

**WELLBEING OF INFORMAL CAREGIVERS OF CANCER PATIENTS  
AT UGANDA CANCER INSTITUTE**

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## **DECLARATION**

I, Kobusingye Annemary, do hereby declare that this research dissertation submitted to the School of Nursing in partial fulfillment for the award of a Bachelor's Degree in Nursing Sciences of Clarke International University has never been presented to any academic institution by anyone in full or part for the award of a degree. The work I have presented in this research dissertation is my own and any other materials contained herein.

Signature \_\_\_\_\_

Date: \_\_\_\_\_

## **APPROVAL**

This research dissertation titled “Wellbeing of informal caregivers of cancer patients at Uganda Cancer Institute” has been produced and submitted to the School of Nursing of Clarke International University under my supervision.

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## **DEDICATION**

I dedicate this piece of work to my late mother, the late Dr. Annet Twinobusingye Ndyomugyenyi, I miss You every day mum.

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## **LIST OF ABBREVIATIONS/ACRONYMS**

ADL	:	Activities of Daily Living
COVID	:	Corona Virus Disease
FC	:	Family Caregivers
FGD	:	Focused Group Discussion
HCPs	:	Health-care professionals
IC	:	Informal Caregiver
ICG	:	Informal Caregiver
NAC	:	National Alliance for Caregiving
SOPs	:	Standard Operating Procedures
SPSS	:	Statistical Package for Social Sciences Research
SSA	:	Sub-Saharan Africa
UCI	:	Uganda Cancer Institute

## **OPERATIONAL DEFINITIONS**

**Informal caregivers:** Person who provides personal care, assisting with medical care, performing household tasks, arranging for outside services, visiting regularly, or providing assistance with coping by a person who is unpaid. An informal caregiver is usually a relative or friend who may or may not live in the same household as the person with cancer who requires care.

**Caregiver burden:** describes the result of a caregiver's self-analysis of the demands of caregiving and the perceived resources available for addressing those demands.

## ABSTRACT

**Background:** Informal caregivers of cancer patients play a key role and provide essential support to cancer patients along the illness trajectory. However, this might put a big burden on the lives and wellbeing of these caregivers.

**Objectives:** This study was conducted among informal caregivers of cancer patients at Uganda Cancer Institute to explore their wellbeing as they take care of their relatives suffering from cancer.

**Methods:** A total of twenty informal caregivers participated in the study. Data was collected through in-depth interviews (eight) and focused group discussions (one for male and the other for female caregivers, each having six participants).

**Results:** Six sub themes emerged from the analysis of data: “negative wellbeing”, “activities of daily living”, “treatment support”, “financial constraints”, “fears and concerns” and “self-rejuvenation”. The sub themes emerged from ten categories of: “full time job”, “challenging role”, “patient feeding”, “patient bathing”, “medicine giving”, “lost employment”, “inability to purchase medicine”, “patient might die”, “spiritual renewal”, and “keeping busy”.

**Conclusion:** Informal caregivers of cancer patients at UCI experience negative wellbeing, attributable to the care giving job being a full-time job and being a challenging role, and also because of financial constraints as well as the fear that the patient might die. However, they cope by listening nourishing message and music.

**Recommendations:** Government and the Uganda Cancer Institute should consider improving the wellbeing of informal caregivers of cancer patients for example through extending to them financial and emotion support activities.

## CHAPTER ONE: INTRODUCTION

### 1.0 Introduction

This chapter provides an introduction to the topic under study. It includes the background to the study, the problem statement, the research objectives, research question, significance of the study and the conceptual framework for the study.

### 1.1 Background to the Study

Worldwide, an estimated 19.3 million new cancer cases (18.1 million excluding nonmelanoma skin cancer) and almost 10.0 million cancer deaths (9.9 million excluding nonmelanoma skin cancer) occurred in 2020. Female breast cancer has surpassed lung cancer as the most commonly diagnosed cancer, with an estimated 2.3 million new cases (11.7%), followed by lung (11.4%), colorectal (10.0 %), prostate (7.3%), and stomach (5.6%) cancers (Sung et al., 2020). Unfortunately, cancer puts the family at risk since it imposes an alternation in the relations among family members. It affects the couple's relationship, their sex life, and it can also be a cause of major trauma among their children and adolescents (Katarzyna *et al.*, 2020). Family caregivers (FCs) of patients with cancer may experience a host of problems, such as anger, hopelessness, being alone, fear, anxiety, burden, and depression (Chang *et al.*, 2013; Stajduhar, 2013; Effendy *et al.*, 2014).

It is estimated that by 2040 the disease burden from cancer in Europe will increase by 21 percent (from 4.2 to 5.2 million new cases annually) while the annual number of cancer deaths will increase by 31 percent (from 1.9 to 2.6 million) (Siegel *et al.*, 2019). The impact and burden on informal caregivers in Europe will grow with the increasing incidence of cancer, the improved prognosis and increased life expectancy of patients, and the increasing reliance on outpatient care services (Haylock, 2010; Goren *et al.*, 2014). Every cancer diagnosis has some effect on the family members and close friends of the patient, for it is estimated that the contributions of informal caregivers account for one-third of the total costs of cancer care (Round *et al.*, 2015).

In the United States of America, the National Alliance for Caregiving (NAC) estimates that 4 million individuals are caring for an adult cancer patient; this estimate accounts for roughly 8% of all care-givers in the United States. Informal/family caregivers are a fundamental source of care for cancer patients in the United States, yet the population of caregivers, their tasks, psychosocial needs and health outcomes are not well understood (American Cancer

Society, 2016). Cancer has been described as a “we-disease” (Kayser *et al.*, 2007) in which informal caregivers are involved in both disease-related and everyday tasks. Informal caregivers (ICGs) of cancer patients are typically involved in the entire trajectory of cancer disease, from diagnosis to survivorship or end of life.

Sub-Saharan Africa (SSA) bears the brunt of this increase. Nearly half a million people were estimated to die of cancer in 2020 in SSA, and the incidence of cancer was projected to increase at least by 40% (Ferlay *et al.*, 2017; Garcia *et al.*, 2017). Therefore, there is greater need for information caregivers in African than any other continent of the world, and this is attributed to African great challenges especially poverty. As such, cancer patients are mainly dependant on relatives and other informal caregivers to provide care to them while undergoing treatment. In Uganda, about 32,617 new cases and 21,829 cancer deaths were registered in 2018 (Ferlay *et al.*, 2018). The cancer estimates for Uganda, come mainly from one population-based cancer registry, Kampala Cancer Registry, established in 1954 in Kampala City, and covers about 8% of the total population (Wabinga *et al.*, 2018). Cancer patients are cared for both formally and informally, with the informal carers playing a substantial role.

Formal caregivers are health-care professionals (HCPs) including nurses, personal support workers, rehabilitation specialists, and physicians who, according to the legislature of society, are paid for the care and support they provide to the patients or clients (Ku, Liu & Wen, 2013). The cancer care team includes those with specialized training in oncology, such as oncologists and oncology nurses, other specialists and primary care clinicians, as well as family caregivers and direct care workers. Informal caregivers are relatives, friends, or neighbors who provide unpaid practical support either on a daily basis or at least twice a week to a patient (Lethin *et al.*, 2016; Shiba, Kondo & Kondo, 2016). They may also be referred to as Family carers (FCs). In Uganda, ICGs are more intensely involved in the process of providing care to cancer patients because of lack of adequate cancer care resources. Active performance of tasks to meet the needs of the cancer patients is likely to elicit significant caregiver burden (Joshua *et al.*, 2017).

Informal caregiving can have positive consequences for the caregiver, including a sense of efficacy, of worth and purpose, of emotional closeness, and satisfaction and pleasure in preserving the patient’s dignity (Anderson & White, 2017; LeSeure & Chongkham-Ang,

2015). However, informal caregivers also carry a heavy burden and report stress, loneliness, isolation, a heavy workload, shame and guilt (Goren *et al.*, 2014; Stenberg *et al.*, 2010). The caregiver burden is defined as “the extent to which caregivers perceive that their emotional or physical health, social life and financial status are suffering as a result of caring for their relatives” (Halpern *et al.*, 2017). Informal caregivers have been described as experiencing psychological, social, relational, emotional, and financial burden (Halpern *et al.*, 2017; Wang *et al.*, 2018). Increased levels of distress and anxiety are reported by half of informal caregivers of patients with advanced-stage cancer (Reblin *et al.*, 2016; Rumpold *et al.*, 2016). Informal caregivers provide long-term care and are often the primary source of physical, social, and emotional support for patients. Depending on the responsibility assigned, caregivers have been classified as primary caregivers if they are mainly responsible for providing and/or assisting with the care recipients’ activities of daily living or secondary caregivers if they assist in care giving or providing support to a care recipient but are not primarily responsible for the day-to-day care or decisions regarding that care. It is important to note that secondary caregivers are critical to the network of support for primary caregivers (Ryba, 2012). Informal caregivers, such as partners, close family members, or friends, provide essential support to cancer patients along the illness trajectory.

During diagnosis and the first phases of the illness, these individuals may offer practical help by accompanying the patient during the diagnostic steps and also psychological support for coping with uncertainty and fear. In the advanced phases of the illness, caregivers may provide assistance and self-care and give emotional support. The burden of cancer is likely considerable across all cultures. The support available to informal caregivers varies across health care organizations and cancer subtypes (Ferrell & Wittenberg, 2017). The limited implementation of support initiatives and measures is likely related to a weak evidence base, difficulties in targeting caregivers’ specific and variable needs, and challenges in identifying a group for targeted intervention (Kent *et al.*, 2016; Frambes *et al.*, 2017).

## **1.2 Problem Statement**

Informal caregivers are generally involved in the entire trajectory of cancer care, from diagnosis, treatment, survivorship and death. Because of inadequate resources in many Low-income countries, informal caregivers take up the responsibility of caring and providing for most of the needs of cancer patients, performing tasks that may range from support with



seeking health care, activities of daily living and basic care needs; and they therefore bare a sizeable burden during the illness of their patients.

The burden associated with caregiving may negatively impact the caregivers psychologically, emotionally, physically and financially. Because of limited support systems, caregivers may experience high stress burden, low quality of life, psychological distress and may lack self-care. This may have a negative impact on their overall quality of life and health. To be able to provide care for another, one needs to be healthy and their needs have to be met, which most caregivers may not have.

