RELATIONSHIP BETWEEN CARE BURDEN, QUALITY OF LIFE AND DEPRESSION AMONG CAREGIVERS OF HOSPITALISED OLDER ADULTS IN A TERTIARY HEALTH INSTITUTION

BY

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(BMS1709638)

A PROJECT SUBMITTED TO THE DEPARTMENT OF PHYSIOTHERAPY, SCHOOL OF BASIC MEDICAL SCIENCES, COLLEGE OF MEDICAL SCIENCES, UNIVERSITY OF BENIN, BENIN CITY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF BACHELOR OF PHYSIOTHERAPY (B.PT) DEGREE

JANUARY, 2025.

CERTIFICATION

This dissertation by Ehiozee Abieyuwa is accepted in its presented form as satisfying the dissertation requirement of the degree of Bachelor of Physiotherapy of the School of Basic Medical Sciences, College of Medical Sciences of the University of Benin.

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DEDICATION

This dissertation is dedicated to my parents Mr and Mrs Felix Ehiozee, my late uncle Mr Osamwonyi Omorogbe and my late grandmothers Mrs Esther Omorogbe and Mrs Grace Ehiozee who made this work a reality.

ABSTRACT

Background: The increasing population of older adults worldwide has heightened the demand for caregiving, especially in tertiary healthcare settings. Caregivers, both formal and informal, face significant physical, emotional, and financial challenges. These burdens can negatively impact their quality of life (QoL) and increase the risk of depression, especially when caring for hospitalized older adults with complex needs. This study aimed to investigate the relationship between care burden, QoL, and depression among caregivers in a tertiary health institution.

Methods: A cross-sectional study was conducted among 80 primary caregivers of hospitalized older adults at the University of Benin Teaching Hospital, Benin City, Nigeria. Participants were selected using convenience sampling and completed structured questionnaires, including the Caregiver Strain Index (CSI) to measure caregiver burden and the WHOQOL-HIV BREF to assess quality of life across multiple domains. Descriptive statistics summarized sociodemographic variables, while Spearman's rho analysis assessed the relationships between care burden, QoL, and depression. Data were analysed using SPSS version 27, with significance set at $p < 0.05$.

Results: Of the 80 participants, 73.8% were female, and 61.3% were married. The mean age was 37.56 ± 11.36 years. The mean Caregiver Strain Index (CSI) score was 10.35 ± 1.65 out of a maximum obtainable score of 13, indicating a high level of strain. QoL scores varied across domains, with the psychological health domain scoring the lowest (14.48 ± 2.37) and the level of independence domain scoring the highest (15.38 ± 2.97). Spearman's rho analysis revealed a negative correlation (rho = -0.027, p = 0.814) between care burden and total QoL and a negative but non-significant correlation (rho = -0.196, p = 0.081) between care burden and psychological health.

Conclusion: Caregivers of hospitalized older adults experience moderate levels of care burden, which influence specific domains of their quality of life, such as social relationships and psychological health. However, no statistically significant relationships were found between care burden, overall QoL, and depression in this study. These findings suggest that while caregiving presents challenges, coping mechanisms like spirituality may mitigate its negative impacts. Targeted interventions are needed to enhance caregiver support systems, focusing on mental health, stress management, and social connections to improve caregivers' overall well-being and quality of life.

Keywords: Care burden, quality of life, depression, caregivers, hospitalized older adults.

ACKNOWLEGDEMENTS

I am grateful to God for the successful completion of my work and his protection and guidance throughout my stay on this campus.

I want to appreciate my supervisor Dr (Mrs) Oluwaseun. S Kubeyinje for taking out time from his busy schedule to listen to me, read and correct my work and also give me proper guidance to deliver the best. I want to appreciate the Head of Department, Dr (Mrs) Chigozie O. Obaseki for her support. Special thanks to the Pioneer Head of Department Prof. Kayode. I. Oke and all the lecturers of the department of Physiotherapy, University of Benin, Prof. A.O Ezeukwu, Prof. J. I. Umunnah, Rev. Sister (Dr) Henrietta Fawole, Dr Nelson Ekechukwu, Dr Bolarinde, Dr (Mrs) A. I. Aiyegbusi, Dr (Mrs) Rita Ativie, Dr. S .N. Oghumu, Mr E. Okhuahesuyi who impacted knowledge in me during my stay in this school, may God bless you richly.

A special thanks to the Head of Department, University of Benin Teaching Hospital, Dr. Taiwo Oyewumi, the Deputy Directors, Physiotherapist, Corpers and interns especially PT Imafidon, PT Ezekiel, PT Adebisi, PT Sylvester and other clinicians in University of Benin Teaching Hospital.

