

**PSYCHOSOCIAL DISTRESS AMONG PATIENTS WITH
CANCER AT MACHAKOS PALLIATIVE CARE UNIT**

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**Psychosocial Distress among Patients with Cancer at Machakos
Palliative Care Unit**

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DECLARATION

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

Signature.....Date.....

Francis Justin Kinoti

This thesis has been submitted for examination with our approval as university supervisors

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JKUAT, Kenya

DEDICATION

This work is dedicated to my late niece Terry Kendi Muthomi who succumbed to primitive neuroectodermal tumor at a tender age of three years in October 2013 while undergoing treatment at Defense Forces Memorial Hospital, Nairobi.

I also dedicate this work to my late dad Francis Kaumbuthu, may his soul continue resting in eternal peace!

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ABBREVIATIONS/ACRONYMS

DSM	Diagnostic and Statistical Manual of Mental Disorders
DT	Distress Thermometer
HADS	Hospital Anxiety and Depression Scale
ICD	International Classification of Diseases`
IPOS	International Psycho-Oncology Society
JKUAT	Jomo Kenyatta University of Agriculture and Technology
MOH	Ministry of Health
NCCN	National Cancer Center Network
NHIF	National Hospital Insurance Fund
PTSD	Post traumatic stress disorder
SoN	School of Nursing
SPSS	Statistical packages for social sciences
UK	United Kingdom
WHO	World Health Organization

OPERATIONAL DEFINITION OF TERMS

Cancer factors They are patient clinical characteristics such as type of cancer, period since diagnosis, staging and type of treatment for psychosocial distress due to cancer.

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.

Institutional factors They are healthcare system related factors such as workload, staff attitude, accessibility and affordability of medical insurance and availability of resources associated with psychosocial distress among the cancer patient

M-TIBA Machakos county government sponsored health scheme as a pilot study for provision of universal health coverage

Palliative care provider A qualified health care professional with post basic training in palliative and hospice care

Practical problems They are child care, housing, insurance/financial, transportation, work/school or difficulties with making treatment decisions faced by the cancer patients as defined by the National Comprehensive Cancer Network.

Psychosocial Distress Problems They are physical, psychological, social and spiritual symptoms and/or concerns reported by the cancer patients

Psychosocial Distress Screening It is an economical, brief, and accurate process of identifying undiagnosed physical, psychological, social and spiritual needs of cancer patients and their caregivers.

Psychosocial Screening Tools They are economical, brief, and accurate instruments used in identifying possible presence of undiagnosed physical, psychological, social and spiritual problems in cancer patients and their caregivers.

Sociodemographic factors Characteristics of the cancer patients to including age, gender, marital status, education level, occupation, residence and family income which contribute to psychosocial distress when a person has cancer.

ABSTRACT

Cancer diagnosis and treatment are emotionally draining to patients and their caregivers. For a long time, treatment for cancer has been associated with pain, suffering and death. These negative consequences of cancer create psychosocial effects such as anxiety and fear. Therefore, there is need to recognize and accurately identify this psychosocial burden on patients by healthcare providers. These professionals can then figure out interventions for these psychosocial issues, possibly even leading to better compliance with overall prescribed treatment, and possibly yielding a better prognosis. The purpose of this study was to determine the prevalence and factors associated with the psychosocial distress among patients diagnosed with cancer at Machakos palliative care unit. Both qualitative and quantitative data were collected through descriptive cross-sectional design. A total of 97 patients were interviewed and filled the questionnaires and the NCCN distress thermometer and problem list. Two focus group discussions were conducted and one palliative care provider was interviewed as a key informant. Quantitative data was analysed using the Statistical Package for Social Sciences (SPSS) for windows version 24. Descriptive statistics such as the means, standard deviation and frequencies were computed. Pearson Chi square test of association and binary logistic regression were computed to determine associations between the independent and the dependent variables. The qualitative data findings were transcribed verbatim and data were analysed for themes about financial problems, pain, chemotherapy side effects, medical insurance, lack of hospital supplies and workload and staffing. Quantitative study findings revealed that majority (72.2%) of the respondents were distressed with 43.2% reporting severe levels of psychosocial distress. Majority of the respondents reported being in pain (83.3%), having problems with decision making about treatment (64.9%), experiencing fatigue (59.8%), having insurance/financial constrains (57.7%), worrying (50.5%) and having problems with eating (50.5%). The results also revealed that male patients diagnosed with cancer were 85% less likely to be distressed compared to female patients (O.R = 0.154, 95% CI 0.039- 0.605). In conclusion, there is a very high prevalence of psychosocial distress among patients with cancer with the leading psychosocial distress being consequence of pain. The study recommended that all patients with cancer be comprehensively screened for psychosocial distress at enrollment for the palliative care services and at prescribed intervals.

CHAPTER ONE

INTRODUCTION

1.1 Background to the Study

Cancer is a general term for a large group of diseases defined by uncontrolled growth and proliferation of cells in any part of the body, from a monoclonal origin, beyond their boundaries with ability to invade adjacent parts of the body and/or spread to the near and distant organs (World Health Organization, 2017). It is the second leading cause of death worldwide, with approximately 14.1 million new cases having been diagnosed in 2012 (International Agency for Research on Cancer and Cancer Research UK, 2014). Over half the cases and nearly two-thirds of deaths occurred in Africa and other low- and middle-income regions. The International Agency for Research on Cancer and Cancer Research, UK (2014) reported that if the recent trends seen globally continue, the burden will increase to 23.6 million new cases each year by 2030.

In Kenya, cancer ranks third as a cause of death after infectious and cardiovascular diseases (Ministry of Health, Kenya, 2017). It causes about 7% of the total national mortality every year. The Ministry of Health estimates that the annual incidence of cancer is about 28,000 new cases with an annual mortality of 22,000 cases. Over 60% of those affected are below 70 years old while the risk of getting cancer before age 75 is 14% and the risk of dying is estimated at 12%. According to the national cancer registry (2014-2016) report, the top three cancers in women are breast, cervical and oesophagus while in men oesophagus, prostate and Kaposi's sarcoma are the most common (MOH, 2017).

Machakos county was ranked number four with the proportion of cancer cases per county (6%) alongside Meru and Nyeri in the Kenyatta National Hospital cancer registry 2014-2016 report by Mudenyio and Mugo (2017). Nairobi county was the leading in the

number of cancer cases at 22%, followed by Kiambu (11%) and Muranga (8%). Cancer is a life-threatening disease that causes high level of psychosocial distress among the patients and their caregivers worldwide (Zabora, BrintzenhofeSzoc , Curbow , Hooker & Piantadosi , 2001).

Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional) social, and/or spiritual nature that may interfere with the ability of a person to cope effectively with cancer, its physical symptoms and its treatment according to the National Comprehensive Cancer Network (NCCN) report (2011). This distress can be placed on a continuum, from common normal feelings of vulnerability, sadness, and fear to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis.

The diagnosis and treatment of cancer are emotionally draining and are associated with pain, suffering and death ((Powe & Finne, 2003) which lead to psychosocial consequences such as anxiety, fear and depression. It is therefore important that psychosocial burden among individuals receiving treatment for cancer be identified so that patients can be effectively helped to cope with these problems. Receiving intervention to resolve psychosocial problems may lead to better compliance with treatment by patients, hopefully resulting in a better prognosis.

Psychologically, a cancer patient experiences severe stress, which of course may be mediated by under-lying factors related to one's life-history and experiences such as the relationship with attachment figures (Grassi , et al., 2015). Sutherland (1956) as cited by Grassi , et al. (2015) described six clinical categories of psychological disorders frequently seen in the trajectory of cancer care after diagnosis. These clinical categories include anxiety, postoperative depression, dependency, obsessive-compulsive reactions, hypochondriac response and paranoid reactions. The clinical features have significant implications for the treatment of patients and to their families. Mitchell, et al. (2011) for

example found that there was a significant relationship between level of psychosocial distress and quality of life among the patients diagnosed with cancer and their caregivers.

In 2009, the International Psycho-Oncology Society (IPOS) unanimously endorsed the concept of distress as the sixth vital sign in cancer settings alongside temperature, respiration, heart rate, blood pressure and pain. The society further determined that distress is a fundamental factor in patient wellbeing and which should be routinely assessed during patient care. Since then, the idea has been adopted and endorsed by the World Health Organization (WHO), ministries of health, NCCN and United Kingdom based charities such as Breast Cancer Care, the British Psychosocial Oncology Society and Macmillan Cancer Support among others (Swash, 2015).

African countries account for over a million cases of cancer per year with an estimated 88-95% of cancer patients presenting late or at the end stage of the disease, during which time they present with severe psychological distress (MOH, 2013). Screening these patients for psychosocial distress and early intervention to alleviate the identified problems is a priority as a measure to improve the patients' quality of life which is the hallmark of palliative care.

The Kenya national palliative care guidelines recommend that patients on palliation and their families/caregivers should be informed of common psychosocial problems facing palliative patients including anxiety, depression, advanced care plans, care for children, finances, will, community support, and family relationships (MOH, 2013). Each of these psychosocial concerns should be assessed comprehensively. The palliative care team, in conjunction with the patient and family/caregivers should also prioritize the identified psychosocial needs of the patient and family with the same being included in the care plan. Therefore, the aim of this study was to determine the prevalence of psychosocial distress and associated factors among patients with cancer.

1.2 Statement of the Problem

Cancer experiences has an implication on patients' level of psychological distress and physical state (Mitchell, et al. 2011). The overall prevalence for distress in cancer patients in America vary from 35.1% (Zabora, et al., 2001) to as high as 75% (Jacobsen, 2007). In Africa, Berhili, et al., (2017) found that in Morocco, psychosocial distress in cancer patients was estimated to be prevalent in 46.6% of the cases. This finding was comparable to what has been found in the American and other Western-countries. In the studies by Zabora et al., 2001, Jacobsen, 2007 and Berhili, et al., (2017), the researchers assessed psychological morbidity and symptoms or problems among patients with cancer using screening and assessment tools such as the NCCN distress thermometer and problem list. However, despite the fact that screening has been proven to be efficacious in reducing levels of distress and improving quality of life among the cancer survivors, it has not yet become standard practice in various oncology and palliative units (Kristin , et al., 2011). This lack of uptake off psychosocial distress assessment is contrary to the World Health Organization guidelines (2005) requiring that all cancer patients be screened for psychosocial distress and be offered adequate psycho-oncological support (Bultz & Carlson, 2005).

In the present study, during a visit at Machakos palliative care unit, the researcher observed that screening tools for psychosocial distress such as distress thermometer and problem list were not being utilized in the care for cancer patients despite being recommended by the ministry of health. Further, no studies have been conducted in Machakos county to determine precisely the prevalence of psychosocial distress among patients with cancer or to identify presenting psychosocial distress problems and the associated factors. Hence, the main objective of this study was to determine the prevalence and factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit.

1.3 Justification

Considering the variability of the experience of distress following diagnosis with cancer and commencement of treatment, it is important to screen patients with cancer continuously for psychosocial distress. Early identification of the distress among the cancer patients, and the treatment and timely referral to alleviate these problems is in line with; the United Nations sustainable development goal number three, the Kenya's economic blueprint vision 2030 and government top four agenda on health, which emphasize investment in people to improve the quality of life for all, at all stages of life. Further, identification of distress and subsequent treatment of cancer patients is a fulfillment of an obligation outlined in the constitution of Kenya article 43, that every person has a right to the highest attainable standard of health.

