AN ASSESSMENT OF THE PATIENTS' PERCEPTION OF COLORECTAL CANCER MANAGEMENT CANCER AT KENYATTA NATIONAL HOSPITAL

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DECLARATION

This dissertation is my original work and has not been submitted or presented for award of a degree or examination at any other university, either in part or as a whole.

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DEDICATION

I dedicate this work to my parents Mr. Harris Chitai and Mrs Jane Shitanda, and daughter Krystal Naima, for their love, support and encouragement.

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ABBREVIATIONS

AJCC.. American Joint Committee on Cancer

CRC...Colorectal Cancer

CT...Computed Tomography

KNH..Kenyatta National Hospital

NCD...Noncommunicable Diseases

NHIF...National Hospital Insurance Fund

RT..Radiotherapy

SPSS...Statistical Package for Social Sciences

SES..Social Economic Status

TNM..Tumour, Node, Metastasis

KII …………………………………………….………….Key Informant Interview

WHO……………………………………………………World Health Organisation

OPERATIONAL DEFINITIONS

Colorectal cancer patients: These are patients aged above 16 years who have been diagnosed with malignant tumor of the colon and/or rectum and are currently undergoing treatment at KNH.

Management of colorectal cancer: This is the comprehensive treatment of colorectal cancer. It includes biological, psychological and social spheres of management. Management practices include screening, diagnosis, treatment, palliative care and psychosocial support, rehabilitation and follow-up.

Perception of management of Colorectal Cancer: This is the colorectal Cancer patients' opinion and feelings regarding their management at Kenyatta National Hospital.

Metastasis: Spread of malignant cells from one organ to another not directly connected with it.

Neoplasm (Tumour): An abnormal mass of tissue that results from abnormal cell proliferation. Neoplasms may be benign or malignant.

Malignant: These are cells that can invade and destroy nearby tissue and also spread to distant sites.

Primary tumour: This is the original tumour in the body.

Secondary tumour: this is a tumour formed at another site after the primary cells metastasis. The cell type in the secondary tumour are the same as the original tumour.

Chemotherapy: The use of drugs or chemical substances to treat cancer.

Palliative therapy: This is an approach that improves the quality of life of patients and their families facing CRC, which is a life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

ABSTRACT

Background: Colorectal cancer (CRC) is one of the most common malignancies worldwide causing 9% of the total cancer mortality. The incidence of CRC has been decreasing in Western countries because of earlier diagnosis and improved treatment modalities; however the mortality is increasing in low and middle income countries and the trend is characterized by late presentation and poor outcome.

Objective: This study sought to establish the patients' perception of colorectal cancer management at KNH.

Methodology: The study utilized a descriptive cross-sectional design and was conducted at surgical and oncology wards and clinics at KNH. Data was collected using a semi-structured, interviewer administered questionnaire, information from the patients' medical records and key informants' guide. Quantitative data was analyzed by Statistical Package for Social Sciences (SPSS) version 20.0 while qualitative data was coded through content analysis according to the themes. Statistical inference was made between variables to draw associations. The results were presented in graphs, charts, tables and in narrative form and statistical inference has been made between variables to draw associations. Ethical principles were upheld during the study.

Results: A total of 68 respondents were enrolled in the study, with majority 55.9% (n=38) being females. The age of the respondents ranged from 16 to 78 years with a mean of 53.5 years and a modal age of 40-59years. Majority 94.1% (n=64) of the respondents had undergone formal education. Most 69.4% (n=47) of the respondents were earning less than Ksh 10,000 per month. Monthly income of the patient was a statistically significant (p=0.001) determinant of patients' perception of CRC management at KNH with those respondents earning less than Kshs 10,000 being 10.22 times likely to say the management was effective compared to those who had no income and this relationship was statistically significant (p=0.042). The cost of CRC diagnosis and treatment was high with majority of the respondents having spent more than Kshs 100,000 so far. Majority 97% (n=67) of the patients were diagnosed with CRC when they presented with symptoms of which the most common were rectal bleeding 69.1% (n=47), change in bowel habits 45.6% (n=31) and abdominal pain51.5% (=35). 60.3% of the patients were diagnosed with CRC more than six (6) months after they presented with symptoms and this had a statistically significant association with their perception on CRC management (p=0.016). The participants whose

diagnostic period was longer than 6 months were 66.3% less likely to perceive the management of CRC at KNH as being effective. There was a statistical significance (P=<0.001) between the treatment modality and the perception of the patient on colorectal cancer management at KNH with those patients who had undergone all the three modalities (surgery, radiation and chemotherapy) being 91% less likely to perceive that CRC management was effective as compared to those who had chemotherapy only [OR=0.09; 95% CI=0.009 – 0.964; P=0.047]

Majority of the respondents felt that the oncology doctors and nurses had adequate training and knowledge (93.7% and 95.3% respectively). Most of the respondents also felt oncology doctors and nurses had a positive attitude (93.9% and 82.1% respectively.) Other health care system factors that influenced the management of CRC included inadequate chemotherapy drugs reported by 70% of respondents, inadequate radiotherapy machines reported by 76.9% of respondents and inadequate bed capacity cited by 58.6% of respondents. Majority of the respondents however felt that the numbers of doctors and nurses was adequate (63.9% and 77.4% respectively.) The key informants however felt the number of specialized health workers was inadequate. Overall, a majority (57.3%) of the respondents felt that the management of CRC at KNH was effective.

Conclusions: The main factors influencing the patient's perception of CRC management at KNH were income, duration of diagnostic period, treatment modality and availability or lack of human and physical resources. The government should increase health funding and allocation for colorectal cancer so that KNH and other health facilities can step up their diagnostic and treatment services. KNH should plan for primary prevention services namely health education and awareness creation so as to increase screening and early diagnosis of colorectal   cancer.

CHAPTER ONE: INTRODUCTION

1.1   Background Information

Cancer is the leading cause of death in economically developed countries and the second leading cause of death in developing countries. The burden of cancer is increasing in economically developing countries as a result of aging population and growth as well as, increasingly, an adoption of cancer-associated lifestyle choices including smoking, physical inactivity, and ''westernized'' diets (Jemal et al., 2011).

Colorectal cancer is a malignant tumour that starts in cells of the colon or rectum. CRC mostly arises from the epithelial lining of the intestine that is they are adenocarcinomas. It may begin as a benign polyp which later becomes malignant and metastasizes to other parts of the body, more commonly to the liver (Devita et al., 2015).

Colorectal cancer is caused by several factors. These include environmental, genetic and inflammatory causes. Studies indicate that genetic factors have the greatest correlation. Environmental factors include diet and lifestyle choices. A diet high in fat and red and processed meat and low in fiber is associated with increased risk. Obesity and lifestyle choices such as smoking, excessive alcohol consumption and physical inactivity are other important risk factors (Dragovich et al., 2014).

In the western world, colorectal cancer has been declining even among the older population due to early detection whereas, in African countries, the population is younger and with more advanced disease and poor prognosis. This limits interventions as only palliative care is possible leading to poor outcomes (Center et al., 2009).

Recent trends in the USA show an increasing incidence and mortality among Africans Americans than whites. Both males and females have approximately the same incidence worldwide. Age is a well known risk factor with incidence peaking at 64 years worldwide.

The mainstay of treatment for colorectal cancer is surgery which includes laparascopic surgical resection, hemicolectomy and anterior resection for stages I-III. The standard adjuvant chemotherapy for stages II-III is 5 Florouracil, Leucovorin and Oxaliplatin commonly called FOLFOX regime. Palliative chemotherapy is used in advanced metastatic disease- stage IV (National Guidelines for Cancer Management, Kenya, 2013).

According to Saidi et al., (2008), there has been an increasing incidence of colorectal cancer at KNH. The average age at the time of diagnosis was 49.2 years which was markedly lower than 70 years in Europe and USA. This earlier diagnosis is also seen in many African countries. It has also been observed that many patients presented late for treatment largely due to unscreening of the population. This therefore led to more advanced cancers and increased mortality.

1.2   Problem Statement

The incidence of colorectal cancer is on the increase causing significant morbidity and mortality worldwide. It accounts for 9% of all cancer cases. It is the third most common cancer worldwide and the fourth most common cause of death (Haggar et al, 2009). Whereas in developed countries the incidence is decreasing, this trend is not seen in low and middle income countries (Hoffman et al., 2013). This is attributed to westernized lifestyle, low screening and late diagnosis, poor patient outcomes and lack of expertise and infrastructure.

Globally, 14,090,149 new cases of cancer were reported in 2012 of which 9.7% were colorectal cancers. The mortality from colorectal cancer was 693,933 which was 8.5% of world's cancer deaths. In 2012, Africa had 846,961 reported cases of cancer of which 41,105 were colorectal cancers. The mortality from colorectal cancer was 5%. Despite the increasing burden of cancer in Africa, it still receives low public health priority due to limited resources and other concerns such as HIV/AIDS, Malaria and Tuberculosis. There could also be general lack of awareness among policy makers, public and private agencies concerning the magnitude of current and future cancer burden (Jemal et al., 2012)

In Kenya, colorectal cancer is the fifth leading malignancy (National Cancer Management Guidelines, Kenya, 2013). 40,999 new cancer cases were reported in 2012, with 4.3% being colorectal cancers and 1272 reported colorectal cancer deaths (Ferlay et al., 2010). Despite this increasing burden of colorectal cancer in Kenya, literature review did not reveal any study that sought to establish the patient's perception on CRC management at KNH.

1.3 Research Questions

1. What are the patient factors that influence their perception on CRC management at KNH?

2. What are the staffing factors that affect the patient's perception of CRC management at KNH?

3. What are the health care system factors that influence the patient's perception of CRC management at KNH?

1.4 Study objectives

1.4.1 Broad Objective

To establish the patient's perception of CRC management at KNH.

1.4.2 Specific Objectives

1. To establish the socio-demographic, socio-cultural and socio-economic factors influencing patient's perception of CRC management at KNH.
2. To determine the influence of the clinical syndrome and stage of cancer on the patient's perception of CRC management at KNH.
3. To assess the effect of staff training, knowledge and attitude on patients' perception of CRC management at KNH.
4. To assess the effect of staffing levels, bed capacity, availability of specialized equipment and supplies on patients' perception of CRC management at KNH.

1.5 Hypothesis

Patient and health care system factors are the main factors affecting patient's perception of CRC management at KNH.

1.6 Study Justification

In the past, cancer has received low priority for healthcare services in sub-Saharan Africa due to the overwhelming burden of communicable diseases. Emerging trends point to the fact that non-communicable diseases (NCD) including CRC are growing health problems that need to be addressed. The Kenya Health Policy (2012-2030) has laid out strategies for reducing overall ill health in Kenya which include reduction in both communicable and non communicable diseases. Key in these strategies is quality management of cancer. Therefore

findings of this study will be instrumental in identifying the factors influencing the patients' perception of management of CRC and therefore contribute to the overall objective of containing the increase in NCDs.

The findings will be important for planning and policy formulation, not only to KNH but also to the Ministry of health as a whole. The results will also highlight the current practice of CRC management vis a vis the expected standard and these will serve as an audit to improve care of CRC patients.

1.7   Key variables

1.7.1   Independent Variables

–   **Patient factors**: Stage of cancer, tumor location, presence of comorbidities, duration before diagnosis, duration before treatment onset, age and sex
–   **Staffing factors**: Staff knowledge and training
–   **Health care system factors**: staffing levels, bed capacity, availability of specialized equipment and supplies

1.7.2   Dependent Variables

- Indicator of effective/ineffective case management as per patient

1.7.3   Confounding Variables

- Patient factors: socio-cultural, socio-economic, lifestyle behavior
- Staffing factors: staff attitudes and beliefs
- Health care system factors: prevailing policies

1.8   Conceptual Framework

Independent Variables   Dependent Variables   Outcomes

- **Patient factors**: Stage of cancer, tumour location, presence of comorbidities, duration before diagnosis, duration before treatment onset, age and sex
- **Staffing factors**: Staff knowledge and training
- **Health care system factors**: staffing levels, bed capacity, availability of specialized equipment and supplies

- Indicator of effective/ineffective case management as per patient

Patients' perception of CRC Management at KNH:

-Effective Management of CRC

-Ineffective Management of CRC

Confounding Variables

Staff attitudes and beliefs

Staff Motivation

Patient SES

<div style="text-align:center">**CHAPTER TWO: LITERATURE REVIEW**</div>

2.1 Definition of colorectal cancer

Cancer is a disease characterized by a loss in the normal control mechanisms that govern cell survival, proliferation, and differentiation. Cells that have undergone neoplastic transformation display signs of immaturity and chromosomal abnormalities. These cells undergo repeated proliferation and migrate to distant sites to colonize various organs. These invasive and metastatic processes and metabolic abnormalities result in tumor related symptoms and eventual death of the patient if the tumor is not eradicated (Devita et al., 2015).

Colorectal cancer is cancer of the large intestine and rectum. The large intestine segments include caecum, ascending colon, hepatic flexure, transverse colon, splenic flexure, descending colon, sigmoid colon, rectosigmoid and rectum (Devita et al., 2015).

2.2 Socio-Demographic Characteristics of Colorectal Cancer Patients

2.2.1 Age

The likelihood of getting colorectal cancer seems to vary with age and geographical location. In western countries, incidence increases with age from 40 years and it is more than 50 times higher in ages 50-70 years (Chalya et al., 2013).

