.5.1 Focused Group Discussions

Data collection using Focused Group Discussion was conducted by the researcher being the moderator among the participants written informed consent from all the participants were obtained before the focus discussion started. Purposive sampling of homogenous groups to participate in focus group discussion was done among breast cancer patients attending their reviews who consented. FGD was conducted among the breast cancer patient on systemic therapy who had not participated in filling the questionnaire. Moderator who was the main researcher controlled the group and the research assistants were able to collect the data.

The research enumerator's role included observing nonverbal interactions and the impact of the group dynamics and documenting the general content of the discussion. Quantitative findings guided generation of a focus group discussion guide which was pre-tested before use (Appendix X). Open-ended questions and narrative questions were used to enable participants to talk freely about their experience of informational and psychological self-management needs. Room previously used for counselling was identified and they were quiet with minimal interruptions, in line with Ministry of Health guideline on Coved 19 protocols. A total of twenty (20) breast cancer patients on systemic therapy participated in a focus group and each session had 8-10 participants. To ensure homogeneity age was considered as from 18-49 years (childbearing age) above 50 years. However, the point of saturation technique was used to determine the point at which the diversity of the responses ceased leading to no new information being gathered. This point was reached after three group discussions were conducted which lasted for 45 minutes in three weeks. Data was digitally recorded, transcribed verbatim then exported to Microsoft word, coded using NVIVO package and analyzed thematically.

3.7.5.2 Quality Assurance

Pretesting for the questionnaires was done at KNH ward 1B, where some breast cancer patients were admitted for other services including systemic therapy administration, ten percent of the study sample size was recruited. All the questions were thoroughly scrutinized, and corrections made.

Internal reliability of items within each factor was assessed using Cronbach alpha with the coefficient criteria set at 0.7. According to (Boyes, 2009) The SCNS SF achieved high internal consistency reporting Cronbach's alpha coefficients for factors ranging from 0.86 to 0.96. Ideally Cronbach's alpha of 0.7 or above is reflected to be indication of internal consistency of a scale (Parker, 2016). For the focus group discussion guide, given the open-ended nature of the questions, the test for reliability was not possible to quantify in as much as all the items on the tool passed the assessment on relevance to the study content. For qualitative data, the researcher established content validity of the data tools through expert reviews with research supervisors, peers and biostatical who also reviewed the data tools for clarity, readability, and comprehensiveness. Also, the researcher engaged a social scientist who also coded each transcript independently and then the comparison was done.

3.7.6 Data Management and Analysis

3.7.6.1 Quantitative analysis

Quantitative data from the questionnaire and SCNF tool was cleaned and checked for completeness. All the raw data was kept safe in a confidential place. Only the researcher was able to access the awaiting data entry. Later the data were coded and entered in MS excel then analyzed using the statistical package for the social sciences version 23.0 (SPSS) package software to obtain descriptive statistics; means, standard deviation, percentages, proportions, and frequencies. Any significant association between self-management needs and independent variables was explored using correlation analysis. Data findings were presented in the form of tables, bar graphs and charts as appropriate. Principal component analysis was used to reduce the data by identifying the set of underlying factors that show the patterns of interdependence between correlated variables.

3.7.6.2 Qualitative Analysis

The researcher utilized thematic analysis steps which involved familiarization, transcription of data, organizing the data, generation of codes and categories which were then linked to the emerging themes and finally, a report was generated depicting the phenomenon of interest (Braun & Clarke, 2006; Researcher together with the data enumerators transcribed data manually where the researcher read each transcript and made a content summary before re-reading each meaning unit. Interesting features were highlighted and generated initial codes. Important themes were developed after which reviewing and naming of the themes were done. To ensure all data has been utilized, researcher compared the notes that were taken during FGD sessions with content summary generated after transcription of data and there were no differences noted. Finally, a comprehensive report was produced based on the phenomenon of interest as experienced by the study participants. To ensure credibility of the process, researcher engaged a social scientist who also coded each transcript independently and then comparison was done. A consensus was reached after it was evident that there were no major differences between the themes generated. Visual display of how the themes were developed through coding from raw data will show validity and rigor of the themes.

3.8 Ethical Considerations

Ethical clearance for the study was sought from KNH/UON ethical review committee (**Appendix XII)**. Hospital clearance to conduct the study was sought from KNH administration (**Appendix XIV**). Participants were well informed about the study, that it was voluntary to participate and that one was free to withdraw from the study without any impact in care. Written consent was obtained from each participant (**Appendix VI, Appendix XI**) before the study commenced. All participants were assured of confidentiality, privacy, anonymity, and the right to withdraw from the study without any effects on the quality of care delivered. Respondents were informed that information obtained will not made available to people outside the study and no personal identifiers will be used for publication.

3.9 Study Results Dissemination

Study results were disseminated at scientific and professional oncology conferences at Mombasa and in academic forums (**Appendix XVI).** Hard and soft copies will be available to JKUAT library for reference. The study was also published in peer reviewed journals (East Africa medical journal on **Journal / East African Medical Journal / Vol. 100 No. 2 (2023) / Articles on** Apr 26, 2023(**Appendix XVI).**

CHAPTER FOUR

RESULTS

4.1 Introduction

The section presents the findings of the study. The results are presented in four sections comprising socio-demographic characteristics, Patient definition of self -management, psychological needs, and information & health system needs. The focus group discussion findings are also triangulated with quantitative findings. Out of the 171 participants, 169 completed the questionnaire making the study sample.

4.1.1 Socio-Demographic Characteristics of the Respondents

Respondents were spread across the ages from 18 years to above 50. The mean age was 45.96. Most of them were aged between 46-49 years (36%, n=61). Respondents aged between 18-25 were the least represented (2%, n=3). On gender, there was one male respondent (0.6%, n=1) and on level of education most had secondary education (43%, n=73) while (36% n=61) had primary and below level of education.

As illustrated in **Table 4.1,** the majority were married (68%, n=115) while (32% , n=54) were not married. More than half of the participants were from the rural areas (64%, n=108). Among the participants (88%, n=149) had no reliable income. Almost half of the participants were unemployed (45%, n =76). About (17%, n=29) had one child and below with the majority having more than 3 children (34%, n=57).

Table 4.1: Demographic Profile

	Total	Percentages	Frequency
			169
Age	18-25	2%	3
	26-33	11%	19
	34-41	34%	57
	42-49	36%	61
	50 and above	17%	29
Gender	Male	0.6%	1
	Female	99.4%	168
Marital Status	Married	68%	115
	Not married	32%	54
Residence Set up	Urban	36%	61
	Rural	64%	108
Reliable source of income	Yes	12%	20
	No	88%	149
Level of Education	Primary and below	36%	61
	Secondary	43%	73
Employment Status	Unemployed	45%	76
	Employed	22%	37
	Self-employed	33%	56
No of Children	1 child and below	17%	29
	Two children	19%	32
	Three children	31%	52
	more than three	34%	57

4.1.2 Source of Information

Majority of the patients (59%, n=100) heard breast cancer information from Health care workers. About (27%, n= 46) of the respondents heard about breast cancer through other sources, to include internet. Only (11%, n=19) got the information from mass media (television and newspaper) and 2% didn’t have any information about breast cancer. (**Figure 4.1)**

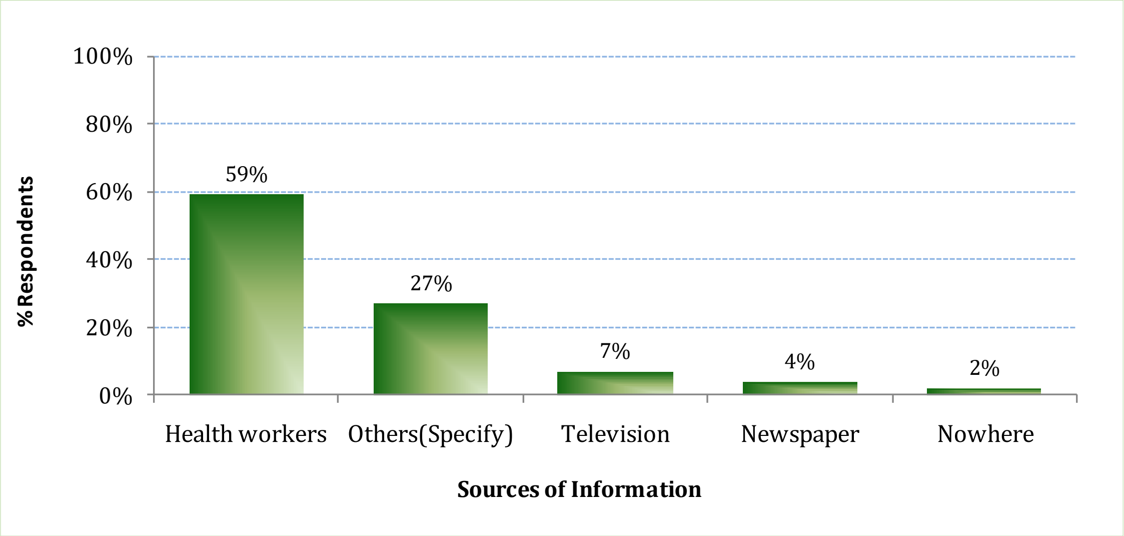


Figure 4.1: Sources of Information

4.1.3 Duration of Breast Cancer

In terms of the duration with breast cancer, more than a half (53%, n=90) of the respondents had lived with the disease for 1 to 2 years. about (9%, n= 15) had lived with breast cancer for more than 5 years. **(Figure 4.2)**

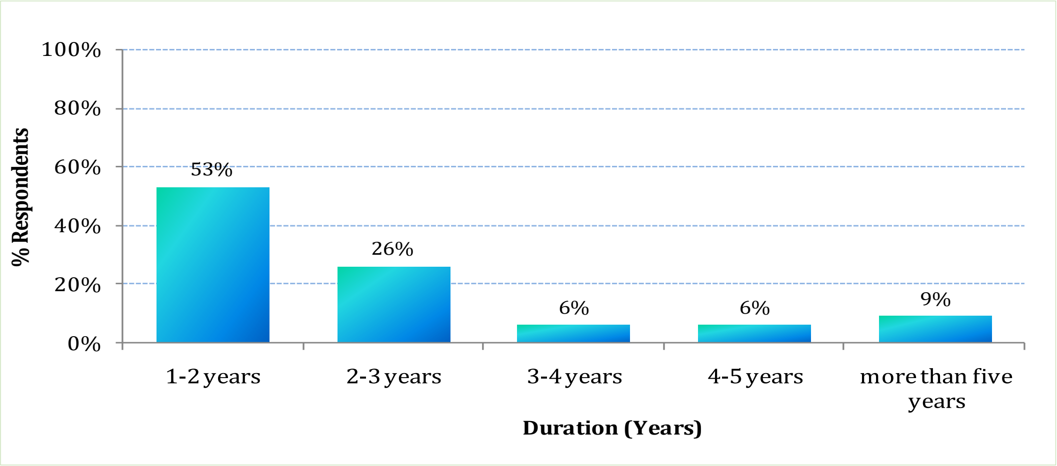


Figure 4.2: Duration of the Breast Cancer

4.1.4 Stage of Diagnosis

Half of the participants had been diagnosed with breast cancer at stage III. About one third of the participants (32%, n=54) at stage II, followed by (11%, n=19) at stage IV and others in stage I at (7%, n=12)

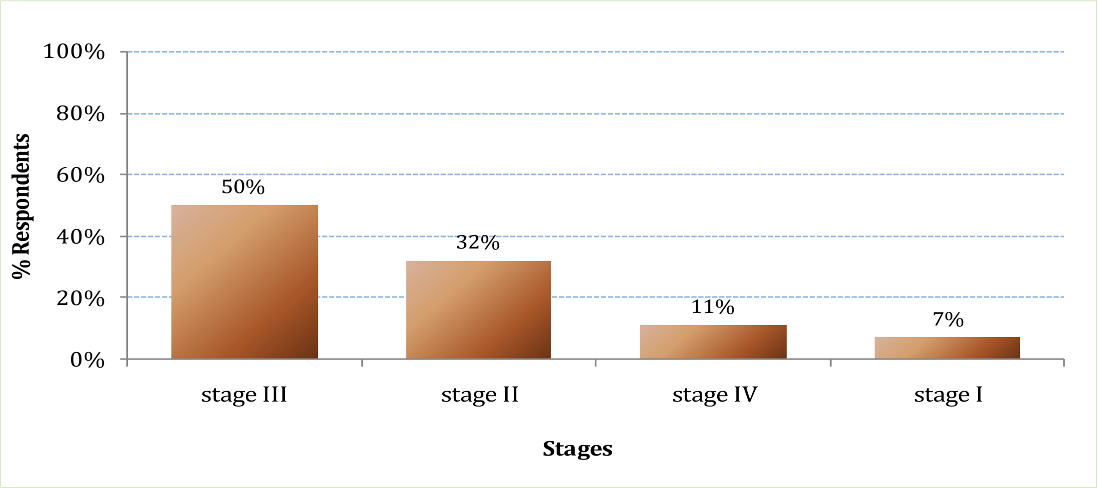


Figure 4.3: Stages of Diagnosis

4.1.5 Current/Past therapy

On the type of therapy, the respondents were having during the time of the study about two third were undergoing chemotherapy only, (10%, n=17) were undergoing chemotherapy and hormonal/targeted therapy at the same time, (6%, n=10) were undergoing hormonal/targeted therapy only, those having chemo and surgery at the same time were (32%, n=54), radiotherapy and surgery were (1%, n=2)each. Those who were having chemo and radiotherapy or chemo, radiotherapy and hormonal therapy or chemo, surgery and radiotherapy were one% each**. (Figure 4.4)**