My heartfelt gratitude to my wonderful parents Mr Felix Ehiozee and Mrs Caroline Ehiozee for their undying love, care, prayers and financial support. To my twin sis Adesuwa Ehiozee and my other siblings Osasere Ehiozee and Uwaila Ehiozee I cannot appreciate you enough for being extremely supportive throughout my stay in the University of Benin. And also my grandpa Mr Ehigie Omorogbe, my late grandma Late Mrs Esther Omorogbe, my darling uncle Late Mr Osamwonyi Omorogbe who made me studied hard to get this degree, my uncle Mr Christopher omorogbe, my aunt Mrs Henrietta Omorogbe, Mrs Kate Aguebor and also to my big daddy the

Elawure of Usen for his encouragement and my uncle and his wife Mr and Mrs Courage Osayi for their support, care and Love throughout my stay in school. Also, my darling uncles and priests Rev Fr (Dr) Charles Omogiate, Fr John Adesotu for all his help, support ,encouragement when I almost gave up, Fr Aisosa Osawe, and Dr Agatha Odaman for all her love, prayers, support, care, encouragement when I needed it the most.

To my amazing friends Ann, Henrietta, Efe, Victor, Elijah I cannot appreciate you enough for being extremely supportive throughout my stay as a student. Thank you all very much.

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CHAPTER ONE

INTRODUTION

1.1 Background of study

The global population is aging at an unprecedented rate, with a significant increase in the number of older adults requiring medical care and support (National Institute of Health, 2016). This demographic shift places substantial pressure on healthcare systems and family members, who often assume the role of caregivers. In many cases, caregivers provide essential support to older adults hospitalized in tertiary health institutions, contributing to their recovery and overall well-being (Ofovwe & Osasona, 2022). However, the caregiving role is frequently associated with substantial emotional, physical, and financial burdens, which can significantly impact the caregiver's quality of life and mental health (Juda, 2016; Ofovwe & Osasona, 2022).

Older adults often have peculiar needs that necessitate the presence of caregivers. These needs arise from a combination of chronic illnesses, cognitive impairments, and functional limitations (Ploeg *et al.*, 2020). Many older adults suffer from conditions such as dementia, arthritis, diabetes, and heart disease, which require continuous medical attention and management (Jaul & Barron, 2017). Additionally, they may experience significant difficulties with activities of daily living (ADLs) such as bathing, dressing, eating, and mobility, making them heavily reliant on caregivers for assistance (Aïdoud *et al.*, 2023). The emotional and psychological aspects of aging, such as loneliness and depression, further complicate their care needs, often requiring caregivers to provide not only physical but also emotional support (Nat lia Gallo & Mendes Ferracioli, 2018). These complex and multifaceted needs highlight the critical role caregivers play in ensuring the well-being and quality of life of older adults. Caregivers can be broadly categorized into formal and informal caregivers (Li & Song, 2019). Formal caregivers are typically trained professionals, such as nurses, therapists, and home health aides, who provide paid care services in various settings, including hospitals, long-term care facilities, and private homes (Li & Song, 2019). They are often equipped with specialized skills and knowledge to manage complex medical conditions and support activities of daily living (Batista *et al.*, 2014; Li & Song, 2019). Informal caregivers, on the other hand, are usually family members, friends, or community volunteers who provide unpaid care out of a sense of duty or affection (Kong *et al.*, 2021). These caregivers may lack formal training and often juggle caregiving responsibilities with other personal and professional obligations (Law *et al.*, 2020). Both formal and informal caregivers play a crucial role in the healthcare continuum, but they may experience different types and levels of care burden and stress (Li & Song, 2019).

Care burden refers to the multifaceted challenges and responsibilities that caregivers face while providing care (Liu, Heffernan & Tan, 2020). These challenges often include managing the older adult's medical needs, assisting with activities of daily living, and coping with the emotional stress of witnessing a loved one's health decline (Williams *et al.*, 2014). As a result, caregivers may experience high levels of stress, fatigue, and emotional exhaustion. The cumulative effect of these stressors can lead to a diminished quality of life and an increased risk of depression (Williams *et al.*, 2014; Liu, Heffernan & Tan, 2020).

Quality of life (QoL) is a broad concept that encompasses an individual's overall well-being, including physical health, psychological state, level of independence, social relationships, and environmental factors (Owczarek, 2010; Rodrigues *et al.*, 2021). For caregivers, the quality of life can be significantly affected by the demands of caregiving, potentially leading to physical health issues, social isolation, and reduced personal time for leisure and self-care (Hoffman & Zucker, 2016). Understanding the impact of care burden on caregivers' quality of life is crucial for developing interventions that can alleviate these negative effects and support caregivers in their roles.

Depression is a common mental health condition among caregivers, characterized by persistent feelings of sadness, loss of interest or pleasure in activities, and various physical and cognitive symptoms (Lespine *et al.*, 2023). The chronic stress associated with caregiving can contribute to the onset or exacerbation of depressive symptoms. Studies have shown that caregivers of hospitalized older adults are particularly vulnerable to depression due to the intense and often prolonged nature of their caregiving responsibilities (Gutiérrez-Sánchez *et al.*, 2023; Mohamed, Abou-Hashim & Shaltoot, 2023). Depression not only affects the caregivers' mental health but can also impair their ability to provide effective care, creating a detrimental cycle that affects both the caregiver and the care recipient (Monahan *et al.*, 2023).

