BURDENS AND COPING MECHANISMS OF CARING FOR A FAMILY MEMBER WITH MENTAL ILLNESS

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A RESEARCH PROJECT SUBMITTED TO THE
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DECLARATION

I declare that this research project is my original work and has not been presented for the award of any degree or diploma in any other university.

Sign: …………………………………………………………. Date 10th October 2023

Entisar Mohamed

C50/26141/2019

This research project has been submitted for examination with my approval as the University supervisor.

Sign: ……………………………………………………………. Date 10th October 2023

Dr. Jane Kiarie

DEDICATION

To my loving and supportive family and friends for constantly encouraging and cheering me on. I dedicate this work to all caregivers who care and suffer in silence, may God give you strength and patience to continue your journey.

ACKNOWLEDGEMENT

I thank God for his grace in giving me with the required strength, insight, and resources during my study trip. I would like to thank my supervisor, Dr. Jane Kiarie, for her invaluable advice, insightful remarks, and support during the whole process of completing my thesis. In addition, I am deeply grateful to the entire Department of Psychology for making my time with them enjoyable.

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ABBREVIATIONS AND ACRONYMS

WHO: World Health Organization (WHO)

OECD: Economic Co-operation and Development (OECD)

KNCHR: Kenya National Commission on Human Rights

FST: Family Systems Theory

DEFINITION OF TERMS

TERM	**DEFINITION**
Economic factors:	Economic factors refer to the financial aspects and influences that can impact a situation or phenomenon (Taylor, 2016)
Psychological factors	These are the mental and emotional elements that affect an individual's thoughts, feelings and behaviour (Sarafino & Smith, 2019)
Social factors	Social factors encompass the societal, cultural and interpersonal aspects that influence people's lives and behaviours (Berkman, 2017)
Burdens	Burdens are the physical, emotional, and financial challenges and responsibilities that caregivers experience while caring for a family member with a mental illness (Mullan et al., (2019).
Coping Mechanisms	These are the strategies, behaviours, or actions that individuals use to manage and adapt to challenging or stressful situations (Lazarus & Folkman, 2014).
Mental Illness	Mental illness refers to a wide range of conditions and disorders that affect a person's thoughts, emotions, behaviour, or mood, often resulting in distress and impaired functioning (APA, 2018).

ABSTRACT

The impact of mental illnesses is not limited to the person with the disorder but extends to their family members who full-fill caretaker roles. Recently more responsibilities for caring for a person with mental illness have shifted to the family. Caregivers might not express what they are going through while caring for mentally ill relatives, and that will lead to more burden and stress. Through a qualitative phenomenological study and in-depth interviews, this study aimed to explore the experiences of caregivers and identify their coping strategies, by exploring barriers that affect family caregivers' ability to cope with their relatives diagnosed with mental illness. The study applied Lazarus and Folkman's (1984) Transaction Model of Stress and coping by collecting samples of caregivers from Nairobi County, Kamili Organization Clinics. This study found out that there was a high prevalence of burden among the family caregivers with 85% of them indicating the burden to occur sometimes, quite frequently, and nearly always whereas only 15% argued not to feel burdened at all. Regarding the patient needs, the respondents indicated the major needs to be total care (26%), medication (26%), and basic needs (22%). Other needs included economic, social, and health support (16%), transportation to the hospital (5%), and food plus moral support (5%). This shows that the patients needed constant and continuous support for their day-to-day needs and observing their mental state. The major changes in caregivers' lifestyles were overwhelming responsibilities (21%), anxiety (14%), increased connection with the patient (14%), economic hardships (14%), frustrations and debt (7%), and struggling to understand their illness (7%). The results revealed that the most challenging aspect was when the patients got sick or worse. Other challenges experienced included mood and attitude, stress and burnout, and financial difficulties. With regards to the modes of support needed, most of the respondents indicated the need for someone to assist in a caring role, counselling, advice, financial aid, the support provided by the government, medication assistance, and support from family members. Other forms of support required were indicated to be having people around, employment opportunities, taking some time out, and spiritual support. The study concludes that family caregivers are more likely to act as supervisors for people with mental illnesses while continuing to go about their everyday lives and chores. The study also concludes that this can overwhelm and affect the family performance, psychosocial health, and financial pressure of the caregivers. The study recommends that health providers focus not only on the patients but also on the caregivers of patients undergoing mental health care, as they experience a lot of stress, which contributes to a feeling of burden. The study also recommends that caregivers be given training on psychoeducation basics and made aware of what they might face in the unexpected situation from their sick relatives and where they may get help. Caregivers could also benefit from community resources for practical and emotional support. Advocacy for a new approach and policy change is needed for caregivers' roles to get more help and support carrying their responsibilities for loved ones with mental illnesses.

CHAPTER ONE

INTRODUCTION

1.1 Background of the study

In 2020, the World Health Organization (WHO) noted that one billion people live with a mental disorder and that mental health remains one of the most neglected areas of public health, especially in developing countries. (Brunier, Sharma, & Daniels, 2020). In addition, the Organization for Economic Co-operation and Development (OECD) indicated that mental illnesses are some of the largest and fastest-growing diseases worldwide. As stated by Lancet Medical Journal (2019), 30% of the world's population suffers from a mental disease, and two-thirds of them receive inadequate or no treatment, especially in developing countries. In Africa, the importance of mental health remains overlooked, and populations are in the increasing need of mental health facilities. According to Kenya's Ministry of Health, one in every four Kenyans has experienced mental illness. Up to 25% of outpatients and 40% of inpatients at medical facilities are estimated to be suffering from mental diseases (KNCHR, 2011).

As global evidence has demonstrated, mental illnesses are fast-growing and impact a large portion of the world's population. Those suffering from mental illnesses in the developing world are particularly vulnerable, as they may not receive adequate treatment. In many cases, a lack of available or sufficient treatment may result in the caring responsibilities being placed on the family. While family caregivers play a central role in the long-term support of their mentally ill relatives, this is not without challenges. Particularly in situations where an individual's condition is chronic, family caregivers may experience a debilitation in their own physical and mental wellbeing.

The stress and burden experienced by family caregivers have been well-documented by many researchers. It has been noted that family caregivers may experience mental and physical stress due to the demands of caring for someone with a mental illness. As a result, researchers have developed the concept of caregiver burden. Caregiver burden refers to the stress and other psychological symptoms that family members and other nonprofessional individuals face while caring for their patients (Pinquart & Sorensen, 2003; Vitaliano, Zhang & Scanlon, 2003).

Importantly, the burden may impact the quality of life and the health of a family caregiver, as well as their ability to care for their mentally ill relative. Through both subjective and objective avenues, burdens manifest themselves in different ways. There are also social and economic implications associated with caregiving that need to be better understood, in order to better support the caregivers in need. These unprofessional settings also lead to psychological distress for the caregiver, who may experience depression or anxiety, due to the intensity of the caregiving situation and responsibilities. Evidently, caring for a family member is a challenging and consuming task, one that requires the availability of professional support to both the mentally ill relative and the family caregiver (Beach, et al., 2000).

Against this background, this study explored these challenges and experiences by family caregivers. Within the context of the lack of adequate access to mental health services especially in the developing world, this study also sought to identify and analyse effective coping strategies for these caregivers, to better inform how the psychological distress and burden associated with caregiving can be addressed and eased. This was particularly useful in settings where family caregiving is the primary and most accessible form of taking care of relatives. Therefore, intervention strategies through recognizing maladaptive stressor appraisals and coping strategies are particularly promising approaches.

1.2. Statement of the Research Problem

The effect of mental illnesses is not restricted to mentally ill individuals but can extend to their family members in different ways (E. Robinson, B. Rodgers, & Butterworth 2008). Family caregivers may experience great levels of stress and burden and the role they undertake to care for their family members can be extremely overwhelming. While academics and consultants have proposed several kinds of resources and interventions, these have not satisfactorily relieved the stress and the burden on caregivers. As such, there are substantial gaps in our current knowledge of the experiences of caregivers, and the approaches to erasing burdens.

Nevertheless, caregivers regularly face different challenges and experiences that might result in stress and psychological issues. This may result in stressors at emotional, physical, and financial levels. These emotional stressors can manifest as isolation, stigma, guilt, and strained relationships (Bademli, Lok, & Kaya Kilic, 2017). On the other hand, physical stressors include the development of physical illnesses or impairments. Finally, on a financial level, stress on the caregiver may relate to their inability or their struggle to afford medical support for their family member with a mental illness. To address these stressors, it is important to develop approaches and policies that provide support to those caring for a family member with a mental illness. As it stands, there is a gap in approaches and sufficient policies to deal with mental health education and support, more attention should be paid to this sensitive area. It is important to note that people's reactions to stressful situations vary. Their stress responses will eventually affect their psychological state, particularly when they face circumstances that challenge their capabilities, and this may create a hazard to the person's physical and psychological well-being.

1.3. The purpose of the study

The main purpose of this was to examine and analyse the impact of mental illness on caregivers and coping strategies in rending care to individuals diagnosed with a mental disorder.

1.4. Objectives of the study

i. To determine the burden experienced by caregivers of mentally ill relatives and its associated effects.
ii. To evaluate the coping mechanisms of family caregivers when caring for individuals with mental illnesses.
iii. To determine the relationship between a caregiver's quality of life and caregiver burden.

1.5. Research Questions:

1. What is the burden experienced by caregivers of mentally ill relatives and its associated effects?
2. What are the coping mechanisms of family caregivers when caring for individuals with mental illnesses?

3. What is the relationship between a caregiver’s quality of life and caregiver burden?

1.6. The justification of the study

A key justification of this study was to comprehend the participants’ experiences and how they cope with stressor situations when caring for a mentally ill family member. Through open-ended questions and the Zarit burden assessment questionnaire, this study captured the participants’ experiences to better identify their needs and requirements. This helped justify and articulate meaningful supportive involvements to enable participants in the research to understand themselves and the challenges of caring. (Sherman and Webb, 1990, p 5; Lichtman, 2013, p 4).

Through this study, a better understanding of the notions of burdens and coping mechanisms was developed, which can supported family caregivers in supporting their family members with a mental illness. It is important to understand how caregivers can support their family members in effective and productive ways, while also ensuring that their stress is cared for and addressed.

1.7. Significance of the Study

From a policy perspective, the findings of the study may inform the development of programs and policies that support caregivers of individuals diagnosed with mental disorders, including respite care, education, and training opportunities. In practice, the study may offer insight into the challenges and stressors that caregivers face and help practitioners develop effective interventions to address these challenges. The study may also highlight the importance of providing emotional and psychological support to caregivers, in addition to practical support.

In terms of public importance, the study may help raise awareness of the difficulties faced by caregivers of individuals with mental disorders and reduce stigma associated with mental illness. By promoting a better understanding of the role of caregivers and the impact of mental illness on their lives, the study may help to promote a more compassionate and supportive society. Further, from an academic perspective, the study may contribute to a better understanding of the experiences of caregivers of individuals with mental disorders, and the coping strategies they use. This knowledge may be used to inform future research and improve the quality of care provided to individuals diagnosed with mental disorders.

1.8. Limitations and Delimitation of the study

This study focused on raising awareness of stress conditions within the caregiving community and provides insight into the nature of stressors that have a predictive connection with a caregiver’s quality of life. Caregiver burden may change throughout caregivers caring for patients with mental illness. Therefore, changes and the different nature of the experiences by interviewees impacted the results of the study. In addition, small sample sizes also impacted the results of this study. Lastly, limited time to conduct this study impacted data collection and analysis. The study was delimited to the Zarit burden assessment in capturing the participants’ responses. The study was also delimited to only specific mental disorders, which may not capture the full range of experiences of caregivers of individuals with different types of mental disorders.

1.9. Assumptions:

The main assumption of this study were as follow;

i. Caregiving is a stressful experience that has an adverse impact on the caregiver and the affected family's quality of life.

ii. The ability of caregivers to cope with stress depends on the perception of the caregiver.

iii. Caregivers may be able to adopt certain types of coping strategies and mechanisms if they can access and make use of knowledge about the illness.

iv. There is a relationship between a caregiver's quality of life and caregiver burden.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter will review the theoretical framework and factors that lead to stress and burdens placed on the families of mentally ill relatives. This section approached systematic reviews of the literature to gain a better understanding of what has been researched and recommended by other scholars.

2.2 Theoretical Framework

A theoretical framework is an arrangement that offers an explanation of a theory that clarifies why the research area under consideration occurs (Abend, 2018). This study was based on the Family Systems Theory.

2.2.1 Family Systems Theory

Family Systems Theory, developed by Murray Bowen in the 1950s, is a prominent theoretical framework in the field of family therapy. This theory posits that individuals cannot be understood in isolation; instead, their behaviours and mental health are intricately connected to the dynamics and interactions within their family system. Family Systems Theory emphasizes that family members are interconnected and influence one another’s thoughts, emotions and actions. It suggests that understanding these relational patterns is crucial for comprehending the functioning of an individual within the family unit.

A study by Lee et al., (2018) titled ‘Family Functioning and Caregiver Burden in Primary caregivers of Patients with Schizophrenia,’ supported the Family Systems Theory. This study explored the relationships between family functioning and caregiver burdens among those caring for relatives with Schizophrenia. The findings revealed that family functioning significantly affected the level of caregiver burden. When family systems were characterized by poor communication, high levels of conflict, or low levels of cohesion, caregivers experienced more stress and burden. This study underscores the importance of understanding family dynamics and their impact on caregiving experiences, aligning with the core tenets of Family Systems Theory.

While Family Systems Theory has been influential, it has faced criticism, primarily for its potential to oversimplify complex family dynamics and its limited consideration of external factors. One critique comes from the “gender-blind” perspective of the theory, as it often does not sufficiently address the unique experiences and roles of men and women within families. Critics argue that it may not adequately account for the influence of societal norms and culture on family interactions, which can impact caregiving experiences. Additionally, some argue that it tends to pathologize family interactions without considering the broader context in which they occur.

Family Systems Theory is highly relevant to the current study as it provides a valuable framework for understanding how family dynamics and interactions can either exacerbate or alleviate caregiver burden. By considering the family as a whole and examining communication patterns, roles, and boundaries, researchers and mental health professionals can better support caregivers and develop interventions that address the systemic issues impacting their well-being. Furthermore, understanding the criticisms of the theory highlights the need to incorporate a more comprehensive and culturally sensitive approach to family dynamics. Figure 2.1 illustrates the Family Systems Model.

