

**BURDEN OF CARE AND DEPRESSION AMONG CAREGIVERS OF PATIENTS
WITH RHEUMATOID ARTHRITIS AND OSTEOARTHRITIS AT KENYATTA
NATIONAL HOSPITAL.**



Dr. Emongole Emmanuel, MBChB (UoN)

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Department of Clinical Medicine and Therapeutics,

University of Nairobi.

*A dissertation submitted in part fulfillment of the degree of Master of Medicine, Internal
Medicine.*

DECLARATION

This research dissertation is my original work and has been presented as a prerequisite for a Master's degree to the Department of Clinical Medicine and Therapeutics, University of Nairobi, Kenya. It has not been presented for any other degree to any other University.

Signature  Date 14/11/23

Dr. Emongole Emmanuel, MBChB (UoN)

APPROVAL BY SUPERVISORS AND CHAIRMAN

This dissertation has been submitted with full approval of my supervisors and the chairman.

Prof. Erastus O. Amayo

Chairman Department of Clinical Medicine and Therapeutics,

University of Nairobi


Signature..........Date. 15/11/2023.....

Prof. Omondi Oyoo

Associate Professor of Medicine

Consultant Physician and Rheumatologist

Department of Clinical Medicine and Therapeutics, University of Nairobi

Signature..........Date 14/11/2023.....

Dr. Syokau Ilovi

Lecturer Consultant Physician/ Geneticist

Department of Clinical Medicine and Therapeutics University of Nairobi

Signature..........Date. 14.11.2023.....

CHAIRMAN OF THE DEPARTMENT APPROVAL

Prof. Erastus O. Amayo

Chairman

Department of Clinical Medicine and Therapeutics,

University of Nairobi.

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF CLINICAL MEDICINE & THERAPEUTICS
P.O. Box 19676-00202 NAIROBI

Signature

Date

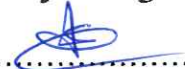
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DECLARATION OF ORIGINALITY

Name of student: Dr. Emongole Emmanuel
Registration No: H58/34051/2019
College: Health Sciences
School: Medicine
Department: Clinical Medicine and Therapeutics
Course name: Master of Medicine in Internal Medicine
Title: Burden of care and depression among Caregivers of Patients with Rheumatoid Arthritis and Osteoarthritis at Kenyatta National Hospital.

Declaration

I am aware that plagiarism (the use of someone else's work without their permission and/or without acknowledging the original source) is wrong. I confirm that all the work submitted for assessment for the dissertation is my own unaided work except where I have explicitly indicated otherwise. I have followed the required conventions in referencing the thoughts and ideas of others. I understand that the University of Nairobi may take disciplinary action against me if there is a belief that this is not my own work or that I have failed to acknowledge the source of the ideas or words in my writing.

Signature 
Date 14/11/23

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LIST OF ACRONYMS AND ABBREVIATIONS

ADL: Activity of daily living

AS: Ankylosing spondylitis

IADL: Instrumental activity of daily living

KNH: Kenyatta National Hospital

LBP: Lower back pain

OA: Osteoarthritis

RA: Rheumatoid arthritis

RD: Rheumatic disease

UON: University of Nairobi

ABSTRACT

Introduction: Caregiving is commonly perceived as a chronic stressor, with caregivers often experiencing adverse psychological, behavioural, and physiological effects on their daily lives and health. The informal caregiver's role is vital in taking care of people with rheumatoid arthritis (RA) and osteoarthritis (OA), but equally important is the burden accompanying such care.

Objective: This study aimed to determine the prevalence and severity of the burden of care and depression in caregivers of patients with RA and OA at the Kenyatta National Hospital. It also explored the caregiving experiences of these caregivers.

Methods: The study made use of a mixed methods approach. We recruited 113 informal caregivers of patients with RA and OA. The burden of care and severity was assessed using the Zarit Burden Interview questionnaire, while depression was assessed using the PHQ-9. A semi-structured interview guide was developed to explore the experiences of the burden of care from 10 caregivers. Descriptive and bivariate analyses were carried out. The qualitative interviews were transcribed verbatim and analyzed using a reflexive thematic approach.

Findings: Our findings showed that the overall burden of care among caregivers was 92%. Varying severity of burden based on the ZBI score found 60.2% experiencing mild to moderate burden and 31.9% experiencing moderate to severe burden. The overall prevalence of depression was 22.2%. 21.2% experienced mild depression, 11.5% had moderate depression, 8% were moderately severe, and 2.7% had severe depression. Our findings showed that caregivers with higher levels of burden experienced significantly higher levels of depression than those with little or no burden. Our qualitative findings highlighted several themes, including challenges faced during caregiving, coping with the need to be available for the patient, the effects of caregiving, such as lost opportunities, the impact on family, especially children and the impact on social life. We also identified strategies to facilitate coping with the caregiver role, such as accepting the situation, planning, and seeking support.

Conclusions: The study highlights a significant physical, emotional, and financial burden associated with caregiving for individuals with RA and OA. An increased risk for depression was found as the burden of care increased.

Recommendations: Burden of care in caregivers is a significant problem. The hospital should raise awareness of caregiver burden and provide psychological support to minimize the burden of care among caregivers taking care of RA and OA patients. A possible area of research is looking at selected patients and caregiver characteristics association with the burden of care.

CHAPTER ONE

INTRODUCTION

1.1 Background

Caregiver/ informal caregiver is someone who has regular contact with the patient and who aids the patient with at least one activity of daily living (1). Caregiver burden can be defined as the strain or load borne by a person who cares for a chronically ill, disabled, or elderly family member (2). In their day to day routine informal caregivers are endowed with the responsibility of taking care of the physical, physiological, social and financial burdens of their patient. Caregivers tend to cater for are our family, children or domestic partners who are affected by these diseases (3). When it does not include remuneration like in formal care, then we can term that as informal caregiving (4).

Caregivers are typically women between the ages of 50 and 60, first degree relatives, housewives, and have primary or secondary level of education (5). Caregiver burden, is a state in which a patient's caregiver suffers due to him or her taking care of the patient. Zarit was the first to describe it in Alzheimer's group of patients' caregivers (6). Terminal cancer, Rheumatoid arthritis and Osteoarthritis are some of the disease entities associated with caregiver burden.

1.2 Problem statement

As rheumatoid arthritis and osteoarthritis advances, an increasing number of patients are dependent on others for assistance, notably members of their own family. Physical and mental health problems are common as a result of caring, including financial troubles and social isolation (7). Caregiving is a relationship in which a family member aids another with daily duties that are very vital in existence of the family member. They strive to meet daily practical demands and provide a sense of companionship for the person receiving it (8). Most individuals with RA and OA are cared for by members of their families or wider social networks (friend, neighbor). Due to several social factors such as gender, cohabitation, and availability, if one of the spouse's children passes away, the remaining spouse's children will take over the caregiving work (9). Because they provide non-specialized, unpaid care, family caregivers are considered informal caregivers. There are a variety of ways to be classified as a formal caregiver, but the

most common is as a salaried individual, organization, institution, or care center (10). Each patient's specific needs are taken into consideration as the disease advances, and the care plan changes accordingly. Among the many services provided by a family caregiver are the following:

- Personal care such as getting dressed, fetching food from the storage room and doing the dishes are all examples of things that can be done with some help.
- The payment of bills, the procurement of medication, the provision of food, and other expenses are examples of procedural support.
- Altering the dosage or kind of medication supplied, using drug administration devices etc

CHAPTER TWO

LITERATURE REVIEW

2.1 An Overview of RA and OA

Rheumatoid arthritis is chronic progressive inflammatory and auto-immune disease that affect the joints, muscles, tendons, ligaments, bones, and organs of the body resulting in painful deformity and immobility (11)(12).

Osteoarthritis is a type of degenerative joint disease that results in breakdown of joint cartilage and underlying bone.

Genetic, family history, environmental triggers, trauma, illnesses, and lifestyle all contribute to having RA and OA (13).

Chronic discomfort and decreased range of motion in one or more parts of the body are hallmarks of RA and OA. Some disease symptoms include swelling, redness, and warmth in the affected areas. From acute and short-lived diseases to chronic and long-lasting ones, they span a wide range of maladies (14).

Joint and connective tissue inflammation, injury and/or pain are hallmarks of RA and OA which have a wide spectrum of symptoms. The incidence increases with age and women are more likely to be impacted. Those who suffer from RA and OA are not only afflicted personally, but society as a whole. Pain, physical impairment and exhaustion impact negatively on patient's well being (14).

2.2 Rheumatoid arthritis and osteoarthritis deterioration

Pain, physical impairment, and exhaustion impact negatively on patients' quality of life (15) (16). RA can cause a slow and steady decline, punctuated by flare-ups and remissions, to a rapidly progressing illness with rapid joint destruction and function loss. Even though each person's disease pattern is unique, the restricted joint movement and extreme pain are experienced by all those affected throughout time. Most persons with RA suffer irreparable joint degeneration and a

loss of function that cannot be reversed. There is no cure for rheumatoid arthritis, but there are ways to minimize discomfort and slow the course of joint degeneration and function loss (17).

In RA patients both mental, non physical and physical health are affected e.g. exhaustion, energy deprivation stress and social isolation (18). Joint damage results in discomfort and immobility making it difficult to do daily activities. In addition, the related discomfort generates feelings of frustration, exhaustion and helplessness. People's lives can be profoundly affected by these restrictions, as a result family members may be unable to participate in recreational activities, work together or fulfill their social responsibilities (19).

By 2020, it was anticipated that more than 50 million Americans or 25 percent of the adult population would have OA, making it a major cause of morbidity and physical impairment among people over the age of 40. With overall annual medical costs topping \$185 billion in 2008, there is a significant financial burden to bear. OA significantly impacts physical function and standard of living, as well as on feelings of melancholy and worry. There is still no clear picture of the causes of OA and the factors that contribute to its progression. As a result, there is no clinical diagnostic or effective treatment for early osteoarthritis and there is no effective disease-modifying medication for late osteoarthritis (20).

2.3 Rheumatoid and osteoarthritic joint pain

The International Association for the Study of Pain defines pain as an unpleasant sensory and emotional experience connected with existing or potential tissue damage or explained in terms of such harm (21). Pain is a common feature RA patients. Morning stiffness is caused by swollen joints that are sensitive to pressure and heat during rest times. Both of these things make it difficult for people to get around, especially first thing in the morning. Pain during exercise is common and people who experience this pain are forced to reduce their regular activities. Preoccupation with their pain due to the fact that it is present all the time leads to focused on pain treatment and coping instead of family, friends and as a result people's personal and social lives are negatively impacted (22). Patients get caught up in a cycle of increasing their emphasis on pain in order to improve their quality of life while also increasing their investment in pain-reduction measures.

Pain and mood have a gender-specific link. This "carryover" of pain intensification appears to have a higher effect in men than in women, who may use more pain coping mechanisms to regulate their emotional states (23)(24). The degree of inflammation, the progression of joint deterioration, and deformities are the primary causes of pain in RA. A variety of other inflammatory mediators may be generated during the course of the disease, resulting in inflammation of nearby brain structures and an increase in irritability in nociceptors (25). Innocuous and pleasant stimuli, such as warmth and gentle caressing, become painful because of this hypersensitivity (26). Catastrophizing about social stress, anxiety, life satisfaction, and neuroticism could all be connected to RA pain (27).

Pain is the most prevalent complaint associated with OA. Its the most prevalent reasons for people to seek medical assistance and they have a detrimental influence on their overall quality of life. Clinical OA is predicted to affect 27 million Americans and 8.5 million Britons based on symptoms and physical results, according to the National Osteoporosis Foundation. A study conducted by the American Osteopathic Association found that thirteen point nine percent aged 25 to 64 adults developed osteoarthritis in more than one joint (23). Synovial tissue expansion and hyperplasia are hypothesized to be generated by a combination of injury and obesity-induced low-grade inflammation in the early stages of osteoarthritis and its responsible for the pain in OA

2.4 Rheumatoid arthritis and osteoarthritis patients' fatigue

It is 2nd most prevalent complication of rheumatoid arthritis and it impacts majorly on one's well being. More than 80% of RA patients reported weariness in at least one study, which impairs both physical and mental functioning. RA is associated with chronic fatigue syndrome (CFS) (28)(29).

Fatigue in RA may be due to overactivity of the immune system, drug related or lack of restful sleep (30). Qualitative investigations demonstrate that the experience of exhaustion varies from person to person regardless of the underlying causes (31).

OA is one of the top 10 primary causes of disability in the world, accounting for a quarter of all cases resulting in high social and economic expenses (32). One of the most common symptoms described by patients with osteoarthritis is exhaustion (33).

Research (33) shows no substantial difference between OA and RA in terms of fatigue levels. Fatigue has been found to be just as prevalent in people with osteoarthritis as pain (11)(34).

2.5 An Overview of burden of care

Informal caregivers go to great heights to tend to RA and OA patients and due to this they have high burden of emotions, physical and mental burden (6).