It is not known if there are available support systems for the caregivers to navigate through the burdens associated with their roles and tasks, and how they cope with their different day to day challenges and burdens. Much focus is placed on the patients while the wellbeing of the caregiver is often neglected. If the wellbeing of caregivers is not assessed and addressed, the impact of the burden they carry may affect the quality of care they offer for their sick ones. It is therefore imperative that a study looking at the wellbeing of caregivers was carried out in order to get information that can guide the designing of interventions to address their needs.

### **1.3 Objectives of the Study**

#### **1.3.1 Main Objective**

To explore the wellbeing of informal caregivers of cancer patients at Uganda Cancer Institute.

#### **1.3.2 Specific Objectives**

- i. To explore the tasks performed by the informal caregivers of cancer patients at Uganda Cancer Institute
- ii. To describe the forms of burden experienced by informal caregivers of cancer patients at Uganda Cancer Institute.
- iii. To explore the coping mechanism of the informal caregivers of cancer patients at Uganda Cancer Institute.

#### **1.4 Research Questions**

- i. What are the tasks performed by the informal caregivers of cancer patients at Uganda Cancer Institute?
- ii. What are the forms of burden experienced by informal caregivers of cancer patients at Uganda Cancer Institute?
- iii. What are the coping mechanisms of the informal caregivers of cancer patients at Uganda Cancer Institute?

#### **1.5 Significance of the Study**

These study findings provide information that will guide advocates for the informal caregiver to ensure services and equipment appropriate to the circumstances are provided. This would also ensure that medical staffs are informed about the needs and problems of informal caregivers.

Findings will create awareness to the health professionals about the tasks performed by the informal caregivers and the need to open communication channels with them and potential ways of improving the quality of patient care by improving the wellbeing of the informal caregiver. The results of this study could help to guide effective coordination essential for informal caregivers to get ready access to information from doctors, nurses and therapists about available medical services and how to use them.

The study provides information about informal caregiver and support available, and provides information about local services available for both the person being cared for and the informal caregiver.

Findings also may provide the future scholars and researchers with information regarding data on the wellbeing of informal caregivers of cancer patients. The study also provides future students a vast amount of information about the situation and importance of informal caregivers of cancer patients.

Findings of this study could guide policy formulation by government regarding caregiving for cancer patients. The informal caregivers who provide care for cancer patients in Uganda need social protection and intervention programs to support them.

## 1.6 Conceptual Framework

The conceptual framework illustrates the relationship between dependent variable and independent variables.

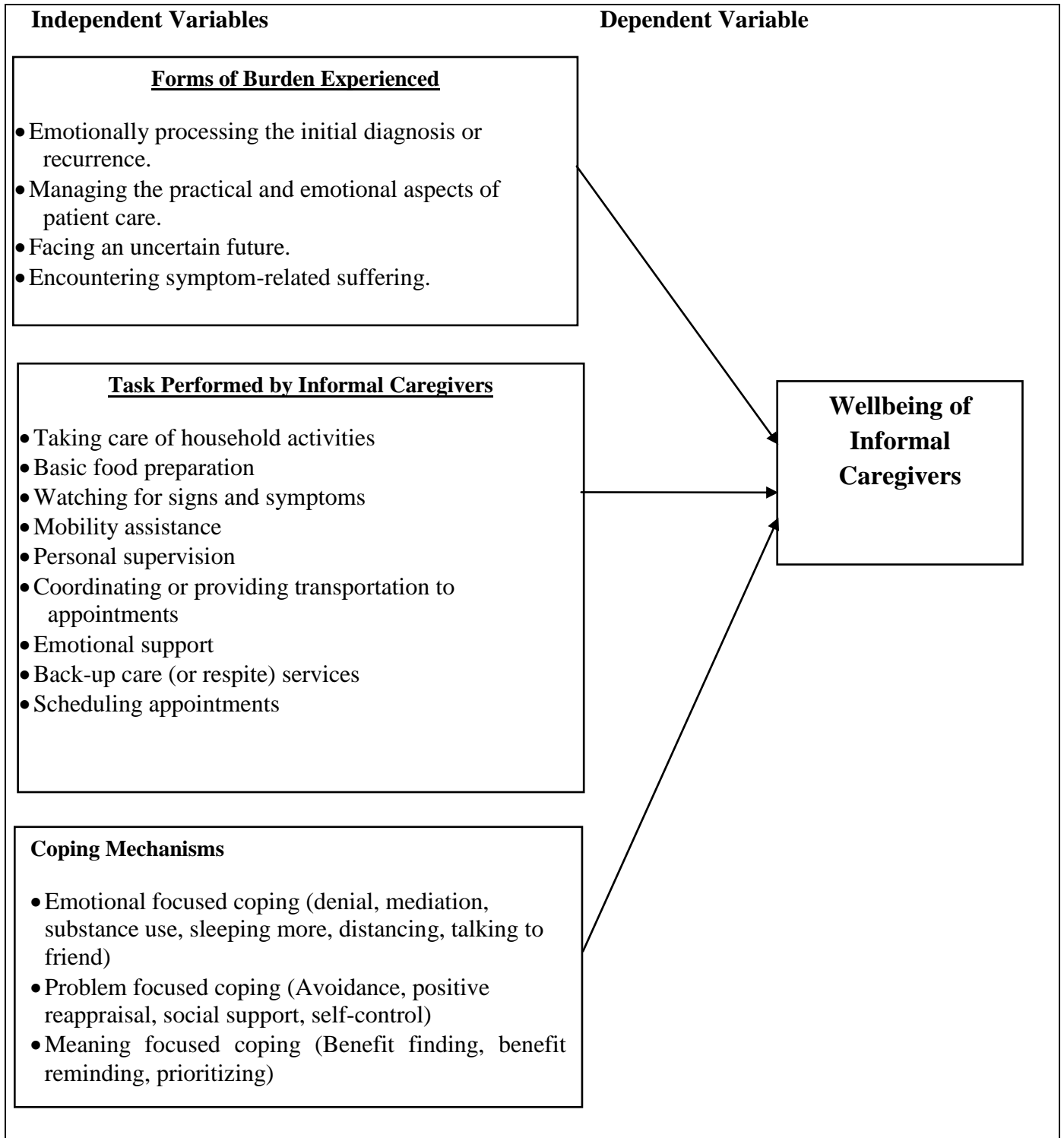


Figure 1: Conceptual Framework

### **Narratives of the conceptual framework**

The framework is a diagrammatic presentation of the relationship between dependent variables and the influencing factors, the independent variables. The dependent variable is informal caregiver's wellbeing which is believed to be influenced by forms of burden of the disease and tasks performed towards caring for the cancer patients. The forms of burden experienced include Emotionally processing the initial diagnosis or recurrence, managing the practical and emotional aspects of patient care, facing an uncertain future, and encountering symptom-related suffering. While the tasks performed include; taking care of household activities, basic food preparation, watching for signs and symptoms, mobility assistance, personal supervision, coordinating or providing transportation to appointments, emotional support, back-up care (or respite) services and scheduling appointments.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.0 Introduction**

This chapter is a review of findings and facts from previously written literature relevant to the specific problems to be investigated. The literature was obtained from research published journals and dissertations, online publication articles in Google, CINAHL, Google Scholar, CDC, WHO, and PubMed. The chapter presents the review of literature in the order of: general information on wellbeing of informal caregivers of cancer patients, the tasks performed by the informal caregivers of cancer patients, the forms of burden experienced by informal caregivers of cancer patients, and the coping mechanism of the informal caregivers of cancer patients.

### **2.1 Wellbeing of Informal Caregivers**

The life of an informal caregiver is stressful and causes an increase in symptoms related to physical, mental, and financial strain (Grant *et al.*, 2013). However, research from several countries around the globe indicate that there was an abundance of literature addressing, caregiver burnout and stress in relationship to the terminally ill patients. There are also informal caregivers who experience all kind of burdens, which can have a negative influence on their physical, emotional and social well-being leading to depression, anxiety, and high levels of stress (Zarit, Todd, & Zarit, 1986; through Guay *et al.*, 2017; Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). For example, partners of cancer patients often experience negative aspects such as feelings of sadness, fatigue or sleeping problems (Stenberg, Ruland & Miaskowski, 2010).

Even in developed countries like Europe and America, informal caregivers experience difficulties with accepting the illness and dealing with it. Moreover, they may feel like they have a duty of care and must be there to support their loved one at all times (De Klerk, de Boer, Plaisier, Schyns & Kooiker, 2015). Some partners even forget to care for themselves including taking care of their own needs, wishes, and free time. This can lead to emotional and physical exhaustion and a so-called “emotional roller-coaster” with feelings of fear, guilt, helplessness and frustration (Stenberg, Ruland & Miaskowski, 2010). Besides, informal caregivers who are taking care of someone.

There are several needs regarding the informal caregivers’ own wellbeing separated from the act of giving care to the loved one. It is more about the informal caregivers themselves. They

may experience the need to share their experience about personal feelings or to talk to people who are in the same situation to feel some support (Sermeus, 2016). This can be done by being in contact with other informal caregivers, such as peer support. It is also possible to share information on social media or meet others in this way (Middelweerd *et al.*, 2015).

Some informal caregivers experience high levels of distress and difficulties coping with their emotions. In line with that, in studies, informal caregivers have indicated the need for information or exercises that can help them with these aspects. Psychological exercises, such as mindfulness-based or relaxation exercises, may be helpful for them (Whitebird *et al.*, 2012). Also, self-compassion, prayers or goal-setting can work as psychological exercises for informal caregivers to decrease stress levels (Neff, Hsieh, & Dejitterat, 2005).

In low resource-settings, such as on the African continent, informal caregivers might also lack time for themselves and are often consumed with feelings of responsibility and guilt when they do find some free time (Stenberg, Ruland & Miaskowski, 2010). This can be reduced by providing informal caregivers more personal recreation and free time, away from caring for their loved one (Cantor, 1983; Liu & Yu, 2017). In a cross-sectional analysis of baseline data on caregivers of patients enrolled in a randomized trial of early palliative care, a significant proportion of caregivers reported elevated levels of anxiety (42.2%) or depression (21.5%). Risk factors for caregiver depression were patients' expectation of cure and patients' use of emotional support coping. Patients' use of acceptance coping was associated with less caregiver anxiety (Nipp *et al.* 2016). A study of caregivers of patients with pancreatic cancer reported similar results: 39% of caregivers had elevated levels of anxiety, and 14% had elevated levels of depression, compared with community norms (Janda *et al.*, 2016).