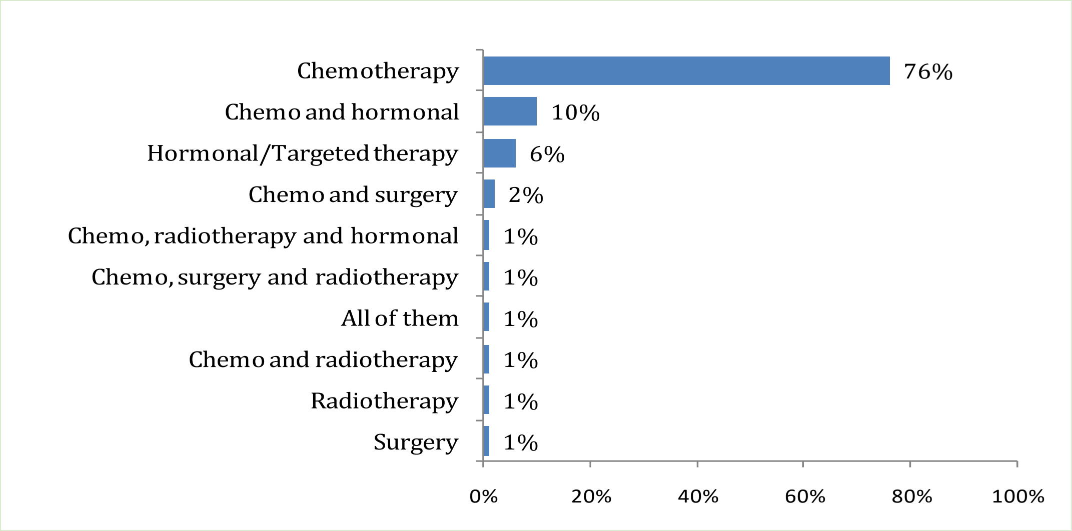


Figure 4.4: Current/Past Therapy

4.1.6 Disease Status

Majority of the patients were in partial remission (59%, n= 100), stable disease was at (19%, n=32) and about (16%, n=27) had progressive disease status. Only (4%, n=7) had a complete remission while (2%, n=4) had inconclusive evaluation.

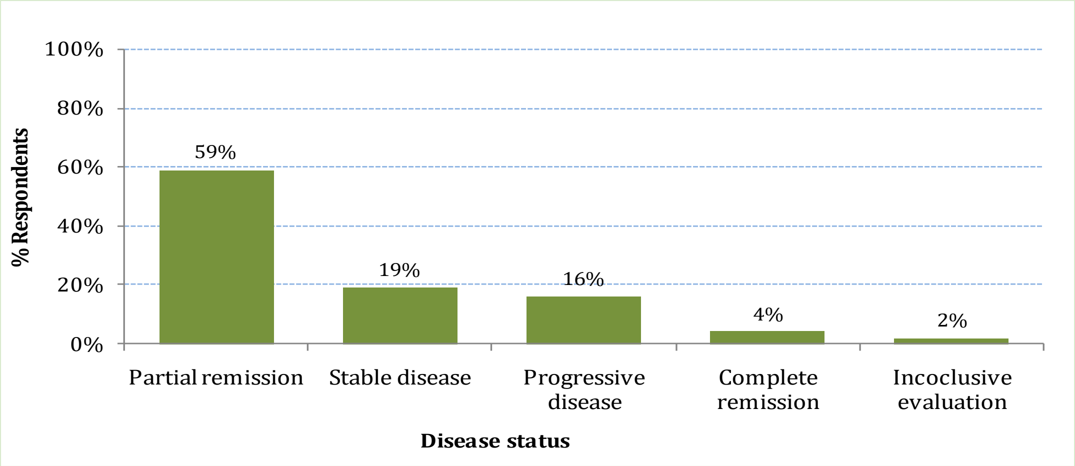


Figure 4.5: Disease Status

4.2 Self-Management

4.2.1 Definition of Self-Management Concept in Relation to Systemic Therapy

Participants were asked to state if they have heard any information on self-management where majority (81%, n=137) stated they have heard. Most of the respondents (54%, n=92) stated the purpose of self-management meant ways to improve health generally. Followed by those who believed the self-management is to understand treatment summaries and their care plans at (39%, n=67).

The majority (81%, n=137) of the participants compared to (19%, n= 32) agreed to have heard some information on self-management.

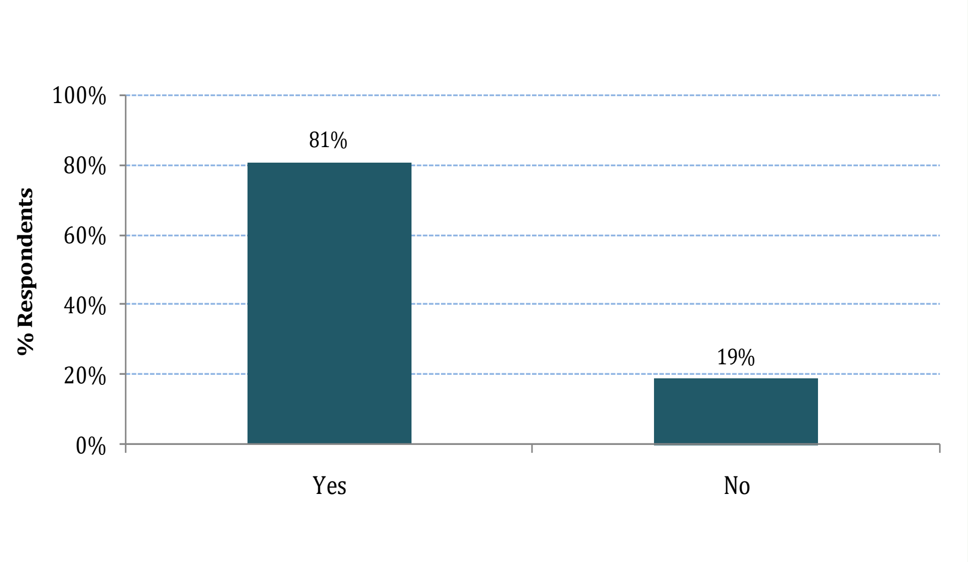


Figure 4.6: Definition of Self-Management

Figure 4.6: is all what self-management is in relation to patient care understanding summarized in nine points. The findings from the questionnaire data revealed that participants had different opinions on what was the definition of self-management.

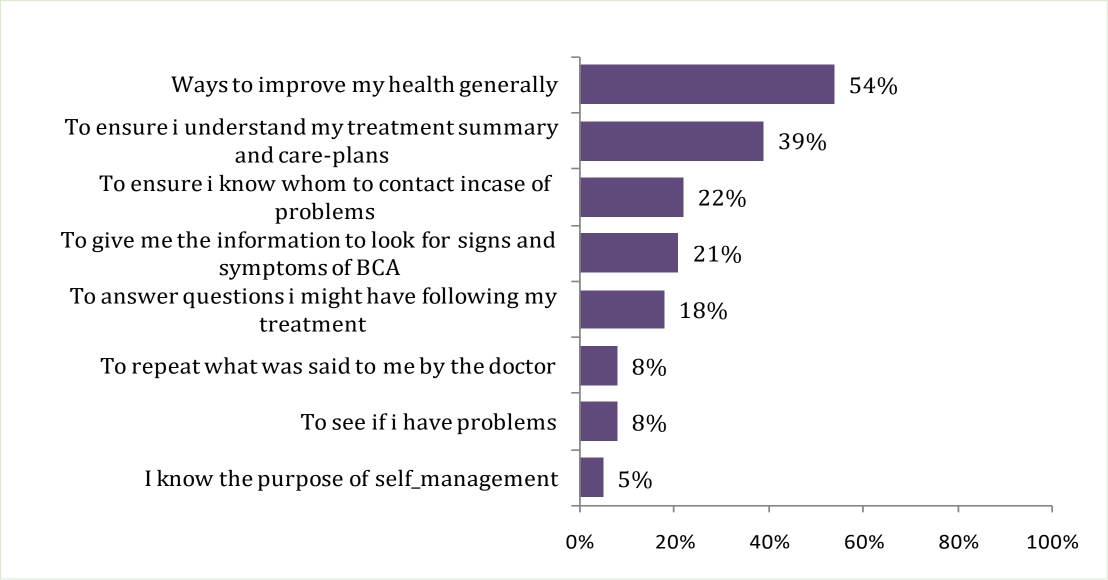


Figure 4.7: Definition of Self-Management

4.3 Psychological Needs

Assessment of the psychological needs was based on the items that identified the gap as follows. Most prevalent unmet supportive care needs in psychological domain were fears about cancer spread (20%, n=34), concerns about the worries of close relatives (17%, n=29), uncertainty about the future (14%, n=24) worry that the results are beyond self-control (13%, n=22), feeling about death and dying (8%, n=14), keeping a positive outlook (6%, n=10),feeling in control of self-feeling (5%, n=8), anxiety (5%, n=8), feeling down or depressed (5%, n=8)feeling of sadness (3%, n=5)**(Figure 4.2)**

Table 4.2: Psychological Needs

	No need	Low need	Moderate need	High Need
Anxiety	55%	27%	12%	5%
Feeling down or depressed	61%	22%	12%	5%
feeling of sadness	64%	22%	12%	3%
fears about the cancer spreading	30%	20%	30%	20%
worry that the result are beyond self-control	37%	25%	24%	13%
Uncertainty about the future	36%	17%	32%	14%
Feeling in control of self-feelings	54%	24%	17%	6%
Keeping a positive outlook	79%	8%	6%	6%
feeling about death and dying	54%	26%	13%	8%
Concerns about the worries of close relatives	32%	16%	35%	17%

4.4 Information and Health System's Needs

Table 4.3 summarizes the informational and health needs as follows. Most prevalent supportive care needs informational and health needs domain were member of staff whom you can share with your condition and follow-up (74%, n=125), information about sexual relationship (62%, n=105), having access to professional counselor (52%, n=88), informed about cancer in control (25%, n=42), explanations of the test results (20% n=34), adequately informed on benefits and side effects of treatment (16%, n=27), informed about results feasibly (20%, n=34) and being given information on aspects concerning illness and side effects (15%, n=25) (**Table 4.3)**

Table 4.3: Information and Health Systems

	No need	Low need	Moderate need	High Need
Being given information on aspects concerning illness and side effects	32%	26%	27%	15%
Explanations of the test results	25%	25%	31%	20%
Adequately informed on benefits and side effects of treatment	25%	37%	22%	16%
Informed about results feasibly	40%	27%	13%	20%
Informed about cancer in control	23%	20%	32%	25%
Informed on ways to help get well	47%	32%	12%	8%
having access to professional counselor	13%	14%	21%	52%
Information about sexual relationships	8%	8%	22%	62%
Being treated like a person	50%	30%	13%	7%
Hospital or clinic pleasant	41%	37%	16%	5%
Member of staff whom you can share with your condition, and follow-up	12%	6%	8%	74%

4.5 Patient Centered Factors Affecting Self-Management

The factors were analyzed in both quantitative and qualitative data. The factors were scaled as strongly agree/Disagree/Average/Agree/Strongly agree. On ability to seek clarification with the health care provider, majority (44%, n=74) strongly agreed they were confident on who to ask for any information pertaining their health status. Among the respondents (71%, n =120) strongly disagreed that their current financial status adequately met their need. **(Table 4.4)**

Table 4.4: Factors Affecting Self-Management

	Strongly disagree	Disagree	Average	Agree	Strongly agree
I’m able to ask /clarify on matters relating to my heath condition with HCP freely	11%	6%	21%	19%	44%
Disease stage has not affected my performance on self-care	19%	16%	18%	16%	32%
My current financial status adequately meets all my care demands	71%	16%	7%	1%	5%
Physical symptom doesn't affect my ability to take care of self	19%	34%	23%	14%	9%
Having other condition has not affected my performance in self-management	24%	32%	24%	10%	10%
Fear, anxiety, and Embarrassment does not hinder Consultation on self-management	16%	14%	20%	11%	39%

4.6 Focus Group Discussion

Focus group interviews revealed 8 subthemes that we organized into 3 themes on factors affecting self-management needs among patients with breast cancer in maintenance phase of systemic therapy: (1) **Physical and psychological symptoms, (2) Lack of information (3) Financial constraints.**

Financial Constraints

More than three quarters of the respondents strongly disagreed (71%, n=14) and disagreed (16%, n=3) that their financial status meets their needs adequately.