Overall there has been an increased incidence of colorectal cancer in the younger population below 50 years. In the US, colorectal cancer is one of the 10 most diagnosed cancers among the ages 20-49 (Haggar et al., 2009). However in African populations the incidence in the younger population is higher with a mean age of 49 at diagnosis as compared to 70 years in USA and Europe (Saidi et al., 2008). The peak age range for diagnosis with colorectal cancer has been shown to be 41-50 years (Ohayis et al., 2011). Younger patients also have more advanced disease at the time of presentation and therefore poorer prognosis than the older population (Amin et al., 2013).

Previous studies is Kenya showed that many young patients presented with advanced colorectal cancer with 71.4 % of lesions being Duke stages C and D (Saidi et al., 2008). This presents a diagnostic and therapeutic challenge as far as management of CRC is concerned and the outcomes are poorer (Chalya et al., 2013).

2.2.2 Family History of Colorectal cancer or adenomatous polyps

Studies have shown that up to 20% of colorectal cancer patients have a positive family history of colorectal cancer or adenomatous polyps. The incidence is higher if the family history is of a first degree relative less than 60 years of age or if there are 2 or more first degree relatives regardless of age (Haggar et al., 2009).

This increased risk may be due to shared inherited genes which may predispose to colorectal cancer. Dietary and other environmental risks are also shared between families and this may account for the risk attributable to positive family history of colorectal cancer or adenomatous polyps (Fernandez et al., 2004). Considering the increased risk due to family or personal history of CRC or polyps, the importance of screening in prevention and control of CRC cannot be overemphasized (Chalya et al., 2013)

2.2.3 Smoking

There is increased incidence of colorectal cancer among smokers with the 12% of colorectal cancer deaths worldwide being attributable to cigarette smoking. Cigarette smokers have a higher relative risk of 1.21 of developing colorectal cancer (Durko et al., 2014) Carcinogens found n cigarette smoke increase cancer growth in colon and rectum and also contribute to the growth on adenomatous polyps. Men and women who smoke cigarettes are also diagnosed with colorectal cancer at an earlier age than their non smoking counterparts (Haggar et al., 2009) In addition to increasing the risk for CRC, smoking after CRC diagnosis also places an individual at an increased risk of mortality (Yang et al., 2015).

2.2.4 Alcohol

Current evidence suggests that excessive consumption of alcohol is associated with an increased risk of colorectal cancer (De Stefani et al, 2008). This increased risk is attributed to the following mechanisms. Alcohol on its own, may have metabolites which are carcinogenic. Alcohol may also facilitate the entry of carcinogens into mucosal cells through dissolving them or by leading to a deficiency in protective and essential nutrients (Haggar et al., 2009).

Individuals who consumed alcohol of more than 30 grams per day and had a positive family history had a relative risk of 2.80 of being diagnosed with colorectal cancer. The meta-analyses by Moskal et al., (2007) also confirmed that high alcohol intake was associated with increased risk of colorectal cancer.

2.2.5   Diet

Studies have shown that Western diets significantly increase the risk of colorectal cancer. The Western diet typically consists of red meat, processed meat and eggs, low fiber and high fat foods (De Stefani et al., 2008).

Western diets favour the development of carcinogenic compounds. Moreover, preparation of meat is usually done in high temperatures which may contribute to the development of compounds with carcinogenic properties (Haggar et al., 2009).

Increased fibre is protective of the gastrointestinal mucosa as it dilutes carcinogens, increases stool bulk and decreases transit time. Studies have demonstrated 10% reduction in risk of colorectal cancer for each 10g/day intake of dietary fibre and cereal fibre and a further 20% reduction for whole grain consumption (Aune et al., 2011).After diagnosis of CRC, a Western diet is associated with increased recurrence, mortality and comorbidities (Blarigan and Meyerhardt, 2015)

2.2.6   Physical Activity and Obesity

Studies have shown that individuals with higher levels of physical activity have decreased risk of colorectal cancer (Fernendez et al., 2004). It has been proposed that individuals who exercise have increased metabolic efficiency which places them at lower risk of colorectal cancer (Haggar et al., 2009).

Lack of physical activity predisposes one to excessive weight gain which means an increased risk of colorectal cancer. Excessive weight leads to increased circulating levels of estrogens and decreased insulin sensitivity, both of which are associated with an increased risk of colorectal cancer (Haggar et al., 2009).

There is increased prevalence of obesity and physical inactivity in many African countries due to increased consumption of calorie dense foods and decreased energy expenditure during occupational activities (Blecher et al., 2011). This will eventually translate into increased risk of conditions brought about by sedentary lifestyle, colorectal cancer included. Moreover, sedentary lifestyle and obesity after CRC diagnosis is associated with increased recurrence mortality and comorbidities (Blarigan and Meyerhardt, 2015)

2.2.7   Socioeconomic status and colorectal Cancer

Previous studies have shown that patients in the lower economic status are more likely to be diagnosed with more advanced colorectal cancer. These patients are also less likely to receive active and timely treatment due to their inability to access and afford diagnostic and therapeutic services (Crawford et al., 2012).

Poorer outcomes among the lower SES have been associated with poorer diet, lower level of education which may hinder access to healthcare and difficulty affording cancer treatment. There has also been a reported increase in post operative complications among the lower SES either due to co morbidity or more advanced disease (Cavalli-Bjorkman, 2012).

2.3   Tumor Characteristics

Right sided lesions are those arising from the caecum, ascending colon, hepatic flexure or transverse colon. Many patients with right sided tumours present with a combination of rectal bleeding and change in bowel habits to increased frequency of defecation or looser stools (Guidelines for the management of colorectal cancer, Association of Coloproctology of Great Britain and Ireland, 2007). These right sided tumours rarely cause faecal obstruction as the tumour mostly grows outwards from one location in the bowel wall.

Left sided lesions are those arising from the descending colon, splenic flexure, sigmoid colon or rectum. These tumours commonly cause faecal obstruction and iron deficiency anemia. Studies in developing countries have demonstrated that most tumours are left sided especially rectosigmoidal (Chalya et al., 2013). This contrasts with developing countries where the tumours are mostly right sided (Saidi et al., 2008). Bearing in mind that patients with left sided tumours have poorer outcomes, early diagnosis of obstructive symptoms is crucial to impact positively on survival.

The tumour stage is the accurate method of determining the prognosis of colorectal cancer patients. Therefore accurate staging is pertinent to the appropriate and effective patient management (Compton and Greene, 2004). The tumour, node and metastasis (TNM) system is the internationally accepted criterion for tumor staging (National Guidelines for Cancer Management, Kenya 2013). Studies in several African countries continue to document that most colorectal cancer patients present late for diagnosis, commonly at Dukes' stages C and D of disease (Saidi et al., 2008). This has mostly been attributed to lack of screening practices.

The symptoms of colorectal cancer include anaemia, rectal bleeding, abdominal pain, change in bowel habits, intestinal obstruction, a palpable abdominal mass and ascites. The most common clinical presentation finding is rectal bleeding (Chalya et al., 2013). This is in keeping with the finding that the tumour site for most Kenyan patients with colorectal cancer is left sided which commonly presents with rectal bleeding (Karuri et al., 2008).

2.4   Health Care System in Colorectal Cancer Management

2.4.1   Comprehensive Management of Colorectal Cancer

The comprehensive management of colorectal cancer includes health promotion, prevention, screening, treatment and palliative care. KNH, being a tertiary level institution should ideally offer all these services (National Cancer Treatment guidelines, Kenya, 2013)

CRC management requires highly skilled manpower, but there is currently a severe shortage of trained personnel to manage cancer across the country (National Cancer Treatment guidelines, Kenya, 2013). The required personnel include oncology nurses, pathologists, surgeons, radio-oncologists, medical oncologists, clinical pharmacists, radiotherapists, physicists and palliative care specialists.

2.4.2   Screening

Screening for colorectal cancer can decrease mortality and prevent occurrence through identification and removal of precancerous polyps (Amini et al., 2013). Evidence also suggests that screening of asymptomatic individuals who are at an average risk of getting colorectal cancer can detect early and curable cancer thereby leading to reduction in overall mortality (Chalya et al., 2013).

The main screening tests are stool tests and structural examination. Stool tests detect cancer and include occult blood and exfoliated DNA test. Structural examinations detect both cancerous and precancerous lesions and include flexible sigmoidoscopy, colonoscopy and CT colonography. Evidence suggests that colonoscopy is the most accurate for early detection and prevention of colorectal cancer (Quintero et al., 2012). Colorectal screening using sigmoidoscopy/ colonoscopy is cost prohibitive and not supported by the health infrastructure in most parts of Africa (Blecher et al., 2011).

2.4.3 Diagnosis

Patients presenting with rectal bleeding and/or changes in bowel habits may be diagnosed by flexible sigmoidoscopy. Thereafter complete visualization of colon is done by colonoscopy, barium enema or computed tomography colonography. These investigations vary in quality but choice also depends on local availability and expertise. Colorectal cancer is ideally confirmed by histology. Other tests which are done include chest x-ray, abdominal and/or pelvic ultrasound to determine metastasis to chest and liver (Guidelines for the management of colorectal cancer, Association of Coloproctology of Great Britain and Ireland, 2007).

The duration of diagnosis in developing countries has been shown to be longer as compared to developed countries. Some of the possible reasons for this diagnostic delay have been attributed to patients' delay in reporting symptoms, health workers' delay through misdiagnosis, and delayed investigations or referring for further investigations (Neal, 2009). In a worldwide review of 52 studies, Mitchel et al., (2007) proposed increased significance of symptoms among patients and development and evaluation of interventions to ensure timely diagnosis and examination by health workers.

2.4.4 Therapeutic Modalities

The mainstay of treatment for colorectal cancer stages I-III is surgery. The choice of surgical option depends on tumour location, age and general condition of the patient, concurrent illness and also patient preference (Cavalli-Bjorkman, 2012).

Surgical options include right hemicolectomy, left hemicolectomy, sigmoidcolectomy and total abdominal colectomy with ileorectal anastomosis. The terms referring to the site of surgery e.g. right hemicolectomy involves caecum, ascending and transverse colon (National Guidelines for Cancer management, Kenya, 2013). Since most of the tumours are left sided the most common resection procedure has been shown to be left hemicolectomy (Chalya et al., 2013). In patients with multiple tumours involving different parts of the colon, colectomy, which involves resection of the entire colon and 10cm of distal ileum, is an option (Cavalli-Bjorkman, 2012).

Surgery and adjuvant treatment with chemotherapy are indicated for stages II and III. The common chemotherapeutic regimens include Oxaliplatin, 5 Florouracil and Leucovorin or Capecitabine. Other therapeutic options include cryotherapy and radiofrequency ablation (National Guidelines for Cancer Management Kenya 2013).

Presently, the role of radiotherapy is limited to specific metastasis such as brain or bone. (Dragovich et al 2014). Despite curative surgery being the mainstay of treatment of colorectal cancer, studies have shown that many patients are unable to benefit from this due to the late presentation witnessed in developing countries. Consequently many patients undergo palliative surgery as compared to curative surgery (Chalya et al., 2013)

In Africa, the availability of surgery and radiotherapy is limited due to lack of skilled manpower, surgical equipment and radiotherapy facilities. Even where facilities exist, the number of centers is inadequate compared to the catchment area. An example is Kenya whereby a single radiotherapy centre covers a population of 10-19.9 million people (Jemal et al., 2012).

The treatment modality has been shown to be a significant factor influencing the patient's perception on management of CRC. A study carried out in Canada by Sandoval et al., (2006) revealed that cancer patients who had undergone radiotherapy only were more likely to be satisfied with the care received as compared to those who had undergone chemotherapy alone or chemoradiation.

Another key aspect in treatment of CRC patients is palliative care and supportive care. Palliative care is done using radiotherapy and chemotherapy with the aim of decreasing pain, bleeding, stenosis and to treat metastasis e.g. bone. Supportive care includes steroids, analgesia, antiemetics and counselling before, during and after treatment (Cavalli-Bjorkman, 2012).

The role of social support in the management of CRC cannot be overemphasized. Patients who live alone and do not engage in any social activities have poorer outcomes and significantly shorter survival span than their more social counterpart (Villingshoj et al., 2006).

2.5   Theoretical Statement

This dissertation drew upon the work of Donabedian (1987) as cited by Burns (2006). Donabedian identifies three dimensions in assessing health care which include the structure, the process and outcome. He suggests elements in provision of health to include health, subjects of care and providers of care. He further proposed that clinical management of patients has multiple components which affect them key among them standards of care, practice styles and costs of care.

According to Vivier (1994) see Burns (2006), the structure primarily focuses on personnel, physical facilities and equipment, range of services, financing and organisation. For this study, the structural components which affected management of CRC include health care funding, staff knowledge and training, equipment, supplies and physical space.

The process entails provision of and receipt of health care from diagnosis to treatment (Burns, 2006). In this study, the process was the actual clinical management of CRC and it includes screening, diagnosis, treatment, rehabilitation and follow-up.

Outcomes are expected to be positive and may include longetivity, comfort and perceived wellness. For this study the outcomes are either effective or ineffective management of colorectal cancer.

The Donabedian model has been modified further to include other important determinants which he did not include. These are patient factors like genetics, socio-demographics, health habits beliefs and attitudes as well as preferences. Other physical, political, economic and physical environment factors may also influence the process, structure and outcome (Burns, 2006) In these study other factors included the patients' socio-demographic characteristics, culture, socio-economic status and the staff motivation, attitude and beliefs.

