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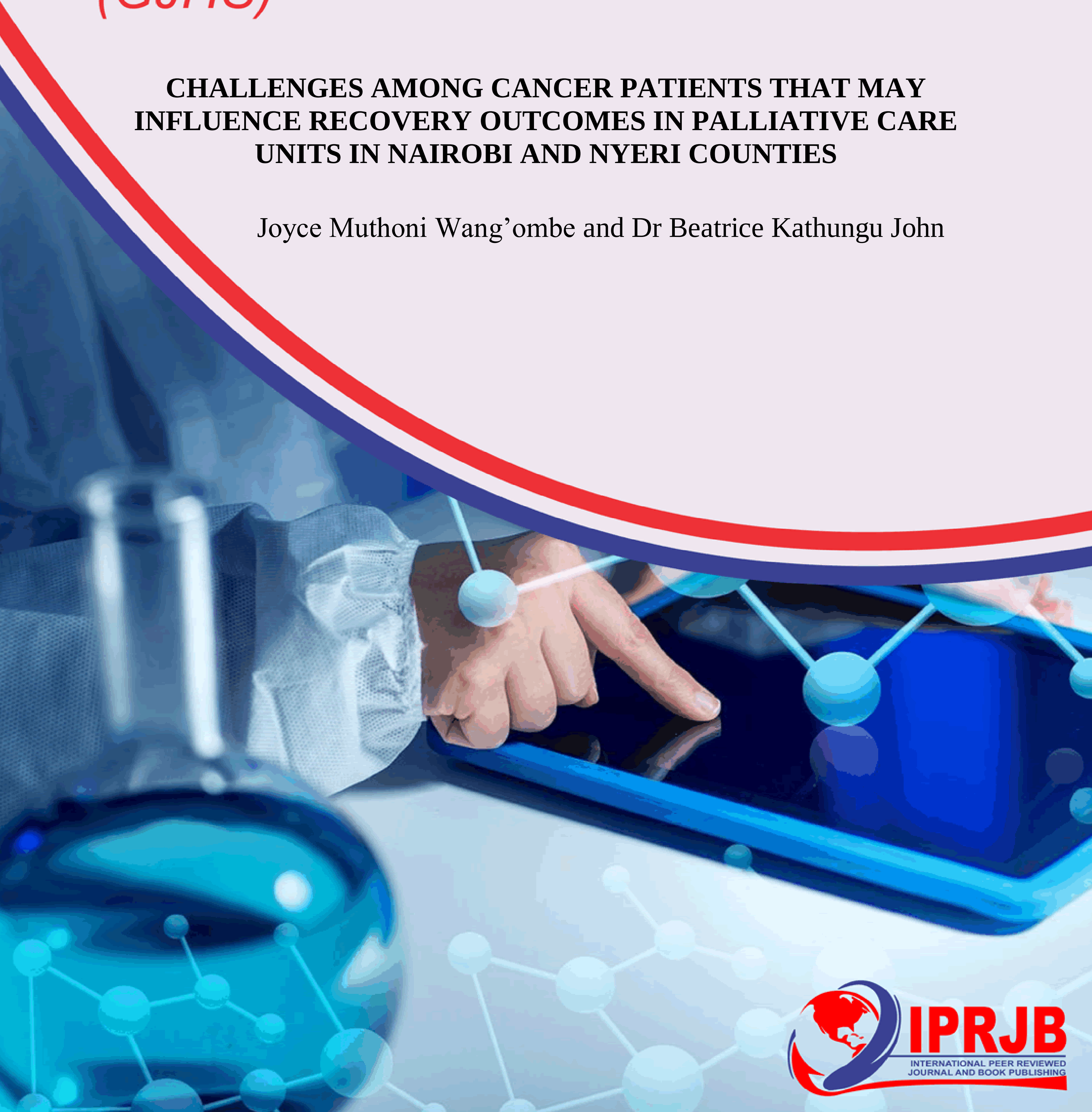

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CHALLENGES AMONG CANCER PATIENTS THAT MAY INFLUENCE RECOVERY OUTCOMES IN PALLIATIVE CARE UNITS IN NAIROBI AND NYERI COUNTIES

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Abstract

Purpose: This study sought to establish challenges among cancer patients that may influence recovery outcomes in palliative care units in Nairobi and Nyeri Counties.