FGD’s regarding financial constraints yielded varied responses but largely agreed within context of quantitative outcomes. Focused group discussion participants observed that lack of adequate financial support, constrained patients endure to adhere to treatment standards are major setbacks in their treatment period.

Another added "*Long distance travel resulting to lateness and rescheduling of appointment, accommodation costs and high costs of drugs are among the financial strains we encounter."* PT006.

"The entire treatment plan is very expensive. NHIF has limits on their approvals, expensive drugs like Herceptin leading to defaulting treatment" PT012.

Inadequate Information and Counselling

The need for information was evidently important.

"*Information given most of the time is not understood due to incoordination between health care works*" PT014.

"Some of the health care workers were in a hurry or over the phones, no time to listen and no time to clear issues." Some health workers are rude and have no time to clear issues."PT023.

"Information on reproductive health issues and how to relate with the sexual partner has not been addressed throughout the treatment plan even in chemotherapy use."

" Despite losing some parts of the body the health care providers didn't provide information on sources of the prosthesis." PT018.

Physical and Psychological Symptoms

From the respondents, several side effects affected their performance especially the first three days post chemotherapy. They reported fatigue, vomiting, nausea and vomiting to be the worst side effects experienced.

One of the respondents said*” I experience pains, heartburns, headache, diarrhea and chills and I can’t support myself even the thing I do without help”* PT009.

Majority mentioned that lack of support was also another issue, especially when one is also experiencing physical problems.

“Long distance from the spouse who offers support is great challenge” PT 010.
Lack of government support was echoed by PT022.
“Long ques awaiting NHIF authorization before treatment and failure to cover very expensive drugs like Herceptin leads to defaulting therapy “PT015.

Table 4.5: Focus Group Discussion Summary

Themes	Sub-Themes	Verbatim Message
Physical and psychological symptoms	Nutrition requirement. Psychosocial issues Physical needs	After chemotherapy gastrointestinal symptoms, food insecurity, inadequate nutritional counselling. Absent parents, change of body image is disturbing (alopecia, loss of body part No counselor I can share with my problem, and I have to seek counselling services elsewhere.” Chemotherapy side effects, disease progression signs and symptoms
Lack of information	Disease process & prognosis Supportive care & counseling.	Breakdown of communication Navigation process barriers, Inadequate counselling sessions
Financial constraints	Expensive treatment plan Travelling and accommodation Laboratory investigation and imaging	Travelling long distances, expensive process of diagnosis and treatment, high cost of accommodation, NHIF (long ques for treatment preauthorization, limits

4.7 Factors Driving Self-Care Management.

4.7.1 Principal Component Analysis

The purpose of PCA is to reduce the data by identifying the set of underlying factors that show the patterns of interdependence between correlated variables, variously referred to as components. The analysis is intended to identify the factors constituents at which self-care levels are highest. The measure of sampling adequacy (KMO) against all variables was found at 0.75, with significance level (BC) found at p = 0.0001 which is acceptable for the PCA. From the analysis, five components were extracted, however only three were retained for analysis because they accounted for a meaningful proportion of the overall management. According to rotation sums of squared loadings, the components collectively explain 55.3% of total variance observed in the study.

The five components can be interpreted into three aspects, namely, ‘Psychological need, ‘Information and Health systems’ and ‘staff related. **Table 4.5** showed that the five components had nineteen items with loads based on communalities[1] and rotated component matrices. The estimates of the variance in each item were >0.50.

Table 4.6: Factor Loadings Matrix

	Rotated Component Matrix(a)				
	Component				
	1	**2**	**3**	**4**	**5**
Percentage of initial eight value	**20.0%**	**12.3%**	**10.0%**	**7.2%**	**5.7%**
Anxiety	0.69	-			
Feeling down or depressed	0.697				
Feeling of sadness	0.648				
Fears about the cancer spreading	0.586				
Worry that the result are beyond self-control	0.741				
Uncertainty about the future	0.728				
Being given information on aspects concerning illness and side effects		0.714			
Explanations of the test results		0.751			
Adequately informed on benefits and side effects of treatment		0.523			
Informed about cancer in control		0.606			
Informed about results feasibly			0.523		
Informed on ways to help get well			0.633		
Being treated like a person			0.725		
Hospital or clinic pleasant			0.645		
Having access to professional counselor				0.816	
Information about sexual relationships				0.735	
Member of staff whom you can share with your condition, treatment, and follow-up				0.757	
Feeling in control of self-feelings					0.73
Keeping a positive outlook					0.756

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 6 iterations.

4.7.2 Correlation Analysis

To triangulate the above analysis, the relationship between different self-management Dimensions and Patient-centered factors affecting self-management was examined using correlation analysis which is a measure of the linear relationship between the respective survey items (self –management needs) and patient centered factors affecting self-management. Pearson’s Product Moment Correlation Coefficient was computed in order to determine existing relationships. Statistically positive significance means an increase in value of the dimension that likely to impact on overall self- care management.

4.7.2.1 Driving Self- Care Management in Respect to Communication.

There is no statistically positive correlation between almost all variables on self-management and the communication except on explanations of the test results. This indicated that improvements directed on Explanations of the test results likely have a meaningful impact on overall communication improvement.

Table 4.7: Driving Self-Care Management in Respect to Communication.

	Pearson Correlation	**P-value**
Anxiety	-0.108	0.176
Feeling down or depressed	-0.1	0.211
feeling of sadness	-0.144	0.074
Fears about the cancer spreading	0.021	0.796
worry that the result are beyond self-control	-0.099	0.213
Uncertainty about the future	-0.121	0.126
Feeling in control of self-feelings	-0.056	0.489
Keeping a positive outlook	-0.052	0.517
feeling about death and dying	-0.057	0.478
Concerns about the worries of close relatives	-0.007	0.928
Being given information concerning illness and side effects	-0.136	0.089
Explanations of the test results	-.232**	0.003
Adequately informed on benefits and side effects of treatment	-0.02	0.806
Informed about results feasibly	0.072	0.366
Informed about cancer in control	0.049	0.538
Informed on ways to help get well	0.047	0.559
having access to professional counselor	0.05	0.529
Information about sexual relationships	0.096	0.23
Being treated like a person	-0.146	0.066
Hospital or clinic pleasant	-0.147	0.065
Member of staff whom you can share with your condition,	0.05	0.532

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

4.7.2.2 Driving Self-Care Management in Respect to State of the Disease

In respect to State of the disease, significant correlation is shown to exist between three variables and state of the disease ‘fears about the cancer spreading (r = -0.188, p < 0.05), ‘Uncertainty about the future(r = -212, p < 0.01)’and ‘Concerns about the worries of close relatives (r = -202, p < 0.05)’indicating that the three attributes are likely to have impact on self -care management.

Table 4.8: Driving Self-Care Management in Respect to State of the Disease

	Pearson Correlation	**P- value**
Anxiety	-0.125	0.118
Feeling down or depressed	-0.034	0.675
feeling of sadness	0.03	0.715
fears about the cancer spreading	-.188*	0.019
worry that the result are beyond self -control	-0.119	0.137
Uncertainty about the future	-.212**	0.007
Feeling in control of self-feelings	-0.074	0.363
Keeping a positive outlook	0.002	0.979
feeling about death and dying	-0.109	0.177
Concerns about the worries of close relatives	-.202*	0.011
Being given information on aspects concerning illness and side effects	-0.084	0.296
explanations of the test results	-0.085	0.291
Adequately informed on benefits and side effects of treatment	0.032	0.69
Informed about results feasibly	-0.093	0.25
Informed about cancer in control	-0.093	0.246
Informed on ways to help get well	0.073	0.362
having access to professional counselor	-0.118	0.142
Information about sexual relationships	-0.126	0.116
Being treated like a person	-0.011	0.895
Hospital or clinic pleasant	0.031	0.702
Member of staff whom you can share with your condition, treatment, and follow-up	-0.072	0.372

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

4.7.2.3 Driving self- care management in respect to financial status.

Looking at financial status, significant correlation is shown to exist between four self-management variables and financial status: ‘Explanations of the test results, having access to professional counselor, Information about sexual relationships and Member of staff whom you can share with your condition, treatment, and follow-up).

Table 4.9: Driving Self- Care Management in Respect to Financial Status

	Pearson Correlation	**P-value**
Anxiety	-0.131	0.098
Feeling down or depressed	0.004	0.958
feeling of sadness	-0.035	0.667
fears about the cancer spreading	-0.074	0.357
worry that the result is beyond self- control	-0.094	0.235
Uncertainty about the future	-0.146	0.065
Feeling in control of self-feelings	0.031	0.708
Keeping a positive outlook	0.105	0.187
feeling about death and dying	0.067	0.406
Concerns about the worries of close relatives	-0.139	0.081
Being given information on aspects concerning illness and side effects	-0.065	0.419
Explanations of the test results	-.163*	0.04
Adequately informed on benefits and side effects of treatment	0.098	0.22
Informed about results feasibly	0.01	0.906
Informed about cancer in control	-0.086	0.279
Informed on ways to help get well	-0.015	0.849
having access to professional counselor	-.172*	0.03
Information about sexual relationships	-.184*	0.02
Being treated like a person	-0.095	0.233
Hospital or clinic pleasant	-0.055	0.491
Member of staff whom you can share with your condition, treatment, and follow-up	-.259**	0.001

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

4.7.2.5 Driving Self- Care Management In Respect To Physical Status

On physical status, there is high correlation with four items namely, keeping a positive outlook, having access to professional counselor, being treated like a person and Hospital or clinic pleasant.

Table 4.10: Driving self- care management in respect to physical status.

	Pearson Correlation	**P-value)**
Anxiety	0.009	0.913
Feeling down or depressed	0.057	0.482
feeling of sadness	0.06	0.46
Fears about the cancer spreading	0.127	0.115
worry that the result are beyond self- control	-0.032	0.693
Uncertainty about the future	0.036	0.653
Feeling in control of self-feelings	0.131	0.11
Keeping a positive outlook	.223**	0.005
feeling about death and dying	-0.032	0.693
Concerns about the worries of close relatives	-0.017	0.828
Being given information on aspects concerning illness and side effects	-0.039	0.627
explanations of the test results	-0.122	0.126
Adequately informed on benefits and side effects of treatment	0.014	0.857
Informed about results feasibly	0.034	0.678
Informed about cancer in control	-0.07	0.387
Informed on ways to help get well	0.046	0.563
having access to professional counselor	-.211**	0.008
Information about sexual relationships	-0.151	0.06
Being treated like a person	.160*	0.045
Hospital or clinic pleasant	.192*	0.017
Member of staff whom you can share with your condition, treatment, and follow-up	-0.099	0.218

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

4.7.2.6 Driving Self- Care Management in Respect to Co-Morbidities

Having other conditions not affecting performance in self-management is strongly linked to having access to a professional counselor and being treated like a person as seen in **Table 4.10**.

Table 4.11: Driving Self-Care Management in Respect to Co-Morbidities.

	Pearson Correlation	**P value**
Anxiety	-0.117	0.15
Feeling down or depressed	0.142	0.084
feeling of sadness	0.099	0.231
fears about the cancer spreading	-0.016	0.843
worry that the result are beyond self- control	-0.019	0.812
Uncertainty about the future	-0.087	0.284
Feeling in control of self-feelings	0.153	0.066
Keeping a positive outlook	0.085	0.295
feeling about death and dying	0.032	0.698
Concerns about the worries of close relatives	-0.054	0.51
Being given information on aspects concerning illness and side effects	0.06	0.462
explanations of the test results	-0.072	0.382
Adequately informed on benefits and side effects of treatment	-0.012	0.883
Informed about results feasibly	0.098	0.234
Informed about cancer in control	-0.074	0.367
Informed on ways to help get well	0.105	0.197
having access to professional counselor	-.226**	0.005
Information about sexual relationships	-0.119	0.147
Being treated like a person	.325**	0
Hospital or clinic pleasant	0.152	0.063
Member of staff whom you can share with your condition, treatment, and follow-up	-0.081	0.323

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

4.7.2.7 Driving Self- Care Management in Respect to Family Support.

In terms of Family support significant correlation exist in five items namely; Feeling in control of self-feelings(r = -.171*, p <0.05), Keeping a positive outlook(r = -.184*, p <0.05), Concerns about the worries of close relatives (r = -.162*, p <0.05), Being treated like a person (r = -.237**, p < 0.01), Hospital or clinic pleasant(r = -.185*, p <0.05)

Table 4.12: Driving Self- Care Management in Respect to Family Support

	Pearson Correlation	P- Value
Anxiety	-0.13	0.104
Feeling down or depressed	-0.069	0.391
feeling of sadness	-0.007	0.928
fears about the cancer spreading	-0.091	0.257
worry that the result are beyond self-control	0.011	0.886
Uncertainty about the future	-0.043	0.59
Feeling in control of self-feelings	-.171*	0.036
Keeping a positive outlook	-.184*	0.021
feeling about death and dying	-0.04	0.623
Concerns about the worries of close relatives	-.162*	0.043
Being given information on aspects concerning illness and side effects	0.067	0.406
explanations of the test results	-0.088	0.276
Adequately informed on benefits and side effects of treatment	-0.103	0.2
Informed about results feasibly	0.022	0.783
Informed about cancer in control	-0.045	0.573
Informed on ways to help get well	-0.147	0.066
having access to professional counselor	0.142	0.075
Information about sexual relationships	0.08	0.322
Being treated like a person	-.237**	0.003
Hospital or clinic pleasant	-.185*	0.021
Member of staff whom you can share with your condition treatment and follow-up	-0.032	0.688

*. Correlation is significant at the 0.05 level (2-tailed).

