

KENYATTA UNIVERSITY

SCHOOL OF HUMANITIES AND SOCIAL SCIENCES

DEPARTMENT OF PSYCHOLOGY

**RELATIONSHIP BETWEEN COUNSELING INTERVENTION AND
PSYCHOLOGICAL WELL-BEING AMONG FAMILY CARE GIVERS OF CANCER
PATIENTS IN KIAMBU COUNTY**

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C50/CE/23825/2012

**A RESEARCH PROJECT SUBMITTED TO THE SCHOOL OF HUMANITIES AND
SOCIAL SCIENCES IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR
THE AWARD OF THE DEGREE OF MASTERS OF ARTS (COUNSELING
PSYCHOLOGY) OF KENYATTA UNIVERSITY**

SEPTEMBER 2018

DECLARATION

This Research is my original work and has not been presented for a degree in any other University or for any other award.

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

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This research has been submitted for review with my approval as university supervisor.

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ABSTRACT

Palliative care is an approach that is supposed to improve the quality of life of terminally ill patients and their families. However, much attention is paid to the patient than the family members who also suffer financial, emotional, social and spiritual effects due to illness. Family members not only experience psychological anguish and guilty due to effects of illness on their loved ones, but also affected by the demands of care giving. Whereas this is the case, few studies have focused on counseling interventions that can help the family care givers. The purpose of the study was to find out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. In order to achieve this purpose, family system theory guided the study. The study adopted a correlation research design. The target population was 600 family care givers who cared for terminally ill in palliative care unit. Purposive and systematic random sampling was used to select 96 family care givers identified by the cancer patient from Thika level 5 hospital, Kiambu level 5 hospital and Gatundu level 4 hospital. Three health care givers from each hospital participated in the study. Questionnaires were used to collect data. The study registered a response rate of 94% and an alpha test-retest reliability coefficient of 0.82 was obtained. The data was analyzed using descriptive and inferential statistics, namely Pearson Moment Correlation Coefficient(r), with the aid of SPSS version 22.0. The data was presented using graphs and tables. The study found that provision of counseling and any social support was essential in enhancing psychological well-being of family care givers of cancer patients. A weak positive correlation was found between psychological well-being and counseling intervention, but the correlation was not statistically significant ($r_s(90) = 0.135, p > 0.05$). Care giving role among the family caregivers was found to affect the psychological well-being of family caregivers. The study also found that the health care givers did not have any professional training in the provision of counseling services that were essential in the provision of quality care in palliative care context. The researcher recommends that the primary care givers should be provided with professional counseling, basic care giving, training and social support. The findings of this study may be helpful in formulating appropriate counseling interventions by Policy Makers, Ministry of Health, Counselors, Hospices and stakeholders who work with terminally ill persons. The family care givers themselves may also benefit from the data generated in this research with regards to self-care.

DEDICATION

This study is dedicated to the Almighty, through whom everything has been possible, my wife, Sarah Mbithe, my son Joel Njoroge and baby Njeri. I thank them for their endless support and patience whenever I gave my studies priority over them. I appreciate my friends and colleagues for their invaluable support and encouragement. May God bless them abundantly.

ACKNOWLEDGEMENT

I wish to express my gratitude to my Creator for giving me the opportunity and strength to pursue this study which has really changed my life.

I am sincerely grateful to my supervisor Dr. John Oteyo for his encouragement, dedication; effort, expert knowledge, constructive criticism and above all his patience were all that I needed to move on. May God bless you. I cannot forget contributions made by all the lecturers who taught me during my course work.

I sincerely appreciate the tireless efforts of the administration and staff of Thika level 5 hospital, Kiambu level 5 hospital and Gatundu level 4 hospital for their support in enabling me carryout my research. I appreciate also the family caregivers of cancer patients who willingly contributed by giving the required information to accomplish this study.

Special thanks to my wife, Sarah, Joel and baby Njeri for your prayers and support during this academic journey. My success is theirs. Once more, God bless you all.

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ABBREVIATIONS & ACRONYMS

AIDS:	Acquired Immune Deficiency Syndrome
GOK:	Government of Kenya.
HIV:	Human Immunodeficiency Virus
KEHPCA:	Kenya Hospices and Palliative Care Association
KEMRI:	Kenya Medical Research Institute
KU-ERC:	Kenyatta University Ethical & Research Committee
MOH:	Ministry of Health
NACOSTI:	National Commission of Science Technology & Innovations
SPSS:	Statistical Package for the Social Science
TB:	Tuberculosis
WHO:	World Health Organization

DEFINITION OF TERMS

- Cancer Patient:** Is a person who is receiving palliative care from a family care giver and health care giver due to a tumor or malignant growth in his or her body.
- Caregiver burden:** It is the degree, to which the family caregiver has suffered socially, emotionally, physically and financially.
- Care giving Role:** Any task or activity that is done by a family member to the cancer patient with an aim of making his life comfortable.
- Challenges:** Problems faced by family care givers and health care givers in providing Palliative care.
- Counseling:** A process of helping an individual to make good adjustment, developing towards maturity by providing him or her with new knowledge and skills that will guide his adjustment.
- Counseling Intervention:** Identified services that care givers are given either individually or in a group in palliative care unit.
- Direct Care:** Is supporting the cancer patient in activities of daily living consistently
- End of life:** The period when it has become obvious that death is unavoidable.
- Family Caregiver:** A family member identified by a cancer patient as the key person who provides direct or indirect care to them for more than a month.
- Family member:** This is a person related to the cancer patient through blood, marriage and adoption.
- Health Care Giver:** A health professional providing palliative care.
- Indirect Care:** This is supporting the cancer patient through the main family care giver.

- Intervention:** Any action or activity that would help the family care givers and health caregivers to provide quality care in palliative care context.
- Palliative Care:** An approach meant to improve the quality of life of patients and their families facing terminal illness.
- Palliative Care Unit:** A health care unit which provides specialized palliative care.
- Psychological Well-being:** An Individual meaningful engagement in life, self-satisfaction, optimal psychological functioning and development at one's true highest potential.
- Terminal illness:** It's an illness which is not cured and will cause death to the patient.

CHAPTER ONE

1.1 Background to the Study

According to World Health Organization (WHO, 2002) palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness? Cancer is causing 13% of all deaths worldwide, which is more than deaths caused by HIV/AIDs, TB and Malaria combined (WHO, 2002). A study that was done by Carpenter (2006) among 260 participants, established that cancer led to increased psychological anxiety and anguish. Cancer burden is expected to increase in Africa, due to aging and growth of population and prevalence of risk factors associated with economic transitions like physical inactivity and smoking (Jemal, Bray, Forman, O'Brien, Ferlay, Center, & Parkin, 2012). Globally, in 2012, 14 million new cases of cancer were reported while in Africa about 715,000 new cases of cancer were reported. According to KEMRI, (2014) about 39,000 cases of cancer are reported annually in Kenya. Moreover, cancer being the third killer disease, is threatening to be unstoppable if nothing is done (Brien & Day, 2012).

A family caregiver is a family member who is giving care to a patient. He could be the spouse, uncle, aunt or the parents of the ill person. In many communities, when a family member is ill, the relatives come together to provide care to their loved ones. Care giving has shifted from hospital and many patients prefer to be at home, hence, the care giving role has been left to the family of the patient (Groves, Dahl, Moum, & Fossa, 2005).

Caregivers have an important role in dealing with the needs of their loved ones who are terminally ill, starting from diagnosis, treatment and often times to death (Northouse, Katapodi, Song, Zhang, & Mood, 2010). Hudson & Aranda, Hayman, (2005) found that care giving brings

positive outcomes despite its negative outcomes. Despite the family care givers knowing that they need to seek for professional help, they were reluctant as they prioritized the needs of the patients(Carolan, Smith, & Forbat, 2015).

A study that was done in America on objective burden, resources and other stressors on caregivers stated that one in four caregivers reported having low confidence in the quality of care they provided (Van Ryn, Sanders, Kahn, van Houtven, Griffin, Martin, & Rowland, 2011). Family caregivers have traditionally provided assistance with bathing, dressing, eating, and household tasks such as shopping and managing finances. While these remain critically important to the well-being of a care recipient, the role of family caregivers has dramatically expanded to include performing nursing tasks which were provided only in hospitals. Due to lack of professional training in nursing the patient at home feel disappointed and distressed especially when they find that they are unable to provide quality care (Reinhard, 2012).

In providing terminal care, the family care givers experience psychological effects but great emphasis is given to the patient by the palliative health workers. Family caregivers are often the sole caregivers to their loved ones, thus the physical, mental, and emotional well-being of the family caregiver impacts how they provide care. As events from one stage of life influence later stages, it is important to note that lack of appropriate and timely family support and resources can dramatically impact the life course of each family member (Reinhard (2012). A study that was done by Tunin and Uziely (2010) the family care givers were not able to provide quality care as they were not trained and lacked any professional support. A caregiver who lacks adequate resources and knowledge in caring for his or her loved one fails to be autonomous and not able to make any decision concerning the patient. Therefore, with psychological and

emotional support, the family caregiver is able to master his environment as well as establish good relations with others (Bevan & Pecchioni, 2008).

Care giving can bring forth negative and positive effects on the caregivers. Positive effects are positive emotions and expression of love on the patient, while negative effects are psychological, physical and social issues which can lead to secondary stress in domains such as relationship issues, work and financial issues (Nijboer, et al., 1999). Caring for a cancer patient is a stressful event due to the chronic aspect of cancer especially from diagnosis, treatment procedures after diagnosis, and side effects of the disease as well as psychological effects of the anticipating death. A study by Northouse (1988) revealed that the patients and their caregivers have higher levels of psychological distress as compared to the general population and they did not differ much in their levels of distress. Care giving interferes with the caregiver's ability to engage himself or herself in activities like work, social outings and recreation. These disrupts the lifestyle of the caregiver which result to emotional distress(Cameron, et al.2002). Caregivers are frustrated by not having useful health information to help their patients which make them feel inadequate in helping their loved ones as it leads to lack of sleep, and worry over the patient's well-being adding to caregiver's stress (Bevan & Pecchioni, 2008). Psychological distress and morbidity have been demonstrated in informal caregivers of palliative patients. In addition, stress may be experienced by having to stand by and observe the disease progress as they are unable to change the situation of the illness (Carolan, Smith, & Forbat, 2015).

Psychological well-being is all about the life of an individual going well. It is a combination of functioning effectively as well as feeling good (Girum, 2012). A sustainable well-being does not require an individual to function well all the time. Feeling some pain at times is normal in life, and being able to overcome the negative effects is important for a long-term psychological well-

being (Dzuka and Dalbert, 2000). However, psychological well-being is mostly compromised when extreme or long lasting emotions interfere with a person's ability to do his daily duties (Huppert, 2009). From this perspective, the psychological well-being of a family care giver is affected by the care giving role. At times, they are unable to speak or seek professional help when faced with negative emotions but rather keep quiet (Coristine 2007). Therefore; there is a need to find out how the family care givers cope with their role as most of the time they are close to their loved one who is terminally ill.

Despite the psychological impact of caring, most caregivers do not seek help. According to Vanderwerker, et al., (2005) in his study with caregivers of cancer patients, almost half of the caregivers who met the diagnostic criteria of psychiatric condition did not seek help. Payne, Smith & Dean, (1999) asserted that for the caregivers to maintain their involvement in caring for the patient, they should be supported. That is why this current study aimed at finding out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County.

Higginson et al (1990) in his study of the views of patients and their families regarding palliative care concluded that the needs of the caregivers may exceed those of the patients. Terminal illness interferes with the family usual activities in caring for a cancer patient, leading to role burden. Balancing one's family roles and other roles expectations associated with palliative care of cancer patient is very challenging to the sole caregiver (Van Ryn, et al., 2011). According to the Ministry of Health (MOH, 2013) in Kenya, family caregivers should be supported in order to ease care giving effects. However, their needs continue to be overlooked as the needs of the patients are prioritized (Reinhard, 2012).

According to Glajchen (2003), family caregivers assume the role of care giving in sudden and extreme circumstances. However, they are burdened as they are not well prepared. These findings point the need of implementing necessary interventions which may mediate negative outcomes which may emanate from providing palliative care at home. As the illness progresses, the caregiver's needs increases such as domestic help, fatigue, financial strains, anxiety, informal support, isolation and information (Harding & Higginson, 2003). In Kenya the cost of treatment of cancer is very expensive. Patients from poor backgrounds get their treatment at Kenyatta National hospital (KNH) which is the cheapest compared to others but with few resources. Patients from rich families get their treatment from private hospitals in the country or abroad where there are better facilities (Kilonzo, 2015).

Despite the Government of Kenya being aware of the effects of care giving role on the family care givers, the health care system has not incorporated family care for patients at home. Moreover, there are few documents on effective ways of guiding family caregivers. If caregivers are well informed and supported while giving care, they would be less anxious and would provide quality care to their loved ones (Given, Charles &Kozachik, 2001). The aim of support is to enable the caregiver to maintain the patient's comfort and quality of life as well as minimize their distress (Nabudere, Obuku, & Lamorde, 2013).