Methodology: The study adopted a correlation research design. The target population were the cancer patients, attending treatment at the three palliative care units in Nairobi and Nyeri Counties. Systematic random sampling technique was used in the study to obtain a sample of 96 participants. Semi structured questionnaires were used to collect data. Data was analyzed using both descriptive and inferential statistics, namely Pearson Moment Correlation Coefficient(r).

Findings: Result showed that, majority of the respondents indicated participating in the programs available at the palliative care institutions, which included; group psychotherapy (91.7%), spiritual support (91.7%) and programs on coping skills (91.7). Others (22.6%) participated in programs such as performing chorals, knitting and board games. The results also showed that 82.1% and 78.6% of the respondents noted that they experienced challenges of being isolated and lacking finances respectively. 50% of the respondents had a challenge in coping with the condition, while 2.4% experienced challenges in adhering to drugs .These findings were not unusual considering that most of the patients were newly diagnosed with cancer and for some respondent's metastasis had set in.

***Unique contribution to theory, practice and policy*:** Patients facing challenges receiving palliative care could adopt group psychotherapy, including cognitive-behavioral, informational, non-behavioral, social support, and using unusual treatments such as music and art therapy to curb cancer. Administrators and medical staff in the palliative care units should create awareness and encourage the attending patients to source for a health insurance cover e.g. National Health Insurance Fund (NHIF) to cater for the cancer disease both outpatient and incase of hospitalization. This will ease the financial burden of cancer on the patient, family and community.

Keywords: *Challenges, cancer patient, Recovery outcomes, palliative care, Nairobi and Nyeri Counties*

INTRODUCTION

Accommodating a long-term illness not only involves physical discomfort but also creates many psychological problems for the patients. Such psychological problems may include depression, anxiety, sleep disturbance and low self-concept which can affect the patients' recovery process (Nadeane, 2006).

This is mainly because there is a close relationship between psychological processes, biological disease processes and their outcomes. Numerous studies (Yurek, Farrar& Andersen, 2000; Turner-Cobb, 2000) have shown that emotional distress and stress are closely related to increased output of the stress-related hormones and to the suppression of the immune function. Further, Lent (2004) explains that the psychological processes which help people to maintain their sense of well-being may be destabilized when confronted by problematic external events such as health threats.

According to the NCI, alteration in system function, such as the gastrointestinal and genitourinary systems treatment side effects, tumor progression, thermoregulation disruption are among some of the sources of physiologic sources of sleep disruption(National Cancer Institute). Identification and treatment of sleep disorders is a key factor in cancer patients, because it is likely to influence other factors such as perception of tolerance of treatment measures, physical symptoms and quality of life (Stepanski, Walker, Schwartzberg, Blakely, Ong, &Houts, 2008). Consequently it is important to identify the potential cause of the sleep disturbance in order to determine the best means of treatment for cancer patients.

In a study conducted at the University of California San Diego, which evaluated the presence of sleep disturbances in cancer patients undergoing chemotherapy before onset of treatment and thereafter (Liu, Fiorentino, Natarajan, Parker, Mills, Sadler, et al, 2009) the study established that patients who had sleep disturbance before starting treatment had clinically worse symptoms during treatment, which negatively impacted the quality of life (Liu, et al, 2009). In conclusion, the study concluded that early identification and treatment of the sleep disturbance would lead to a decrease in the severity of symptoms and help improve patients' overall quality of life (Liu, et al, 2009).

Studies have shown that a good survival rate for a cancer patient can be significantly affected by a weight loss greater than 6% of normal weight at the time of cancer diagnosis (Wolff, 2007). According to Carver (2006) weight loss is a common phenomenon among people with cancer and is usually the first noticeable sign of the disease. National Cancer Institute (2010) reports that up to 40% of people diagnosed with cancer report unexplained weight loss at the time of diagnosis, and up to 80% of people with advanced cancer experience weight loss and cachexia (muscle loss).

There are several interventions that can be used to enhance AQ among cancer survivors. The benefits of group psychotherapy interventions with cancer survivors cannot be gainsaid (Lepore& Coyne, 2006). The majority of these interventions fall into four distinct categories: education, coping, emotional support, and psychotherapy (Fawzy, 1999). There are many studies on each of these types of psychotherapeutic group intervention encompassing various populations, settings, treatments, and modalities.Psycho education intervention - Ferlic, Goldman, and Kennedy (1979) proposed that going beyond the traditional support group was necessary to examine the patient's adjustment to illness, communication, cancer-related knowledge, psychological adjustment to illness, and self-concept (Ferlic, Goldman, & Kennedy, 1979).