Social and family factors can influence the health outcomes and quality of life of informal caregivers. Little is known about the distribution and correlates of such factors for caregivers of cancer patients. The results indicate the importance of personal and caregiving-related characteristics and the broader family context to social factors. Future work is needed to better understand these pathways and assess whether interventions targeting social factors can improve health or quality-of-life outcomes for informal cancer caregivers (Litzelman *et al.*, 2016).

Noonan *et al.* (2017) examined the relationship between meaning in caregiving--positive beliefs about the caregiving situation and the self as caregiver--and the psychological well-

being of 131 informal caregivers to community-residing frail elders. Measures of well-being included depression, self-esteem, mastery, role captivity, and loss of self. Meaning in caregiving explained a significant portion of the differences in depression and self-esteem scores even after demographic and stressor variables had been controlled. Meaning was not related to mastery, role captivity, or loss of self. The conceptual parameters of meaning in caregiving are discussed, as are directions for future research.

A cross-sectioned descriptive design and 210 caregivers providing care to advanced cancer patients were purposely selected. The results indicated that the caregivers were in their youthful and active economic age, dominated by females, Christians, spouses, partners and parents. The burden levels experienced by the caregivers were as follows: severe (46.2%), moderate (36.2%) and trivial of no burden (17.6%). The forms of burden experienced were physical (43.4%), psychological (43.3%), financial (41.1%) and social (46.7%), quite frequently and nearly always. Psychological and social forms of burden had the highest weighted score of 228 in terms of magnitude of burden (Akpan-Idiok & Anarado, 2019).

Many psychological factors have been investigated among informal caregivers. Individuals experience a diverse set of emotions when caregiving, related to the relationship with the recipient, the gravity of the recipient's condition, the caregiving role, and their own life. Emotion regulation is thus particularly essential to them and plays an important role in their caregiving experience. One study highlighted that alexithymia was a risk factor for burnout, especially for emotional exhaustion and depersonalization (Gérain & Zech, 2019). Similarly, emotional competencies appear to be a promising resource for the caregiver. Emotional competencies have been found to play a role in preventing professional and parental burnout (Gérain & Zech, 2019), (Görgens-Ekermans & Brand, 2017; Mikolajczak *et al.*, 2018) and identified as a promising target of intervention to reduce informal caregivers' psychological distress (Weaving *et al.*, 2019). More broadly, personality traits also seem to have an impact on subjective burden and informal caregiver burnout (Chiao *et al.*, 2015; Gérain & Zech, 2018).

One of the ways to consider emotion regulation is in terms of individuals' ways of coping. Caregivers who have a submissive or helpless approach (Duygun & Sezgin, 2018; Yılmaz *et al.*, 2019) or who engage in denial (Onwumere *et al.*, 2017) appear more prone to caregiver burnout than caregivers with coping strategies such as confident and optimistic approaches

(Yılmaz *et al.*, 2019) or positive reappraisal and active coping (Onwumere *et al.*, 2017). More generally, the use of a wider range of coping strategies appears to lead to less subjective burden (Adelman *et al.*, 2019). However, these coping styles are global dispositions regarding emotion regulation. The investigation of the coping strategies used when actually experiencing the situation – e.g., through ecological momentary assessment would allow us to understand if they are effective responses to the stress caregivers' face.

Cognitions, especially (dys)-functional thoughts and perceived competence, also play an important role in the caregiving experience. Perceived ability to cope with the care-recipient's illness or behaviors is a predictor of burden and burnout (Cuijpers and Stam, 2000). It is directly related to caregivers' needs for knowledge regarding the recipient's health issue (Zarit and Zarit, 2015), and to self-efficacy (Ducharme *et al.*, 2017). Regarding the caregiving role, lack of choice in becoming the caregiver is associated with higher subjective burden (Adelman *et al.*, 2019). Intrinsic motivation to care appears to be a protective factor for informal caregiver burnout (at least for emotional exhaustion, in Kindt *et al.*, 2015). Constant worrying and need for control in the caregiving role appear to be risk factors, as they require chronic alertness on the part of the caregiver (Cuijpers and Stam, 2000; Lindström *et al.*, 2017). More generally, a strong sense of coherence appears to be a protective factor against burnout (Götze *et al.*, 2015; Goetzmann *et al.*, 2017).

The physical health of caregivers is a factor that determines their involvement in caregiving. Healthy caregivers often take more responsibility in caregiving (Pinquart and Sörensen, 2007). The experience of somatic disorders, illness, or chronic pain has been shown to put pressure on caregivers, making them more prone to burnout (Hattori *et al.*, 2000, 2001; Demirhan *et al.*, 2017). While this is especially acute for aging caregivers, it is a factor in all caregivers' capacities to provide care and in the difficulties they may face. Future research should thus consider more closely how the evolution of caregivers' physical state could affect their ability to manage the situation and impact their mental health.

## **2.2 Tasks performed by the informal caregivers of cancer patients**

The roles and tasks played by informal caregivers are multifaceted, with different aspects of patient care and needs being provided for. In a recent study that looked at the role, impact and support of informal caregivers of palliative care patients in Uganda, Nigeria and Zimbabwe, caregiver roles were reported to be both clinic and home related. Caregivers



managed information and attended clinic appointments, as well as supported patients with activities of daily living and basic tasks like bathing and nutrition (Adejoh *et al.*, 2020). Informal caregivers do not only care for their loved ones, but also carry out different tasks. For example, they provide emotional support, take responsibilities for the household and children, and manage the care receivers' diseases by scheduling appointments or administering medication (Guay *et al.*, 2017; Stenberg *et al.*, 2010).

The home care of cancer patients requires extra effort and management. The daily life activities of patients performed by caregivers consist of shopping for the patient and house, creating suitable living areas to accommodate patient mobility, helping with financial transactions of the house and the patient, and supporting patient nutrition. Informal caregivers are also responsible for controlling the body temperature and pain of the patient (Karabulutlu, 2014). A study that looked at the role of family caregivers and perceived burden when caring patients hospitalized with advanced cancer reported that the tasks performed by most caregivers included providing emotional support, preparing meals, giving medication, transporting patients to hospitals and feeding (Muliira, Kizza & Nakitende, 2018).

According to the study by Muliira *et al.* (2018) about the roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients, a perspective from a low-income country, it was observed that caregivers of cancer patients perform several tasks. The most time-consuming tasks for adult children and spouses were providing emotional support, transportation, and monitoring symptoms. The tasks regularly performed by most caregivers were: providing emotional support (79.8%), feeding (68.5%), transporting to other appointments (62.5%), preparing meals (55%), and giving medications (46.4%).

According to the results of another study (Milbury *et al.*, 2020), being a caregiver means helping with the daily needs of the patient. As such, caregivers of cancer patients perform a number of tasks, including: giving personal care (such as bathing, dressing or shaving), helping with medical care (such as changing a bandage or giving an injection), doing household chores (such as cleaning, cooking, or laundry), and often doing doctor visits and pick up medicines on their patients' behalf. Further, they also give emotional and spiritual support, make appointments and planning care and services by phone or email.

### **2.3. Forms of burden experienced by informal caregivers of cancer patients**

Burden of care is a concept that describes the physical, emotional, social, and financial problems that can be experienced by family care givers.

Studies have shown that informal caregivers experience several forms of burden in the process of caring for persons suffering from cancer. Caregiving has been reported to cause general strain, disappointment, and isolation among family caregivers (Muliira *et al.*, 2018). According to the results of a 2016 study by the NAC (2016), it was observed that caregiving for patients with cancer was noted to be episodic and lasted for approximately 2 years on average. According to this study, 50% of the caregivers reported high emotional stress related to caregiving; 25% reported high financial strain; 50% had employment disturbances and to work for an average of 35 hours per week; 43% reported needs for help managing emotional and physical stress; 40% wanted help making end-of-life decisions; 33% wanted help keeping their friend or relative safe at home (NAC, 2016).

According to other studies (Litzelman, Green & Yabroff, 2016; El-Jawahri *et al.*, 2015), caregiving was reported to be relational, and as such burden associated with it can stem from the relationship the caregiver has with the cancer patient especially toward the terminal end of life. There are important implications for the interconnectedness between patient and caregiver that requires the attention of the oncology clinician. For example, Kershaw *et al.* (2015) indicated that caregivers of patients with cancer develop both mental and physical health problems.

In another study, it was reported that the psychological well-being of caregivers need serious attention as it also seems to influence patients' evaluations of the quality of their care. In this survey which involved 689 patients and their caregivers, there were cases of depression reported among the caregivers who participated in the study, and the levels of depression correlated with the patients' quality of life and care they were receiving (Litzelman *et al.*, 2016).

According to another study which involved 23 informal caregivers of patients with advanced colorectal cancer, caregivers suffered the following burdens: emotional burden, stress, physical difficulties, and social difficulties. In a telephone survey conducted with 196 caregivers of patients with renal cell carcinoma to study the associations between psychological adjustment and caregivers' experiences and unmet needs (Oberoi *et al.*, 2016);

investigators demonstrated that 64% of caregivers had at least one significant unmet need; 53% had three or more unmet needs; and 29% had ten or more unmet needs. Elevated anxiety was found in 29% of respondents, and depression was found in 11% of respondents. Unmet information needs and worse experiences of care during surgery were risk factors for caregiver depression. Unmet information needs were the only risk factor for anxiety.

Caregivers of patients with advanced-stage lung or colorectal cancers have also reported elevated levels of anxiety or depression. In a cross-sectional analysis of baseline data on caregivers of patients enrolled in a randomized trial of early palliative care (Nipp *et al.*, 2016), a significant proportion of caregivers reported elevated levels of anxiety (42.2%) or depression (21.5%). Risk factors for caregiver depression were patients' expectation of cure and patients' use of emotional support coping. Patients' use of acceptance coping was associated with less caregiver anxiety. A study of caregivers of patients with pancreatic cancer reported similar results: 39% of caregivers had elevated levels of anxiety, and 14% had elevated levels of depression, compared with community norms (Janda *et al.*, 2017).

According to the study by Akpan-Idiok & Anarado (2014) about the perceptions of burden of caregiving by informal caregivers of cancer patients attending University of Calabar Teaching Hospital, the forms of burden experienced by the caregivers were physical (43.4%), psychological (43.3%), financial (41.1%) and social (46.7%), quite frequently and nearly always. Psychological and social forms of burden had the highest weighted score of 228 in terms of magnitude of burden. The result further showed that there was a significant and inverse association between caregivers' burden and the care receivers' functional ability.