Although, the support interventions are useful in helping the caregivers, they are delivered by highly trained professionals making them very expensive in accessing them especially from rural areas (Girgis, Lambert, Johnson, & Waller, 2013). Counseling for caregivers enhances coping, problem solving abilities, self-esteem, and sense of control and decreasing emotional distress when providing care at home. However, many clinical settings do not include such services (Given, Charles & Kozachik, 2001). According to Proot and Abu-saad, (2003) the challenges

that are experienced by family care givers are many and they require a professional to handle them. These findings point the need of educating and training the care givers concerning the vulnerable position of the terminally ill.

Studies support that cancer affects patients as well as their significant others (Turner-Cobb, 2000). The family is gradually replacing the professional health worker in providing unfamiliar care to the ill person. The psychological processes which is essential in helping the care givers to maintain their sense of well-being is destabilized by their role burden. Therefore, it becomes difficult for them to be independent, have a positive relation with others as well as master their environment (Lent 2004). According to Given et al., (2001) if the family caregivers are informed and psychologically supported they would have a positive psychological well being. Despite, the evidence of the psychological effects of care giving on the family care giver, there is inadequate data on effective counseling interventions to curb these effects and do not seek counseling services as the needs of the patients comes first (Northouse et al., 2010), hence the current study set out to establish the relationship between counseling intervention and psychological well-being of family care givers.

1.2 Statement of the Problem

Families in Kenya are facing worsening Cancer scenarios as it is ranked third in causing death (KEMRI, 2014). In the effort to deal with the epidemic, the MOH in collaboration with other partners have put effort in introducing palliative care in order to help the family care givers and their loved ones who are terminally ill (Brien & Day, 2012). According to Kenya News Agency (2017) cancer is the highest killer disease in Kiambu County. Family care givers experience physical, psychological, social, spiritual and financial challenges once their loved ones are diagnosed with cancer and as they take care of them. Family care givers are expected to focus on

the needs of the cancer patients, be available, and provide nursing tasks to them (Haley et al., 2003). Majority of the family care givers are not trained and prepared to carryout care giving role thus, leading to overstraining, helplessness as well as lack of opportunity to complain, therefore suffering silently (Ferrell, et al.,1998).

Although the care giving role is stressful, some care givers cope well and tolerate the care giving burden. However, some find the care giving role to be emotionally challenging and they are unable to cope thus, being unable to provide quality care to their loved ones (Lambert, et al., 2013). Despite the expansion of palliative care services in the hospitals in Kiambu County, including palliative counseling and family therapy, the family care givers have increased responsibility for cancer patient and this care has detrimental effects on their psychological well-being since they are reluctant to share their issues as they do not want to be seen as if they are complaining (Hudson et al., 2013). Despite the studies indicating that counseling services help in mitigating the psychological distress of the family caregivers, there is scarcity of literature on counseling intervention among family care givers of cancer patients, and its relationship to recovery of their psychological well-being. Therefore, this prompted the need to find out the role that counseling intervention might play on the burden of care giving role among the family caregivers' psychological well-being in Kenya and particularly in Kiambu County.

1.3 Purpose of the Study

The purpose of the study was to find out the relationship between counseling intervention and psychological well-being of family care givers of cancer patients in Kiambu County.

1.4 Objectives of the Study

The main objectives of this study were:

- i. To determine the psychological well-being of the family care givers of cancer patients
- ii. To establish how care giving role affect the psychological well-being of family care givers of cancer patients.
- iii. To establish the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in the provision of palliative care.
- iv. To investigate the challenges that affect the provision of counseling services among the family care givers in palliative care context.
- v. To find out the intervention measures to deal with the challenges that affect the provision of counseling services among the family care givers in palliative care context.

1.5 Research Questions.

The following were the research questions for the study.

- i. What is the psychological well-being of the family care givers of cancer patients?
- ii. How does care giving role affect the psychological well-being of family care givers of cancer patient?
- iii. What is the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in the provision of palliative care?
- iv. What are the challenges that affect the provision of counseling services among the family care givers in palliative care context?
- v. What intervention measures can help in dealing with the challenges that affect the provision of counseling services among family care givers in palliative care context?

1.6 Justification and Significance

The study was of great interest to the researcher as it sought to find out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. Care giving role affect the psychological adjustment of family care givers and increase as the patient's level of performance decreases. Care givers assume the role of care giving without any prior preparation and training, thus being unable to provide quality care. With the increasing number of cancer cases in Kenya, family care givers have little to offer as they lack professional support and training. Even though the Government of Kenya is decentralizing the treatment of cancer from Kenyatta National Hospital, few studies have been done on the relationship between psychological well-being and counseling intervention; therefore, more research is needed in order to address and identify how the family care giver's psychological well-being was affected by their role in order to suggest suitable counseling interventions that may help them provide quality care to their loved ones.

The study may be instrumental in suggesting areas concerning counseling that are not effectively conducted with an aim of improving the counseling services in addressing the primary caregiver's needs in hospitals in Kiambu County. The findings of the study may also be useful to the Ministry of Health in ensuring that every hospice and palliative care unit has a professional palliative counselor.

The findings of the study were anticipated to be useful to the palliative counselors, health institutions, palliative care associations, hospice agencies, Ministry of Public Health, policy-makers, and universities offering counseling courses, KEHPCA, stakeholders in health, professional counselors, terminally ill patients and their families, researchers and curriculum

planners in medical field. The findings and recommendations may help the policy makers to formulate proper policies related to counseling interventions in helping the family caregivers.

The study may help the counselors to develop interest in researching for further information on how to deal with issues affecting family care givers. The study may add more knowledge which may be more useful to present and future scholars.

1.7 Scope and Limitations

The following were the limitations of the study:

The study was done in palliative care units in Thika level 5 hospital, Kiambu level 4 hospital and Gatundu level 4 hospital in Kiambu County, Kenya. The study focused on the relationship between the counseling intervention and psychological well-being. The study used a co relational research design which sought to establish the relationship between counseling intervention and psychological well-being. The researcher could therefore make conclusions on the relationship of the two variables.

The study was limited as it only covered Kiambu County. Therefore the findings could only be generalized to other populations with caution due to the specific characteristics of Kiambu County that may be different for other counties.

The study targeted the family care givers who were 18 years and above in both sexes who had provided care to a cancer patient for more than a month. Those who were below 18 years were excluded as the researcher perceived that they required different approaches in mitigating their psychological issues.

1.8 Assumptions of the Study

The study was carried out with the assumptions that;

- i. The family care giver's psychological well-being was affected while providing palliative care.
- ii. There would be family care givers available in the palliative care unit who would be willing to participate in the study.
- iii. The family care givers would give bias-free, honest as well as accurate information.
- iv. The palliative care units would be willing to assist for the study to be carried out in their hospital.
- v. The health workers in palliative care units would explore various counseling interventions that would be used to support family care givers while taking care of their loved ones.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter contains a review of literature on finding out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. The chapter has two major sections. The first section begins by examining the theoretical framework of the study. The second section has a review of related literature according to the study objectives, a summary of the literature review and a conceptual framework

2.2 Theoretical Frame Work

There are different theories that explain the psychological effects experienced by family care givers while caring for their loved ones. This study was guided by family system theory as it explains human behavior in various environments.

2.2.1 Family System Theory

Family system theory was developed by Bowen (1913-1990). Bowenian theory helped in understanding the impact of terminal illness on the family. A family is a system with interrelated elements, which show similar behaviors, regular interactions and are interdependent to one another. A change in one area of the system affects the rest of the system. Bowen views a family as emotional unit. In a family, the members are emotionally connected; they influence each other's thoughts, emotions, feeling and actions. The connection within the family provides each member with approval, support and attention from one another. Thus, within the system, if one

family member has a problem, the whole family system is interfered. Most of the time disease management is done in a family. Every member of a family is aware that any disease especially cancer affects the whole family in various ways. These means, great value is not placed on the patient only but also to other members of the family. In a family where everybody is supporting each other and are free to express to one other, maintain a sense of connection and adapt to changes that affect the family (Aoun, 2005).

Terminal illness has significant and enduring effects on psychological, social and financial well-being of the family care givers. Family system theory specifies that a change in one part of the system affects the rest of the system. Some families have closed and rigid boundaries, while others have diffuse and open boundaries. Families with rigid boundaries function in a non-adaptive and isolated manner. Families with diffuse boundaries have little identity, function chaotically and have little sense of connection with each other. Families that are able to support one another and allow each other to express their individuality are able to adapt to changes that affect the family system (Kristjanson, & Aoun, 2004). When caring for a cancer patient, the family members should be incorporated in the treatment process. According to family system approach, cancer can be considered as an experience that brings the whole family together; every family member is interdependent on each other in coping with the illness (Gritti, 2012).

Family connection which is a tenet of family system emphasis that a family care givers, like a cancer patient need to be supported and cherished(Simpson & Rholes, 2015).The basis of the need to care for the family care givers is an attachment circuit that is In the brain of all human beings. Moreover, it motivates the desire for emotional support (Mikulincer &Shaver, 2007).The cancer patients who receives care giving from other family members that are empathetic as well as responsive to their needs; develop internal working models that enhance autonomy and

positive relationship with others. With support and security comes optimism in one's life. In addition, higher levels of care giving (closeness, caring and affection) leads to higher self esteem, better psychological adjustment and more social competence. In a family characterized by negative family connection process leads to mistrust, rejection and neglect of the loved ones (George & Solomon, 1999).

Family individuation is important for the whole system to operate in a secure manner. The family care givers needs to be nurtured and cherished. When the family care givers are emotionally supported they become effective In their role as well as autonomous (Barber & Schluteman, 2008).An individuated family system that has interpersonal boundaries, the members think and speak for themselves, are encouraged, and are ready to accept other family member's differences thus directing all their efforts towards mastering their environment as well as developing their capacity for an autonomous action (Coontz, 2015). In case of a negative individuation, there is no comfort, thus leading to a less accurate interpersonal perception. In this particular environment, it becomes difficult for the family care giver to become differentiated self or develop a sense of personal autonomy (Bell, & Bell, 2009).

According to Bowen (1978) the main driving force for every family is the anxiety of balancing of the connectedness and separateness among the family members. In this perspective, the differentiation of self guides the essential strategies that help in regulating the emotional distance of the family members. If the family caregiver is able to exert his own autonomy while caring for the cancer patient, then the family system is maintained (Kristjanson, & Aoun, 2004). The low ends of differentiation of self in a family lead to tension, emotional cut-off, triangulation and conflict between family members (Bowen, 1978). A study that was done by Krycak, Murdock & Marszalek, (2012), an individual who had lower levels of differentiation, experience higher

levels of psychological distress as well as daily stress. Since differentiation is linked with psychological adjustment, self-control and well being, it is essential to provide emotional support to a family care giver. From this perspective, differentiation of self should be maintained in order to improve the care givers relational well-being and better functioning in their role (Lampis, 2016). Therefore, through the family support and the provision of effective counseling intervention, a family care giver should not experience emotional cut-off and reactivity in providing their quality care (Wei, Vigel, Ku, & Zakalik, 2005).

The purpose of counseling is to help the family care givers to understand the problem as well as acknowledge the fear and anxiety of mourning that can affect their capacity to face the challenge that they have to cope with. When diagnosed with cancer, it causes distress. However, the patient is never alone; his family also experiences the psychological effects of the disease to the patient. The system theory describes how the patient and the family's daily life are interconnected. The family caregiver takes the care giving role as they deal with symptom management and frequent hospitalization. Even though he or she does not take the care giving role he or she may be needed to adjust when a family member has a terminal illness as they are affected emotionally, behaviorally, cognitively and being forced to change their daily routines, future plans, and meaning and feelings of self (Mehta, Cohen, & Chan, 2009). Additionally, when a family a member is diagnosed with cancer, the homeostasis of the family system is interfered and the force of individuality and togetherness may conflict. For example, a member may stop working in order to have enough time to take care of the ill member. Moreover, the elder child may assume the role of a parent. Therefore, there was a need not only to concentrate on the cancer patients but also the family members as a whole with suitable interventions (Sherman, & Simonton, 1999).

2.3 Review of Empirical Studies

The following section reviewed the related studies in the following subtopics: Meaning of psychological well-being, components of psychological well-being, how care giving role Affect the psychological well-being of family care givers and counseling intervention.

2.3.1 Psychological Well-being of Family Care Givers

There is no consensus on the definition of the psychological well-being. Yet, many research and theories have been done using this construct. Thus, scholars and psychologist have found the concept of psychological well-being to be complex, but it serves as an umbrella for many constructs to assess the psychological functioning of an individual (Girum, 2012). Psychological well-being is about an individual living well. It's a combination of an individual functioning well and feeling good. Experience of negative emotions is part of life and being able to manage these painful emotions is important for a long time well-being. However, psychological well-being is compromised by negative emotions that are felt for a long time, and those that are extreme, thus hindering an individual from functioning properly in his daily life (Huppert, 2009). Deci and Ryan (2008) defined Psychological well-being as living in a deep satisfying life. This concept maintains that a person should actualize his potential in whatever he or she does.