**. Correlation is significant at the 0.01 level (2-tailed).

CHAPTER FIVE

DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Discussion

5.1.1 Socio-Demographic Characteristics of the Study Participants

This study showed that the majority of the participants were adult female patients receiving treatment for cancer at KNH and this information was in line with the Globocan (2020) where male was less than one percentage among the breast cancer patients. Majority were married and with children, residing in rural areas and had had no reliable income source as most were unemployed or were in low-income kind of self-employment. Most of the respondents had either secondary or primary education which was different from a study by Griesser (2011) where majority of the respondents had professional level of education. Similar socio-demographic attributes were reported in several related studies.

5.1.2 Definition Sof Self-Management

The findings from the questionnaire data revealed that participants had different opinions on what self-management meant. Majority of the respondents stated that self-management was an integral concept that meant ways to improve health generally. Also, the finding on self-management revealed that understanding treatment summaries and achieving care plans were important aspects. This was similar to a study done by Yamanaka (2018), who found that self-management concept is a process in which patients solved cancer related problems by themselves through interaction with the healthcare professionals. Also started that to improve this concept the nurses should continuously assess patients needs based on nurse patient relationship, individualized advice to each patient, goals set and patient ability to implement to laid down strategies. Similar studies in line with the findings indicated that patients defined self -management as a way to engage and actively involve themselves in their care which resulted in better health care with chronic diseases (Harley, *et al.* 2012). Also, according to Ogunbayo (2017), emphasis on identifying patient meaning with SM concept and taking an active role helped to develop and maintain the SM skills.

5.1.3 Factors Affecting Self-Management

The study revealed the participants agreed or strongly agreed that fear, anxiety, and embarrassment didn't affect their ability to clarify information. This was in contrast with studies finding that stated fear and anxiety and lack of knowledge were the greatest barrier is achieving self-management (Chuo, 2016 & Australia, 2016).

In quantitative and qualitative finding financial constraints appeared to have a great impact in patients' performance in self -care. A similar study revealed that participants experienced unmet needs when monthly household income was lower (Yoon, 2019).

The study findings revealed that physiological and psychological needs were among other factors that affected effective self-management among breast cancer patients. A similar study conducted by Ostby et al., (2018) found that Physiological, psychological, and psychosocial factors were identified as barriers to successful self-management in breast cancer.

5.1.4 Psychological Needs

Findings revealed that breast cancer patients at KNH did experience various psychological needs during transition. Psychological items discussed that identified the needs include concerns about the worries of close relatives, uncertainty about the future and fears about the cancer spreading were the leading needs requiring additional help compared with the other items that didn't have much impact. Similar studies among breast cancer patients revealed that most unmet needs are from the psychological domain and relate to fears over the cancer diagnosis and prognosis, concerns over the burden that the disease will impact on the immediate family and need for psychological support (Green, 2011; Sharma, 2021 & Matsuyama, 2013). A similar observation in support of psychological needs was done and revealed that patients with complex health needs present challenges to self-management related to the prioritization of self-care, a greater risk for depression or psychological distress. Also, that healthcare providers must remain vigilant during self-management support activities with their clients for the quick detection of psychological distress and the treatment of mental health issues (by Gobeil-Lavoie,(2019)

On correlation analysis most frequently unmet needs that impacted on self-management were psychological needs to include anxiety, feeling down, feeling of sadness, fear about cancer spread, and worrying about cancer spread. A similar study conducted among breast cancer patients revealed that the most unmet self-management needs were from the psychological domain (Edid *et, al.,* 2016).

5.1.5 Informational Needs

Based on the cross tabulation in Informational needs, on matters pertaining sexual issues there was significant relationship across variables tested to include level of education, residence setting, income reliability and marital status. Sexuality was a very personal issue and gaps identified on these issues needed to be considered from assessment, planning and implementation of individual patients care plans. The health care professional should create discussion with the patients if they so want and because their needs were dynamic, there's need for assessment during every visit. Subsequently, members of staff whom you could share with about your condition and follow-up, information about sexual relationships and having access to professional counselor were top items that patients expressed they needed additional support. Other studies on cancer patients' needs during their treatment pointed out that informational needs of patients on oncology care required to be addressed (Faubion,2019**)**. Some of the informational needs that had an impact were being given information on aspects concerning illness and side effects, explanation of the results, adequate information on benefits and side effects on treatment and informed about cancer in control. This showed that informational needs such as explanations of the test result, effect of treatment on sexual relationships among others required to be addressed. Similar observations have been reported in various studies conducted among breast cancer patients which reveal that the informational needs domain constitute an unmet supportive need among patients on cancer care management (Dwarswaard *et al*., 2016; Edib *et al*., 2016; Green *et al*., 2011; Halkett *et al* 2012; Kumarasamy, 2016 & Lamminen *et al*., 2013).

Similar studies done indicated a substantial need for a constructive relationship with healthcare providers who, by respecting and communicating with patients, would help empower them. In support of the study Gobeil-Lavoie (2019), stated that patients received conflicting information from healthcare professionals and in order to help these patients as much as possible, it is important that healthcare providers offer a personalized evaluation of their needs, as well as proper follow-up, and ensure good coordination between various health professionals.

5.2 Conclusions

The study found that.

- Most of the respondents were able to define self-management concept; however, they were limited to only one aspect of self -management.
- Breast cancer patients in the study experienced various psychological needs, particularly uncertainty about the future and fears about the cancer spreading.
- The current breast cancer patient care fails to meet informational needs, particularly sexual issues.
- Patients encounter a wide range of patient-centered factors as they take an active role in improving self -management needs**.**

5.3 Recommendations

5.3.1 Recommendation to Health Care Providers

1. Patient definition of self -management needs to be incorporated with the patient health education to help the patients understand all the aspects of self-management.
2. Continuous assessment, planning and implementation of patient care plans addressing on the needs with bridge the gaps in patient cancer care trajectory.
3. Timely rendering and provision of psychosocial support by the health care workers among breast cancer patients during their transition period should be emphasized.
4. Information on sexual needs should be assessed and addressed during the routine patients' visits.

5.3.2 Recommendations for Future Research

1. Further research on all the five domains in self-management to explore if the other domains not tested would have a greater impact in patient self-management.
2. Focus of single cancer diagnosis limited the study to only the breast cancer patients, so additional research on other types of cancers to have a wide range of experience across cancer type will be helpful. This will make generalization of the information valid.
3. Future research would see the exploration and expansion of all other factors associated with self-management other than the patient centered factors,

REFERENCES

Anderson, M. L., Goodman, J., & Schlossberg, N. K. (2011). *Counseling adults in transition: Linking Schlossberg's theory with practice in a diverse world*. Springer Publishing Company.

Allemani. C., Weir, H., Carreira, H., Harewood, R., Spikka, D., Wang, X.-S., et al. (2009). Analysis of individual data.: *Global surveillance of cancer survival*, 997-1010.

Allen, J. D., Savadatti, S., & Gurmankin Levy, A. (2009). The transition from breast cancer ‘patient’ to ‘survivor’. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *18*(1), 71-78.

Australia, C. O. (2016). Clinical Oncology Society of Australia Model of Survivorship Care Working Group. *Model of Survivorship Care, 1*, 1-25.

Boger, E., Ellis, J., Latter, S., Foster, C., Kennedy, A., Jones, F., ... & Demain, S. (2015). Self-management and self-management support outcomes: a systematic review and mixed research synthesis of stakeholder views. *PloS one*, *10*(7), e0130990.

Boyes, A., Girgis, A., & Lecathelinais, C. (2009). Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of evaluation in clinical practice*, *15*(4), 602-606.

Chen, S. C., Lai, Y. H., Liao, C. T., Chang, J. T. C., & Lin, C. C. (2009). Unmet information needs and preferences in newly diagnosed and surgically treated oral cavity cancer patients. *Oral Oncology*, *45*(11), 946-952.

Cheng, K. K. F., Wong, W. H., & Koh, C. (2016). Unmet needs mediate the relationship between symptoms and quality of life in breast cancer survivors. *Supportive care in cancer*, *24*, 2025-2033.

Chou, F. Y., Kuang, L. Y., Lee, J., Yoo, G. J., & Fung, L. C. (2016). Challenges in cancer self-management of patients with limited English proficiency. *Asia-Pacific Journal of Oncology Nursing*, *3*(3), 259-265.

Clark, C. M., & Springer, P. J. (2012). Nurse residents' first-hand accounts on transition to practice. *Nursing outlook*, *60*(4), e2-e8.

Cochran, S., & Banner, D. (1977). Spall studies in uranium. *Journal of Applied Physics*, *48*(7), 2729-2737.

Coulter, A., Roberts, S., & Dixon, A. (2013). Delivering better services for people with long-term conditions. *Building the house of care. London: The King's Fund*, 1-28.

Dinkel, A., Schneider, A., Schmutzer, G., Brähler, E., & Häuser, W. (2016). Family physician–patient relationship and frequent attendance of primary and specialist health care: Results from a German population-based cohort study. *Patient education and counseling*, *99*(7), 1213-1219.

Dwarswaard, J., Bakker, E. J., van Staa, A., & Boeije, H. R. (2015). Self-management support from the perspective of patients with a chronic condition: a thematic synthesis of qualitative studies. Health expectations. *An international journal of public participation in health care and health policy*, *19*(2), 194-208.

Edib, Z., Kumarasamy, V., binti Abdullah, N., Rizal, A. M., & Al-Dubai, S. A. R. (2016). Most prevalent unmet supportive care needs and quality of life of breast cancer patients in a tertiary hospital in Malaysia. *Health and quality of life outcomes*, *14*, 1-10.

Faller, H., Brähler, E., Härter, M., Keller, M., Schulz, H., Wegscheider, K., ... & Mehnert, A. (2017). Unmet needs for information and psychosocial support in relation to quality of life and emotional distress: A comparison between gynecological and breast cancer patients. *Patient education and counseling*, *100*(10), 1934-1942.

Faubion, S. S., & Kingsberg, S. A. (2019). Understanding the unmet sexual health needs of women with breast cancer. *Menopause*, *26*(8), 811-813.

Fletcher, B. S., Miaskowski, C., Given, B., & Schumacher, K. (2012). The cancer family caregiving experience*: European Journal of Oncology Nursing, 16*(4), 387-398. 7

Foster, C., & Fenlon, D. (2011). Recovery and self-management support following primary cancer treatment. *British journal of cancer*, *105*(1), 21-8.

Foster, C., & Roffe, L. (2009). An exploration of the internet as a self-management resource. *Journal of Research in Nursing*, *14*(1), 13-24.

Gaspard, K. J., Porth, C. M., & Matfin, G. (2009). Disorders of hemostasis. *Pathophysiology–concepts of altered health states. Wolters Kluwer Health*, 262-77.

Gobeil-Lavoie, A. P., Chouinard, M. C., Danish, A., & Hudon, C. (2019). Characteristics of self-management among patients with complex health needs: a thematic analysis review. *BMJ open*, *9*(5), e028344.

Green, S. D., Bradley, H. E., Knobf, M. T., Prigerson, H., Diggiovanna, P. M., & McCorkle, R. (2011). Self-management and transition of women with advanced cancer disease. *Journal of pain and symptoms management, 42*(4), 517-525.

Griesser, A. C., Vlastos, G., Morel, L., Beaume, C., Sappino, A. P., & Haller, G. (2011). Socio-demographic predictors of high support needs in newly diagnosed breast cancer patients. *European journal of cancer care*, *20*(4), 466-474.

Halkett, G. K., Kristjanson, L. J., Lobb, E., Little, J., Shaw, T., Taylor, M., & Spry, N. (2012). Information needs and preferences of women as they proceed through radiotherapy for breast cancer. *Patient education and counseling*, *86*(3), 396-404.

Hautamäki-Lamminen, K., Lipiäinen, L., Beaver, K., Lehto, J., &KellokumpuLehtinen, P. L. (2013). Identifying cancer patients with greater need for information about sexual issues. *European Journal of Oncology Nursing*, *17*(1), 9-15

Hesketh, R. (2023). *Introduction to cancer biology*. Cambridge University Press

Hubbeling, H. G., Rosenberg, S. M., González-Robledo, M. C., Cohn, J. G., Villarreal-Garza, C., Partridge, A. H., & Knaul, F. M. (2018). Psychosocial needs of young breast cancer survivors in Mexico City, Mexico. *PloS one*, *13*(5), e0197931.