#### **2.4 Coping mechanism of the informal caregivers of cancer patients**

Coping has been defined as "those changing cognitive and behavioral efforts developed for managing the specific external and/or internal demands judged as exceeding or surpassing the individual's own resources" (Lazarus and Folkman (2019). The function of problem-focused coping is to change the troubled person-environment relationship by acting on the environment or oneself. The function of emotion-focused coping is to change the meaning of what is happening, which mitigates the stress even though the actual conditions of the relationship have not changed.

Informal caregivers of patients with cancer tend to use both types of strategies to combat most stressful events. For example, in a quantitative study by Canadian researchers Chapman

and Pepler (2018) examined the relationships between general coping style, hope, and anticipatory grief.

The authors found a moderate relationship between these variables for family members of palliative care patients. Hope correlated with confrontive coping, which is described as problem-solving and provided an incentive for constructive coping with loss. Steele and Fitch (2016), explored the use and effectiveness of coping strategies employed by family caregivers of patients with terminal cancer. The participants used coping strategies such as keeping busy, thinking positively, and learning more about the problem and found that talking the problem over with family and friends was an effective coping strategy. In an interpretive descriptive research, 29 active family caregivers were interviewed about the coping strategies used and the perceived factors that influence their ability to cope (Stajduhar *et al.*, 2018).

The researchers reported that the three most prominent ways of coping reported by the family caregivers were: (a) planful problem-solving; (b) seeking social support; and (c) self-controlling. The participants identified 5 factors that influenced their ability to cope including: (1) the caregiver's approach to life, (2) the patient's illness experience, (3) the patient's recognition of the caregivers' contribution to his or her care, (4) the quality of the relationship between the caregiver and the dying person, and (5) the caregiver's sense of security (Stajduhar *et al.*, 2018).

A randomized controlled trial by McMillan *et al.* (2016) with three groups of 354 family caregivers of community hospice patients with advanced cancer demonstrated the positive outcomes of problem-focused coping strategies. The researchers claim that the group trained in problem-solving strategies had improved caregiver quality of life and also lower burden related to patients' symptoms and caregiving tasks compared to the other two groups that received training in emotion-focused strategies or no training. Similarly, problem-focused coping strategies have been positively effective for caregivers of patients with cancer (Houts *et al.*, 2016) and cancer patients (Sobel & Worden, 2017).

A cross-sectional study used data from the Cancer Care Outcomes Research & Surveillance Consortium to the correlations among health behaviors and coping strategies in a population of lung and colorectal cancer caregivers. The finding indicated that many informal caregivers

reported regular exercise (47%) and adequate sleep (37%); few reported smoking (19%) or binge drinking (7%). Problem-focused coping was associated with greater physical activity and less adequate sleep (effect sizes [ESs] up to 0.21,  $p < .05$ ). Those with some physical activity scored higher on emotion-focused coping, while binge drinkers scored lower (ES = 0.16 and 0.27,  $p < .05$ ). Caregivers who reported moderate daily activity, current smoking, binge drinking, and feeling less well rested scored higher on dysfunctional coping (ES up to 0.49,  $p < .05$ ) (Litzelman *et al.*, 2018).

A descriptive research design, with the use of a convenience sample found that majority of the caregivers employed emotionally focused ways of coping with the caregiving burden such as: "I was hoping for a miracle" (mean 2.19), "I was hoping that time would change things and simply waited" (mean 2.14) and "I found consolidation in my faith to God" (mean 2.05). Assertive ways of coping such as "I expressed my anger to the patient" (mean 0.78) and "I dared to do something risky" (mean 0.98) were less likely to be used by the caregivers. This means that Caregivers employ various strategies in order to cope with the strains associated with the complex physical and emotional demands involved in caring (Papastavrou *et al.*, 2017).

## **2.5 Summary of Reviewed Literature**

In summary, caregivers provide essential support and resources to the person with cancer. The role of informal caregiver, however, creates demands that may exceed the caregiver's resources and, ultimately, cause negative psychological consequences. The review of literature provides information about the demands of caregiving for cancer patients, the resources valued by caregivers, potential moderators, and coping strategies. The process begins with the primary appraisal, which is a judgment about the relevance of the health threat and any demands on the caregiver. A demand that is judged to be relevant receives a secondary appraisal to evaluate the likelihood that available resources have the potential to reduce or overcome the demand. Burden is perceived to be high when the difficulty of the demand outweighs the available resources. Coping strategies also determine whether the psychological consequences of the perceived burden are negative or positive.

## **CHAPTER THREE: METHODOLOGY**

### **3.0 Introduction**

This chapter describes the study design, study area, study population, study unit, selection criteria, sample size determination, sampling procedures, study variables, data collection techniques, data collection tools, data management and analysis, quality control measures, ethical consideration, limitation of the study and plan for dissemination.

### **3.1 Study Design**

The study adopted a descriptive cross-sectional design in which qualitative data was collected from caregivers of cancer patients. A cross-sectional design was chosen because data was collected at one point in time.

### **3.2 Study Area**

The study was carried out at Uganda Cancer Institute (UCI) which is a public, specialized, tertiary care medical facility owned by the Uganda Ministry of Health. The facility is located along Upper Mulago Hill Road, on Mulago Hill, in the Kawempe Division of Kampala, about 4.5 kilometres (2.8 mi) north of the central business district of the city. The geographical coordinates of the institute are: 00°20'29.0"N, 32°34'40.0"E (Latitude: 0.341389; Longitude: 32.577778). The main focus of UCI is on research, training, consultation, prevention and treatment of cancer in areas of Pediatrics, Oncology, Gynecology, Radiotherapy, surgery, pharmacy. Recently UCI started venturing into bone marrow transplants. Patients also receive palliative care and rehabilitation services.

The new building, called the "Uganda Cancer Institute/Fred Hutchinson Cancer Research Center Clinic and Training Institute", is a project of the UCI/Hutchinson Center Cancer Alliance, a collaboration of UCI and the Fred Hutchinson Cancer Research Center in Seattle, Washington, USA. In May 2015, the completed facility opened and began attending to patients. The facility (UCI) maintains an in-patient and out-patient facility with a capacity of 80 beds and, on average of about 200 out-patients daily. The UCI has been selected for this study because of being the main cancer treatment and referral center in Uganda.

### **3.3 Sources of Data**

Primary data was collected from the caregivers of cancer patients (study participants). Secondary data was obtained from peer reviewed published articles and Uganda Ministry of health publications.

### **3.4 Study Population**

Target population: Informal caregivers of cancer patients

Accessible population: Informal Caregivers of cancer patients at Uganda Cancer Institute

#### **3.4.1 Inclusion Criteria**

The study included informal caregivers who voluntarily consented in writing to participate in the study. Only those aged at least 18 years of age were included as this is the age of consent in Uganda. Further, only those who had cared for their patient with cancer for a period of at least a month were included so as to enable only those with experience to participate in the study.

#### **3.4.2 Exclusion criteria**

The study excluded those who: 1) who were not in the right mental or psychological state to participate in the study, 2) those who were not available at the time of the study, 3) those who were busy/engaged and therefore couldn't have time to concentrate, and 4) those who were personally known to the researcher.

### **3.5 Sample Size Determination**

The study was conducted among twenty informal caregivers who met the study inclusion criteria for participation in this study. The sample size for in-depth interviews was determined by saturation point. In the current study, saturation was obtained at the eighth informal caregiver in line with Creswell (2013) who recommended that for qualitative studies, a sample size of 6-12 is adequate as saturation is reached around this number where by adding more respondents does not result in getting additional perspectives or information from the respondents. For focus group discussions, 6 participants were included per group (Krueger & Casey, 2002).

### **3.6 Sampling Procedures**

Purposive sampling technique was used to select participants for the study (MacDougall & Fudge, 2001). In this method, the research team approached the informal care-givers and briefed them about the study purpose and processes. Those who met the study inclusion criteria were considered for the study.

### **3.7 Study Variables**

This study was guided by the following variables

#### **3.7.1 Dependent Variable**

This was the outcome variable and therefore it was the wellbeing of the informal caregivers of cancer patients.

#### **3.7.2 Independent Variables**

These were the predictor variables. As such, they were the different aspects that determine people's wellbeing. These were therefore the aspects of physical, psychological, socioeconomic wellbeing, and coping mechanisms.

### **3.8 Data Collection Techniques**

Data was collected through in-depth interviews and two Focus Group Discussions (FGD) as described by (MacDougall & Fudge, 2001). The purpose of the study was explained to the participants after which an informed consent was obtained. Voice recordings were done for both the in-depth interviews and FGDs.

### **3.9 Data Collection Tools**

Semi structured interview guides were developed for both in-depth interviews and FGDs. They contained two sections: the first section was for collecting information about participant demographic characteristics while the second part consisted of open-ended questions to allow the respondents to give their varied opinions in line with the study objectives of the wellbeing of informal caregivers of cancer patients, forms of burden, the tasks they performed in the process of caring for their patients, and their coping mechanisms. The interview guides were translated into the Luganda language since it was the commonly spoken language at UCI.



### **3.10 Quality Control Measures**

This was done to ensure that the research tools measure was intended to be measured. Quality control measures was included validity and reliability checks as well as training of research assistants in the administration of the research tools. The data collection tools were pretested in order to ensure that the contents/questions were easily understandable for the respondents. It was done by interviewing five informal caregivers at Nsambya Hospital which is also located within Kampala City. After pre-testing, adjustments were made in the research tool in order to make it easily understandable for the main study respondents.

#### **3.10.1 Training of Research Assistants**

Two (2) research assistants were involved in the study to support the principal researcher during the data collection process. Together with the principal researcher, they formed the data collection team. The research assistants were at least diploma nurses who had gone through research processes. However, they had to undergo a day's training/mentorship exercise to equip them for the data collection exercise.

### **3.11 Data Management Measures**

These included data editing and data coding.

#### **3.11.1 Data Management and Analysis**

Quantitative data on participant demographic characteristics was coded and entered into Microsoft Excel and analyzed using descriptive statistics of frequencies and percentages. For qualitative data, the voice recordings were transcribed verbatim in MS word. The transcribed data was thematically analyzed according to Braun and Clarke's guide for thematic analysis (Braun & Clarke, 2006). The transcriptions were read over again to gain familiarity with the data, after which codes were generated. Themes and repeated views were searched from the coded extracts and entire data set, then sub-themes were generated. The subthemes were read through and emerging themes formed.