According to Ryff (1989) Psychological well-being has six components: Environmental mastery, autonomy, positive relations with others, personal growth, purpose in life and self-acceptance. He further says that a person who has a purpose in life is able to function normally. Having a purpose in life means having a sense of direction and meaning I one's life. For a person to function positively he or she should have intentions and goals. If a person is able to understand his life's purpose and intentionality he or she will feel that there is meaning and purpose in life.

If the family care giver is able to function normally, he or she will feel that he has purpose to his life and that loved of his loved one, thus providing quality care (Hudson, 2003).

Ryff discussed environmental mastery as the ability to create a suitable environment that a person is living. Every individual should participate actively in the mastery of the environment they are living to enable themselves to have positive psychological functioning. The demands of life, requires an individual to manipulate as well as control any complex environment and advance to change it creatively through mental or physical activities. Participating actively and in mastering the environment is essential in developing a positive psychological functioning (Ryff, 1989). A study that was done by Elnagar, & El Gahsh, (2017) found that as the duration of care increased the feeling of being burden as well increased. This study indicates that the psychological well being of family care givers was affected negatively as they were unable to cope any longer.

Ryff discussed autonomy as being self-determined to do whatever he or she a person wants, and cannot be controlled by agencies outside their control. Any perception of lack of control, of a certain situation produces a feeling of despair and individual's will power is diminished (Tsihoaane, 2006). Ryff (1989) equated autonomy with attributes such as internal locus of control, self-determination, independence and individuation. A fully functioning person does not need other people to approve his or her actions, but he or she is able to elevate his own standards. The family care givers are at risk of being confronted with negative psychological changes, in which they are unable to control. As the situation of the patient continues to deteriorates, the family care givers psychological well-being as they develop a feeling of hopelessness, helplessness and they do not have the power to also control their lives (Coristine, Janz and Glossop, 2004). Similarly, Tsihoaane (2006) found that, family caregiver's distress increased

after they realized the situation under their control was out of their hand. Also, Mirsoleymani, Rohani, Matbouei, Nasiri, & Vasli, ((2017) found that family care givers were overwhelmed by their role as they were distressed after realizing that their loved one was not recovering. From this result, it indicates that family care givers lost their autonomy as they did not have any control as the illness of their loved one progressed. Therefore, it is essential to find out how the psychological well-being of family care givers are affected as they provide care.

Ryff (1989) refers positive relations with others as trusting personal relationship, warm and having feeling of affection and empathy. The central component of mental health is having greater love and deeper friendship with others. Self actualizers have strong feelings of affection and empathy for others as they possess deeper friendship, love and identify with others. Warm relating is a sign of maturity (Ryff,1989).The family care givers who are not able to have a supportive relationship with their loved ones as well as being unable to have new components, risk in developing poor psychological well-being(Hudson, 2003). Similarly, Kim, & Shin, (2017) found that lack of any family support, led to a distressed care giver. This implies lack of any support, affects the family care givers as they did do a lot in changing the situation of their loved

According to Ryff (1989) having personal growth refers to being able to develop their potential, expand and grow as a person. Any individual who is open to experience will function well and develop himself than a person who is not open to any experience. A study that was done by Yeh, Wierenga, & Yuan, 2009) in Taiwan revealed that family caregiver who did not find their role helpful to them their psychological well being was affected.

According to Ryff (1989) a person who is positive about himself or herself functions positively. Self-acceptance is the central characteristic of optimal functioning, self-actualization and maturity. A study that was done by Northouse, et al., (2012) found that family caregivers lacked

positive attitude towards their role as they were distressed as the phases of cancer varied. Similarly, a study that was done among 139 family care givers by Kim, & Shin, (2017) in Korea found that their self-esteem was highly affected by seeing the conditions of their loved ones deteriorating at home.

2.3.2 Effects of Care Giving Role on Psychological Well-Being of Family Care Givers

Caring for a cancer patient at home is a stressful experience to their family care givers. Patients' depression and the progress of the disease influence the psychological and emotional aspect of the care giver. The remaining concern is that, some care givers are able to cope while others are not able to cope under the same situation (Nijboer, et al, 2001). Caring for a cancer patient has a psychological implication on the family members. The only way of alleviating the distress is to ensure that they are supported by the health care givers. However, many studies indicate that the family care givers have unmet needs, despite the input of the health care professionals since the usual approaches to the carers are not sufficient (Hudson, Aranda, & Kristjanson, 2004). As the patient illness progresses, there is an increasing involvement and more care demands are left on the informal caregivers which leads to anxiety and depression (Dumont, et al, 2006). If family care givers are supported and informed on their care giving role, they would be less anxious and would provide quality care to the ill patient (Given et al., 2001). However, they are reluctant to share their issues with any one as they do not wish to be seen to be complaining about their loved one (Payne et al., 1999).

Care giving affects the psychological adjustment of the family caregivers as well as increasing their care giving burden (Weitzer, McMillan & Jacobsen, 1999). A study that was done in United Kingdom by (Dumont *et al*, 2006) on 212 caregivers for caring for their loved ones with

advanced cancer found that psychological distress of family caregivers increased according to the deterioration of the patient performance status. Despite the level of depression, care givers rarely make use of any mental health services in mitigating their emotional distress (Northouse, et al., 2010). Some patients and caregivers do not access specialist services because of the emotional difficulties in discussing death and dying (Girgis, Lambert, Johnson, Waller, & Currow, 2013).

Grunfeld & Coyle (2004) found that caregivers experience substantial depression and stress at the patient diagnosis and it increased when the patient reached the advanced stage of the illness, showing that the caregiver's distress was greater or equal to that of the patient. However, the family care givers were reluctant to disclose their issues to the health care providers, because they did not want to put their needs first before the patient's needs. Moreover, they believed that distress was inevitable and could not be improved (Ramirez, Addington-Hall & Richard, 1998).

High levels of anxiety in palliative care are related to concerns about fear of loss and being alone, coping with the situation, concern about the future. These factors may be seen as stressors influencing the caring situation. (Groves et al, 2005). Studies have revealed that an intervention like group intervention may lead to understanding and knowledge of coping, adjusting to the caring role (Okamoto, Wright, & Foster, 2012). Despite the interventions that were directed to the family care givers being acceptable and applicable, it was difficult to conclude that they were accessible to the family care givers (Hudson, et al. 2012). Studies have shown that coping skills are effective in alleviating the psychological needs of the care givers, However, they are unsustainable and costly (Lambert, et al. 2013). These findings suggest that counseling intervention are essential to the family care givers, but they are costly and that is why the current

study seeks to find out the intervention that are essential in helping the family care givers cope with their role so that they can provide quality care to their loves ones who are terminally ill.

The health care system has not fully incorporated intervention for patients. Moreover, there are few intervention strategies to help the family care giver of cancer patients. Given, et al., (2003) mentioned that when providing palliative care, families give new meaning to the disease and its consequences in light of their religious and spiritual beliefs and thus help alleviate their suffering. They do so as a way of coping and finding a meaning to the anticipated loss. According to Payne et al. (1999) there is need to develop appropriate ways of offering psychological support to the family care giver so that they can sustain their care giving role as well as maintaining their psychological well-being.

2.3.3. Relationship between Counseling Intervention and Psychological Well-Being of Family Care Givers

Family care givers take care of cancer patient without any prior preparation and training. Due to the demands of their role, they are affected psychologically. If family care givers do not seek for help, they developed psychological effects that have an effect on their well-being (Kotkamp-Mothes, Slawinsky, Hindermann, & Strauss, (2005). A Study that was done by Northouse, Katapodi, Schafenacker, & Weiss, 2012), revealed that there is a reciprocal relationship between evidence-based interventions and psychological well-being. These interventions reduce anxiety and distress that is associated with care giving role. From this study, it is clear that the family care giver's psychological well-being improves when they are engaged in counseling interventions. Similarly, Northouse, Katapodi, Song, Zhang, & Mood, (2010), found that interventions that are targeted to care givers of cancer patient, positively affect their psychological well-being thus being able to continue providing quality care to their loved ones.

The family care givers who did not receive any counseling interventions, their psychological well-being were affected. A study that was done by Haley, (2003), found that a family care giver who did not receive any psychological assistance; they were distressed, as they were unable to change the situation of their loved one. A similar study found that, family care givers who did not seek any help from a therapist, they were not able to make wise decisions or engage in a satisfying event (Girgis, Lambert, Johnson, Waller, & Currow, 2012). Similarly, a study that was done among family care giver of colorectal cancer patients, found that, family care givers were distressed as they did not receive any professional help from a counselor. It is clear from the literature reviewed that family care givers who received care were able to provide quality care to their loves ones. However, the situation was not the same to those who did not get any care as they were distressed.

2.3.4. Challenges That Affect the Provision of Counseling Services to the Family Care

Givers

Palliative care is a new phenomenon in the modern world. The majority of the patients and their families suffer physically, psychological and socially. Lack of care to the family care givers make them succumb to social, emotional and psychological effects as they are unable to cope with their role. The family care givers who did not receive palliative care from a profession suffer and are burdened by their role (Northouse, et al., 2010).

Health care givers acknowledge that providing care to the family members as well as the patients is an enormous challenge. Family caregivers, as care recipient of palliative care continue to have unmet needs (Hudson, et al, 2012). Although family care givers provide long-term care to a person suffering from cancer, they receive little information; preparation and support to enable them provide quality care to their loved one. According to WHO (2014) about 29 million people

die due to cancer-related complications and new cases continue to be experienced. This implies that care giver's roles have increased drastically because of caring for a cancer patient at home, where there are inadequate health care resources and health care providers. Family care givers are only involved in limited interventions, because the majority of the programs are meant for the cancer patient (Northouse, et al., 2010).

Family caregivers of cancer patients receive little support from specialists and from patient themselves (Zwahlen, Hagenbuch, Jenewein Carley & Buchi, 2011). A study that was done in China by (Cui & Song, 2014) on needs of family caregivers of advanced cancer patient who were hospitalized found that they had high unmet needs. These needs included needs of knowledge on the disease, treatment and support from health professionals, burden of paying for the treatment, work status of the caregiver, former care giving experience and length of care giving Payne et al. (1999) in their combined qualitative and quantitative study in New York reported that primary caregivers often felt reluctant to share their concerns with friends as they did not wish to be seen as complaining about the patient. Thus, they appeared to be relatively isolated in terms of emotional support (Given et al, 2001). Therefore, it was essential to study how the family care givers coped with the psychological effects of care giving as the psychological and emotional support in palliative care unit was only geared at the patients only.

The study of counseling services in palliative care unit is essential as family caregivers requires a professional support despite their reluctance to share their feelings with the palliative nurses. In a study that was done In Israel by (Tunin & Uziely 2010), found that information needs were ranked higher than the support needs and the caregivers preferred the doctor to help them. In addition, health professionals referred all emotional issues to social workers. Thus, it is important to have multidisciplinary approach in helping caregivers of cancer patients especially counseling

interventions. A study that was done by (Teno, et al.2015) on the need to improve the quality of end-of-life cares stated that families reported that health professionals were likely to discuss spiritual concerns in 2011-2013 than the year 2000. Caregivers experience a wide range of challenges, psychological effects, social and cultural issues surrounding death and dying. As the health of the patient worsens the family caregiver is required to continue providing care as well as preparing for impending death (Cameron, et al. 2004). The studies reviewed shows that effective interventions are underdeveloped hence the caring interventions needs more study (Hudson, et al. 2013). Moreover, relatives are often reluctant to disclose their worries, or seek help, fearing this might detract from the patient's needs (Foster, et al. 2015). From the reviewed literature, it's evident that family caregivers have not been accessing professional counseling services as priority was on the cancer patient. It is the high time that the family care givers receive professional help as well as being engaged in support programs as they require counseling services to help them adjust and cope in the provision of quality care.

2.3.5. Interventions Measures to Deal with the Challenges

Counseling is important to caregivers of cancer patients as it helps them develop self-understanding, growth and emotional acceptance. It helps them make good decisions and develop coping skills as well as coming into terms with their feelings and inner conflicts. Family care givers are only involved in limited interventions, because the majority of the programs are meant for the cancer patient (Northouse, et al., 2010). Since the majority of the supportive programs are meant for the cancer patients, it is the high time that the family care givers are incorporated to the same programs as they experience psychological issues that hinder them from providing quality care. Any support from the health care giver would help the family care givers to respond to their care demands positively (Given et al., (2001). According to Hudson (2004)

health care giver's support to the family care givers is a core tenet of palliative care philosophy. Family care givers are the sole source of support to cancer patients and they experience various challenges due to little or no preparations. A study that was done by (McMillan, 2006) on 354 family caregivers of community palliative care cope interventions showed that they improved in quality of life and burden of patient's symptoms

The family care giver requires skills, knowledge in order for them to do their tasks towards the cancer patient. A study that was done by (Reinhard, Given, Petlick, & Bemis, 2008), revealed that psycho-education should be provided to the family caregivers as they will be able to take care of their patient. Similarly, a study that was done by (Zarit, Stephens, Townsend, & Greene, 1998), found that providing counseling interventions to the family caregivers helps in improving their sense of control in their role. Since family care givers are like clients, they should be provided with educational interventions so that they can become confident in providing effective and safe care. A study that was done by Zarit and colleagues (1998) found that the family care givers who utilized adult day care services had lower levels of anger, stress as well as depression. Also, Sorenson and colleagues (2002) in their study found that the use of respite day care interventions helped in reducing the care giver's depression as well as increased their psychological well-being. Similarly, a study that was done by Reinhard, Given, Petlick, & Bemis, 2008), found that the family care givers who were put under home care intervention had a higher psychological well-being and were positive in providing their role. From this perspective, it is clear that counseling interventions are essential in ensuring that family care givers continue providing palliative care. However, the family care givers who did not receive any care were not able to cope with their care giving role. Since interventions are essential in ensuring that family

care givers provide quality care to the loved ones, there was a need to carry out a study to find out some counseling interventions that would help the family care givers in their role.