Given the increasing number of older adults requiring hospitalization and the essential role of caregivers in their care, it is imperative to explore the relationship between care burden, quality of life, and depression among caregivers in tertiary health institutions. Understanding these interconnections can provide valuable insights into the challenges faced by caregivers and inform the development of targeted support strategies and interventions. By addressing the care burden and improving the quality of life for caregivers, it is possible to enhance their mental health and well-being, ultimately benefiting both caregivers and the older adults they support.

1.2 Statement of the Problem

Caregivers of hospitalized older adults often face significant challenges that can impact their well-being (Popli and Panday, 2018). The burden of caregiving responsibilities, including physical, emotional, and financial demands, can be overwhelming. This care burden can detrimentally affect the quality of life of caregivers, leading to heightened stress, physical health problems, and reduced overall well-being (Mohamed, Abou-Hashim and Shaltoot, 2023). Additionally, the constant demands and pressures associated with caregiving may increase the risk of depression among these caregivers (Hoffman and Zucker, 2016).

The hospitalization of older adults exacerbates these challenges, as it often involves prolonged periods of intensive caregiving, frequent hospital visits, and the management of complex medical needs (Rocha-Balcázar *et al.*, 2018). Caregivers may experience increased anxiety and uncertainty about their loved ones' health outcomes, further intensifying their emotional strain (Basile *et al.*, 2021). The disruption of normal routines and additional logistical challenges, such as coordinating with healthcare professionals and managing hospital procedures, can add to the caregivers' burden (Rocha-Balcázar *et al.*, 2018). This heightened level of stress during hospitalization periods can have a significant impact on caregivers' physical and mental health, making it crucial to address their needs during such times.

Despite the critical role caregivers play in the healthcare system and the potential adverse effects on their well-being, there is a paucity of comprehensive research examining the intricate relationships between care burden, quality of life, and depression in this context. Understanding these relationships is essential for developing targeted interventions and support mechanisms to alleviate caregiver burden, enhance their quality of life, and mitigate the risk of depression.

This research aims to investigate the correlation between care burden, quality of life, and depression among caregivers of hospitalized older adults in a tertiary health institution. By exploring these interconnections, the study seeks to provide valuable insights into the challenges faced by caregivers and inform policies and practices that can support their mental health and overall well-being.

1.3 Research Questions

I. What is the overall quality of life (QoL) of caregivers of hospitalized older adults in a tertiary health institution?

II. What is the relationship between care burden and overall quality of life of caregivers of hospitalized older adults?

III. What is the prevalence of depression among caregivers of hospitalized older adults as measured by a standardized depression scale?

IV. What is the relationship between care burden and depression among caregivers of hospitalized older adults?

1.4 Aim of Study

I. To investigate the relationship between care burden and quality of life among caregivers of hospitalized older adults in a tertiary health institution.

II. To investigate the relationship between care burden and depression among caregivers of hospitalized older adults in a tertiary health institution.

1.4.1 Specific Objectives

I. To assess the quality of life of caregivers using a validated quality of life instrument.

II. To determine the correlation between care burden scores and quality of life scores among caregivers.

III. To determine the prevalence and severity of depression among caregivers.

IV. To determine the correlation between care burden scores and depression levels among caregivers.

1.5 Hypotheses

1.5.1 Main Hypotheses

I. There will be no significant relationship between care burden and overall quality of life of caregivers of hospitalized older adults.

II. There will be no significant relationship between care burden and depression among caregivers of hospitalized older adults.

1.6 Significance of study

The findings of this study have the potential to benefit a wide range of stakeholders, including caregivers, patients and healthcare professionals. By addressing the challenges faced by caregivers, this research aims to create a positive ripple effect throughout the healthcare system.

Enhancing Patient Care: The well-being of caregivers directly impacts the quality of care they provide to hospitalized older adults. By ensuring caregivers have a good quality of life, patients are more likely to receive better care, leading to improved patient outcomes.

Developing Effective Interventions: Knowledge of how care burden affects QoL enables the development of effective interventions to alleviate caregiver stress. Interventions can be designed to specifically address the most burdensome aspects of caregiving, improving overall caregiver well-being.

Understanding the Caregiver Experience: Assessing the quality of life (QoL) of caregivers provides a comprehensive understanding of their well-being. Caregivers often face significant physical, emotional, and social challenges, and measuring their QoL can highlight the areas where they need the most support.

Informing Policy and Practice: The insights gained from this analysis can inform policies and practices within healthcare institutions, ensuring that caregiver support is integrated into patient care plans. This holistic approach can lead to better outcomes for both caregivers and patients.

1.7 Scope of study

The study was conducted at the University of Benin Teaching Hospital (UBTH), focusing on caregivers of hospitalized older adults. A total of 80 caregivers who met the inclusion criteria participated in the research. The study aimed to assess caregivers' quality of life using a validated instrument, specifically the WHOQOL-HIV BREF, and to analyse the correlation between care burden and quality of life scores.

1.8 Limitation of Study

I. **Subjectivity of Self-Reported Measures**: The study relied on self-reported measures to assess care burden, quality of life, and depression, which are subject to personal bias, recall bias, and social desirability bias. This may have influenced the accuracy of the data collected.