Coping skills intervention -Psychotherapy groups with a focus on coping skills and strategies are another avenue for enhancing AQ to cancer survivors. Researchers have stated that about one-third to one-half of cancer survivors will experience clinically significant levels of distress during the course of their illness, and coping skills groups are an effective means of treatment (Blake-Mortimer, et al, 2010). A particularly stressful component of cancer care is chemotherapy treatment and coping skills such as relaxation and stress management training have proven useful in managing anticipatory nausea (Faul, Jim, Williams, Loftus, & Jacobsen, 2010). Researchers hypothesized that pre-treatment coping skill level would reduce distress and increase AQ (Faul, Jim, Williams, Loftus, & Jacobsen, 2010).

Emotional Support intervention-It has been studied is the use of emotional support groups for cancer survivors and co-survivors (Goodwin, Leszcz, Ennis, & Koopmans, 2001). These groups can be professionally administered or led by a peer survivor; they can be closed and structured or open and unstructured; they can also be focused on informational support as opposed to emotional support. This can be done in a comprehensive review of discussion, education, and combining group interventions.

Psychotherapy intervention-Multiple reviews have shown that group psychotherapy, including cognitive-behavioral, informational, non-behavioral, social support, and using unusual treatments such as music and art therapy which are useful and beneficial in supporting cancer survivors throughout the trajectory of the illness (Uitterhoeve, et al., 2004).

Studies have shown that while majority of cancer survivors lead healthy, active lives, cancer can sometimes have long-term effects on the body, such as chronic pain, interrupted sleep patterns, weight loss and diminished quality of life. Pain dramatically affects the quality of life while disturbances in sleep patterns can lead to significant daytime tiredness (Berger, 2009). Disrupted sleep patterns are usually associated with aging, illness, situational stress and drug treatment (National Sleep Foundation, 2014). Research has shown that approximately one-third to one-half of people with cancer experience sleep disturbance (Savard& Morin, 2001).

Other factors that may disrupt the sleep patterns of cancer patients include physical illness, hospitalization, pain, drugs, the psychological impact of a malignant disease and other treatments for cancer (Berger, 2009). Poor sleep negatively affects performance and daytime mood.

Estimates by the National Cancer Institute (2010) indicate that nearly 45% of cancer patients' experiences sleep disturbances. While there exists psychological and physiological sources of sleep pattern disruption, research has shown that cancer patients are at a greater risk for physiologic disturbances (Berger, 2009). The most commonly reported symptoms of sleep disruption by cancer patients include: insomnia, excessive fatigue, excessive sleepiness and leg restlessness (Parish, 2009).

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Korstjens (2006) conducted a longitudinal study (n = 658) to address problems in a 12-week rehabilitation group program for cancer patients in the Netherlands. The study combined physical exercise and psycho-education. At baseline, participants reported a low quality of life, measured by sleep disturbances and high experience of pain. At the end of the 12 week rehabilitation, participants reported significant improvements on both variables: in experience of pain and sleep patterns. The findings of this study clearly indicate that the recovery outcomes among cancer patients is multifaceted, a situation the proposed research intends to investigate bearing in mind the different population characteristics. The study presented a methodological gap as it adopted a longitudinal research design while our current study will adopt a correlational research design.

Pain in cancer can be caused by the disease itself or by the treatments and is common in patients with cancer. Approximately 30% to 50% of people with cancer experience pain while undergoing treatment, and 70% to 90% of people with advanced cancer experience pain. (Lesarge and Portenoy, 1999)

A study by Adriaan (2013) at the University of Stellenbosh, South Africa to compare the experience of pain on cancer survivors' quality of life in a rehabilitation Programme employing behavioral, cognitive and self-management therapies, established that participants showed significant, clinically relevant reduction of pain. In physical functioning, he found vitality and health change. The researcher concluded that behavioral interventions did have beneficial effects on cancer survivors' quality of life. The study presented geographical gap as it was done in South Africa while our current study will be done in Kenya.