Prevalence and morbidity due to rheumatic diseases has been increasing globally (35)(36), particularly in sub-Saharan Africa (37). Both RA and OA have been associated with functional and work disability; Elena et al (38) in a retroactive population based study in functional disability in RA versus the general population found that RA significantly affected the quality of life and was one of the most common conditions associated with functional disability (twice as much as those without RA); OA has been noted to be the leading cause of disability (39)(40). The detriments of RA and OA are loss of employment for the patient, general body weakness, they experience chronic depression and are unable to work efficiently, which then translate to low economic growth. In later stages RA and OA patients can experience continuously being dysfunctional and deformed and this can impact negatively on their quality of life (41)(42).

Caregiver burden is substantial while taking care of rheumatoid arthritis and osteoarthritis patients (43).

In Kenya there is scarcity of data on caregiver burden in RA and OA; Gatua et al (44), who looked at caregiver burden in hemodialysis patients. There is one study that attempted to link the burden that patients have in line with rheumatoid arthritis (45). This study missed to link caregivers as a scope making it more prudent to look at those areas of distress that greatly affect caregivers as well.

There is gap in research that needs to be filled by increasing the body of knowledge on risk factors, rehabilitation and the consequences that are social to rheumatoid arthritis and osteoarthritis. There is also essentiality in having programs that are designed for RA and OA in the community; these programs should encompass community participation.

As a daily routine, the care to patient should be marked by undying effort, a lot of empathy, high peak energy, this will have high impact on patient recovery. Taking care of the RA and OA patient could be accompanied by stress that is constant for a long time as a result of the disease chronicity. Poor caregiving results are also highly attributed to the caregivers' view of the burden (46).

Measures that are quantitative generally do not bring out the source of burden. There being fewer studies that talk about how loved ones care for their families and friends, there needs to be more studies on the caregivers who tend for individuals (47). There should be available structures that support services designed to reduce caregivers high burden. This study aimed to bring to light the experiences informal caregivers have and what support structure can be put in place.

2.6 Extent and nature of burden in caregivers

Caregivers may have positive and negative experiences and in other times both in their line of duty (4). Emotional, financial, psychological and physical burden may result depending on the patient tended to and the variables relating to the informal caregiver (6). In a general setting chances are that due to the never ceasing burdens the caregiver is eminently going to become ill psychologically, will have questions about what they are doing with their lives, can have burnout syndrome and will occasionally feel depressed (6)(48).

2.7 What informal caregivers do?

Traditionally, informal caregivers have been defined as either providing assistance with activities of daily living (ADLs) or providing assistance with instrumental activities of daily living (IADLs) In the first group there are self-care undertakings such as going to the toilet and taking a bath, clothing, eating, whereas IADL are daily living activities like assisting with household tasks, meal preparation, grocery shopping , assistance with transportation, housework and gardening .

They provide care that is of direct help to these patients e.g. helping them move around, offering medication to them and tending to their wounds, they facilitate the coordination of care, the

appointments booking in due time, they also are in the sharp lookout for any side effect that could occur from the medication and also act as a source of comfort to the patient.

2.8 Informal caregivers sociodemographic and economic circumstances

Caregiver characteristics, objective parameters and patient characteristics are all important and contribute to burden of care of the caregivers (49). Burden of care is not only limited to the patient characteristics but the task being received, duration, the level of emotional attachment with the said patient and supervision given by the caregiver (50). Factors such as the age, financial problems, disrupted schedules, marital status, income, occupation, education level, duration of caring, caregiver sex and financial support contribute to burden of care (3).

2.8.1 The age of caregiver

There is no consistency in research on the effect of caregiver age on caregiver burden. It is possible that caregiving pressures have a greater impact on the physical health of older caregivers who have previously experienced health problems, and that being younger in age is also a significant predictor of caregiver burden (51).

Informal caregivers who are younger than 65 years old may feel more burdened than older informal caregivers because of poor experience and lack of psychological preparedness. This is because caregivers who are young typically assume the responsibility with little experience (52). Informal caregivers who are younger are more stressed out than older caregivers. Younger caregivers may be under more stress because they have other responsibilities such as a job, in addition to caring for their loved ones (53).

2.8.2 Sex of the Caregiver.

Those of female sex are more well-versed with care giving responsibilities compared to the male sex because they are better at dealing with stress and strain than their male colleagues, who are not culturally educated to do the same (54). The responsibility of caregiving falls disproportionately on women because of society's expectations regarding women's duties as carers and nurturers (54)(55). According to demographic surveys, more women than men are involved in caregiving (56) .

Caregiver depression and physical health are more pronounced among caregivers than among the general population, which may be due to the stressors that caregivers face (57). The fact that women bear unequal burden as caregivers translates to a rise in the gap between men and women in terms of depression and physical health (57). In addition to their multiple caregiving roles and other sex-related challenges, female caregivers bear unequal burden as caregivers because they spend more time with their loved ones, receive less support with caregiving responsibilities, and devote more time to intensive personal care and household chores. Depressed and troubled because of caring for the elderly, caregiving-related stress and burnout are more likely to affect them. The sex gap in caregiving may be closing (57); male caregivers numbers in the United States is on the rise, despite the fact that women are traditionally considered to be the primary caregivers in their households (57)(58).

2.8.3 The day to day occupation

"Occupation" is a person's employment classification. A job can be categorized as professional or non-professional depending on the nature of the work. Caregiver occupation has been demonstrated to have a considerable impact on caregiver well-being and burden (22).

In order to manage and meet care demands caregivers' workplace requirements may vary, which might have a negative effect on their professional roles. Workers who are caregivers have a higher rate of absenteeism and lower productivity because of their duties. They have a hard time juggling work and helping out at home and their career and family responsibilities. As an alternative, working gives some caregivers a break from their daily caregiving duties and serves as a stress reliever (3).

2.8.4 Finances

Rheumatoid arthritis and osteoarthritis patients rely on these caregivers for assistance in different areas of life, including physical health, social and emotional well-being, and even financial security (2). Research consistently shows a correlation between caregiver load and caregivers' experiences. Work and family finances can be affected by caregiving, such as juggling a job with caring for family members (1). Some of the financial costs are related to the immediate payment of caregiving bills, while others are related to the loss of income or money earned from a job due

to the necessity of caring for a loved one (34). Many caregivers have to alter their work schedules, take time off, or cut back on their hours because of their caregiving obligations.

First impressions are that the findings are in line with prior research on caregiver stress (59). Caregivers who earn less money have been shown to be less stressed than those who earn more. However, this directly contradicts the claim that those who earn more money are less stressed (60). Even if they have a lot of money, they may be more stressed out by this. It's possible that more research into this is needed.

2.8.5 Education

Educational attainment has been shown to influence the level of stress felt by caregivers. Caregiver stress is more common among caregivers with less education than those who have a higher level of education and are employed. According to the research, carers' stress levels may be affected by their educational degree (61). An educational program for caregivers is a structured experience that utilizes a variety of tactics such as teaching and counseling to affect a patient's knowledge and healthy behavior (62). Health education is essential in preventing the onset and progression of OA and RA. Aside from these topics, caregiver education is also critical in minimize the deleterious effect of RA and OA on both the patient and caregiver (29)(63).

2.9 The hardship of caring for rheumatoid arthritis and osteoarthritis patients for an extended period of time

Caregivers helped patients for thirty three hours per week including fifteen hours with ADLs and eighteen hours with household activities; Matheson et al (18) in a qualitative study on caregivers found that psychological burden was substantial in caregivers as they experienced frustrations and distress. 'It's a restricted life' as caregivers had to cut back on previously enjoyable moments and had difficulty making future plans and caregivers had to adjust their lives and adapt practical and psychological ways to cope; In a mixed qualitative approach study acknowledged high burden in caregivers of patients with OA which was related to both patient and caregiver factors (19).

Despite some caregivers attributing the process as positive and nurturing, caregiving can be detrimental to the health, lead to high financial distress, problems relating to the mental well-

being of individual and could lead to social isolation. In instances where the caregiver views caregiving as aloof and tedious, it could result to less care of the patient resulting in poor control of RA and OA (13)(64).

2.9.1 Informal carers' emotional health

Caregivers' emotional well-being may be contradicted by the expectation that they conceal their feelings, regardless of how they feel when providing informal care to the patients especially if related. The sentiments of devotion, warmth, love, remorse, anxiety, frustration and rage that caregivers experience when caring for their loved ones are common and understandable (65). Caregivers reported feeling good about themselves after helping someone in need (34). Taking part in support groups by caregivers helps to alleviate stress because caregivers share their experiences and work together to support and assist one another.

2.9.2 Caregiving in social and familial contexts

Family caregivers may be forced to postpone accomplishing major milestones and give up on their aspirations in order to care for their sick relatives. Studies show that extended and intense caregiving causes social isolation in family caregivers. While caring for loved ones, caregivers were unable to participate in spiritual, social and family activities that would have provided them with a feeling of well-being. Due to the fact that they delay seeking medical attention for physical problems, family caregivers are now more vulnerable to the stress of being a caretaker.

2.10 Research instruments

In order to gather data on the extent of caregiver burden and explain the experiences of informal caregivers with caregiving, several instruments was utilized.

2.10.1 Sociodemographic questionnaire

The researcher created a questionnaire to collect pertinent data on demographic, these included sex, age, marital status, educational attainment, employment, income, residence, relationship to patient, diagnosis of RD, duration of disease, duration of caring, financial support and other health conditions of the patients studied.

2.10.2 The Zarit Burden Interview questionnaire

Since its inception in 1980, Dr. Zarit Ran has developed the Zarit Burden Interview questionnaire with 29, 22, 18, 12, and 4 item options. The ZBI can be used for a variety of tasks, including to screen caregivers in order to identify high risk carers, burden comparison across diverse populations, and evaluating treatment outcomes. For assessing caregivers' subjective load, the 22-item version is the most popular. It's important to note that the ZBI is distinct from a symptom or problem list. When a problem arises, a checklist is generally used to determine whether or not the caregiver is in a state of agitation or distress. In contrast to other measures of emotional discomfort, the ZBI is not a diagnostic tool for depression. When it comes to assessing a caregiver's emotional toll, load gives a more precise and direct measure than depression. There are a wide variety of conditions for which the ZBI can be used, from strokes to cancer to persistent mental illness to guardians of children with serious mental or physical health issues (66)(67). Several facets of a caregiver's life are considered by the ZBI when assessing their subjective burden, including their relationship burden (6 items), emotional well-being (7 items), social and family life (4 items), financial well-being (1 item), and the feeling of having no control over one's own destiny (4 items).

Health, money, social life, and interpersonal interactions are all well-represented in the construct validity. Excellent internal consistency, has a Cronbach's alpha coefficient of 0.92%. Retest reliability was calculated at 0.71. A wide range of demographics may use the test because it was unaffected by factors such as gender, age, region, language, or marital status. A French and Japanese dub is available. In Nigeria, caregivers of cancer patients have used it to assess their burden, and in South Africa, caregivers of HIV orphans have used it to assess their burden. Female carers of HIV/AIDS patients and informal caregivers caring for stroke patients at Kenyatta National Hospital (KNH) were both assessed using the 22-item version which has been validated to be used in Kenya. Permission and approval to translate (swahili) and use the ZBI questionnaire was sought from the developers of the tool. The translated version was sent to the developer for validation before use. The Swahili ZBI has been used before in our setting by mahinda et al, 2016 in evaluation of caregiver burden in stroke patients. There was no back translation of the Swahili ZBI tool.

The ZBI tool was preferred for this study due to the excellent internal consistency, good retest reliability, approval from developers to use it in the study, easy of use and already validated and used in previous studies in Kenya.

Other tools for assessment of caregiver burden such as Caregiver Reaction assessment scale (CRA) and Caregiver Strain Index (CSI) had lower Cronbach alpha score of 0.7 and 0.69 respectively and therefore the ZBI had a relatively excellent internal consistency. These tools have also not been validated to be used locally.

2.10.3 The depression scale, patient health questionnaire (PHQ-9)

The depression module is a nine-item tool used in primary care to diagnose depression. The DSM 4 criteria for diagnosing depression disorders are broken down into nine categories. Depressive symptoms are confirmed by this test. With an 88 percent sensitivity and specificity, a score of 10 or higher indicates a diagnosis of severe depression. It has a Cronbach's alpha scores of 0.839 . Depression is characterized as mild, moderate, moderate severe, or severe based on the number of depressive symptoms a person experiences. In the past, the PHQ-9 was tested in Sub-Saharan Africa and Kenya and found to be reliable (68)(69). Self-administered or interviewer-administered, it's quick and easy to use. Translated into Swahili, the tool's test-retest and internal consistency have been verified (70).

2.10.4 Open-ended interview guide

Caregiver experiences and burdens of giving RA and OA patients' care were examined through the development of a open-ended interview guide. The interview guide is found in Appendix 9 and 10.