### **3.12 Ethical Considerations**

Approval to conduct the research was sought from the Clarke International University's Research Ethics Committee (CIU-REC). An introductory letter was obtained from the School of Nursing and Midwifery and presented to the administration of Uganda Cancer Institute from whom administrative clearance was sought.

The purpose of the study, study processes, and the reason for participating in the study were explained to the participants after which a voluntary written informed consent was obtained. Participants were informed of their rights, especially the right to stop participating in the study at any point if they felt so.

Confidentiality was maintained by using identifier codes instead of names and the interviews and FGDs were conducted in a selected space away from crowds.

### **3.13 Covid-19 Mitigation Plan**

Due to the challenges brought by the CORONA VIRUS (COVID-19) pandemic affecting crowding, the researcher adhered to the Standard Operating Procedures (SOPs) set by the Ministry of Health. During the in-depth interviews, the interviewer and interviewee maintained two meters sitting distance between them and for the FGD, seats were arranged two meters apart. Disposable masks were provided for all the study participants; and the researcher provided alcohol-based sanitizers which were used just before and at any point during and after the interviews and FGDs, as was necessary.

### **3.14 Limitations of the Study**

The study relied on self-reported data, which could have been affected by recall and social desirability bias. However, this was alleviated by allaying the respondents' fears and assuring them of confidentiality so that they don't fear to divulge important information needed in the study.

## CHAPTER FOUR: STUDY RESULTS

### 4.0 Introduction

In order to explore the wellbeing of informal caregivers of cancer patients at UCI, this study was conducted among twenty informal caregivers who met the study inclusion criteria. In-depth interviews were conducted among 8 informal caregivers as saturation was obtained at the eighth respondent, in line with Creswell (2013) who recommended that for qualitative studies, a sample size of 6-12 is adequate as saturation is reached around this number where by adding more respondents does not result in getting additional perspectives or information from the respondents. For focus group discussions, we included 6 participants per group (Krueger & Casey, 2002).

### 4.1 Demographic Characteristics

*Table 1: Distribution of in-depth interview respondents by their demographic characteristics*

Variable	Frequency (n=8)	Percentage (%)
<b>Age</b>		
18-25 years	05	62.5
Above 25 years	03	37.5
<b>Gender</b>		
Female	04	50.0
Male	04	50.0
<b>Level of education</b>		
Primary Education	04	50.0
Secondary Education	04	50.0
<b>Employment status</b>		
Employed	00	0.0
Not Employed	08	100.0
<b>Relationship to patient</b>		
Parent	05	62.5
Sibling	03	37.5

According to the study results summarized in table 1 above, 05(62.5%) of the study participants were aged 18 – 25 years. Half were females; half were of primary education; 05(62.5%) were taking care of their biological parents. All were not employed at the time of the study.

### 4.2 Wellbeing of Informal Caregivers of Cancer Patients at UCI

The study found that wellbeing of informal caregivers of cancer patients at UCI to be mainly negative. This mainly emerged from the categories of caregiving being a “full time job” and being “challenging” role. Table 2 below shows the themes, sub themes and categories that emerged from the study.

Table 2: Themes and Categories emerging from analysis

Theme	Sub theme	Categories
Wellbeing	Negative wellbeing	Full time job Challenging role
Performed tasks	Activities of daily living Treatment support	Patient Feeding Patient Bathing Medicine giving
Forms of burden	Financial constraints Fears and concerns	Lost employment Inability to purchase medicine Patient might die
Coping mechanism	Self-rejuvenation	Spiritual renewal Keeping busy

#### 4.2.1 Sub Theme One: Negative Wellbeing

Analysis of study findings show that all study participants experienced negative wellbeing as a result of taking care of their relatives suffering from cancer. This sub theme emerged from two categories of: “full time job” and “challenging role”. Participants reported that caregiving for cancer patients is a full-time job which requires the caregiver to be present with the patient all of the time. This can be observed from their quotes below:

*“... it is a full time job.... You can’t leave the patient in that state... you cannot at all. You have to devote yourself fully ...” (P.1)*

*“... it is difficult because you have to be around full time to take care of the patient. You cannot move away to have some enjoyments ...” (P.6)*

*“... you have to be available all the time. All days of the week.. no resting.... You to be available full time ...” (P.7)*

*“... you have to be present every day ... it is a full time job... you can’t leave him alone ...” (P.8)*

*“... it is a full time job... you must be present all the time ...” (participant 3 of Male FGD).*

*“...caregiving for the patient is a full time job... you have to be present all the time to help your patient ...” (participant 1 of female FGD).*

Study participants reported that caregiving for cancer patients is a challenging role, and mentioned several constraints that make caregiving to cancer patients challenging. This is evidenced in some of their quotes below:

*“... it’s not easy to take care of the patient ...not easy at all ... it is really a challenging job ...” (P.1).*

*“... I find it challenging ...sometimes the patient needs medicine and you don’t have money to buy it. Or food and you can’t buy it.” (P.3).*

*“... it is challenging especially when it comes to getting adequate items and supplies to use like medicine and what to use while in hospital... it is not easy at. It is very challenging... I have no one to run to...” (P.8)*

*“... the job canbe challenging because you have to put in everything ... you have to put in a lot of time ... and sometime you don’t have what to use while in the hospital ...” (Participant 1of Male FGD).*

*“... it can be challenging ... sometimes you get worried that they patient is about to die ...” (Participant 2 of Male FGD).*

*“... it is very challenging ... a lot of things are involved ... the job is very demanding ... you have to be ready to face any eventualities...” (Participant 4 of Female FGD).*

*“... caretaking for the patient is really a challenging job more-so because you have to be present all the time....” (Participant 6 of Female FGD).*

### **4.3 Tasks performed by the informal caregivers of cancer patients at UCI**

The study found that informal caregivers of cancer patients perform a number of tasks which are categorized into: “activities of daily living” and “treatment support”.

#### **4.3.1 Sub Theme Two: Activities of daily living**

Analysis of study results showed that study participants performed activities of daily living, mainly “patient feeding” and “patient bathing” of their patients suffering from cancer. This is evident from some of their quote below:

*“... it is me who feeds the patient ... sometimes he wakes up when he is very weak and unable to feed himself ... I therefore feed him ...” (P.2).*

*“... I give food to the patient ...sometimes he gets up without strength and you say let me feed him...” (P.3)*

*“...I wash the clothes, I look for food, prepare and serve... and sometimes feed the patient. I do a lot things...” (P.6)*

*“... I do many things...like feeding when the patient cannot do alone ...” (P.7)*

*“... I do feed the patient because sometimes she is weak ...” (Participant 6 of Male FGD)*

*“... one of the things that I do very often is to feed my patient ... you can't fail to do it when you see the patient is not able to do it for himself ...” (Participant 4 of female FGD)*

*“... bathing is one of the things I do often .... If the patient is weak you have to bathe him ...” (P.3)*

*“...sometimes I have to bathe the patient ...” (P.5)*

*“... I sometimes bathe the patient ...” (Participant 6 of Male FGD).*

*“... I always bathe the patient because she is not able to do it for herself ...” (Participant 4 of Female FGD).*

#### **4.3.2 Sub Theme Three: Treatment Support**

The study found that caregivers of cancer patients played an active role in giving treatment to their relatives suffering from cancer. This sub theme emerged from the category of: “medicine giving”. This is evidenced in some of their quotes below:

*“... I give treatment to the patient ...” (P.3)*

*“... I also give treatment...” (P.7).*

*“... I call health workers to come and give treatment. I go and buy medicine.. year.. many things. ...” (P.8)*

*“... I do many things ... including giving treatment to my patient. ...” (Participant 1 of Male FGD).*

*“... I also participate in giving treatment to the patient. ...” (Participant 4 of Female FGD).*

#### **4.4 Forms of burden experienced by informal caregivers of cancer patients at UCI**

The study found that informal caregivers of cancer patients experience some burdens as they care for their relatives with cancer. The forms of burden were categorized into: “financial constraints” and “fears and concerns”.

#### **4.4.1 Sub Theme Four: Financial Constraints**

Study participants reported having financial constraints as they took care of their relatives with cancer. This sub theme emerged from two categories of: “lost employment” and “inability to purchase medicine’.

The study found that caregivers of cancer patients who participated in the study lost employment as a result of the caregiving job being a fulltime one. This can be evidenced from their quotes below:

*“... I am unable to work ... because all the time I am here taking care of the patient ...” (P.1).*

*“... in those days I could get time and go do some work and get some money but now you are always taking care of the patient so you don’t get that time, you have no support...” (P.2).*

*“... you have to be here looking after the patient ... you cannot be able to work because you have to be here with the patient ...” (P.3).*

*“... I lost my job to take care of the patient ...” (P.5)*

*“... I am unable to work ... so as to take care of the patient ... I had to leave my job...” (P.8)*

*“... I do not work ...I am here in the hospital taking care of my sibling ...” (Participant 2 of Male FGD).*

*“...you can’t leave the patient here to go and work ...” (Participant3 of Male FGD)*

*“... you cannot leave and go work because you are always worried he might die ...” (Participant 2 of Female FGD).*

The study found that caregivers of cancer patients experienced the challenge of inability to purchase medicines for their patients, as is evident from their quotes below:

*“... the medicine is very expensive ... I sometimes don't have the money to buy all prescribed medicine it ...” (P.3)*

*“...sometimes the patient needs medicine and I don't have money to buy it...” (P.5)*

*“... I sometimes fail to buy the medicines ...” (P.6)*

*“... there is a challenge that you have to buy everything in the hospital, you buy medicine ...” (Participant 4 of Male FGD).*

*“... I will not differ from my colleagues. We need the government to help us because in most cases money is needed in everything starting with medicine, ...” (Participant 6 of Male FGD).*

*“... medicines are not readily available and we have to buy it yet I don't have the money sometimes for buying all the needed medicine ...” (Participant 6 of Female FGD).*

#### **4.4.2 Sub Theme Five: Fears and Concerns**

Study participants expressed fears and concerns as they took care of their relatives with cancer. These fears were mainly related to the concern that their relative suffering from cancer could die any time. The study found that informal caregivers who participated in the study had the fear and concern that their patient might die soon. This can be observed in the quote below:

*“... I am always worried that the patient may die ...” (P.1)*

*“... you are always worried he might die so you have to be near him as you suffer from poverty as well ...” (P.3)*

*“... I fear that my patient might die ...” (P.5)*

*“... I always have the worry that my patient is going to die (Participant 3 of Male FGD)*

*“... I am always worried that he is going to die any time. (Participant 4 of female FGD)*

#### **4.5 Coping mechanism of the informal caregivers of cancer patients at UCI**

The study found that informal caregivers of cancer patients had some coping mechanisms in relation to their negative wellbeing as they took care of their relatives suffering from cancer. This was mainly through self-rejuvenation mechanisms.