Few studies have been conducted to investigate screening protocols for on psychosocial distress screening among patients with cancer at the oncology and palliative clinics in Kenya such as Machakos Palliative Care Unit. Therefore, the present study will be a spring board for future studies with cancer patients at the Machakos Palliative Care Unit. The findings in the present study will provide information that could inform clinical staff, administrators, county government and the national government on the importance of screening patients with cancer for psychosocial distress and especially at a time when the government has just completed setting up Machakos cancer treatment and research Centre.

1.4 Research questions

- i. What is the prevalence of psychosocial distress among patients with cancer at Machakos Palliative Care Unit?
- ii. Which are the sociodemographic factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit?

- iii. What are the cancer factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit?
- iv. What are the institutional factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit?

1.5 Main Objective of the study

The aim of the study was to determine the prevalence and factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit

1.6 Specific Objectives

- a) To determine the prevalence of psychosocial distress among patients with cancer at Machakos Palliative Care Unit
- b) To determine the sociodemographic factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit
- c) To determine the cancer factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit
- d) To establish the institutional factors associated with psychosocial distress among patients with cancer at Machakos Palliative Care Unit

1.7 Theoretical Framework

The conceptual framework for this study was informed by the comfort theory (Kolcaba, 2010). The theoretical propositions guide analyses of intentional assessment of patient and family by nurses.

Kolcaba investigated the meaning of comfort, which she defined as a substantive need in palliative care and identified ease, relief and transcendence as the three forms of comfort. She operationalized comfort as an outcome of care, which is the state of being strengthened by having needs for relief, ease, and transcendence met in 4 contexts of

experience namely, physical, psychospiritual, sociocultural, and environmental (Parker & Smith, 2010). She argued that if the three comfort needs are fulfilled, the patient will feel relieved or will have enhanced comfort further facilitating health seeking behavior.

Patients are said to experience comfort in the sense of relief when specific needs are met while ease is the state of the patients' contentment. Kolcaba described transcendence as a state of comfort in which patients are able to rise above their challenges (Kolcaba , 2010).

The comfort theory consists of six major propositional statements (Peterson & Bredow, 2009). The first propositional statement is that healthcare needs, which Kolcaba (2010) defined as the patient needs that arise from stressful health care situations such as cancer diagnosis. The nurses are tasked with determination as to whether the comfort need can be met within the existing settings in which patients with cancer are treated. In oncology, psychosocial needs are identified by assessing the level of distress and the presenting psychosocial problems, during every visit or at prescribed intervals. Psychosocial distress is the dependent variable for this study. It is through screening for the distress and accompanying problems in oncology and palliative care settings, that nurses and other healthcare providers, are able to individualize the care needs of the patients and enhance their comfort hence enhancing their quality of life.

The second proposition is that nurses are tasked to plan interventions and coordinate their activities to fulfill the unmet comfort needs of the patients. Kolcaba (2010) stressed on importance of managing pain for patients, assessing their vital signs such as the psychosocial distress and administering medication as comfort interventions that help patient to regain comfort. Likewise, the researcher in the present study saw nurses as having a role in intervening to identify the psychosocial distress problems and level of distress among patients with cancer in order to achieve the desired outcome, which is enhanced comfort and improved quality of life. The nursing intervention can include

directly managing the distress or a timely referral to appropriate professional(s) for services to alleviate psychosocial distress.

The third proposition is that there are intervening variables which are defined as consisting of anything that affects the outcome of care, that is, anything that can enhance comfort or cause discomfort to the patient or client (Kolcaba , 2010). Alligood and Tomey (2002) proposed that possible intervening variables included age, attitude, emotional state, financial wellbeing, prognosis, past experiences in life and available support systems. The listed variables were consistent with one of the purposes of the present study, which was to determine sociodemographic and other factors associated with psychosocial distress impacting the comfort status of patients with cancer.

The fourth proposition is that enhanced comfort is the immediate desirable outcome of nursing care. When interventions targeting comfort are delivered consistently over time, they are theoretically correlated to a trend toward increased comfort levels and reduced psychosocial distress, consequently promoting the desired health seeking behaviors. Three variables, health care needs, nursing interventions and intervening variables work in tandem leading to achievement of enhanced comfort. Enhanced comfort then leads to better health seeking behaviors (Kolcaba , 2010).

The fifth proposition is that Health seeking behavior is a state of health as defined by the recipient in collaboration with the nurse (Alligood & Tomey, 2002). Once patients attain enhanced comfort, they work collaboratively with family and nurses in order to enhance health seeking behavior which then cultivates more comfort. In this theory health seeking behaviors are conceptualized as internal motivation or external supporting structure that facilitates better health or leads to a peaceful death.

The sixth proposition is that when a patient is satisfied with health care services, the health institution retains its integrity and improves the health seeking behaviors among patients (Kolcaba, 2010). Facilities or institutions using best policies and best practices

such as timely and routine psychosocial distress screening are able to promote health seeking behaviors.

In summary, Kolcaba identified comfort as a vital part of the treatment and recovery for all the patients. The theoretical propositions are that comfort is an active endeavor for the nurses to meet, targeting enhancement of patient and family comfort (Alligood & Tomey, 2002). The theory aims to prevent problems and incidences likely to cause discomfort. In the perspective of this theory, in palliative care, the aim is to provide maximum comfort to the patient and the family. This can only be achieved through prompt identification of distress or discomfort and providing access to comfort interventions. By adopting comfort theory in palliative care for cancer patients, nurses and other healthcare providers would place comfort at the center of care, which would include timely screening for distress or discomfort even when patients do not complain or present with any problems.

1.8 Conceptual Framework

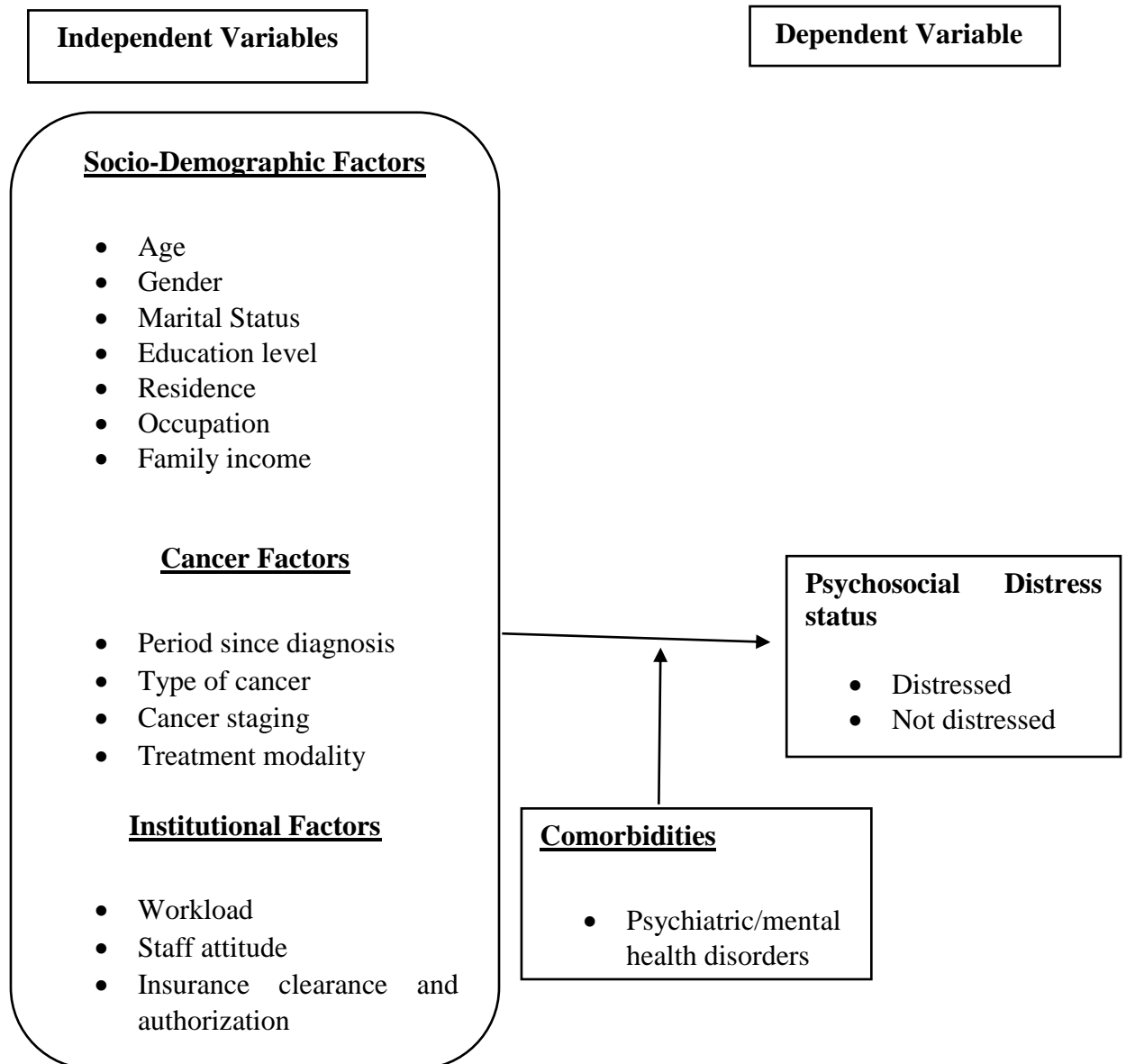


Figure 1.1: Conceptual Framework

CHAPTER TWO

LITERATURE REVIEW

2.1 Psychosocial distress among patients with cancer

Psychosocial distress is an indication of a need for additional support to address the unmet psychosocial needs of patients with cancer, (Swash, 2015). A review of literature indicates that there is a high prevalence of psychosocial distress among people diagnosed with cancer which directly affects the quality of life for patients and their caregivers. Little has been done to investigate the prevalence and the demographic and cancer disease factors associated with of psychosocial distress among patients with cancer in Kenyan and African context. Much of what is known about the above listed factors is based on studies conducted in Western studies.

Diagnosis with a life-threatening disease like cancer induces significant levels of psychological and emotional distress among patients and their caregivers (Bultz & Carlson, 2005). Understanding these psychosocial issues is pertinent to implementation of support care interventions that are efficient and effective while making use of limited healthcare resources (Swash, 2015).

The 2008 report of the Institute of Medicine entitled *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, emphasized the importance of screening patients for distress and psychosocial health needs as the first step towards providing quality cancer care (Kristin , et al., 2011). The National Comprehensive Cancer Network echoed the same sentiments insisting that psychosocial distress should be recognized, monitored, documented and treated promptly at all stages of the cancer care (NCCN, 2011).

2.2 Prevalence of psychosocial distress among patients with cancer

Zabora et al. (2001) assessed the prevalence of psychological distress among patients by cancer sites at The Johns Hopkins University School of medicine Hospital in America. They concluded that the overall prevalence of psychological distress among patients with cancer was 35.1%. This prevalence varied by cancer type with people diagnosed with lung experiencing the most rated of distress (43.4%), followed by those with brain (42.7%), gynecological (29.6%), prostate (30.5%), and colon (31.6%) cancer. People with pancreatic cancer had the highest rates of depression (56.3%) and anxiety (56.7%).

In Doha Qatar, a study carried out at Hamad medical corporation, by Hassan et al. (2018) to assess psychosocial distress among cancer patients using distress thermometer, indicated an overall prevalence of 62% with a cut of 4 out of 10, *visa vis* 17% with a cut off of 7 out of 10. The researchers concluded that there was a substantial presence of distress among patients diagnosed with cancer in Qatar than what was reported internationally.