International Agency for Research on Cancer (IARC) Working Group on the Evaluation of Cancer-Preventive Strategies (2016). *Breast Cancer Screening. IARC Handbooks of Cancer Prevention*. Vol 15. IARC Press; 2016

Kantsiper, M., McDonald, E. L., Geller, G., Shockney, L., Snyder, C., & Wolff, A. C. (2009). Transitioning to breast cancer survivorship: perspectives of patients, cancer specialists, and primary care providers. *Journal of general internal medicine*, *24* (2), 459-66.

Kim, S. H., Park, S., Kim, S. J., Hur, M. H., Lee, B. G., & Han, M. S. (2020). Self-management needs of breast cancer survivors after treatment: results from a focus group interview. *Cancer nursing*, *43*(1), 78-85.

Lawn, S., Delany, T., Sweet, L., Battersby, M., & Skinner, T. (2015). Barriers and enablers to good communication and information-sharing practices in care planning for chronic condition management. *Australian Journal of Primary Health*, *21*(1), 84-89.

Lehmann, J., Machira, Y. W., Schneidman, M., & Chuma, J. (2020). Economic and Social Consequences of Cancer in Kenya.

Linden, W., Vodermaier, A., MacKenzie, R., & Greig, D. (2012). Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender, and age. *Journal of affective disorders*, *141*(2-3), 343-351.

Loh, S. Y., Packer, T., Chinna, K., & Quek, K. F. (2013). Effectiveness of a patient self-management programme for breast cancer as a chronic illness: a non-randomised controlled clinical trial. *Journal of Cancer Survivorship, 7*, 331-342.

Lorig, K. R., & Holman, H. R. (2003). Self-management education: history, definition, outcomes, and mechanisms. *Annals of behavioral medicine, 26*(1), 1-7.

Lovell, m., Agar, M., Luckett, T., Davidson, P. M., Green, A., & Clayton, J. Australian survey of current practice and guideline use in adult cancer pain assessment and management: Perspectives of palliative care physicians. *Journal of Palliative Medicine, 16*, 1403-1409.

Makau-Barasa, L. K., Greene, S., Othieno-Abinya, N. A., Wheeler, S. B., Skinner, A., & Bennett, A. V. (2020). A review of Kenya's cancer policies to improve access to cancer testing and treatment in the country. *Health Research Policy and Systems*, *18*(1), 1-10.

Matsuyama, R., Kuhn, L. A., Molisani, A., Maurren, C., & Genderson, W. (2012). Cancer patients' information needs the first nine months after diagnosis. *Patient Education and counseling, 90*, 96-102.

McConigley, R., Holloway, K., Smith, J., Halkett, G., Keyser, J., Aoun, S., et al. (2011). The diagnosis and treatment decisions of cancer patients in rural Western Australia. *Cancer Nursing, 34*(4), E1-E9.

McCorkle, R., Ercolano, E., Lazenby, M., Schulman-Green, D., Schilling, L. S., Lorig, K., & Wagner, E. H. (2011). Self-management: Enabling and empowering patients living with cancer as a chronic illness. *CA: a cancer journal for clinicians*, *61*(1), 50-62.

Merab, E. (2016). *KNH plans to end outpatient services in two years in bid to reduce congestion.* Nairobi: KNH.

Morrison, V., Henderson, B., Zinovieff , F., Davies, G., Cartmell , R., Hall, A., et al. (2011). Common, important, and unmet needs of cancer outpatient. *European Journal of Oncology Nursing, 16*(2), 115-123.

Ogunbayo, O. J., Russell, S., Newham, J. J., Heslop-Marshall, K., Netts, P., Hanratty, B., & Kaner, E. (2017). Understanding the factors affecting self-management of COPD from the perspectives of healthcare practitioners: a qualitative study. *NPJ primary care respiratory medicine*, *27*(1), 54.

Orem DE. Nursing: concepts of practice. St Louis, MO: Mosby-Year Book Inc, 1991

Ostby, P. L., Armer, J. M., Smith, K., & Stewart, B. R. (2018). Patient perceptions of barriers to self-management of breast cancer–related lymphedema. *Western journal of nursing research*, *40*(12), 1800-1817.

Parker, S. (2016). Clinical Guidelines for the Management of breast cancer. *guidelines for-the-management-of-breast-cancer, 1,* 29-30.

Regan, M., Mills, J., & Ristevski, E. (2012). Cancer care coordinators' relationships with the multidisciplinary team and patients: Everything to everyone. *Australian Journal of Cancer Nursing, 13, 12–19, 13,* 12-19.

Salvatore, A., Ahn, L., Jiang, S., Lorig, L., & Ory, G. (2016). National study of chronic disease self-management: 6-monthand 12-month findings among cancer survivors and. *24*, 1714-1722.

Sharma, R. (2021). Global, regional, national burden of breast cancer in 185 countries: evidence from GLOBOCAN 2018. *Breast Cancer Research and Treatment*, *187,* 557-567.

Shea, K. A., Steinberg, D. M., & Santiago, R. A. (2019). Bridging the gap: A pilot program to understand and meet the needs of pediatric patients and families as they transition off cancer-directed therapy. *Journal of Pediatric Oncology Nursing*, *36*(2), 86-92.

Smith, T., Dow, L. A., Virago, E., Hutcherson, J., Lyckholm, L., & Matsuyama, R. (2010). Giving honest information to patients with advanced cancer maintains hope. *Oncology Williston Park, 24*, 521-525.

Villarreal-Garza, C., Platas, A., Martinez-Cannon, B. A., Bargalló-Rocha, E., Aguilar-González, C. N., Ortega-Leonard, V., et al. (2017). Information Needs and Internet Use of Breast Cancer Survivors in Mexico. *Breast J, 23*, 373-375.

Wei, C., Mangling, Yan, W., Qiong, F., & Yuan, E. (2016). The patient-provider discordance in patient's needs assessment. *Journal of clinical Nursing*, *26*, 125-132.

WHO. (2018). *International agency for Research on cancer.* Geneva Switzerland.

Wittal, M. D. (2018). Bridging gap from oncology setting to community care through a cross Canada environmental scan. *Canadian Oncology Nursing Journal, 28*(1), 38-53.

Wagnild, G., Rodriguez, W., & Pritchett, G. (1987). Orem's self-care theory: a tool for education and practice. *Journal of Nursing Education*, *26*(8), 342-343.

Yamanaka, M. (2018). A concept analysis of self-management of cancer pain. *Asia-Pacific Journal of Oncology Nursing*, *5*(3), 254-261.

Yoon, Y. S., Jung, B., Kim, D., & Ha, I. H. (2019). Factors underlying unmet medical needs: a cross-sectional study. *International journal of environmental research and public health*, *16*(13), 2391.

APPENDICES

Appendix I: Questionnaire

Socio-demographic characteristics

1. Age (years) ………………….
2. Gender 1. Male ☐ ☐ 2. Female
3. Marital status Single ☐ Married ☐

   Divorced ☐ Widow/widower. ☐

4. Location. Urban ☐ Rural ☐
5. Reliable source of income ☐ Yes ☐ No
6. Level of education None primary ☐ secondary tertiary ☐
7. Occupation: Unemployed ☐ ☐ Employed ☐ ☐ Self-employed
8. Number of children: one child ☐ two children ☐ ☐ three children ☐

   More than three children ☐

9. Source of information on breast cancer

a. Nowhere ☐
b. Newspaper ☐
c. Television ☐
d. Health workers ☐
e. others ☐

10. Duration with breast cancer

a. 1-2 years ☐
b. 2-3 years ☐
c. 3-4 years ☐
d. 4-5 years ☐
e. Above five years ☐

11. Stage at diagnosis

a. Stage 1 ☐

b. Stage 11 ☐

c. Stage 111 ☐

d. Stage IV ☐

12. Past/Current therapy

a. Chemotherapy ☐

b. Surgerly ☐

c. radiotherapy ☐

d. Hormonal/Targeted therapy ☐

13. Disease status

a. Complete remission ☐

b. Partial remisssion ☐

c. Progressive disease ☐

d. Stable disease ☐

e. Inconclusive evaluation ☐

Appendix II: Understanding Self-Management

PART A

Have you ever heard about self-management (self-care)? YES ☐ NO ☐

IF yes continue with Part B

PART B

The participants were asked to tick against what they think the purpose of self-management is, nine options were given. Allowed to tick as many options as possible.

	Item	
1	To see if I have problems	
2	To repeat what was said to me by the doctor	
3	To ensure I know whom to contact if I have problems in future	
4	To ensure I understand my treatment summary and care-plans	
5	To give me information to help look for signs and symptoms of breast cancer	
6	To answer questions, I might have followed my treatment	
7	To discuss ways in which I can improve my health generally	
8	I do know what the purpose of self-management is	
9	Others (Specify)	

Patient factors affecting self-management.

	Item	Strongly disagree	Disagree	Average	Agree	Strongly agree
1.	I'm able to ask for information /seek clarification on matters pertaining my health condition freely with my health care givers.					
2.	Disease stage has not affected my performance on self-care.					
3.	My current financial status adequately meets all my care demands					

	Item	Strongly disagree	Disagree	Average	Agree	Strongly agree
4.	A physical symptom doesn't affect my ability to take care of self.					
5.	Having other conditions has not affected my performance in self-management					
6.	Fear, anxiety, and embarrassment does not hinder consultation on self-management					

Appendix III: Dodoso

1. Umri (kwa miaka) ………………………

2. Jinsia Kiume [ ] Kike [ ]

3. Hali ya ndoa Sijaolewa [ ] Nimeolewa [ ] Nimetalakiwa [ ]

Mjane [ ]

4. Makazi Mjini [ ] Kijijini [ ]

5. Je, uko na mapato ya kila wakati? Ndio [ ] La [ ]

6. Kiwango cha elimu Sina elimu [ ] Elimu ya msingi [ ]

Elimu ya Sekondari [ ] Elimu ya Chuo [ ]

7. Kazi Sina kazi [ ] Nimeajiriwa [ ] Nimejiajiri [ ]

8. Idadi ya watoto Mtoto mmoja [ ] Watoto wawili [ ] Watoto watatu [ ]

Zaidi ya watoto watatu [ ]

9. Chanzo cha habari kuhusu saratani ya matiti

Hakuna mahali [ ]

Kwa magazeti [ ]

Kwa runinga [ ]

Kwa mhudumu wa afya [ ]

Kwingineko [ ]

10. Muda ambao umekuwa na saratani ya matiti

Mwaka 1 – Miaka 2 [ ]

Miaka 2 – Miaka 3 [ ]

Miaka 3 – Miaka 4 [ ]

Miaka 4 – Miaka 5 [ ]

Kwa zaidi ya miaka 5 [ ]

11. Hatua ya matibabu

Hatua ya kwanza [ ]

Hatua ya pili [ ]

Hatua ya tatu [ ]

Hatua ya nne [ ]

12. Matibabu ya sasa hivi/muda uliopita

Tiba ya kuchomwa [ ]

Upasuaji [ ]

Tiba ya miale [ ]

Tiba ya homoni [ ]

13. Hali ya ugonjwa

Ondoleo kamili la dalili [ ]

Ondoleo la muda la dalili [ ]

Ugonjwa unaozidi [ ]

Ugonjwa uliothibitiwa [ ]

Tathmini isiokamilika [ ]

UFAHAMU WA UTUNZAJI WAKIBINAFSI

SEHEMU YA A

Je, umeshawahi kusikia kuhusu utunzaji wa kibinafsi (au kujitunza mwenyewe)?

Ndio [ ] La [ ]

Ikiwa jibu lako ni Ndio, endelea na Sehemu ya B

SEHEMU YA B

Washiriki watahitajika kuweka alama kuhusiana na wazo lao kuhusu madhumuni ya utunzaji wa kibinafsi, chaguzi tisa zimepeanwa.