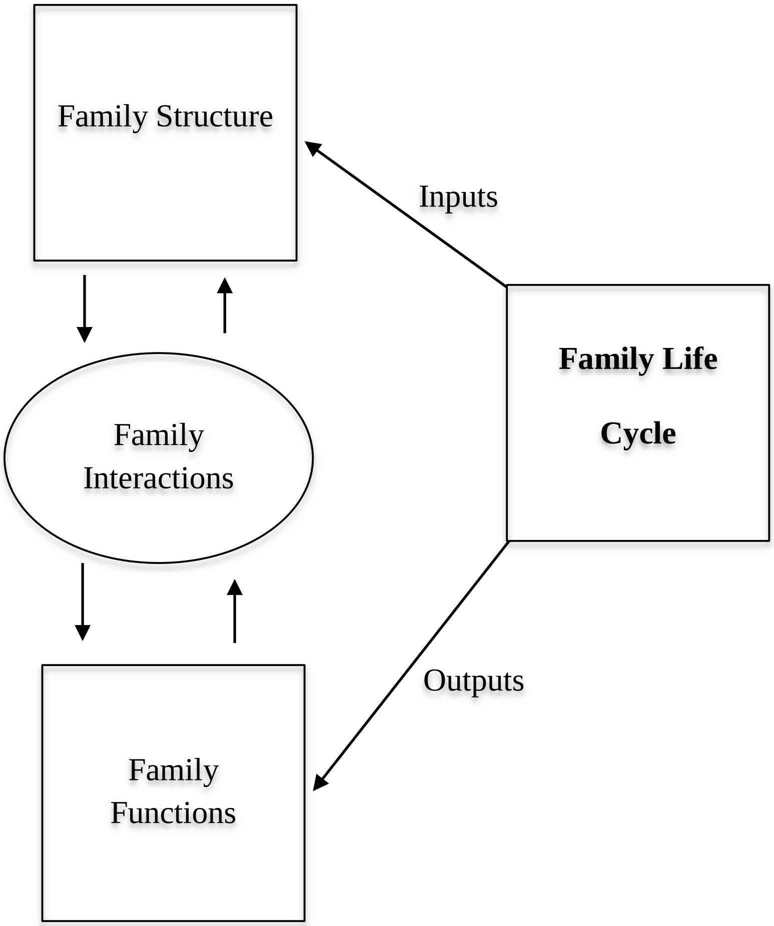


Figure 2.1 Family Systems Model

Source: Researcher (2023)

2.3 Historical Perspective of Mental Health Care

Mental health care has shifted from institution-based care to community-based care. In the late 18th century, the establishment of asylums in Europe and the colonies was one of the first moves to institutionalize mental health care. This institutionalization was an isolation approach, which restrict those with mental illnesses in one place, to keep them away from the rest of society due to the nature of their sickness. As a result, these people were in danger of mental and physical abuse at the hands of mental institutions. These institutions were built to confine persons with mental illnesses to a single location, separating them from their communities. The formation of a humane care movement by opponents of these asylums. Dr. Philippe Pinel of France, William Tuke of England, and Benjamin Rush of the United States all called for "moral therapy," or empathic care for persons suffering from mental illness. Eventually, various nations accepted this moral therapy technique.

While the moral treatment movement changed approaches to mental health policy, there are still critics of asylum conditions, who claim that conditions in many asylums did not change. On the contrary, they argue that due to underfunding and overcapacity, conditions worsened. Headed by consumer activists and civil rights lawyers, the deinstitutionalization movement developed, in the hope of improving the living situation of these institutions. Community-based care advocates contended that institutionalized care constituted an infringement of a patient's human rights since patients were frequently socially isolated, had lost their independence and duties, and was fighting to exist outside of the institution. WHO was in support of this movement and soon, countries began closing mental health institutions and improving their capacity for caring for those with mental illnesses within the community. (Sydney Block & Stephen A,2020).

As Peter Berger and Thomas Luckmann noted, the legitimization of deinstitutionalization by the WHO engrained the said approach. In addition, deinstitutionalization led to a shift in mental health care responsibilities to families, where families now had a bigger role to perform. This role of caring was accompanied by (perhaps unforeseen) physical, psychological, social, and financial burdens on those families. Critics of the deinstitutionalization approach, such as Seth J. Prins (2011), claim that the approach failed to satisfy its purpose, as many patients found themselves in communities that did not have satisfactory and adequate services. Consequently, this could lead to abonnement, isolation, homelessness, and different forms of abuse. Prins and others have recommended reinforcing hospital care with more competent staff, to ensure that patients are supported professionally and humanly.

The establishment of institutional care and its policy for caring for mentally ill people have resulted in a form of violence against people with mental illness. Stigma and discrimination have arisen as a consequence, even among general healthcare providers. While deinstitutionalization has attempted to reform the mental health support setting, there have been many positive outcomes as well as gaps and pressures in the informal caregiving settings. As a form of primary care, studies have shown informal caregiving has improved the lives of patients. Therefore, community-based services should be supported and scaled up to support patients and bring about positive outcomes.

In the same breath, institutional care still has s space in mental health provision, as some patients may require institutional care at some point in their treatment plans.

Mental health care history has demonstrated that there are several lessons and opinions to take into consideration when evaluating how to support patients and their caregivers in satisfactory approaches, such as respect, moral guidance, and humane treatment. Importantly, the literature has emphasized the importance of consideration of their individualism and remaining culturally sensitive when administrating care, as stigma and culture can greatly shape the provisions of care offered. Therefore, it is critical to understand how culture and respect can impact caregiving, in order to effectively administer and support treatment (Lopez, et al., 2010).

2.4 The Burden f the Family on Caring for Mentally ill Persons

There have been several psychological studies conducted since the mid-19th century that have shown the toll that families and individuals with mental illness take on one other. As defined by Grad and Sainsbury (1966), a family's "burden" is everything that occurs as a result of having to take care of a mentally sick relative. A caregiver's thoughts about caring for a patient may be expressed to others as a "subjective burden," while "objective burden" refers to time away from family that may be both real and evident in some manner. According to Montgomery, Gonyea, and Hooyman (1985), subjective stress is created by the caregiver's emotional responses to caring experience and how to perceive the burden of care, whereas objective load is the interruption or change in many parts of the caregiver's home life such as finances and time devoted to caring.

As previously indicated, the attitudes and behaviours of family members caring for people with mental diseases are described by objective or subjective burdens (Swaroop et al., 2013). Caregivers are under pressure from a combination of objective and subjective obligations that may lead to mental, physical, and financial exhaustion. This fact can be serious since the health of those who care for the mentally ill is directly correlated to their well-being status in many aspects. The fact that family caregivers are likely to go on with their regular daily routines even while providing care for their loved ones is another cause of stress. Berg-Weger in 2000 confirmed the fact that the stressful situation of caring will be more while doing other daily responsibilities. Therefore, family caregivers are more prone to mental and physical health issues than the general population (Berg-Weger, 2000).

American research prepared by Berg-Weger found that individuals who care for family members who suffer from Alzheimer's or dementia are more likely to suffer from depression. Caregiver depression affects as many as 38% to 60% of those who provide care (Berg-Weger, 2000). When a family member suffers from a serious mental illness, they are more likely to be a victim of violent crime than the general population, and that is due to their mental status (Teplin and colleagues, 2005). Anger was aimed toward family members in half of the violent patients sent to psychiatric facilities, according to the report by Teplin et al. in 2005.

2.5 Family dynamics

Family members are the core caregivers of people with mental illness (Malhotra, 2016). Family plays a significant part in caring for people with mental illnesses in many ways, including supervising their mental state and treatment, helping in daily activities, ensuring their safety, accompanying them to a hospital or clinic, providing emotional care, and assisting them with their finances. The family also plays an important role in making sure that the patient follows their treatment while accepting fluctuations in patient behaviour, such as aggressiveness (Venkatesh, Andrews, Parsekar, Singh, & Menon, 2016). Being a caregiver is something that cannot be predicted, so caregivers need to be able to accept and adapt to these unexpected circumstances. These can cause family members to feel burdened and sometimes helpless (Kizilirmak & Kucuk, 2016).

The family burden is also related to traditional and cultural understandings of mental illness (Von Kardorff, Soltaninejad, Kamali, & Eslami Shahrbabaki, 2016). The denial, stigma, and discrimination against mental health problems have been a major barrier within many communities, especially in developing countries, and it is not only affecting people with mental disorders, but it also burdens the family (Varghese, Pereira, Naik, Balaji, & Patel, 2017). Seven main themes related to caregivers' burdens will be summarised, investigated, and analyzed including knowledge, emotional burden, bodily burden, medicine, financial burden, social load, health care, and government assistance.

2.5.1 Inadequate Knowledge

Being unaware of the diagnoses and the consequence of the disease is not helpful when it comes to caring for a patient. Caregivers must be knowledgeable about the causes, treatment, and management of mental illness (Fitryasari et al., 2018; Krupchanka et al., 2018). When gaining information about the concerned case the ability to help and care will have a positive outcome for the patient and the caregiver.

2.5.2 Emotional Burden

the emotional burden is experienced by almost all family members. These emotions include denial, sadness, anger, and shame due to the changes and unpredictable of the patient's behaviors and fearing that patients may harm themselves or their surroundings (Fitryasari et al., 2018). Emotional burdens may also lead to the family blaming themselves for the causes and the uncertainty of the future. The dependency of the patient on the caregivers' assistance may lead to the caregivers believing that the patient cannot operate without them, and that can cause more worried and burden. (Dice et. al., 2017; Von Kardorff et al., 2016). Relatives may also be concerned when the diagnosis is permanent about the incapability of the patients to live normal lives (Gater et al., 2014; Radfar et al., 2014). The caretakers may be anxious about who would take care of the patients if they no longer could. Lastly, if the patient struggles with cognitive difficulties, the family may be concerned about different kinds of abuse when interacting with the outside community.

2.5.3 Treatment Burden

The administration and management of the treatment might be difficult and draining or demanding (Von Kardorff et al., 2016), particularly in situations where treatment is long-standing. Sometimes, families may be in denial that their family member is mentally ill, and this may lead to treatment being conducted and administered later than desired (Venkatesh et al., 2016).

2.5.4 Physical Burden

A physical burden is also faced by the family in the situation of caring. Family caregivers may not have time for relaxation or a functional daily routine (Fitryasari et al., 2018; Tristiana et al., 2018). The caregivers may also feel tired, lose energy or have sleeping disorders (Von Kardorff et al., 2016). According to Hernandez & Barrio, 2015, chest pain and increased blood pressure are common symptoms reported by caregivers. As a result of the responsibilities linked with being caregivers, they frequently suffer from chronic physical and mental exhaustion (Prevo et al., 2018; Radfar et al., 2014).

2.5.5 Financial Burden

Financial burden may also be felt by the family. A lot of capital is required for medical and caring expenses. Costs may include regular visits to the health care centers, medications, transportation costs to the hospitals, food, and daily essentials (Fitryasari et al., 2018; Gater et al., 2014; Tristiana et al., 2018; Von Kardorff et al., 2016). In 2018, Krupchanka et al., reported that families are required to provide financial support since the patients cannot live independently.

2.5.6 Social Burden

Social burden not only arise from society, but it can also come from close members of the family. Stigma and discrimination are the hardest burdens, as they frequently trigger other burdens such as emotional, financial, and physical burdens (Krupchanka et al., 2018). The stigma faced by the families is classified into four types: labelling, stereotyping, separation, and discrimination. Labelling may offend the family because people with mental illnesses may be called names such as “madman,” which indicates that they cannot be cured. Stereotypes come from other people’s beliefs that the patients can hurt others. Separation and discrimination may mean that families feel isolated, as they might not be able to join and participate in social events due to the fluctuating and unexpected behaviour of the patients (Fitryasari et al., 2018).

2.5.7 Health Services and Government Support

Difficulties linked to the health services and government support are experienced by families. These may involve insurance, transportation, and the support of the medical bills (Ebrahimi et al., 2018; Krupchanka et al., 2018; Tristiana et al., 2018; Von Kardorff et al., 2016). Distant and unfree cost healthcare services mean that the families use more money on transport, adding to that the medication costs and psychiatric/consultation fees. The need for governmental support for the communities’ clinics is essential in the area of mental health services. (Tristiana et al., 2018).

2.6 Factors Correlated to Caregiver Burden

Some factors associated with burden and psychological distress experienced by a family caregiver will be grouped into the following three categories (Am Fam Physician, 2020):

2.6.1 Caregiver’s Factors

a. Age: the older the caregiver becomes, the more they may be worried about who will care for the sick relative in the future. (Fujino & Okamura, 2019). In 2017 Juvang, Lambert & Lambert found that the time the caregivers spent caring for the sick relative will influence the burden on them, the same influence will happen when related to the age factor. They concluded that anxiety and concern for older caregivers about the future of their sick relatives will affect their physical health and mental status. The older the caregiver becomes, the more they may be concerned about who will care for the sick family member in the future (Fujino & Okamura, 2019).

b. Gender: Women and men feel burdens in different ways. Schneider and Hemsworth (2018) mention that women have a higher potential for caregiving in comparison to men, they found that women caregivers tended to experience more depressive/anxiety symptoms and higher-level grief of burden than men caregivers. This has been justified by how gender identity and roles in the society can impact the overall caring dynamic.

c. Education level: Juvang, et al., (2017) argued that education levels have negative correlations with caregivers' burden. The higher the degree of education, the higher an individual's salary will be. Therefore, a higher salary may lessen the financial difficulties associated with caring for a sick relative. The level of awareness and education of the caregiver also correlates with their ability to access information about the mental health condition or deal with a tense event if necessary. Therefore, the caregiver's awareness stage and educational status affect the burdens experienced by the caregiver.

d. Income status: the level of income has an important factor in the well-being of the caregiver. In 2006 Andren and Elmstahl carried out a study in Sweden to explore the connection between the caregiver's income and the burden of caring for relatives with dementia. The study confirmed that low income can act as a source of stress and was correlated to developing more burden on the caregivers. Moving on with their daily life activities, the caregivers had to find time and sources to care for their sick relatives.

e. Health status: Mengdan & Lambert (2007), reported that the status of health is considered a leading indicator of a caregiver's burden. Therefore, caregivers with good health status felt minor levels of subjective tension burden (Fujino and Okamura, 2009).

f. Time spent per day: The amount of time spent on caring every day has an impact on burden and suffering level (Chii & Hsing-Yi, Pin and Hsiu 2009). According to research done by Juvang, Lambert, and Lambert (2007), the more time spent with a sick family member, the greater objective burdens seem, and that will be reflected in subjective burdens as well. For example, the more time a caregiver spends with a sick family member, the less time they have for themselves. This can have negative implications for the caregiver's ability to effectively perform everyday activities.

g. Cultural: Janevic and Connell in 2001, carried out a study that investigated the cultural factors, such as ethnicity, to understand how they influence caregiving. The study showed that different ethnic and racial groups responded to the burden in manners. This had to do with the different coping mechanisms and social support they received, which had an influence on how different races and communities reacted to stressful events. Spurlock (2005) added that African Americans more often were able to use prayer as a major coping strategy, while Caucasian groups often focused on seeking professional support.

h. Subjective perception: Romeis (as cited by Chou, 2000) stated that to assess burden, it would be important to base it on how caregivers are able to accept and understand the needs of the mentally sick person and perceive the burden of care. Further understanding of how caregivers are organizing themselves and how they access resources to support those in need, was also important.