CHAPTER THREE: STUDY METHODOLOGY

3.1 Study Design

This was a descriptive cross-sectional qualitative and quantitative study to establish the patients' perception of CRC management at Kenyatta National Hospital

3.2 Study Area

The study was carried out at surgical, medical and oncology wards, and oncology and surgical outpatient clinics at Kenyatta National Hospital in Nairobi Kenya. The surgical wards are 5A, 5B, 5C and 5D. These wards admit the CRC patients for perioperative care. The medical ward is 8C and it admits all medical patients but has also got a hemato-oncological unit. It admits male and female patients with all forms of cancer and has got a bed capacity of 52. The purely oncology ward is GFD. It has a bed capacity of 40 and also admits all forms of cancer. The outpatient clinic is clinic 23.

3.3 Study Population

The study population included patients diagnosed with colorectal cancer at KNH and medical personnel working at the oncology clinic and wards.

3.4 Inclusion Criteria

- Patients diagnosed with colorectal cancer at KNH.
- Patients who had given informed consent.
- Medical personnel working at adult oncology wards and clinic at KNH.

3.5 Exclusion Criteria

- Patients diagnosed with colorectal cancer at KNH and are below 16 years of age.
- Nursing and medical students on training or internship at oncology wards and clinic, KNH.

3.6 Sample Size Determination

Data from KNH Health Information Department showed that the number of patients seen at KNH with colorectal cancer in 2014 January to November was 167. The sample size will thus be determined using Fisher et al (1999) formula,

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

Where n is the desired sample size, z is the normal standard deviation at 95% sample interval (1.96) and p is the prevalence of patients who have the desired characteristics in the study. D is the standard error at 95% confidence interval. Q is (1-p) which is 1-0.5=0.5

$$n = \frac{1.96^{\ 2}\ 0.5\ (0.5)}{0.05^2}$$

n =384.16

According to Mugenda and Mugenda (2003), if the target population is less than 10,000 the sample size is adjusted as follows:

$$nf = \frac{n}{1 + \frac{n}{N}}$$

Where nf is adjusted sample size, n is the earlier calculated sample size using the Fisher et al formula while N is the population size. Since the total population of patients seen at KNH is about 167 which is less than 10,000, the above alternate formula was used to calculate the sample size.

$$nf = \frac{384.16}{1 + \frac{384}{167}}$$

nf =116.4 which is approximately 116

Therefore the sample size for the study is 116 patients diagnosed with colorectal cancer.

3.7 Sampling Interval

Sampling Interval (x) = Total number of patients with colorectal cancer seen at KNH

Sample size

X= 45/40 = 1.125

This is approximately 1 therefore all study subjects were included in the study.

3.8 Recruitment and Training of Research Assistants

Two research assistants were trained on questionnaire administration and other issues related to the research. They were be recruited among Bachelor of Science in Nursing interns at KNH.

3.9 Study Instruments

A pre-tested semi-structured interviewer administered questionnaire developed by the researcher was used to collect quantitative data from the sampled colorectal cancer patients. An interview schedule was used to collect qualitative data from the key informants.

3.10 Pre-testing of Study Instruments

Pretesting of study tools was done at Kenyatta National Hospital Oncology Clinic. The pre-test results were used to improve the study tools for validity and reliability.

3.11 Data Collection, Cleaning and Entry

The questionnaire was administered by the researcher and two research assistants. Upon completion of the questionnaires, they were checked for completeness, cleaned and information in them entered into the computer in preparation for data analysis.

Key informants were selected by the researcher and comprised 2 medical officers working in Cancer Treatment Centre, 2 nurses working in oncology unit, 1 pharmacist working at the oncology unit and 1 medical physicist. They were requested to give their views on management of colorectal cancer at KNH. Data from the key informants was tape recorded and the principal investigator also took short notes of the interview.

The medical files of patients with CRC were reviewed to determine tumor stage, site, treatment and follow-up modalities. A checklist was used to collect this information from each patient's file.

3.12 Data Analysis and Presentation

Data was analysed using Statistical Package for Social Sciences (SPSS) version 20.0 Descriptive statistics were utilised to summarise data on respondent characteristics and this was presented in narrative and pictorial format using graphs, charts and tables as applicable.

For categorical variables such as gender, level of education, marital status, religion and income generating activity, frequencies and percentages were computed and presented in frequency tables, pie charts and bar graphs. For numerical variables such as age, income, means and standard deviation were calculated for normally distributed data. Median and interquartile range were calculated and presented in a frequency table for skewed data.

To test for the association between two variables such as stage of CRC and management of CRC, Chi-square and students t test were used to determine significance of association of the variables. Associations between the variables will be calculated at 95% confidence interval at P-value 0.05.

3.13   Ethical considerations

The research proposal was submitted to KNH/UON/ Ethics and Research Committee for clearance and approval to conduct the research. Informed consent was obtained from potential respondents before being enrolled into the study. An informed consent form containing study objectives, duration, risks and benefits, confidentiality of records, contact information and the respondents' right to participate or withdraw voluntarily was attached to the questionnaire. Minors were informed of the same and gave assent before participating in the study. The privacy, confidentiality and dignity of respondents was assured as the questionnaires did not have any form of identification. The completed questionnaires were handled by the principal researcher only and the trained research assistants and were kept under lock and key.

3.14   Dissemination plan

The results of this study will be presented as a thesis in partial fulfillment of the requirements for award of the Master of Science in Nursing (Oncology Nursing) Degree of The University of Nairobi. The results will also be presented to the relevant authorities at KNH in order to inform decisions and activities that will lead to improvement of management of CRC. The results will also be presented for publishing in scientific journals and presented in scientific conferences and seminars.

CHAPTER FOUR: RESULTS

This study sought to establish the patients' perception of colorectal cancer management at KNH. The study involved 68 respondents and their results are presented below.

4.1   Demographic data

4.1.1   Age of the Respondents

The mean age of the respondents was 51.6 years (SD $\pm$12.7), a median of 53.5 years, with a minimum of 16 years and a maximum of 78 years. The majority 82.3% (n=56) of the respondents were aged 40 years and above. Additional analysis revealed no statistical significance (p=0.816) between age of the respondent and their perception on the management of CRC at KNH (Fig. 1)
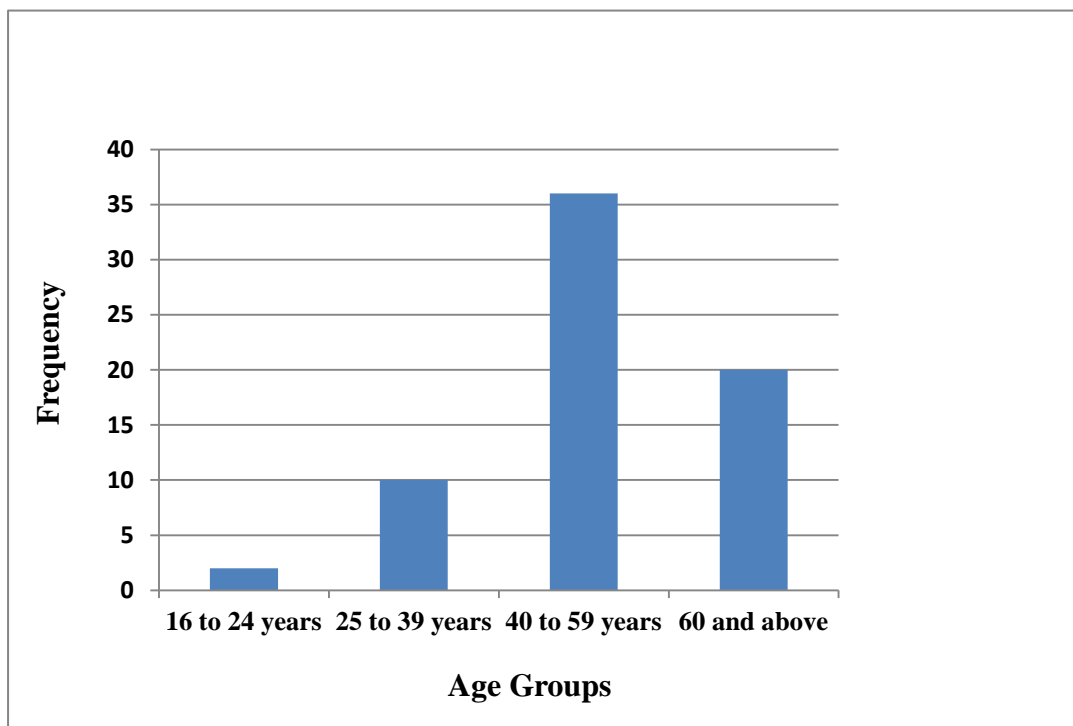
Figure 1: Distribution of the age groups for the study respondents

4.1.2   Gender of the Respondents

Majority 55.9% (n=38) of the respondents were females (Fig. 2). The relationship between gender and the perception of patients on CRC management at KNH did not yield any statistical significance (p=0.376).
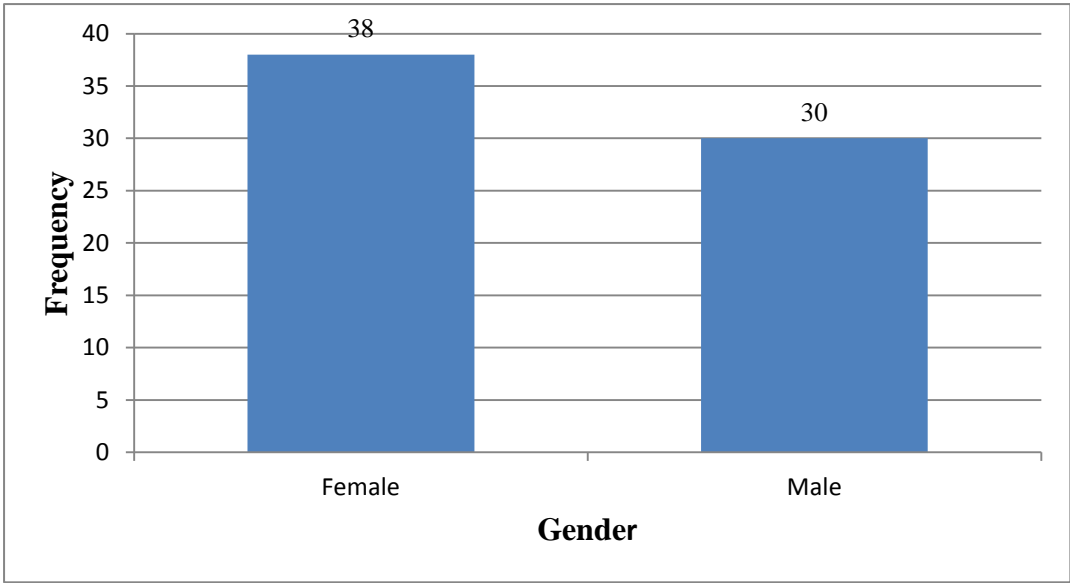
Figure 2: Distribution of gender among study respondents

4.1.3 Education Level of the Respondents

Majority 94.1% (n=64) of the study respondents had formal education. Of these, 35.3% (n=24) had primary, 48.5% (n=33) had secondary, while 10.3% (n=7) had tertiary education, respectively (Fig. 3.) The respondents who had no formal education were 27% less likely to say that the management of CRC was effective as compared to those who had formal education. This relationship was however not statistically significant [OR=0.73; 95% CI=0.095-5.594; P=0.762].
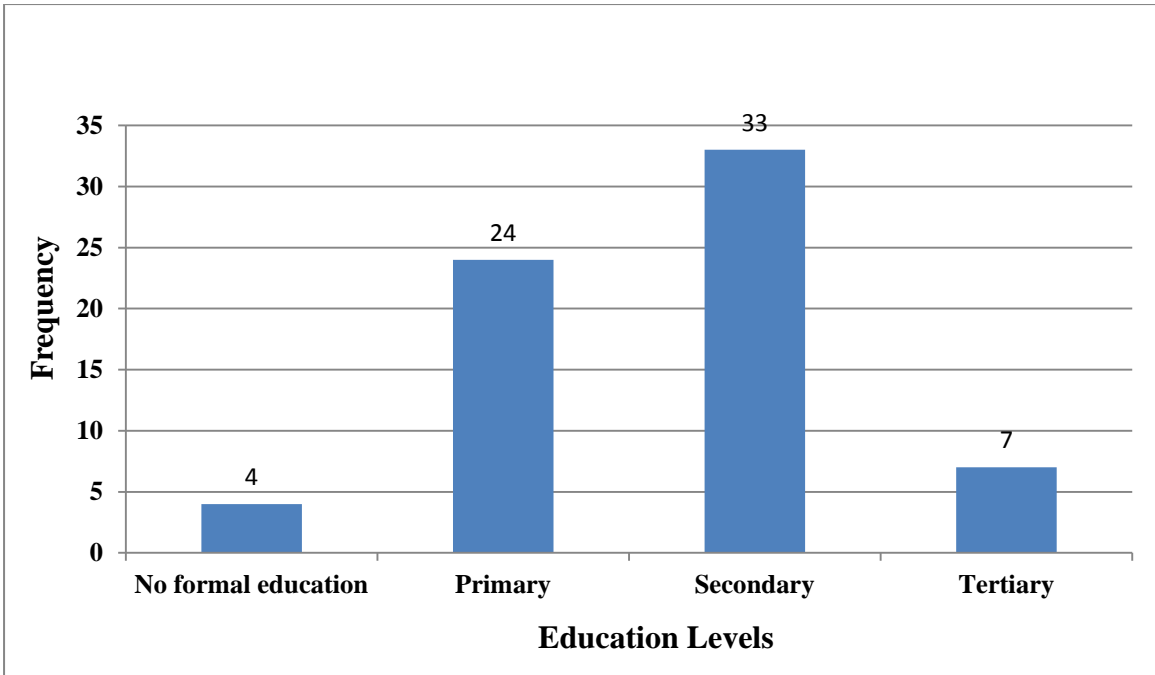
Figure 3: Distribution of Levels of education for the Study Respondents