Hudson et, al., (2009) suggested that caregivers should be supported because they are affected by terminal illness in terms of physical, psychological and financially, thus being unable to provide quality care. In addition, they don't get proper information on care giving and they are socially isolated (Andershed, 2006). Aoun and Kristjanson, (2005) supports these by saying sources of stress for care giving are uncertainty of treatment, lack of knowledge regarding patient care, difficult in accessing services, financial burdens, lack of support, changes in paid employment and worries associated with unknown future. Furthermore, caregivers carry dual responsibility of caring for the patients to prepare for death while coming to terms with their own grief and the impending loss. Although there are identified need for resources and information, family care givers remain in the background (Kristjanson, 1997). At times, the health care system does not recognize their key role of care giving (Stetz & Brown, 1997). Despite the known effects of patient's illness on the care givers, little is known of intervention strategies to mitigate these effects (Northouse, et al., 2010), and that is why the current study aimed at studying counseling intervention that would help the family care givers improve their psychological and emotional well-being.

2.4 Summary of Literature Review and Theoretical Framework

According to the literature review, providing care to cancer patient is a difficult process as the role of care giving affects the Psychological well-being of family care givers. Family system theory provides good ground of helping caregivers of cancer patient in dealing with their issues and the importance of involving family members in caring of the ill patient. If the psychological issues are not handled through counseling, they may cause more suffering to the family care givers even after the death of the ill person. It was therefore, important to find out the effective and appropriate counseling interventions to curb the care giving effects on the family care givers of cancer patients with an aim of improving their psychological well-being.

2.5 The Conceptual Framework

The study drew some independent and dependent variables which all played key roles in addressing the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. The following diagram captures the conceptual frame work of the study.

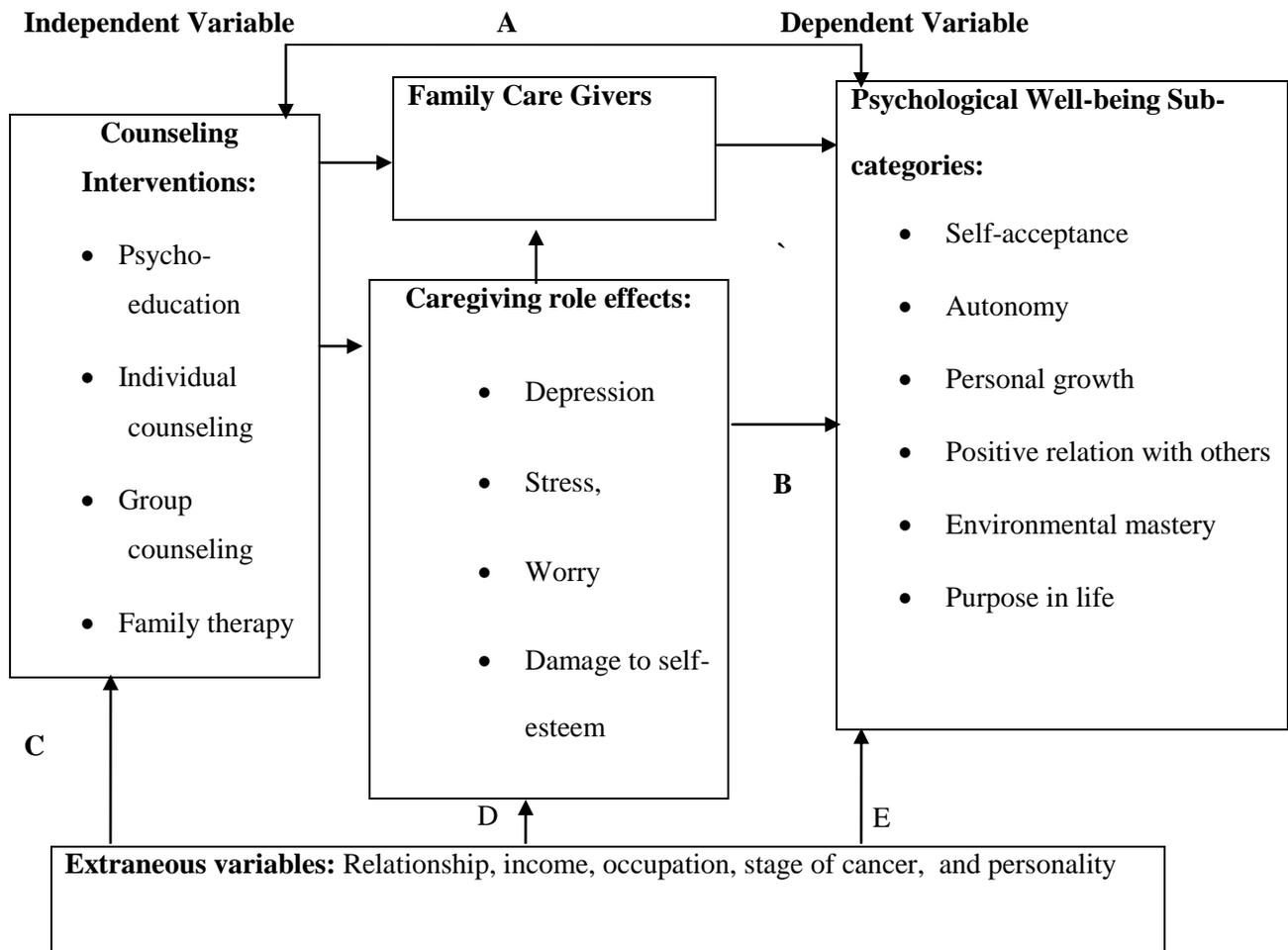


Figure 2.1: Interaction of independent variables, dependent variables and extraneous variables.

Explanation of the Conceptual Framework

A- Counseling intervention predicts the level of psychological well-being.

B-Counseling mitigates the effect of caregiving.

C, D and E- Extraneous variables could have confounding effects on counseling intervention, caregiving role and psychological well-being.

The conceptual framework illustrates the relationship between independent variables and dependent variables and how they are helpful to the study. It illustrates that family care givers cannot provide quality care without counseling intervention. Family care givers experience psychological strain while providing palliative care to their loved ones. Caregiver's background and characteristics influences the care giving aspects. Counseling intervention help the caregivers to adjust and cope with the caregiver's role hence, improving their psychological well-being.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

The purpose of the study was to find out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. This chapter highlights the procedures that the researcher used in collecting and analyzing the data in order to answer the research questions. The chapter focused on the research design, study variables, site of the study, target population, sampling techniques and sample size, research instruments, validity and reliability, pilot study, data collection procedures, data analysis and presentation and data management and ethical consideration.

3.2 Research Design

This study used correlational research design. Cohen, Manion and Morrison (2000) holds that correlational research designs are generally intended to establish three aspects in relation to the two variables under study; first, examines the extent to which two or more variables relate to one another. Secondly, determining whether a relationship exists, the magnitude and direction of the relationship. The design was therefore relevant for the study because the researcher intended to find out the relationship between two variables: counseling intervention and psychological well-being and the nature of the relationship in terms of magnitude and direction.

3.3 Study Variables

The study focused on establishing the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. In this study, variables were divided into two. These were independent and dependent variables.

The independent variable in this study was counseling intervention. The dependent variable was psychological wellbeing. The subcategories of psychological well-being include: autonomy, personal growth, environmental mastery, positive relations with other, purpose in life and self-acceptance.

3.4 Site of the Study

The study was carried out in Kiambu County in Kenya. Kiambu County has three hospitals offering palliative care. The researcher used purposive sampling to select the hospital with a palliative care unit or a hospice. The three hospitals are: Thika level 5 hospital, Kiambu level 5 hospitals and Gatundu level 4 hospitals. The area of the study was appropriate as it served patients who lived in the urban and rural areas. Moreover, the Kenyan Government plans to decentralize the provision of cancer management services from Kenyatta National Hospital to Kiambu County, Kisumu and Mombasa referral hospitals in order to ease the burden among low-income families of seeking cancer services in Nairobi County. According to Kenya News Agency, as outlined by Kiambu County statistical abstract, cancer is the highest killer disease in Kiambu County (2017). In 2016, there were 783 deaths in Kiambu County as a result of cancer complications (Kenya News Agency, 2017). Therefore, due to the rising number of deaths as a result of cancer incidences, there was a need to find out the relationship between the psychological well-being and counseling intervention among the family care givers of cancer patients in Kiambu County.

3.5 Target Population

There were approximately 600 cancer patients who got their services at Thika level 5 hospitals, Kiambu level 5 hospitals and Gatundu level 4 hospital (Thika level 5 hospital Record, 2017). The participants of the study were family care givers who accompanied their loved ones in

palliative care units and hospices in the hospitals as well as three health care givers from each hospital. The health caregivers were included in the study because they provided counseling interventions to the family care givers. The family care givers who took part in the study were the ones identified by the patient as the main care giver. The study focused on the caregivers who were eighteen years and above from each gender. The researcher perceived that caregivers who were eighteen years and below had counseling needs that required a different approach to study them.

3.6 Sampling Techniques and Sample Size

The study used purposive sampling to select three hospitals that offered palliative care in Kiambu County. The hospitals were purposively selected since they were the only public hospitals that offered palliative services in Kiambu County. The researcher also identified family care givers who were acknowledged by the cancer patient as the main care giver to draw a sample from the population. The researcher used purposive sampling because it only focused on particular characteristics that were of interest to the researcher in order to answer the research questions. The study sample comprised of nine health workers and 96 family care givers who accompanied their loved ones to the palliative care unit and hospice in Kiambu County. The criterion of selecting the health care givers was based on health care givers who were offering palliative services. Approximately 600 cancer patients were served at palliative care units in the three hospitals and from these a sample size was determined through a formula that was stipulated by Aday and Cornelius (2006). The formula was found to be suitable since the study was about the family caregivers of cancer patients

$$N = Z^2_{\alpha/2} P(1-P)/e^2$$

Where:

n = sample size,

$\alpha = 0.05$

Z = Z statistic for a level of confidence (95% level of confidence used, therefore Z value is 1.96).

P = expected prevalence of proportion

e = precision (in this case, $e = .05$).

Use of .50 as the estimate is because a .50/.50 split in the proportion that did/did not attend the cancer unit tends to yield the largest sample size requirements.

$$N = 1.96^2 \times 0.05(1-P)/e^2$$

$$n = Z^2 P (1-P)/e^2 = (1.96)^2 (.05 \times .5) / (.05)^2 = 96$$

Therefore, the study drew a sample total of 96 participants.

The study also adopted a systematic random sampling technique. Systematic random sampling was a method that involved selecting the participants from a sampling frame in a systematic way rather than a random manner. Based on this, every second care giver who accompanied a cancer patient was selected from a list until the required number was attained. The initial point for the selection was chosen at random (Kothari, 2004). From each palliative care unit in every hospital a second caregiver was selected and included in the study. This was likely to enhance accuracy of the findings as it had captured population characteristics from the three hospitals.

The researcher purposively selected three health workers providing palliative care as the sample size in every hospital. In order to get the required sampling size of the family care givers, the researcher had to check the records of cancer patients being served in those hospitals. The researcher was accompanied by a palliative care nurse who helped in making contacts with the family care givers and establishing rapport. The total sample size was 105 respondents as shown in Table 3.1

Table 3.1: Sample Population

Participants	Thika	Gatundu	Kiambu	Total
Nurses	3	3	3	9
Family care givers	32	32	32	96
Total	35	35	35	105

3.7 Research Instruments

The study used self-constructed questionnaire in collecting the data. The researcher used self-administered questionnaire to the family care givers due to the literacy level of the respondents. In case a caregiver was not able to read and understand the items in the questionnaire, I had to read and interpret for them. Moreover, I filled their responses in the questionnaire. The researcher also obtained the views of the health care givers by use of a questionnaire. The items on the questionnaires were made simple in order to be effective as instruments for data collection. The questionnaire had open ended and closed ended questions to collect views from the respondents. Open ended questions helped in getting in-depth information. The researcher used a questionnaire because it was suitable for use with a large population and it was easy to accumulate the data. Each item in the questionnaire was developed to address the study questions. The questionnaire of the family caregivers had four sections. Section one had demographic information, section two collected data on the psychological well-being of family care givers. This section had nine items that were adopted from Ryff's (1989). Section three contained items that helped in collecting data on care giving effect on the psychological well-being of family caregivers and section four collected data on counseling services that were offered in palliative care unit. The questionnaire of the health care givers sought for the demographic information and status of counseling in palliative care.