2.11 Conceptual framework

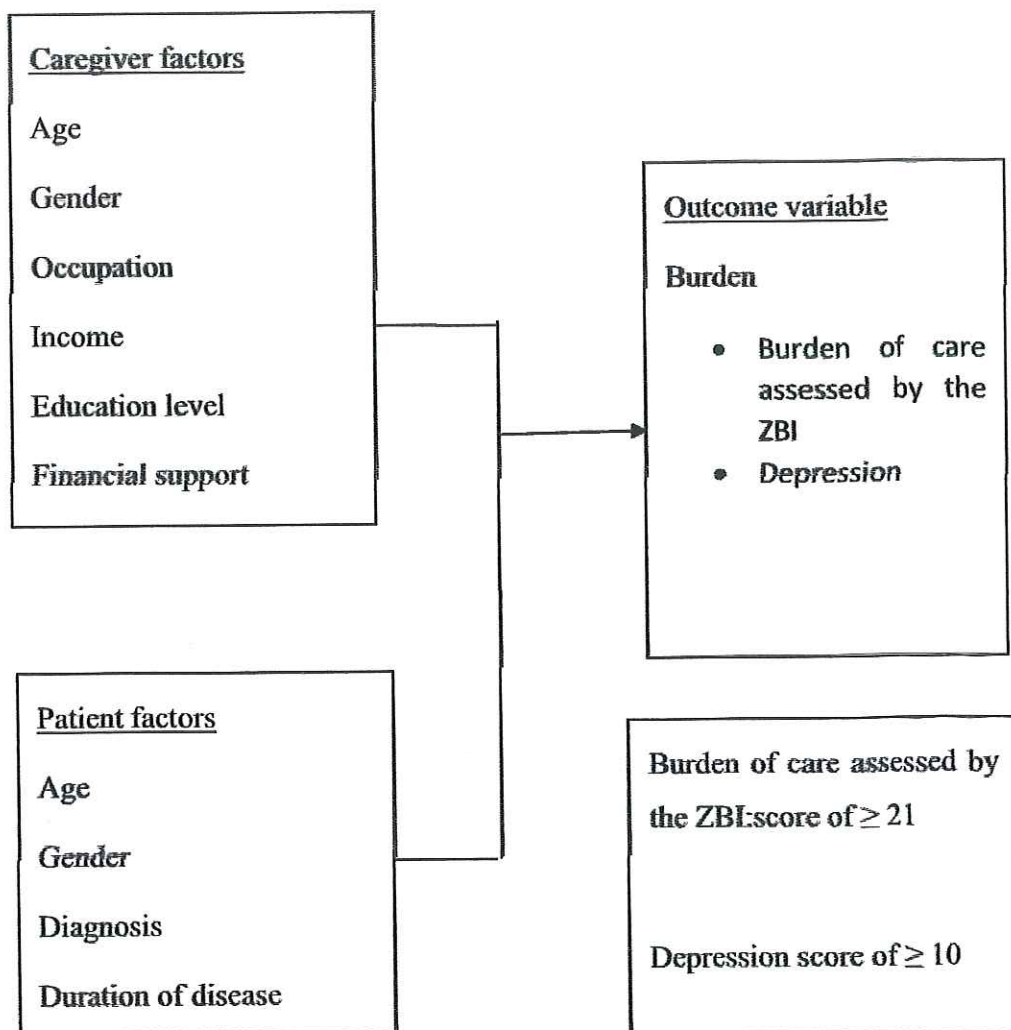


Figure 1: Conceptual framework

2.12 Justification

Urbanization has led to a shift in emphasis away from community-based care towards a more narrow focus on the nuclear family.

OA and RA patients with disability depend on their family members for assistance. Caregivers strive to meet daily practical demands and provide a sense of companionship for the person receiving it (71) and as a result, Physical and mental health problems, financial troubles and social isolation are common as a result of caring (72).

Caregivers are particularly at risk as the disease advances especially in the middle and late stages, when it can have a negative impact on quality of life leading to the loss of a career and the source of income. During these phases of the illness, the demand for physical and mental care increases round-the-clock and enormous financial costs must be borne throughout. Basic communication with their loved one is also impaired. It is even more challenging for these caregivers to care for their spouse and children as well as other members of their family. To our knowledge, there are no local data on the prevalence of burden in caregivers of rheumatoid arthritis and osteoarthritis and how they view their experiences of caring. In order to better understand how informal caregivers view their caregiving position and how they seek aid from other individuals or organizations, it is necessary to analyze the experience of caregiving for informal caregivers from their own perspective. This study aims to define selected caregivers and patient factors that may contribute to distress. Data from this study will inform educational programs at the family level, support groups and policy changes that cushion caregivers from financial, emotional and physical challenges.

2.13 Research questions

1. What is the burden of care in caregivers of patients with RA and OA?

2.14 Objectives

2.14.1 Broad objective:

To determine the burden of care in caregivers, depression and its associated factors in patients with RA and OA at Kenyatta National Hospital.

2.14.2 Specific objectives:

Primary objectives

1. To determine prevalence and severity of burden of care in caregiver
2. To determine prevalence and severity of depression.
3. To explore experiences of burden of care in caregivers who take care of RA and OA patients

Secondary objectives

4. To determine the association between burden of care; depression, sociodemographic factors, selected patient and disease factors

CHAPTER THREE

METHODOLOGY

3.1 Study design

This study employed a cross-sectional and qualitative method design with a non-probabilistic convenience sample of 113 informal caregivers of RA and OA patients being treated at the Kenyatta National Hospital Rheumatology clinic.

3.2 Study site location

Rheumatology clinic at Kenyatta National Hospital's (a teaching and referral hospital with 1800 beds and over 6,000 employees).

3.3 Study population

Informal caregivers of patients with RA and OA who visit the Rheumatology clinic at KNH were included in the study population.

3.4 Case definition

An informal caregiver is defined as someone who is above 18 years of age, has regular contact with the patient and who aids the patient with at least one activity of daily living. Activities of daily life include tasks such as getting dressed, cleaning one's teeth, and caring for one's body and personal hygiene, which are regarded to be routine tasks.

3.4.1 Inclusion criteria

1. Caregivers of patients with RA and OA with at least 3 months of the diagnosis
2. Caregiver who has been caregiving for one month or more
3. Informed consent provision by the caregiver

3.4.2 Exclusion criteria

1. A caregiver diagnosed with a mental illness or unable to communicate

3.5 Sample size estimation

According to data acquired from the KNH health records, an estimated number of 180 patients above the age of 18 are on follow up for RA and OA in Rheumatology clinic. It was then possible to draw a representative sample of the population and calculate the sample size based on the formula for finite populations. The calculation was done as follows:

$$n = \frac{NZ^2P(1 - P)}{d^2(N - 1) + Z^2P(1 - P)}$$

Where

n' = sample size with finite population correction,

N = size of the target population = 180

Z = Z statistic for 95% level of confidence = 1.96

P = Estimated prevalence of burden using Zarit burden interview or depression (3)

d = margin of error = 5%

Table 1: Sample size estimation

Variable	P	n
Burden using Zarit burden interview	80%	104
Depression	26.7%	113

A minimum of 113 caregivers were sampled to determine prevalence of both burden and depression within 5% level of precision. Qualitative in-depth interviews with some of the informal caregivers were conducted as well. The 10 individuals were selected from the 113 through convenient sampling, with every 10th participant taking part in the interviews. For qualitative data a sample size of between 10-15 is usually enough to achieve data saturation (73). The interviews aimed at understanding in detail the difficulties faced by carers in caring for RA and OA patients.

3.6 Recruitment, consenting and data collection procedures

Files of patients booked for clinic in KNH are taken to the health information office the day

before the clinic. On the day before the rheumatology clinic, in coordination with the health information team, the principal investigator and the trained assistant (undergraduate level 3 MBChB student) looked through the files to identify patients with RA and OA diagnosis, and their names were written down for easy and orderly identification on the day of the clinic. On the clinic day, the principal investigator and the trained assistant arrived at least two hours before the start of the clinic, at the patients' waiting bay. The patients of interest were identified at the waiting bay by calling out their names. The patients and their caregivers were then approached one by one, and after introduction, they were briefly informed about the study. Those who accepted to participate were requested to remain behind after being attended to at the clinic. After the patient had been attended to, the trained assistant got the patient's file from the doctor's room, and directed the caregiver to a room not in use at the clinic and ask the patient to wait at the waiting area. The caregivers who meet the inclusion were asked to sign a consent form for participation in the study. They then proceeded to fill in the sociodemographic form with the help of the trained assistant, where needed, using information from the file. The ZBI and PHQ9 forms were then self-administered to the caregiver in either English or Kiswahili based on their choice.

Every 10th caregiver involved in the quantitative arm was invited on a later date for in-depth interviews at their convenience; a total of 10 caregivers were required for the qualitative arm of the study. Clarifications about the study's scope, methodology, and intended outcomes were made available on a need-to-know basis. The services individuals received at the clinics were not affected by their refusal to participate in the study.

In cases where the patient had not been accompanied by the caregiver but had one, they were requested to share the phone numbers of their caregivers who were contacted, and briefly informed about the study and all those who accepted to participate were given a specific time and place to come participate in the study. Participation in the interviews was facilitated financially in the case of those invited to do so on a later date for the quantitative arm and all those in the qualitative arm.

For the qualitative arm of the study the researcher used open-ended interview that gathered information on the experiences of the caregivers in relation to the burden of taking care of

patients with RA or OA. Interviews lasted between 30-45 minutes and were audiotaped, with the interviewer also taking notes.

3.7 The ZBI-22 questionnaire

The 22 questions questionnaire was self administered to caregivers regarding how the patient's RA and OA affected their own lives. The caregiver indicated how often they have experienced each symptom for each item (never, rarely, sometimes, quite frequent or nearly always). The overall score for the ZBI ranges from 0 to 88 and is based on a Likert scale with five points ranging from 0 (never) to 4 (almost always). The higher the scores the heavier the load. A score of 21 and above indicated burden. Interpretation was as follows

0 - 20: little or no burden

21 - 40: mild to moderate burden

41 - 60: moderate to severe burden

61 - 88: severe burden

3.8 PHQ9

Nine-item tool used was self administered. The caregiver indicated how often they have experienced each symptom for each item. Its based on a likert scale ranging from 0 (not at all) - 3 (nearly every day). The overall score ranges from 0 to 27 with a score of 10 or higher indicates a diagnosis of depression

- **None to minimal 0-4**
- **Mild 5-9**
- **moderate 10-14**
- **moderately severe 15-19**
- **Severe 20-27**

3.9 Data collection

Informed consent forms were provided to research participants who satisfied the eligibility requirements and were willing to participate. The researcher conducted demographic, ZBI-22, and PHQ-9 surveys after gaining informed consent. Data collection took place in a separate room so that we were able to ensure privacy of the survey respondents. It took between 30 and 45 minutes to complete the tests. The questionnaires were both in Kiswahili and English. The participants were given the option to choose the language of the questionnaire they wanted to use. After data collection the principal respondent translated the Kiswahili questionnaires to English for data coherence.

For the qualitative aspect of the study, 10 of the 113 participating care givers were asked about their experiences with care. Every tenth (10th) participant was invited to participate in the interviews at a later date. Respondents were interviewed until no new information or themes emerged. Caregivers shared their stories of caregiving, discussed the challenges and benefits of long-term caregiving, and described the support networks available to help alleviate their caregiver load. With the help of the semi-structured interview guide, the PI conducted the interviews (Appendix 9 and 10) at the rheumatology clinics, in a private room. Each interview ran between 30 and 45 minutes, both audio taping and taking down notes were used for each interview. Transcription of the data was done using services of a qualified transcriber.

3.10 Quality Assurance

The study's focus was on making sure that participants completely comprehend the research questions and the study's aim. The PI kept an eye on data quality throughout the investigation (e.g., are responses legible, are all questions answered, are necessary tools used). Logs were kept during the duration for any unexpected or unfavorable events that occurred. A safe environment was provided for the storage of all research materials, such as consent and assent forms, questionnaires, and the results of the study. A password-protected PC was used to store all audio recordings. Passwords were required for all regularly copied files on computers.

3.11 Data Management and Analysis

Data was entered in Microsoft Excel 2016 spreadsheet after it has been coded. Data cleaning was

done and exported into SPSS version 21 statistical software. Descriptive statistics was used to summarize caregiver and patient characteristics into percentages for categorical variables and means or medians for continuous data. Prevalence of caregiver burden was calculated as a percentage of the total population. Prevalence of caregiver depression was calculated as a percentage of the total population. Presence of burden and depression among caregivers was associated with the selected caregivers' patients' characteristics.

- ✓ Associations with categorical variables e.g., sex was tested using chi square test
- ✓ Comparison of means e.g., age was done using Student's t test. Mann Whitney U test was used to compare medians between groups as appropriate.

Statistical significance was interpreted at 5% level (p value less or equal 0.05 was significant).