As such, the burden should be addressed and taken into consideration the caregiver’s subjective perception.

2.6.2 Patient Factors

a. Age: Juvang, et al., (2007) realized that the caregivers have significant responsibilities when caring for younger patients over extended periods of time. Research has been done in Chile also found that caregivers who assist patients with schizophrenia faced a greater level of strain and burden, and that happens due to the additional attention and time needed to care for younger patients (Caquezo-Urizar & Gutierrez-Maldonado, 2006).

b. Clinical symptoms Several studies have revealed that a patient's clinical symptoms might be an indicator of the caregiver's burden (Perlick, et al., 2006). For example, having long-lasting treatment and chronic symptoms might make a caregiver's burden more stressful than having occasional patient illness symptoms (Grandon, Jenaro, and Lemos, 2008). Hence, a major factor affecting the burden of caregivers has to do with the severity of patient symptoms, which require more time and energy (Wey and Chun-Jen, 2008).

c. Disability in daily life: As the patients struggle to carry out everyday activities and social functions due to the severity of their disease, the need for help is essential. For example, disruptive behaviour and the long-term nature of the disease can result in the increased dependency of patients on caregivers. As a result, the caregiver would have limited time, and energy to pay attention to their own activities and well-being.

2.6.3 Environment Factors

a. Mental health service and its utilization: In 2006, Roick, Heider, Toumi, and Angermeyer conducted a study that showed the importance of health services facilities in the community.

When there are adequate, close, and satisfactory health facilities, both patients and caregivers will benefit and carry on their daily activities to some extent.

b. Social support: The negative support from the social network can increase the burden on the caregivers.

In 2009, Chii, Hsing-Yi, Pin, and Hsiu reveal the importance of social and family connections for healthier coping and adaptation. When caregivers receive social support, their burdens will decrease. The same outcome from Magliano et al. in 2000 indicated that the importance of the support from the relatives and the social networks to decline the burdens on the caregivers.

2.7 Coping Strategies in Caregivers of Patients with Mental Illnesses

Lazarus and Folkman (1999 & 1984) define "coping" as a person's ability to deal with external or internal challenges that are beyond the individual's resources. They claim that coping is what individuals do to shield themselves from the consequences of life's events. The two authors also stressed that coping is related to one's inner emotional life as well as life stressors (Lazarus and Folkman, 1984). In the latest version of his definition, Lazarus concluded two main concepts as mediators that can affect the procedure of adaptation to the stress: cognitive appraisal and coping.

The first process, which is the cognitive appraisal, is the evaluation of the consequence of what is happening to the individual's wellbeing, and it is determined by situational and personal factors, such as norms and values, motives, anticipations, goals, capacities, skills, abilities, resources, and constraints. In 1991 Lazarus developed the emotion theory in a relation to the stress theory, where he distinguished two basic styles of appraisal, the first one is the primary appraisal and the other one is the secondary appraisal. The two said appraisals rely on diverse grounds of information. Primary appraisal involves the concerns whether something of unpleasant or a treat consequence of the individual's well-being occurs due to stressor, while secondary appraisal deals with the coping choices/strategies and evaluation of the resources that the individual must notice to prevent threats. The last concept of the notion is the process of reappraisal, and it is continuing procedure for re-evaluating the nature of the stressor and the approaches for coping.

The coping techniques are behavioural and cognitive methods that help individuals to cope with problematic and unexpected circumstances. They are two kinds of coping strategic approaches: problem-focused approach and emotion-focused approach. A problem solution-focused approach to issue solving entails first identifying the stressor, then brainstorming various solutions, and then reducing the possibilities down to the one that works best. Emotion-focused coping strategies are considered less adaptive since they rely on avoidance to reduce the caregiver's stress-related emotional response (Magliano et al., 1999). One example of an emotional-focused method is coping with stress-induced mood changes (Lazarus & Folkman, 1984).

Depending on their demographics, patients and caregivers may use a variety of coping strategies (Magliano et al., 1999). Emotional strategies are more typically used by younger caregivers and caregivers of younger patients, but problem-focused solutions are more commonly used by senior caregivers (Magliano et al., 1999). Emotional coping methods mostly be used to deal with health issues (Lazarus and Folkman, 1984). In order to address the problem head-on, it is important to seek knowledge or direction and enlist the assistance of friends and family. However, these stress-management measures were inadequate, resulting in a retreat and an effort to ignore the situation. When they feel they can manage a difficult circumstance, such as the patient's hostile behaviour, they use avoidance and evasion (Nehra et at., 2005). Some family members prefer to withdraw completely from the ill person. Nasser Hassan et al. (2011) discovered that caregivers of schizophrenia patients used positive judgment and avoidance coping in an Egyptian cross-sectional study. Avoidance and other ineffective coping methods may result in a lack of concern for the sufferer. Shibre et al., (2001) discovered that prayer was a commonly used way of coping by family members in another cross-sectional study on the impact of schizophrenia among 178 family members of individuals with schizophrenia conducted in Ethiopia, and they attributed the illness to magical origins and used prayer for guidance (Shibre et al., 2001).

To cope with the threat of physical hostility, some patients may employ emotional coping mechanisms (Scafuza and Kupiers, 1999). Caregivers who deal with the symptoms of patients suffering from significant mental disorders often have a lot of work to accomplish to be able in carrying out the tasks of caring for the sick relative (Scafuza and Kupiers, 1999). Different factors such as social support, coping skills, and cognitive evaluation have all been shown to impact caregiving support for a mentally ill relative (Scafuza and Kupiers, 1999). Furthermore, members of the family need to utilize a communication approach in order to cope with the situation. It is typical for people to discuss how they are feeling and what they are thinking about the mental health situation of their sick relative (Lazarus and Folkman, 1984). However, due to the denial and stigma associated with mental illness, families may find it difficult to address the subject. As a result of this, caregivers face increasing pressures and strains to fulfill the caring task in a healthy environment (Stengler-Wenzke et al., 2004).

Some families turn to religious and spiritual traditional approaches to help them deal with caring for a mentally ill loved one. Spiritual approaches have been identified and approved to assist individuals to cope with stress (National Alliance on Mental Illness, 2005). This may be accomplished by adherence to beliefs and concepts, as well as participation in worship and rituals. Spirituality may be practiced alone or with others (private prayer), and it has been demonstrated to relieve stress and improve family well-being (Rammohan et al., 2002). This may be the case in certain cases when a family member is unable to give enough care or assistance due to their own religious or spiritual views. Caregivers of a mentally ill loved one often use social support systems, such as friends, neighbours, family, and extended family, in addition to institutional support systems, such as health care institutions (Lazarus and Folkman, 1984).

2.7 Theoretical Perspective

The study was guided by the Transactional Model of Stress and Coping Theory (Lazarus and Folkman 1987) which act to clarify the connection between how family caregivers' efforts to care for mentally ill family members can negatively affect both behavioural and cognitive responses that people use to survive internal and external stressors perceived, especially when caregiving and the demands exceeds their personal capabilities, energies, and resources. Therefore, this theory will be used comprehensively to examine stress, burden, and coping strategies. To find out how does one's environment affect their behaviour in a burden situation? This perspective will be seen the individual and their environment relationship through an active and mutually collective connection and emphasizes that an individual possesses the ability to consciously choose to create environments they exist in, through entering a state of adaption (Lazarus, 1984).

According to the theory, psychological stress occurs when an individual's environment feels threatened to their well-being. Cognitive appraisal and coping are processes that can mediate the person's reaction to these environments and their demands. Therefore, appraisals can help to analyse perceived control of an individual's situation and resources. Using this theory can determine both the individual's reprisal and psychological adjustment. Additionally, this theory can act as a guide on how best to use specific coping strategies. Hence, coping strategies depend on personality patterns and cognitive experiences by involving and applying mental drive in a way that can reduce stress. This drive can be conscious or unconscious, the goal of all coping mechanisms is to reduce the stress and restore balance.

Based on this model, stress arises from the transaction between an individual and their environment, which includes both objective stressors and the individual's subjective appraisal of those stressors. In the context of caregiving, the burden of caregiving can be a significant stressor for caregivers. The Transactional Model suggests that the caregiver's appraisal of the burden of caregiving is crucial to understanding their stress levels. Specifically, if a caregiver appraises the caregiving situation as a threat to their well-being, they are more likely to experience high levels of stress. The model also suggests that the coping mechanisms that a caregiver employs can impact their experience of stress. Coping mechanisms can be either problem-focused or emotion-focused. Problem-focused coping involves taking direct action to manage or solve the problem, while emotion-focused coping involves managing the emotional distress caused by the problem. The Transactional Model suggests that both problem-focused and emotion-focused coping mechanisms can be effective for caregivers, depending on the nature of the caregiving situation.

2.8 Conceptual Framework

The conceptual framework is a diagrammatic illustration of the relationship between the study variables. This research study is guided by the below variables as shown that, the stressors (economic factors, psychological factors, and social factors) will be the independent variables while the burdens of caregivers will form the dependent variables.

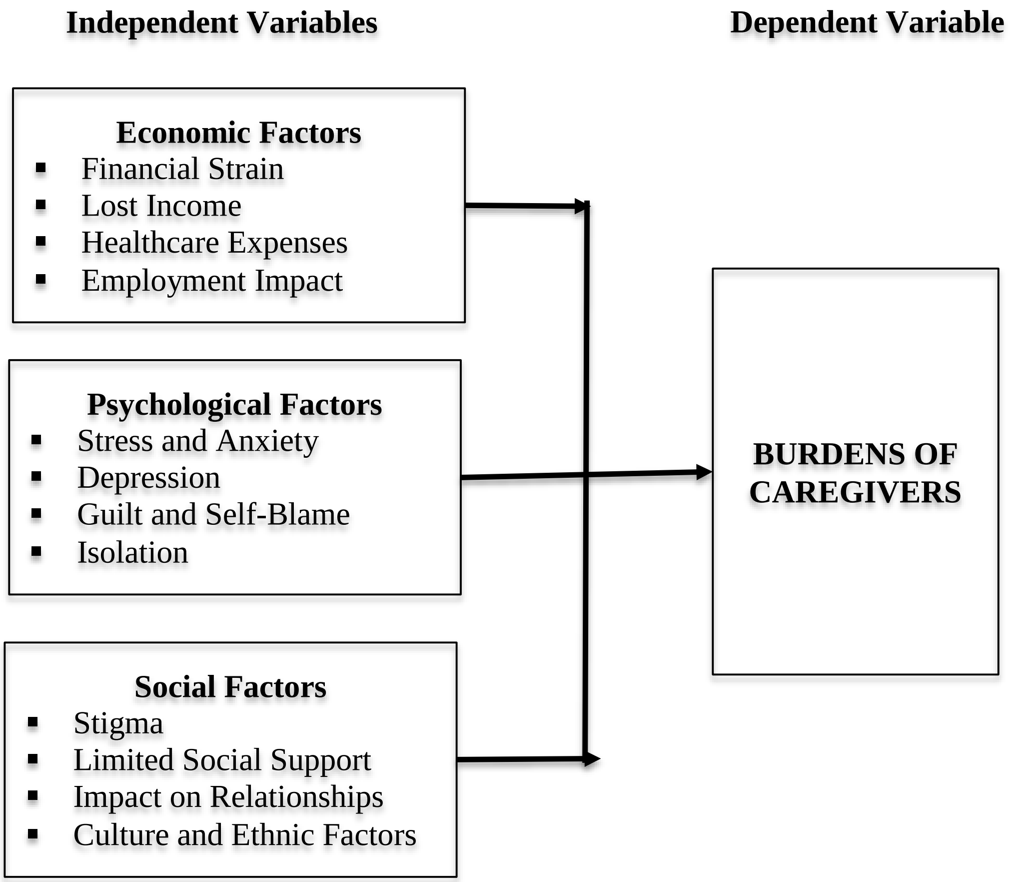


Figure 2.2 Conceptual Framework

Source: Researcher (2023)

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

This chapter presented an explanation of the research methods and processes that were utilized in this study. This chapter also explained the different steps of the research, which include the choice of participants, the data gathering techniques, reliability and validity, and the procedure of data analysis.

3.2. Study Design

This study adopted exploratory research design. Exploratory research is used to investigate a problem or research question in an exploratory manner, without the intention of providing conclusive evidence or definitive answers. The goal of exploratory research is to gain a deeper understanding of a research topic or issue, to generate new ideas, and to identify potential avenues for further research. This is used in the early stages of a research project, when the researcher has limited knowledge or understanding of the research problem or topic. The research is often conducted using qualitative methods, such as interviews, observations, and focus groups, which allow the researcher to collect rich, descriptive data about the research topic. One of the main justifications for using exploratory research in the collection of qualitative data is that it allows researchers to gain a more in-depth understanding of the research topic or issue. By collecting qualitative data through methods such as interviews and observations, researchers can gather rich, detailed information that can help them to develop a deeper understanding of the research topic, to identify potential areas of interest or concern, and to generate new ideas or hypotheses that can be further investigated in future research (De Vaus, 20, p 6; Leedy and Ormrod, 2014).

3.3 Target Population

The study targeted family caregivers whose relatives have been diagnosed with mental illnesses, and whom they attended and are being treated at Kamili Organization Clinics in Nairobi. The target population was the ones responsible for observing and caring for mentally ill relatives and providing unpaid home-based support for more than one year. They were over eighteen years old.