1	Kujua ikiwa niko na shida	
2	Kuweza kurudia yale niliyoambiwa na daktari	
3	Kuhakikisha kuwa najua nitakaye asiliana naye iwapo nitapata matatizo kwenye siku zijazo	
4	Kuhakikisha kuwa naelewa muhtasari wa matibabu yangu na mipango ya utunzaji	
5	Kunipa habari za jinsi ya kutambua ishara na dalili za ugonjwa wa saratani ya matiti	
6	Kuweza kujibu maswali ambayo ninaweza kuwa nayo kufuatia matibabu yangu	
7	Kujadili njia/mbinu zakuniwezesha kuboresha afya yangu kwa ujumla	
8	Sifahamu/sijui madhumuni ya utunzaji wa kibinafsi ni yepi	
9	Mengine	

Mambo/sababu zinazohusiana na mgonjwa na ambazo huathiri utunzaji wa kibinafsi

		Sikubaliani kabisa	Sikubaliani	Wastani	Nakubaliana	Nakubaliana kabisa
1.	Wahudumu wa afya hutumia lugha inayoeleweka wanapotoa habari kuhusu uboreshaji wa utunzaji wa kibinafsi					
2.	Nimehusika katika majadiliano yaliyohusisha wahudumu wa afya tofauti yalioboresha jinsi huwa najitunza mwenyewe					
3.	Hali yangu ya kifedha kwa sasa inakimu ipasavyo mahitaji yangu ya utunzaji					
4.	Dalili za kimwili huwa haziathiri uwezo wangu wa kujitunza mwenyewe					
5.	Kuwa na hali zingine za kiafya hakujaathiri jinsi ninavyojitunza mwenyewe					
6.	Hofu, wasiwasina					

	aibu huwa hazinizuii kufanya mashauriano juu ya kujitunza mwenyewe					

Appendix IV: SCNS –SF 34 [English Version]

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 five possible answers to choose from.

1	No need	**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.
3	Some need	**Low need for help**	This item caused me little concern or discomfort. I had little need for additional help.
4		**Moderate need for help**	This item caused me some concern or discomfort. I had some need for additional help.
5		**High Need for Help**	This item caused me a lot of concern and discomfort. I had a strong need for additional help.

		Not applicable (no need)	Satisfied No needs)	low need (some need)	Moderate (Some need)	High needs Some needs)/
		1	2	3	4	5
	PSCHOLOGICAL NEEDS					
1	Anxiety					
2	Feeling down or depressed					
3	Feelings of sadness					
4	Fears about the cancer spreading					
5	Worry that the results of treatment are beyond your control					
6	Uncertainty about the future					

7	Learning to feel in control of your situation					
8	Keeping a positive outlook					
9	Feelings about death and dying					
10	Concerns about the worries of those close to you					
	INFORMATIONAL AND HEALTH SYSTEM					
11	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home					
12	Being given explanations of those tests for which you would 1like explanations					
13	Being adequately informed about the benefits and side-effects of treatments before you choose to have them					
14	Being informed about your test results as soon as feasible					
15	Being informed about cancer which is under control or diminishing (that is, remission)					
16	Being informed about things you can do to help yourself to get well					
17	Having access to professional counselling (e.g.,					

	psychologist, social worker, counsellor, nurse specialist) if you, family, or friends need it					
18	Being given information about sexual relationships					
19	Being treated like a person not just another case					
20	Being treated in a hospital or clinic that is as physically pleasant as possible					
21	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment, and follow-up					

Thank you for completing this survey.

Appendix V: SCNS –Sf 34 [Kiswahili Version]

Ili tuweze kuwa na mpangilio bora wa huduma kwa waliopatikana na saratani, tungetaka kujua ikiwa mahitaji yako yanayotokana na kuwa na saratani yanatimizwa. Kwa kila mojawapo ya vitu vifuatavyo, ashiria iwapo umehitaji msaada kwa jambo hilo katika kipindi cha mwezi mmoja uliopita. Chagua jibu lako kati ya majibumatano yalioashiriwa.

1	Hamna haja	Haitumiki	Jambo hili halikunitatiza hata kidogo
2		**Nimeridhika**	Nilihitaji msaada kwa jambo hili, na nilipata msaada na nikaridhika
3	**Kuna Haja**	**Msaadawa kiwango cha chini**	–Jambo hili lilinitatiza. Nilihitaji msaada ingawa kidogo tu.
4		**Msaada wa kiwango cha katikati-**	Jambo hili lilinitatiza. Nilihitaji msaada zaidi.
5		**Msaada wa kiwango cha juu**	Jambo hili lilinitatiza. Nilihitaji msaada zaidi

		Haitumiki (Hamna haja)	Nimeridhika (Hamna haja)	Msaada wa kiwango cha chini (Kuna Haja)	Msaada wa kiwango cha katikati (Kuna Haja)	Msaada wa kiwango cha juu (Kuna Haja)/
		1	2	3	4	5
1	Wasiwasi					
2	Kukosa uchangamfu					
3	Kujihisi na huzuni					
4	Uwoga kuwa saratani itasambaa					

5	Wasiwasi kuwa matokeo ya matibabu iko nje ya uwezo wako					
6	Kutokuwa na uhakika kuhusu siku za usoni					
7	Kujifunza kuhisi kuwa uko na udhibiti wa hali yako					
8	Kuwa na mtazamo mzuri					
9	Hisia za kifo na kukufa					
10	Wasiwasi kuhusu walio karibu nawe					
11	Kupewa taarifa za muhimu kuhusiana na ugonjwa wa saratani					
12	Kupewa maelezo kamilifu kuhusiana na vipimo vyovyote vinavyohitajika					
13	Kupewa maelezo kamilifu kuhusu faida na madhara yoyote ya matibabu kabla ya matibabu kuanza					
14	Kuarifiwa kwa haraka kuhusu matokeo ya vipimo					
15	Kuelezewa kuhusu saratani iliodhibitiwa au inayopungua					
16	Kuarifiwa juu ya mambo tofauti					

	unayoweza kufanya ili upate nafuu					
17	Kuwa na nafasi ya kupata ushauri nasaha kutoka kwa wataalamu					
18	Kupewa taarifa kuhusu mahusiano ya kimapenzi					
19	Kuchukuliwa kama mtu na sio kama kesi nyingine					
20	Kuhudumiwa katika hospitali au kliniki iliyoko kwenye hali nzuri iwezekanavyo					
21	Kuwa na mhudumu wa afya unayeweza kuongea naye kwa wazi kuhusuiana na hali yako ya afya, matibabu na ufuatilizi					

Ahsante kwa kushiriki katika utafiti huu

Appendix VI: Participants' Information Sheet (English Version)

Principal Investigator: Ann Wanjiru Gitahi Tel: 0727934438

School of Nursing

Jomo Kenyatta University of Agriculture and Technology

P.O. Box 62000-00200

Nairobi

Co-Investigators

Dr. Drusilla Makworo

Senior Lecturer

School of Nursing

Jomo Kenyatta University of Agriculture and Technology

James Odero Ochieng

Lecturer

School of Nursing

Jomo Kenyatta University of Agriculture and Technology

Introduction

Hello! My name is Ann Wanjiru Gitahi, a nursing student from JKUAT. The purpose of this consent information is to give you the information you will need to help you decide whether or not to be a participant in the study.

i) Your decision to participate is entirely voluntary

ii) You may withdraw from the study at any time without necessarily giving a reason for your withdrawal

iii) Refusal to participate in the research will not affect the services you are entitled to in this health facility or other facilities. I'm conducting a study on 'Self-management satisfaction among breast cancer patients during the transition period from active to maintenance phase of systemic therapy at KNH'. This will be a descriptive cross -sectional study at CTC, you are invited to participate in this study.

The following information is important to make an informed decision.

What if you want to participate in the study?

If you agree to participate in this study, the following things will happen:

Trained research assistant will assist you to complete questionnaire either in Kiswahili or English whichever language you are comfortable. Will ensure privacy where you will be comfortable answering questions. This will take approximately 30-40 minutes.

May I continue? YES / NO

Purpose of the study

Background and objectives: The purpose of the study is to explore self-management satisfaction among breast cancer during transition from active to maintenance phase of systemic therapy. You are therefore considered a suitable participant for this study because you are one with breast cancer already undergoing systemic therapy.

Benefits

The condition will not improve after participating in this research, but the information gained will help you assess your current situation and how you can make it better and understand your role in the treatment plan. Appropriate referrals in case need will be done promptly and free health education on areas of concern. Information will help us prepare tools and programs to help on self-management aspects in future.

Risks/Harms/Discomforts

All information collected from you will be maintained privately and confidentiality maintained. No names will be used in the study, rather a code will be used for the same reasons. However, no system of protecting your confidentiality can be absolutely secure, so it is still possible that someone could find out you were in this study and could find out information about you.

Also, answering questions in the interview may be uncomfortable for you. If there are any questions you do not want to answer, you can skip them. You have the right to refuse the interview, or any questions asked during the interview.

Monetary gain/refund

There will be no direct monetary benefits or compensation for participation in the study.

No financial implication participating in this study.

What participation means:

Participation is voluntary.

The study will involve filling out a questionnaire and SCNF data collection tool, and it’s expected to take 30-40 minutes. The only people who will know you are research subject is the research team who may be the nurses who take care of you. No information about you or provided by you will be disclosed to others without your written permission except, if necessary, to protect your rights or welfare of required by the law. When the results are published or discussed in conference no information will be included that would reveal your identity.

You have freedom to:

1. Decide whether to participate or not.
2. Answer the questions with which you are comfortable.
3. Withdraw from the study at any point and your information is confidential and destroyed.

Future Clarity and More Information:

You are free to contact; The researcher, Ann Wanjiru Gitahi JKUAT, School of Nursing, Tel.0727-934438; Email.annewanjiru30@gmail.com

Lead Supervisors Name: Dr. Drusilla Mokoro, Tel no 0721 262-355 School of Nursing (JKUAT); Email Address dmakworo@jkuat.com

You may also contact Chairperson KNH/UON-ERC, through the following address 19676-00202 Kenyatta N. Hospital; Tel 2726300-9, Ext 44102.

Appendix VII: Participants' Informed Consent Form

I serial number (………....) do agree to participate in the study on self-management satisfaction among breast cancer patients during transition from active to maintenance phase of systemic therapy at KNH.

I am informed that my participation is voluntary, and no financial benefits are provided.

I have also been informed that my information will be confidential and securely maintained and it will not be possible to identify the information with me. I'm also informed that I can withdraw from the study at which level I find appropriate to do so.

I therefore willingly and voluntarily agree to participate in the study on self-management satisfaction among breast cancer patients during the transition period from active to maintenance phase of systemic therapy.

Participants signature…………………………… Date…………………………..…

Researcher's signature…………………………… Date…………………………..…

For more information and clarification, you are free to contact; The researcher, Ann Wanjiru Gitahi JKUAT, School of Nursing, Tel.0727-934438; Email.annewanjiru30@gmail.com

Lead Supervisors Name: Dr. Drusilla Makworo, Tel no 0721 262-355 School of Nursing (JKUAT); Email Address dmakworo@jkuat.com

You may also contact Chairperson KNH/UON-ERC, through the following address 19676-00202 Kenyatta N. Hospital; Tel 2726300-9, Ext 44102.

Appendix VIII: Fomu ya Maelezo Kuhusu Idhini (Kiswahili Version)

Mtafiti mkuu: Ann WanjiruGitahiTel:0727934438

ShuleyaWauguzi

Chuo Kikuu cha JKUAT

Sanduku la Posta 6200-00200

Nairobi

Watafiti wenza

Daktari Drusilla Makworo

Mhadhiri Mkuu

ShuleyaWauguzi

Chuo Kikuu cha JKUAT

James Odero Ochieng

Mhadhiri

ShuleyaWauguzi

Chuo Kikuu cha JKUAT

Utangulizi

Hujambo! Jina langu naitwa Ann Wanjiru Gitahi, mwanafunzi katika chuo kikuu cha JKUAT. Lengo la fomu hii ya maelezo kuhusu idhini ni kukueleza taarifa muhimu zitakazokuwezesha kuamua iwapo utashiriki au hautashiriki kwenye utafiti huu.

Cha muhimu ni kuwa

i) Uamuzi wako wa kushiriki ni wa hiari

ii) Unaweza kuacha kushiriki katika utafiti huu wakati wowote bila ya kutoa sababu yoyote ya uamuzi huu

iii) Kukataa kushiriki katika utafiti huu hakuta athiri huduma ambazo huwa unapata katika kituo hiki cha afya.

Ninafanya utafiti kuhusu ugonjwawasarataniyamatitikwawanawakewanapopokeamatibabuyadawazasarataniwakimalizakipindi cha kwanza nakuanzakipindi cha kufuatia.

Taarifa ifuatayo ni muhimu katika kufanya uamuzi wako:

Ikiwa utakubali kushiriki katika utafiti huu, mambo yafuatayo yatafanyika:

Utasaidiwa na mtafiti msaidizi kulijaza dodoso la utafiti huu. Usiri wa maelezo utakayotoa utahimizwa na majadiliano yetu yatachukua muda wa dakika arobaine.

Je, naweza endelea? Ndio / La

Lengo la utafiti huu

Lengo kuu la kufanyautafiti huu nikuhusuugonjwawasarataniyamatitikwawanawakewanapopokeamatibabuyadawazasarataniwakimaliza kipindi cha kwanza nakuanzakipindi cha kufuatiaUmekaribishwakuwamshirikiufaayekwasababuukokatikahalihii.

Faida za utafiti

Afya yako haitabadilika kwa kushiriki kwa utafiti, lakini majibu tutakayopata itakusaidia kujua ujuzi wako kwa wakati huu na kuelewa baadhi ya mahitaji na jukumu zako katika matibabu.