Interviews with caregivers was conducted to gain an understanding of their experiences caring for patients with RA and OA. For all transcriptions and translations, an experienced qualitative data expert and the PI were present to ensure that they are error-free. The qualitative data was analyzed qualitatively and presented using narratives. The responses from the caregivers were quoted verbatim in the results to illustrate some of the experiences related to the diseases.

3.12 Ethical considerations

Prior to submission to the University of Nairobi/Kenyatta National Hospital ethics research committee for approval, this project was presented to the Department of Clinical Medicine and Therapeutics. The PI obtained formal permission and clearance from the Rheumatology clinics in charge, once the study was approved by the ethics committee.

Participants were approached at the clinic when all necessary approvals were obtained. The study's goal and objectives were explained to the caregivers, and opportunity was given to them to ask questions. Participation was voluntary and the data caregivers provide were used solely for the purposes of the research. There was no penalization for those who refused to participate or withdraw from the study, and their withdrawal had no effect on the services they sought at the institution.

In order to engage in the study, participants had to have met the study's inclusion requirements

and agreed to participate. Political affiliation, gender, color, sexual orientation or physical disability were not a factor in the study. Each and every one of the eligible volunteers were provided a thorough explanation of the study's methodology as well as its goals and purposes, and they were given the option to join at their own volition.

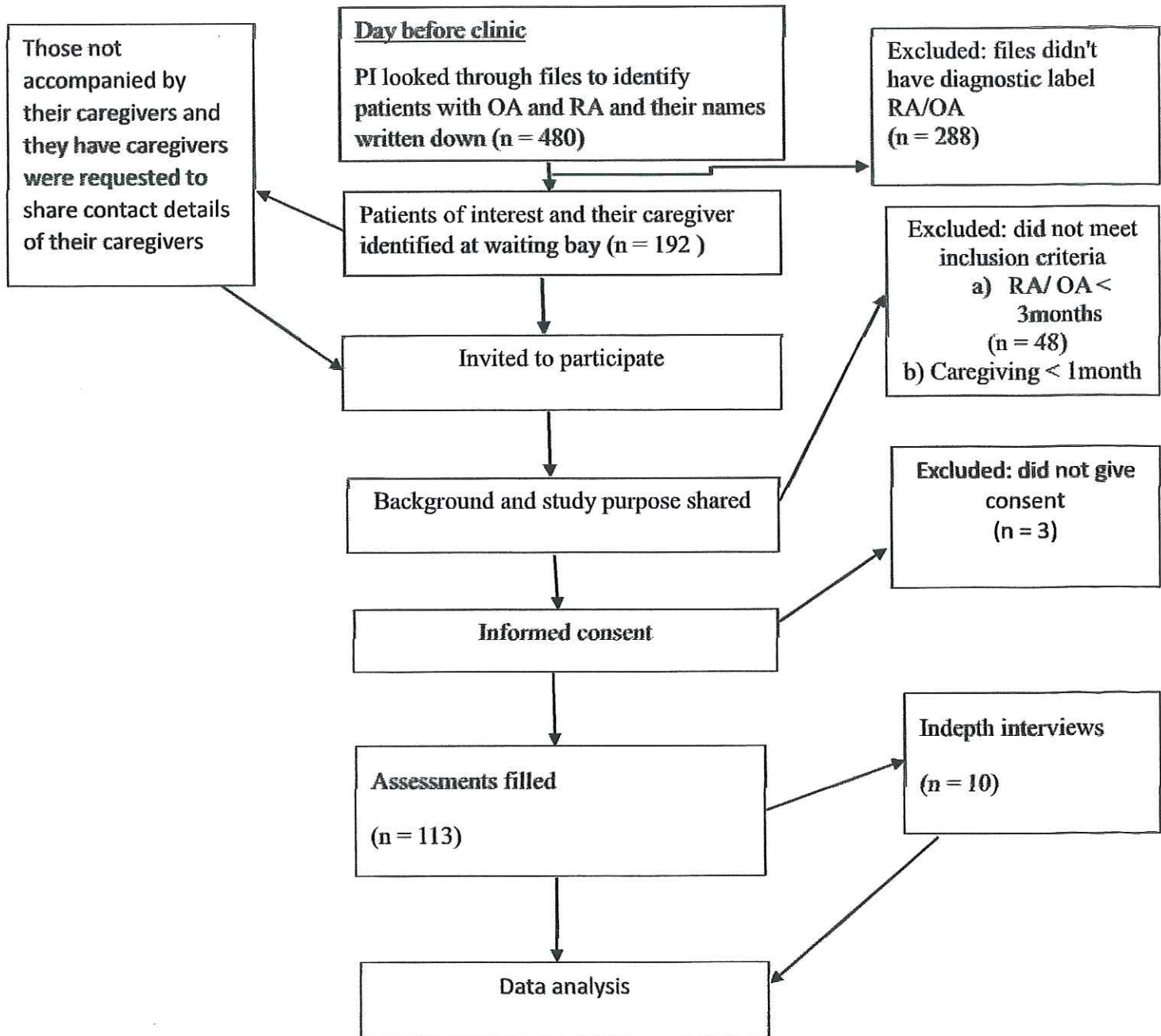
It was ensured that the participants' data was kept private and will only be used for research purposes. Participants' identities were protected by the researcher. In order to protect the anonymity of the participants, no personal information about them was included in the questionnaires or transcripts. Participants were identified by secure serial codes rather than names on the questionnaires, which was stored in a password-protected locked safe and computer. The recorded audio interviews were transcribed and translated. Transcripts were kept on a password-protected computer after audio files were erased.

Participants in the quantitative component of the study were not compensated. Those requested to come on a later date in the quantitative arm of the study and all those in the qualitative study were given a facilitation fee of Kenyan shillings (Ksh) 500.

There were no known hazards to participants' health as a result of this study. In cases when the participant's mental health was in jeopardy, the PI recommended them to the KNH's Mental Health section for additional evaluation. Caregivers identified with depression were referred to relevant clinics.

Study participants may potentially benefit from this study's findings, which will help patients and professionals better understand the hardship that caregivers of patients with RA and OA face.

3.13 Requirment Flow Chart



CHAPTER FOUR

RESULTS

4.0 Caregiver and Patients Characteristics

4.0.1 Caregiver characteristics

This study interviewed 113 caregivers of RA and OA patients on follow-up at the KNH Rheumatology outpatient clinic. As presented in Table 1 majority of caregivers were female (62.8%) with mean age of 40 years, married with a median duration of caring for RA and OA patients at 2.5 years. More than half had tertiary education and 73.5% were employed.

Result Table 1: Caregiver characteristics

Variable	Frequency (%)
Age in years	
Mean (SD)	40.0 (SD12.6)
Min-max	20.0-69.0
Sex	
Male	42 (37.2)
Female	71 (62.8)
Marital status	
Single	39 (34.5)
Married	70 (61.9)
Divorced	4 (3.5)
Education level	
Primary	12 (10.6)
Secondary	40 (35.4)
Tertiary	61 (54.0)

Employment	
Full time	21 (18.6)
Part time	15 (13.3)
Self-employment	47 (41.6)
Retired	5 (4.4)
Unemployed	15 (13.3)
Housewife	10 (8.8)
Average monthly income(kenya shillings)	
Less than 2000	22 (19.5)
2001-5000	21 (18.6)
5001-10000	17 (15.0)
10001-15000	22 (19.5)
15001-20000	5 (4.4)
30000 above	20 (17.7)
Not indicated	6 (5.3)
Caregiver relationship to the patient	
Wife	10 (8.8)
Husband	13 (11.5)
Father	3 (2.7)
Mother	17 (15.0)
Brother	3 (2.7)
Sister	5 (4.4)
Son	20 (17.7)
Daughter	39 (34.5)
Cousin	1 (0.9)
Aunt	1 (0.9)
Grandmother	1 (0.9)

Duration of caring of patient (years)	
Median (IQR)	2.5 (1.0-6.0)
Min-max	0.25-30.0

4.0.2 Characteristics of the patients

As presented in Table 2 mean age of patients was at 52.0 yrs, majority being female (75.2%) with majority having rheumatoid arthritis (71.7%). The median duration of having the disease was 3 years, with 81.4% having medical financial support mainly through NHIF (70.7%). The rest of the characteristics are shown in the table.

Result table 2: Patients characteristics

Variable	Frequency (%)
Age in years Median (IQR)	52.0 (37.0-61)
Sex Male Female	28 (24.8) 85 (75.2)
Disease suffered OA RA	32 (28.3) 81 (71.7)
Duration of disease (years) Median (IQR) Min-max	3.0 (1.0-6.0) 0.25-30.0
Patient has other chronic disease or disability Yes No	37 (32.7) 76 (67.3)
Chronic disease or disability (n=37) Asthma Chronic small vessel disease COPD Diabetes mellitus Hypertension	1 (2.7) 1 (2.7) 1 (2.7) 9 (24.3) 24 (64.9)

Peptic ulcer disease	1 (2.7)
Availability of financial support	
Yes	92 (81.4)
No	21 (18.6)
Type of financial support (n=92)	
NHIF	65 (70.7)
Private insurance	3 (3.3)
Family	23 (25.0)
Friends	1 (1.1)

4.1 Prevalence of burden of care and Depression in Caregivers

4.1.1 Prevalence and severity of burden of care in caregiver

Overall caregiver burden was 92%. As shown in Table 3, majority (60.2%) of caregivers had mild to moderate burden followed by moderate to severe burden at 31.9%. None of the caregiver had severe burden.

Table 3: Prevalence and severity of burden of care in caregiver

Variable	Frequency (%)	95% CI
Burden score category		
0-20 little or no burden	9 (8.0)	3.5, 13.3
21-40 mild to moderate burden	68 (60.2)	51.3, 69.0
41-60 moderate to severe burden	36 (31.9)	23.0, 40.7

4.1.2 Prevalence and severity of depression in caregivers

Overall prevalence of depression was at 22.2%. As shown in Table 4, caregiver prevalence of depression was distributed throughout the PHQ9 scale. Majority at 77.8% had none, minimal and mild depression.

Table 4: Prevalence and severity of depression

Variable	Frequency (%)	95% CI
Depression severity		
None-Minimal depression	64 (56.6)	47.8, 65.5
Mild depression	24 (21.2)	14.2, 29.2
Moderate depression	13 (11.5)	6.2, 17.7
Moderately severe depression	9 (8.0)	3.5, 13.3
Severe depression	3 (2.7)	0.0, 6.2

4.2 Factors Associated With Caregivers' Burden of care

As shown in Table 5 and 6, none of the caregivers' characteristics and patients characteristics were significantly associated with the burden of care as the study was not powered enough (small sample size) to make any statistical association.

Table 5: The association of caregiver characteristics with burden of care

Variable	Little or no burden	Mild to moderate burden	Moderate to severe burden	P value
Age in years				
Mean (SD)	44.0 (14.5)	37.8 (12.1)	43.3 (12.5)	0.066
Sex				
Male	3 (33.3)	22 (32.4)	17 (47.2)	0.323
Female	6 (66.7)	46 (67.6)	19 (52.8)	
Marital status				

Single	1 (11.1)	26 (38.2)	12 (33.3)	0.553
Married	8 (88.9)	40 (58.8)	22 (61.1)	
Divorced	0	2 (2.9)	2 (5.6)	
Education level				0.376
Primary	1 (11.1)	5 (7.4)	6 (16.7)	
Secondary	2 (22.2)	25 (36.8)	13 (36.1)	
Tertiary	6 (66.7)	38 (55.9)	17 (47.2)	
Employment				0.651
Full time	4 (44.4)	11 (16.2)	6 (16.7)	
Part time	0	8 (11.8)	7 (19.4)	
Self-employment	1 (11.1)	30 (44.1)	16 (44.4)	
Retired	2 (22.2)	3 (4.4)	0	
Unemployed	1 (11.1)	9 (13.2)	5 (13.9)	
Housewife	1 (11.1)	7 (10.3)	2 (5.6)	
Average monthly income				0.153
Less than 2000	1 (12.5)	16 (24.2)	5 (15.2)	
2001-5000	1 (12.5)	13 (19.7)	7 (21.2)	
5001-10000	2 (25.0)	11 (16.7)	4 (12.1)	
10001-15000	0	12 (18.2)	10 (30.3)	
150001-20000	0	5 (7.6)	0	
30000 above	4 (50.0)	9 (13.6)	7 (21.2)	
Caregiver relationship to the patient				0.194
Wife	0	9 (13.2)	1 (2.8)	
Husband	1 (11.1)	6 (8.8)	6 (16.7)	
Father	0	0	3 (8.3)	
Mother	2 (22.2)	8 (11.8)	7 (19.4)	
Brother	0	3 (4.4)	0	
Sister	0	2 (2.9)	3 (8.3)	
Son	1 (11.1)	13 (19.1)	6 (16.7)	
Daughter	3 (33.3)	27 (39.7)	9 (25.0)	

Cousin	0	0	1 (2.8)	
Aunt	1 (11.1)	0	0	
Grandmother	1 (11.1)	0	0	
Duration of caring of patient (years)				
Median (IQR)	6.0 (3.5-11.0)	2.0 (1.0-5.0)	4.0 (1.0-7.0)	0.184

Table 6: Patient factors associated with burden of care

Variable	Little or no burden	Mild to moderate burden	Moderate to severe burden	P value
Age in years				
Mean (SD)	38.6 (16.9)	52.5 (16.2)	45.9 (19.3)	0.030
Sex				
Male	0	25 (36.8)	3 (8.3)	0.001
Female	9 (100.0)	43 (63.2)	33 (91.7)	
What is the disease of your patient?				
OA	1 (12.5)	23 (34.3)	8 (23.5)	0.267
RA	7 (87.5)	44 (65.7)	26 (76.5)	
Duration of disease (years)				
Median (IQR)	5.5 (0.8-7.5)	2.0 (1.0-5.0)	4.5 (1.5-8.0)	0.213
Chronic disease or disability				
Yes	1 (11.1)	22 (32.4)	14 (38.9)	0.234
No	8 (88.9)	46 (67.6)	22 (61.1)	
Access to financial support				
Yes	8 (88.9)	59 (86.8)	25 (69.4)	0.194
No	1 (11.1)	9 (13.2)	11 (30.6)	

4.3 Association Between Burden of care and Depression in Caregivers

As shown in Table 7, the study was not powered enough to make statistical significant association. A trend was seen whereby depression score was significantly higher among caregivers with more severe burden of care compared to those with little or no burden of care. Caregivers with little or no burden of care had none to mild level of depression while more than 10% of those with mild to moderate burden of care reported moderate to severe depression. On the other hand, 44% of the caregivers with moderate to severe burden of care reported moderate to severe depression.