Hollingshaus and Rebecca (2015) observe that although diagnosis with a major chronic illness tends to weigh heavily on the patient's well-being. Little attention is paid to gender variations in mental health following diagnosis. To test how diagnosis with cancer affected the AQ over time, a sample of 12,271 older adults was utilized in the European Union. The study explored AQ variation and whether sex differences were accounted for. Results showed that while male patients reported higher AQ scores than female patients. Females generally reported more depressive symptoms than males, but the increase following diagnosis was smaller for females. The study presented geographical gap as it was done in European while our current study will be done in Kenya

Andrade, Muniz, Lange, Schwart, Echevarria and Guanilo (2010) conducted a descriptive cross-sectional study, with 264 Brazilian cancer survivors under medical assessment, data was collected through interviews. It was ascertained that the characterization of this population is relevant, because it will contribute to identifying factors which promote high resilience. The results indicated a higher level of resilience among the males (49.1%), while majority of women showed moderate resilience (45.9%). This finding with a study conducted in America in the Oncosinos/Hospital Regina in Novo Hamburgo-RS in 2007. In the study the researchers examined the degree of resilience of 418 oncology patients who were undertaking chemotherapy treatment. The study showed that female patients had lower resilience scores compared to their male counter parts. (De Silva, 2007).The study presented a conceptual gap as it examined the degree of resilience of 418 oncology patients who were undertaking chemotherapy treatment.while our current study sought to find out nature of recovery outcomes among cancer patients attending palliative care in Nairobi and Nyeri County

Cohen etal (2014) conducted an exploratory cross sectional study of 92 individuals aged between 27-87 years, diagnosed with colorectal cancer stage ii-iii, 1-5 years prior to enrollment in the study. Results found that older age men had less cancer related problems and this was associated with higher resilience and lower emotional distress. Findings were that there is better adjustment of older patients with cancer and increased professional support should be provided for patients with low resilience. The study presented a methodological gap as it adopted a exploratory cross sectional research design while our current study will adopt a correlational research design.

A study by De Silva (2007), which examined the resilience scores in a cohort of cancer patients undergoing chemotherapy, it was established that patients with high levels of resilience identified early in the treatment of cancer had more positive psychological and recovery outcomes. As Henselmans, Helgeson, Seltman, Vries, Sanderman, Ranchor (2010) report that during the first year of treatment for cancer, patients who reported no significant clinical distress exhibited higher levels of resilience compared to women who reported significant levels of distress. This suggests that cancer patients who have a higher level of resilience report less clinical distress which may indicate favorable recovery outcomes

METHODS AND PROCEDURES

This study adopted a correlational research design to establish challenges among cancer patients that may influence recovery outcomes in palliative care units in Nairobi and Nyeri Counties. Research was carried out at the three palliative care units in Nyeri and Nairobi Counties which are: Nyeri County Referral Hospital (CRH), Nairobi Hospice and Nyeri Hospice.The total target population for one month as per the data below was an estimated 637 patient's The areas were chosen as a research site because the government of Kenya plans to decentralize essential cancer management activities from Kenyatta National Hospital in Nairobi to Nyeri, Mombasa and Kisumu County referral hospitals so as to ease the cost of the disease for low income families. These regions were identified by the Ministry of Health as the regions with the highest prevalence of cancer (Mulemi, 2010).The study adopted a systematic random sampling technique. Systematic random sampling is a method that involves selecting subjects from a sampling frame in a systematic way rather than a random manner. Based on this every third person was selected from a list until the study attained a total of 96 participants.The study utilized a self-scoring questionnaire administered to the participants to collect data on establish challenges among cancer patients that may influence recovery outcomes in palliative care units in Nairobi and Nyeri Counties. The completed questionnaires were coded and the participants' responses scored and keyed into a computer data file. Descriptive statistics, namely; means, percentages and frequencies were used in the analysis. In addition inferential statistics, namely Pearson Moment Correlation Coefficient was applied to calculate the nature, power, and direction of the association between two continuous variables, namely the recovery outcomes and AQ.

RESULTS

This section presents the findings on objective two which sought to establish challenges among cancer patients that may influence recovery outcomes in palliative care units in Nairobi and Nyeri

Counties. Challenges encountered in palliative care were assessed with dimensions namely level their participation in the different programs in palliative care that ranged from group psychotherapy, social support groups, spiritual support and coping skills , challenges they faced while participating in the programs and challenges they experienced while participating in these programs, the findings were presented in percentages The findings are presented in the subsections that follow beginning with respondents' participation into different palliative care programs followed by perceived challenges that the respondents experienced

Respondents Participation in different Palliative Care Programs

In this section data is presented on respondents' participation into different palliative care programs in general using frequencies and percentages.