II. **Cross-Sectional Design**: The cross-sectional nature of the study limits the ability to infer causality between care burden, quality of life, and depression. It only provides a snapshot at one point in time, without tracking changes over time.

III. **Single-Centre Study:** The study was conducted at a single tertiary health institution, which may limit the generalizability of the findings beyond this setting.

1.9 Definition of Terms

I. Older adults: Refers to individuals 60 years of age or older (United Nations, 1991).

II. Care burden refers to the multifaceted challenges and responsibilities that caregivers face while providing care (Liu, Heffernan and Tan, 2020).

III. Quality of Life: The degree to which a person or group is healthy, comfortable, and able to enjoy the activities of daily living (Merriam-Webster Dictionary).

IV. Depression: A mood disorder that is marked by varying degrees of sadness, despair, and loneliness and that is typically accompanied by inactivity, guilt, loss of concentration, social withdrawal, sleep disturbances, and sometimes suicidal tendencies (Merriam-Webster Dictionary).

1.10 List of abbreviations

QoL: Quality of Life

UBTH: University of Benin Teaching Hospital

CHAPTER TWO

LITERATURE REVIEW

Literature Review Outline

1. Introduction

- Background Information
- Overview of caregiving for hospitalized older adults

- Importance of studying caregivers in a tertiary health institution

2. Concept of caregiving

- Types of caregiving
- Duties of a caregiver

3. Caregiver Burden

- Definition and Dimensions
- Physical, emotional, and financial burdens
- Measurement Tools
- Commonly used scales (e.g., Zarit Burden Interview)
- Factors Contributing to Care Burden
    - Patient's health condition
    - Caregiver's personal circumstances
- Impact on Caregivers

4. Quality of Life

- Definition and Components
- Health related quality of life
- Measuring quality of life in health care research
- Domains of Quality of Life
- Determinants of Quality of Life
- Measuring tools to access Quality of Life
- Commonly used QoL instruments (e.g., SF-36, WHOQOL-BRIEF)
- Impact of Caregiving on Quality of Life

5. Depression among Caregivers

- Prevalence
- Measurement Tools for Depression

    - Commonly used scales (e.g., Beck Depression Inventory)

6. Relationship between Care Burden, Quality of Life, and Depression

- Interconnections
- How care burden affects quality of life and depression
- How quality of life moderates the relationship between care burden and depression

7. Context of Tertiary Health Institutions

- Characteristics of Tertiary Health Institutions
- Impact on Caregivers
- Unique challenges and resources available

8. Conclusion

- Synthesis of the Literature
- Overall understanding of the relationship between care burden, quality of life, and depression

9. Empirical Table

2.1 Introduction

As the global population ages, the demand for healthcare services for older adults has surged, necessitating an increased reliance on caregivers (National Institute of Health, 2016). In tertiary health institutions, caregivers play a crucial role in the care and support of hospitalized older adults, often facing substantial challenges in this demanding role (Popli & Panday, 2018; Oluwasanu, Oladepo & Ibitoye, 2021). The burden of caregiving encompasses a variety of dimensions, including physical, emotional, financial, and social strains, which can significantly impact the caregiver's overall quality of life (QoL) and mental health (Handayani, Kusumaningrum & Dwidiyanti, 2024). Among the mental health issues that caregivers may experience, depression stands out as a prevalent concern, affecting their well-being and ability to provide effective care (Pan and Lin, 2022; Lespine *et al.*, 2023).

Understanding the intricate relationship between care burden, quality of life, and depression is essential for developing interventions and support systems aimed at alleviating the adverse effects on caregivers. This literature review seeks to explore the existing research on these interconnected aspects, by synthesizing the evidence, the review aims to provide a comprehensive overview of how caregiving responsibilities influence the quality of life and mental health of caregivers in tertiary health settings, ultimately contributing to better support mechanisms for this population.

2.2 Concept of Caregiving

The etymology of caregiving defined by the Oxford English Dictionary (2024) is as follows:

"caregiving adj. and n. (a) adj. characterized by attention to the needs of others, esp. those unable to look after themselves adequately; professionally involved in the provision of health or social care; (b) n. attention to the needs of a child, elderly person, invalid, etc"

The Merriam Webster dictionary (2024) defines caregiving as "a person who provides direct care, as for children, elderly people, or the chronically ill". Drentea (2007) refers to caregiving as "the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological or developmental needs" (Hermanns and Mastel-Smith, 2015). Furthermore, Drentea (2007) differentiates caregiving from caring for children, which is parenting; however, if activities performed on behalf of another person are outside of normal expectations, such as caring for an adult child with cancer, then it is considered caregiving (Hermanns and Mastel-Smith, 2015). Conversely, Pearlin, Mullan, Semple, and Skaff (1990) defined caregiving as the "behavioural expression of (one's) commitment to the well-being or protection of another person" (Hermanns & Mastel-Smith, 2015). Caregiving is, in and of itself not a role, rather it entails identified actions within the context of a relationship (Hermanns & Mastel-Smith, 2015). The definitions presented speak to the activities involved in aiding another individual who is dependent in some way.

2.2.1 Types of Caregivers

Caregivers can be broadly categorized into formal and informal caregivers, each with distinct roles, responsibilities, and challenges.