Table 7: Depression associated with burden

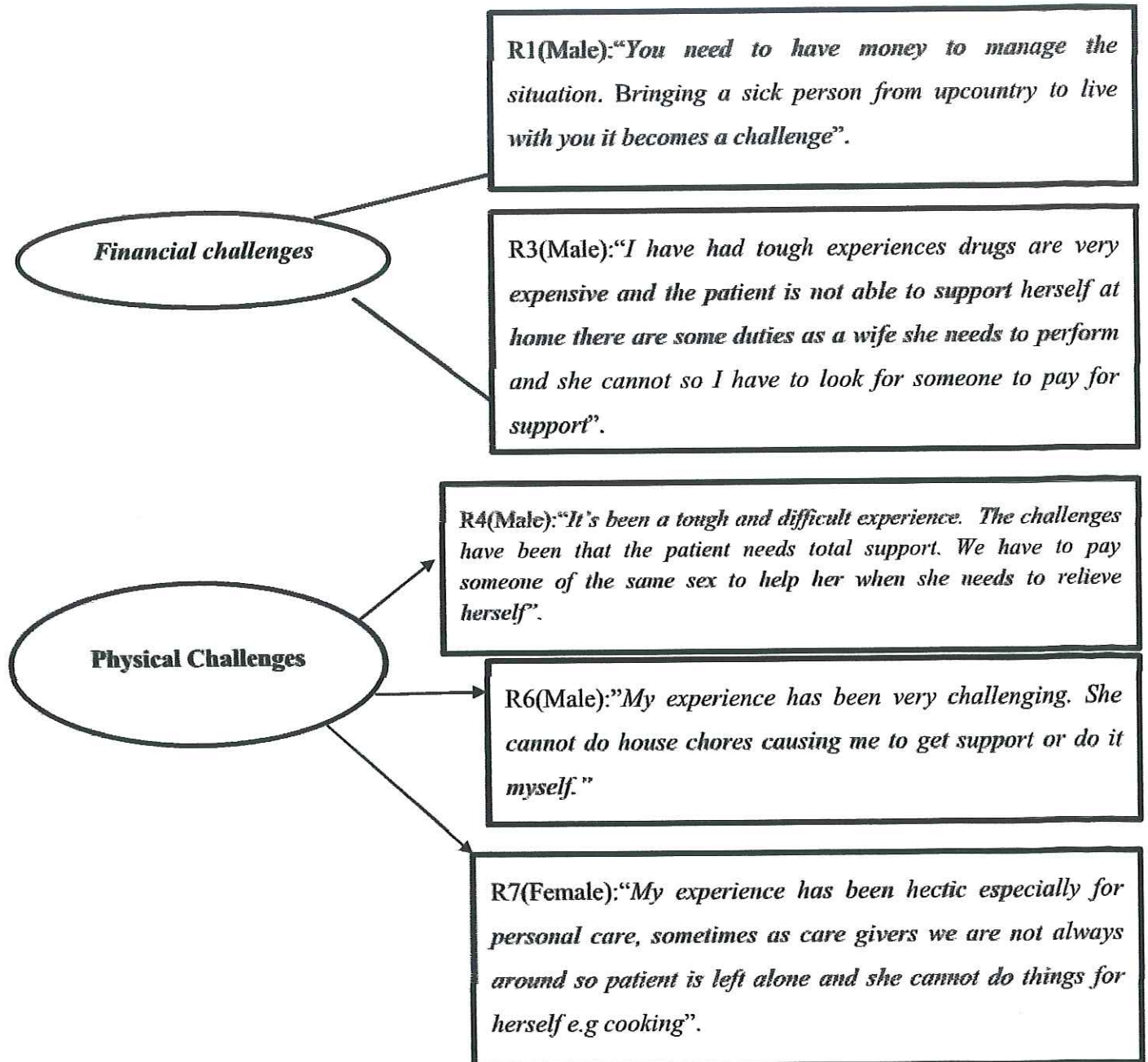
Variable	Little or no burden	Mild to moderate burden	Moderate to severe burden	P value
Depression severity				
None depression	4 (44.4)	25 (36.8)	3 (8.3)	<0.001
Minimal depression	3 (33.3)	24 (35.3)	5 (13.9)	
Mild depression	2 (22.2)	10 (14.7)	12 (33.3)	
Moderate depression	0	5 (7.4)	8 (22.2)	
Moderately severe depression	0	3 (4.4)	6 (16.7)	
Severe depression	0	1 (1.5)	2 (5.6)	

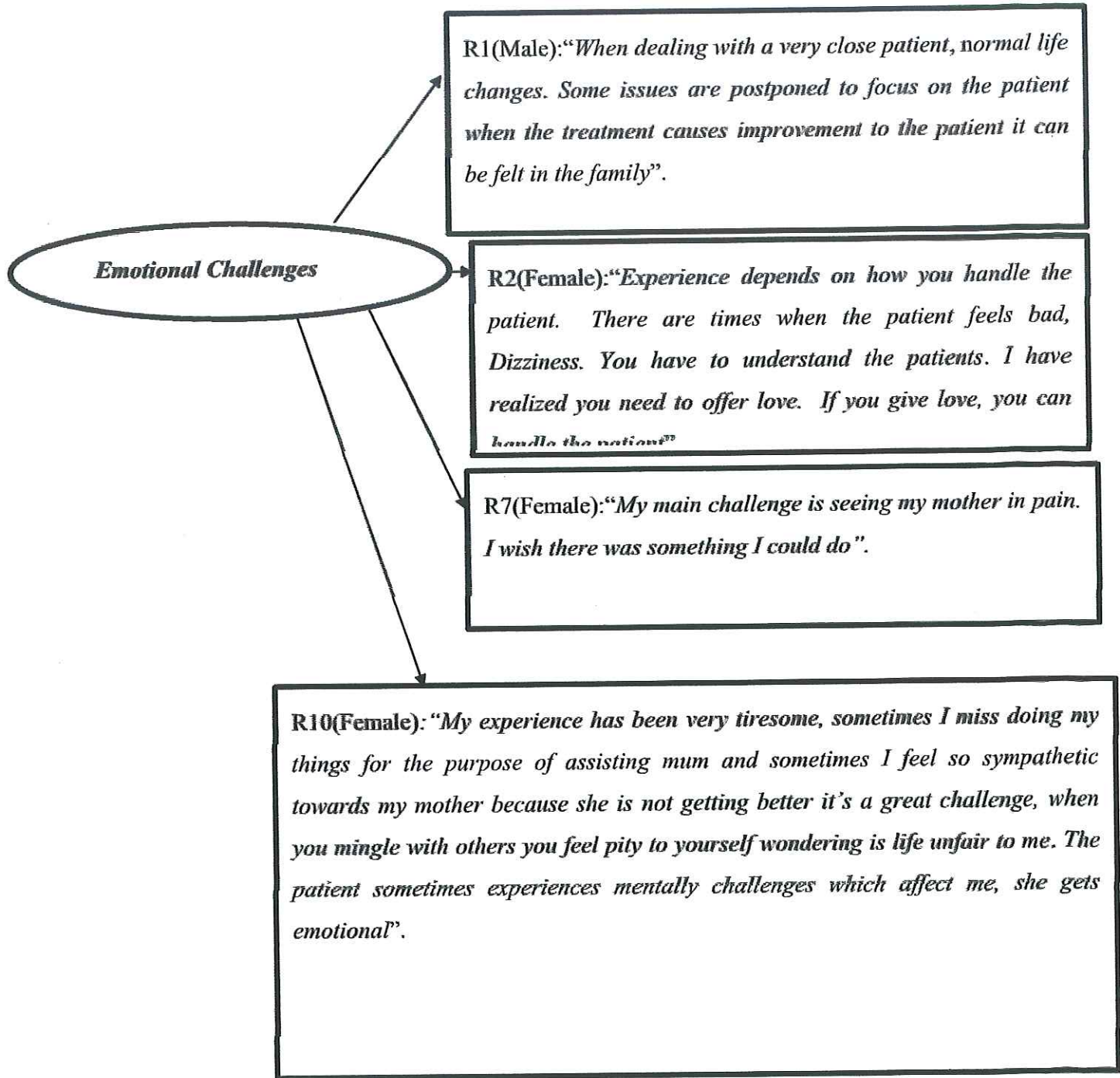
4.4 Experiences of Burden of care in Caregivers who Take Care of RA and OA Patients

Themes were developed under each of the 4 open ended semistructured questions used as guide in qualitative data collection as follows

QUESTIONS	THEMES
1. Challenges experienced as a caregiver	Financial Physical Emotional
2. Coping with challenges experienced as a caregiver	Acceptance Use of prayers Planning Family support Sociolizing
3. Coping with challenges experienced as a caregiver	Balancing time Family cooperation Coping based on disability level Sacrifice
4. Coping with challenges experienced as a caregiver	Lost opportunities Family effect Social life effect Financial effect Emotional effect

1. Challenges experienced as a caregiver





2. Coping with challenges experienced as a caregiver

Acceptance

R1(Male): *"I accept the situation and manage as advised. One has to squeeze oneself to a certain level, go an extra mile and budget for the situation"*.

Use of Prayers

R2(Female): *"Acceptance and prayer help in coping with the burden of caregiving....."*.

Planning

R4(Male): *"We have a good arrangement at place of work to get time to return home and check on her when need be"*. As regards the financial burden; *"We had to take salary in advance to cater for the patient. We also took up the services of a person from a massage parlor who comes to assist at a*