4.1.4 Marital Status

Majority 72.1% (n=49) of the respondents were married followed by widowed, 13.2% (n=9), singles, 11.8% (n=8), and divorced 2.9% (n=2), respectively (Fig 4).
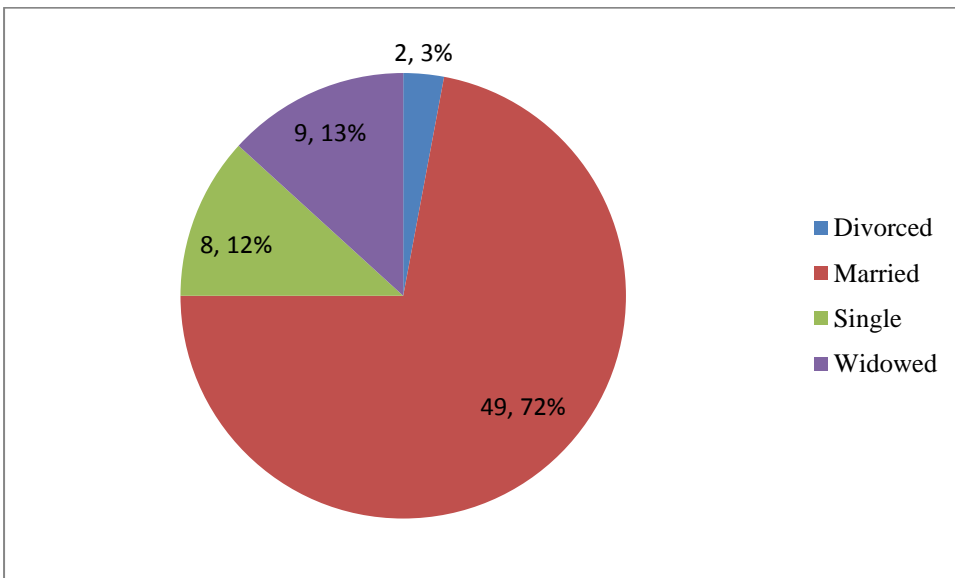
Figure 4: Distribution of Marital Status for the Study Respondents

4.1.5   Religion of the Respondents

Overall, most 94.1% (n=64) of the respondents were Christians (Fig 5).
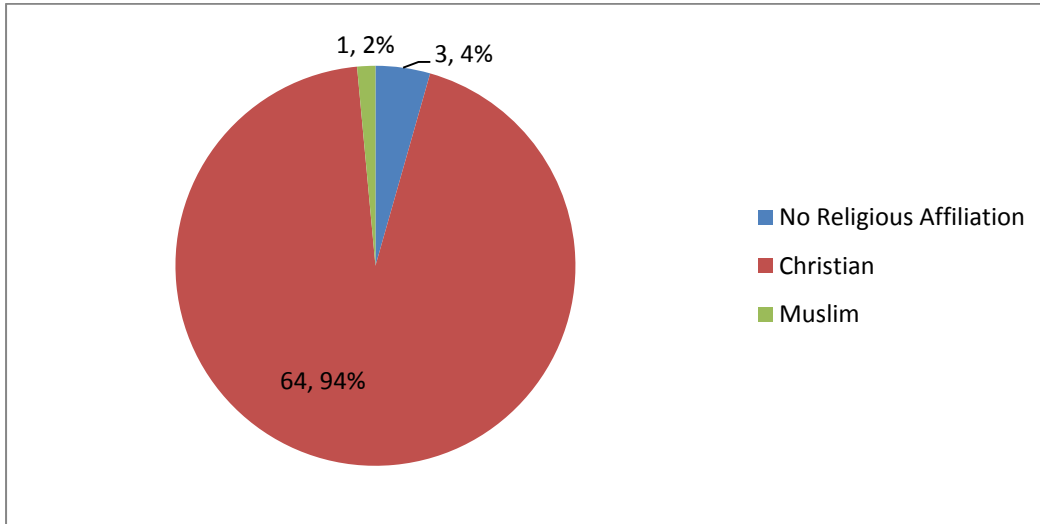
Figure 5: Distribution of Religious Affiliation the Study Respondents

4.1.6   Occupation Status of the Respondents

Most 52.9% (n=36) of the study respondents were self-employed, followed by the un-employed 23.5% (n=16), formally employed 19.1% (n=13) and retired 4.4% (n=3) as shown in figure 6 below.
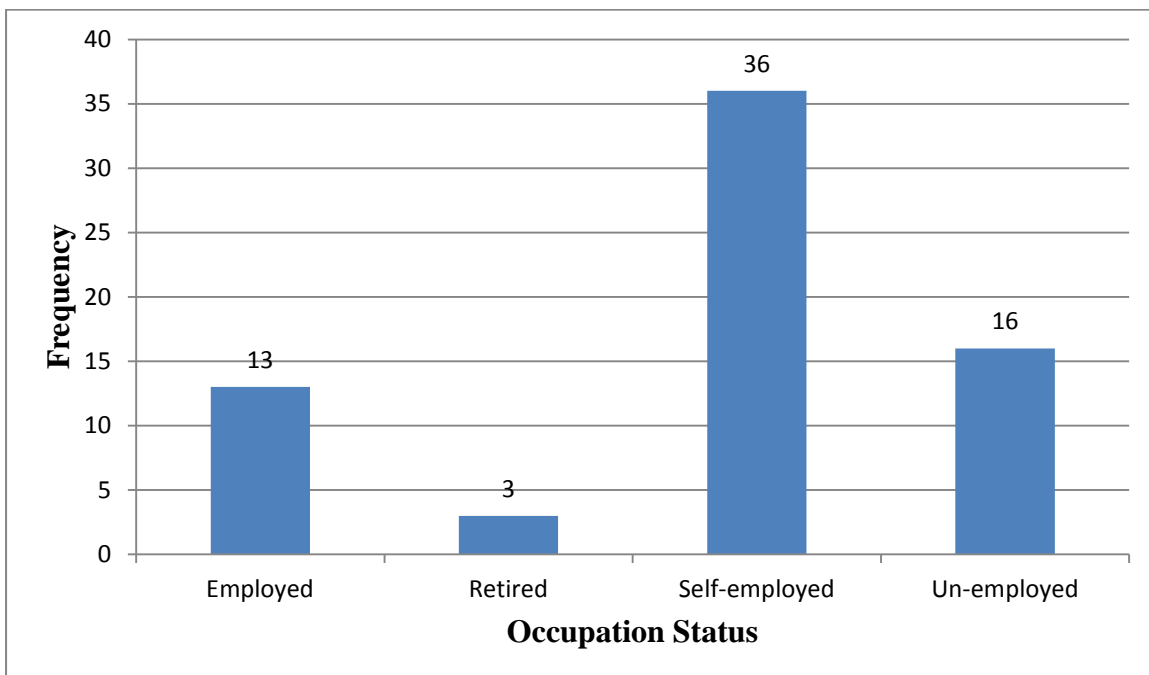
Figure 6: Distribution of Occupation Status for the Study Respondents

4.1.7   Monthly Income of the Respondents

Most 69.4% (n=47) of the respondents were earning below Ksh 10,000, while those earning above Ksh 10,000 were 14.7% (n=10). Study respondents who did not have an income source made up 16.2%, (n=11). The modal income level was Kshs 1,000-10,000 (Fig. 7)
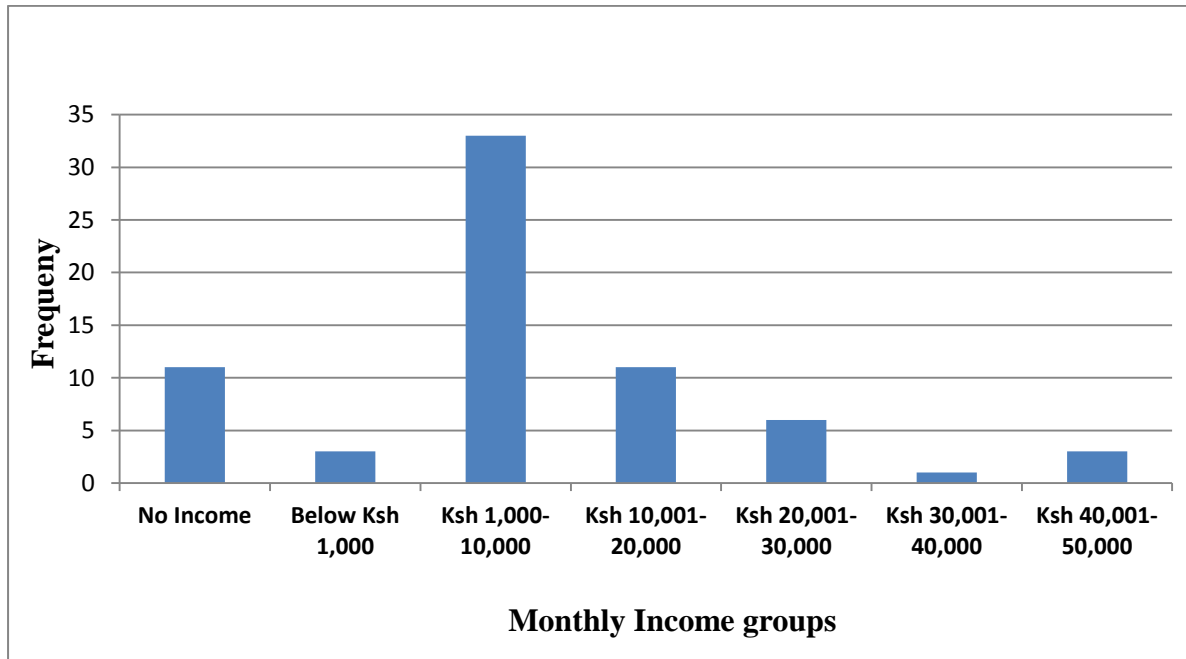
Figure 7: Distribution of monthly income for the Study Respondents

There was a significant (p=0.016) statistical relationship between the monthly income of a respondent and their opinion on colorectal cancer management. Further analysis showed that those respondents who earned less than Kshs 10,000 were 10.2 times likely compared with those with no income to perceive the management of CRC at KNH as being effective [OR=10.22; 95% CI=1.092-95.625; P=0.042]. The respondents who earned above Ksh 10,000, were 1.35 times likely when compared to those with no income to say that the management of CRC is effective; however this relationship is not statistically significant, [OR=1.35; 95% CI=0.146 – 12.372; P=0.793] as seen in Table I below.

Table 1: Association between monthly income of the patient and perception on management of CRC at KNH

Monthly Income	Adjusted Odds Ratio	P-Value	[95% Confidence Interval] for the Odds Ratio
No Income	Reference		
Ksh 10,000 and below	10.22	**0.042**	[1.092 - 95.625]
Ksh 10,001 and above	1.35	0.793	[0.146 – 12.372]

4.1.8   Health Insurance Cover

Majority 91.2% (n=62) of the study respondents had enrolled with NHIF membership while 2% (n=2.9) had private insurance and 5.9% (n=4) had no health insurance cover (Fig 8).
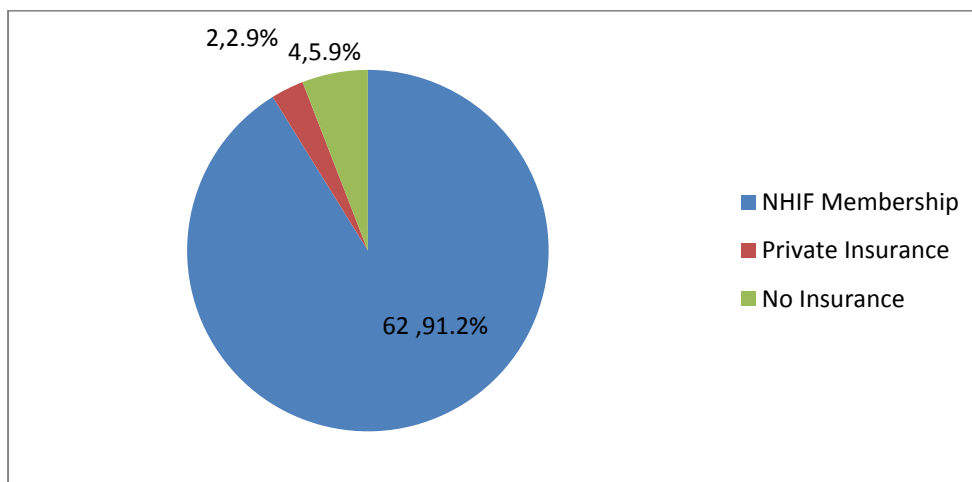
Figure 8: Distribution of Health Insurance status of the Study Respondents

The services offered by the respondents' health insurance cover included in-patient services, 97.1% (n=66), with chemotherapy and surgery accounting for (42.6, n=29) and (22.1, n=15) respectively. Investigations, out-patient services, radiotherapy and consultation fees were reportedly minimally covered (Table 2).