3.8 Validity and Reliability

Content validity was enhanced by ensuring that the research instrument measured what it was intended to measure by ensuring the instrument measured specific domain being studied. The literature review revealed that caregivers of cancer patient were affected negatively by the care giving role and required adequate interventions, in order to improve their psychological well-being. The theoretical framework guided the formulation of the items. The aim of validating the instrument was to ensure there were no unclear and ambiguous items to the participants. In addition, the researcher consulted with the supervisor who read and proofread the items and provided feedback to make adjustment to the questionnaire to ensure clarity. Test and re-test method was used to test the reliability of the research instrument. The pre-testing helped in identifying any deficiencies in the instrument before the actual study. The method was used to a group who were not included in the actual study. Correlation coefficient was computed to determine the reliability of the instrument and a coefficient alpha of 0.82 was obtained which meant that the instrument was reliable as it was above 0.7 as suggested by Rosner (1995). The researcher and the assistant researcher made sure that the tools were scored correctly and the data was coded appropriately.

3.9 Pilot Study

In order to ensure the research instruments were reliable and valid, the researcher conducted a pilot study on 10% of 96 participants as a representative population of the study. According to Mugenda and Mugenda (2003) the number of respondents required for a pilot study should be between 1 and 10% of the study sample. Therefore, a total of ten participants were obtained and were not included in the actual study. Purposive sampling was used to get the pilot participants with similar characteristics in Murang'a hospice. The researcher chose Murang'a County since it

had similar features as Kiambu County. The pilot study helped in identifying some of the short comings likely to be experienced during the actual study. The short coming of the research instrument was corrected to enhance its effectiveness in capturing and measuring the variables of interest.

3.10 Data Collection Procedures

The main data collection instrument that was used in this study was a questionnaire. The administration of the questionnaire was done by the researcher to the family care givers as they visited palliative care unit and the hospice while accompanying their loved ones, with the help of a trained assistant researcher. The researcher sought for the services of the research assistant who was health care giver to create rapport and explain the rationale of the study to the family care givers. The questionnaires were researcher-assisted to the majority of the participants. The researcher sought for the services of the research assistant as she helped the participants who needed further explanation in answering the questions. The researcher also assisted most of the participants as they were old and needed further explanation in order to answer the questions. The health care givers who provided palliative care were given their own questionnaire. Those who agreed to take part in the study were briefed on the study and given a consent form to sign in the palliative care unit. The participants were given an ample time to fill the questionnaires and later the researcher collected them on the same day. The completed questionnaires of the family care givers and the health care givers were filed, kept safe and coded for analysis.

3.11 Data Analysis and Presentation

Descriptive statistics are essential in organizing the data and summarizing the information. The data collected was sorted, scored and coded with an aid of SPSS version 22.0. The data analysis used both qualitative and quantitative procedures. Quantitative data was analyzed using

frequencies and percentages. Moreover, inferential statistics; Pearson Moment Correlation Coefficient was used in order to determine the nature, power and the direction of the association between psychological well-being and counseling intervention. Qualitative data was analyzed in line with the objective of the study using content analysis that involved categorizing all the responses into themes as well as tallying the participant's opinions in order to develop insights. The results were presented using graphs and tables. Consequently, the recommendations and conclusion were drawn.

3.12 Data Management and Ethical Consideration

The researcher sought for a permission to conduct research from National Commission of Science Technology and Innovation (NACOSTI). After the study was approved and a permit obtained, the researcher sought for a subject protection approval from Kenyatta University Ethical & Research Committee (KU-ERC). The researcher also got an authorization letter from the County director of health in Kiambu County to carry out the study in the hospitals. Further permission was sought from the head of Palliative department in three hospitals in Kiambu County.

The researcher maintained confidentiality throughout the study to protect respondents' identity and participation by using codes to identify the respondents on the questionnaires. The researcher informed and explained the study to the respondents before recruiting them and obtained informed consent from them through signing of a consent form. Respondent participation was voluntary and no coercion was applied.

CHAPTER FOUR

DATA ANALYSIS RESULTS AND DISCUSSION

4.1 Introduction.

This chapter presents the findings of the study on the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County, Kenya. Demographic characteristics are presented first, followed by the findings of the study which were guided by specific study objectives.

4.2 Demographic Characteristics of Family Care Givers

This section presents the demographic characteristics of the family care givers of cancer patients. The sample size composed of 96 participants who provided care to their loved ones who had cancer. However, the response rate was 94% which consisted of 90 respondents. Data was collected on the following socio-demographic characteristics: gender, age, marital status, place of residence, level of education, duration of care and religion. The results were as follows;

4.2.1 Gender of the Family Care Giver

Data was collected on the gender of the respondents. The findings are presented in Figure 4.1.

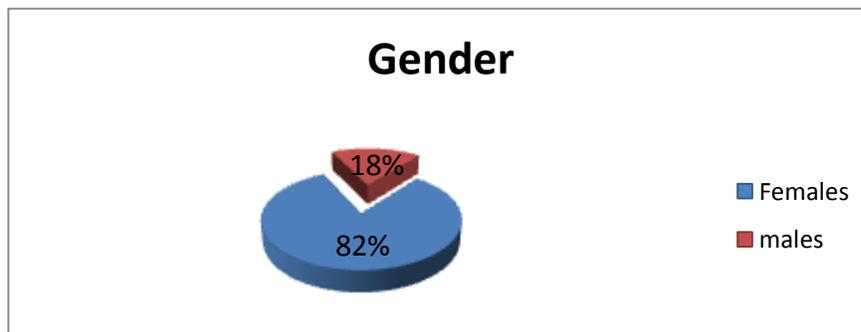


Figure 4.1 Distributions of Respondents by Gender

As indicated in Figure 4.1, the majority of the primary care givers were females (82%). This implies that the role of care giving was left to the females since it was their duty according to various traditions while the men look for finances to take care of the patient. These results were similar to a national survey that was done by Arno, Levine & Memmontt (1999) in the United States that found that 24 and 27.6 million family care giver who provided palliative care to loved ones who had a chronic illness. The majority of them were women as the majority were home keepers.

4.2.2 Age of the Family Care Giver

The respondents were drawn from different age groups. The findings are presented in Figure 4.2.

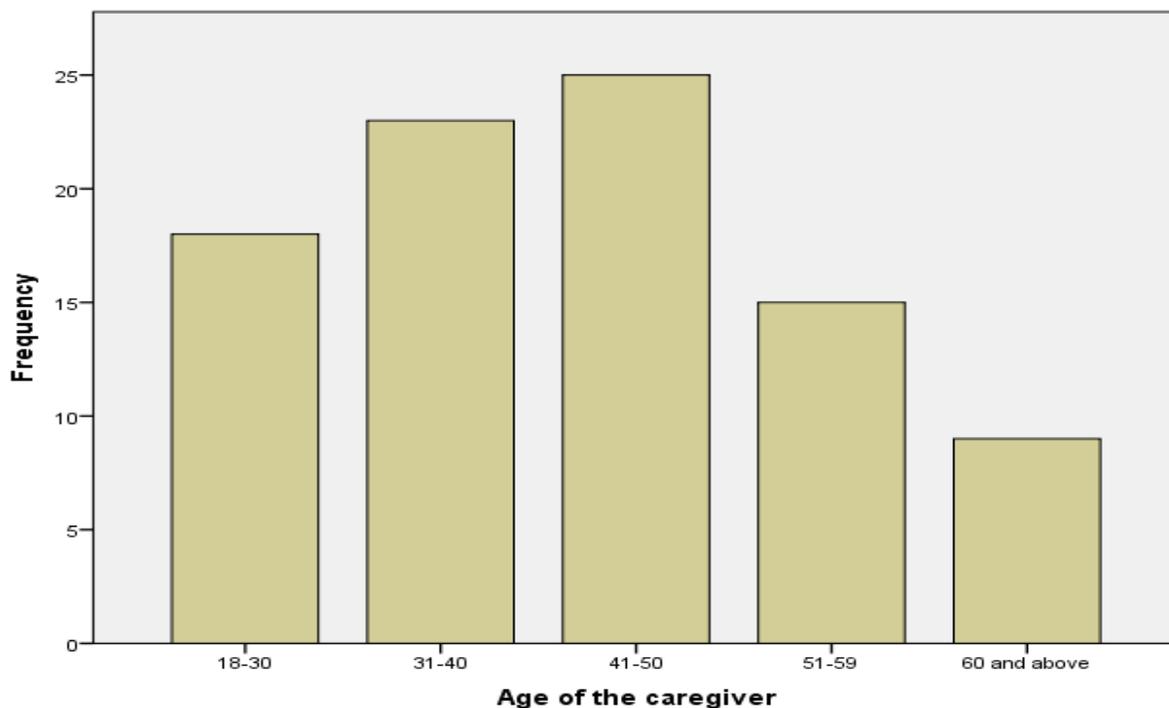


Figure 4.2: Respondents by Age Category

The findings in Figure 4.2, show that majority of the respondents were aged between 41-50 years old (25), followed closely by those of ages 31-40 years old (23). The care givers who were 60 years and above were few(9). This implies that the majority of the care givers were not young,

which means that they had to leave other responsibilities like jobs, families and their social life to take care of the patient. These findings are in line with a study by Creamer (2002) who found that care giving role is burdening the family care givers as they have to leave their daily duties to concentrate on the patient.

4.2.3. Marital Status of the Respondents

The researcher sought to establish the marital status of the respondents. The findings are presented in Table 4.1

Table 4.1 Marital Status of the Respondents

Marital Status	Frequency	Percent
Married	52	57.8
Single	20	22.2
Widow	15	16.7
Divorced	1	1.1
Separated	2	2.2
Total	90	100.0

As shown in Table 4.1 the majority of the respondents (57.8%) who were providing care were married, 22.2% were single, 16.7% were widows and only one had divorced. This implies that the majority of those who were providing palliative care had other responsibilities and issues to deal with since the majority were married.

4.2.4 Respondent's Place of Residence

The researcher sought to establish the place of residence of the respondents. The findings are represented in Table 4.2

Table 4.2 Respondent's Place of Residence

County	Frequency	Percent
Kiambu County	67	74.4
Murang'a County	20	22.2
Others	3	3.3
Total	90	100

From Table 4.2, the majority of the respondents 74.4% were from Kiambu County, and 25.5% % were from other neighbouring counties. This implies that the results obtained could be applied in Kiambu County as the majority of the respondents were from the same County.

4.2.5 The Respondent's Education Level

The researcher sought to establish the educational level of the respondents. The findings are shown in Table 4.3.

Table 4.3 Respondent's Educational Level

Level of Education	Frequency	Percent
University Level	16	17.8
College Level	24	26.7
Secondary Level	25	27.8
Primary Level	24	26.7
Others	1	1.1
Total	90	100.0

From Table 4.3, 27.8% had completed secondary education, 26.7% had completed primary level and college, 17.8% of the respondents had completed university, and only 1.1% had not attended

any formal school. This implies that the majority of the care givers had the capacity to understand the instructions from the health care except only one who needed further help as he had not attended any formal school.

4.2.6 Respondent’s Length of Caregiving

The researcher sought to establish the marital status of the respondents. The findings are shown in Table 4.4.

Table 4.4 Respondent’s Length of Caregiving

Duration	Frequency	Percent
6 months	13	14.4
6-one year	22	24.4
Over one year	55	61.1
Total	90	100.0

From Table 4.4., majority of the respondents (61.1%) had provided care over one year and 14.4% had provided care for 6 months only. This implies that the majority of the care givers were experienced but they needed more help as care giving role had interfered with their daily chores. These results are similar to a study that was done by Burger (2009) who found that care giving role interfered with the quality of life among the family care givers. These results clearly indicates that in order to improve the quality of life among the family care givers, effective counselling as well as other support programs should be provided in palliative care unit in Kiambu County (Adriaan 2013).

4.2.7 Respondent's Religion

The researcher sought to establish the religion of the respondents. The findings are shown in Table 4.5.

Table 4.5 Respondent's Religion

Religion	Frequency	Percent
Protestant	46	51.1
Catholic	44	48.9
Total	90	100.0

From Table 4.5, majority of the respondents (51.1%) were Protestants while (48.9%) were followers of the Roman Catholic.

4.3. Demographic Characteristics of the Health Care Givers

This section outlines the characteristics of respondents whose age, gender, experiences, academic and professional qualification of nurses who provided palliative care are discussed.

4.3.1. Gender of the Health Care Givers

The researcher sought to establish gender of the respondents. The findings are represented in Table 4.6.