In Sri Lanka, Weeratunga, Senadheera, and Ekanayake (2016) found that in tertiary care hospitals in the Southern province the reported majority(65%) of study participants with cancer had severe distress levels. The highest prevalence of distress was found among patients with lung cancer (84%), followed by those with uterine (79%), oral (69%), colon (59%) and breast cancer (57%). The researchers concluded that psychosocial distress affects all cancer patients and is a significant health problem. They observed that the level of distress is mediated by socio-economic and medical factors such as the level of income and the type of cancer.

In China's Kaohsiung Chang Gung Memorial Hospital, Taiwan, Chiou et al. (2016) assessed the prevalence of psychosocial distress among patients with cancer using the routine distress thermometer and Chinese health questionnaire screening instrument. They found that 22.1% of the study subjects had significant levels of distress that needed

intervention, a prevalence level that was lower than reported by other researchers. However, the disparity of findings when compared with previous studies was attributed to the research methods that Chiou and colleagues used, retrospective research, which was different from the prospective designs used in other studies.

Consistent with what had been found in other studies, in Morocco, Berhili, et al. (2017) found that at national institute of oncology, 46.6% of patients with breast cancer were distressed. The researchers suggested that the detection of associated characteristics with psychosocial distress should be as accurate and as comprehensive as possible, in order to detect patients at risk for psychosocial distress and provide them with adequate support.

2.3 Psychosocial distress problems presenting among patients with cancer

Cancer patients suffer from a high symptom burden, which persist for long after the cancer diagnosis and initial cancer therapy (or can occur again during the long-term therapy or due to complications in the disease trajectory). The high symptom burden is associated with a substantial increase in feelings of hopelessness and helplessness adversely impacting the quality of life for patients and their families (Hutter, et al., 2013). The emotional reactions and psychosocial consequences of having cancer ranged from anxiety, fear, sadness and depression, to helplessness and hopelessness as well as psychiatric like symptoms and disorders such as adjustment disorders, anxiety disorders, posttraumatic stress disorder, depression, family conflicts or existential crises (Mehnert, et al., 2012).

In one prospective study Loscalzo and Clark, (2007) found that participants with cancer (who were living in the USA) had fatigue (41.9%), sleep disorders (32.5%), financial worries (31.1%), pain (29.4%) and general fear and worry (28.2%) among other psychosocial concerns. Understanding treatment options (15.0%) was the highest reported concern that patients in the study wanted to discuss with members of their

treatment staff. The majority of the study participants (68.3%) were females; however, the researchers found no gender differences in the overall distress.

Brennan , Gingell , Brant and Hollingworth (2012) conducted a study to refine the distress management problem list in order to ensure a holistic therapeutic conversation for patients diagnosed with cancer in the United Kingdom. The patients in their study reported the following features of distress; fatigue (70%), worry, fear and anxiety (45%) and sleep problems (38%). Other problems included loss of memory and lack of concentration (30%) and loneliness or sense of isolation (15%).

Assessing psychological distress in cancer patient in two academic hospitals in Masshad University, Iran, Taghizadeh, et al. (2018), identified the following concerns among their study participants; fatigue (68.8%), pain (59.4%), difficulty in transportation (59.4%), anxiety (57.2%) and sadness (50.4%).

Fortis et al. (2017) investigated the prevalence and factors associated with supportive care needs among Mexican patients newly diagnosed with breast cancer at Le Raza national medical center in Mexico City. About 44% of their study participants reported psychosocial distress problems and unmet needs. The most prevalent psychosocial problems included lack of access to health system/information pertaining condition and management (68%) and the least prevalent problems were the physical concerns.

2.4 Sociodemographic factors associated with psychosocial distress among patients with cancer

Taghizadeh, et al. (2018) assessed psychological distress among patients with cancer in two academic hospitals in Masshad University, Iran. They found that greater distress was experienced by female patients, rural residents, those with low levels of education, drug abusers, those who were divorced and those with low functional status.

In another study, Priscilla, et al. (2011) explored socio-demographic and clinical factors associated with quality of life among patients with haematological cancer in Ampang Hospital, Kuala Lumpur, Malaysia. They found that female patients with haematological cancer reported much better global quality of life and lower distress than male patients. Quality of life was also better among younger patients (those below the age of 40 years) than older patients. Younger patients reported fewer symptoms of constipation but more symptoms of nausea and vomiting. The male patients reported more financial difficulties compared with female patients.

In South Africa, Edwards and Greeff (2017) explored grassroots feedback about challenges posed by diagnosis of cancer. They found that financial challenges were the main problem, highlighted by 40% of the participants. Financially vulnerable households in which the patients were primary breadwinners, had low incomes, small state grants or were unemployed were most worried about finances. Financial stress, loss of income, loss of employment, the burden of additional costs, difficulties accessing financial support and medical aid challenges were reported as common and devastating for many patients.

In Tanzania, Swai (2011) investigated psychiatric morbidity among adult patients with cancer at Ocean Road Cancer Institute, Dar es salaam. They found that marital status, occupation, and level of education were independent variables that were significantly associated with psychiatry morbidity specifically suicide and depression among study participants. Those who were living with a spouse were less prone to depression (19.5%) compared to those who were single (45.9%) and those who were widows/separated (35.9%). Patients with no formal education were less prone to suicide (25.8%) compared to the rest in the other levels of education (31%-38).

Further, Ogoncho (2014) conducted a multivariate linear regression analysis to determine predictors of quality of life among patients with gynecological cancer at

Kenyatta National Hospital. One further found that age, level of education, occupation, and average monthly income were predictors (explained much of the variability) of quality of life. Further, quality of life was directly correlated with of psychosocial distress. Also, a liner combination of a monthly income of 5000 Kenya shillings and above, being 65years or older and having primary or tertiary levels of education significantly predicted quality of life and lower having psychosocial distress among patients with gynecological cancer.

2.5 Cancer disease factors associated with psychosocial distress among patients with cancer

Hassan et al. (2018) conducted a study to assess psychosocial distress among cancer patients at Hamad medical corporation, Doha, Qatar. The patients in their study who were at their initial phase of the disease (56%) and undergoing treatment (54%) had the highest levels of psychosocial distress. Also, patients with breast and lung cancer had the highest levels of distress, 69% and 70% respectively.

In another study, Johnson, Gold and Wyche (2009) assessed distress among women with gynecologic cancer in Oklahoma Cancer Institute in America and established that there were no significant relationships with type of cancer, stage of cancer, or insurance status and distress level.

In South Korea, Park, Chun, Jung and Bae, (2017) investigated the predictors of psychological distress trajectories in the first year after a diagnosis with breast cancer. They observed that most of the women experienced low levels of distress after surgery which further decreased over time. Their study also found that 20% of the patients reported consistently high levels of distress over time, after surgery up to six months after adjuvant treatment. The researchers concluded that old age, depression, nervousness and pain were significant predictors of high distress trajectory.

In a study conducted in Turkey, Toptas et al. (2014) established that medical history and management, family history of cancer, period since diagnosis, cancer awareness, past and current treatments and use of painkillers were factors associated with quality of life among patients with cancer. The study also revealed that patients who received chemotherapy within three months were more likely to experience adverse effects in terms of role and social functioning and were more likely to report nausea and vomiting, loss of appetite and lethargy than patients who did not receive chemotherapy. The researchers attributed this finding to the toxic effects of chemotherapy. Likewise, patients who received radiotherapy in the recent three months had lower quality of life and role functioning scores and were more likely to report constipation and lethargy than patients who did not receive radiotherapy. The researchers noted that 14.8% of the study participants used antidepressants.

In an investigation of psychiatric morbidity among adult cancer patients in Tanzania, Swai (2011) found that patients on palliative care involving combination therapies were more suicidal than those receiving monotherapies. Further, Ogoncho (2014) found that among patients with cancer in Kenyatta National Hospital the modality of treatment and duration of illness were significant predictors of quality and level of psychosocial distress.

2.5 Institutional factors associated with psychosocial distress among patients with cancer

In a study conducted at Novant Health Hemby Children's Hospital in Charlotte, North Carolina, Stanley (2017) investigated barriers and facilitators of psychosocial assessments in the pediatric oncology. The researcher found that barriers to such assessments included lack of time and staff training/confidence in administering the assessments and contextual factors such as lack of resources and clinic size. The author recommended that oncology units formalize a process of universal screening for

psychosocial distress, use team approach and develop screening protocols and resources to inform referrals.

Michelle (2013) conducted a meta-analysis to determine the summary perception of implementing rapid screening for depression and emotional distress in routine cancer care by staff. The author found that 35.5% of the clinicians felt that screening patients for psychosocial distress was not useful. The researcher identified three variables that were associated with high staff satisfaction with screening; training, talking with patients about psychosocial distress and improved detection of the psychosocial problems. The researcher concluded that screening for psychosocial distress in settings where patients with cancer received care likely increased recognition and quality of psychosocial care but only if barriers to such screening were addressed. Finally, Swai (2011) found that 50.7% of the participants in the study suffered from psychiatric related morbidities. The researcher observed that none of these patients had the problems documented in the clinical file notes.

Kimani (2015) investigated factors influencing progressive utilization of palliative care services among cancer patients at the Nairobi Hospice. The author found that 59% of the study participants had medical insurance, mostly from the statutory National Health Insurance Fund (NHIF). The insurance did not however meet the cost of palliative care. Thus, possession of medical insurance was shown to reduce utilization of palliative care services by 4.1%, contrary to an earlier study by Joseph, Elizabeth and Susan (2006) that showed the reverse to be true. The researcher also established that approximately 27% of the respondents resided in Nairobi county while about 73% were from other counties in Kenya. Kimani recommended establishment of facilities that provided palliative care services in each county for easy access to treatment which would also go a long way in reducing psychosocial distress especially in regard to transportation and financial concerns by patients with cancer.

CHAPTER THREE

STUDY METHODOLOGY

3.1 Introduction

In this chapter the research materials and methods that were used will be described including the research design, study area, study population, sample size and sampling procedure, eligibility criteria, data collection tools and methods, data analysis and ethical considerations.

3.2 Study area

The study was conducted at Machakos county referral hospital palliative care unit. The hospital is located in Machakos county, Machakos town constituency. Machakos county borders Nairobi and Kiambu counties to the west, Embu County to the North, Kitui county to the East, Makueni county to the south, Kajiado county to the south west and Muranga and Kirinyaga counties to the north west.

Machakos Palliative Care Unit commenced operations in April 2011 and currently it is viewed as a place for mentoring those who would like to start palliative units in Kangundo sub-county hospital, Makueni and Kitui county hospitals. The Unit serves patients in Machakos, Kajiado, Makueni and Kitui counties.

Machakos palliative unit is ran as an outpatient clinic and is open Monday through Friday. The unit had a total of 718 registered patients under care with approximately 400 being cancer patients while the rest were patients suffering from terminal and chronic illnesses such as HIV/AIDS, diabetes and chronic heart disease. The palliative care block is adjacent to the hospital blood bank and consist of three rooms; consultation, office of the person in charge and a store. The clinic is operated by two trained palliative care providers; a registered palliative nurse and a palliative care occupational therapist.

3.3 Research design

The study was a descriptive cross-sectional design applying both the quantitative and qualitative approaches. The quantitative and qualitative study approaches complement each other which allow the researcher to view the study variables through multiple lenses hence generating different kinds of knowledge (Burns & Grove, 2011).