This study was conducted using a qualitative research method and content analysis approach in 2022. Qualitative studies are suitable for understanding phenomena in their context and the appearance of relationships between concepts and behaviours between individuals and comparing them with psychological theories. Fourteen family caregivers for mental and psychological patients who come to Kamili Organization clinics in Nairobi were selected based on the method of targeted sampling. The data was collected based on the experiences of family caregivers who provide care for patients at home. The integration criteria for the participants were as follows: the age between 18 and above, the provision of care for patients suffering from the disease for at least one year, and without any financial return, as well as the willingness to participate in this study.

3.4 Sampling Techniques and Sample Size

The population size of this study was the caregivers of mentally ill patients who followed up at Kamili Organization Clinics in Nairobi during the period from March 2022 to April 2022.

The nonprobability/purposive method was the sampling technique for this study. This technique supported the study in obtaining the study sample size for the participants who were the family caregivers of the patients. The research sought out elements that meet specific criteria, therefore, purposive sampling was used to cover the range of perspectives of the questionnaire. The target number was between 10 to 15 family members, and the interview was done for 14 family members (Bloor M, 2001). The research participants were the primary caregivers for mentally ill individuals being cared for more than one year.

3.5. Variables

The study variables included the impacts of caregiving and the effects on primary caregivers. The dependent variables were the burdens of caregivers, while the independent variables were identified as stressors (economic factors, psychological factors, and social factors). Intervening variables were the demographic factors, such as sex, age, and the marital status of caregivers.

3.6. Research Site

The study for this research was conducted at Kamili Organization Clinics in Nairobi County. The clinics deliver a diagnosis, treatment, and support to patients and their families. The Kamili organization was established in 2009, and it provides free mental health services via 30+ clinics across Kenya. The study selected these facilities because Kamili Organization clinics have a sufficient targeted population and are easily accessible.

3.7. Research instruments

The research targeted focus groups are caring for mental disorder family members. Participants were provided with a semi-structured questionnaire to explore their views and experiences, to provide a deeper understanding of their situations and experiences (Cresswell JW, Plano Clark VL, 2007). In this type of questionnaire/interview, the participants were asked several questions that are prepared beforehand (Berg, 2007, p.8).

This study used Zarit Caregiver Burden Interview (ZBI-12) to allow respondents to share feelings and opinions, and that supported the main research question and purpose. The open-ended questionnaire was used to capture details burdens among the caregivers.

Participants in the study completed a socio-demographic questionnaire, and the amount of load was assessed using the Short Form Zarit Burden Interview (ZBI-12) (Hebert, Bravo, and Preville 2000). The ZBI is a self-report consisting of 12 questions. Each item on the questionnaire is a statement that the caregiver must rate on a 5-point scale. The instrument will demonstrate high validity and reliability in evaluating careers' burden of care (Herbert, Bravo, Preville, & Bollen, 2000).

For the questionnaire and interview, the following questions were asked:

1. How long have you been caring for your family member?

1. What type of care does the patient need?
2. How has your life changed since s/he was diagnosed?
3. What is the most rewarding aspect of being a caregiver?
4. What is the most challenging aspect?
5. Do you take time for self-care?
6. How do you cope with caregiving overall?
7. When things get difficult, do you have someone you can talk to?
8. What type of support would help in your situation?
9. What activities help reduce your stress?
10. What kind of interventions can the health providers offer to help you manage your stress?

3.8 Data Collection

The potential participants for this study were the caregivers who are accompanying their sick relatives to Kamili Organization Clinics. Obtaining informed consent with an explanation of the purpose of the research and the confidentiality of the information was ensured before the administration of the questionnaire. It took four weeks to collect and analyze the data.

All participants were evaluated with Zarit Burden interview plus Semi-Structured face-to-face interviews. Before the interview, the questions were subjected to several analyses to test their reliability, validity, and ability to elicit responses to measure and evaluate participants' caregiving experiences. The questionnaire was designed to capture the characteristics of the study participants and adopted the drop and pick the method to collect primary data with open-ended questions. This explained the issue of the study and assess the data on variables of interest to allow answering the stated research questions, check hypotheses, and evaluation outcomes. The secondary data was collected and used in this study from sources that are credible and published, books, newspapers, internet articles, and research articles by other researchers. Semi-structured face-to-face interviews were used to collect data. I also needed a Swahili translator, because some escorts do not speak fluent English. At first, I asked family caregivers to explain their experience in general on the day of caring for their patients. All the questions asked in this study revolve around the experiences of caregivers at home and following their ideas using more exploratory and in-depth questions to investigate explanations, such as "Can you explain this more?". The duration of the interview ranged from 45to 60 minutes and was conducted in a quiet and comfortable place for the participants. The data was collected and analysed simultaneously and continued until the topic appeared, and the saturation of the data was reached.

3.9 Data Validity and Reliability

To ensure validity, this research utilized, and operationalized definitions related to the social and psychological concepts relevant to this thesis. With regards to the questionnaires that were utilized to conduct the interviews, efforts were put forth to ensure they are relevant to the overall aim of the study. Lastly, all research instruments utilized to conduct this study were selected based on relevant feedback on the appropriateness of the instruments. Reliability in qualitative research is measured by the stability of the procedure and the results of the data. To achieve this point Lincoln and Guba 1985, explained the trustworthiness in research through credibility, authenticity, transferability, dependability, and confirmability of the data resource and procedure. The research ensured that all participants are selected carefully and that their backgrounds reflect the research aims. It also ensured that they were made fully aware of the aims of the research (Lincoln and Guba 1985)

3.9.1 Reliability

Reliability was tested as shown in table 3.1

Table 3.1 Reliability Measures

Type of reliability	Description	Application and Testing
Test-Retest Reliability	This measures the consistency of results when the same rest is administered to the same participants at two different points in time	Administered the same questionnaire to a sample of caregivers on two separate occasions with a time gape in between. Calculated the correlation between their responses
Inter-Rater Reliability	Evaluates the consistency of results when multiple raters or observers assess the same phenomenon	Had multiple trained observers assess and rate the coping mechanisms used by caregivers. Calculated inter-rater reliability using methods like Cohen's Kappa
Internal Consistency Reliability	Measures the degree of consistency among items within a single instrument or questionnaire	Utilized Cronbach's alpha coefficient to assess the internal consistency of the questionnaire items related to caregiver burden and coping mechanisms.

Parallel Forms Reliability	Assesses the constituency of results when two different but equivalent forms of a test are administered to the same participants.	Developed two versions of the questionnaire with comparable content. Administered both versions to a subgroup of caregivers and compared the responses for consistency.

Source: Researcher (2023)

3.9.2 Validity

Table 3.2 presents the measures of validity

Table 3.2 Validity Measures

Type of Validity	**Description**	**Application and Testing**
Content Validity	Evaluates whether the research instruments (Questionnaire) adequately covers all aspects of the research topic	Conducted a thorough review of existing literature and consulted experts in the field to ensure that the questionnaire items comprehensively addressed caregiver burden and coping mechanisms.
Construct Validity	Determines whether the instrument measures the theoretical construct it is intended to measure	Conducted factor analysis to confirm that the questionnaire items loaded onto the expected factors related to caregiver burden and coping mechanisms
Criterion Validity	Assesses whether the research instrument can predict or correlate with an external criterion (e.g., a validated measure of caregiver stress)	Administered both the research questionnaire and an established measure of caregivers. Calculated the correlation between the two measures

Source: Researcher (2023)

3.10 Data Analysis

After collecting the data, a procedure of coding, categorizing, and identification was used to extract and analyse the data using descriptive and content analysis. The qualitative data were analysed using NVIVO software. Through NVIVO, important themes and categories emerged through examination and comparison. (Patton, 2002). This research required a qualitative questionnaire because the data sought was based on words and narratives, not numbers (Monette, Sullivan, ad DeJong, 2011).

3.11 Ethical Considerations

This research is sensitive in nature. Therefore, ethical considerations must be recognized by the researcher and participants. Firstly, all participants will be treated with respect and courtesy.

The participants were provided with informed consent forms before they participated in the research study. The principle of informed consent guaranteed that the researcher provided sufficient information and assurances about taking part. The researcher also ensured that participants understood the purpose of the study as scholarly research. Participants were not subjected to harm in any way, and privacy and confidentiality were guaranteed to them. The use of offensive, discriminatory, or other unacceptable language was also prohibited.

CHAPTER FOUR

DATA ANALYSIS, PRESENTATION AND INTERPRETATION

4.1 Introduction

This chapter constitutes the results of the data collected, analysed, and interpreted by the researcher. The research aimed to establish and explore caregivers' experiences and identify their coping strategies, by exploring barriers that affect family caregivers’ ability to cope with their relatives diagnosed with mental illness. Specifically, the chapter presents the study findings as per the specific research objectives.

4.2 Caregiver's Demographic Characteristics

The study participants completed a socio-demographic questionnaire which supported collecting data regarding social variables such as age, gender of the caregivers, as well as the duration of the caregiving role. They also completed the short version of the Zarit Short Form Burden Interview (ZBI-12) (Hebert, Bravo, and Preville 2000). The Zarit Burden Interview is a self-report consisting of twelve questions. It is one of the most frequently used methods to assess psychological and emotional burdens on caregivers in clinical and research settings.

4.2.1 Gender of caregivers

This section aimed at determining the gender of the caregivers. Figure 4.1 shows the results obtained.

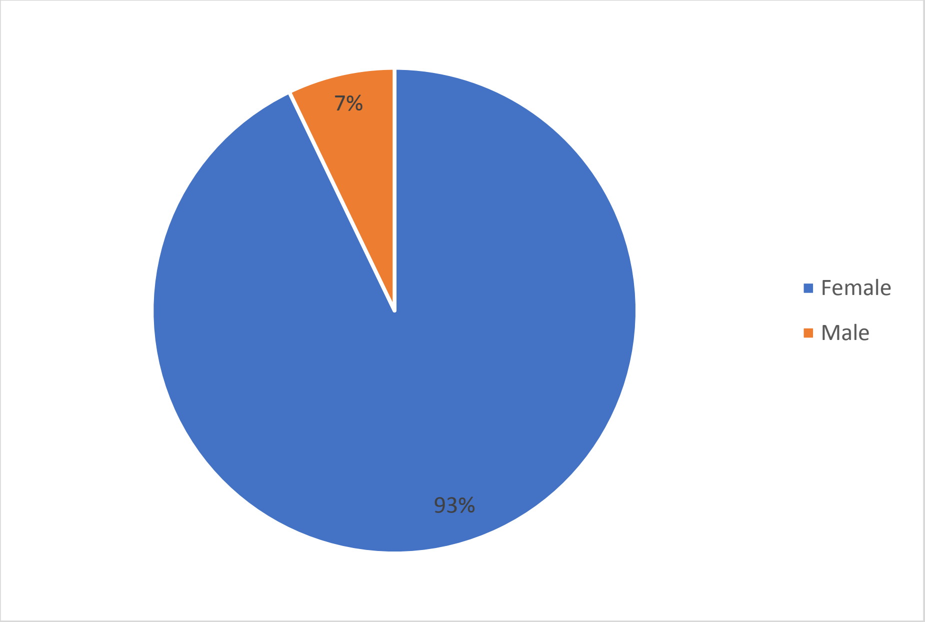


Figure 4.1 Gender of Caregivers

Source: Researcher (2023)

The results as shown in Figure 4.1, revealed that most of the caregivers were female 93% while the remaining 7% were male. These findings on the caregivers being predominantly females is concurrent with literature on caregiver burden that has generally depicted that indeed most women tend to be the caregivers in similar situations. Schneider and Hemsworth (2010) also mention that women have a higher potential for caregiving in comparison to men, they found that women caregivers tended to experience more depressive/anxiety symptoms and higher-level grief of burden than men caregivers.

4.2.2 Age of the caregivers

The study also aimed to the determination of the age of caregivers. The results are shown in Table 4.1 and Figure 4.2.

Table 4. 1 Age of Caregivers

Age	**Frequency (n)**	**Percent (%)**
Below 40 years	3	21%
40-50 years	6	43%
Above 50 years	5	36%
Total	**14**	**100%**

Source: Researcher (2023)

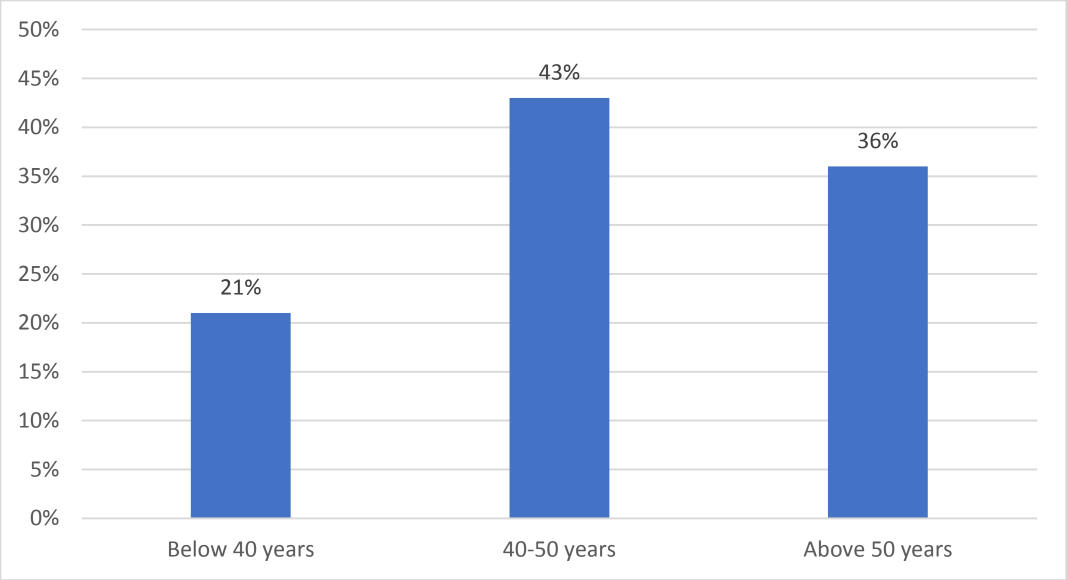


Figure 4. 2 Age of Caregivers

Source: Researcher (2023)

On the age of the caregivers, the results indicated that 43% were between 40 to 50 years, 36% were above 50 years and 21% were below 40 years. This shows that majority of the respondents were above 40 years (79%). The older the caregiver becomes, the more they may be concerned about who will care for the sick family member in the future (Fujino & Okamura, 2009).