Table 4.6 Gender of the Health Care Givers

Gender	Frequency	Percent
Male	3	33.3
Female	6	66.7
Total	9	100.0

The results presented in the table above indicated that 66.7% of the nurses were females and 33.3% were males. This shows that there were many females in palliative care compared to men.

4.3.2 Age of the Health Care Giver

Figure 4.3. Represents the age of the nurses who provided health care in palliative care unit.

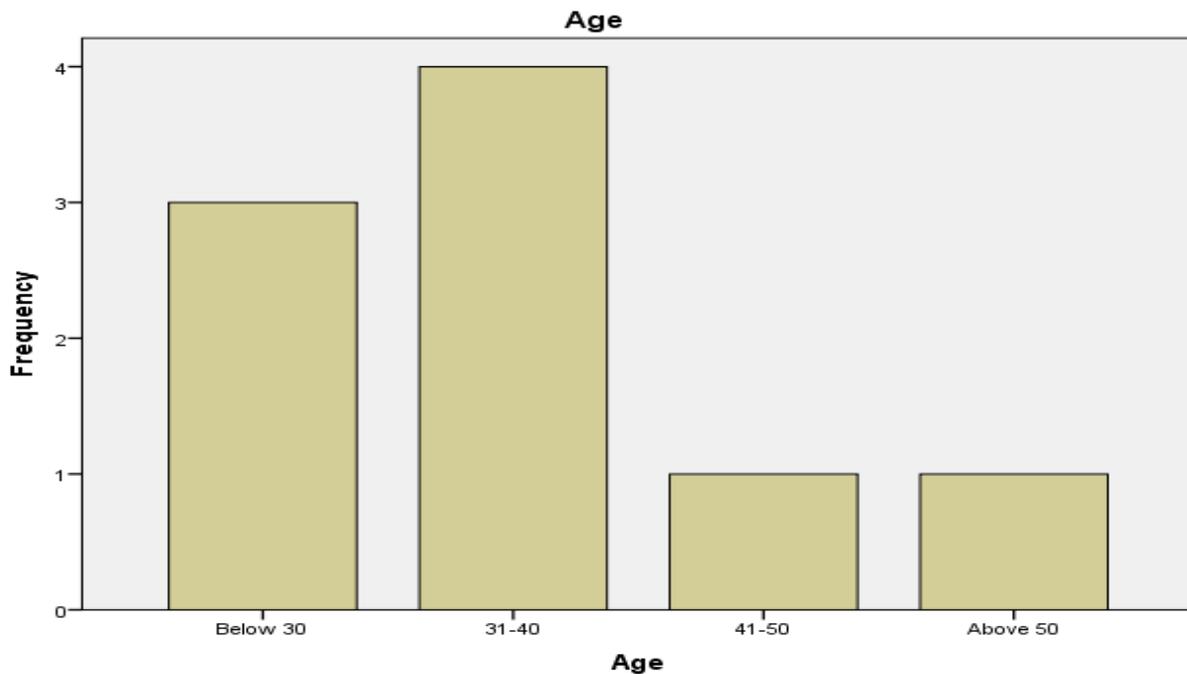


Figure 4.3 Age of the Health Care Giver

The results presented in the graph above showed that the majority of the nurses were between the ages of 31- 40. In addition, the nurses who were below 30 years were many compared to nurses who were above 40 years old.

4.3. 3 Category of the Hospital

The researcher sought to establish level of the hospital that was providing palliative care. The findings are represented in Table 4.7

Table 4.7 Category of the Hospital

Category of the Hospital	Frequency	Percent
Level 5 hospital	6	66.7
Level 4 hospital	3	33.3
Total	9	100.0

From the table above, it's clear that the majority of the hospitals that provided palliative care in Kiambu County were level 5 hospitals (67.7%), compared to level 4 hospitals (33.3%).

4.4. The Findings of the Study According To the Study Objectives

The findings on the study objectives are presented in the subsections 4.3.1. To 4.3.5.

4.4.1 Psychological Well-Being of Family Caregivers

Objective one sought to establish the psychological well-being of family care givers of cancer patients. To measure the psychological well-being, respondents were presented with 9 items that assessed how they felt about themselves, on a six point likert scale. Since there were 9 items, the highest possible score was 54(9*5) and the lowest possible score was 9(9*1). An individual's total score was derived from the addition of the total 9 items. Psychological well- being has six subcategories among them being autonomy, environmental mastery, personal growth, positive relations with others, purpose in life and self-acceptance. Item i and ii measured autonomy, iii and v measured personal growth, vii measured purpose in life, ix measured the level of self-

acceptance, viii measured environmental mastery and IV and VI measured positive relations with others. The findings are presented in Table 4.8.

Table 4.8 Frequencies on Levels of Psychological well-Being

Levels of Psychological Well-being	Frequency	Percent
Low levels of psychological well-being	0	0.0
Moderate levels of psychological well-being	27	30
High levels of psychological well-being	63	70
Total	90	100

Findings from table 4.8 indicate that the majority of the respondents (70%) had high psychological level, while 30% of the respondents had moderate psychological well being. In addition, there was no participant who had low psychological well-being. From the analysis, it is clear that the majority of the care givers had a high psychological well- being. This implies that the family care givers were able to continue with their care giving role (LeSeure, & Chongkhamang, 2015). Further, some care givers had moderate level of psychological well-being. This could be attributed by the majority of the care givers participating in various interventions in palliative care facilities (Given et al. (2001). These results were similar with a study on psychological well being among care givers by Hudson et, al., (2009) as he found that caregivers who were psychologically and emotionally supported provided quality care to their relative who is terminally ill. Emotional and Social support may have attributed to high psychological well-being among the family care givers.

4.4.2 Effects of Care Giving Role on the Psychological Well-being of Family Care Givers

Objective two sought to find out how care giving role affected the psychological well-being of family care givers. The effects on psychological well-being were assessed using a 5- point likert scale. Since the total number of items on the entire scale was 8 items, the maximum possible score for an individual in the scale was 40(5*8) while the minimum possible score was 8(8*1).The findings are shown on Table 4.9.

Table 4.9 Effects of Care Giving Role on The Psychological Well-being of Family Care Givers.

Levels of Psychological well-being	Levels of Care giving							
	Low		Moderate		High		Total	
	N	%	N	%	N	%	N	%
Low	00	00	00	00	00	00	00	00
Moderate	03	11.1	23	85.2	01	3.7	27	100%
High	13	20.6	47	74.6	03	4.8	63	100%
Total	16	17.8	70	77.8	04	4.4	90	100%

Findings from Table 4.9 indicate that there were no participants who had low psychological well-being. The participants, who had a high level of psychological well-being 47 (74.6%), were moderately affected while providing care to their loved ones. In addition, the majority of the family care givers (70) were moderately affected by their care giving role. These results suggest that the majority of the care givers were positive with their role as they were only affected moderately Given et al. (2001). These results are similar to the study that was done by (Pinquart

& Sorensen, 2004) who found that some caregivers are positive in their role thus having less psychological effects. The family care givers were not highly affected by their role as they may have obtained support from relatives, friends, counsellors and palliative nurses (Yuen Locke, Liu and Szeto, 2003). Therefore, the current study will be of great benefit in suggesting effective strategies and interventions that can help in improving the psychological well being of family care givers.

Table 4.10: Chi-Square Analysis

Chi-Square Tests			
	Value	df	Asymp. Sig. (2-sided)
Pearson Chi-Square	1.284 ^a	2	.526
Likelihood Ratio	1.372	2	.504
Linear-by-Linear Association	.655	1	.418
N of Valid Cases	90		

From the table 4.10 the Pearson chi-square is 1.284 with a p-value of 0.526 and the likelihood chi-square statistic is 1.372 with a p-value of 0.504. Therefore, with an alpha level of 0.05 there was no significant statistical relationship between psychological well being and care giving. This means that the distribution of levels of psychological well being will be similar for all values of the levels of care giving.

4.4.3 Relationship between Counseling Intervention and Psychological Well-Being

Objective three sought to find out the relationship between counseling intervention and psychological well-being. In order to understand the relationship, the researcher had to find out how caregiving role psychologically affected the family care givers while providing palliative care. In addition, the researchers also sought out the importance of counseling to the family care

givers. Finally, the researcher conducted a Pearson Product Moment Correlation Coefficient in order to understand the relationship between the psychological well-being and counseling intervention. Pearson Moment Correlation was chosen since the two variables met the following assumptions: Normal distribution, linear relationship, could be measured in a continuous way. In establishing whether there was a linear relationship, a scatter plot of the relationship between psychological well-being and counseling intervention was plotted as well as a table was obtained.

4.4.3.1 Psychological Effects of Palliative Caregiving among Family Care Givers

The researcher sought to establish the psychological effects of palliative caregiving on family care givers. The findings are presented in Table 4.11.

Table 4.11: Psychological Effects of Palliative Caregiving among Family Care Givers

Statements	Most Applicable		Applicable		Undecided		Least Applicable		Not Applicable		Total count	Total Percentage
	F	%	F	%	F	%	F	%	F	%		
Hopelessness	34	37.7%	34	37.8%	2	2.2%	11	12.2%	9	10.0%	90	100.0%
Anxiety	36	40.0%	45	50.0%	6	6.7%	3	3.3%	0	0.0%	90	100.0%
Distress	49	54.4%	36	40.0%	2	2.2%	1	1.1%	2	2.2%	90	100.0%
Fear of impending death	38	42.2%	28	31.1%	7	7.8%	11	12.2%	6	6.7%	90	100.0%
Reduced Self esteem	15	16.7%	24	26.7%	9	10.0%	30	33.3%	12	13.3%	90	100.0%
Feeling isolated	29	32.2%	28	31.1%	6	6.7%	14	15.6%	13	14.4%	90	100.0%

The findings from the Table 4.11 established that while providing palliative care to cancer patients: 87.7% felt hopeless, 93.3% were anxious, 95.5% were distressed, 85.5% feared the impending death, and 76.7% had low self-esteem, 78.9% felt isolated. The results of the study were similar to a study that was done by Payne, Smith and Dean (1999) who found that

caregiving makes the family care givers to experience frustration, hopelessness, tiredness and psychological anxiety.

4.4.3.2 Importance of Counselling

The researcher sought to establish the importance of counselling on family care givers. The findings are presented in Table 4.12.

Table 4.12: Importance of Counselling

Statements	Very Important		Important		Undecided		Least Important		Not Important		Total	
	F	%	F	%	F	%	F	%	F	%	F	%
Hopelessness	54	60%	31	34.4%	4	4.4%	1	1.1%	0	0.0%	90	100 %
Anxiety	47	52.2%	35	38.9%	5	5.6%	1	1.1%	2	2.2%	90	100 %
Distress	47	52.2%	38	42.2%	3	3.3%	1	1.1%	1	1.1%	90	100 %
Fear of impending danger	63	70 %	21	23.3%	3	3.3%	2	2.2%	1	1.1%	90	100 %
Reduced self-esteem	44	48.9%	33	36.7%	5	5.6%	6	6.7%	2	2.2%	90	100 %
Feeling isolated	43	47.8%	35	38.9%	5	5.6%	5	5.6%	2	2.2%	90	100.0%

Findings from Table 4.12, indicated that the majority of the family care givers agreed that counselling was important especially when dealing with hopelessness (94.4%), anxiety (91.1%), distress (94.4 %), fear of impending death (93.3%), a care giver who had low self-esteem (85.6%) and 86.7% when dealing with a care giver who felt isolated. These findings are similar to the study that was done by Northouse et al., (2012) that examined the impact of caregiving on the psychological well-being of family caregivers and cancer patients, and found that counselling interventions improved the psychological well-being of family caregivers.

4.4.3.3 Correlation between Psychological Well-Being and Counselling Intervention

The researcher sought the relationship between the psychological well-being and counselling intervention. The results are presented in Table 4.13.

Table 4.13: Correlation between Psychological Well-Being and Counselling Intervention

		Correlations	
		Psychological well-being	Counseling Intervention
Psychological well-being	Pearson Correlation	1	.135
	Sig. (2-tailed)		.204
	N	90	90
Counseling Intervention	Pearson Correlation	.135	1
	Sig. (2-tailed)	.204	
	N	90	90

As shown in table 4.13 a Pearson product-moment correlation coefficient was run to assess the relationship between counselling intervention and psychological well-being. There was no statistically significant relationship between the two variables since the Sig. (2-Tailed) value is 0.204 which is greater than $p > 0.05$. In addition, Pearson's r is 0.135 which means that the strength of association between variables was a weak positive correlation. Therefore, there was no association between psychological well-being and counselling intervention even though it's a weak (positive) linear relationship.