3.4 Study Population

Participants in the study were adult patients with cancer under care at Machakos Palliative Care Unit. Based on the palliative care unit register, the average number of patients with cancer seen per day in the year 2018 were five, which translated to 100 adult cancer patients per month. There are two trained palliative care providers working in the palliative care unit who were also recruited to participate in the study as key informants.

3.5 Sample size determination and Sampling procedure

Since the population was relatively small the researcher used the census method, where the entire population was considered as the study sample size. A total of 97 patients filled out the data gathering questionnaires and twelve participated in a focus group discussion. One trained palliative care provider working in palliative care unit was purposively recruited into the study and was interviewed as a key informant. The other provider was not able to participate because was on annual leave during the study period.

3.6 Inclusion Criteria

All cancer patients above the age of 18 years seeking palliation services at Machakos Palliative care unit with histologically confirmed malignancy were eligible to participate

in the study. Trained palliative care providers working in palliative unit were also included in the study.

3.7 Exclusion criteria

Patients who were seriously ill, those who were suffering from psychiatric and mental disorders and nursing interns and students were also excluded from the study.

3.8 Data collection tools

Data were collected using four instruments: the semi-structured questionnaires, NCCN distress thermometer and problem list, a focus group discussion guide and a key informant interview guide. The Questionnaire used to collect the quantitative data consisted of three sections: Section 1- sociodemographic; section 2- cancer factors; and section 3- institutional factors associated with psychosocial distress among patients with cancer with a total of 17 items which was developed following an extensive literature review.

National Cancer Center Network distress thermometer and problem list was used to gather data on self-reported level of psychosocial distress and the accompanying problems. Distress thermometer is a self-report tool that is used to assess psychosocial distress from patients with cancer (Donovan, Grassi, McGinty, & Jacobsen, 2014). It consists of a visual analogue scale to which the patient responds by indicating level of distress from 0 = no distress to 10= extreme distress over a period of one prior week. The level of distress as classified into three categories: mild distress = a rating by patient of less than 4, moderate distress = rating of 4-7, and severe distress = a rating greater than 7 (NCCN, 2010). According to the NCCN guidelines, scores of four or higher suggest a level of distress that has clinical significance indicating a state of distress by the patient while a patient scoring less than four is reported as not distressed. Administration of the 39- item Problem List, which is on the same page as the distress

thermometer, involved asking patients to identify their problems causing psychosocial distress on the list in five different categories; practical, family, emotional, spiritual/religious, and physical.

Focus group discussion guide was utilized to collect the qualitative data from patients with cancer. It was used to guide focus- group discussion of presenting psychosocial distress problems and factors associated with psychosocial distress as a result of diagnosis with cancer. The researcher managed the group dynamics to ensure subjects' freedom to express and clarify their views in ways that were less likely to occur in one-on-one interviews (Burns & Grove, 2011). Two focus group discussions were conducted. Both groups (A and B) comprised of 6 participants each.

Finally, the key informant was interviewed to gather additional information from an expert perspective about the psychosocial distress problems with which patients with cancer presented, sociodemographic information about these patients and cancer and institutional factors associated with psychosocial distress. The key informant interview was semi-structured.

3.9 Pretest of the questionnaire

Pretest data were gathered using the semi structured questionnaires at Machakos palliative care unit. The questionnaire was administered to 10 (10%) participants a week prior to commencement of the actual study. According to Orodho (2005) about 10% of the entire sample is adequate for pre-testing. The participants were encouraged to make suggestions about the instructions, clarity and relevance.

3.10 Validity and reliability of data collection tools

Distress thermometer (DT) has been validated in numerous adult cancer populations in many countries. Validity was established using the Hospital Anxiety and Depression

Scale (HADS), General Health Questionnaire-12 (GHQ-12) and Brief Symptom Inventory-18 (BSI-18), (Gessler , et al., 2008). Gessler and colleagues found the instrument to be valid for screening patients with cancer and their families for psychosocial distress. In a study conducted in the United Kingdom, Gessler et al. (2008) demonstrated that when a cut-off of was set at a score of 4 rather than 5, sensitivity of the psychosocial distress thermometer was 79% better when compared with HADS and 81% sensitivity compared to GHQ-12. Ninety-five percent of patients in the study were correctly diagnosed for distress indicating that the DT was a valid instrument for screening of patients with cancer for psychosocial distress.

3.11 Data collection and data collection procedure

Data were collected using semi-structured questionnaires, NCCN distress thermometer and problem list, a focus group discussion guide and a key informant interview with the help of two research assistants, from 9th September 2019 to 9th October 2019.

The researcher began by recruiting two research assistants who were nurse interns on their one-year internship at Machakos level five hospital. The research assistants received one day training on the research protocols with emphasis on data collection procedure, data collection tools and research ethics.

The semi-structured questionnaires and NCCN distress thermometer and problem list were administered by the research assistants under supervision by the researcher.

A total of 12 patients diagnosed with cancer aged between 30 – 60 years and who had commenced cancer treatment took part in focused group discussions which were conducted. The potential benefits were explained to study respondents in order to gain their cooperation and to establish rapport with them. The researcher was the facilitator while one research assistant took field notes and the other one recorded the discussion

on an audio-recording device. The questions to establish the discussion were posed in order from general to more specific.

The researcher also conducted the key informant interview with the trained palliative care provider working in the unit during the study period.

3.12 Data management

The data gathered using the questionnaires and screening tools were cleaned and checked for completeness then entered into a computer and analyzed using SPSS for windows version 24. Descriptive statistics were computed to derive means, standard deviation, percentages, proportions and data frequencies and the findings are presented in form of tables, bar graphs and charts as appropriate. Chi square test of association and binary logistic regression was computed to determine statistical association between the independent and the dependent variables with the confidence interval set at 95%.

The information gathered from focus group discussion and key informant interview were transcribed by the researcher and analysed manually by the researcher. The researcher read through each transcript and summarized its content before re-reading each meaning unit (sentence, phrase or paragraph) and coding it with an essential meaning code. Emerging codes were then by meaning, generating a thematic description for each group of codes and finally generated an exhaustive description of the phenomenon of interest as experienced by study respondents. To enhance the credibility of qualitative data, an experienced social scientist coded the transcript independently and comparison was done. There were no major differences that were found and the themes were agreed upon.

3.13 Ethical considerations

An introduction letter was obtained from Jomo Kenyatta University of Agriculture and Technology- School of Nursing after which the proposal was presented to The Nairobi Hospital Bioethics and Research Committee for ethical clearance and approval (Ref: TNH/ADMIN/CEO/13/08/19). Clearance to collect data was also be obtained from the National Council of Science and Technology (License No.: NACOSTI/P/19/1024), Machakos County Referral Hospital management team and the person in charge of Machakos palliative care clinic unit. Further, the researcher wrote to the National Cancer Center Network requesting permission to use DT and problem list and permission was obtained.

For confidentiality purposes, respondent's personal identifier details were not required and this was made known to them. The patients were interviewed in one of the palliative care unit rooms after receiving care from the palliative care team. A confirmation of the consent by the client was obtained by signing a consent form attached to the questionnaire (see appendix). Further, all information generated from the study was treated with confidentiality and only reported as a group data summary without disclosing any potentiality of identifying information for any research participant.

CHAPTER FOUR

RESULTS AND FINDINGS

4.1 Introduction

In this chapter the study findings based on the quantitative and qualitative data obtained from questionnaires, two focused group discussions with the cancer patients and one key informant interview with a palliative care provider at Machakos palliative care unit are presented.

A total of 100 questionnaires were administered and only 97 were complete for analysis translating to 97% response rate. Qualitatively, six themes emerged from the focus group discussion, and key informant interview. These were; financial problems, pain, chemotherapy side effects, medical insurance, lack of hospital supplies and workload and staffing. The findings are organized according to research objectives/questions.

4.2 Sociodemographic characteristics of the respondents

4.2.1 Age, gender and marital status of the respondents

The demographic information of the study respondents is presented in Table 4.1. Out of the 97 participants, 36.1% (n=35) were above the age of 58 years and the majority (70.1%, n=68) were females while 69.1% (n=67) were married.

Table 4.1: Distribution of respondents by age, gender and marital status

Variable	Frequency(n)	Percentage
Age in years		
18-27	6	6.2%
28-37	9	9.3%
38-47	20	20.6%
48-57	27	27.8%
58 and above	35	36.1%
Total	97	100%
Gender		
Male	29	29.9%
Female	68	70.1%
Total	97	100%
Marital status		
Single	6	6.2%
Married	67	69.1%
Divorced/separated	11	11.3%
Widowed	13	13.4%
Total	97	100%

4.2.2 Level of education and residence of the respondents

In terms of the level of education, 43.3% of the study participants (n=42) had attained primary education while the majority, 78.4% (n=76) lived in rural areas (see Table 4.2).

Table 4.2: Distribution of respondents by level of education and residence

Variable	Frequency (n)	Percentage
Level of education		
Never gone to school	16	16.5%
Never gone to school but can read and write	5	5.2%
Primary	42	43.3%
Secondary	25	25.8%
Post-secondary	9	9.3%
Total	97	100%
Residence		
Urban	21	21.6%
Rural	76	78.4%
Total	97	100%

4.2.3 Respondents County of residence

Majority of the study respondents (64.9%, n= 63) were residents of Machakos county (see figure 4.1).

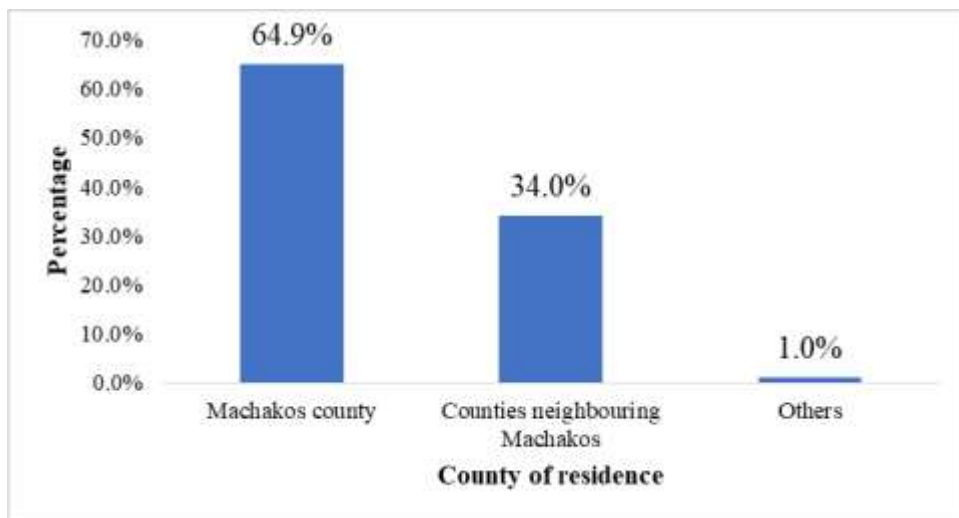


Figure 4.1: Respondents County of residence

Among the respondents who came from counties neighboring Machakos, 38.2% (13) resided in Makueni, 29.4% (10) in Kajiado county and 23.5% (8) in Kitui counties (see figure 4.2).