Formal Caregivers

Formal caregivers are professional individuals who are trained and compensated for providing care services (Care, 2010; Li & Song, 2019). They typically work within healthcare institutions, home care agencies, nursing homes, or assisted living facilities. Formal caregivers can include nurses, nursing assistants, home health aides, and personal care aides (Care, 2010; Li & Song, 2019). Their duties often encompass:

Medical Care: Administering medications, managing medical equipment, and performing health assessments (National Institute on Aging, 2023).

Providing specialized care such as wound care, physical therapy, and monitoring vital signs.

Personal Care: Assisting with activities of daily living (ADLs) such as bathing, dressing, and grooming (McGilton *et al.*, 2020).

Helping with mobility and transfers to prevent falls and injuries.

Household Tasks: Performing light housekeeping, meal preparation, and ensuring a clean and safe living environment (Stone, 2004)

Assisting with transportation to medical appointments and social activities.

Formal caregivers are integral to the healthcare system, particularly for patients with complex medical needs or those requiring continuous supervision. They are trained to provide high-quality care, adhere to medical protocols, and collaborate with other healthcare professionals to ensure comprehensive care plans (Care, 2010; Li and Song, 2019).

Informal Caregivers

Informal caregivers are typically family members, friends, or neighbors who provide care without formal training or financial compensation (Li and Song, 2019). They often take on caregiving responsibilities out of love, duty, or necessity. Informal caregivers are the cornerstone of long-term care, especially for older adults (Reinhard, Montgomery & Gibson, 2008). Their duties often include:

Personal Care: Helping with ADLs such as bathing, dressing, feeding, and toileting (Shugrue *et al.*, 2019)

Providing companionship and emotional support to alleviate loneliness and depression.

Healthcare Management: Coordinating medical appointments, managing medications, and communicating with healthcare providers (Feinberg *et al.*, 2010).

Monitoring health conditions and recognizing signs of medical issues.

Household Management: Performing IADLs such as cooking, cleaning, shopping, and managing finances (Schulz *et al.*, 2016).

Ensuring a safe and accessible home environment.

Emotional and Social Support: Offering emotional support, comfort, and a sense of stability (Schulz *et al.*, 2016). Encouraging social interaction and participation in community activities.

Informal caregivers often juggle caregiving with other responsibilities such as employment and childcare (Li & Song, 2019). This dual burden can lead to significant physical, emotional, and financial strain. Despite the challenges, informal caregivers play a vital role in providing personalized and compassionate care, often deeply understanding the needs and preferences of their loved ones.

2.2.2 Duties of a Caregiver

Caregiving ranges from assistance with daily activities and providing direct care to the care recipient to navigating complex health care and social services systems. The domains of the caregiving role include: assistance with household tasks, self-care tasks, and mobility; provision of emotional and social support; health and medical care; advocacy and care coordination; and surrogacy (Schulz *et al.*, 2016). Each domain has multiple tasks and activities. Cutting across these domains are ongoing cognitive and interpersonal processes in which caregivers engage including, for example, continual problem solving, decision making, communicating with others (family members and health and human service professionals), and constant vigilance over the care recipient's well-being (Gitlin & Wolff, 2012). How caregivers manage these tasks depends on their values, preferences, knowledge, and skills, as well as the accessibility, affordability, and adequacy of health care, and other resources (Schulz *et al.*, 2016).

Assisting with Household Tasks, Self-Care, Mobility, and Supervision: Nearly all caregivers help older adults in need of care with household tasks such as shopping, laundry, housework, meals, transportation, bills, money management, and home maintenance (Wolff *et al.*, 2016). These responsibilities are often daily ones if the older adult needs help because of health or functional limitations.

Providing Emotional and Social Support: When older adults first need caregiving because of increasing frailty or onset of a debilitating disease, they need emotional and social supports that are different from the usual exchanges among family members (Brody, 1985). One important change is in the balance of reciprocity in the caregiver–care recipient relationship. With increasing needs, the care recipient may be able to give less to the relationship while needing more from it, despite efforts to maintain some reciprocity (Pearlin *et al.*, 1990). In addition, the care recipient's own emotional response to his or her changing circumstances may require a higher level of emotional support from the caregiver. Caregivers may find themselves dealing with unfamiliar depressive symptoms, anxiety, irritability, or anger in the care recipient (Schulz *et al.*, 2016).

Health and Medical Care: Family involvement in health and medical tasks at home is not new, but it has become more common, and is often far more complex than in the past. Older adults' homes have become de facto clinical care settings where caregivers are performing an array of nursing or medical tasks once provided only by licensed or certified professionals in hospitals and nursing homes (Schulz *et al.*, 2016). This is, in part, the result of ongoing efforts to shorten lengths of hospitalizations and reduce nursing home placements, coupled with increasingly complex options for the medical treatment of chronic and acute conditions in non-institutional settings. The "Home Alone" study by the AARP Public Policy Institute and the United Hospital Fund documented the marked impact of this trend on the roles of caregivers. More recent caregiver surveys continue to find similar results (Wolff *et al.*, 2016).