Table 2: Services covered by health insurance cover

Medical Scheme Services	Total =68 (n)	Percentage
In-Patient Services	66	97.1
Investigations	4	5.9
Surgery	15	22.1
Out-Patient Services	3	4.4
Radiotherapy	2	2.9
Chemotherapy	29	42.6
Consultation Fees	1	1.5

4.1.9   Cost Incurred in Colorectal Cancer Treatment

Majority 83.8% (n=57) of the respondents reported to have spent a lot of money (above Kshs 100,000) on diagnosis and treatment of CRC (Table 3).

Table 3: Cost incurred for CRC diagnosis and treatment

Cost Incurred	Total =68 (n)	Percentage
Ksh 1,000-10,000	0	0.0
Ksh 10,001-50,000	3	4.4
Ksh 50,001-100,000	7	10.3
Ksh 100,001-500,000	50	73.5
Above Ksh 500,000	7	10.3

4.1.10 Health care financing

NHIF as a source of treatment fund scored high 82.4% (n=56) while other sources included family/friends contributions 75.0% (n=51), personal business 36.8% (n=25), harambees 20.6% (n=14) and salary 10.3% (n=7) respectively (Table 4)

Table 4: Health care financing

Sources of treatment funds	Total = 68 (n)	Percentage
Salary	7	10.3
Personal business	25	36.8
Family/Friends contributions	51	75.0
Harambees	14	20.6
Medical Insurance Cover	56	82.4
Others	0	0.0

4.2 Lifestyle Characteristics of the study respondents

Majority 61.8% (n=42) of the respondents had been exposed to smoking through primary and/or secondary sources. Of the 23.5% (n=16) who had used nicotine/tobacco themselves, 75% (n=12) had quit at the time of the study. Similarly 33.8% (n=23) of the respondents reported having used alcohol and 95.6% (n=22) had quit as at the time of the study. Most 76.5% (n=52) of the respondents engaged is some form of intentional/occupational physical activity (Table 5).

Table 5: Lifestyle Characteristics of the Study Respondents

Characteristic	Groups	Total=68 n (%)
Past Nicotine/Tobacco Use	Smoker	16 (23.5)
	Non-smoker	50 (73.5)
Stopped Nicotine/Tobacco Use	Stopped Smoking	12 (75.0)
	Current smoker	4 (25.0)
Exposure to secondary nicotine/tobacco use	Exposed	26(36.2)
	Not exposed	42(61.8)
Past Alcohol Use	Has used Alcohol	23 (33.8)
	Has not used alcohol	30 (44.1)
Stopped Alcohol Use	Has quit alcohol use	22 (95.7)
	Current use of alcohol	1 (4.3)
Participate in Intentional/Occupational Physical Activities	Yes	52 (76.5)
	No	14 (20.6)

4.3   Colorectal Cancer Characteristics of the study respondents

4.3.1   Family History of Colorectal Cancer

Among the respondents, 7.3% (n=5) had a positive family history of colorectal cancer (Table 6).

Table 6: Family history of Colorectal Cancer

Characteristic	n (68)	Percentage
Positive Family history CRC	5	7.4
No family History of CRC	63	92.6

4.3.2 Diagnosis of CRC

Majority 57.4% (n=39) of the respondents, were diagnosed at other hospitals and thereafter referred to KNH Oncology Unit for further management (Fig 9).
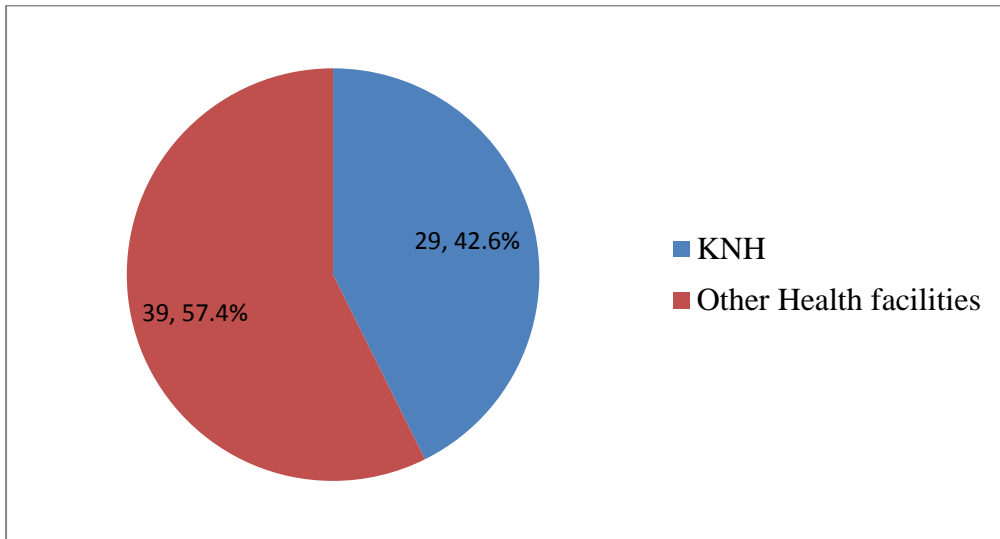
Figure 9: Distribution of health facility where diagnosis of CRC was made

Majority (97.0%, n=67) of the respondents were diagnosed with colorectal cancer after having presented with symptoms while only 1.5% (n=1) were diagnosed through routine screening (Fig 10).
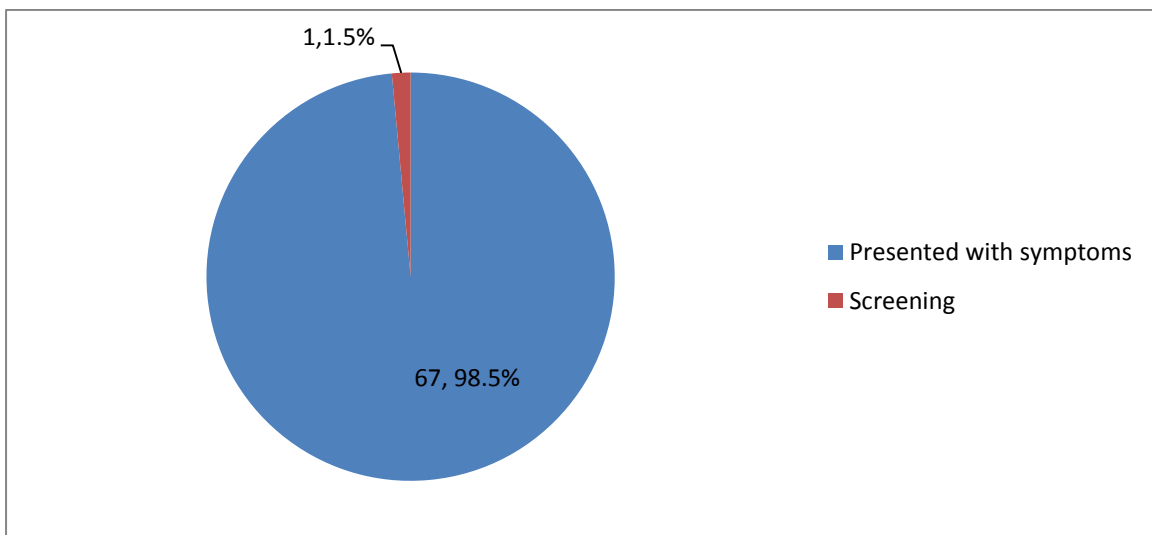
Figure 10: Distribution of mode of diagnosis of CRC

4.3.3 Symptomatology of CRC

The most common 69.1% n=47) symptom experienced by respondents was rectal bleeding, followed by abdominal pain 51.5% (n=35) and change in bowel habits (45.6%, n=31). Other common symptoms included unexplained tiredness 30.9% (n=21), unexplained weight loss 35.3% (n=24), and abdominal distention (17.6%, n=12) as shown in Table 7 below.

Table 7: Symptomatology of CRC

Symptoms experienced	Total =68 (n)	Percentage
Rectal bleeding	47	69.1
Change in bowel habits	31	45.6
Unexplained tiredness	21	30.9
Unexplained weight loss	24	35.3
Abdominal pain	35	51.5
Abdominal distention	12	17.6
Others	18	26.5

4.3.4 Duration of Symptoms before Diagnosis of CRC

The mean duration in months from symptoms presentation to diagnosis was 17.2 months (SD± 29.6 months), the median was 11, with a minimum of zero (0) and a maximum duration of 159 months. Majority 60.3% (n=41) of the study respondents were diagnosed with CRC more than 6 months after presenting with symptoms, with only (26.5%, n=18) being diagnosed within 6 months after presentation. The relationship between duration of symptoms to diagnosis and perception of the patient on management of CRC was statistically significant (p=0.016) as seen in Table 8 below. The participants whose diagnostic period was longer than 6 months were 66.3% less likely to perceive the management of CRC at KNH as being effective. However this relationship was not statistically significant [OR=O.337; 95% CI=0,442-10.779; P=0.337]

Table 8: Association between duration of symptoms to diagnosis and perception of patients on management of CRC

		Effective Management of Colorectal Cancer Cases, n (%)		
Months from symptom presentation to diagnosis	**Total=68** **n%**	**Yes (n=39)**	**No(n=29)**	**X^2 Test**
0-6 months	18 (26.5)	10 (25.6)	8 (27.6)	**No X^2 value, used Fisher's exact due to low cell numbers** **P=0.016**
7-12 months	25 (36.8)	18 (46.1)	7 (24.1)	
13-24 months	12 (17.6)	4 (10.2)	8 (27.6)	
25 months and above	4 (5.9)	0 (0.0)	4 (13.8)	

4.3.5 Duration from CRC diagnosis to treatment initiation

The mean duration in months from diagnosis to initiation of treatment was 3.3 months (SD± 7.9 months), a median of zero (0), with a minimum of zero (0) and a maximum duration of 47 months. Majority 64.7% (n=44) of the study respondents were initiated with CRC treatment within 6 months of diagnosis, with 14.7% (n=10) starting treatment within 1 year of diagnosis and 3% (n=2) starting treatment after 1 year respectively. The relationship between duration of time from diagnosis to treatment initiation and the perception of the patient on CRC management was not statistically significant (p=0.478) as seen in Table 9 below.

Table 9: Association between duration from diagnosis to treatment initiation and the patient perception on management of CRC

| Months to treatment initiation after diagnosis | Total = 68 (n) | Effective Management of Colorectal Cancer Cases, n (%) | | X^2 Test |
		Yes (n=39)	No(n=29)	
0-6 months	44 (64.7)	26 (66.7)	18 (62.1)	**No X^2 value, used Fisher's exact due to low cell numbers**
7-12 months	10 (14.7)	5 (12.8)	5 (17.2)	
13-24 months	1 (1.5)	0 (0.0)	1 (3.4)	
25 months and above	1 (1.5)	0 (0.0)	1 (3.4)	**P=0.478**

4.3.6 Tumor Stage at Diagnosis

Most 66.2% (n=45) of the study respondents were diagnosed with advanced stage colorectal cancer (Table 10). This was supported by majority of the key informants, who felt that many patients with CRC present with advanced diseased of beyond stage three hence the care given to most patients is palliative in nature.

"*Many of the patients with colorectal cancer cannot be cured as they present at KNH with advanced disease. We can only palliate their symptoms.*"*(KI 1)*

The relationship between tumor stage at diagnosis and perception of the patient on CRC management did not yield statistical significance (p=0.477)

Table 10: Association between tumor stage at diagnosis and perception of the patient on CRC management

| Tumour Stage at Diagnosis | Total n=68 (%) | Effective Management of Colorectal Cancer Cases, n (%) | | X^2 Test |
		Yes (n=39)	No(n=29)	
Stage I	5 (7.3)	3 (7.7)	2 (6.9)	**No X^2 value, used Fisher's exact due to low cell numbers**
Stage I I	18 (26.5)	13 (33.3)	5 (17.2)	
Stage IIIA	15 (22.1)	9 (23.1)	6 (20.7)	
Stage IIIB	25 (36.8)	11 (28.2)	14 (48.3)	**P=0.477**
Stage IV	5 (7.3)	3 (7.7)	2 (6.9)	

4.3.7 Tumor Site and Type of Surgery carried out

Most of the respondents had left sided tumors with the most common location being rectum comprising (55.9% n=38), sigmoid (23.5%, n=16) and recto-sigmoid junction (10.3%, n=7) as shown in Table 11.

Table 11: Tumor Site and Type of Surgery carried out

Tumour Site	Caecum	5 (7.3)
	Ascending Colon	6(8.8)
	Sigmoid Colon	16(23.5)
	Rectum	38(55.9)
	Recto-Sigmoid Junction	7(10.3)
Type of Surgery	Hemicolectomy	15 (22.1)
	Resection	24 (35.3)
	Not Defined	10 (14.7

4.3.8   Treatment Modality

Overall, most 72.1% (n=49) and 76.5% (n-=50) of the respondents had undergone surgery and chemotherapy respectively while 28% (n=19) had radiotherapy. Table 12 below shows the number of respondents who had used each modality either alone or in combination. Some 10% (n=14.7) of the respondents had used alternative treatment methods in addition to conventional treatment while 2.9% (n=2) of the respondents had not started treatment at the time of the study.