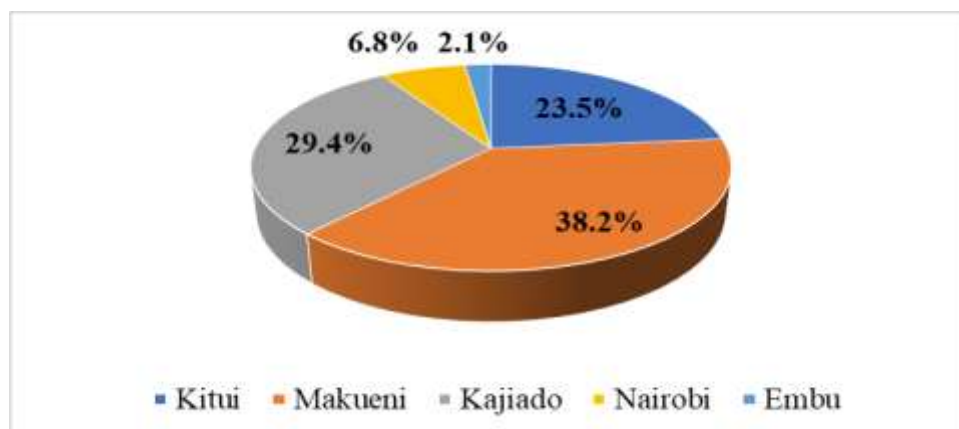


Figure 4.2: Respondents residing in neighboring counties

4.2.4 Occupations of the respondents

The occupations of the respondents are summarized in figure 4.3. Some of them, 45.4% (n=44) were farmers, 32% (n=31) were unemployed, 10.3% (n=10) business persons, 9.3% (n=9) formally employed while 3.1% (n=3) were informally employed.

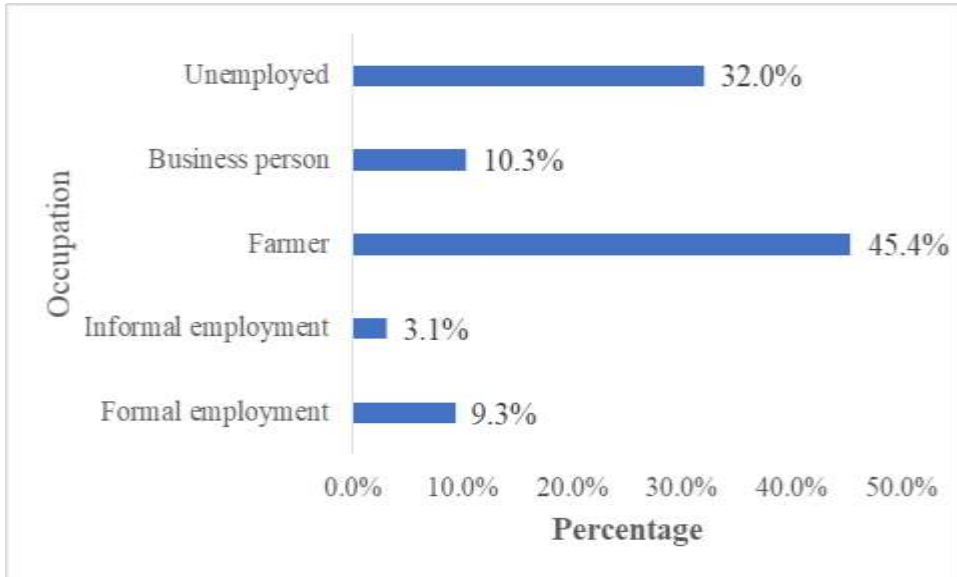


Figure 4.3: Occupation of the respondents

4.2.5 Respondent's nuclear family monthly income

The majority of the study participants, 82.5% (n=80) reported that the monthly nuclear family incomes was below Ksh. 10,000 as presented in table 4.3.

Table 4.3: Respondent’s monthly nuclear family incomes in Ksh.

	Frequency (n)	Percentage
Below 10,000	80	82.5%
10,001 – 20,000	12	12.4%
20,001 – 30,000	3	3.1%
Above 30,000	2	2.1%
Total	97	100%

4.3 Psychosocial distress among patients with cancer

4.3.1 Level of psychosocial distress among the respondents

Using a self-scoring NNCN distress thermometer with scores from 0-3 (indicating mild distress), 4-7 (indicating moderate distress), 8-10 (indicating severe distress), 41.2% (n=40) of the respondents experienced severe distress, as can be seen in Figure 4.4, 30.9% (30) of the respondents experienced moderate and 27.8% (n=27) experienced mild distress.

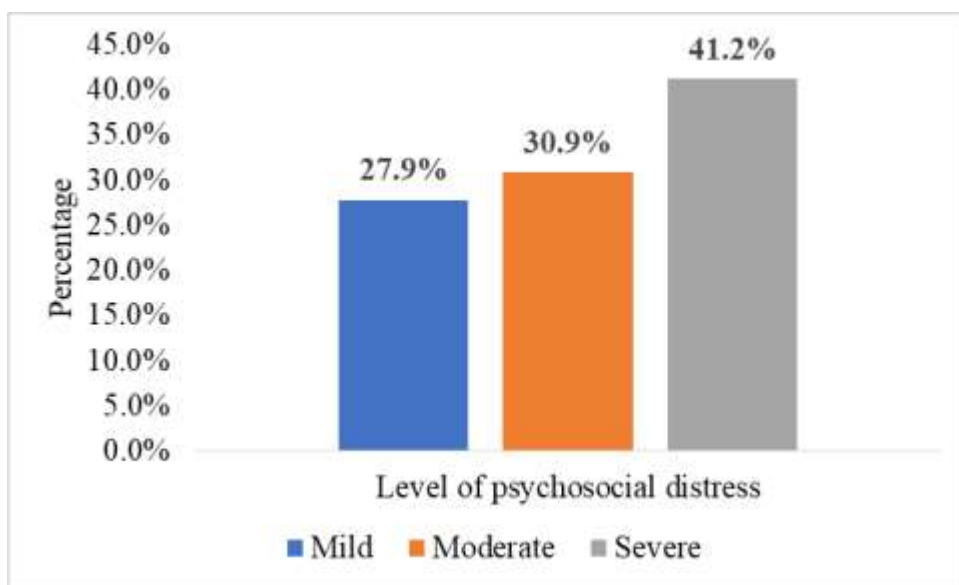


Figure 4.4: Level of psychosocial distress among the respondents

4.3.2 Psychosocial distress status among the respondents

The respondents were further categorized into two groups, with those scoring 0-3 in the “no distress” and those scoring 4-10 in the “distressed” groups. A significant majority of study participants (72.2%, n=70) scored 4 and above indicating they were distressed as shown in figure 4.5.

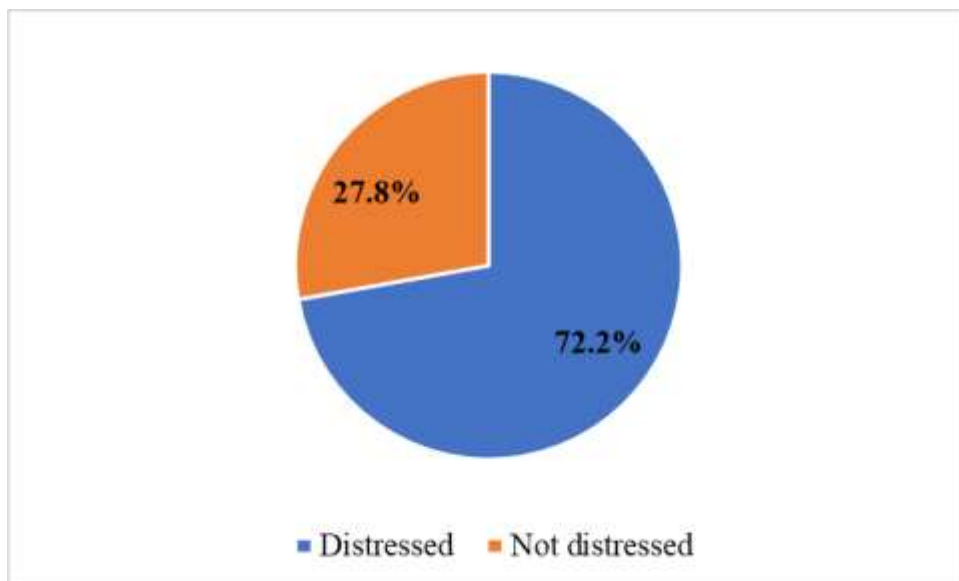


Figure 4.5: Psychosocial distress status among the respondents

4.3.3 Psychosocial distress problems presenting among patients with cancer

4.3.3.1 Practical problems among the respondents

The practical problems presented by cancer patients at Machakos palliative care unit are summarized in Table 4.4. The majority, (64.9%, n= 63) of the respondents reported having problems making treatment decisions while 57.7% (n=56) either had insurance/financial constraints.

Table 4.4: Practical problems among the respondents N=97

Problem	Yes, n (%)	No, n (%)
Child care	32(33.0)	65(67.0)
Housing	5(5.2)	92(94.8)
Insurance/financial	56(57.7)	41(42.3)
Transportation	43(44.3)	54(55.7)
Work/school	20(20.6)	77(79.4)
Treatment decisions	63(64.9)	34(35.1)

4.3.3.2 Family problems among the respondents

An overwhelming majority of the study participants (96.9%, n= 94) reported that they did not have concerns with their ability to have children (see Table 4.5).

Table 4.5: Family problems among the respondents N = 97

Problem	Yes, n (%)	No, n (%)
Dealing with children	23(23.7)	74(76.3)
Dealing with partner	16(16.5)	81(83.5)
Ability to have children	3(3.1)	94(96.9)
Family health issues	21(21.6)	76(78.4)

4.3.3.3 Emotional problems among the respondents

A majority of the respondents (50.5%, n=49) reported worry as the main concern while nervousness (22.7%, n=22) was the least reported problem under the emotional problems as shown in table 4.6.

Table 4.6: Emotional problems among the respondents N = 97

Problem	Yes, n (%)	No, n (%)
Depression	32(33.0)	65(67.0)
Fears	39(40.2)	58(59.8)
Nervousness	22(22.7)	75(77.3)
Sadness	24(24.7)	73(75.3)
Worry	49(50.5)	48(49.5)
Loss of interest in usual activities	32(33.0)	65(67.0)

4.3.3.4 Spiritual/religious concerns among the respondents

Majority, 71.1% (n=69) of the cancer patients interviewed did not report spiritual/religious concerns while 28.9 (28) expressed religious/religious concerns (see figure 4.6).

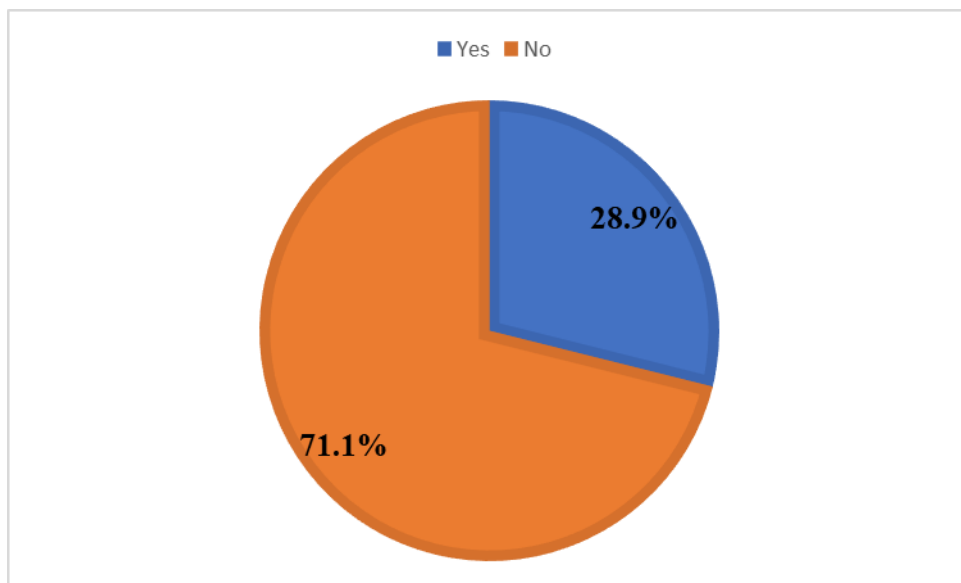


Figure 4.6: Spiritual/religious concerns among the respondents

4.3.3.5 Physical problems among the respondents

As can be seen in table 4.7, the majority of the respondents 83.3% (n= 80) reported pain as the major problem while 59.8% (n= 58) reported fatigue and 50.5% (n=49) reported eating as the physical problems they had experienced in the past one week.