4.2.3 Duration of the caregiving role

The study also investigated the duration the caregivers had taken care of their mentally sick relatives. The findings are shown in Table 4.2 and Figure 4.3.

Table 4. 2 Duration of the caregiving role

Duration	Frequency (n)	Percent (%)
Less than 3 years	3	21%
3-6 years	5	37%
7-10 years	3	21%
Above 10 years	3	21%
Total	**14**	**100%**

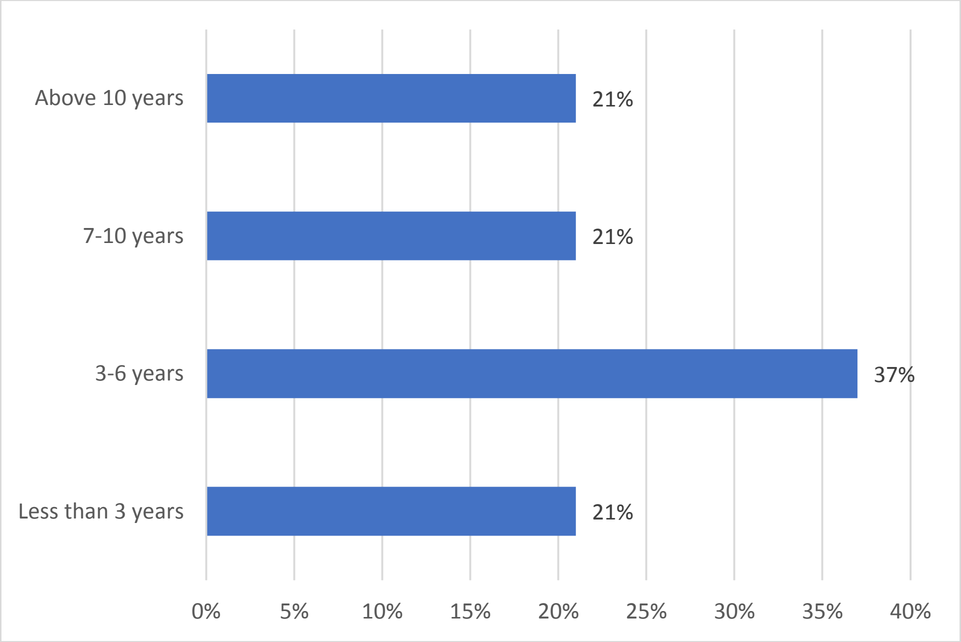


Figure 4. 3 Duration of the caregiving role

Source: Researcher (2023)

The results further revealed that on the duration of the caregiving role, 36% of the respondents have been caring for the patients for a period of between 3 to 6 years, 21% each for a period of fewer than 3 years, 7 to 10 years and above 10 years. This implies that the majority of the caregivers had cared for the patients for a considerable length of time of over 3 years (79%) hence aware of their needs and special demands.

4.3 Patients Demographic Characteristics

This section sought out at determination of the demographic characteristics of the mental patients including their age and gender.

4.3.1 Gender of mental patients

This section sought to find out the gender of the mental patients cared for. Figure 4.4 shows the results obtained.

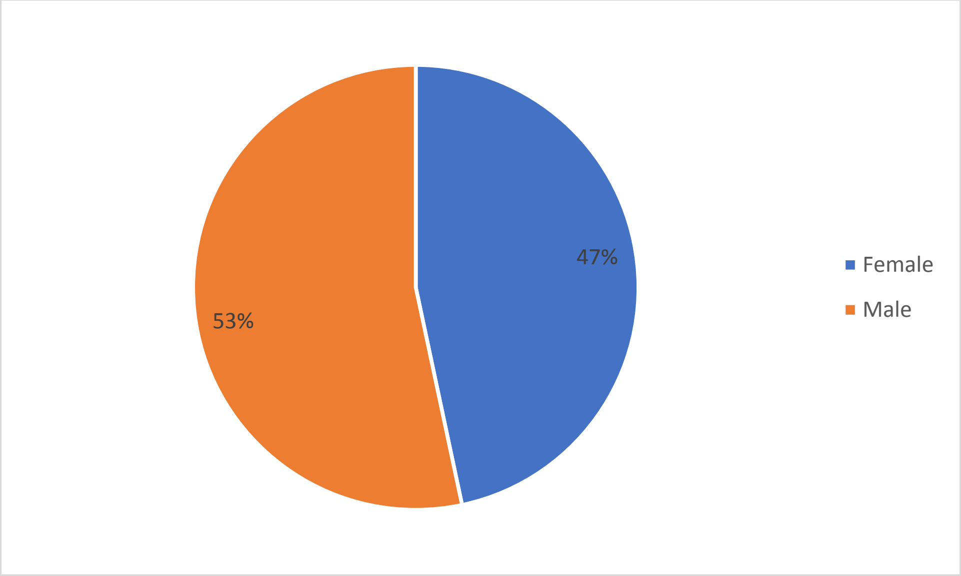


Figure 4. 4 Patients Gender

Source: Researcher (2023)

The results revealed that 53% were male while 47% were female showing an equal representation of gender among the mental patients studied.

4.3.2 Age of the mental patients

This section aimed at determining the age of the mental patients. Table 4.3 shows the responses obtained.

Table 4. 3 Patients Characteristics

Age	Frequency (n)	Percent (%)
Below 20 years	5	33%

21-30 years	2	13%
31-40 years	1	7%
41-50 years	3	20%
Above 50 years	4	27%
Total	**14**	**100%**

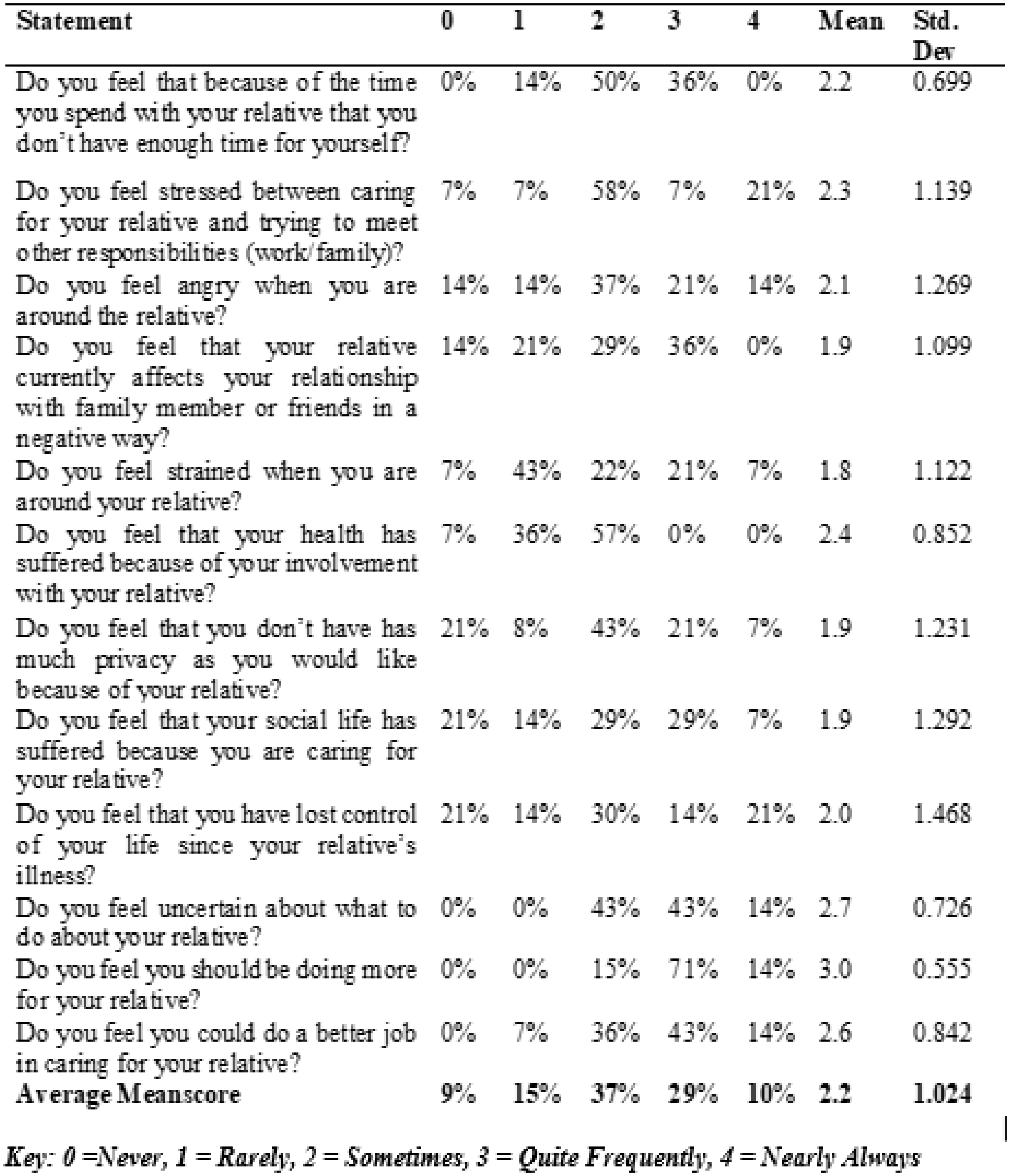
Source: Researcher (2023)

As shown in Table 4.3, 33% were below 20 years, 27% were above 50 years, 20% were between 41 to 50 years, 13% were between 21 to 30 years, and 7% were between 31 to 40 years. This implies that most of the mental patients were above 20 years (67%) and hence relatively old. According to Juvang, Lambert, and Lambert, (2007) caregivers feel burdened when they take care of younger patients over a long period. The younger patients require more caregiving attention and time.

4.4 Burden on caregivers of mentally ill relatives and its associated effects

The objective of the study was to determine the burden on caregivers of mentally ill relatives and its associated effects. To achieve this, Zarit Caregiver Burden Interview was used to allowing respondents to share feelings and opinions, and that will support the main research question and purpose. This tool is useful as it can address challenges faced by caregivers. The Zarit Caregiver Burden Results are shown in Table 4.4.

Table 4. 4 Zarit Caregiver Burden Results



Statement	0	1	2	3	4	Mean	Std. Dev
Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0%	14%	50%	36%	0%	2.2	0.699
Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	7%	7%	58%	7%	21%	2.3	1.139
Do you feel angry when you are around the relative?	14%	14%	37%	21%	14%	2.1	1.269
Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	14%	21%	29%	36%	0%	1.9	1.099
Do you feel strained when you are around your relative?	7%	43%	22%	21%	7%	1.8	1.122
Do you feel that your health has suffered because of your involvement with your relative?	7%	36%	57%	0%	0%	2.4	0.852
Do you feel that you don't have has much privacy as you would like because of your relative?	21%	8%	43%	21%	7%	1.9	1.231
Do you feel that your social life has suffered because you are caring for your relative?	21%	14%	29%	29%	7%	1.9	1.292
Do you feel that you have lost control of your life since your relative's illness?	21%	14%	30%	14%	21%	2.0	1.468
Do you feel uncertain about what to do about your relative?	0%	0%	43%	43%	14%	2.7	0.726
Do you feel you should be doing more for your relative?	0%	0%	15%	71%	14%	3.0	0.555
Do you feel you could do a better job in caring for your relative?	0%	7%	36%	43%	14%	2.6	0.842
Average Meanscore	**9%**	**15%**	**37%**	**29%**	**10%**	**2.2**	**1.024**

Key: 0 =Never, 1 = Rarely, 2 = Sometimes, 3 = Quite Frequently, 4 = Nearly Always

The findings as shown in Table 4.4 indicated that the majority of the respondents felt to be doing more for their relatives quite frequently with a mean of 3.0. Most of the respondents also felt that because of the time spent with the relative they don’t have enough time for themselves, are stressed between caring for the relative and trying to meet other responsibilities, are angry when they are around the relative, lost control of their life since the relatives’ illness, uncertain about what to do about their relative and could do a better job in caring for their relatives sometimes with means of 2.2, 2.3, 2.1, 2.4, 2.0, 2.7, 2.6 and 2.2 respectively.

However, a small extent was noted on the respondents feeling that their mentally sick relatives currently affect their relationship with a family member or friends negatively, strained when they are around their mentally sick relatives and don’t have as much privacy as they would like because of their relatives and that their social life has suffered because they are caring for their mentally sick relatives rarely with means of 1.9, 1.8, 1.9 and 1.9 respectively. Based on the average score, 9% of the respondents felt that they were never burdened, 15% felt that they were burdened rarely, 37% felt that they were burdened sometimes, 29% felt that they were burdened quite frequently and 10% felt that they were burdened nearly always. This shows that there was a high prevalence of burden among the family caregivers with 85% of them indicating the burden to occur sometimes, quite frequently, and nearly always having an average mean of 2.2 and standard deviation of 1.024.

4.5 Requirements of family caregivers when caring for individuals with mental illnesses

The study sought to establish the requirements of family caregivers when caring for individuals with mental illnesses. Specifically, this included the type of patient needs, changes in lifestyle, and the challenging aspects and rewarding aspects of caregiving.

4.5.1 Type of patient needs

This section was sought out to determination of the needs of the mentally sick relative. The results are shown by Table 4.5 and Figure 4.5.