There was a statistical significance (**P=<0.001)** between the treatment modality and the perception of the patient on colorectal cancer management at KNH (Table 12). Further analysis showed that the patients who had undergone all the three modalities (surgery, radiation and chemotherapy) were 91% less likely to perceive that CRC management was effective as compared to those who had chemotherapy only [OR=0.09; 95% CI=0.009 – 0.964; P=0.047]

Table 12: Association between treatment modality and perception of the patient on CRC management

Treatment modality for Colorectal cancer		Effective Management of Colorectal Cancer Cases, n (%)		
Groups	Total=68 (n)	Yes (n=37)	No(n=29)	X^2 Test
Surgery	10(14.7)	10	0	**No X^2 value, used Fisher's exact due to low cell numbers**
Chemotherapy	12(17.6)	6	6	
Radiation	2(2.9)	1	1	
Surgery and Chemotherapy	25(36.8)	18	7	**P=<0.001**
Surgery and Radiation	2(2.9)	0	2	
Surgery, chemotherapy and Radiation	12(17.6)	1	11	
Chemotherapy and Radiation	3(4.4)	1	2	

4.3.9 Treatment Complications

Complications after surgery were reported by 16.3% (n=8) of the respondents. The complications included wound gaping, wound infections, pain, bleeding and delayed healing. Majority 84% (n=42) of the respondents reported side effects of chemotherapy while 78.9% (n=15) of the respondents reported radiotherapy related side effects (Table 13).

Table 13: Complications Experienced during treatment modalities

Treatment Modality	Reported complications or side effects [Total=68 (n %)]	No complications or side effects reported [Total=68 (n %)]
Surgery	8 (16.3)	41 (83.7)
Chemotherapy	42 (84.0)	8 (16.0)
Radiotherapy	15 (78.9)	4 (21.1)
Alternative Treatment	8 (72.7)	3 (27.3)

4.3.10 Co-morbidities

A majority (76.5%, n=52) of the study respondents had no other co-morbidities (Fig. 11).
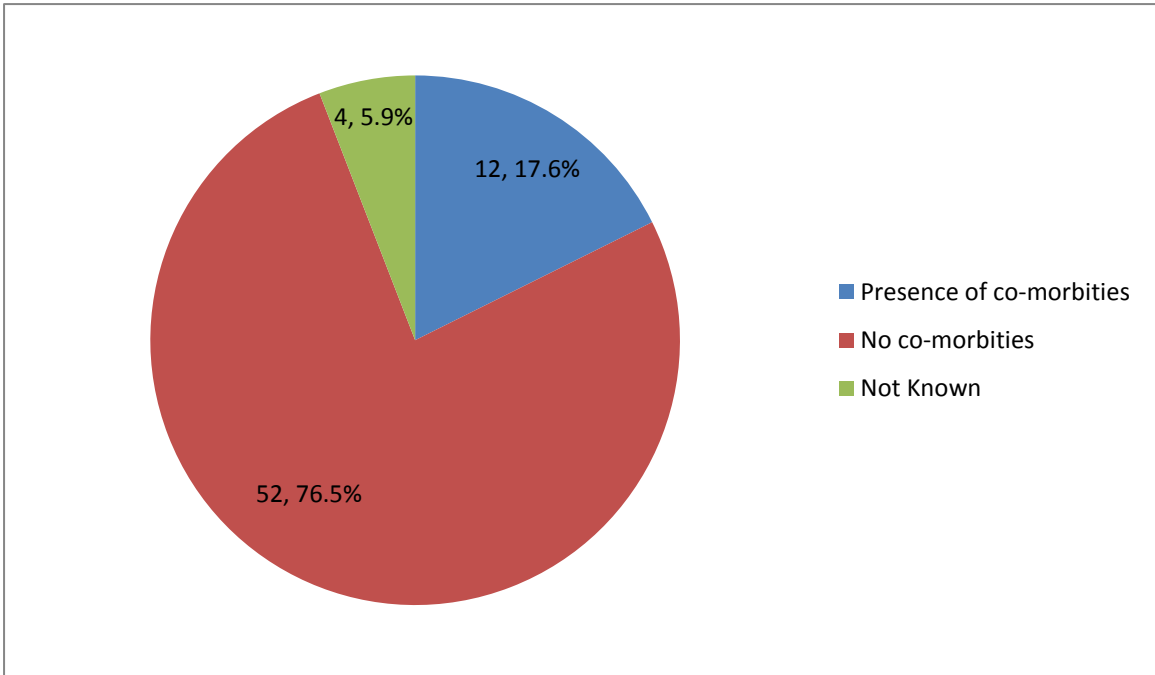
Figure 11: Distribution of Co-morbidities among study respondents

4.3.11 Tumor Recurrence and Palliative Care

Among the respondents, 11.8% (n=8) were on second line treatment after tumor recurrence. Only a small fraction (23.5%, n=16) of the study respondents had been referred to the palliative care unit (Table 14).

Table 14: Presence of Tumor recurrence and palliative care services

		Total=68 (n%)
Has tumor recurred	Tumor recurrence	8 (11.8)
	Not finished first line treatment	50 (73.5)
Offered palliative Services	Yes	16 (23.5)
	No	48 (70.6)

4.4 Analysis of participant opinions regarding availability & quality of treatment facilities at KNH's Oncology Unit

A majority 76.9% (n=20), of the respondents who had undergone radiotherapy felt that the number of radiotherapy machines at the KNH's Oncology Unit was inadequate. Most, 63.9% (n=43) and 77.4% (n=53) of the respondents felt that the number of oncology doctors and nurses were adequate respectively. A large number, 70.0%, (n=35) of the study respondents felt that chemotherapy drugs were not always available. More than half, 59.1%,(n=15) of the respondents felt that the waiting time for radiotherapy was lengthy, similarly more than half too, 58.6% (n=34) of them, felt that getting a bed in oncology ward took too long; while 58.3% (n=21) felt that waiting time before surgery was minimal (Table 15).

Table 15: Analysis of participant opinions regarding availability & quality of treatment facilities at KNH's Oncology Unit

NO	ITEM	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree
1.	Number of radiotherapy machines at KNH is adequate (n=26)	7.7%	11.5%	3.8%	15.4%	61.5%
2.	Number of oncology doctors at KNH is adequate (n=68)	34.4%	29.5%	6.5%	18.0%	11.5%
3.	Number of nurses at the KNH oncology wards and clinics is adequate (n=68)	53.2%	24.2%	8.1%	14.5%	0.0%
4.	Chemotherapy drugs are always available at KNH (n=50)	12.0%	10.0%	8.0%	14.0%	56.0%
5.	The waiting time for radiotherapy is minimal (n=26)	4.5%	13.6%	22.7%	9.1%	50.0%
6.	The waiting time before surgery is minimal (n=36)	19.4%	38.9%	5.5%	22.2%	13.9%
7.	Getting a bed in oncology wards is speedy (n=58)	24.1%	13.8%	3.4%	8.6%	50.0%

As part of the questionnaire, the patients were asked what in their opinion could be done to improve the management of colorectal cancer at KNH. Majority of the respondents requested that bed capacity be increased and chemotherapy be availed at KNH always. Once chemotherapy was made always available, their treatment costs would be drastically reduced as NHIF would cater for all inpatient costs.

"The management should increase the bed capacity of the oncology ward. I have to spend the night at Accident and Emergency department in order to ensure I get a bed the following day. There are so many patients but so few beds."(Q 37)

"I waited 5 months before getting a bed in the oncology ward. During this time the cancer keeps spreading in my body."(Q48)

"The hospital should ensure all chemotherapy drugs are available. We have NHIF cover and the monthly contribution has now been increased to Ksh 500. Therefore if the drugs are available, the cost would be catered for by NHIF and thus reduce our financial burden."

Majority of the key informants were of the opinion that inadequate space could also be negatively impacting the effective management of colorectal cancer. The space is inadequate not only as lack of beds for inpatient admission of colorectal cancer patients but also inadequate working space for the staff working in oncology units. The outpatient consultation areas were also noted to be squeezed and crowded therefore not ideal for history taking.

"At oncology pharmacy there is one small room which serves as the office and also store for drugs. The 7 staff can not all fit in and work at the same time."(KI 6)

"The bed capacity of the main oncology ward GFD is 30. All colorectal cancer patients need to be admitted for at least 3 days if taking intravenous chemotherapy. Frequently very few of these beds are empty and many patients are sent home to try again the following week."(KI 5)

"The consultation areas like GFC offer no privacy to patients during history taking. The patient has a right to treated with dignity during history taking and examination." (KI 3)

All the key informants also felt that effective management of colorectal cancer at KNH was being hindered by lack of chemotherapy at the hospital. The respondents felt that it was vital for the chemotherapy drugs to be availed at KNH so that the cost can be covered by NHIF hence decrease the financial burden of colorectal cancer treatment to patients.

"Colorectal cancer patients usually come to KNH on Mondays to be admitted for chemotherapy regime which needs to be administered for two days. Usually a drug may be missing, for instance there was a time Leucovorin was missing in the whole of Nairobi. These patients have to be sent back home till next Monday. Apart from the financial challenge to the patients, who have frequently travelled from far, this also impacts negatively on the fight against colorectal cancer. Many are the times chemotherapy drugs are missing in KNH thereby patients have to purchase from other pharmacies at a higher cost. A drug like irinotecan has been missing for a long time…each dose costs over Kshs 12,000 which is unaffordable to many patients." (KI 5)

Most of the key informants felt that there was a shortage of specialized staff trained in oncology who may manage colorectal cancer patients more effectively. There was also no multi-disciplinary clinic consisting of all the specialists involved in management of colorectal cancer patients.

"There are only 6 Medical Officers at the Cancer Treatment Centre, none has had specialized oncology training so they all rely on on-job training." There are 3 medical oncologists hence they cover too many patients (KI 2)

"The number of nurses at the oncology unit is adequate. However, none has had specialized oncology training. Majority of the nurses have however attended a one week palliative care sensitization course." (KI 1)

"There are only 4 medical physicists at KNH but currently only one on duty therefore he is overwhelmed by the large number of patients." (KI 4)

"There are 7 staff at the oncology pharmacy. This number is inadequate to cover all the oncology wards at KNH. Also only one staff member is a specialized clinical pharmacist." (KI 6)

"There is no multidisciplinary clinic to wholistically manage the colorectal cancer patients. Rather, we have fragmentation of care whereby if the patient needs surgery, he will attend the surgery clinic and when through he starts the radio-oncology clinic."

All the key informants agreed that having only one radiotherapy machine is a big hindrance to effective management of colorectal cancer patients at KNH. Some of the key informants also felt that other equipment important for management of colorectal cancer was inadequate.

"The radiotherapy machine is only one…it is old and overused. It is supposed to serve 50 patients per day but usually serves 120 patients per day leading to frequent breakdowns. Currently the next available bookings for new patients are for 2017, two years from now." (KI 4)

"There are only 2 biological safety cabinets. Consequently we have to prepare chemotherapy outside the chambers due to increased numbers of patients. We need three more for optimal functioning."(KI 6)

"There are no infusion pumps for administration of chemotherapeutic agents. Drugs like 5 Fluorouracil should be administered over long hours which would be more convenient with an infusion pump." (KI 3)

Table 16: Analysis of common themes emerging from in-depth interview with key informants

Theme
Inadequate bed capacity and working space
Insufficient supply of chemotherapeutic drugs
Lack of specialized staff
Inadequate specialized equipment
Late presentation and diagnosis of CRC patients

4.5   Analysis of participant opinions regarding knowledge, training & attitude of medical personnel at KNH's Oncology Unit

Majority 93.7% (n=64) and 95.3% (n=65) of the respondents felt that the medical doctors and nurses at the KNH's Oncology Unit respectively were well trained and knowledgeable on colorectal cancer management. Similarly a large majority 93.9% (n=64) and 82.1% (n=56) of the respondents felt that the medical doctors and nurses at the KNH's Oncology Unit respectively were respectful, approachable and prompt (Table 17).

Table 17: Analysis of participant opinions regarding knowledge, training & attitude of health workers at KNH's Oncology Unit

NO	ITEM	Strongly Agree	Agree	Neither agree or disagree	Disagree	Strongly Disagree
1.	Medical doctors at KNH Oncology wards and clinic are well trained and knowledgeable (n=68)	78.1%	15.6%	4.7%	1.6%	0.0%
2.	Nurses at KNH Oncology wards and clinic are well trained and knowledgeable (n=68)	69.2%	26.1%	1.5%	3.1%	0.0%
3.	Medical doctors at KNH Oncology wards and clinic are respectful, polite, approachable and promptly attend to patient concerns (n=68)	62.1%	31.8%	3.0%	3.0%	0.0%
4.	Nurses at KNH Oncology wards and clinic are respectful, polite, and approachable and promptly attend to patient concerns. (n=68)	56.7%	25.4%	8.9%	7.5%	1.5%

4.6 Source of Information for CRC

The most 70% (n=48) common source of information on CRC was health workers in all health facilities while 20.6% (n=14) of the study respondents had not received any information on the same (Table 18).

Table 18: Sources of CRC Information

Source of information on Colorectal cancer	n=68	Percentage
Health workers at KNH	34	50.0
Media	3	4.4
Internet	1	1.5
Friends and relatives	4	5.9
Health workers at other facilities	14	20.6
No Information received	14	20.6

4.6 Analysis of respondents' opinion about the management of colorectal cancer cases at the KNH's Oncology Unit

More than half of the study respondents, (57.3%, n=39) felt that the management of colorectal cancer cases at the KNH's Oncology Unit was effective (Table 19).

Table 19: Respondents' opinion about the management of colorectal cancer cases at the KNH's Oncology Unit

Characteristic	Groups	Total=68 n (%)
Management of Colorectal Cancer Cases	Effectively Managed	39 (57.3)
	Ineffectively Managed	29 (42.7)

CHAPTER FIVE: DISCUSSION

This chapter is a discussion of the results and study findings accrued from this study.