Table 4.7: Physical problems among the respondents**N = 97**

Problem	Yes, n (%)	No, n (%)
Appearance	31(32.3)	65(67.7)
Bathing/dressing	15(15.5)	82(84.5)
Breathing	5 (5.2)	92(94.8)
Changes in urination	12(12.4)	85(87.6)
Constipation	27(27.8)	70(72.2)
Diarrhea	4(4.1)	93(95.9)
Eating	49(50.5)	48(49.5)
Fatigue	58(59.8)	39(40.2)
Feeling swollen	16(16.7)	80(83.3)
Fevers	16(16.5)	81(83.5)
Getting around	28(28.9)	69(71.1)
Indigestion	37(38.1)	60(61.9)
Memory/concentration	10(10.3)	87(89.7)
Mouth sores	9(9.3)	88(90.7)
Nausea	19(19.6)	78(80.4)
Nose dry/congested	6(6.2)	91(93.8)
Pain	80(83.3)	16(16.7)
Sexual	35(36.1)	62(63.9)
Skin dry/itchy	9(9.3)	88(90.7)
Sleep	42(43.3)	55(56.7)
Substance abuse	3(3.1)	93(96.9)
Tingling in hand/feet	9 (9.3%)	88(90.7%)

4.3.3.6 Qualitative data analysis on presenting psychosocial distress problems among patients with cancer

Theme 1: Financial problems

The respondents agreed that financial constraint was a major concern for patients seeking services at Machakos palliative care unit. For example, the key informant stated that;

“... financially they are distressed and majorities don't have money to seek further treatment after the cancer has been histologically confirmed.”

During the focus group discussion, many of the respondents diagnosed with cancer indicated problems with financial troubles. In this regard, participant 3 Group B stated that;

“... sometime I'm sent for diagnostic imaging in private imaging centers which is expensive”.

Similarly, participant 1 Group A stated

“... currently I'm on a fully paid up NHIF chemotherapy treatment in a private hospital in Nairobi but facing transport problems to get there every week...”

Further, participant 3 Group A was concerned that;

“Whenever I'm called to be reminded of a clinic appointment, I really get stressed up because most of the time I don't have fare readily available”

Theme 2: Pain

Findings from both the key informant interview and focus group discussions concurred that pain was the most prevalent psychosocial distress problem experienced by the patients with cancer. According to the key informant;

“...it depends with the state of the patient but most of them present with pain especially those in advanced stages with cancer metastasis, they present either with neuropathic or nociceptive pain. The pain at time can be emotional or psychological, hence have to put the patient on many pain medication regimes

trying to manage the pain, though there are a good number who will benefit from counselling more than the pain medications.”

Further, focus group participant 3 Group A stated;

“... some other time the pain medications are out of stock in the hospital pharmacy and forced to buy. When I don't have money, I have to go back home in pain hoping I will find the drugs stocked during the next appointment.”

Another participant stated that;

“...my problem is pain; I am always in pain even when I take the medications.”
(Participant 4, Group A).

Finally, a participant in group B stated that;

“... the expensive pain drugs are not always available in the hospital pharmacy, many of the times I have to buy from the private chemists.” (Participant 2, Group B)

4.4 Sociodemographic factors associated with psychosocial distress among patients with cancer

Pearson Chi-Square test of association was used to compute statistical association between sociodemographic factors and psychosocial distress among the patients with cancer. Among the factors in the analysis, only gender ($P=0.013$, $\chi^2= 6.149$) had statistically significant association with psychosocial distress. Females were more likely to be distressed than their male counterparts. (See table 4.8).

Table 4.8: Sociodemographic factors associated with psychosocial distress among patients with cancer

	n (%)	Not distressed	Distressed	χ^2 /Fishers exact test	p-value
Age in years					
18-27	6(6.2)	0	6		
28-37	9(9.3)	1	9		
38-47	20(20.6)	5	15	6.095	0.259
48-57	27(27.8)	8	19		
58 and above	35(36.1)	13	22		
Gender					
Male	29(29.9)	13	16		
Female	68(70.1)	14	54	6.149	0.013
Marital status					
Single	6(6.2)	0	6		
Married	67(69.1)	20	47	5.133	0.201
Divorced/separated	11(11.3)	5	6		
Widowed	13(13.4)	2	11		
Level of education					
Never gone to school	16(16.5)	4	12		
Never gone to school/can read & write	5(5.2)	1	4		
Primary	42(43.3)	10	32	1.856	0.730
Secondary	25(25.8)	9	16		
Post-secondary	9(9.3)	3	6		
Residence					
Urban	21(21.6)	5	16		
Rural	76(78.4)	22	54	0.467	0.494
Occupation					
Formal employment	9(9.3)	4	5		
Informal employment	3(3.1)	0	3		
Farmer	44(45.4)	15	29	5.890	0.202
Business person	10(10.3)	3	7		
Unemployed	31(32.0)	5	26		
Nuclear family income in Ksh.					
Below 10,000	80(82.5)	22	58		
10,001 – 20,000	12(12.4)	3	9	0.706	0.778
20,001- 30,000	3(3.1)	1	2		
Above 30,000	2(2.1)	1	1		

4.5 Cancer factors associated with psychosocial distress among patients with cancer

There was a statistically significant association between type of cancer ($\chi^2=18.934$, $p=0.035$), period since diagnosis ($\chi^2=11.629$, $p=0.010$) and receiving cancer treatment ($\chi^2=10.473$, $p=0.001$) and psychosocial distress among patients with cancer. All the cancer treatment modalities, chemotherapy ($\chi^2=8.062$, $p=0.005$), radiation ($\chi^2=4.471$, $p=0.034$), surgery ($\chi^2=9.748$, $p=0.002$) and hormonal ($\chi^2=8.831$, $p=0.009$) had a statistically significant association with psychosocial distress as presented in table 4.9.

Table 4.9: Cancer factors associated with psychosocial distress among patients with

	n (%)	Not distressed	Distressed	χ^2 /Fishers exact test	P-value
Type of cancer					
Breast	20(20.6)	6	14		
Cervical	18(18.6)	4	14		
Oesophagus	9(9.3)	3	6		
Prostate	5(5.2)	5	0		
Kaposi's sarcoma	2(2.1)	0	2	18.934	0.035
Lung	3(3.1)	1	2		
Pancreatic	2(2.1)	0	2		
Colon	9(9.3)	3	6		
Leukemia	4(4.1)	1	3		
Bladder	2(2.1)	1	1		
Mandibular	2(2.1)	0	2		
Ovarian	3(3.1)	0	3		
Others	18(18.6)	3	15		
Period since diagnosis					
Less than 1 year	55(56.7)	11	44		
1-3 years	22(22.7)	6	16	11.629	0.010
3-5 years	7(7.2)	2	5		
More than 5 years	13(13.4)	8	5		
Cancer staging					
Stage I	5(5.2)	2	3		
Stage II	24(24.7)	6	18		
Stage III	18(18.6)	7	11	7.058	0.085
Stage IV	14(14.4)	5	9		
Don't know	36(37.7)	7	29		
Whether received cancer treatment					
Yes	49(50.5)	19	30	10.473	0.001
No	48(49.5)	8	40		
Chemotherapy modality					
Yes	30(30.9)	13	17	8.062	0.005
No	67(69.1)	14	53		
Radiation modality					
Yes	28(28.9)	11	17	4.471	0.034
No	69(71.1)	16	53		
Surgery modality					
Yes	22(22.7)	11	11	9.748	0.002
No	75(77.3)	16	59		
Hormonal modality					
Yes	7(7.2)	5	2	8.631	0.007
No	90(92.8)	22	68		

4.5.1 Qualitative data analysis on Cancer factors associated with psychosocial distress among patients with cancer

Theme: Chemotherapy side effects

Chemotherapy side effects was the major theme that was generated in relation to cancer factors associated with psychosocial distress objective. According to the key informant;

“...patients who are on chemotherapy are more distressed due to the cytotoxic drugs side effects and adverse reactions. Although they might be educated and counselled before commencement of the treatment, once the side effects set in, they are really distressed.”

Further, a comment by a participant in group A implied that chemotherapy is a factor greatly associated with psychosocial distress in cancer due to the side effects of the treatment.

“After a chemotherapy session I loss appetite and vomit excessively.”
(Participant 1, Group A).

4.6 Institutional factors associated with psychosocial distress among patients with cancer

As summarized in table 4.10, no institutional factor listed was statistically significantly associated with psychosocial distress.

Table 4.10: Institutional factors associated with psychosocial distress among patients with cancer

	n (%)	Not distressed	Distressed	χ^2 /Fishers exact test	P-value
Whether respondent has medical insurance					
Yes	85(87.6)	26	59	1.980	0.283
No	12(12.4)	1	11		
Specific medical insurance					
NHIF	26(26.8)	7	19	6.497	0.102
M-tiba	33(34.0)	9	24		
NHIF & M-tiba	25(25.8)	11	14		
Others	2(2.1)	0	2		
Whether ever been screened for PD					
Yes	51(52.6)	18	33	4.263	0.058
No	46(47.4)	9	37		
Free to share PD problems with provider					
Yes	91(93.8)	24	67	2.191	0.159
No	6(6.2)	3	3		

4.6.1 Qualitative data analysis on Institutional factors associated with psychosocial distress among patients with cancer

Based on the focus group discussions and the key informant interview findings a total of three themes emerged under the institutional factors associated with psychosocial distress objective. They were; medical insurance, lack of hospital supplies and staffing and workload.

Theme 1: Medical insurance

In this regard, the key informant stated;

“Patients who don’t have a medical insurance are more distressed because cancer treatment is expensive. At times, they sell their assets including land to access the treatment”.

Another participant expressed similar frustration in regard with access to imaging and treatment authorization and clearance period by NHIF;

“NHIF authorization for chemotherapy and diagnostic imaging takes too long. I had to wait for two weeks before my chemotherapy authorization went through which was really distressing”. (Participant 2, Group B).

Theme 2: Lack of hospital supplies

Patients with the medical insurance also experience challenges while assessing care. According to one of the participants, the hospital at times runs out of resources and supplies forcing patients to incur extra expense to purchase drugs from private chemists;

“I’m registered with the M-Tiba medical cover but there are times when the hospital pharmacy runs out of supply and I have to pay out of pocket to purchase the prescribed medication in privately ran chemists”. (Participant 6, Group A).

Theme 3: Staffing and workload

The Palliative care provider highlighted the disparity in workload and staffing at the palliative care clinic as a major contributor to distress;

“...only two clinical staff are currently working at the palliative care unit against a high workload given they require close attention and prolonged sessions than the general patients.” (Key informant).