Table 1: Participation in different Palliative Care Programs

Program	Frequency	Percent
Group psychotherapy	77	91.7
Social support groups	64	76.2
Spiritual support	77	91.7
Coping skills	77	91.7
Others	19	22.6

From table 1, majority of the respondents indicated participating in the programs available at the palliative care institutions, which included; group psychotherapy (91.7%), spiritual support (91.7%) and programs on coping skills (91.7). Others (22.6%) participated in programs such as performing chorals, knitting and board games. The challenges were identified by providing a column in the questionnaire for the respondents to fill in their challenges in regard to the palliative care programs. .

Table 2 Respondents Perceived Challenges in Palliative care Programs

In this section data is presented on respondents' perceived challenges into different palliative care programs in general using frequencies and percentages

Challenge	Frequency	Percent
Coping with Cancer Illness	42	50.0
Financial support	66	78.6
Social Support	69	82.1
Spiritual support	63	75.0
Drug adherence	2	2.4

From table 2, 82.1% and 78.6% noted that they experienced challenges of being isolated and lacking finances respectively. 50% of the respondents had a challenge in coping with the condition, while 2.4% experienced challenges in adhering to drugs

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

Summary

Findings on the challenges that the respondents encountered in palliative care units was done in relation to the programs that was offered at the palliative care facilities established that majority of the respondents experienced challenges of being isolated and lacking finances respectively. The findings draw a similarity with the findings by Yeolekar & Mehta, (2008) which was conducted on challenges in a palliative care unit and identified pain and symptom control, psychological and spiritual support and identification of alternative sites as key challenges.

The study findings also agreed with Robert Lent (2004) Restorative Model of Well-Being theory which informed the study, that cognitive and behavioral coping strategies, personality variables, coping self-efficacy, and social support and resources determine the resolution of the problem and recovery of life satisfaction. The findings of the study are in agreement with Ferlic, Goldman, and Kennedy (1979) who proposed that going beyond the traditional support group was necessary to examine the patient’s adjustment to illness, communication, cancer-related knowledge, psychological adjustment to illness, and self-concept.

In the current study the respondents were appreciative of the counselling strategy of psychotherapy offered at the palliative units. The study findings revealed that cancer patients’ indicated that they benefited immensely during group therapy which caused them to find universality in response to cancer illness amongst themselves. The findings also concur with the findings by Blake-Mortimer, et al, (2010) which stated that about one-third to one-half of cancer survivors will experience clinically significant levels of distress during the course of their illness, and coping skills in the groups are an effective means of treatment.

In the study by Faul, Jim, Williams, Loftus, & Jacobsen, (2010) it was found that, a particularly stressful component of cancer care is chemotherapy treatment and coping skills such as relaxation and stress management training have proven useful in managing anticipatory nausea. This finding is consistent with the current study findings where respondents found coping skills to be important in managing the cancer disease since they go a long way in enhancing AQ and promoting higher levels of recovery outcomes.

Findings by Elsie (2017) also concluded that in Kenya, one of the major issues facing cancer patients is access to finances. Cancer diagnosis and treatment is quite expensive, therefore most patients in the lower earning class struggle to access medical and palliative care especially in Kenyatta National Hospital due to high costs. According to the findings most families have to change their lifestyles in order to redirect some of their finances to the patient’s treatment. The findings are also consistent with the findings by David C. Currow, Marie Fallon, Nathan Cherny, Russell K. Portenoy, and Stein KaasaIn (2015) that found that in the United States, many hospices are small and are forced to limit access or deny treatment with accepted palliative interventions because of the high cost factor which is a major challenge encountered in palliative care unit.

Conclusion

The study concluded that that the main challenges facing patients receiving palliative care were related to their economic background because the services and treatment are quite expensive and thus the patients feel isolated due to lack of finance.

Recommendation

The study recommended that the counsellor in collaboration with the administrators and medical staff in the palliative care units should create awareness and encourage the attending patients to source for a health insurance cover e.g. National Health Insurance Fund (NHIF) to cater for the cancer disease both outpatient and incase of hospitalization. This will ease the financial burden of cancer on the patient, family and community which was identified as a challenge

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