Table 4. 5 Type of mentally patient needs

Need	Frequency	Percent
Basic Needs	4	22%
Transportation to hospital	1	5%
Economic, social and health support	3	16%
Total care	5	26%
Food and moral support	1	5%
Medication	5	26%

Total	**14**	**100%**

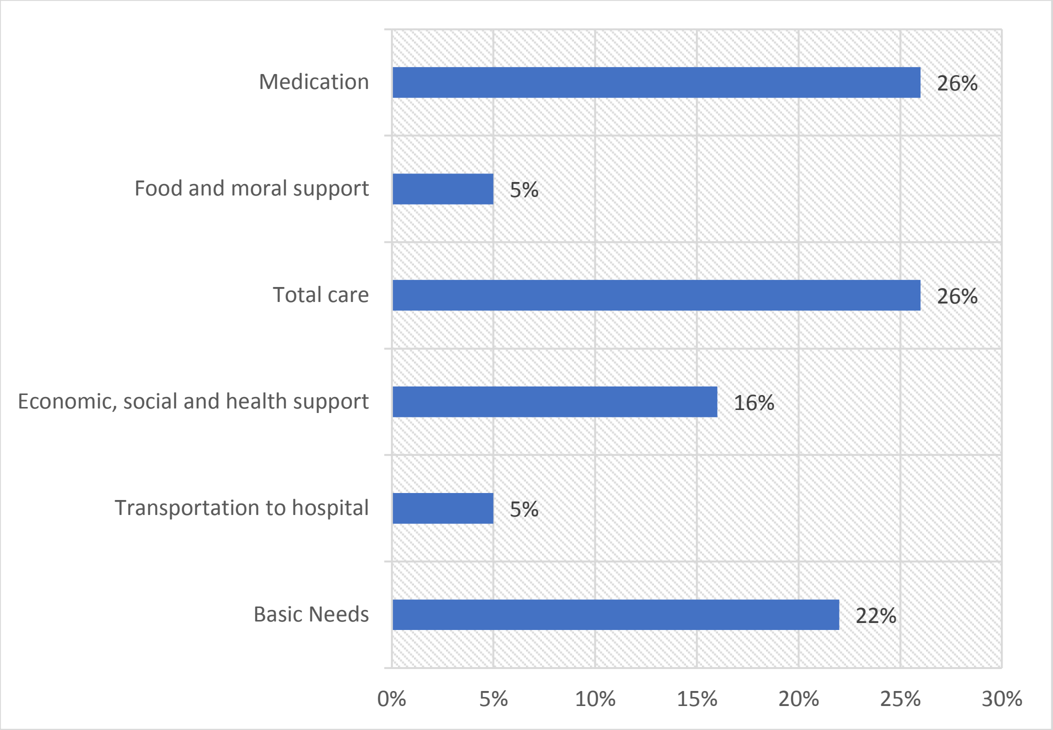


Figure 4. 5 Type of patient needs

Source: Researcher (2023)

Regarding the mentally patient needs, the respondents indicated the major needs to be total care (26%), medication (26%), and basic needs (22%). Other needs included economic, social, and health support (16%), transportation to the hospital (5%), and food and moral support (5%). This shows that the mentally sick relative needed overall support during their daily activities but also taking the required medications.

4.5.2 Change in lifestyle

This section was set out to investigate the change in the lifestyle of the caregivers brought about by taking care of the mentally sick relative. Table 4.6 presents the results obtained.

Table 4. 6 Change in lifestyle

Change	**Frequency**	**Percent**
Anxiousness	2	15%
Caring for him, observing him	1	7%
Increased connection	2	14%
Frustrations, debt	1	7%
Economic hardships	2	14%
No effect	2	14%
Overwhelming responsibilities	3	22%
Struggling to understand their illness	1	7%
Total	**14**	**100%**

Source: Researcher (2023)

As per Table 4.6, the major changes were overwhelming responsibilities (22%), anxiety (15%), increased connection with the patient (14%), economic hardships (14%), frustrations and debt (7%), and struggling to understand their illness (7%). However, some of the caregivers (14%) indicated that they experienced no changes while taking care of their patients.

4.5.3 Rewarding aspects of caregiving

The study aimed to investigation of the rewarding aspects of caregiving. Table 4.7 shows the results obtained.

Table 4. 7 Rewarding aspects of caregiving

Aspect	Frequency	Percent
Caring for themselves	5	37%
Connecting-together	1	7%
Have learnt to cope	3	21%
Love and care for family	1	7%
Obedience	1	7%
Them being happy	3	21%

Total	**14**	**100%**

Source: Researcher (2023)

4.5.4 Challenging aspects of caregiving

The respondents were also required to indicate the most challenging aspects of caregiving. The results as shown in Table 4.8 revealed that the most challenging aspect was when the patients got sick or worse. Other challenges experienced included financial challenges, mood, and attitude, stress as well as financial challenges. This implies that the caregiving role was a highly challenging activity which explains why most of the caregivers ended up being overwhelmed.

Table 4. 8 Challenging aspects of caregiving

Challenge	**Frequency**	**Percent**
Family dynamics	1	7%
Financial challenges	3	21%
Mood and attitude	3	21%
Stress	3	21%
When they got sick	4	30%
Total	**14**	**100%**

Source: Researcher (2023)

4.5.5 Time for self-care

This section aimed at assessing whether the caregivers had time for self-care and how they spent this time. The results as per Table 4.9 and Figure 4.6 indicated that the majority of the respondents had time for self-care (71%), 15% had no time for self-care while the remaining got time rarely or some time with percentage frequencies of 7% each. Those who had time for self-care described they used this time for prayers and fellowships, self-acceptance, and visiting other family members.

Table 4. 9 Time for self-care

Response	**Frequency**	**Percent**
No	2	15%
Rarely	1	7%
Sometime	1	7%
Yes	10	71%
Total	**14**	**100%**

Source: Researcher (2023)

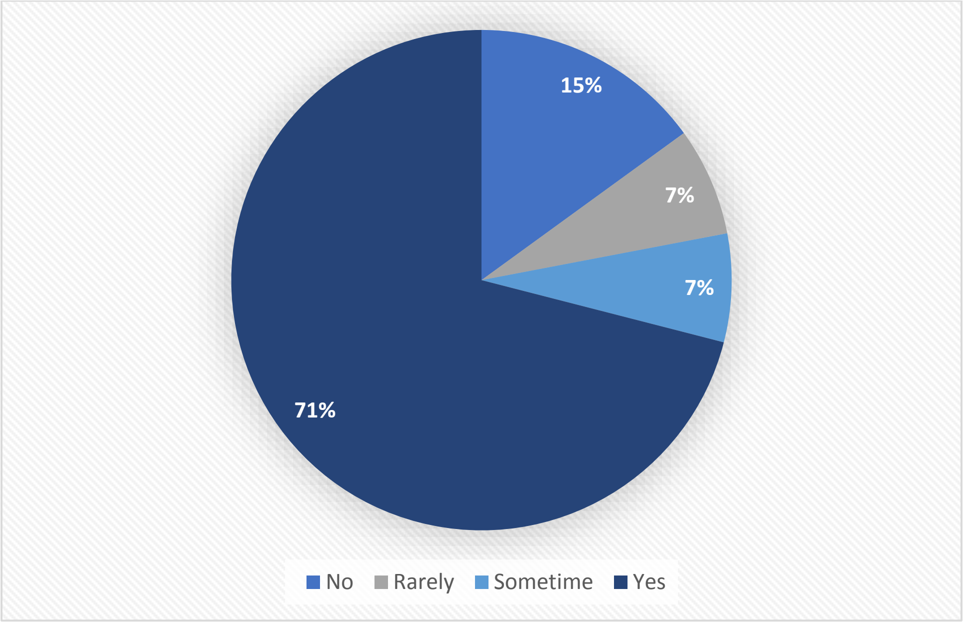


Figure 4. 6 Time for self-care

Source: Researcher (2023)

On the rewarding aspects of caregiving, the respondents pointed out that the mentally sick relative being able to care for themselves, having learned to cope and them being happy were the most rewarding aspects having percentage frequencies of 36%, 21%, and 21% respectively. Other rewarding aspects were indicated to be connecting with the sick relative, love, care for the family, and patient obedience.

4.5.6 Coping mechanisms

The study further investigated the coping mechanisms of the caregivers. The results are shown in Table 4.10.

Table 4. 10 Coping mechanisms

Mechanism	**Frequency**	**Percent**
Church and prayers	6	43%
Family and friends support	5	36%
Extracurricular activities	3	21%
Total	**14**	100%

Source: Researcher (2023)

From the responses obtained, the majority of the respondents coped through church and prayers, as well as getting support from friends and family. In addition, others coped by undertaking extracurricular activities which helped ease their minds from the demanding caregiving tasks as per Table 4.10. The study further inquired as to whether the caregivers talked to others as a form of coping. All the respondents agreed to talk to others with the majority talking to family members and friends. On the contrary, other caregivers opted to keep everything to themselves.

4.6 Suggestions and recommendations for the type of support that can be provided to caregivers caring for a family member with a mental illness

The study also sought to determine the type of support that can be provided to caregivers caring for a family member with a mental illness. Particularly, the study investigated the support needed, stress-relieving activities, and support interventions.

4.6.1 Support needed

This section was set out in investigating the support that the mentally sick relative required. The findings are shown in Table 4.11.

Table 4. 11 Support needed

Type of support	Frequency	Percent
Having a helper	1	7%
Advice	1	7%
Counselling	1	7%
Educational support	2	15%
Financial support	1	7%
Family support	1	7%
Government support	2	14%
Having people around	1	7%
Medication support	2	15%
Spiritual support	1	7%

Taking some time off	1	7%
Total	**14**	**100%**

Source: Researcher (2023)

On the support needed, the majority of the respondents indicated the need for a helper, counselling, advice, financial support, government support, medication support, and family support. Other forms of support required were indicated to be having people around, employment opportunities, taking some time out, and spiritual support. These will not only ensure that they can perform their caretaking duties effectively but also prevent them from being overwhelmed.

4.6.2 Stress-relieving activities

The study also sought to determine some of the stress-relieving activities undertaken by the caregivers. The results obtained are presented in Table 4.12.

Table 4. 12 Stress-relieving activities

Activity	Frequency	Percent
Church, fellowship and prayers	6	44%
Going out with friends	2	14%
Swimming, Running and walking	3	21%

Talking to a friends and family	3	21%
Total	**14**	**100%**

Source: Researcher (2023)

Most of the caregivers described that they undertook religious activities including going to church fellowship and prayers. Other stress-relieving activities were noted to be going out with friends, swimming, running, walking, and talking to friends and family.

4.6.3 Support interventions

The study also inquired about the support interventions that the caregivers felt they needed. Table 4.13 and Figure 4.7 show the results obtained.

Table 4. 13 Support interventions

Support intervention	**Frequency**	**Percent**
Chance to share their experiences	4	29%
Counselling	2	14%
Financial support	4	29%
Government support	1	7%
Medication support	3	21%

Total	**14**	**100%**

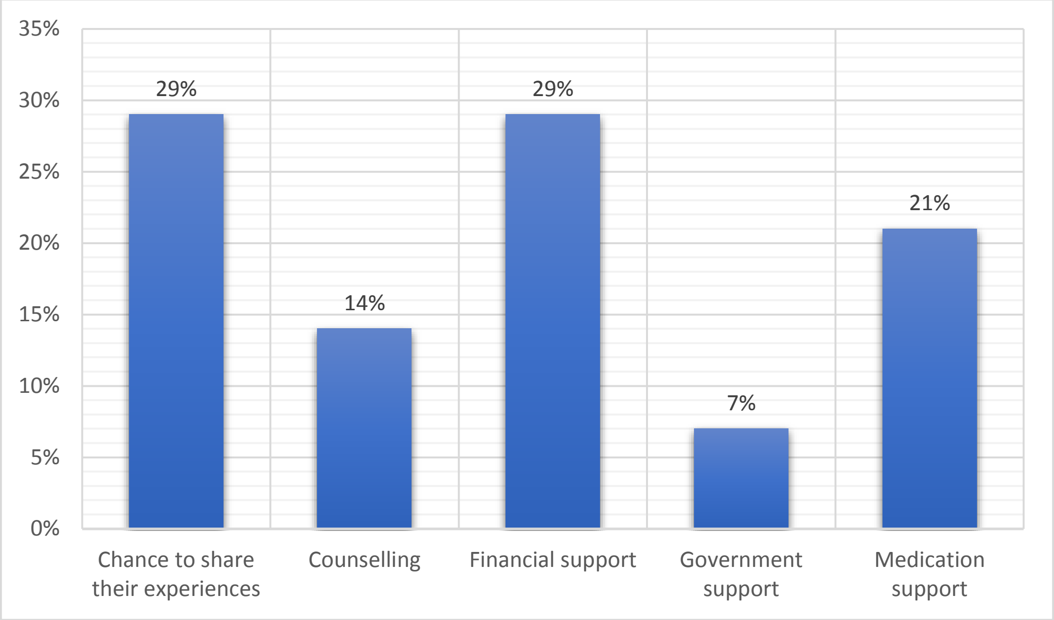


Figure 4. 7 Support interventions

Source: Researcher (2023)

As shown, by the support interventions suggested by the caregivers, the majority of them indicated having a chance to share their experiences, as well as getting medical and financial support. The respondents also suggested other interventions such as counselling and government support.

4.7 In-depth Interview Responses

The study undertook in-depth interviews in order to capture detailed information on the study objectives.

4.7.1 Burden on caregivers of mentally ill relatives and its associated effects

On the burden on caregivers of mentally ill relatives and its associated effects, an interviewee stated,

> *"Being a caregiver to a mentally ill relative can be an enormous burden that can affect every aspect of life. The emotional strain can be incredibly taxing, leading to feelings of frustration, guilt, anxiety, and depression. Caregivers are also often forced to make difficult decisions regarding the care and wellbeing of their loved ones."*

Another one added that,

> *"The responsibilities of caregiving can take up a significant amount of time and effort, leaving little room for self-care or other interests. The financial impact of caring for a mentally ill relative can also be significant, with the costs of medication, therapy, and hospitalization adding up quickly."*

4.7.2 Requirements of family caregivers when caring for individuals with mental illnesses

On the requirements of family caregivers when caring for individuals with mental illnesses, the interviewees explained that caring for a family member with a mental illness requires a great deal of patience, understanding, and flexibility. Caregivers must also be able to provide emotional support while also assisting with daily tasks such as bathing, dressing, and managing medication. They must also be vigilant for any signs of relapse or changes in mood or behavior. Effective communication skills were also revealed to essential, as well as a willingness to learn about the illness and its treatments. Based on this, caregivers must be prepared to deal with the challenges that come with navigating the healthcare system and finding appropriate resources for their loved one.

4.7.3 Challenging aspects of caregiving and coping mechanisms

From the responses obtained, it was evident that the most challenging aspects of caregiving for a mentally ill relative is the unpredictability of the illness. The interviewees described that it can be difficult to know how to respond to sudden mood swings, outbursts, or other behavioral changes. Caregivers may also experience feelings of isolation and a lack of support from others who don't understand the unique challenges they face. Coping mechanisms for these challenges were described to include seeking out support groups and other resources for caregivers, practicing self-care, and seeking professional counselling if necessary.

An interviewee sensitized that,

> *"It is important for caregivers to set boundaries and recognize when they need to take a break from caregiving to avoid burnout."*

4.7.4 Suggestions and recommendations for the type of support that can be provided to caregivers caring for a family member with a mental illness

The interviewees noted that one of the most important things that can be done to support caregivers is to provide access to resources and information about the illness and its treatment.