4.7 Binary Logistic regression model of factors associated with psychosocial distress among patients with cancer

After adjusting for possible confounders of the predictor variables that were significant under Chi-Square/Fishers exact test of association, the results revealed that male patients diagnosed with cancer were 85% less likely to be distressed compared to female patients (O.R = 0.154, 95% CI 0.039- 0.605) as presented in table 4.11

Table 4.11: Binary Logistic regression model of factors associated with psychosocial distress among patients with cancer

Variables	Not distressed	Distressed	Adjusted OR	95% CI	P. Value
Distress status: 1= Distressed, 2= Not Distressed (Ref)					
Gender					
Male	13	16	0.154	0.039- 0.605	0.007
Female	14	54	Ref		
Period since diagnosis					
Less than 1 year	11	44	4.993	0.729 - 34.177	0.101
1-3 years	6	16	4.822	0.714 - 32.572	0.107
3-5 years	2	5	5.862	0.501 - 68.545	0.159
More than 5 years	8	5	Ref		
Whether received cancer treatment					
Yes	19	30	0.245	0.040 - 1.502	0.128
No	8	40	Ref		
Chemotherapy modality					
Yes	13	17	0.840	0.136 - 5.170	0.851
No	14	53	Ref		
Radiation modality					
Yes	11	17	0.895	0.146 - 5.508	0.905
No	16	53	Ref		
Surgery modality					
Yes	11	11	1.229	0.219 - 6.901	0.815
No	16	59	Ref		
Hormonal modality					
Yes	5	2	0.402	0.043 - 3.767	0.425
No	22	68			

CHAPTER FIVE

DISCUSSION

5.1 Sociodemographic characteristics of the respondents

The study revealed that there were more females (70.1%) than male patients with cancer enrolled for palliative care services at Machakos palliative care unit. The findings were consistent with what was found by Angachi (2014) that there were more females than males attending oncology and palliative care clinic at Moi Teaching and referral hospital and also compared favorably with the MOH (2017) estimated incidence indicating that breast and cervical cancers were the most commonly diagnosed malignancies in Kenya. The study also revealed that only 36.1% of the participants were above the age of 58 years which was different from findings in earlier studies that cancer was primarily a disease of older people. According to the ministry of health (2013) cancer treatment guidelines, over 60% of those suffering from cancer were below 70 years while the risk of getting cancer before 75 years of age was 14%. The majority of the respondents in the present study (69.1%) were married and 78.4% resided in rural areas.

5.2 Psychosocial distress among patients with cancer

5.2.1 The Prevalence of psychosocial distress among patients with cancer

In this study the NCCN distress thermometer and problem list, a self-report tool for assessing psychosocial distress in patients with cancer was used to assess distress among patients with cancer at Machakos palliative care unit. The majority of the study participants (72.2%) were distressed with 41.2% indicating severe levels of psychosocial distress. The findings revealed substantial distress among patients with cancer at Machakos palliative care unit than reported internationally. For example, in Qatar, Hassan et al. (2018) reported an overall distress prevalence of 62% which was slightly

lower than the findings in the current study. Likewise, in Sri Lanka Weeratunga et al, (2016) reported that 65% of the participants in their study had severe levels of distress.

5.2.2 Psychosocial distress problems presenting among patients with cancer

In both the qualitative and quantitative data, this study showed that pain and financial problems were prevalent among patients with cancer.

Quantitatively, the most prevalent presenting psychosocial distress problems among patients with cancer were pain (83.3%), problems making treatment decisions (64.9%), fatigue (59.8%), insurance/financial constrains (57.7%), worry (50.5%) and eating (50.5%). These findings are in agreement with findings by Taghizadeh, et al. (2018) in Iran that fatigue and pain were among the most frequently presenting psychosocial problems among patients with cancer.

Similarly, Loscalzo and Clark (2007) found that fatigue (41.9%), sleep (32.5%), finances (31.1%), pain (29.4%) and fear and worry (28.2%) were the top five problems reported by patients with cancer.

The finding that pain is the most prevalent distress problem is consistent with a study by Doyle et al, (2017) in India who found that 88% of the patients with cancer in their study reported pain and felt that they received inadequate pain management care. The key informant further elaborated that there are patients who suffer from psychological pain and would benefit from professional counselling but unfortunately there is no clinical psychologist attached to the unit. From the focus group discussions, the researcher in the present study found that there was a shortage of opioids and other pain management medications in the hospital pharmacy contributing to chronicity of pain among the patients with cancer, the majority of whom could not afford to purchase this medication from private pharmacies.

The majority of the patients with cancer (64.9%) also reported to having a problem in making treatment decisions. The limited number of healthcare professionals in oncology clinics in Kenya means that these health care providers have little time to educate

patients about their diagnosis and available treatment options. This shortcoming, coupled with low literacy levels as established in this study, could explain the problems expressed by patients in making treatment decisions. This finding would be comparable to what Stacey (2010) found in Ottawa, Ontario Canada that patients who were not satisfied with information offered after diagnosis by the oncology team, felt that more discussion was needed to answer their question so as for them to be an active part of decision making about their care.

5.3 Sociodemographic factors associated with psychosocial distress

In the present study, male patients diagnosed with cancer were 85% less likely to be distressed compared to female patients diagnosed with cancer (O.R = 0.154, 95% CI 0.039- 0.605). This finding was consistent with the results in a study by Taghizadeh, et al. (2018) indicating greater distress among female patients with cancer in Iran. However, in Malaysia, Priscilla, et al., (2011) found that female patients with cancer actually reported lower distress levels than their male counterparts.

5.4 Cancer factors associated with psychosocial distress among patients with cancer

Hassan et al. (2018) found that among patients in the initial phase of the disease (56%) and those undergoing treatment (54%) had the highest psychosocial distress level. The findings by Hassan et al, differed with the findings in the present study as period since diagnosis and receiving cancer treatment were found not to be statistically significant.

The key informant and the focus group discussion respondents singled out chemotherapy as the modality of treatment associated with psychosocial distress among patients with cancer due to the short term and long-term cytotoxic effects of the treatment. These findings are in agreement with the results by Toptas et al (2014) indicating that Turkish patients on chemotherapy were more likely to experience adverse effects and were more

likely to report nausea and vomiting, loss of appetite and lethargy hence higher levels of psychosocial distress than those not receiving chemotherapy.

5.5 Institutional factors associated with psychosocial distress

There was no variable listed under institutional factors that was statistically significantly associated with psychosocial distress. According to Bultz and Carlson (2005) all cancer patients should be screened for psychosocial distress and offered adequate psycho-oncological support. However, based on the findings in the present study, having been screened for psychosocial distress ($\chi^2=4.263$, $P=0.058$) was not statistically significantly associated with distress.

Lack of medical insurance and delay in authorization of medical insurance, lack of medical supplies and disparity in workload and staffing emerged as themes of factors associated with psychosocial distress among patients with cancer from the qualitative findings. According to the key informant, patients who did not have medical insurance were more distressed. However, the majority of the patients (87.6%) in the study had medical insurance, either from the National Hospital Insurance Fund (26.8%) or the Machakos county government sponsored health scheme which is a pilot test for universal health coverage, M-TIBA (34.0%) or both (25.8%). During the focus group discussions, the study participants felt that medical insurance should be streamlined for better access to services by reducing authorization bureaucracies. The respondents recommended that the hospital pharmacy ensure that there were adequate supplies, especially for pain medications in order to reduce financial burden and suffering among patients.

CHAPTER SIX

CONCLUSION AND RECOMMENDATION

6.1 Conclusion

- The results in the present study indicated that the prevalence of psychosocial distress among patients with cancer at Machakos palliative care unit was 72.2%.
- Pain, problems in making treatment decisions, fatigue, insurance/financial constraints, worry and eating problems were the most common psychosocial distress problems reported by patients with cancer at Machakos palliative care unit.
- male patients diagnosed with cancer were 85% less likely to be distressed compared to female counterparts.
- Chemotherapy was identified as the treatment modality most associated with psychosocial distress among patients with cancer.
- Authorization bureaucracies by NHIF and lack of medical supplies, especially pain medication are contributors to psychosocial distress among the patients with cancer at Machakos palliative care unit.

6.2 Recommendations

1. All patients with cancer should be comprehensively screened for psychosocial distress at enrollment for the palliative care services and at prescribed intervals. Patients with moderate to severe levels of distress should be referred for intervention by the appropriate care providers, such as the clinical psychologists, psychiatrist, chaplain or a social worker.
2. As recommended by participants in the focus group discussions, the Machakos County department of health and the hospital management should ensure there is continuous supply of morphine and other palliative care pain management drugs.

3. The ministry of health and the National Hospital Insurance Fund board should come up with a policy to fast-track insurance clearance and authorization process for patients on treatment for cancer.
4. In future, a longitudinal study is needed to assess psychosocial distress among patients with cancer in all palliative clinics and cancer treatment centers in Kenya so as to make firm conclusions about the psychosocial needs of this patient population.

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APPENDICES

Appendix I: Respondent information sheet and consent form

My name is **Francis Justin Kinoti**, a Master of Science in Nursing degree (Oncology and palliative care) student from **Jomo Kenyatta University of Agriculture and Technology** conducting a study on **PSYCHOSOCIAL DISTRESS AMONG PATIENTS WITH CANCER AT MACHAKOS PALLIATIVE CARE UNIT** in partial fulfillment of the requirements for the conferment of the degree.

You are kindly requested to participate. Taking part in this study is **voluntary** and you have a right to refuse to take part in the study. You are all free to withdraw your participation during the process of data collection. Refusal to participate in this study will not deny you any service offered in the clinic. You will read this form once you have understood the information given; you can decide if you wish to participate in the study or not.

You will be provided with a questionnaire which you will answer as appropriate to the various parts. The study will be coded; hence no names will be indicated. All information obtained in the course of the study will be held in confidence.

There are no risks involved except the time you will take in filling the questionnaire and the attached distress thermometer and problem list that will take between twenty and thirty minutes.

There is benefit to the patients as an individual because they will be diagnosed for psychosocial distress and referred appropriately. The result from the research will help improve management of psychosocial distress among patients with cancer in Kenya.

As you participate you will answer the questions. There will be no right or wrong answers, but

you answer as the case applies to you as an individual situation. You are free to ask any questions any time. Thank you for your response and time.

Do not write your name on the Questionnaire and kindly put a tick in the choices given and answer the other questions appropriately.

Respondent Consent

I have read and understood the above information and the nature and kind of the study has been explained to me by the researcher. I know the information I give shall be accorded the necessary confidentiality to benefit and purpose of the study. I understand that I may at any time during the study revoke the consent without any loss or penalty.

Sign: Date:

(Or Thumb print)

I (interviewer) confirm that the above respondent read the consent explanation OR read it to him/her, answered all questions raised and that she/he has agreed to participate in the study and can withdraw any time.

Sign: Date:

Appendix II: Study questionnaire

Questionnaire serial number..... Interviewer ID.....

Date of interview...../...../.....

Part 1: Sociodemographic factors associated with psychosocial distress among patients with cancer

Q1. What is your age in years?

1. 18 – 27 []
2. 28 – 37 []
3. 38 – 47 []
4. 48 – 57 []
5. 58 and above []

Q2. What is your gender?

1. Male []
2. Female []

Q3. What is your marital status?

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

Q4. What level of education have you attained?

1. Never been to school []
2. Never been to school but can read and write []
3. Primary education []
4. Secondary education []
5. Post-secondary education []

Q5. What is your religion?