5.1: Respondents' Characteristics

The study results showed that colorectal cancer affects majorly those older than 40 years with a peak range of 41-50 years. This finding mirrors previous studies in African counties which reported the mean age of CRC patients to be 51.6 years compared to 70 years seen in patients in Western countries (Ohayi et., 2011). The tendency of CRC to affect younger age groups in Africans may be due to genetic predisposition, environmental influence, chronic infections and poor immune status (Center et al., 2012)

CRC in this study affected more females than males. A similar finding was observed by Gado et al., (2014) whereby 59% of the respondents in a hospital based study in Egypt were females. In contrast, previous studies at KNH (Saidi et al., 2008), Subsaharan Africa (Graham et al., 2012) and the USA (American Cancer Society, 2014) have shown higher incidence of CRC in males than females. The female preponderance observed in this study may be attributed to purposive sampling method used in the study and may therefore not be generalisable to the population at large.

The study revealed that majority of the respondents, who were in the lower income levels, were likely to perceive the management of colorectal cancer at KNH as being effective. This finding correlates with Cavalli-Björkman N, 2012 who found that the patient's socio-economic status influenced how they perceived their management and also how the health workers perceived them. The patients from a lower SES were more easily satisfied due to limited options and access to various health services. Lower SES is associated with lack of knowledge which may have influenced the patient's perception.

The findings show that CRC diagnosis and treatment at KNH is costly and this is typical of cancer in general in many low and middle income countries as reported by Jemal et al., 2012. Even though majority of the respondents had NHIF cover, the services offered were minimal due to lack of drugs and supplies at KNH. Subsequently, the patients have to incur out of pocket expenditure which they can ill afford.

A significant majority of the respondents had been exposed to smoking, which is a known risk factor for colorectal cancers worldwide, according to the National Guidelines on Cancer

management, Kenya, 2013. Many studies have found that nicotine and tobacco use increases the risk of CRC in both past and present users. (Durko, L. & Malecka-panas, E., 2014). Despite CRC diagnosis, some of the respondents had not quit smoking and this placed them at an increased risk not only of CRC mortality, but also other cancers and non communicable diseases. The adverse effect of smoking on CRC mortality was reported in a study by Yang et al., (2015). Smoking among CRC patients may be associated with lack of knowledge on risk factors and association of smoking and poor outcomes in CRC treatment.

A significant percentage of the respondents had a positive family history of colorectal cancer. This correlates with previous studies which show that 5-10% of colorectal cancer patients have a positive family history and the susceptible genes have been identified (Haggar et al., 2009). Studies have reported that individuals with relatives with colorectal cancer have an increased risk of being diagnosed with CRC (Rees et al., 2008), hence targeted screening is therefore an area that may be considered in susceptible individuals, in addition to awareness creation and widespread community education.

5.2   Colorectal Cancer Characteristics

Majority of the respondents were diagnosed with advanced stage colorectal cancer. This may be attributed to the low screening rates observed in this and many other studies in African countries (Center et al., 2009). The results also contrast with developed countries like USA where more than half of the patients are diagnosed with local-regional disease due to widespread screening (Siegel et al., 2014). Low screening in our setup may be attributed to decreased access to diagnosis and treatment which has been observed in socioeconomically deprived environments. Late presentations may also be attributed to lack of knowledge and inefficient referral mechanisms, as most of the respondents were diagnosed in peripheral health facilities.

Regarding the anatomical location of CRC at presentation, there were more left sided tumors, with the most common site being the rectum. This finding is in agreement with previous studies in African countries which showed the most common site to be rectum followed by the sigmoid colon (Saidi et al, 2008). However, this contrasts with findings in Western countries which have shown higher incidence of right sided tumors (Chalya et al., 2009). The reason for these anatomic differences may be an interplay of genetic and lifestyle factors, an

example being that most smokers have right sided tumors and Western countries have higher smoking rates. (WHO global report on trends in prevalence of tobacco smoking, 2015)

The study found that the most common symptom experienced by the respondents before diagnosis were rectal bleeding, abdominal pain and changes in bowel habits. This finding mirrors a previous study at KNH by Karuri et al., 2008 and therefore rectal bleeding, especially when associated with abdominal pain and changes in bowel habits can be a predictor of colorectal cancer, hence the importance of further investigations when a patient presents with it.

The study results showed a diagnostic period of more than six months for majority of the respondents. This lengthy duration of diagnosis is also noted in previous studies at KNH (Karuri et al., 2008) and may been attributed to patient, geographical and physician factors namely lack of finances, lack of awareness on the guidelines for management of CRC and huge geographical distances.   In contrast, the diagnostic period in developing countries is shorter with a mean of three months (Majumdar et al., 1999). Even though several studies have shown that a lengthy diagnostic period does not automatically translate to advanced colorectal cancer due to long latency period of 10yrs, it may however mean more complications and poorer quality of life for the patient. The results also showed delayed initiation of treatment after diagnosis with CRC. This could have been caused by financial constraints faced by the respondents and shortage of radiotherapy machines and oncology beds at KNH.

There was a significant relationship between the treatment modality and perception of the patient on CRC management, with patients who had received all the modalities being the least likely to say the management was effective. This may be attributed to delayed waiting time before radiotherapy and chemotherapy caused by inadequate radiotherapy machines, oncology beds and chemotherapy drugs. Similar findings were reported in a study done by Sandoval et al., (2006) in Canada whereby those patients who had undergone all the treatment modalities were 37% less likely to report the quality of care as being good.

5.3   Health Care System Characteristics

The study results showed that the main institutional factors which affected the patient's perception on colorectal cancer management at KNH were shortage of chemotherapy drugs and inadequate radiotherapy machines and oncology beds. This significant shortfall in resources has been demonstrated in studies done in several low and middle income countries. (Hanna et al., 2010) This inadequate investment on human and infrastructural support for cancer control may be attributed to the low health budget allocation both at the central government level and also at the institutional level.

It is noteworthy that majority of the respondents felt that the oncology staff had a positive attitude as they were mostly cited as being respectful, polite, approachable and prompt in attending to the patient's needs. This correlates with similar findings from a study in multiple sites in the USA whereby patients' experiences with medical and nursing teams were generally good, ranging from 84-90% (Ayanian et al., 2010).

The study results showed that the primary source of information regarding colorectal cancer was health workers at both KNH and other health facilities. In contrast, the media was the least common source of information. This findings are in agreement with Chen X. and Siu L. (2001), who found that majority of cancer patients in Canada received most health information from health workers. The findings emphasize the important role health workers have in provision of accurate and up to date information. As such, the health workers' training and knowledge should be in line with current practice. The media has a crucial role to inform, educate, support, share, advocate and raise funds for cancer treatment (Lapointe et al., 2014). Therefore there should be collaboration between health workers and media to increase awareness on CRC screening, diagnosis and treatment

5.4 LIMITATIONS OF THE STUDY

The data collected relied on the memory of the respondents; there is therefore the possibility of recall bias and socially desirable responses.

The study was done in the largest referral public hospital; therefore the results may not be generalisable to patients in private hospitals and the health facilities at lower levels. The study did not achieve the target sample size due to unavailability of some patients due to their treatment regimes. This being a novel study, this limitation will be taken into consideration when designing and implementing future studies.

5.5 CONCLUSION

The patient factors which affected their perception of CRC management at KNH were monthly income, SES, duration of diagnostic period and treatment modality received. The health care system factors which influenced the patient's perception included inadequate bed, chemotherapeutic drugs and radiotherapy machines. The CRC patients were generally satisfied with the staffing levels, knowledge, attitude and practice. Despite the challenges, overall the study results demonstrated that majority of colorectal cancer patients were of the opinion that CRC management at KNH was effective.

5.6 RECOMMENDATIONS

1. Screening of high risk population should be done at all levels of the health care system and appropriate referral done to minimize time lag from presentation of symptoms to diagnosis and treatment of CRC.
2. Implementing primary prevention interventions such a health education on CRC risk factors and early signs and symptoms to both patients and health workers though media campaigns.
3. Improve institutional and national budgetary allocation towards cancer control so as enable equipping of the oncology unit with adequate human and physical resources.

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APPENDICES

Appendix 1: Respondents' Consent Form

My name is Mary Anyona Chitai. I am a Master of Science in Oncology nursing student at the University of Nairobi, School of Nursing. I intend to conduct a research titled '**Determinants of management of colorectal cancer patients at Kenyatta National Hospital'**. I kindly request your participation in this study.

The purpose of this information is to give you details pertaining to the study that will enable you make an informed decision regarding participation. You are free to ask questions to clarify any of the aspects we will discuss in this information and consent form.

Background and Objective: There has been an increasing incidence of Colorectal Cancer (CRC) in Kenya. The number of patients dying from CRC is also high. The purpose of this study is to identify the determinants of management of CRC at KNH. The results will be useful in identifying areas of improvement in screening, treatment and follow-up of patients with colorectal cancer. This will eventually result in early detection and decreased prevalence of CRC.

Participation: This will require completion of a questionnaire which will take 15 minutes of your time. No names are required in the questionnaire. A code will be given to maintain anonymity and confidentiality.

Benefits: There is no direct monetary benefit in participating in this study. However the findings from the study will be useful in identifying the challenges faced in management of CRC at KNH. The findings will be availed to the management of KNH to aid in putting in place measures that will improve the management of CRC at KNH.

Risks: There are no economic or physical risks to participating in the study. You may however spend some more time at the hospital as you are answering the questions.

Confidentiality: Confidentiality will be maintained and the information you provide will only be used for the intended purpose of the study. In addition, your name will not be required on any forms or used during publication of the final report thus ensuring your anonymity. All materials used during the study will be under lock and key and only the

personnel involved in this study will have access to them. Electronic files will be saved on password and fire-wall protected computers.

Voluntary participation: Participation in this study is voluntary. Refusal to take part will not attract any penalty. You retain the right to withdraw from the study without any consequences.

In case of any problem or concern, please contact me on mobile phone number 0722 695 688 or email address mchitai@yahoo.com. You can also contact any of the following persons:

1. The director, School of Nursing, University of Nairobi, P.O.Box 19676-00202 Nairobi, Telephone number 020-2726300, extension 43673
2. The chairperson, KNH/UON Ethics & Research Committee, P.O.Box 20723-00202
3. Nairobi, telephone number 020-726300-9

Respondent's consent declaration statement

If you consent to Participate in the study please sign below:

I hereby consent to participate in this study. I have been informed of the nature of the study being undertaken and potential risks explained to me. I also understand that my participation in the study is voluntary and the decision to participate or not to participate will not affect my employment status at this facility in any way whatsoever. I may also choose to discontinue my involvement in the study at any stage without any explanation or consequences. I have also been reassured that my personal details and the information I will relay will be kept confidential. I confirm that all my concerns about my participation in the study have been adequately addressed by the investigator and the investigator have asked me questions to ascertain my comprehension of the information provided.

Participant's Signature........................... Date........................

Researcher/Research Assistant:Name:..

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

Appendix 2: Questionnaire for patients

<u>Instructions</u>

Please do not write your name on the questionnaire

Please put a tick (√) in the box that indicates your appropriate response

Where no choices are given please fill in the appropriate answer.

<u>SOCIO-DEMOGRAPHIC</u>

1.   How old are you in years?   ....

2.   Gender   ☐Male   ☐ Female

3.   Educational level.

   1. ☐ Primary   2. ☐ Secondary   3. ☐ Tertiary   4. ☐ Others

4.   Marital Status

   1. ☐ Single   2. ☐ Married   3. ☐ Widowed   4. ☐Divorced

5.   Religion: 1.☐ Christian   2. ☐ Muslim 3. ☐ Hindu 4. ☐ Others ………...

6.   Please indicate county of residence.   ....

7.   Please indicate your home county.   ....

8.   What is your occupation?

   1. ☐ Employed   2. ☐ Self-employed 3. ☐ Un employed 4. ☐Retired

9.   Approximately how much is your monthly income?

1. ☐ Below Ksh 1000   2. ☐ Ksh 1,000-10,000   3. ☐ Ksh 10,001–20,000

4. ☐ Ksh 20,001-30,000   5. ☐ Ksh 30,000-40,001   6. ☐ Ksh 40,001-50,000

7. ☐ Ksh 60,001-70,000   8. ☐ Ksh80,001-90,000   9. ☐ Ksh 90,001-100,000

10. ☐ Above 100,000

10. Are you a member of National Hospital Insurance Fund (NHIF)? ☐ Yes ☐ No

11. Are you a member of any other medical Insurance Scheme? ☐ Yes ☐ No

12. What services does your medical Insurance Scheme cover? **(Tick (√) all applicable)**

1. ☐ In-Patient Services   2. ☐ Investigations   3. ☐ Surgery

4. ☐ Out-Patient Services 5. ☐ Radiotherapy   6. ☐ Chemotherapy

7. ☐ Consultation Fees

13. How much cost have you incurred to treat the condition?

1. ☐ Ksh 1,000-10,000   2. ☐ Ksh 10,001–50,000   3. ☐ Ksh 50,001-100,000

4. ☐ Ksh 100,001-500,000 5. ☐ Above Ksh 500,000

14. How do you raise funds for treatment? **(Tick (√) all applicable).**
1. ☐ Salary   2. ☐ Personal Business   3. ☐ Family/Friends contributions
4. ☐ Harambees   5. ☐ Medical Insurance Cover
5. ☐ Others (Please specify) ....

....