An interviewee noted that,

> *"This can include access to counselling services, support groups, and education about medications and other treatments. Respite care services can also be invaluable in giving*

> *caregivers a break from their responsibilities. Financial support can help alleviate some of the financial strain of caring for a mentally ill relative. Employers can also play a role in supporting caregivers by offering flexible work arrangements or other accommodations."*

Another interviewee stated that,

> *"The most important thing that can be done to support caregivers is to acknowledge the vital role they play and provide them with the tools and resources they need to care for their loved ones while also taking care of themselves."*

4.8 Summary of the Key Findings

Through a qualitative phenomenological study and in-depth interviews, this study aimed to explore caregivers' experiences and identify their coping strategies, by exploring barriers that affect family caregivers' ability to cope with their relatives diagnosed with mental illness. The study applied Lazarus and Folkman the "Transaction Model of Stress and Coping" by collecting samples of caregivers from Nairobi County, Kamili Organization clinics. A summary of key findings is presented below as per the research objectives.

The first objective of the study was to determine the burden on caregivers of mentally ill relatives and its associated effects. The findings indicated that the majority of the respondents felt to be doing more for their relatives quite frequently. Based on the average score from the Zarit Caregiver Burden Interview, only 15% of the respondents felt that they were never burdened, 15% felt that they were burdened rarely, 37% felt that they were burdened sometimes, 29% felt that they were burdened quite frequently and 10% felt that they were burdened nearly always. This shows that there was a high prevalence of burden among the family caregivers with 85% of them indicating the burden to occur sometimes, quite frequently, and nearly always having an average mean of 2.2 and standard deviation of 1.024. The majority of the participants reported having difficulty with the caring role, such as the distance from the mental health facilities is far and that consume time and money. One of the participants stated the following *"The facility is far from my home, which require considerable drive time and money to take my son for his appointments, I feel executed and tried all the time. We do not have any nearby hospital that I can go to in case of emergency).* They also mentioned that the dynamic of the relationship has been changed due to the sickness, and this ends up in more psychological, financial, and physical burdens. An old female participant (70-year-old), whose is caring for her husband and son mentioned that "*I have to care for my son and husband at the same time, doing all the chores, food, bath, household chores, and medications. My relationship with them became more command and observational, we hardly have normal conversation, and that makes me most of the time down. Adding to that I must find ways to secure our financial obligations).* The demands on the other side also increased, and that can be reflected in the restriction they found themselves for having less time to do the things they used to do.

The second objective of the study aimed to evaluate and analyze the requirements and the coping mechanisms of family caregivers when caring for individuals with mental illnesses. With regards to the burden placed on the family, the study found that caring for a family member with a mental illness created both objective and subjective burdens. The objective burdens included disruption of the caregiver's daily activities, social isolation, and financial and employment difficulties. Regarding the patient needs, the respondents indicated the major needs to be total care (26%), medication (26%), and basic needs (21%). On the other hand, subjective burdens included the emotional strain experienced by family caregivers which included fear, denial, anxiety, sadness, anger, guilt, loss, stigma, and rejection. The major changes in caregivers' lifestyles were overwhelming responsibilities (21%), anxiety (14%), increased connection with the mentally sick relative (14%), economic hardships (14%), frustrations and debt (7%), and struggling to understand their illness (7%). One of the caregivers said *"Apart from the financial difficulties, I am supposed to do all the tasks at home and at the same time taking care of my daughter. This made me unable to control the course of my daily life. My dissatisfaction with what I am in is not my choice and cannot leave my daughter alone at home. My fear for her at the beginning of her illness made me feel shamed and in a shock of her condition. I was always in conflict with her, violent in wards, and I reached a state of beating her. I ignite with shame on myself".*

On the rewarding aspects of caregiving, the respondents pointed out that the mentally sick relatives being able to care for themselves, having learned to cope and them being happy were the most rewarding aspects having percentage frequencies of 36%, 21%, and 21% respectively. Many of the participants also reported that caring for their mentally sick relative bought them together as a family, and they are trying to provide the best care they could. Mr. G. reported "One of the most challenging diseases affecting humans is mental and neurological diseases. When my daughter was diagnosed, her mother and I cried, but in the end, we accepted it. Her condition now is relatively stable, she takes treatments regularly and goes to school, we fear for her when she is away from our eyes. We explained to the school staff and our relatives her condition, and we thank God anyway".

The respondents were also required to indicate the most challenging aspects of caregiving. The results revealed that the most challenging aspect was when the sick relatives got sick or worse, and they reported difficulty with seeing their behaviours and personality changes. Other challenges experienced included mood and attitude, stress as well as financial challenges. This implies that the caregiving role was a highly challenging activity which explains why most of the caregivers ended up being overwhelmed and needed help and support to avoid further frustration and to enable them to fulfill their caring role. Ms. D. said *"My mother has become a different person since she has diagnosed with Alzheimer's disease. Her personality changed, and she became like a little girl. I am very depressed about her condition before she was the head of the house, but now I must do anything for her and the household chores, adding to that I must go for my work. I am tired, exhausted, have no time for myself, and depressed".*

The study further investigated the coping mechanisms of the caregivers. From the responses obtained, the majority of the respondents coped through church and prayers, as well as getting support from friends and family. Participant E. stated the following *"I know that everything is in God's hands, illness and healing. So, I always pray to God to give me the strength to continue and forgive my moments of anger at my sick sister".* In addition, others coped by undertaking extracurricular activities which helped ease their minds from the demanding caregiving tasks, such as physical exercises and going out with friends. The study further inquired as to whether the caregivers talked to others as a form of coping. All the respondents agreed to open about how they felt to release some stress from the caring tasks. Most of them indicated that talking to family members and friends has a good outcome on their morale. On the contrary, other caregivers opted to keep everything to themselves. Participant M. reported the following *"I need someone by my side to share with me some of the tasks to take care of my father. My siblings live far from my house and my mother is old now, so, most of the time I'm doing everything alone. I have a close friend and I always talk to her about what I am going through. Having someone close to me to talk to helps me in coping with the stress and the psychological pressures I'm going through".*

The last objective of the study was to determine the type of support and recommendations that can be provided to caregivers caring for a family member with a mental illness. On the support needed, most of the respondents indicated the need for someone to be around to help with the caring role, counselling and psychoeducation also needed to assist in the coping processes, advice from support groups and friends can assist in coping, financial support, government support, medication support, and family support. In this regard participant Ms. T. stated *"At the beginning of my sister's illness, I didn't know what happened to her. Whenever I go with her to the clinic, the doctor would only ask if any changes happened in her condition and prescribed the medicines accordingly. I must read a lot about similar cases so that I can be able to understand her condition, and still not coherent and accurate. When we started coming to Kamili Clinic, the counsellor explained to me* *the condition in detail and gave me some time to express what I am going through. I believe that every caregiver should have counselling sessions to maintain his or her psychological wellbeing".*

Other forms of support required were indicated to be having people around, employment opportunities, taking some time out, and spiritual support. The study also sought to determine some of the stress-relieving activities undertaken by the caregivers where most of the caregivers described that they undertook religious activities including going to church fellowship and prayers. In addition, on the support interventions suggested by the caregivers, many of them indicated having a chance to share their experiences with a professional counsellor will be a good asset in releasing some stress and guiding them throughout the caring process. They also indicated the need of getting medical and financial support. The respondents also suggested other interventions from the medical health facilities and the government in supporting mental health programs and psychoeducation. This implies that caring for a family member is a challenging and consuming task, one that requires the availability of professional support to both the mentally ill relative and the family caregiver (Beach, et al., 2000).

CHAPTER FIVE

SUMMARY, DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

5.1 Introduction

This chapter covers a summary of the recommendations and discussions drawn from the findings compared to the existing literature. This is followed by conclusions made thereafter and recommendations to both policy and practice.

Caring for patients with mental disorders is associated with many sacrifices. Caregivers need to adapt their personal lives to take care of their patients at the expense of social, family, recreational, and even professional life. These adaptive coping strategies often remain unrecognized by society and healthcare professionals, which can generate various hidden mental illnesses such as depression and anxiety among caregivers.

Most of the studies published to review and evaluate the psychological impact on caregivers for patients with mental illness highlighted the psychological burden that exists among caregivers for patients with mental disorders, and the importance of helping these caregivers to develop their sense of cohesion as an effective coping mechanism to overcome stress-related responses. Those studies associated the stress burden among caregivers with the development of posttraumatic stress disorder (PTSD). Majority of the theories on psychology draw attention to the seriousness of post-traumatic stress and have emphasized the importance of paying attention to the needs of caregivers. Post-traumatic stress is defined as a reaction to a traumatic event that the person can’t handle, and it can affect his biological and nervous system, which will generate strong feedback feeling, and can be reflected in his inability to act properly, and an imbalance in the unconscious Defence mechanisms. All of that will generate a feeling of fear and insecurity because of the traumatic event, resulting in many mental illnesses appearing for the post-traumatic strike.

Most families of severely mentally ill patients are unprepared to cope with the onset of the illness. Although caregivers play a key role in reducing the frequency and length of hospitalization as well as self-harm and suicidal behaviours in patients with severe mental illness, caregiving is an exhausting process that can have negative physical, psychological, emotional, social, and financial impacts on caregivers.

5.2 Discussion of results

This is presented per the study objective as follows:

5.2.1 Burden on caregivers of mentally ill relatives and its associated effects

This study found out that there was a high prevalence of burden among the family caregivers with 85% of them indicating the burden to occur sometimes, quite frequently, and nearly always whereas only 15% argued not to feel burdened at all. Other studies have reported similar high prevalence rates of caregiver burden. Ramanujan, et al (2017), reported that 95.5% prevalence rate where 58% of the caregivers in their study experienced severe burden and 36.5% had a moderate burden. Comparably, Amritsar, et al., (2018) reported that 54.15% of their study participants developed stress while caregiving. The study concluded that the caregivers' quality of life was significantly affected due to their nature of commitment and that they needed emotional support.

This is explained by Family System Theory which supports the burdening impact that caring for a mentally ill relative may have on the whole family.

5.2.2 Requirements and coping mechanisms of family caregivers when caring for individuals with mental illnesses

Regarding the mentally sick relative needs, the respondents indicated the major needs to be total care (26%), medication (26%), and basic needs (21%). On the other hand, subjective burdens included the emotional strain experienced by family caregivers which included fear, anxiety, sadness, anger, guilt, loss, stigma, and rejection. The major changes in caregivers' lifestyles were overwhelming responsibilities (21%), anxiety (14%), increased connection with the patient (14%), economic hardships (14%), frustrations and debt (7%), and struggling to understand their illness (7%). According to Kristjanson and Aoun (2004), although the caregiver may have regular interaction with medical professionals on behalf of the patient, the health professional may be unaware of the detrimental impact of caring on the caregiver's quality of life.

The respondents were also required to indicate the most challenging aspects of caregiving. The results revealed that the most challenging aspect was when the patients got sick or worse. Other challenges experienced included social challenges, mood, and attitude, stress as well as financial challenges. This implies that the caregiving role was a highly challenging activity which explains why most of the caregivers ended up being overwhelmed. The study further investigated the coping mechanisms of the caregivers. From the responses obtained, the majority of the respondents coped through church and prayers, as well as getting support from friends and family. In addition, others coped by undertaking extracurricular activities which helped ease their minds from the demanding caregiving tasks.

The study further inquired as to whether the caregivers talked to others as a form of coping. All the respondents agreed to talk to others with the majority talking to family members and friends. On the contrary, other caregivers opted to keep everything to themselves. Comparably, Brown, Biegel, and Tracy, (2011) in their study looked at the social impact of caregiver burden on women who took care of family members who had substance use disorders and other mental disorders, they established that overburdened caregivers didn't know how to ask for help or even refused to do so because of the accompanying social stigma.

5.2.3 Suggestions and recommendations for the type of support that can be provided to caregivers caring for a family member with a mental illness

According to the study, the major coping techniques are issue-focused coping, which addresses a problem directly by adjusting a component of a scenario, and emotion-focused coping, which refers to flexible emotional responses to the problem. These coping techniques are connected to the patient's level of function and the length of the condition. The more caregivers adopt problem-focused coping mechanisms, the longer the illness duration and the lower the level of function. Comparably, Gottlieb and Wolfe 2002 supported the relevance of coping methods employed by family caregivers with dementia to increase the caregiver's health. The majority of participants indicated a need for aid in the form of financial and governmental assistance, as well as having people nearby for further help and counseling.

Another study by Bhatia and Gupta in 2003, indicated the need for the same support adding to that more education and information about the medical conditions of their relatives. It is important to avoid the use of maladaptive coping strategies, to prevent poor quality of living (physically and psychologically).

The study also sought to determine some of the stress-relieving activities undertaken by the caregivers where most of the caregivers described that they undertook religious activities including going to church fellowship and prayers. In addition, on the support interventions suggested by the caregivers, the majority of them indicated having a chance to share their experiences, as well as getting medical and financial support. The respondents also suggested other interventions such as counselling and government support. According to WHO, (2020) negative responses from their communities can increase the family's sense of loneliness and affect their social interactions. Society's failure to acknowledge the burden of mental disorders on family members means that little help is offered to them.

5.3 Conclusion

The study concluded that the well-being of the relatives with mental disorders is conditional on the level of burden of the caregivers. The study concludes that family caregivers are more likely to act as supervisors for people with mental illnesses while continuing to go about their everyday lives and chores. The study concludes that this can overwhelming and will have some effect on the family's performance, psychosocial health, and financial pressure on the caregivers. Compared to the general population, caregivers of mentally ill patients experience a high prevalence of burden symptoms in caregivers of mentally ill patients. The intensity of the burden varied from mild to severe, with most people suffering from it regularly. In addition, the study concludes that there is a social burden that it imposes on the caregiver. This can be manifested in the form of a reduction of social activities, impact on a caregiver’s routine, and financial strain. Ntsayagae, et al., (2019) also points out that there is a lack of emotional coping among the family caregivers. This further signals the importance of facilitating support and interventions for family caregivers, in the hopes to support their mental health and lessen the burdens they may feel. Various interventions are required to help address issues related to the burden among caregivers of mentally ill relatives.

5.4 Recommendations

The findings of this study, healthcare the study recommends that health providers should focus not only on the patients but also on the caregivers of patients undergoing mental health care, as they experience a lot of stress, which contributes to a feeling of burden. Health providers must carefully check caregivers for signs of burden and burnout and provide appropriate treatment. This not only enhances the provider's treatment, but it also improves the patient's care.