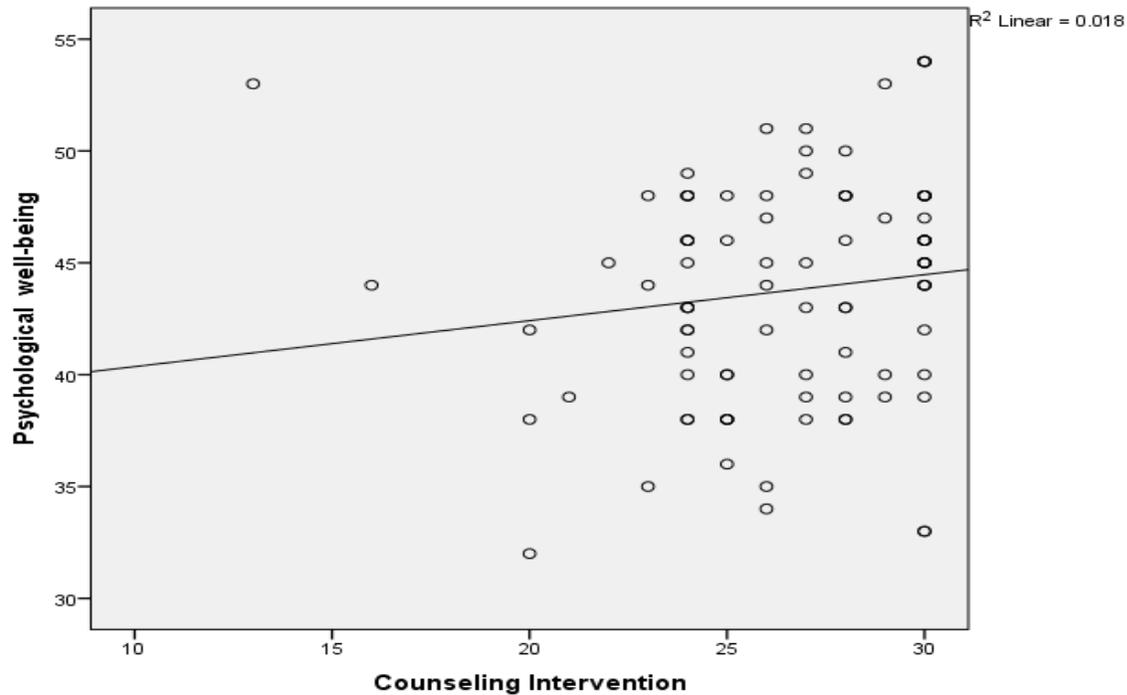


Figure 4.4. Scatter plot of the Relationship between Psychological Well-being and Counselling Intervention

Findings from the figure above indicate that there was an evidence of a weak (positive) linear relationship between psychological well-being and counselling interventions. Higher score of psychological well-being corresponded with a higher score of counselling interventions and higher scores of counselling interventions corresponded with higher scores of psychological well-being. This is a clear indication that Pearson Product Moment Coefficient Correlation(r) could be run and it's significant tested. These results were in line with a study that was done by Elnagar et al. (2017) on the relationship between psychological well-being and coping strategies since he found that psychological well-being of family care givers improved when provided with various counselling interventions. Similarly, Hudson (2003) said that positive reappraisal and psychological support led to the provision of quality care to the cancer patient. This means if

counselling programs are professionally provided in palliative care units in Kiambu County, the family care givers will be positive in their role.

4.4.4 Challenges Experienced in Provision of Palliative Care

Objective four sought to establish the challenges that affected counselling service provision in palliative care. Family caregivers find themselves with many unanswered questions while taking care of their patient. These questions related to psychological, social, and financial issues. Counselling services are provided in the hope that they will help the family caregivers to cope and continue providing quality care to their loved ones.

4.4.4.1 People to Approach when Faced with a Problem

The researcher sought to find out the people that family care givers were most likely to seek for advice when faced with a psychological issue. The results were presented in Table 4.14.

Table 4.14 People to Approach When Faced With a Problem

People	Frequency	Percent
Religious authorities	35	38.9
Professional counsellor/psychologist	18	20.0
Friends	31	34.4
Traditional healers	2	2.2
Nurse	4	4.4
Total	90	100.0

Findings from Table 4.14 indicated that the family caregivers sought help from religious authorities 38.9%, 34.4% from friends, 20% from professional counsellor and psychologist, 2.2% from traditional healers and 4.4% from nurses. This implies that the majority of family care givers sought for help mostly from their friends and religious leaders since they are approachable and they could not be charged as opposed to counsellors who charge for their professional

services. These findings were similar to a study that was done by Yuen Loke, Liu, Szeto (2000) who found that the family care giver sought for psychological support from their friends as they lived close to them and understood their role as well as it had no cost.

4.4.4.2 Training in Counselling

The researcher sought to find out the academic and professional qualification of the nurses providing palliative care unit in the hospital. The findings are as shown in the Table 4.15.

Table 4.15 Training in Counseling

Response	Frequency	Percent
Yes	8	88.9
No	1	11.1
Total	9	100.0

Findings from Table 4.15 showed that the majority of the nurses (88.9%) had some training in counselling.

4.4.4.3 Professional Qualification

The researcher sought to establish professional qualification of palliative nurses. The findings are as shown in Table 4.16.

Table 4.16 Professional Qualification of Nurses

Qualification	Frequency	Percent
Certificate in Counselling	2	22.2
Diploma in Counselling	0	0.0%
Bachelor's Degree in Counselling	0	0.0%
Workshop/Seminar	6	66.7
None	0	0.0%
Missing	1	11.1
Total	9	100.0

Findings from Table 4.16 showed that the majority of nurses were holders of a workshop or seminar certificate (66.7%) and 22.2% had acquired a certificate after undergoing a counselling course.

4.4.4.4 Type of Counselling Offered in Palliative Care Unit

The researcher sought to find out the mode of counseling palliative care unit. The findings are shown in the Table 4.17.

Table 4.17 Type of Counseling Offered In Palliative Care Unit

Type	Frequency	Percent
Group counselling	3	33.3
Individual counselling	6	66.7
Total	9	100.0

Findings from Table 4.17 showed that nurses provided individual counselling (66.7%) compared to group counselling (33.3%).

4.4.4.5 Other Purpose of a Counselling Room

The researcher sought to establish other purpose of a counseling room. The findings are as shown in Table 4.18.

Table 4.18 Other Purpose of a Counselling Room

Purpose	Frequency	Percent
Clerical Work	4	44.4
Examination and other procedures concerning the patients	4	44.4
Family support	1	11.1
Total	9	100.0

Findings from Table 4.18 showed that despite having a counselling room, the same room was used for other purposes such as clerical work (44.4%) as well as examination and other procedures (44.4%). Additionally, the family care givers received a family support in the same room which was 11.1%.

4.4.4.6 Counselling Resources Used in Palliative Care Unit

The researcher sought to establish the kind of counseling resources that were used in palliative care unit. The findings are shown in Table 4.19.

Table 4.19 Counseling Resources Used in palliative Care Unit

Resources	Frequency	Percent
Magazine	5	55.6
Text books	4	44.4
Total	9	100.0

From Table 4.19, it's clear that the use of magazine (55.6%) was mostly used compared to the text books (44.4%).

4.4.4.7 Areas Dealt with in Counselling

The researcher sought to establish the areas that counseling dealt with in palliative care unit? The findings are shown in Table 4.20.

Table 4.20 Areas Dealt with in Counseling

Areas	Frequency	Percept
Breaking of bad news and bereavement	7	77.8
Family support	1	11.1
Treatment adherence	1	11.1
Total	9	100.0

Findings from Table 4.20 showed that the main aspects of counselling handled by a nurse counsellor in palliative care included breaking of bad news and bereavement, family support and treatment adherence. Breaking of bad news and bereavement counselling (77.8%) was mostly provided. The least handled aspect was family support and treatment adherence each at (11.1%).

4.4.4.8. The Most Issues Dealt With in a Counseling Session

The researcher sought to establish whether there was a schedule for meeting with family care givers. The findings are shown in Table4.21.

Table 4.21. The Most Issues Dealt with in a Counseling Session

Issues	Frequency	Percent
Disclosure and Bereavement	5	55.6
Coping Mechanisms	1	11.1
Social and psychological issues	1	11.1
Symptom management	1	11.1
complications Terminal illness	1	11.1
Total	9	100.0

Findings from Table 4.21 showed that the most issues that were dealt with in palliative counseling were disclosure and bereavement (56.6%) and other issues such as terminal illness complications, symptom management, coping mechanism and social and psychological issues each at 11.1%.

4.4.4.9 How Family Care Givers Sought Counseling Services

The researcher sought to establish whether family care givers voluntarily sought counseling services in palliative care unit. The findings are shown in Table 4.22.

Table 4.22 How Family Care Givers Sought Counseling Services

Response	Frequency	Percent
Yes	5	55.6
No	4	44.4
Total	9	100.0

Findings from Table 4.22 showed that the family care givers who voluntarily sought for counseling was 55.6% and those who did not were 44.4%. This implies that the family care givers acknowledge that they need counseling for them to continue providing quality care

4.4.4.10. Hindrances to Counseling Services for Care givers

The researcher sought to establish the factors that hindered the family care givers from seeking counseling services. The results are presented in Table 4.23.

Table 4.23 Hindrances to Counseling Services for Care givers

Factors	Frequency	Percent
Fear of what will be said about them	5	55.6
Lack of Time	4	44.4
Total	9	100.0

Findings from Table 4.23 showed that family caregivers feared to volunteer themselves for counseling because they did not want to be seen as if they were putting their issues first than those of their patients (Payne et al., 1999).

4.4.4.11 Other Programs That Help in Dealing with the Issues Affecting Family Care Givers

The researcher sought to establish whether there were other programs that were implemented to cater for family caregiver counseling issues. The findings are shown in Table 4.24.

Table 4.24 Other Programs That Help in Dealing with the Issues Affecting Family Care Givers

Programs	Frequency	Percent
Family day	3	33.3
Psych education	4	44.4
Home based care	2	22.2
Total	9	100.0

Findings from Table 4.24 showed that the program that was needed most was teaching the family caregiver on how to care for their loved ones. Psych-education (44 %) was the most important since the family caregivers needed to know how to feed and administer drugs to their loved ones compared to the family day (33.3%) and home based care (22.2%). These results were similar to (Reinhard 2012) who said that family care givers took caregiving role when they were not well trained.

4.4.4.12 Challenges Affecting Palliative Care Unit

The researcher sought to establish the challenges that palliative care unit faces when dealing with issues of family caregivers. The findings are shown in Table 4.25.

Table 4.25 Challenges Affecting Palliative Care Unit

Challenges	Frequency	Percent
Privacy and lack of enough space	4	44.4
Overcoming biasness in the family	1	11.1
Not able to deal with denial among the caregivers	2	22.2
The caregiver not being co-operative	2	22.2
Total	9	100.0

Findings from Table 4.25 indicated that the challenge that palliative counselors mostly faced was the issue of privacy and lack of enough space which was (44.4%). In addition, they were not able

to deal with denial (22.2%) as well as the caregivers were not cooperative (22.2%). Moreover, palliative counselors were not able to handle biasness in the family (11.1%).

4.4.5 Interventions

4.4.5.1 Family Care Giver’s Suggestions on How to Improve Counselling Provision in Palliative Care Unit

Objective five sought to establish different ways that could help improve counselling services in palliative care. The findings are presented in Table 4.26.

Table 4.26: Family Care Giver’s Suggestions on How to Improve Counselling Provision in Palliative Care Unit

Intervention	Frequency	Percent
To have enough professional palliative counsellors	25	27.8
To have more counselling rooms for privacy purposes	6	6.7
To have more sessions with the caregiver	18	20.0
Psych educating the caregiver about the disease	21	23.3
To have several family day care	2	2.2
Extending more palliative services to the patient's home	1	1.1
Missing	17	18.9
Total	90	100.0

Findings from Table 4.26, showed that the majority of family caregivers (27.8%) thought that if there was enough professional counsellors in palliative care, counselling services would be effective, 23.3% claimed that caregivers should be taught on how to care for the patient, 20% said that it was essential to have more sessions since they would help him or her provide quality care to the patient, 6.7% said that it was essential to have more counselling rooms since confidentiality should be maintained, 2.2% said that the department should have several family day care, 1.1% said that teaching the caregiver on how to take care of the patient in the hospital

was not enough and emphasized that the nurse counsellor should also provide more help when the caregiver was unable to do so. These results concurred with the findings of (Given et al., 2012) who found that any support given to the family care givers helped them to provide quality care.

4.4.5.2 Health Care Giver’s Suggestions on How to Improve Counselling

Provision in Palliative Care Unit

The researcher sought to establish various ways of improving counselling provision in palliative care unit. The results are presented in Table 4.27

Table 4.27: Healthy Care Giver’s Suggestions on How to Improve Counselling Provision in Palliative Care Unit

Interventions	Frequency	Percent
To have a spacious private room for counselling	8	88.9
To have a professional palliative counsellor	1	11.1
Total	9	100.0

Findings from Table 4.27 showed that the only way that could enable counselling services to be provided in palliative care effectively and professionally was to have spacious private rooms (88.9%) and professional counsellors (11.1%). This implies that despite having nurses who acted as counsellors, it is essential to have palliative counsellors who will deal with issues raised by the family care givers. These findings were similar to a study that was done by Deeken et al., (2003) which found that if the family care givers are supported psychologically, they would deliver quality care, be less anxious and integrate care in their lives well. Therefore, the provision of effective palliative counselling is essential in alleviating psychological distress among the family care givers.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This section presents the summary of the findings, conclusions and recommendations of the study on the relationship between counselling intervention and psychological well-being among family care givers of cancer patients in the provision of palliative care, in Kiambu County. The chapter begins with the summary of the findings as per the objectives, followed by the conclusion drawn from the summary, and finally the recommendations from the study.