Hatari/madhara

Hakuna hatari au madhara itakayokupata kwa kushiriki katika utafiti huu.

Mapato/zawadi

Hakuna mapato ya kushiriki katika utafiti huu.

Kuhusukushiriki

Kushiriki ni kwa hiari yako. Utaulizwa maswali yanayokuhusu. Kujibu maswali kutachukua kati ya dakika 30 na 40.

Habari utakazopeana zitaandikwa na hazitapewa watu wasiohusikana utafiti huu.Habari yako itawekwa siri na haiwezikutambulishwa nawe.

Unaouhuruwa:

1. Kushiriki au kutoshiriki
2. Kujibumaswaliuliyosawanayo
3. Kusitishakushirikiwakatiwowotenaripotiyakoitalindwanakuharibiwa

Ikiwautakuwanamaswali au jambololoteungetakakuongelelea kuhusu utafiti huu, jisikie huru kuwasilianana mtafiti, Ann W. Gitahi, shule ya Uuguzi, Chuo Kikuu cha JKUAT namba ya rununu: 0727-934438, baruapepe: annewanjiru30@gmail.com

Ama, mhadhirimsimamizimtafiti Daktari DrusillaMakworo, ShuleyaUuguzi, Chuo Kikuu cha JKUAT.Simuyarununu 0721262355, barua pepe: dmakworo@jkuat.ac.ke.

Au wasilianana mwenyekitiwakamatiinayochanganuzamaswaliyautafitiyaHopitaliya Kenyatta na Chuo Kikuu cha Nairobi kupitiasanduku la posta 19676-00202 Nairobi amaNambariyaSimu 2726300-9, Ext 44102.

Appendix IX: Fomu ya Kutoa Idhini ya Kushiriki

Mimi (nambari ya siri) ………………. natoa idhini yangu kwa hiari kushiriki katika utafiti ambao nimeelezwa lengo, faida madhara yake. Nimejulishwa kwa mbakushiriki kwangu ni kwa hiari na hakuna faida zozote za kifedha nitapokea.

Nimejulishwapiakwambaujumbenitakaotoautawekwakisirinahautawezakutambulishwanami.Nafahamu pianawezakusitishakushiriki katika utafiti huu kwawakati wowote.

Hivyobasinatoaidhiniyangukushirikikatikautafiti huu

Sahihiyamshiriki ………………… Tarehe…………………….

Sahihi ya mtafiti mkuu ……………………… Tarehe…………………….

Kwahabarinamaelezo zaidi, unao huruwa kuwasiliana na:

Mtafiti, Ann W. Gitahi, Shule ya Uuguzi, Chuo Kikuu cha JKUAT namba ya rununu:0727-934438, barua pepe: annewanjiru30@gmail.com

Ama, mhadhirimsimamizimtafiti Daktari DrusillaMakworo, ShuleyaUuguzi, Chuo Kikuu cha JKUAT.Simuyarununu 0721262355, barua pepe: dmakworo@jkuat.ac.ke.

Au wasilianana mwenyekitiwakamatiinayochanganuzamaswaliyautafitiyaHopitaliya Kenyatta na Chuo Kikuu cha Nairobi kupitiasanduku la posta 19676-00202 Nairobi amaNambariyaSimu 2726300-9, Ext 44102.

Appendix X: Permission To Use SCNS –SF 34

On Thu, Jan 24, 2019 at 2:18 AM Allison
Boyes<allison.boyes@newcastle.edu.au> wrote:
Dear Ann,

Your email has been forwarded to me from Cancer Council NSW.

You are permitted to use the SCNS-SF34 in your postgraduate research.

Attached are the User Manual and some key references which will be of assistance to you.

Regards,
Allison

Dr Allison Boyes | NHMRC Early Career Fellow
Faculty of Health & Medicine | School of Medicine & Public Health

T: +61 2 4042 0703
E: allison.boyes@newcastle.edu.au
W: newcastle.edu.au/profile/allison-boyes
orcid.org/0000-0003-1721-0533
The University of Newcastle (UON)
University Drive, Callaghan NSW 2308 Australia

Ranked in the top 1% of universities in the world by
QS World University Rankings 2017/18
CRICOS Provider 00109J

-----Original Message-----
From: Mark Ludbrooke<markl@nswcc.org.au>
Sent: Monday, 21 January 2019 9:11 AM
To: Allison Boyes<allison.boyes@newcastle.edu.au>
Subject: FW: Request to use SCNS SF 3

Appendix XI: Focused Group Discussion Guide

1. Introduction: Topic and all members present.

2.How were you prepared to cope with anxiety, fear, worries, feelings related to treatment? PROBE:

3. How did the health team make you understand clearly and straightforward information relating to your care especially after the completion of intensive treatment session?

4. What are the myths and misconceptions about some information from other sources like social media from the health team?

5. Which areas do you think were inadequately addressed during your visits for treatment? Probe

6.Other than the Nurse and the physician, who else impacted your health in terms of health counseling?

PROBE:

7. When you feel you need help, whom do you turn to?

8. Let's summarize the key points for our discussion.

9. Do you have any questions?

Appendix XII: Focus Group Discussion Consent Document (English Version)

Principal investigator: Ann Wanjiru Gitahi

Tel.No 0727934438

Purpose

The study explores the major roles of breast cancer patients during transition from intensive to maintenance phase of systemic therapy and tries to understand some of the hindering factors towards its achievement.

Procedure

As part of this study, you will be placed in a group of 6-12 individuals. The moderator will ask you several questions while facilitating the discussion. This focus group will be audio-recorded and note-taker was present. However, your responses will remain confidential, and no names will be included in the final report. You can choose whether to participate and you may stop at any time during the course of the study.

Please note that there are no right or wrong answers to focus group questions. Respect one’s opinion and refrain from interrupting others. However, feel free to be honest even when your responses counter those of other participants.

Benefits and risks

Your participation may help in gathering views which could be implemented and help others. However, no risk is anticipated other than those experienced during an average conversation.

Confidentiality

Should you choose to participate, you will be asked to respect the privacy of other focus group members by not disclosing any content discussed during the study. Data will be analyzed but as stated above your responses will remain confidential and no names will be included in any reports.

Contacts

If you have any questions or concerns regarding this study, please contact me.

The researcher, Ann Wanjiru Gitahi JKUAT, School of Nursing, Tel.0727-934438; Email.annewanjiru30@gmail.com

Lead Supervisors Name: Dr. Drusilla Makworo, Tel no 0721 262 355 School of Nursing (JKUAT); Email Address dmakworo@jkuat.com

You may also contact Chairperson KNH/UON-ERC, through the following address 19676-00202 Kenyatta N. Hospital; Tel 2726300-9, Ext 44102.

I understand this information and voluntarily agree to participate fully under the conditions stated above.

Signature ……………………. Date…………………………………….

Appendix XIII: Fomu ya Kutoa Idhini kwa Washiriki wa Majadiliano ya Vikundi

Mtafiti mkuu: Ann Wanjiru Gitahi

Namba ya rununu: 0727934438

Lengo

Lengo kuu la kufanya utafiti huu ni kuchunguza majukumu ya wagonjwa wa saratani yamatiti kwa wanawake wanapopokea matibabu ya dawa za saratani wakimaliza kipindi cha kwanza nakuanzakipindi cha kufuatia. Utafiti huu pia utachunguza sababu zinazozuia ufanisi wa matibabu haya.

Utaratibu

Kama sehemu ya utafiti huu, mtawekwa katika vikundi ya watu kati ya sita na kumi na wawili. Msimamizi atawauliza maswali na kuongoza majadiliano. Majadiliano hayo yataandikwa na kuwekwa pia kama kumbukumbu. Walakini, maelezo yatakayotolewa yatawekwa kwa siri and hakuna majina ya utambulizi itakayowekwa kwenye ripoti ya mwisho. Unao uhuru wa kuamua iwapo utashiriki au hautashiriki na unaweza sitisha kushiriki wakati wowote utafiti ukiendelea.

Tafadhali kumbuka hakuna jibu sawa au baya katika majadiliano haya. Ni vizuri tuheshimu maoni ya kila mmoja na tusiwe wa kusitisha wengine wanapotoa mchango wao. Walakini, jisikie huru kutoa maoni yako kwa njia ya uaminifu hata ikiwa ni tofauti na maoni ya wengine.

Mapato na madhara

Kushiriki kwako kutachangia maoni ambayo huenda yakatekelezwa na kuwasaidia wengine. Walakini, hakunamapato au madhara utakayopata kwa kushirikikatika utafiti huu.

Usiri

Ukiwa utaamua kushiriki katika majadiliano haya, utaulizwa uheshimu maoni ya washiriki wengine kwa kutoyafichua nje ya majadiliano yenyewe. Maelezo utakayotoa yatabaki kuwa siri kwa mtafiti na hakutakuwa na kutambulisha majina ya washiriki wa majadiliano haya kwenye ripoti zozote zitakazotayarishwa.

Mawasiliano

Ikiwa uko na maswali yoyote au unahitaji maelezo zaidi kuhusiana na utafiti huu, tafadhali wasiliana na:

Mtafiti, Ann W. Gitahi, shule ya Uuguzi, Chuo Kikuu cha JKUAT namba ya rununu: 0727-934438, baruapepe: annewanjiru30@gmail.com

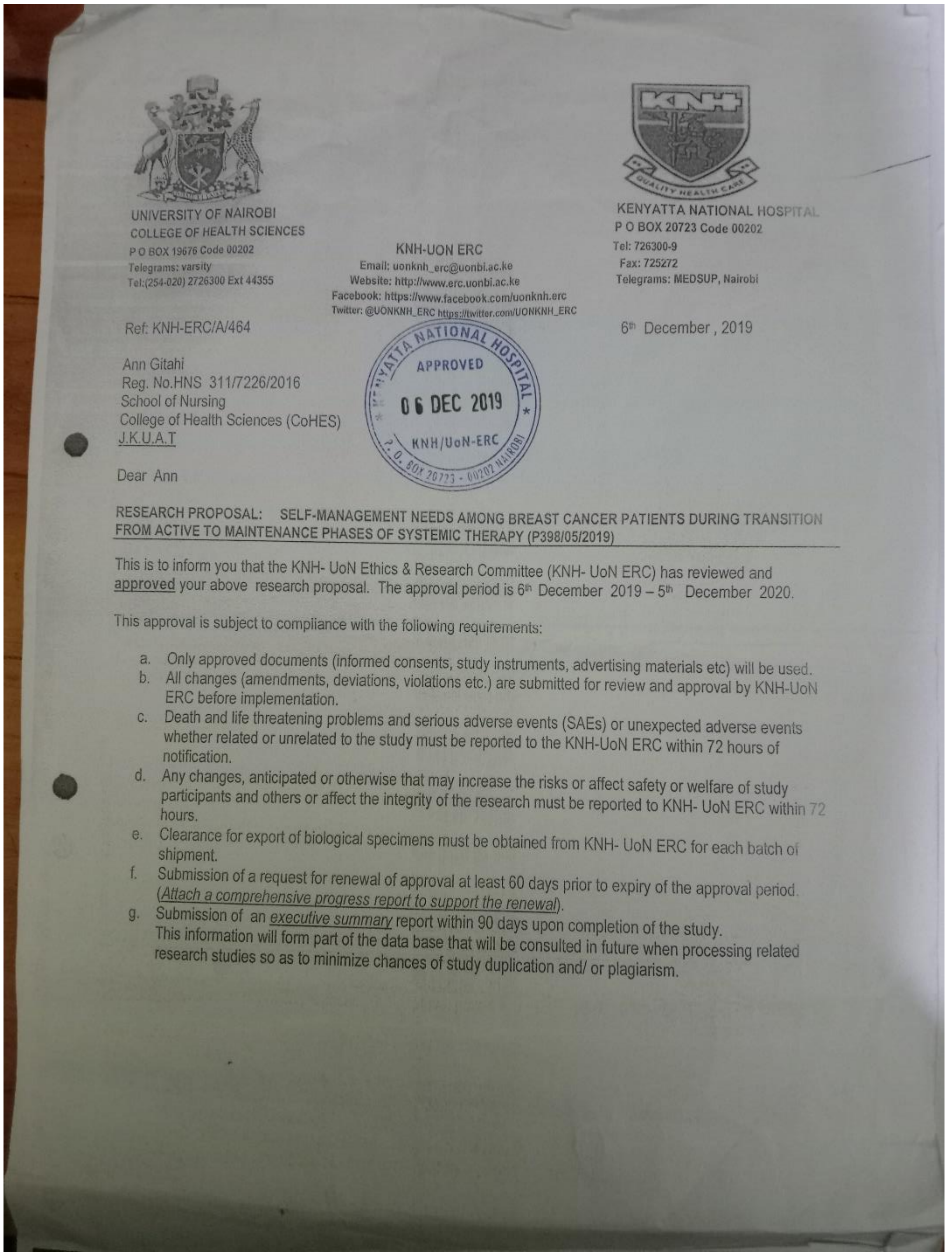
Mhadhirimsimamizi, Daktari DrusillaMakworo, ShuleyaUuguzi, Chuo Kikuu cha JKUAT.Simu ya rununu 0721262355, Barua pepe: dmakworo@jkuat.ac.ke.