#### 4.5.1 Sub Theme Six: Self-Rejuvenation

Study participants tried to cope with their negative experience in relation to caring for their relative with cancer, through self-rejuvenating activities. This sub theme emerged from two categories of: “spiritual renewal” and “keeping busy”.

The study found that caregivers of cancer patients who participated in the study tried a number of spiritual means as coping mechanisms in relation to their negative experiences as they took care of their relatives suffering from cancer.

This can be evidenced from their quotes below:

*“... I listen to the word of God ...” (P.1)*

*“... what I have done, is to listen to gospel music, it strengthens me so much, listening to the radio, there are some programmes, they take away the worry, and also reading books ...” (P.2)*

*“...I read the bible, listen to gospel music...” (P.3)*

*“... I listen to gospel music ... so as to take care of the patient ...” (P.4)*

*“... what I do is to leave everything in God’s hands. I also pray and also listen to gospel music ...” (P.5)*

*“... I listen to the word of God most of the time through listening to gospel messages over the radio...” (P.6)*

*“... I always listen to the word of God to get courage ” (Participant 2 of Male FGD)*

*“... I read the bible and listen to gospel preaching on the radio ...” (Participant 5 of Male FGD)*

*“... I listen to gospel music ... Participant 3 of Female FGD).*

*“... I listen to the word of God ...” (Participant6 of Female FGD).*

Some study participants coped through keeping themselves busy, as can be observed in the quote below:

*“... I talk to friends. I keep myself busy...” (P.4)*

*“... I also do things that keep me busy... and talk with friends and family. We keep encouraging each other....” (P.5)*

*“... I keep myself busy ...” (Participants 2of Male FGD).*

*“... I try keeping myself busy so that I don't focus so much on the challenges at hand...” (Participants 5 of female FGD).*

### **Summary of Results**

This chapter presented the main findings of the study that was conducted to explore the wellbeing of informal caregivers of cancer patients at UCI. In summary, the study found that informal caregivers of cancer patients at UCI experience negative wellbeing, and this was mainly attributed to the caregiving job being a full-time job and being a challenging role. However, they perform a number of tasks for their patients suffering from cancer, and these were categorized into activities of daily living (tasks such as patient feeding and patient bathing) and treatment support (task being medicine giving). The study found the forms of burden experienced by informal caregivers of cancer patients at UCI to include financial constraints (such as loss of employment and inability to purchase medicine) and fears and concerns (the fear that the patient might die). The study found the coping mechanism of the informal caregivers of cancer patients at UCI to include mainly self-rejuvenation (spiritual renewal activities, and keeping themselves busy).

## **CHAPTER FIVE: DISCUSSION**

### **5.0 Introduction**

This chapter presents the discussion, conclusion and recommendations from the main findings of the study that was conducted to explore the wellbeing of informal caregivers of cancer patients at UCI.

### **5.1. Wellbeing of Informal Caregivers of Cancer Patients at UCI**

The study found that informal caregivers of cancer patients at UCI experience negative wellbeing. This is mainly attributed to the caregiving job being a full-time job and being a challenging role. This may probably be explained by the fact that cancer is a highly feared and demanding disease that takes a great toll on not only the patients but their caregivers as well. The psychological, social and other burdens associated with the disease make it very demanding, therefore requiring full time attention and being very challenging. The job being full time and challenging could also be attributed to the fact that the informal caregivers were attending to close relatives (parent or sibling) whom the social obligation requires the caregiver to give close attention and support to the loved ones. These findings in essence imply that informal caregivers of patients with cancer are themselves at increased risk of poor quality of life and might result in long term poor or negative health outcomes, which might in future discourage others from volunteering to take up caregiving role for loved ones with cancer.

The above findings are in line with De Klerk et al. (2015) who also reported that caregivers of cancer patients feel like they have a duty of care and must be there to support their loved ones at all times. Similarly the current study is supported by Stenberg et al. (2010), Janda et al. (2016) and Nipp et al. (2016) who also reported patient caregivers in their respective studies as experiencing negative wellbeing, especially in terms of worry and stressful moments. However, this is different from those who give care to cancer patients who are not close relative, in which case they might not be obligated to be present with the patient all the time (Sermeus, 2016). This in essence implies that caregiving for parents or close relatives suffering from cancer; societal and family constructs evoke emotions and other challenges that lead to negative experiences of such caregivers.

## **5.2 Tasks Performed by Informal Caregivers of Cancer Patients at UCI**

The study found that the tasks performed by informal caregivers for their patients suffering from cancer included: Activities of Daily Living (ADL) (tasks such as patient feeding and patient bathing) and treatment support (task being medicine giving). This could be attributed to the fact that cancer, especially in terminal stages, might debilitate the patients so that he/she is unable to perform self-help activities such as feeding, bathing or even taking medicine, thereby requiring the caregiver to help out with such activities. These findings might however, be to the implication that effective management of patients with cancer might not be possible without the support and active participation of the information caregivers of these patients. Activities such as patient bathing, feeding, and helping with treatment can only be done well by a person who is committed and has the love for the patient.

The above finding is supported by other studies on tasks performed by informal caregivers of cancer patients. For example, Adejoh et al. (2020) found out that patient caregivers support their patients with activities of daily living and basic tasks like bathing and nutrition, and treatment giving. The finding is further supported by Karabulutlu (2014) and Guay et al. (2017) who also reported medication administration as part of the tasks performed by patient caregivers, and addition to activities of daily living like feeding and patient their patients. A similar study by Muliira et al. (2018) about the roles of family caregivers and perceived burden when caring for hospitalized adult cancer patients in a low-income country observed that caregivers of cancer patients perform several tasks that include providing emotional support, feeding, transport to appointments, preparing meals and giving medications; agreeing with the results of the current study.

However, in the current study, informal caregivers did not mention scheduling appointments or home-based care yet these were pointed out by Guay et al. (2017) and Adejoh et al. (2020), whose studies reported that caregivers were scheduling appointments with physicians as part of the task that are performed by patient caregivers. The difference in findings may be attributed to the fact that the informal caregivers in the current study were attending to admitted patients, hence the study participants could have restricted themselves to tasks performed while at the hospital (since also the discussion dwelt around activities of the past two weeks).

### **5.3. Forms of Burden Experienced by Informal Caregivers of Cancer Patients at UCI**

The study found the forms of burden experienced by informal caregivers of cancer patients at UCI to include financial constraints (such as loss of employment and inability to purchase medicine) and fears and concerns (the fear that the patient might die). Financial constraints could be attributed to the fact that caregiving was a fulltime job which made it hard for them to be employed and get money to help out during the process of caregiving. This finding could also be attributed to the caregivers in the study being mainly of low levels of education (secondary and below), which could have made it hard for them to gain meaningful employment. These findings imply that there is need for timely and good financial support, especially to help out with the procurement of medicines and other supplies that ease the process of caregiving for patients with cancer.

The above finding is supported by other studies especially in low resource settings. For example, Muliira et al. (2018), Adejoh et al. (2020) and Milbury et al. (2020) in their studies reported that financial constraint was some of the challenges experienced by patient caregivers in limited resources settings, and this was attributed to the caregiving role being fulltime as was also the case in the current study setting. Caregivers may not be able to engage in meaningful and gainful work as their time is taken up by caring for their loved ones. In the current study, caregivers reported experiencing the fear that the patient might die. This could probably be attributed to the fact that the participants in the current study were mainly caregivers of admitted patients. Their presence on admission wards could have led to them observing negative scenes of other patients dying, and this could have made them believe that death is the end of their relatives suffering from cancer.

It could also be attributed to the fact that the participants were caregiving for their close relatives (parent or sibling) which could have roused emotional attachments and fears, in line with Stenberg et al. (2010), Guay et al. (2017) and El-Jawahri et al. (2015) who also reported that caregiving is relational and as such burden associated with it can stem from the relationship the caregiver has with the cancer patient especially toward the terminal end of life. A diagnosis of cancer has also been often times been considered a death sentence and therefore met with a belief that the patient may die and this may serve as a constant worry for both the patients and caregiver.

#### **5.4 Coping Mechanism of Informal Caregivers of Cancer Patients at UCI**

The study found the coping mechanism of the informal caregivers of cancer patients at UCI to include mainly self-rejuvenation (spiritual renewal activities, and keeping themselves busy). Coping through spiritual renewal activities can probably be attributed to the fact that Uganda is a highly religious country with Christians and Muslims comprising about 99% of Uganda's population (Uganda Bureau of Statistics, 2014). This could have influenced the caregivers in the current study to resort to spiritual renewal to cope with the burdens they experienced as they took care of their relatives suffering from cancer. This finding is supported by Muliira et al. (2018) and Stajduhar et al. (2018) who also in their studies pointed out participation in spiritual activities as one coping with the challenges associated with patient care giving.

In the current study, informal caregivers of cancer patients also cope with their caregiving challenges through keeping themselves busy, and this is supported by Steele and Fitch (2016) and Lazarus and Folkman (2019) who also in their respective studies pointed out keeping busy as one of the coping strategies by patient caregivers. Keeping one's self busy may temporarily eliminate the constant preoccupation that caregivers may have about their patients and their respective conditions and fate; and the challenges that come with the role. However, participants in the current study did not mention a strategy of talking about their challenges with family, which was reported to be an effective coping strategy according to Steele and Fitch (2016).

Nonetheless, the difference in findings can be attributed to the current being conducted in a national referral setting which receives clients from different parts of the country, some of which are very distant, and therefore it could have been hard for a patient to be taken care of by many family members. As such talking over the challenges with family members could have been difficult.