LIFESTYLE CHARACTERISTICS

15. Have you used nicotine or tobacco products in the past? ☐ Yes   ☐ No

16. If yes:

a) Indicate the date you started using the products   ....

b) Indicate the type used.

1. ☐ Cigarettes   2. ☐ Cigars 3. ☐ Chewing   4. ☐ Pipe

5. ☐ Patch/gum   6. ☐ E cigarettes

c) Indicate the number per day ....

17.   Have you quit use of nicotine or tobacco products? ☐ Yes ☐ No

If yes:

Indicate the date you stopped using the products ....

18.   Have you lived with anyone who smoked nicotine or tobacco products?

☐ Yes   ☐No

19.   Have you used alcohol or alcoholic beverages in the past? Yes ☐   No ☐

20.   If yes:

a) Indicate the date you started using the products ....

b) Indicate the type used.

1. ☐ Beer 2. ☐ Wine 3. ☐ Local Brew   4. ☐ Spirits

c) Glasses or Bottles you drink per day ....

d) Number of days you drink per week ....

21.   Have you quit use alcohol or alcoholic beverages? Yes ☐   No ☐

If yes:

Indicate the date you stopped using the products ....

22.   Do you participate in any intentional or occupational physical activities?

(Examples include walking, dancing, jogging, active sports, digging, carpentry, aerobics, swimming, construction, martial arts, cycling)

☐ Yes   ☐ No

If yes:

a) For how many minutes per day? ....

b) For how many days per week? ....

54

23.   Please indicate the number of servings per day you have for each of the following food types.

a) Vegetables ....

b) Fruits   ....

c) Red Meat   ....

d) Whole grains   ....

e) Processed meats (e.g. bacon, sausage)   ....

COLORECTAL CANCER FACTORS

24.   Do you have a family history of cancer?   ☐ Yes   ☐ No

If yes:

a)   Indicate which family member ....
b)   Which type of cancer ☐ Colon or Rectal Cancer   ☐ Other Cancers

If Other Cancers indicate which one ....

25.   When were you diagnosed with colorectal cancer? ....

26.   Wherewas the diagnosis made? ....

27.   How did you find out you have colorectal cancer?

1.   ☐Screening   2. ☐ Had symptoms

28.   If 2) above, which of the following symptoms did you experience before seeking medical help?

1. ☐ Blood in faeces 2. ☐ Changes in bowel habits   3. ☐ Unexplained tiredness

4. ☐ Unexplained weight loss   5. ☐ Pelvic abdominal pain

6. ☐ Yellowing of the skin   7. ☐ Abdominal distension

8. ☐ Others ....

29.   When did you first notice these symptoms? ....

30.   After your diagnosis, from which source did you receive information concerning colorectal cancer?

1. ☐ Health workers at KNH   2. ☐ Media   3. ☐ Internet

4. ☐ Friends and relatives   5. ☐ Others ....

6. ☐ No information received

31. When was treatment initiated for the colorectal cancer?..........................

       a) Please give reasons for the time indicated above.

       ....

       ....

32.   Which treatment have you had for colorectal cancer?

1. ☐ Surgery   2.☐ Chemotherapy   3. ☐ Radiotherapy

4. ☐ Herbal/Alternative medicines   5. ☐ Others.................................

5. ☐ Treatment not started.

33.   If you had surgery, did you experience any complications after surgery?

                          ☐ Yes   ☐ No

       a) If yes please indicate the complication.

       ....

       ....

34.   If you had chemotherapy, did you experience any of the following side effects?

1. ☐ Hair loss   2. ☐ Fatigue   3. ☐ Nausea and vomiting   4. ☐ Anaemia

5. ☐ Easy bruising and bleeding   6.☐ Mouth sores/ulcers   7. ☐   Loss of appetite

8. ☐ Sleep problems   9. ☐ Diarrhoea and constipation

10.☐ Others ....

....

35. If you had radiotherapy, did you experience any of the following side effects?

1. ☐ Skin irritation e.g. blistering, peeling   2. ☐ Nausea   3. ☐ Stoolleakage (Incontinence)

4. ☐ Rectal irritation, diarrhoea, painful bowel movements or blood in the stool

5. ☐ Frequency, burning or pain while urinating or blood in the urine

6. ☐ Fatigue/tiredness

7. ☐ Others ....

36. If you had Herbal/Alternative medicines, did you experience any side effects?

☐ Yes   ☐ No

a) If yes please indicate the complications.
....
....

37. If you had other treatment options, did you experience any side effects?

☐ Yes   ☐ No

a) If yes please indicate the complications.
....
....

38. How did you deal with the side effects of treatment?

....

....

....

....

....

39.   Do you have any other medical condition?   ☐ No   ☐ Yes

If yes please indicate which one...

40.   Since treatment has your tumour recurred?   ☐ Yes   ☐ No

41.   Have you been offered palliative treatment?

1. ☐ Yes   2. ☐ yes but declined   3. ☐ No   4. ☐ Not indicated

AVAILABILITY & QUALITY OF TREATMENT FACILITIES AT KNH

42.   In your opinion, rate the following

1. Strongly agree (**SA**), 2. Agree (**A**), 3. Neither agree or disagree i.e. Neutral (**N**)
4. Disagree (**D**) 5. Strongly disagree (**SD**)

NO	ITEM	1	2	3	4	5
a.	Number of radiotherapy machines at KNH is adequate					
b.	Number of oncology doctors at KNH is adequate					
c.	Number of nurses at the KNH oncology wards and clinics is adequate					
D	Chemotherapy drugs are always available at KNH					
E	The waiting time for radiotherapy is minimal					
F	The waiting time before surgery is minimal					
G	Getting a bed in oncology wards is speedy					

43. On a scale of 1 to 5 rate the following services at KNH.

1. Strongly agree (**SA**), 2. Agree (**A**), 3. Neither agree or disagree i.e. Neutral (**N**)
4. Disagree (**D**) 5. Strongly disagree (**SD**)

NO	ITEM	1	2	3	4	5
7a.	Medical doctors at KNH Oncology wards and clinic are well trained and knowledgeable					
7b	Nurses at KNH Oncology wards and clinic are well trained and knowledgeable					
7c	Medical doctors at KNH Oncology wards and clinic are respectful, polite, approachable and promptly attend to patient concerns					
7d	Nurses at KNH Oncology wards and clinic are respectful, polite, and approachable and promptly attend to patient concerns.					

44. In your opinion, what can be done to improve the management of patients with colorectal cancer at KNH?

....
....
....
....
....

Appendix 3: Key Informant Interview Consent Form

You have been invited to participate in an interview as a key informant on a study on determinants of management of colorectal cancer patients Kenyatta National Hospital. The interview will take approximately 20 minutes. By signing this form you indicate your consent to participate in this study. Your participation is voluntary. Anonymity will be maintained and you will not be identified in any way even in the final report. There are no percedived risks or direct incentives for your participation. Neither will you be inconvenienced or compromised in any way.

In case of any problem or concern, please contact me on mobile phone number 0722 695 688 or email address mchitai@yahoo.com. You can also contact any of the following persons:

1. The director, School of Nursing, University of Nairobi, P.O.Box 19676-00202 Nairobi, Telephone number 020-2726300, extension 43673
2. The chairperson, KNH/UON Ethics & Research Committee, P.O.Box 20723-00202
3. Nairobi, telephone number 020-726300-9

Consent declaration statement

I willingly accept to participate in this study having been given adequate information about it and given an opportunity to seek clarification

Participant's Signature............................   Date........................

Principal Researcher.. Signature................ Date....................

Appendix 4:   Key Informant Interview Guide

Information to the key informant

The following questions will act as a guide to the interview regarding the determinants of management of colorectal cancer at Kenyatta National Hospital. You will not be identified in any way in the information you provide so feel free to give your views or comments during the interview.

Interview Questions

1. In your opinion, what are the factors influencing management of colorectal cancer at KNH?
2. What are your thoughts about the staffing situation at KNH oncology wards and clinic?
3. Kindly give your comments on the physical infrastructure in place for management of patients with colorectal cancer at KNH?
4. What are the challenges faced in the management of colorectal cancer at KNH?
5. What do you suggest can be done to improve management of colorectal cancer at KNH?

Appendix 5: Checklist for Patients' Files

1. Tumour stage at diagnosis
2. Investigations carried out on the patient before, during and after treatment.
3. Tumour site
4. Treatment modality
5. Intention of treatment
6. Type of surgery
7. Drugs used for chemotherapy, Number of Cycles
8. Supportive treatment

Appendix 6: Colorectal Cancer Staging

TNM definitions

Primary tumour (T)

TX	Primary tumour cannot be assessed
T0	No evidence of primary tumour
Tis	Carcinoma in situ
T1	Tumour 2 cm or less in greatest dimension
T2	Tumour more than 2 cm but not more than 5 cm in greatest dimension
T3	Tumour more than 5 cm in greatest dimension
T4 *	Tumour of any size that invades adjacent organ(s), e.g., vagina, urethra, bladder
[Note: *Direct invasion of the rectal wall, perirectal skin, subcutaneous tissue, or the sphincter muscle(s) is not classified as T4.]	

Regional lymph nodes (N)

NX	Regional lymph nodes cannot be assessed
N0	No regional lymph node metastasis
N1	Metastasis in perirectal lymph node(s)
N2	Metastasis in unilateral internal iliac and/or inguinal lymph node(s)
N3:	Metastasis in perirectal and inguinal lymph nodes or bilateral internal iliac and/or inguinal lymph nodes

Distant metastasis (M)

MX	Distant metastasis cannot be assessed
M0	No distant metastasis
M1	Distant metastasis

Appendix 7: AJCC Stage Groupings

Stage 0	Tis, N0, M0
Stage I	T1, N0, M0
Stage II	T2, N0, M0 T3, N0, M0
Stage IIIA	T1, N1, M0 T2, N1, M0 T3, N1, M0 T4, N0, M0
Stage IIIB	T4, N1, M0 Any T, N2, M0 Any T, N3, M0
Stage IV	Any T, any N, M1

Appendix 8: Letter to Ethics and Research Committee

Mary Anyona Chitai,

School of Nursing Sciences,

University of Nairobi,

P.O Box 30197,

Nairobi.

Admission No: H56/67838/2013

25th February 2015

The Chairman,

Kenyatta National Hospital Ethics and Research Committee

P.O Box 20723-00202

Nairobi.

Dear Sir/Madam,

RE: PERMISSION TO CONDUCT RESEARCH AT KENYATTA NATIONAL HOSPITAL

I hereby request for approval to conduct a research study titled **Determinants of management of colorectal cancer patients at Kenyatta National Hospital**.

I am a second year postgraduate student at the University of Nairobi, School of Nursing Sciences pursuing a Master of Science in Nursing (Oncology Nursing) and undertaking this study as a requirement for the course.

Attached is the Research proposal for the study.

Looking forward to your favourable response.

Yours Faithfully,

Mary Anyona Chitai.

Email Adress: mchitai@yahoo.com

Mobile no. 0722695688

Appendix 9: Letter to the Chief Executive Officer, Kenyatta National Hospital

Mary Anyona Chitai,

School of Nursing Sciences,

University of Nairobi,

P.O Box 30197,

Nairobi.

The Chief Executive Officer,

Kenyatta National Hospital,

P.O. Box 20723-00202,

Nairobi

Dear Madam,

REF: PERMISSION TO CONDUCT RESEARCH AT KENYATTA NATIONAL HOSPITAL

I hereby request for approval to conduct a research study titled "**Determinants of management for colorectal cancer at Kenyatta National Hospital"** in your institution.

I am a second year postgraduate student at the University of Nairobi, School of Nursing Sciences pursuing a Master of Science in Nursing (Oncology Nursing) and undertaking this study as a requirement for the course.

Looking forward to your favourable response.

Yours Faithfully,

Mary Anyona Chitai.

Email Address: mchitai@yahoo.com

Mobile No. 0722695688

Appendix 10: Letter of Approval from KNH / UON ERC
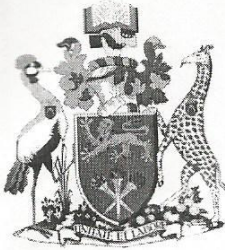
UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
P O BOX 19676 Code 00202
Telegrams: varsity
(254-020) 2726300 Ext 44355

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

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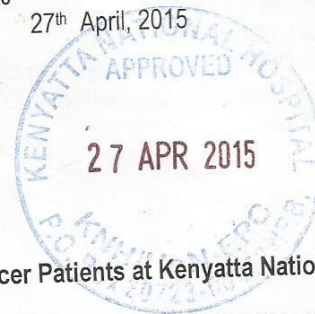Telegrams: MEDSUP, Nairobi

27th April, 2015

APPROVED

2 7 APR 2015

Ref: KNH-ERC/A/193

Mary Chitai Anyona
School of Nursing
University of Nairobi

Dear Mary

Research Proposal : Determinants of Management for Colorectal Cancer Patients at Kenyatta National Hospital (P110/03/2015)

This is to inform you that the KNH/UoN-Ethics & Research Committee (KNH/UoN-ERC) has reviewed and **approved** your above proposal. The approval periods are 27th April 2015 to 26th April 2016.

This approval is subject to compliance with the following requirements:

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

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

Yours sincerely,

PROF. M. L. CHINDIA
SECRETARY,   KNH/UON-ERC

c.c.   The Principal, College of Health Sciences, UoN
        The Deputy Director CS, KNH
        The Chair, KNH/UoN-ERC
        The Director, School of Nursing Sciences, UoN
        Supervisors: Dr. Samuel Kimani, Dr. Blasio Omuga