Au wasilianana mwenyekitiwakamatiinayochanganuzamaswaliyautafitiyaHopitaliya Kenyatta na Chuo Kikuu cha Nairobi kupitiasanduku la posta 19676-00202 Nairobi amaNambariyaSimu 2726300-9, Ext 44102.

Nimeelewa maelezo haya na nimeamua kushiriki kwa hiari nikizingatia masharti yaliyoelezewa hapo juu.

Sahihiyamshiriki …………………………… Tarehe………….……………….

Appendix XIV: KNH-OUN Ethical Review Approval



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/464

6th December , 2019

Ann Gitahi
Reg. No.HNS 311/7226/2016
School of Nursing
College of Health Sciences (CoHES)
J.K.U.A.T

APPROVED
06 DEC 2019
KNH/UoN-ERC

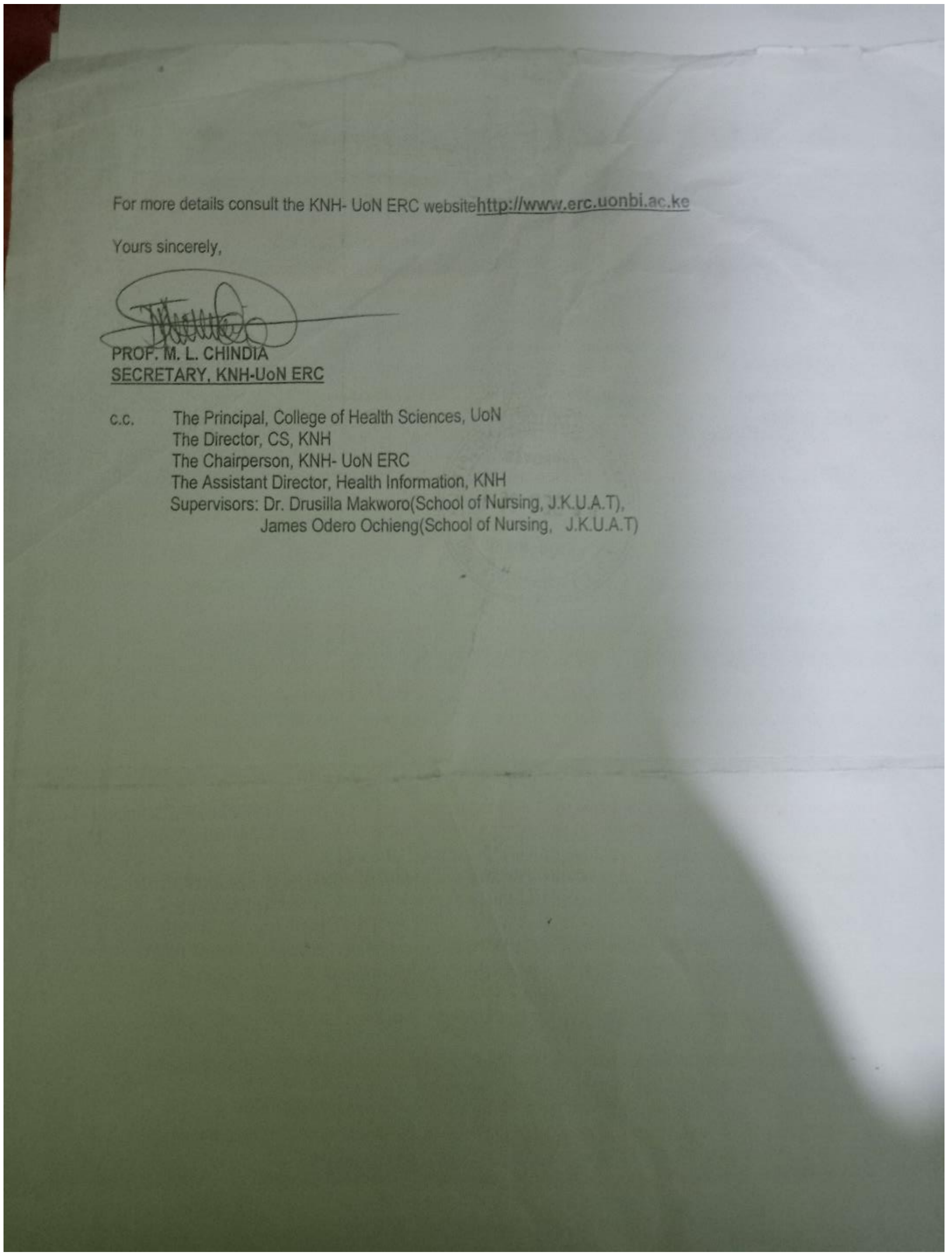
Dear Ann

RESEARCH PROPOSAL: SELF-MANAGEMENT NEEDS AMONG BREAST CANCER PATIENTS DURING TRANSITION FROM ACTIVE TO MAINTENANCE PHASES OF SYSTEMIC THERAPY (P398/05/2019)

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 6th December 2019 – 5th December 2020.

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.



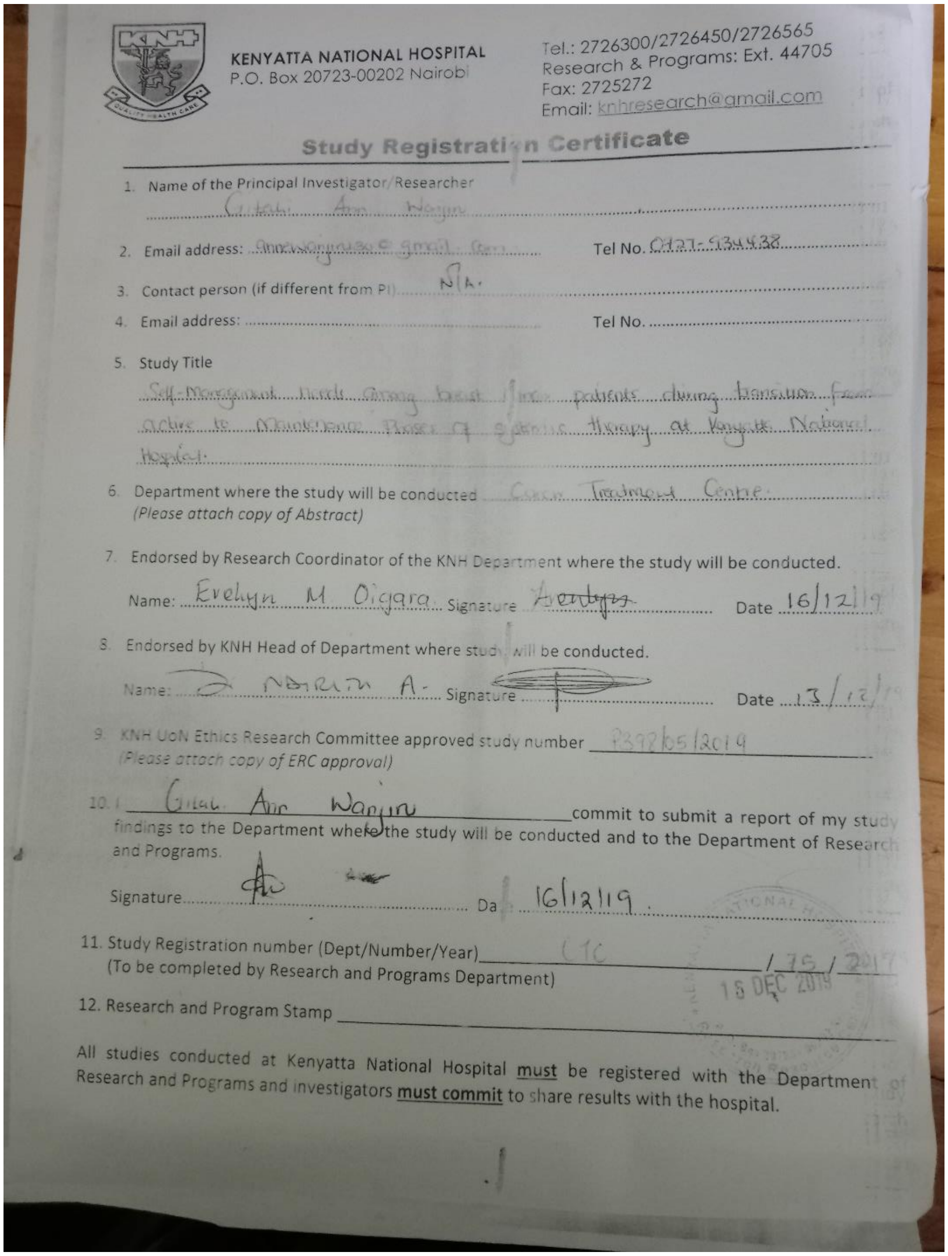
For more details consult the KNH- UoN ERC website**http://www.erc.uonbi.ac.ke**

Yours sincerely,

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

c.c.
The Principal, College of Health Sciences, UoN
The Director, CS, KNH
The Chairperson, KNH- UoN ERC
The Assistant Director, Health Information, KNH
Supervisors: Dr. Drusilla Makworo(School of Nursing, J.K.U.A.T),
James Odero Ochieng(School of Nursing, J.K.U.A.T)

Appendix XV: KNH Research Program Registration Certificate



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
Gitau Ann Wanjiru

2. Email address: [illegible] Tel No. 0727-934438

3. Contact person (if different from PI) N/A.

4. Email address: .... Tel No. ....

5. Study Title
Self-Management needs among breast cancer patients during transition from active to maintenance phases of systemic therapy at Kenyatta National Hospital.

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: Evelyn M Oigara Signature .... Date 16/12/19

8. Endorsed by KNH Head of Department where study will be conducted.
Name: [illegible] A. Signature .... Date 13/12/19

9. KNH UoN Ethics Research Committee approved study number P398/05/2019
(Please attach copy of ERC approval)

10. I Gitau Ann Wanjiru commit to submit a report of my study findings to the Department where the study will be conducted and to the Department of Research and Programs.
Signature .... Date 16/12/19.

11. Study Registration number (Dept/Number/Year) CTC / 75 / 2019
(To be completed by Research and Programs Department)

12. Research and Program Stamp
15 DEC 2019

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

Appendix XVI: Publication

https://www.ajol.info/index.php/eamj/article/view/246502

Appendix XVII: Conference Presentation

Speaker Presentations

Title	PSYCHOLOGICAL AND INFORMATIONAL NEEDS AMONG BREAST CANCER PATIENTS
Presentation Type	Oral presentation
Theme	Palliative care and survivorship
Abstract	Information is paramount to patients because it helps them to understand their cancer, treatment, make decisions and cope with interventions. Consequently, lack of information has been identified to be the greatest hindering factor in seeking medical attention, especially among cancer patients on different therapies. The psychological domain address needs associated with feelings and coping mechanism of the patient. Maladaptive psychological responses such as anxiety neurosis, depressive symptoms and maladaptive disorders are common if the emotional distress following intensive treatment therapy is not addressed on due time. When demands on self-care exceed the ability to perform it results in a self-care deficit. **Objective:** To assess psychological and informational needs among breast cancer patients during transition from active to maintenance phase of systemic therapy at KNH.

Study design: Descriptive cross-sectional research design.

Settings: KNH Cancer Treatment Centre

Population: Breast cancer patients transitioning from active to maintenance phases of systemic therapy at KNH.

Main outcome measures: Age, gender, education level, marital status, residence setting, income reliability, psychological and informational needs among study participants.

Materials and methods: Descriptive cross-sectional study was carried out among 169 breast cancer patients on systemic therapy at KNH. Data was collected using questionnaire and SCNS-SF 34 tool, analyzed using various descriptive statistics including frequencies and percentages using Statistical Package for the Social Sciences (SPSS) version 23.0. Core factors behind interdependence between correlated variables were identified using Principal Component Analysis via Rotated Component Matrix presented in tables.

Results: In psychological needs domain; concerns about the worries of close relatives (35%), uncertainty about the future (32%) and fears about the cancer spreading (30%) were the outstanding aspects for which additional help was needed. In

	informational needs domain, member of staff whom you can share with about your condition and follow-up (74%), information about sexual relationships (62%) and having access to professional counselor (52%) were items that patients expressed needed additional support. **Conclusion**: Breast cancer patients at KNH experienced psychological and informational needs during transition phase from active to maintenance phase of systemic therapy. Therefore, interventions directed at addressing the psychological and informational needs of breast cancer patients during transition is necessary
Presenting Author	Mrs Ann Wanjiru Affiliations: Kenyatta University Teaching Referral and Research Hospital, Kenya
Co-Author	Dr. Drusilla Makworo Affiliations: Jomo Kenyatta University of Agriculture and Technology
Co-Author	Mr. James Odero Affiliations: Jomo Kenyatta University of Agriculture and Technology