Understanding the obstacles that caregivers confront in their caregiving experience will be a vital first step in improving caregiver wellbeing, which will in turn have a good impact on the patient's health. The study thus recommends that when developing mental health strategies for caregivers, it is critical to consider the coping characteristics that help them cope with their responsibilities and to create interventions that help them do so.

The study recommends that caregivers should be considered counselling during therapy for mentally ill patients. This is because they may be dealing with emotional and psychological issues that are interfering with their ability to care for others. They should also undergo a psychological evaluation to determine whether they require assistance. It is also critical to recognize caregivers' experiences and help them find ways to keep optimism alive. This will benefit both the caregivers and the people for whom they provide care for.

The study also recommends that caregivers be given training and made aware of what they will face and where they may get help. This is crucial since it allows them to completely understand their tasks and what to expect. They should be made aware of potential negative self-perception and self-stigma, as well as construction techniques to deal with these issues. Caregivers should also be encouraged to seek aid more frequently. They should be encouraged to seek help if they require it. This lessens the emotional, social, psychological, and economic toll.

Further recommendation from the study is that the Ministry of Health, in partnership with hospital Mental Health departments, develop and execute caregiving training programs. Caregiving burden screening is made a requirement for all institutions that provide mental health care, both public and private. This is critical in increasing the efficacy of caregiver services, hence lowering the levels of burden and subsequently improvement of patient care.

5.4.1 Recommendations for Further Research

The study has provided a starting point for further research on the burden placed on the family in caring for their mentally ill family caregivers. However, certain areas have emerged from the study necessitating further research be conducted. To begin with, the study was limited by the methodology used whereby it focused only on mental hospitals located in Nairobi County. This may not be an actual representation of the phenomenon in other hospitals in other regions. Further studies are thus suggested on other hospitals in other regions of the country to enable comparison to be made.

Caregivers may also benefit from community services that provide both practical and emotional assistance. Peer support groups, in which older caregivers with less caregiver load are paired with younger caregivers, might be a viable solution. This sort of support group might make caregivers who are feeling overwhelmed by their responsibilities feel more optimistic, which would enhance their general health. Advocating for a legislative reform that would allow for flexible employment arrangements for caregivers who require time off from work to care for loved ones with mental disorders.

The study established barriers that impeded the caregiving process. The study thus recommends further studies be conducted on these barriers and ways through which the barriers may be alleviated. Multi-disciplinary research leading to evidence-based practice approaches to home-based mental ill patient care should be encouraged. In addition, it Is important to investigate the efficacy of interventions supporting family caregivers in Kenya. In doing so, more effective interventions may also be identified. In the same breath, it would be useful to conduct a study concerning the changing conditions and nature of burdens placed on family members caring for those in their lives with mental illnesses.

Caregiver efforts are often underestimated and overlooked by the community and health professionals and are often seen as part of the family's responsibility to provide care and a free health care resource. Regardless of what I mentioned earlier, the lack of supervision, guidance, and health awareness of the quality of the disease and how to deal with it, or in other words, there is a lack of information sharing about the mental health burden suffered by caregivers and the resulting burden on public health on society.

It is still unclear in the literature how to classify different mental disorders in terms of psychological impact on caregivers, although most studies have confirmed the negative impact when providing support and assistance. There is no classification under any literary study on how to diagnose and deal with the difficulties and stress experienced by the caregiver and should be considered and classified in DSM-5 as a mental disorder.

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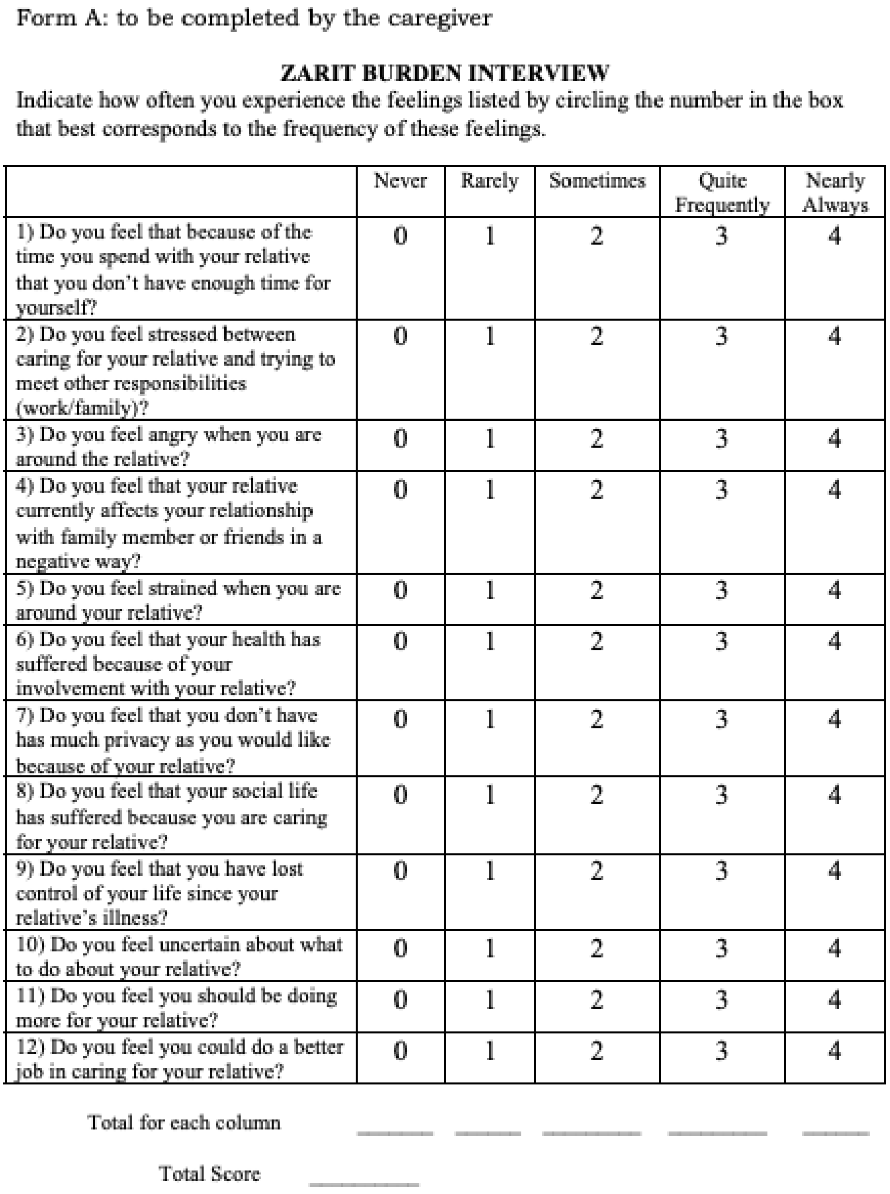
APPENDICES

Appendix I: Zarit Burden Interview



Form A: to be completed by the caregiver

ZARIT BURDEN INTERVIEW

Indicate how often you experience the feelings listed by circling the number in the box that best corresponds to the frequency of these feelings.

	Never	Rarely	Sometimes	Quite Frequently	Nearly Always
1) Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?	0	1	2	3	4
2) Do you feel stressed between caring for your relative and trying to meet other responsibilities (work/family)?	0	1	2	3	4
3) Do you feel angry when you are around the relative?	0	1	2	3	4
4) Do you feel that your relative currently affects your relationship with family member or friends in a negative way?	0	1	2	3	4
5) Do you feel strained when you are around your relative?	0	1	2	3	4
6) Do you feel that your health has suffered because of your involvement with your relative?	0	1	2	3	4
7) Do you feel that you don't have has much privacy as you would like because of your relative?	0	1	2	3	4
8) Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9) Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
10) Do you feel uncertain about what to do about your relative?	0	1	2	3	4
11) Do you feel you should be doing more for your relative?	0	1	2	3	4
12) Do you feel you could do a better job in caring for your relative?	0	1	2	3	4

Total for each column _______ ______ _________ _________ ______

Total Score _________

Appendix II : Semi-structural Interview Questionnaire:

The following are semi-structured/ interview questions:

1. How long have you been caring for your family member?

2. What type of care does the patient need?

3. How has your life changed since s/he was diagnosed?

4. What is the most rewarding aspect of being a caregiver?

5. What is the most challenging aspect?

6. Do you take time for self-care?

7. How do you cope with caregiving overall?

8. When things get difficult, do you have someone you can talk to?

9. What type of support would help in your situation?

10. What activities help reduce your stress?

11. What kind of interventions can the health providers offer to help you manage your stress?

Appendix III: Research permit

REPUBLIC OF KENYA

NATIONAL COMMISSION FOR
SCIENCE,TECHNOLOGY & INNOVATION

Ref No: **110376**

Date of Issue : **03/February/2022**

RESEARCH LICENSE

This is to Certify that Ms.. Entisar Abdelwahab mohamed of University of Nairobi, has been licensed to conduct research in Nairobi on the topic: The Burdens and Coping Mechanisms of Caring for a family member with a mental illness for the period ending : 03/February/2023.

License No: **NACOSTI/P/22/15367**

110376
Applicant Identification Number

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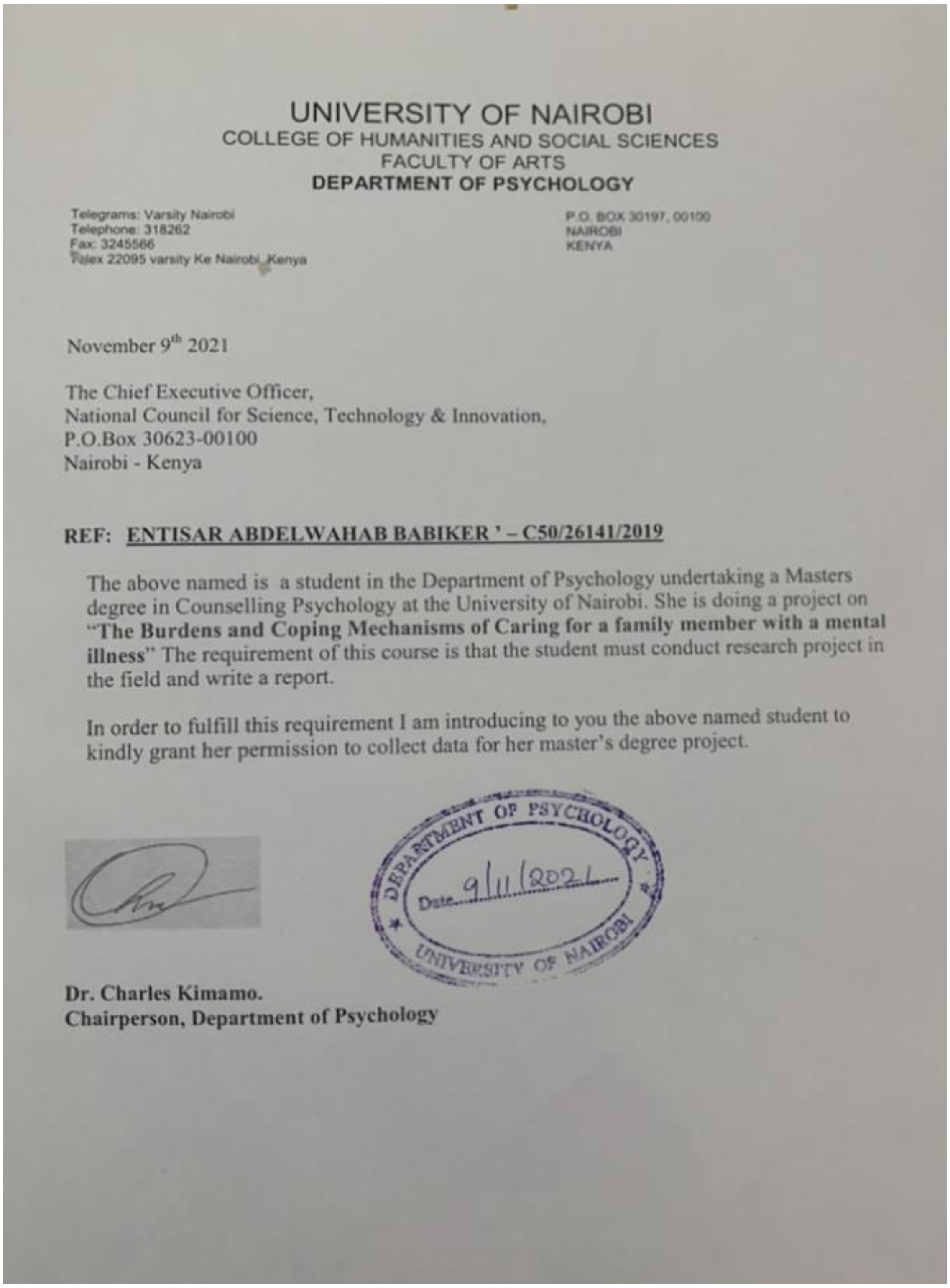
Scan the QR Code using QR scanner application.

Appendix IV: Introductory letter



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November 9th 2021

The Chief Executive Officer,
National Council for Science, Technology & Innovation,
P.O.Box 30623-00100
Nairobi - Kenya

REF: <u>ENTISAR ABDELWAHAB BABIKER ' – C50/26141/2019</u>

The above named is a student in the Department of Psychology undertaking a Masters degree in Counselling Psychology at the University of Nairobi. She is doing a project on **"The Burdens and Coping Mechanisms of Caring for a family member with a mental illness"** The requirement of this course is that the student must conduct research project in the field and write a report.

In order to fulfill this requirement I am introducing to you the above named student to kindly grant her permission to collect data for her master's degree project.

Date 9/11/2021

Dr. Charles Kimamo.
Chairperson, Department of Psychology

Appendix V: Respondent Consent Form:

I consent to being a respondent in this Master's study at Nairobi University by **Entisar Mohamed** on the "BURDENS AND COPING MECHANISMS OF CARING FOR A FAMILY MEMBER WITH MENTAL ILLNESS"

The consent is given voluntarily without coercion after the researcher has asked for it.

I understand that I may voluntarily withdraw from participating in the research without giving notice or any justification. The research has also assured of confidentiality and sole use of the material for academic study. Its sole purpose is to improve knowledge in the field of project management.

I also understand that I will provide written information which may be accessible by other parties in the university including the supervisors.

The consent is given based on the understanding that the results shall be shared with me if I will be interested on the email: Entisar@students.uonbi.ac.ke

……………………………..	………………………….
Respondent Signature	Date