## **CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS**

### **6.0 Conclusion**

1. Informal caregivers of cancer patients at UCI experienced negative wellbeing, and this was attributed to the caregiving job being a full-time job and being a challenging role, and also because of financial constraints (such as loss of employment and inability to purchase medicine), as well as the fear that the patient might die.
2. The care givers performed important activities of daily living tasks (such as patient feeding and patient bathing) and treatment support tasks (such as medicine giving) for their relatives suffering from cancer.
3. The coping mechanisms used by caregivers included spiritual renewal and keeping themselves busy

### **6.1 Recommendations**

Basing on the study findings, discussion, and conclusion, the following recommendations are suggested in order to improve the wellbeing of information caregivers of cancer patients:

- Government should consider improving the wellbeing of informal caregivers of cancer patients for example through extending to them financial and emotional support activities.
- Government should ensure to avail adequate funds to the cancer institute so as the ensure adequate availability of medicine and thereby save informal caregivers from the burden of having to buy medicines for their patients.
- The Uganda Cancer Institute ought to put in place psychosocial support services for caregivers of cancer patients in order to improve their wellbeing as they take care of their patients.
- Family and social support organizations are hereby called in to support in improving the welfare of informal caregivers of cancer patients by advocating for improved financial support and other items needed for effective care of patients with cancer.

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## APPENDICES

### APPENDIX I: INFORMED CONSENT TO PARTICIPATE IN THE STUDY

#### **Study Title: Wellbeing of informal caregivers of cancer patients attending Uganda Cancer Institute**

Wellbeing of informal caregivers of cancer patients attending Uganda Cancer Institute

Investigator/institution identity

Hello, my name is \_\_\_\_\_ I am a student at Clarke International University undertaking this project as a requirement for the award of a Bachelor's degree in Nursing Science. I would like to invite you to participate in this research study. Before you give your permission, I would like to tell you what will be asked. If you have any questions, feel free to ask.

Objectives

This study seeks to explore the wellbeing of informal caregivers of cancer patients attending Uganda Cancer Institute

Procedures

You are being asked to complete a questionnaire. This interview will take approximately 15-45 minutes. Researchers will ask you the questions. There are no right or wrong answers; we want to know about you, your opinions and experiences. You may be contacted to participate in a focus group discussion lasting approximately one hour to discuss matters related to this study.

Are there any risks or discomforts from participating in the study?

I will conduct the interview in a private and safe space to ensure privacy. The only potential risk in participating in this study is that you may feel uncomfortable answering some of the more personal questions however you may decide not to respond to questions that you are not comfortable with.

Possible benefits, compensation and costs of this study

The information collected may be helpful in finding strategies to improve the wellbeing of the informal caregivers of cancer patients. There is no cost for participating in this study. There is no reward for participating or compensation. However, participants found to have health related information needed to study will be linked/referred to relevant service providers.

What are your rights as a participant?

Your participation will be entirely voluntary. You are free to stop the interview at any time without giving any reason.

#### Confidentiality

All your responses will be confidential. We will assign a unique identification number, so that your name is not linked to the answers that you give. The results of the study will be presented in a respectful manner, and information that could enable anyone to identify you personally will be reported.

#### Questions and contacts

If you have any questions for me, about the study or the consent document, please ask before signing, and I will do my best to answer them. You will receive a copy of this consent form if you like. If you have additional questions or if you need to discuss any other aspect of the study, you can contact the researcher at +256 782 683824.

This study has been reviewed and approved by the Clarke International University Research and Ethics Committee (CIUREC) .

**STATEMENT OF INFORMED CONSENT**

Please tick the box which best describes your assessment of understanding of the above informed consent document:

- I have read the above informed consent document and understand the information provided to me regarding participation in the study and benefits and risks. I give consent to take part in the study and will sign the following page.
- I have read the above informed consent document, but still have questions about the study; therefore, I do not yet give my full consent to take part in the study.

Signature of Person Taking Part in Study      Date

---

Name of Person Taking Part in Study

---

Thumb print of Person Taking Part in Study

---

Signature of Person Obtaining Informed Consent / Research Authorization Date

---

Name of Person Obtaining Informed Consent / Research Authorization



## TRANSLATED CONSENT FORM

### **Ekigendelerwa:**

**Okunonyerezakumbeeraz' abajanjabioabaabantuabalabiriraabalwaddebakansawanoku**

**Uganda Cancer Institute**

### **Ebikwatakumunonyereza**

Amanyagangenze Kobusingye Annemary, nga ndimuyizikukasozzik' abayivu aka Clarke International University, gyensomeraemisomogyangeby' obusawo. Obw' obujanjabi.

Mukaseera kano ninaokunonyerezakwendikookunyambako mu kumalirizaemissomogyange. Nga tonabakwetaba mu kunonyerezakuno, nsabambeerekobyenkulambulira. Oli wa Ddembe okubbuzakibuzokyonna.

### **Ekigendererwa**

**Ekigendererwaky' okunonyerezakunokyakunyambakumanyakumbeeraz' abajanjabioabaabantuabalabiriraabalwaddebakansawanoku Uganda Cancer Institute**

### **Emitendera**

Okunoonyerezakunokujakubamuokukubuzakubibuuzo nga bw' ombuuliraendowoozayo. Kigyakutwalaeddakikikawakati wa 15 ku 45. Omunoonyereza agenda kuba nga akubuzayokubibuuzo nga bwawandiikaokuddibwamukwo.

Okuddibwamukwokwonnakugyakusibwamuekitiibwa. Oyiinzaokusabibwaokwetaba mu kuwaendowaazaokw' abantuabangiko mu guluupu, nga kuyiinzaokutwalaesaawa nga emu. Waliwoobuzibuobaokunyigirizibwakwonaolw' oketaba mu kunonyerezakuno?

Okunoonyerezakunokugendakunokugendakukolebwa mu kyama. Oyiinzaokuwulira nga anyigirizibwamuolw' ebibuuzobyengendaokubuuza kubanga

bikwatakumbeeragy' owuliramuolw' omwagalwa wo omulwadde. Naye oli wa Ddembe obutaddamuebibuuzoebimu.

### **Emiganyulwog' okukirizaokwetaba mu kunonyerezakuno**

Obubakabw' ogendaokumpabugendakukozesebwa mu ngerieneyambako mu kusala amagezi agayiinzaokuyambako mu kuterezaembeeraz' abajanjabib' abalwaddebakansa.

Togendakuweebwansiimbiolw' okukirizaokwetaba mu kunonyerezakuno. Naye bwewanabeerawoembeeraeyetagisa ggwe okufunaobuwereza mu mbeeragy' olimu, oyiinzaokuyungibwabutereevukubakulu be kikwatako.

### **Ddembe kily'olina mu kwetaba mu kunoonyerezakuno**

Okwetaba mu kunonyerezakuno si kwa buwazen'akatono. Oli wa ddembeokukirizaokwetaba mu kunonyerezakunoobaneda. Era oli wa Ddembe okukuvaamuobuddebwonnasiingaon'olaba nga bw'ekisaniidde.

### **Okukuumaebyamma**

Ebintu byonna by'onooyogerabigendakutwalibwa era okukwatibwa nga by kyama. Tetugendakukozesa manya ggo; naye tugendakukuwaenambaenekusifu nga yiyowekkatesobolakumanyibwamuntumulalayena. Ebinaava mu kunoonyerezebwakunonabobigendakukwatibwa nga bya kyama, era tebigendakubeerakongeriyonnagyebiyiinzaikulagabifakumuntuyennaey'etabye mu kunonyerezakunno.

### **Okwebuza**

Bw'obaolinayoekibuuzokyonny'oyagalaokumbuzaeky'etabakukunonyerezakunno, oli wa ddembeokufunaolupapulalunoosoboleokwebuza. Osobolan'okunkubirakusimu enow a mange osoboleokufunaokuddibwamukwonnakwewetaaga: +256 782 683824.

Okunonyerezakunokukakasiddwaab'olukiikoolw'ekebeggyaebikwakukunonyerezaokwengeri ng'eno olwa Clarke International University Research and Ethics Committee (CIUREC).

**OKUKAKASA OKWETABA MU KUNONYEREZA KUNO**

Nsabaotikkingeakabokisiwansiwanoakalaga nti okirizaokwetaba mu kunonyerezakunoobaneda.

Ntegeddebulungiebimbuliiddwa nga bikwatakukunoonyerezakunoelankakasiza nti nzikiriza mu buntu nga sikakiddwaokugwetabamu. Kyenvuddentekaekinkumukyange wa manga.

Mpulirizabulungiebimbuliiddwa nga bikwatakukunoonyerezakuno naye nkaylinamuby'eninaokwekenenya nga sinabakusalawonakukirizakwetabamukunonyerezakunno.

Amanyag'omuntuakirizaokwetaba mu kunonyerezakunno

\_\_\_\_\_ Ennaku z'omwezi: \_\_\_\_\_

Name of Person Taking Part in Study

Ekinkumuk'omuntuakirizaokwetaba mu kunonyerezakunno

\_\_\_\_\_ Ennaku z'omwezi: \_\_\_\_\_

Omukonogw'omuntuakakasizaokusalawokunno

\_\_\_\_\_ Ennaku z'omwezi: \_\_\_\_\_

## APPENDIX II: INDIVIDUAL INTERVIEW GUIDE

Hello, ....., I am a Student of Clarke International University Formerly International Health Sciences University pursuing a Bachelor's Degree in Nursing Sciences. I am carrying out an academic research as part of the requirements to attain the degree, the study is titled: "Wellbeing of informal caregivers of cancer patients at Uganda Cancer. I am conducting a brief interview, so as to gain more insights on the topic. I will seek your consent to record the interview so that we can transcribe and do further analysis of your responses.

### Demographic characteristics

1. What is your age in complete years? ..... years
2. What is your gender?            1. Male            2. Female
3. What is your relationship to the patient?
  1. Spouse
  2. Sibling
  3. Parent
  4. Child
  5. Friend
  6. Other (Specify
4. What is your highest level of education?
  1. Primary
  2. Secondary
  3. Diploma
  4. Degree
  5. No education
5. What best describes your employment status?
  1. Formally employed
  2. Self employed
  3. Not employed
  4. Others (Specify)
6. For how long have you been caring for this patient?
7. In the past week, about how many hours have you devoted to providing care and/or support for your loved one?
8. How would you describe your wellbeing since your patient got diagnosed with cancer and what is the reason for your answer?

9. On a scale of zero to ten, how would you rate your self-care?
10. On a scale of zero to ten, how would you rate your current health status?
11. What are the different tasks that you perform for your patient?
12. What forms of burden have you experienced as an informal caregiver?
13. May you explain to me how you cope with the burden associated with taking care of your patients
14. What do you think can be done to improve your caregiving experience?