5.2. Summary of the Findings

In this section, the researcher summarized the findings of the study in accordance to the five research study objectives.

5.2.1 Psychological Well-Being of the Family Care Givers.

Analysis of the data indicated that 30% and 70% of the respondents had moderate and high psychological well-being respectively. From the analysis, there was no participant who had a low psychological well-being.

5.2.2 Effects of Care Giving Role on the Psychological Well-being of Family Care Givers

The results obtained indicated that there was no participant who had a low psychological well-being. The majority of the family care givers 70 (77.8%) were moderately affected by their role. Chi-square analysis indicated that there was no statistical relationship between care giving and psychological well-being.

5.2.3 Relationship between Counselling Intervention and Psychological Well-Being among Family Care Givers of Cancer Patients in the Provision of Palliative Care

After the analysis it was found that there was a weak positive correlation; $r(90) = 0.135$, $p > 0.05$. The relationship between psychological well-being and counselling intervention was not statistically significant at 0.05 levels.

5.2.4 The Challenges Affecting Counselling Provision in Palliative Care

The study established that 66.7% had only a seminar workshop certificate which indicated that the family caregivers lacked any professional help. In addition, in palliative care unit there was a counselling room but it was used for other purposes such as clerical work, examination and diagnosing a patient. All these challenges occurred because the palliative department was recently started and was in the process of being devolved to counties in Kenya.

5.2.5 Intervention Measures to Deal with the Challenges

The family caregivers revealed that they needed help from a professional palliative counsellor (27.8%) a counselling room (6.7%), have more sessions with the counsellors (20%) and being trained on how to take care of the patient (23.3%). The health care givers on the other hand added that it was essential to have a spacious counselling room (88.9%) and a professional counsellor in their unit (11.1%).

5.3 Conclusion of the Study

The study was undertaken to find out the relationship between counselling intervention and psychological well-being of family care givers in palliative care in Kiambu County. The researcher made several conclusions which are related to the five research questions.

. The study found out that the majority of the family care givers in Kiambu County had high levels of psychological well-being. Therefore, majority of the family care givers were able to function normally despite the effects of care giving which could be attributed to the kind of support they received from palliative nurses, friends, counselors and religious leaders.

The study found that the majority of the family care givers who participated in the study were moderately affected emotionally and psychologically by their role. From the above conclusions, the family caregiver's psychological well-being was affected because they were overwhelmed by their role as well as lack of professional palliative counseling.

The study found that there was an evidence of a weak (positive) linear relationship between the counseling intervention and psychological well-being, with an increase in counseling intervention relating to an increase in psychological well-being. Even though the correlation was not significantly tested, more studies need to be done before concluding that an increase in counseling intervention correlated positively to an increase in psychological well-being.

The study found that majority of the family care givers lacked professional palliative counseling, adequate information in caring for their patients and lack of confidentiality. Therefore, these could be some of the factors that hindered effective counselling in helping family care givers cope in their caring role.

The study found that interventions such as counseling, support groups, psycho-education, family therapy and training helped the family care givers to be positive in their role as well as provided quality care to their loved ones.

5.4 Recommendations of the Study

The following recommendations were made based on the findings of the study for policy makers, and implementers including further research. The recommendations of the study are related to the five research questions.

5.4.1. Recommendations for Policy Makers and Implementers

To enhance psychological well-being among the family care givers of cancer patients the following measures should be instituted in palliative care unit.

- i. The findings of this study showed that the level of psychological well-being of family care givers was high. Therefore, counselling interventions should be provided by a professional in order to help the family care givers and continue having a high level of psychological well-being and empower those who may be adversely affected by their role.
- ii. It was evident from the findings that caregiving role interfered with their daily schedule some lost hope and had low self-esteem. It is therefore important to provide professional training and counselling to the family care givers to enable them to provide quality care to their loved ones with an aim of ensuring that their psychological well-being will never be interfered with by their role.

- iii. The findings of this study showed a positive correlation between counselling intervention and psychological well-being. It is therefore recommended that the family care givers be supported psychologically through various counselling interventions with an aim of helping them live a quality life and provide quality care to their loved ones.
- iv. The study shows that there were various challenges that hindered effective provisions of palliative care to the family care givers such as lack of professional counsellor, inadequate information on how to care for the patient and lack of a spacious counselling room. Therefore, it is recommended that the government should support the palliative care staff to attend a counselling course in order to equip them with skills and knowledge in order for them to be able to implement counselling programs. Also, the government should provide more funds for expansion of palliative care unit in order to have spacious rooms where counselling can take place as well as to enhance confidentiality.
- v. The study reveals that there are many important programs that should be implemented to help the family care givers such as peer counselling, having several support groups, a family day and psycho-educating the family care givers with the necessary knowledge and skills needed to take care of the cancer patient at home.

5.5. Recommendations for Further Research

This study recommends further study on the following areas to address its limitations:

- i. A similar study should be conducted to find out the relationship between psychological well-being and counselling intervention on family care givers in another county.
- ii. A similar study should be conducted to find out the support offered by the hospital administrators towards counselling programs in palliative care.

- iii. A comparative study should be conducted to find out whether there is a difference between the psychological well-being and counselling intervention between a female and a male family care giver.

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Appendix 1: Questionnaire for Primary Care givers

The researcher is a post graduate student at Kenyatta University pursuing master of counseling psychology. This research questionnaire is designed to find out the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. Please respond to all the items in the questionnaire in an honesty way. The information you give will be treated with confidentiality.

Instructions

- I. Please answer all the questions in the spaces provided by ticking in the appropriate space or writing your responses as the-question may demand.**

- II. Do not write your name**

SECTION A: THE RESPONDENTS DEMOGRAPHIC INFORMATION

1. Gender: (a) Male () (b) Female ()
2. What is your age: (a) 18-30 () (b) 31-40 () (c) 41-50 () (d) 51-59 ()
(e) 60 and above ()
3. Marital status: (a) Married () (b) Single () (c) Widow () (d) Divorced ()
(e) Separated () (f) others ()
4. Place of residence: (a) Kiambu County () (b) Murang'a County () (c) others ()
5. Highest Level of Education attained: (a) University () (b) College () (c) Secondary
(include "A" level) () (d) Primary () (e) Others ()
6. For how long have you been a care giver?
(a) 6 months () (b) 6-one year () (c) Over one year ()
7. Do you belong to a religion? Tick one of the boxes:
(a) Protestant () (b) Catholic () (c) Muslim (d) Greek Orthodox ()

SECTION B: Ryff's Scale of Psychological Well-Being of Family Care Givers

The following statements describe how you feel about yourself as well as your life. Please tick the statement that describes the degree to which you disagree or agree with each statement.

Put ✓ mark that best describes the degree to which you disagree or agree	Strongly Disagree	Disagree	Disagree Slightly	Agree Slightly	Agree	Strongly Agree
1. I am not the kind of person who gives in to social pressures to think or act in certain ways						
2. Being happy with myself is more important to me than having others approve of me.						
3. With time, I have gained a lot of insight about life that has made me stronger, and more capable person						
4. My friends and I sympathize with each other's problems						
5. I enjoy seeing how my views have changed and matured over the years.						
6. Most people see me as loving and affectionate.						
7. I am an active person in carrying out the plans I set for myself.						
8. My daily life is busy, but I derive a sense of satisfaction from keeping up with everything						
9. I like most aspects of my personality.						

SECTION C: How Care Giving Role Affect the Psychological Well-being

In this section there are statements that describe how you feel about your care giving role. Please tick ✓ appropriately in the boxes that describes how you feel in the past few weeks

Statements	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
1. Care giving roles has made me get confused and dis-oriented					
2. Care giving roles has helped to improve my relationship with the patient					
3. Care giving role interferes with my daily schedule					
4. Care giving role is interesting as I have acquired new skills					
5. Care giving role has made me lose hope in life					
6. Care giving role has made me lose my self esteem					
7. I feel strained when I am around my relative.					
8. I am afraid of what future holds for my relative.					

SECTION D: PSYCHOLOGICAL EFFECTS

The following are some of the psychological effects that primary care givers experience. Tick the one that is applicable to you.

Effects	Most Applicable	Applicable	Undecided	Least Applicable	Not Applicable
Hopelessness					
Anxiety					
Distress					

Fear of impending death					
Reduced self-esteem					
Feeling isolated					

SECTION E: COUNSELING INTERVENTION

1. Whom do you go to when faced with psychological issues?

- (a) Religious authorities ()
- (b) Professional counselor/psychologist ()
- (c) Friends ()
- (d) Psychiatrist ()
- (e) Traditional Healers ()
- (f) Nurse ()
- (g) Others (specify) ()

.....

2. In the process of care giving, have you ever sought counseling services?

If yes, please rate how important was counseling in dealing with the following psychological effects.

Effects	Very Important	Important	Undecided	Least Important	Not Important
Hopelessness					
Anxiety					
Distress					
Fear of impending death					
Reduced self-esteem					
Feeling isolated					

3. What do you think may be done in order to improve counseling in palliative care?

.....

.....

.....

The End

THANK YOU

Appendix 11: Health Care Givers Questionnaire
Please tick ✓ where appropriate

Section One: Demographic data

1. Gender Male () Female ()

Age bracket of the respondent

below 30 ()

31-40 ()

41-50 ()

Above 50 ()

1. Category of the hospital

Level 5 hospital ()

Level 4 hospital ()

2. For how long have you been a palliative counselor

0-5 Years () 6-10 Years () 11-15 Years () Over 15 Years ()

3. Do you have any training in Counseling?

Yes () No ()

If yes, which professional qualification do you have?

Certificate in counseling ()

Diploma in counseling ()

Bachelors' degree in counseling ()

Workshop/Seminar certificate () none ()

SECTION Two: Status of Counseling in the palliative care unit.

4. Is there any other person who participates in counseling in the palliative care unit?

Nurses () Social worker ()

Any other specify.....

5. Does counseling have a schedule for meeting with family care givers? Yes () No ()

6. If yes, how does it operate?

Daily () Weekly () Monthly () When Needed ()

7. What mode of counseling is offered in the palliative care unit?

Group counseling () Individual counseling ()

8. Is there a counseling room? Yes () No ()

What other purpose is the counseling room used for?

.....
.....

9. What counseling resources do you use in the palliative care unit?

Magazines () Text books () CDs and Videos ()

Any other

10. What areas does counseling deal with?

.....
.....

11. Which are the most issues dealt with during the counseling session when helping a family care giver?

.....
.....

12. Do the family care givers voluntarily offer themselves for counseling services?

Yes () No ()

b. If No, what hinders them from seeking the counseling services?

.....
.....

13. Apart from counseling, which other programs do you have to cater for family care givers counseling issues

.....
.....

14. Mention some of the challenges that your department faces in dealing with issues of family care givers.....

.....
.....

15. Suggest some of the ways of improving counseling in your department.

.....
.....

END

THANK YOU

Appendix 111: An Introduction Letter

My name is Stephen Kiragu Muita. I'm a master's student at Kenyatta University. I'm conducting a research study on "the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. The information you give will only be used for the above study.

Procedures to be followed

Participation in this study will require you to answer a questionnaire that will be provided. The information will only be used for the intended research purposes and will bear no identifying information. You have the right to refuse participation in this study. Please remember the participation in this study is voluntary. You may ask questions related to the study at any time.

You may refuse to respond to any questions and may stop responding at any time. You may also stop being in the study at any time without any consequences.

Discomforts and Risks

The study involves no known risk to you and contains no deception. However if any of the questions make you uncomfortable, you may refuse to answer these questions if you so choose.

Benefits

Participation in this study is voluntary and if you choose to participate, your information will help in understanding the impact of counseling on the psychological well-being of family care givers of cancer patients in Kiambu County. In case of any counseling needs, the services will be offered.

Confidentiality

Privacy and confidentiality will be ensured. You are not required to write your names on the questionnaire to ensure anonymity. The questionnaires will be kept in a private office in order to ensure privacy.

Contact Information

If you have any questions you may contact Dr. John Oteyo on 0725237845 or the Kenyatta University Review Committee Secretariat on chairman.kuerc@ku.ac.ke, secretary.kuerc@ku.ac.ke or secretariat.kuerc@ku.ac.ke

Investigator’s Statement

I, the undersigned have explained to the volunteer in a language that he/she understands, the procedures to be followed in the study and the risks and benefits involved.

Name of the investigator.....

Investigator’s signature

Date

Appendix 1V: Consent Form for the Respondent

The information regarding my participation in the study on the relationship between counseling intervention and psychological well-being among family care givers of cancer patients in Kiambu County. I have been given a chance to ask questions and my questions have been answered to my satisfaction. My participation in this study is entirely voluntary. I understand that my record will be kept private.

Signature

Date