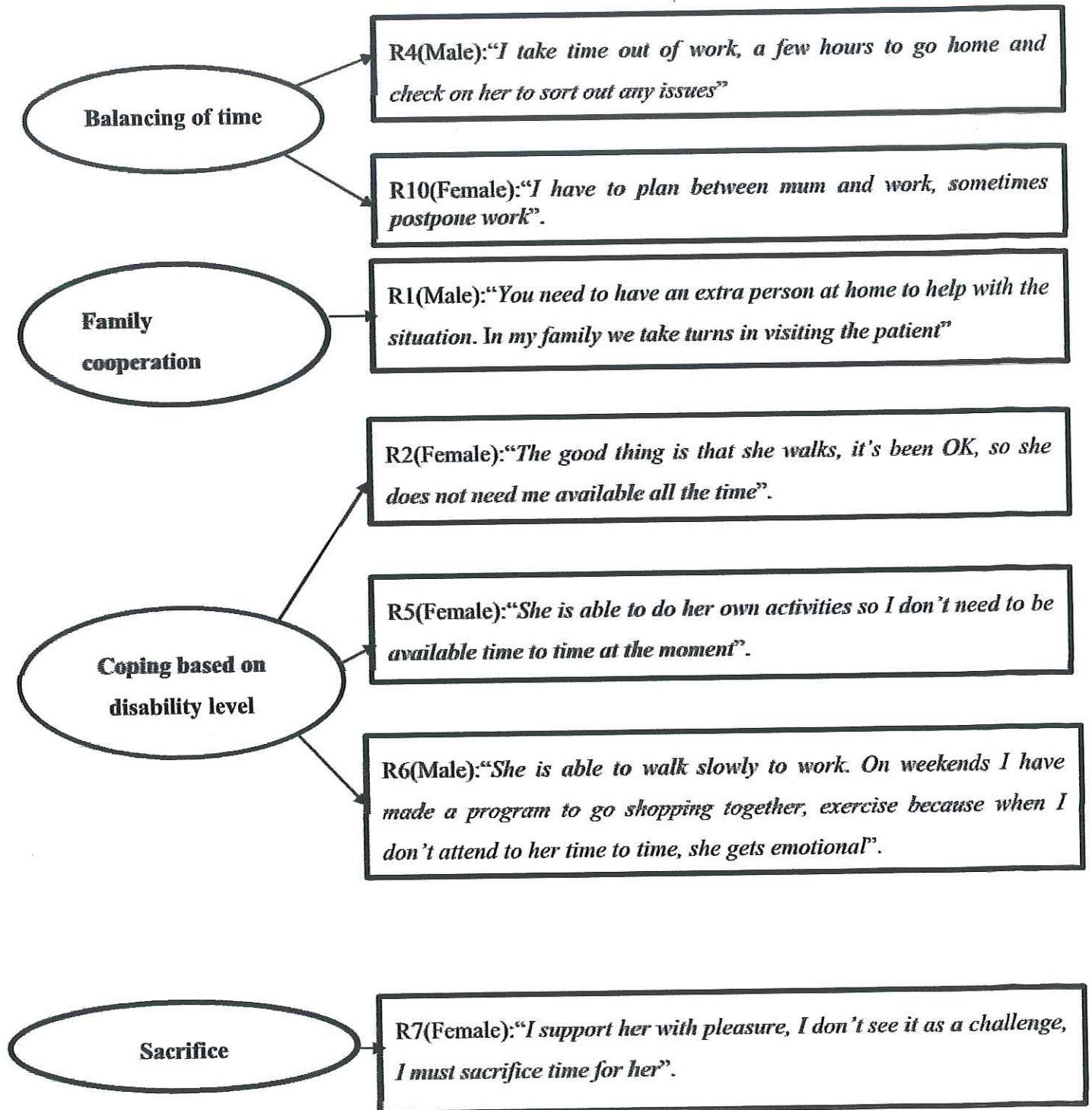
Family support

R7(Female): *"As for the challenging on seeing my mother in pain. Apart from giving her the medicine as advised, I am praying and wishing her well since there is nothing else I can do. I mobilize my sisters and brothers for help"*.

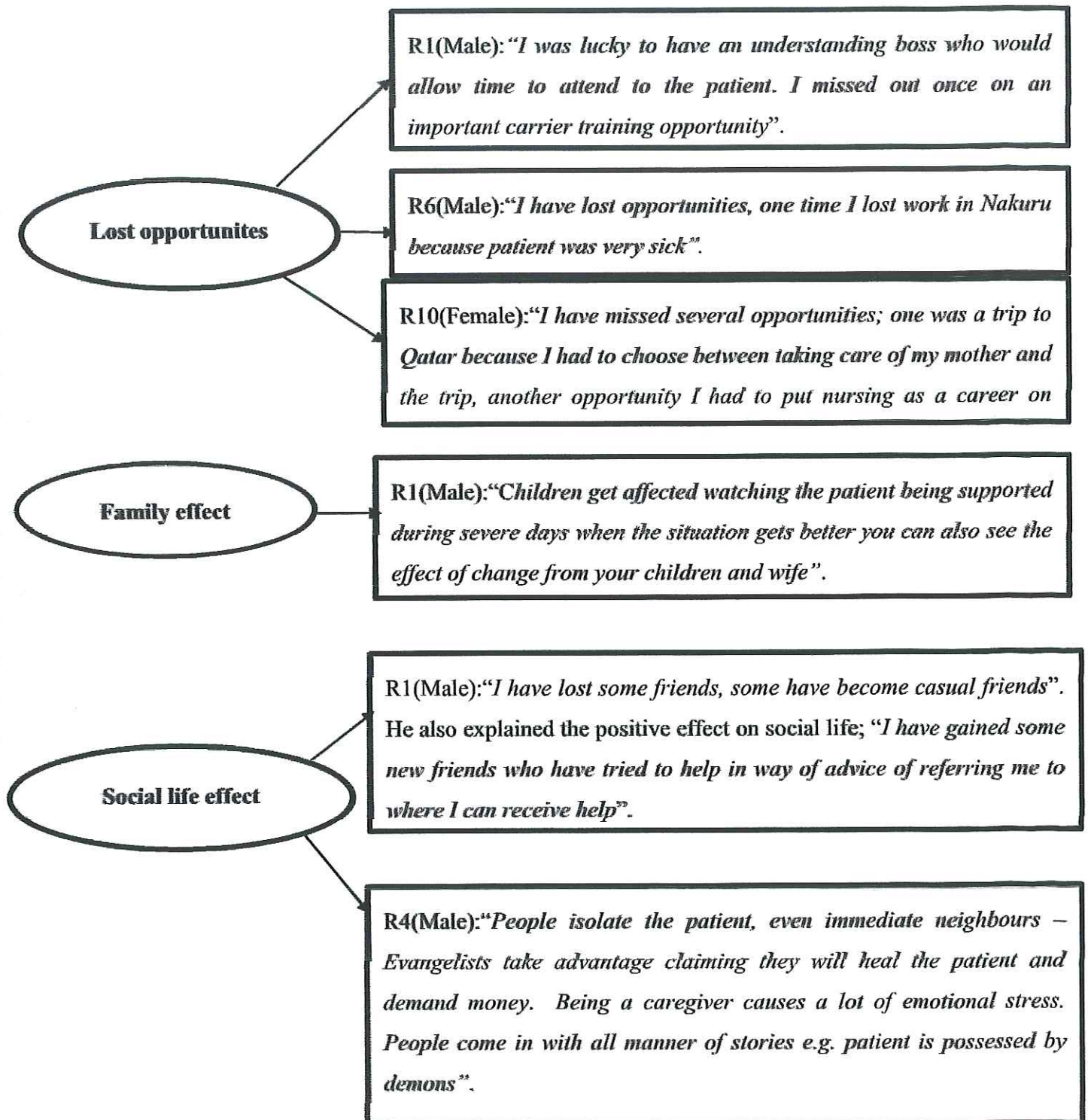
Socializing

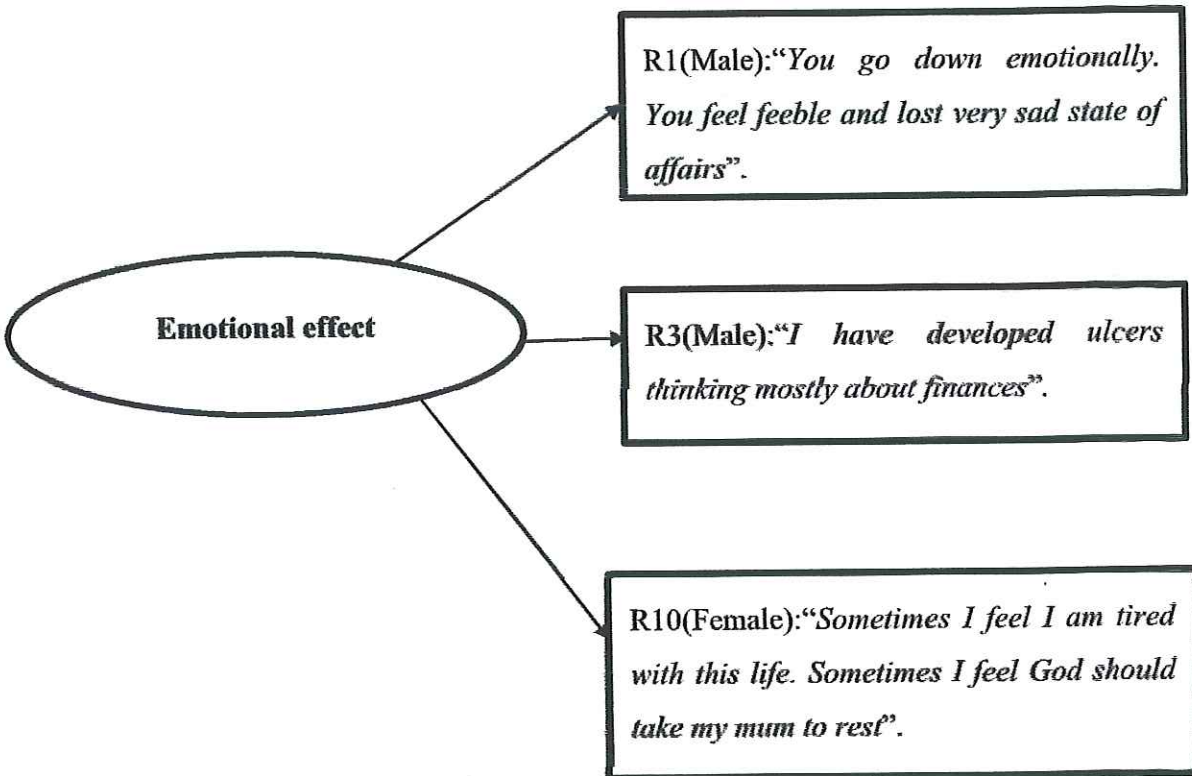
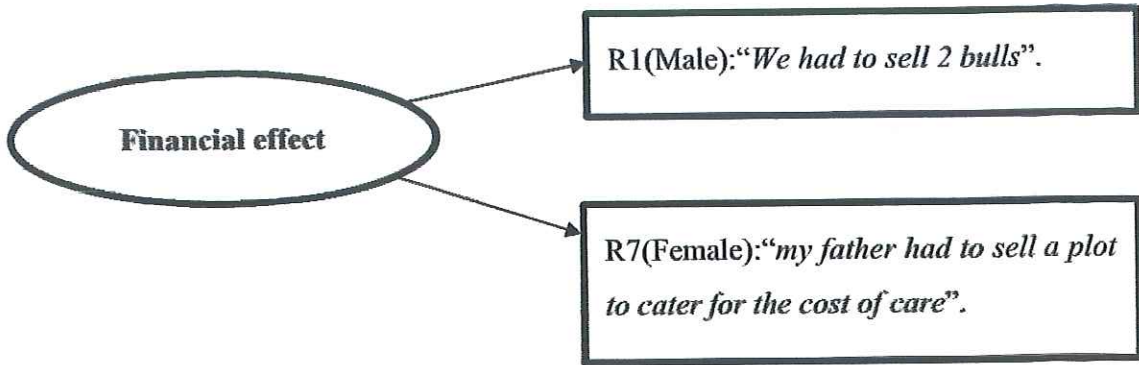
R10(Female): *"I mingle with friends to avoid crying and thinking. I socialize by planning day and time"*.

3. Coping with the need to be available for the patient



4. Effect of taking care of the patient





CHAPTER 5

DISCUSSION, LIMITATIONS , CONCLUSION AND RECOMMENDATION

5.0 Introduction

5.1 Caregiver characteristics

Cross sectional study in caregivers of OA and RA by Safinaz et al (16), also found out that majority of the caregivers were female. Other than being of female sex the prevalence of being married, mean age of caregivers and mean time spent caring for patients in this study was similar to studies by Ru et al (3) at 71.8%, 93.3%, 47% and 24 months respectively. Cross sectional study on caregivers by Nagoyoshi et al (50) in caregivers of RA patient highlighted mean age 46 years of their caregivers and females were 73.2% of the caregivers. Riemsa et al (43) in a cross sectional study on burden of care in RA patients had 55% females, mean age of caregivers was 58 years and 93% of the caregivers were married. Females worldwide have traditionally been known to take the role of care giving (40) and this could also partly explain the high prevalence of female caregivers in this study. Most of the caregivers in this study were young, female, educated, married. Negative social effects due to being young reduces productivity and increase likelihood of missing work activities this would partly explain why majority being self employed earned less in a month (< 15000 K shillings). Being educated can have several implications on the burden of care: self ability to be aware of coping mechanisms and to seek health promoting behaviours and a gap for education and training programs to these caregivers in order to reduce their level of care burden. Majority of caregivers being daughters would suggest in this culture caring is related to family intimacy and obligation, linked together with solidarity and reciprocity of roles from generation to generation (40)(43).

5.2 Patient characteristics

The median age of the patients was 52.0 years (SD 17.7 years) and 75.2% were females. The disease suffered was mainly RA reported in 68.1% of the participants and the median duration of the disease was 3 years. About a third (32.7%) reported having other chronic diseases or disabilities. Majority (81.4%) had access to financial support which was mainly NHIF. Results of this study on patient age and sex is similar to other studies for instance Guoxia et al (74) in a

cross sectional study on caregivers of RA patients in china found majority of patient were female and mean age was 52 years. Ru et al (3) , Nagayoshi et al (50) and Riemsa et al (43) also had majority of the patients being female with mean age of between 47, 64 and 62 years respectively.

Possible reasons for above results could be RA has been known to affect mainly females in the age bracket of 16-40 years (12).The proportion of RA was also greater than OA patient possibly due to specialization of the rheumatology clinic after establishment of a separate osteoarthritis clinic as a separate entity under another department. Majority of the patient had insurance cover in this study, this would be a protective factor possibly because those patients without insurance cover their caregivers would be more involved financially leading to more burden.