Advocacy and Care Coordination: Family caregivers often serve as advocates and care coordinators. As advocates, their role is to identify and to help care recipients obtain needed community and health care resources. This may involve determining the care recipient's eligibility for specific services and the potential costs. More often than not, the older adult and the caregiver encounter bewildering and disconnected systems of care that involve an array of entities including health care providers, public- and private-sector community-based agencies, employers, and multiple potential payers (e.g., Medicare, Medicaid, and private Medigap plans) (Bookman & Kimbrel, 2011). Caregivers must navigate these multiple, evolving, and increasing complex systems, often without assistance. The role of coordinator often falls to the family caregiver, who must patch together the services that an older adult need and also serve as the primary communication link among all the involved parties. Many people, such as some racial or ethnic groups, LGBT caregivers, and individuals with limited health literacy, face the additional challenge of finding culturally and linguistically tailored services appropriate to their care recipients' needs (Napoles *et al.*, 2010).

Decision Making and Surrogacy: Caregivers are often involved in decision making with and, in some circumstances, for care recipients. However, the nature of caregivers' involvement varies. Types of decision-making roles include directive; participatory; supportive or guiding; advisory; advocacy; and trying to hold back and let the older adult decide (Garvelink *et al.*, 2016). Care recipients with cognitive impairments may require surrogate decision making, as discussed below, although individuals with mild to moderate cognitive impairment often have the ability to express preferences and make choices (Whitlatch, 2008). Frail older adults may be able to express their preferences, but lack executional autonomy or the ability to carry out their decisions without considerable assistance from a caregiver (Gillick, 2013). Caregivers and care recipients may confront many kinds of decisions, including decisions about treatment choices, location of care, and end-of-life care (Gillick, 2013; Garvelink *et al.*, 2016).

Preparedness for Caregiving: Given the multifaceted and complex nature of the caregiving role as described above, preparedness for caregiving is essential. Caregivers need specialized knowledge and skills relevant to their particular needs, as well as broadly defined competencies, such as problem-solving and communication skills (Gitlin & Wolff, 2012). Yet the available evidence indicates that many caregivers receive inadequate preparation for the tasks they are expected to assume. In the 2015 National Alliance for Caregiving and AARP Public Policy Institute survey, half (51 percent) of caregivers of older adults age 50 and older with Alzheimer's disease or dementia reported that they provide medical/nursing tasks without prior preparation. Thirty percent of Alzheimer's disease caregivers had informational needs about managing challenging behaviors and 21 percent wanted more help or information about incontinence. In the Home Alone study, more than 60 percent of the caregivers reported learning how to manage at least some medications on their own (Schulz *et al.*, 2016). Forty-seven percent reported never receiving training from any source. Caregivers described learning by trial and error and feared making a mistake.

In summary, the family caregiving role is broad in scope, and often requires a significant commitment of time. The complexity of the caregiving role has increased in recent years. Whereas families traditionally have provided emotional support and assisted their older members with household and self-care tasks, family caregivers now provide health and medical care at home, navigate complicated and fragmented health care and LTSS, and serve in a surrogacy role that has legal implications. Given the scope and complexity of the family caregiving role, ensuring that caregivers are well prepared is essential. Yet caregiver educational needs are not systematically addressed and training in the performance of caregiving tasks is inconsistent at best.

2.3 Caregiver Burden

Caregiver burden, a subjective state reflecting the individual caregiver's perceptions, is a widely accepted feature of many caregiving studies that measure the effects of caregiver stressors and emotional symptoms (Hildebrand, 2016). Zarit and colleagues defined caregiver burden as “the extent to which caregivers perceive the adverse effect that caregiving has on their emotional, social, financial, and physical functioning” (Zarit, Orr & Zarit, 1985). Caregiving is a highly individualized experience, as such carers may experience burden due to care demands exceeding resources (e.g., financial, physical), lack of social connections, and/or having multiple conflicting responsibilities (Liu, Heffernan & Tan, 2020). Adelman and colleagues found that caregiver burden was greater in caregivers who were female, had less education, resided with the care recipient, had depression, were socially isolated, incurred financial stress, spent more time caregiving, and lacked the choice to be a caregiver (Adelman et al., 2014).

Caregiving role may change over time depending on the nature of the patient's condition, the uncertainty of the disease and the associated adverse effects persist (Kent *et al.*, 2016). Caregiver burden is also associated with poor self-care, sleep deprivation, and adverse health behaviours, such as alcohol and substance use (Adelman *et al.*, 2014; Webber *et al.*, 2020). Notably, high level of caregiver burden is also negatively associated with care-recipient's physical and mental health (Secinti *et al.*, 2023). Alleviating caregiver burden is thus a critical priority given its impact on carers and care-recipients' emotional, social, financial, physical, and spiritual functioning.