- 1. Christian []
- 2. Islam []
- 3. Traditionalist []
- 4. Others (specify)

Q6. Where do you reside?

- 1. Urban []
- 2. Rural []

Q7. Which is your current county of residence?

- 1. Machakos county []
- 2. Counties neighboring Machakos county [](specify)
- 3. Others [] (specify)

Q8. What is your Occupation?

- 1. Formal employment []
- 2. Informal employment []
- 3. Farmer []
- 4. Business person []
- 5. Unemployed []
- 6. Others(specify).....

Q8. What is your nuclear family income estimate per month in Ksh?

- 1. Below 10,000 []
- 2. 10,001-20,000 []
- 3. 20,001-30.000 []
- 4. Above 30,000 []

Part II: Cancer Factors associated with psychosocial distress among patients with cancer

Q10.What type of cancer are you diagnosed with?

- 1. Breast []
- 2. Cervical []
- 3. Oesophagus []
- 4. Prostate []
- 5. Kaposi's Sarcoma []
- 6. Lung []
- 7. Pancreatic []
- 8. Colon []
- 9. Leukemia []
- 10. Bladder
- 11. Mandibular
- 12. Ovarian
- 13. Others (specify)

Q11.What is the period since the cancer diagnosis?

- 1. Less than 1 year []
- 2. 1-3 years []
- 3. 3-5 years []
- 4. More than 5 years []

Q12.What is the latest cancer staging by your healthcare provider?

- 1. Stage I []
- 2. Stage II []
- 3. Stage III []
- 4. Stage IV []
- 5. I don't know []

Q13.What Modalities of treatment have you undergone since diagnosis?

(You can give multiple responses as appropriate)

- 1. Chemotherapy []
- 2. Radiation []
- 3. Surgery []
- 4. Hormonal therapy []
- 5. None of the above []

Part II: Institutional factors associated with psychosocial distress among patients with cancer

Q1. Do you have a medical insurance cover?

- 1. Yes []
- 2. No []

If yes, which specific medical insurance cover?

Q16. Have you ever been screened for psychosocial distress at Machakos palliative care unit?

- 1. Yes []
- 2. No []


Q17. Do you feel free to share your psychosocial distress problems with the palliative care provider at Machakos palliative care unit?

- 1. Yes []
- 2. No []

If no, why?

Appendix III: Psychosocial distress screening tool

Part I: Distress Thermometer and Problem List



National
Comprehensive
Cancer
Network*

NCCN Distress Thermometer and Problem List for Patients

NCCN DISTRESS THERMOMETER

Instructions: Please circle the number (0–10) that best describes how much distress you have been experiencing in the past week including today.

Extreme distress

10

9

8

7

6

5

4

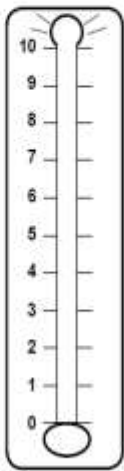
3

2

1

No distress

0



PROBLEM LIST
Please indicate if any of the following has been a problem for you in the past week including today.
Be sure to check YES or NO for each.

<u>YES</u>	<u>NO</u>	<u>Practical Problems</u>	<u>YES</u>	<u>NO</u>	<u>Physical Problems</u>
<input type="checkbox"/>	<input type="checkbox"/>	Child care	<input type="checkbox"/>	<input type="checkbox"/>	Appearance
<input type="checkbox"/>	<input type="checkbox"/>	Housing	<input type="checkbox"/>	<input type="checkbox"/>	Bathing/dressing
<input type="checkbox"/>	<input type="checkbox"/>	Insurance/financial	<input type="checkbox"/>	<input type="checkbox"/>	Breathing
<input type="checkbox"/>	<input type="checkbox"/>	Transportation	<input type="checkbox"/>	<input type="checkbox"/>	Changes in urination
<input type="checkbox"/>	<input type="checkbox"/>	Work/school	<input type="checkbox"/>	<input type="checkbox"/>	Constipation
<input type="checkbox"/>	<input type="checkbox"/>	Treatment decisions	<input type="checkbox"/>	<input type="checkbox"/>	Diarhea
			<input type="checkbox"/>	<input type="checkbox"/>	Eating
			<input type="checkbox"/>	<input type="checkbox"/>	Fatigue
<input type="checkbox"/>	<input type="checkbox"/>	<u>Family Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Feeling swollen
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with children	<input type="checkbox"/>	<input type="checkbox"/>	Fevers
<input type="checkbox"/>	<input type="checkbox"/>	Dealing with partner	<input type="checkbox"/>	<input type="checkbox"/>	Getting around
<input type="checkbox"/>	<input type="checkbox"/>	Ability to have children	<input type="checkbox"/>	<input type="checkbox"/>	Indigestion
<input type="checkbox"/>	<input type="checkbox"/>	Family health issues	<input type="checkbox"/>	<input type="checkbox"/>	Memory/concentration
			<input type="checkbox"/>	<input type="checkbox"/>	Mouth sores
			<input type="checkbox"/>	<input type="checkbox"/>	Nausea
<input type="checkbox"/>	<input type="checkbox"/>	<u>Emotional Problems</u>	<input type="checkbox"/>	<input type="checkbox"/>	Nose dry/congested
<input type="checkbox"/>	<input type="checkbox"/>	Depression	<input type="checkbox"/>	<input type="checkbox"/>	Pain
<input type="checkbox"/>	<input type="checkbox"/>	Fears	<input type="checkbox"/>	<input type="checkbox"/>	Sexual
<input type="checkbox"/>	<input type="checkbox"/>	Nervousness	<input type="checkbox"/>	<input type="checkbox"/>	Skin dry/itchy
<input type="checkbox"/>	<input type="checkbox"/>	Sadness	<input type="checkbox"/>	<input type="checkbox"/>	Sleep
<input type="checkbox"/>	<input type="checkbox"/>	Worry	<input type="checkbox"/>	<input type="checkbox"/>	Substance use
<input type="checkbox"/>	<input type="checkbox"/>	Loss of interest in usual activities	<input type="checkbox"/>	<input type="checkbox"/>	Tingling in hands/feet
<input type="checkbox"/>	<input type="checkbox"/>	<u>Spiritual/religious concerns</u>			

Other Problems: _____

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Part II: Computation of total distress scores and problems by the researcher

A) DT scores: 1. 0 -3 [] 2. 4-7 [] 3. 8-10 []

B) Problem list scores, (NO=0, YES=1):

Total problem list Score.....

Appendix IV: Focused group discussion schedule

1.Introduction

I want to thank you all for taking your time to meet me today. My name is Francis Justin Kinoti, a master of science in nursing (Oncology and palliative care) student at Jomo Kenyatta University of Agriculture and Technology. I am conducting research on psychosocial distress among patients with cancer at Machakos palliative care unit in partial fulfillment of the requirements for the award of the degree.

This discussion should take about one hour. I will be taking notes and the discussion will be recorded to avoid missing on any comments you will give.

All responses will be kept confidential and for education purposes only. All information you will give will not identify anyone as a respondent. You don't have to talk about anything you don't want to.

Are you willing to participate in the focused group discussion?

Yes..... No.....

2.What are the psychosocial distress problems which you are currently experiencing under the following sub-heading;

- i. Practical problems (for example child care, housing, insurance/financial, treatment decisions etc.)
- ii. Family problems (for example dealing with children, dealing with partner, ability to have children, etc.)
- iii. Emotional problems (for example depression, fears, nervousness, sadness, worry, loss of interest in usual activities etc.)
- iv. Spiritual/religious concerns (for example loss of faith and relating to God etc)

- v. Physical problems (for example appearance, bathing/dressing, fatigue, indigestion, pain, sexual etc.)
4. Now let us discuss institutional factors that you think are associated with cancer distress at Machakos palliative care unit such as waiting time, availability of palliative care commodities, staff attitude etc.)
 5. Let's summarize key points from our discussion.
 6. Do you have any questions?

Thank you for the active participation in the study

Appendix V: Key informant interview guide

My name is Francis Justin Kinoti, a master of science degree in nursing (Palliative and oncology care) student at Jomo Kenyatta University of Agriculture and Technology. I am conducting research on psychosocial distress among patients with cancer at Machakos palliative care unit in partial fulfillment of the requirements for the award of the degree. Thank you for agreeing to be interviewed as a key informant.

This interview will take about 30 minutes. The interviewer will be taking notes and the interview will be recorded to avoid missing on any comments you will give.

All responses will be kept confidential and for education purposes only. All information you will give will not identify you as a respondent. You don't have to talk about anything you don't want to.

Are you willing to participate in the interview?

Yes..... No.....

1. What is your level of education and/or certification(s)?
2. How long have you worked in the palliative care unit?
3. What are the common psychosocial distress problems have you observed among patients with cancer?
4. Which factors do you think are associated with psychosocial distress under the following sub-headings?
 - i. Sociodemographic factors
 - ii. Cancer factors
 - iii. Institutional factors
5. Let's summarize key points from our discussion.

Appendix VI: Approval letter to collect data at Machakos palliative care unit

2nd September 2019

Machakos Palliative Care unit
Address: PO Box 19, Machakos 90100
Email: machakospcu@gmail.com
Telephone: +254 44-21685

Francis Justin Kinoti
Jomo Kenyatta University of Agriculture and Technology (JKUAT)
P.O Box 6200-00200
Nairobi

Dear Francis,

RE: PERMISSION TO CONDUCT RESEARCH AT MACHAKOS PALLIATIVE CARE UNIT

Reference is made to your request to conduct a study on **Psychosocial Distress among Cancer Patients at Machakos Palliative Unit** through the hospital medical superintendent.

Having met all the requirements, approval has been granted for a period of one month starting 9th September 2019. In line with the institution research policy, you will be required to submit a copy of final research findings to the unit.

Yours sincerely,


foc

Elijah Musau

In charge, Machakos palliative care unit.



Appendix VII: Introduction letter by JKUAT-SON



Appendix VIII: Ethical review approval letter



THE NAIROBI HOSPITAL

Our Ref. TNH/ADMIN/CEO/13/08/19

13 August 2019

Mr. Francis Justin Kinoti
Jomo Kenyatta University (JKUAT)
P. O. Box 62000 - 00200
Nairobi

Dear Francis,

**RE: PSYCHOSOCIAL DISTRESS AMONG CANCER PATIENTS AT MACHAKOS
PALLIATIVE CARE UNIT**

Reference is made to your request for ethical review of the research proposal on the above.

We are pleased to inform you that ethical review has been done and approval granted. In line with the research projects Policy, you will be required to submit a copy of the final research findings to the Committee for records.

Yours sincerely,
FOR: THE NAIROBI HOSPITAL

Christopher Abeid M.D.
AG. CHIEF EXECUTIVE OFFICER

C.c. Chairman - Bioethics & Research Committee



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Email: hosp@nbihosp.org | Website: www.nairobihospital.org

Appendix IX: National Commission for Science, Technology & Innovation research license

 REPUBLIC OF KENYA	 NATIONAL COMMISSION FOR SCIENCE, TECHNOLOGY & INNOVATION
Ref No: 916024	Date of Issue: 18/September/2019
RESEARCH LICENSE	
	
This is to Certify that Mr. FRANCIS KINOTT of Jomo Kenyatta University of Agriculture and Technology, has been licensed to conduct research in Machakos on the topic: PSYCHOSOCIAL DISTRESS AMONG CANCER PATIENTS AT MACHAKOS PALLIATIVE CARE UNIT for the period ending : 18/September/2020.	
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