5.3 Prevalence of Burden of care and severity in caregivers

The overall burden of care in caregivers was 92%. The caregivers exhibited different severity of burden, with 60.2% having mild to moderate and 31.9% presenting with moderate to severe burden, little or no burden was found to be 8%, no caregiver had severe burden of care. Several studies have used the Zarit Burden Interview to assess caregiver burden, and the results of this study are generally consistent with findings of other studies.

Ru et al (3) in a cross sectional study in RA patients in China had a prevalence of caregiver burden at 80% compared with the burden of care in this study at 92%. Guoxia et al (74) and Nagayoshi et al (50) had moderate caregiver burden at prevalence of 44% and 45% respectively using the Caregiver burden inventory score (CBI).

The results of this study have practical applications for both research and clinical practice. From a research perspective, these findings highlight the need for more targeted interventions to address caregiver burden. While the current study did not examine the effectiveness of any specific interventions, programs such as respite care, education and training, and social support may help to reduce caregiver burden though studies on effectiveness of these interventions are lacking. Future research should continue to explore the effectiveness of these and other interventions in reducing caregiver burden and improving the well-being of both caregivers and care recipients.

From a clinical perspective, these findings suggest that healthcare providers should be aware of

the potential for caregiver burden and proactively screen for it. The Zarit Burden Interview or other validated measures of caregiver burden can be easily administered in clinical settings to identify caregivers who may be experiencing significant burdens. Healthcare providers can then work with these caregivers to develop individualized care plans that address their specific needs and reduce their burden. This may include referrals to community resources, such as support groups, as well as education and training on providing effective care while also taking care of themselves.

5.4 Prevalence and severity of Depression

The overall prevalence was at 22.2%. The distribution of PHQ-9 scores indicated that none - minimal depression was 56.6%, 21.2% had mild depression, 11.5% had moderate depression, 8% had moderately severe depression, and 2.7% had severe depression. A cross sectional study by Ru et al (3) in caregivers of RA patients, 27% of the caregivers had depression using The Centre depression self rating scale compared with 22.2% in this study. The prevalence of depression among caregivers in this study appears to be influenced by multiple factors. Caregiving for individuals with RA and OA can be physically and emotionally demanding, and this can lead to feelings of depression and burnout (75). Caregivers who lack support may feel overwhelmed and may be more likely to experience depression as a result (76). Additionally, individual and social characteristics of caregivers, such as a history of depression or limited financial resources, may increase their risk of depression. However, despite these risk factors, many caregivers in this study were found to have minimal or no depression, suggesting that there may be protective factors, such as social support networks or effective coping strategies, that help to mitigate the negative impacts of caregiving.

It is worth noting that the prevalence of depression among caregivers can vary widely depending on the population being studied and the measurement tools used. For instance, Ru et al, 27% of the caregivers had depression using The Centre depression self rating scale compared with 22.2% in this study .

This difference in prevalence may be due to cultural differences in attitudes toward mental health or differences in the measurement tools used. These findings suggest that the prevalence of depression among caregivers may be different across different caregiving populations and that

the PHQ-9 tool may help measure depression in caregivers.

The results have important implications for research and practice. From a research perspective, the findings suggest that the PHQ-9 tool may be a valuable instrument for measuring depression in caregivers. It identified a significant proportion of caregivers with moderate to severe depression. The study also highlights the need for more research on the factors that influence depression in caregivers, including the role of social support, coping strategies, and caregiver characteristics. From a practical perspective, the results suggest that healthcare providers should be aware of depression among caregivers and should screen for depression regularly. Providers may also consider referring caregivers to support groups or other resources to help them manage the emotional and physical demands of caregiving. Additionally, interventions aimed at improving social support and coping strategies may help to reduce the risk of depression among caregivers though research on effectiveness of these interventions is warranted.

5.5 Experiences of burden of care in caregivers who take care of RA and OA patients

The study found that caregivers who take care of RA and OA patients experience physical, emotional and financial burdens due to the demands of caring for their loved ones. These findings were similar to other studies for instance Karen et al (19) in a mixed qualitative study in caregivers of OA patients, Barbic et al (77) in family caregivers and a qualitative study by Janice et al (24) in rare rheumatic conditions. These caregivers employed different strategies including acceptance, use of prayers, organizing themselves in advance, involving the whole family and socializing in trying to cope with the challenges which were also similar strategies employed by caregivers in other studies (4)(18). Caregiving in some of the caregivers led to lost opportunities, disrupted social life, loss of finances, negative and positive effects on the whole family and emotional effects. These effects of caregiving were also reported by Kwo et al (78) in a prospective longitudinal study in cancer patients and Noelia Alfaro et al (5) in a descriptive exploratory qualitative study. Kirsh et al (79) in a descriptive study in people living with RA found that caregivers of individuals with RA experience high levels of stress and emotional distress and may face challenges accessing support and resources. The experiences of burden reported by caregivers who take care of RA and OA patients in this study are likely due to the chronic nature of these conditions, which require ongoing care and management. Caregivers

face physical, emotional, and financial challenges associated with providing care, including assisting with daily tasks, managing medication and healthcare expenses, and dealing with the emotional toll of caregiving. The burden of caregiving may lead to decreased quality of life for caregivers and increase the risk of caregiver stress and burnout. These findings underscore the importance of providing support and resources to help caregivers manage the challenges of caring for a loved one with RA or OA, and to maintain their own health and well-being.

These studies highlight the need for healthcare providers to address the burden experienced by caregivers of RA and OA patients and provide support to help mitigate the physical, emotional, and financial consequences of caregiving. Support could be in the form of providing respite care, offering counseling or support groups, and providing education and training on self-care and stress management strategies both at individual and family level.

5.6 Association Between Burden of care; Depression, Sociodemographic Factors, Selected Patient and Disease Factors

The study was not powered enough due to small sample size to make statistically significant association between burden of care, depression, sociodemographic factors, selected patients and disease factors. However a trend was noted whereby depression score was higher among caregivers with more severe burden of care compared to those with little or no burden. Caregivers with little or no burden had no to a mild level of depression, while more than 10% of those with mild to moderate burden reported moderate to severe depression. On the other hand, 44% of the caregivers with moderate to severe burden reported moderate to severe depression. This highlight a possible area for future research.

5.7 Study Limitations

The following were the study limitations

1. **Self-reported data from participants was used in this study and its accuracy may not be verified. Self-report questionnaire results might be inflated or overstated.**
2. **Because KNH is a major referral hospital, the results of this study cannot be extrapolated to smaller institutions.**
3. **No objective evaluation were performed to assess patients degree of physical disability or self care ability**

5.8 Conclusions

Caregivers burden of care in RA and OA is high and in varying degrees with majority exhibiting mild to moderate burden. The prevalence of depression in caregivers was considerable, majority in this study having moderate depression. The study highlights the significant physical, emotional, and financial burden associated with caregiving for individuals with RA and OA. A trend exists between caregiver burden and depression, as the burden of caregiving increased, the severity of depression among caregivers also increased. This study was not powered enough to form any statistically significant associations between burden of care and caregivers' characteristics, patient characteristics.

5.9 Recommendations

1. **The hospital needs to raise awareness about caregiver burden and challenges faced by caregivers.**
2. **There is a need for the hospital to provide caregiver support groups which will help reduce feelings of isolation and provide a sense of community for caregivers.**
3. **Comprehensive discharge plan should be developed in order to ensure that caregivers are prepared to care for their loved ones after they leave the hospital.**
4. **Future studies should try investigate association between burden of care; depression, selected patient and caregiver factors.**
5. **Future studies should try investigate effectiveness of some interventions like respite care, education etc on alleviating caregiver burden.**

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APPENDICES

Appendix 1: Informed Patient Consent Form

INFORMED CONSENT FOR RESEARCH STUDY

**TITLED: BURDEN OF CARE AND DEPRESSION AMONG CAREGIVERS OF PATIENTS
WITH RHEUMATOID ARTHRITIS AND OSTEOARTHRITIS AT KENYATTA
NATIONAL HOSPITAL**

Institution:

University of Nairobi, College of Health Sciences, Department of Clinical Medicine and
Therapeutics,

P.O BOX 30197-00400, Nairobi.

Principal Investigator:

Dr. EMONGOLE EMMANUEL

P.O.BOX 50926-00200, Nairobi.

Phone: 0712254696

Lead Supervisors: Prof. Oyoo/ Prof. Amayo/ Dr.Ilovi

Department of Clinical Medicine and Therapeutics (UoN).

Ethical Approval No:.....

Introduction

I am Dr. Emongole Emmanuel, a postgraduate student pursuing a degree in Master of Medicine in Internal Medicine at the University of Nairobi. This form will give you information you need to decide if you want to participate in the study. If you have any questions, do not hesitate to ask for clarification.

Purpose of Study

I am carrying out a study to assess burden of care and depression among caregivers of patients with rheumatoid arthritis and osteoarthritis at Kenyatta National Hospital.

Your rights as a participant

Your participation in this research is voluntary and if you refuse to participate in this study, your treatment will not be affected. If you choose to participate and not answer certain questions, you are free to do so. If you choose to participate in the study fully you will be required to sign the informed consent and be subjected to fill in a set of three questionnaires. You are free to terminate the interview and withdraw from the study at any time. You are free to ask questions before signing the consent form.

Assurance of confidentiality

All your responses as well as your results will remain confidential. Your individual responses will be stored in a locked place under my control and will only be seen by my statistician and me.

Benefits to you as a participant

Your participation in the study bears no cost to you but the findings will be used for your individual benefit. Information obtained will improve knowledge to health care givers at Kenyatta National hospital.

Contacts

Consent form – patient / next of kin

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions that I have asked have been answered to my satisfaction.

I consent voluntarily to participate as a participant in this research.

Name of Participant/ Next of kin:

Signature / Left thumbprint of subject:

Date:

Investigator's statement:

I, the Principal Investigator, have fully informed the research participant on the purpose and implication of this study.

Signed:

Date:

Appendix 2: Fomu ya Idhini

RIDHAA YA KUFHAMISHWA KWA UTAFITI

INAYOITWA: MZIGO WA HUDUMA NA KUDIKISHWA MIONGONI MWA WALEZAJI WA WAGONJWA WA RHEUMATOID ARTHRITIS NA OTEOARTHRTIS KATIKA HOSPITALI YA TAIFA YA KENYATTA.

Taasisi:

Chuo Kikuu cha Nairobi, Chuo cha Sayansi ya Afya, Idara ya Tiba ya Kliniki na Tiba

P.O BOX 30197-00400, Nairobi.

Mpelelezi Mkuu:

Dr. EMONGOLE EMMANUEL

P.O.BOX 50926-00200, Nairobi.

Phone: 0712254696

Wasimamizi Wakuu: Prof. Oyoo/ Prof. Amayo/ Dr.Ilovi

Department of Clinical Medicine and Therapeutics (UoN).

Nambari ya Uidhinishaji wa Kimaadili:.....

Utangulizi

Mimi ni Dkt. Emongole Emmanuel, mwanafunzi wa shahada ya uzamili ninayefuata shahada ya Uzamili ya Tiba katika Tiba ya Ndani katika Chuo Kikuu cha Nairobi. Fomu hii itakupa taarifa unayohitaji ili kuamua kama ungependa kushiriki katika utafiti. Ikiwa una maswali yoyote, usisite kuuliza kwa ufafanuzi.

Kusudi la Kusoma Ninafanya utafiti kutathmini mzigo wa matunzo na mfadhaiko miongoni mwa walezi wa wagonjwa walio na baridi yabisi na osteoarthritis katika Hospitali ya Kitaifa ya Kenya.

Haki zako kama mshiriki

Ushiriki wako katika utafiti huu ni wa hiari na ukikataa kushiriki katika utafiti huu, matibabu yako hayataathirika. Ukichagua kushiriki na kutojibu maswali fulani, uko huru kufanya hivyo. **Ukichagua kushiriki katika utafiti kikamilifu utahitajika kutia sahihi kibali cha taarifa na kutakiwa kujaza seti ya dodoso tatu.**

Uko huru kusitisha mahojiano na kujiondoa kwenye utafiti wakati wowote. Uko huru kuuliza maswali kabla ya kusaini fomu ya idhini.

Uhakikisho wa usiri

Majibu yako yote pamoja na matokeo yako yatabaki kuwa siri. Majibu yako ya kibinafsi yatahifadhiwa mahali pamefungwa chini ya udhibiti wangu na yataonekana tu na mwanatakwimu wangu na mimi.

Faida kwako kama mshiriki

Kushiriki kwako katika utafiti hakutakugharimu chochote lakini matokeo yatumika kwa manufaa yako binafsi. Taarifa zitakazopatikana zitaboresha ujuzi kwa wahudumu wa afya katika hospitali ya Kitaifa ya Kenyatta.