2.3.1 Measurement Tools

Caregiver burden was originally operationalized by Professor Steven Zarit of Pennsylvania State University in 1980. His tool, the Zarit Burden Interview (ZBI), is used world-wide (Gratão *et al.*, 2019). Many other caregiver burden tools exist which health care providers could potentially use to measure caregiver burden. Caregiver burden instruments often focus around the different disease processes of the person being cared for (Pop *et al.*, 2022). There are numerous examples of how caregiver burden has been examined by how specific disease entities affect the caregiver. These include: examining caregiver burden that results from caring for an individual with a chronic physical illness (Ghazali *et al.*, 2015), caring for the elderly (Schulz *et al.*, 2020), caring for those with cancer and in need of palliative care (Yuen and Wilson, 2021), caring for people with dementia (Jeste, Mausbach & Lee, 2021), and caring for those with psychiatric illness (Chadda, 2014), Caregiver burden tools have been used in many countries and several caregiver burden tools have also been translated into other languages (Liu, Heffernan & Tan, 2020).

2.3.1.1 Commonly used scales

Caregivers' feelings of stress and burden can be assessed with standardized questionnaires and interviews. Although stress and burden are not diagnostic labels in and of themselves, they are key components of the profile of psychological distress experienced by many caregivers (American Psychological Association, 2020).

These tools include:

Zarit Burden Interview: The Zarit Burden Interview, a popular caregiver self-report measure used by many aging agencies, originated as a 29-item questionnaire (Gratão *et al.*, 2019). The 29-item instrument is included in Zarit et al., 1980. The revised version contains 22 items. Each item on the interview is a statement which the caregiver is asked to endorse using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly Always). For shorter administration, shorter versions, ranging from 1 to 18 items, have been developed. A study by Yu, Yap and Liew (2019) found that the 6-item version was the most optimal short version as it provided similar diagnostic utility to the original 22-item version with the fewest items.

The Caregiver Strain Index (CSI): The Caregiver Strain Index (CSI) is a screening tool used to assess the level of strain experienced by individuals providing care to others, particularly elderly or chronically ill family members. Developed in 1983 by Robinson, the CSI is a 13-item questionnaire that covers various aspects of caregiving, including:

1. Employment: The impact of caregiving on work responsibilities and performance.
2. Financial: The financial burden and costs associated with caregiving.

3. Physical: Physical strain and health issues resulting from caregiving tasks.
4. Social: The effect of caregiving on social life and personal relationships.
5. Time: The amount of time required for caregiving and its impact on the caregiver's schedule.

Respondents answer each item with "yes" or "no" based on their experiences. Each "yes" response is scored as 1 point, and the total score ranges from 0 to 13. Higher scores indicate a higher level of caregiver strain (Robinson, 1983). The CSI is widely used in clinical and research settings to identify caregivers who may need additional support and resources.

Brief Measures of Secondary Role and Intrapsychic Strains: (Pearlin *et al.*, 1990) in a widely cited publication, presented a stress and coping model of family caregiving which includes both primary stressors (e.g. actual caregiving tasks) and secondary strains. Secondary strains are “spill over” effects--e.g., ways in which being a caregiver can produce stress proliferation in other areas of life. Understanding these secondary strains can be important for clinicians and researchers. Pearlin and colleagues distinguish between two kinds of primary stressors: Secondary Role Strains and Secondary Intrapsychic Strains. These scales have been used extensively in caregiving research, providing substantial evidence for their construct validity (Hilgeman *et al.*, 2009; Judge, Menne & Whitlatch, 2010; Figueiredo, 2017).

Caregiver Reaction Scale: The Caregiver Reaction Scale (CRS; Qualls & Kenny, 2008) is a new scale that was adapted for use in a clinical setting from the research instrument used to develop a model of caregiver burden and competence developed by Pearlin, Mullan, Semple and Skaff (1990). The measure includes subscales that assess feelings of role captivity, overload, relational deprivation, competence, personal gain, coping, family beliefs and conflict, job conflicts and financial disruption. Two advantages of this scale for clinical settings include the simplicity of its response format (1-4 Likert-type scale ranging from not at all to completely) and its inclusion of a broad range of possible caregiver responses. In addition to assessing multiple social and emotional impacts of caregiving, the scale taps feelings of competence and self-efficacy as well as family distress and conflict.

Caregiver Self-Assessment Questionnaire: This 18-item, caregiver self-report measure was devised by the American Medical Association as a means of helping physicians assess the stress-levels of family caregivers accompanying chronically ill older adult patients to their medical visits. Caregivers are asked to respond either “Yes” or “No” to a series of statements, such as “During the past week or so, I have felt completely overwhelmed” and “During the past week or so, I have felt strained between work and family responsibilities” (American Psychological Association, 2020).

Perceived benefits of caregiving: While caregiving is often highly stressful, many caregivers report that caring for a loved one has positive aspects. Caregivers may report that caregiving gives their lives meaning, produces pride in their successes as caregivers, and is gratifying in allowing them to give Caregiving benefits back to someone else (American Psychological Association, 2020). (Folkman and Moskowitz, 2000), have noted that benefit-finding can be an important way of coping with stress, contributing to “meaning-based coping”, and not just adopting “rose-coloured glasses.” The Perceived Benefits of Caregiving Scale includes 11 items, and was developed by Sr *et al.*, 2000. Response options that have been used include a Yes/No format, and a 5-point Agree/Disagree scale. Alpha coefficients of over .7 have been reported for both formats of the scale. Items ask caregivers whether their experiences as caregivers have, for example, “given more meaning to your life” and “made you feel important.”