**Thank You for your time**

## TRANSLATED INDIVIDUAL INTERVIEW GUIDE

Nyabo/ssebo, amanyagangenze Kobusingye Annemary, nga ndimuyizikukasoziik'abayivu aka Clarke International University, gyensomeraemisomogyangeby'obusawo.

Obw'obujanjabi. Mukaseera kano ninaokunonyerezakwendi, nga njagalaokumanyakumbeeraz'abajanjabiobaabantuabalabiriraabalwaddebakansawanoku Uganda Cancer Institute. Nga abamu kubanjabi abo, nsabaokunyumyakonamwe, mbeere nga mbabuzayokubibuuzo ng abwe

mumbuiliraebilwoozobyammwenga'omulamwagw'okunonyerezakunno bwe guli.

Nsabaonzikirizembeera nga byetwogerambirikodiinga.

1. Olinaemyakaemekka?
2. Oli musajjaobamukazzi?
3. Omulwaddeomuyitaotya?
4. Wasomakompakakwenkanaki?
5. Ebyenfunabyobiyimiriddebitya?
6. Omazebbangaki nga ojjanjabaomulwadde wa kansa mu kifo kino?
7. Mu wiki emu eyiise, buddebwenkanakibwomazeng'olabirilaomulwadde wo?
8. Mubufuunze,  
nyonyolaembeerayobulamubwookuvalwewatandikaokujanjabaomulwaddewoalinak  
ansa.
9. Olowoozaogwawa mu mbeerayong'olabirilaomulwadde wo?
10. Olowoozaogwawa mu mbeeraz'obulamubwong'olabirilaomulwadde wo?
11. Milimokigy'okoleraomulwaddeebiseeraebisiinga?
12. Mubufuunze, nyonyolaobuzibubw'oyiseemung'olabirilaomuntu wo  
ajanjabirwaobulwadde bwa cancer mu kifo kino?
13. Bintukiby'okozeokusobolaokutambuzaobulamu?
- 14.** Olowoozakikiekiyinzakolebwaokulongoosaembeeraz'abajanjabib'abalwaddebaka  
nsa mu kifo kino?

*webale nnyo*

### APPENDIX III: FGD INTERVIEW GUIDE

Hello, ..... a Student of Clarke International University Formerly International Health Sciences University pursuing a Bachelor's Degree in Nursing Sciences is carrying out an academic research. As part of the requirements to attain the degree, the study is titled: "Wellbeing of informal caregivers of cancer patients at Uganda Cancer. I am conducting a brief interview, so as to gain more insights on the topic. I will seek your consent to record the interview so that we can transcribe and do further analysis of your responses.

**Interviewer's Name:** \_\_\_\_\_ **Date of the interview:** \_\_\_\_\_

1. How would you describe the wellbeing of informal caregivers of cancer patients in this place?
2. What is the reason for your answer?
3. What are some of the burdening experiences you have seen or heard about the informal caregiver of cancer patients?
4. What are the different tasks performed by the informal caregivers of cancer patients in this place?
5. What do you think are the coping strategies of informal caregivers of cancer patients in this place?
6. What do you think can be done to improve the caregiving experience and people giving care to individuals diagnosed with cancer in this facility?

*Thank You for your time*

## TRANSLATED FGD INTERVIEW GUIDE

Nyabo/ssebo, amanyagangeze Kobusingye Annemary, nga ndimuyizikukasozzik'abayivu aka Clarke International University, gyensomeraemisomogyangeeby'obusawo.

Obw'obujanjabi. Mukaseera kano ninaokunonyerezakwendi, nga

njagalaokumanyakumbeeraz'abajanjabioabaabantuabalabiriraabalwaddebakansawanoku

Uganda Cancer Institute. Nga abamu kubajanjabi abo, nsabaokunyumyakonamwe, mbeere

nga mbabuzayokubibuuzo ng abwe

mumbuuliraebiloozobyammwenga'omulamwagw'okunonyerezakunno bwe guli.

Nsabamunzikirizembeera nga byetwogerambirikodiinga.

**Nze:..... Ennaku z'omwezi:**

.....

1. Oyinzakunyonyolaotyaaembeeray'abajanjabib'abalwaddebakansa mu kifo kino?  
Olowoozansongakievirakoembeerabw'etyo?
2. Olowoozamberakiezisiingaokuleetaobuzibuerialabajanjabib'abalwaddeba cancer?
3. Embeeraezonaweoziyiseemuobaozilabyekobulabiku bantu abalala?
4. Abajanjabib'abalwaddebakansa mu kifo kino baterakukolamirimoki?  
Obujanjabibwobabukolabatya?
5. Olowoozaabajanjabib'abalwaddebakansa mu kifo kino basobolabatyaokuyita mu bibasomooza bye bayitamu?
6. Olowoozakikiekiyinzakukolebwaokulongoosaembeeraz'abajanjabib'abalwaddebakansa mu kifo kino?

Mwebale nnyo okwetaba mu kwogeraganyakuno



APPENDIX IV : INTRODUCTORY LETTER



SON  
School of Nursing  
and Midwifery

(+256) 0312 307400  
deanson@ciu.ac.ug  
www.ciu.ac.ug

Kampala, 7<sup>th</sup> May 2021

Dear Sir/Madam,

RE: ASSISTANCE FOR RESEARCH

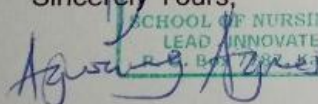
Greetings from Clarke International University.

This is to introduce to you **Kobusingye Annemary** Reg. No. **2017-BNS-FT-AUG-001** who is a student of our University. As part of the requirements for the award of a Bachelors degree in Nursing of our University, the student is required to carry out research in partial fulfillment of the award.

Her topic of research is: **Wellbeing of Informal Caregivers of Cancer Patients attending Uganda Cancer Institute.**

This therefore is to kindly request you to render the student assistance as may be necessary for research. I, and indeed the entire University are grateful in advance for all assistance that will be accorded to our student.

Sincerely Yours,

  
SCHOOL OF NURSING & MIDWIFERY  
LEAD · INNOVATE · TRANSFORM  
B.P. 7782, Kampala - Uganda

07 MAY 2021

#Make a Difference



Kawagga Close, off Kalungi Road, Muyenga  
Block 224 | Plot 8244 Bukasa Kyadondo  
P.O.Box 7782 Kampala-Uganda

## APPENDIX V: APPROVAL LETTER FROM RESEARCH ETHICS COMMITTEE



(+256) 0312 307400  
rec@ciu.ac.ug  
www.rec.ciu.ac.ug

02/07/2021

To: Annemary Kobusingye

Clarke International University  
+256782683824

**Type:** Initial Review

**Re: CLARKE-2021-92: WELLBEING OF INFORMAL CAREGIVERS OF CANCER PATIENTS ATTENDING UGANDA CANCER INSTITUTE, ,**

I am pleased to inform you that at the **19th** convened meeting on **29/06/2021**, the Clarke International University REC, committee meeting, etc voted to approve the above referenced application.

Approval of the research is for the period of **02/07/2021** to **02/07/2022**.

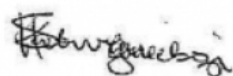
As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes.
3. Reports of unanticipated problems involving risks to participants or any new information which could change the risk benefit: ratio must be submitted to the REC.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by participants and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Continuing review application must be submitted to the REC **eight weeks** prior to the expiration date of **02/07/2022** in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study.
6. The REC application number assigned to the research should be cited in any correspondence with the REC of record.
7. You are required to register the research protocol with the Uganda National Council for Science and Technology (UNCST) for final clearance to undertake the study in Uganda.

The following is the list of all documents approved in this application by Clarke International University REC:

No.	Document Title	Language	Version Number	Version Date
1	consent form	Luganda	1.0	--
2	individual interview guide	Luganda	1.0	--
3	individual interview guide	English	1.0	--
4	proposal clean copy	English	2.0	--
5	Risk management plan	ENGLISH	1.0	--
6	Data collection tools	LUGANDA	1.0	--
7	Data collection tools	ENGLISH	1.0	--

Yours Sincerely



Samuel Kabwigu

For: Clarke International University REC

## APPENDIX VI: CORRESPONDENCE LETTER



### Uganda Cancer Institute

Upper Mulago Road, P.O. Box 3935, Kampala - Uganda. Tel:+256 414 540 410 Website: [www.uci.or.ug](http://www.uci.or.ug)

15<sup>th</sup> July, 2021

Ms. Annemary Kobusingye  
Student

**RE: Permission to Conduct Research at Uganda Cancer Institute (SR. 19/21)**

Thank you for choosing Uganda Cancer Institute for your study titled *“Wellbeing of Informal Caregivers of Cancer Patients Attending Uganda Cancer Institute”*. The study was reviewed and accepted to be conducted at UCI. This decision was based on the fact that your study had a primary approval from **Clerk International University REC.**

Please take note of the following as you conduct research at UCI;

- i) The conduct and discipline of your study staff will be governed by the rules that govern the conduct and discipline of Public Officers.
- ii) Abide by the National Council for Science and Technology (UNCST) regulations for conducting research involving human participants and all relevant regulations. Thus ensure timely renewal of approvals to avoid expiration because we will expect you to avail us proof of renewal to allow you to continue with study conduct after the expiry date.
- iii) You are requested to do thorough protocol training for your staff to ensure effective implementation of the study. You should also deliver the updated certificate (s) of human subject's protection for each of your study staff at UCI to the Research and Ethics Review Office before study implementation.
- iv) You're requested to follow the presidential directives and ministry of health guidelines of **COVID-19** prevention as you implement the study activities to stay safe. Please

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refer research participants reporting with signs and symptoms of covid-19 for appropriate treatment.

- v) Your contact person or Supervisor at UCI is **Sr. Rose Nakinga** and you are expected to work closely with her throughout your conduct of research at UCI.
- vi) On completion of your study, you are required to deposit a copy of your dissertation with the Uganda Cancer Institute Research Office and Executive Director's office.

This administrative clearance will be terminated if you or your staff act or behave contrary to the Uganda Cancer Institute's values and principles.

By copy of this letter, the UCI Clinical Head and Senior Hospital Administrator are informed about your study and strongly urged to take action in case of any malpractices observed as you conduct research at UCI.

Sincerely,



Dr. Noleb Mugisha

**For Head Research and Training, UCI**

C.C. Executive Director, UCI

“ Senior Hospital Administrator, U.C.I.

“ Clinical Head, UCI

“ **Sr. Rose Nakinga, UCI (Supervisor)**