Fomu ya idhini - mgonjwa / jamaa wa karibu

Nimesoma habari iliyotangulia, au imesomwa kwangu. Nimepata fursa ya kuuliza maswali kuhusu hilo na maswali yoyote ambayo nimeuliza yamejibiwa kwa kuridhika kwangu. **Ninakubali kwa hiari yangu kushiriki kama mshiriki katika utafiti huu.**

Jina la Mshiriki/ Ndugu wa karibu:.....

Saini / kidole gumba cha kushoto cha somo:.....

Tarehe:

Kauli ya mchunguzi:

Mimi, Mpelelezi Mkuu, nimemfahamisha mshiriki wa utafiti kikamilifu kuhusu madhumuni na

maana ya utafiti huu.

Imesainiwa: Tarehe:

Appendix 3: Caregiver Sociodemographic Questionnaire

Caregiver factors

1. Name:

2. Age (DoB):

Age	Month	Year

3. Sex:

Male ___ Female ___

4. Marital status

Single ___ Married ___ Widowed ___ Divorced ___

5. Education level:

No education ___ Primary level ___ Secondary level ___ Tertiary level ___

6. Employment/source of income:

Full time ___ Part time ___ Self-employed ___ Retired ___ Unemployed ___
Housewife ___

7. Average monthly income:

less than 2000 ___ 2001-5000 ___ 5001-10000 ___ 10001-15000 ___ 15001-20000 ___
20001-30000 ___ 30000 above ___

8. Duration of caring of patient(months/years).....

Patient factors

9. Age: (DOB)

10. Sex

Male.....female.....

11. What is the disease of your patient?.....

12. Duration of disease (months/years):

13. Does patient have any other chronic disease or disability?

Yes ___ No ___

If yes, which one?

14. Relationship to the patient:

15. Availability of financial support to take care of patient's medical needs?

Yes ___ No ___

If yes, what/who?

NHIF ___ Private insurance ___ Family ___ Friends ___

Appendix 4: Dodoso la Mlezi wa Demografia

1. Jina:

2. Umri (DoB):

Umri	Mwezi	Mwaka

3. Jinsia:

Mwanaume ___ Mwanamke ___

4. Hali ya ndoa

Mseja ___ Ameolewa ___ Mjane ___ Ametalikiana ___

5. Kiwango cha elimu:

Hakuna elimu ___ Ngazi ya msingi ___ Ngazi ya sekondari ___ Ngazi ya elimu ya juu ___

6. Ajira/chanzo cha mapato:

Muda kamili ___ Muda wa ziada ___ Nimejiajiri ___ Mstaafu ___ Hana ajira ___ Mama mwenye nyumba ___

7. Wastani wa mapato ya kila mwezi:

chini ya 2000 ___ 2001-5000 ___ 5001-10000 ___ 10001-15000 ___ 15001-20000 ___
20001-30000 ___ 30000 na juu ___

8. Muda wa kumhudumia mgonjwa(miezi/miaka).....

Sababu za mgonjwa

9. Umri

Umri	Mwezi	Mwaka

10. Jinsia

Mwanaume.....mwanamke.....

11. Mgonjwa wako ana ugonjwa gani?.....

12. Muda wa ugonjwa (miezi/miaka):

13. Je, mgonjwa ana ugonjwa mwingine wowote sugu au ulemavu?

Ndio ___ la ___

Kama ndiyo, ipi?.....

14. Uhusiano na mgonjwa:

15. Upatikanaji wa msaada wa kifedha kushughulikia mahitaji ya matibabu ya mgonjwa?

Ndio ___ la ___

Kama ndiyo, nini/nani?

NHIF ___ Bima ya kibinafsi ___ Familia ___ Marafiki ___

Appendix 5: Zarit Burden Interview

Instructions: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relatives ask for more help than he/she needs

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

4. Do you feel embarrassed over your relative's behavior?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

5. Do you feel angry when you are around your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

7. Are you afraid what the future holds for your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

8. Do you feel your relative is depended upon you?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

9. Do you feel strained when you are around your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

10. Do you feel your health has suffered because of your involvement with your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

11. Do you feel that you don't have as much privacy as you would like, because of your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

12. Do you feel that your social life has suffered because you are caring for your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

13. Do you feel uncomfortable about having friends over, because of your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

14. Do you feel your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

16. Do you feel that you will be unable to take care of your relative much longer?

0. Rarely 1. Rarely 2. Sometimes 3. Quite 4. Nearly always

frequently

17. Do you feel you have lost control of your life since your relative illness?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

18. Do wish you could leave the care of your relative to someone else?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

19. Do you feel uncertain about what to do about your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

20. Do you feel you should be doing more for your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

21. Do you feel you could do a better job in caring for your relative?

0. Rarely 1. Rarely 2. Sometimes 3. Quite frequently 4. Nearly always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all much 1. A little 2. A little 3. quite a little 4. Very much much

Appendix 6: Zarit Burden Interview (Swahili version)

MAELEKEZO: Ifuatayo ni orodha ya taarifa, ambazo zinaonyesha jinsi watu wakati mwingine wanahisi wakati wa kumtunza mtu mwingine. Baada ya kila taarifa, onyesha ni mara ngapi unahisi hivyo; kamwe, mara chache, wakati mwingine, mara kwa mara, au karibu kila wakati. Hakuna majibu sahihi au mabaya.

1. Je! Unahisi jamaa yako anauliza msaada zaidi ya anavyohitaji?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

2. Je! Unahisi kuwa kwa sababu ya muda unaotumia na jamaa yako kuwa hauna wakati wa kutosha kwako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

3. Je! Unajisikia mkazo kati ya kumtunza jamaa yako na kujaribu kufikia majukumu mengine kwa familia yako au kazini?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

4. Je! Unahisi aibu juu ya tabia ya jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

5. Je! Unahisi hasira wakati uko karibu na jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

6. Je! Unahisi kuwa jamaa yako kwa sasa anaathiri uhusiano wako na wanafamilia wengine au marafiki kwa njia mbaya?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

7. Je! Unaogopa hali ya baadaye kwa jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

8. Je! Unahisi jamaa yako anakutegemea?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

9. Je! Unahisi shida wakati uko karibu na jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

10. Je! Unahisi afya yako imeumia kwa sababu ya ushiriki wako na jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

11. Je! Unahisi kuwa hauna faragha Kama vile ungependa, Kwa sababu ya jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

12. Je! Unahisi kuwa maisha yako ya kijamii yameteseka kwa sababu unamjali jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

13. Je! Hujisikii wasiwasi juu ya kuwa na marafiki tena, kwa sababu ya jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

14. Je! Unahisi jamaa yako anaonekana anatarajia umtunze, kana kwamba ni wewe tu ambaye angemtegemea?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

15. Je! Unajisikia kuwa hauna pesa za kutosha kumtunza jamaa yako, pamoja na matumizi yako yote?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

16. Je! Unahisi kuwa utashindwa kumtunza jamaa yako Kwa muda mrefu zaidi?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

17. Je! Unahisi umepoteza udhibiti wa maisha yako tangu ugonjwa wa jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

18. Je! Unatamani ungemwachia mtu mwingine matunzo ya jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

19. Je! Unahisi hauna uhakika juu ya nini cha kufanya juu ya jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

20. Je! Unahisi unapaswa kufanya zaidi kwa jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

21. Je! Unahisi unaweza kufanya kazi bora katika kumtunza jamaa yako?

0. Kamwe 1. Mara chache 2. Wakati mwingine 3. Mara kwa Mara 4. Karibu Daima

22. Kwa jumla, unajisikia mzigo gani katika kumtunza jamaa yako?

0. Sio kabisa 1. Kidogo 2. Kiasi 3. Kidogo kabisa 4. Sana

Appendix 7: PHQ-9 Questionnaire

Pick the one that is most accurate to describe your experience.

Over the last two weeks have you been bothered by any of these problems

	Not at all	Several days	More than half the days	Nearly every day
Little interest or pleasure in doing things				
Feeling down, depressed, or hopeless				
Trouble falling or staying asleep or sleeping too much				
Feeling tired or having little energy				
Poor appetite or overeating				
Feeling bad about yourself or that you are a failure or have let yourself or your family down				
Trouble concentrating on things, such as reading the newspaper or watching television				
Moving or speaking so slowly that other people could have noticed. Or the opposite being so fidgety or restless that you have been moving around a lot more than usual				
Thoughts that you would be better off dead, or of hurting yourself				
If you checked off any problem, how difficult have these problems made it for you to do your work, take care of things at home, or get along with other people				

Appendix 8: PHQ-9 Questionnaire (Swahili Translation)

Kidodosi Juu ya Afya ya Mgonjwa

	Haijatokezea kabisa	Siku kadhaa	Zaidi ya nusu ya siku hizo	Takriban kila siku
Kutokuwa na hamu au raha ya kufanya kitu				
Kujisikia tabu sana au kukata tamaa				
Matatizo ya kupata usingizi au kuweza kulala au kulala sana				
Kujisikia kuchoka au kutokuwa na nguvu				
Kutokuwa na hamu ya kula au kula sana				
Kujisikia vibaya au kujiona kuwa umeshindwa kabisa au umejiangusha au kuikatisha tama familia yako				
Matatizo ya kuwa makini kwa mfano unaposoma gazeti au kuangalia runinga/Televisi hizi				
Kutembea au kuongea taratibu sana mpaka watu wakawa wameona tofauti? Au kinyume kwake kwamba hutulizana unahangaika sana kuliko ilivyo kawaida				
Mawazo kuwa ni afadhali zaidi ufe au ujidhuru kwa namna fulani				

Appendix 9: Semi-Structured Interview Questions

I'd like us to talk about your experience as a caregiver to someone dealing with rheumatoid arthritis and osteoarthritis. I'd like to know about how you became a caregiver to the patient and what your experience has been so far, looking at challenges and possible opportunities for support. Where possible I'd like you to go into details giving examples from your experience as caregiver. My interest is in what you think and feel about those experiences. If you need to stop or don't want to carry on just let me know.

Tell me about your experience taking care of someone with RA/OA.

1. We understand that taking care of a sick person is challenging, what has been your challenges?
2. How do you cope with taking care of the patient?
3. How do you cope with the need to be available to the patient from time to time? (support to do personal activities e.g. standing, walking; clinic attendance)
4. What has been the effect of taking care of your patient? (Probe: lost opportunities, family, social, finances, emotional)

We are done, thank you for answering my questions. Is there anything you would like to add or ask? Or something you feel is important that we didn't talk about?

Thank you for taking the time to speak with me, all the best.

Appendix 10: Semi-Structured Interview Questions (Swahili translation)

Ningependa tuzungumzie uzoefu wako kama mlezi kwa mtu anayeshughulika na ugonjwa wa arthritis ya rheumatoid na osteoarthritis. Ningependa kujua kuhusu jinsi ulivyokuwa mlezi kwa mgonjwa na uzoefu wako umekuwaje hadi sasa, ukiangalia changamoto na fursa zinazowezekana za usaidizi. Inapowezekana, ningependa ueleze kwa undani ukitoa mifano kutoka kwa uzoefu wako kama mlezi. Nia yangu ni katika kile unachofikiria na kuhisi kuhusu matukio hayo. Ikiwa unahitaji kuacha au hutaki kuendelea nijulishe.

1. Tunaelewa kuwa kumhudumia mgonjwa ni changamoto, changamoto zako zimekuwa zipi?
2. Je, unakabiliana vipi na kumtunza mgonjwa?
3. Je, unakabilianaje na uhitaji wa kupatikana kwa mgonjwa mara kwa mara? (msaada wa kufanya shughuli za kibinafsi k.m. kusimama, kutembea; kuhudhuria kliniki)
4. Kumtunza mgonjwa wako kumekuwa na matokeo gani? (Chunguza: fursa zilizopotea, familia, kijamii, kifedha, kihemko)

Tumemaliza, asante kwa kujibu maswali yangu. Je, kuna chochote ungependa kuongeza au kuuliza? Au kitu ambacho unahisi ni muhimu ambacho hatukuzungumza?

Asante kwa kuchukua muda wa kuzungumza nami, kila la heri.

PLAGIARISM REPORT

BURDEN OF CAREGIVERS OF PATIENTS WITH RHEUMATOID ARTHRITIS AND OSTEOARTHRITIS AT KENYATTA NATIONAL HOSPITAL.

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LEAD SUPERVISOR AND CHAIRMAN OF DEPARTMENT APPROVAL

This dissertation has been submitted with the Approval of my lead supervisor and the chairman of the Department of Clinical Medicine and Therapeutics


Lead Supervisor

Prof. Erastus O. Amayo

Chairman

Department of Clinical Medicine and Therapeutics,

University of Nairobi.

Signature  Date 15/11/2022


Chairman of the Department

Prof. Erastus O. Amayo

Chairman

Department of Clinical Medicine and Therapeutics,

University of Nairobi.

Signature  Date 15/11/2022

UNIVERSITY OF NAIROBI
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF CLINICAL MEDICINE & THERAPEUTICS
P.O. Box 10676-00202 NAIROBI