Picot Caregiver Rewards Scale: The Picot Caregiver Rewards Scale (PCRS) is a 25-item, uni-dimensional scale measuring the positive consequences of caregiving. Respondents rate the degree to which items describe positive consequences of their caregiving on a 5-point Likert scale, ranging from "Not At All" to "A Great Deal” (Hsueh *et al.*, 2014; American Psychological Association, 2020).

The Brief Assessment Scale for Caregivers (BASC) of the Medically Ill: The Brief Assessment Scale for Caregivers (BASC) of the Medically Ill is a tool designed to measure the burden and stress experienced by caregivers of medically ill patients. It provides a concise way to evaluate the psychological and emotional impact of caregiving. Key features of the BASC include:

1. Structure: The BASC typically consists of a series of questions that assess different dimensions of caregiver burden, such as emotional stress, physical strain, and social impact.
2. Scoring: Caregivers respond to each item using a Likert scale, which might range from "strongly agree" to "strongly disagree." The responses are then totalled to provide an overall burden score.
3. Domains: The scale covers multiple aspects of caregiving, including:
   - Emotional well-being: Feelings of sadness, anxiety, and depression.
   - Physical health: Fatigue, sleep disturbances, and physical health problems.
   - Social life: Impact on social activities and relationships.
   - Financial strain: Economic impact of caregiving duties.
4. Purpose: The BASC is used to identify caregivers at risk of high stress and burden, guiding interventions and support services to alleviate their strain and improve their quality of life (Glajchen *et al.*, 2005).

The BASC is a practical tool in both clinical and research settings, helping to tailor support for caregivers of medically ill individuals.

2.3.2 Factors Contributing to Care Burden

Various patient-related and caregiver-related factors that affect caregiver burdens have been found to contribute to care burden (Rigby, Gubitz and Phillips, 2009). The patient-related factors include patients' daily dependence, anxiety, depression and caregiver-related factors were presented as female, depression, anxiety, lack of a sense of coherence, daughters-in-law, and the time and effort spent in caring responsibilities (Rigby, Gubitz & Phillips, 2009; Zhu & Jiang, 2018). Furthermore, the socioeconomic and care cultural factors are also significant factors influencing the high caregiver burden (Choi-Kwon *et al.*, 2005; Han *et al.*, 2017). In addition, unemployment status was found to be a factor that increases the burden of care (Berdina, Rodionov and Sergeev IYu, 1982). On the other hand, in the socio-cultural aspect, the patriarchal care culture has affected the burden of women and daughters-in-law as primary caregivers (Bhattacharjee *et al.*, 2012; Han *et al.*, 2017). However, the significance of factors may be altered by changes in public health services and sociodemographic backgrounds.

2.3.3 Impact on Caregivers

During the period of caregiving, the caregivers experience stress and burden resulting from the rigorous activity of caregiving, which can have a negative impact on their physical, psychological, and social lives, thereby decreasing their quality of life (QoL) (Caputo, Pavalko and Hardy, 2016). Thus, caregivers are at risk of developing psychiatric disorders (Mosquera *et al.*, 2016). Caregiver burden has been proven to account for poor physical and emotional health (Mosquera *et al.*, 2016). Studies on caregivers suggest that caregiving is associated with psychological complaints such as depression and poor physical and psychological QOL (Prince *et al.*, 2012; Vitaliano *et al.*, 2014; Hansen & Slagsvold, 2015). A recent study concluded that caregiving was associated with distress, anxiety, stress, and depression (Gupta *et al.*, 2015).

Caregiving also has positive outcomes such as appreciation from patients, improved family cohesion, developing resilience, and gaining a sense of self-worth and accomplishment (Bauer *et al.*, 2013). These positive aspects of caregiving have been found to be associated with lower levels of caregiver burden for life (Pinquart and Sörensen, 2003a).

2.4 Quality of Life

The term QoL was first used in the form of a keyword in the medical literature databases in 1975 (Post, 2014). Initially the socio-psychological aspect of QoL and its determinants were identified. During the last decade of the 20th century, researchers started focussing on the assessment of subjective aspects of QoL of individuals (Sosnowski *et al.*, 2017). Few years later, the World Health Organization affirmed that there is a need for evaluate and enhance people's QoL (World Health Organisation, 2012). Since then it has been widely used for the evaluation of individual's feeling about his/her well - being focusing on various favourable and adverse conditions of life (Kaur & Kaur, 2023). Quality of life has different meanings to different people and as per area of application. The term health-related QoL (HRQoL) is more commonly used in health care research to remove any ambiguity in the definition of QoL.

In 1980s, term 'HRQoL' was first introduced in published medical literature. It includes all those aspects related to QoL which relates to health. However, in literature both terms i.e., QoL/ HRQoL are often used interchangeably, but these two are distinct concepts (Kaur & Kaur, 2023). QoL is reflected as overall satisfaction of person with his /her life, which may be evaluated as single concept or can be split into various domains (Kaur and Kaur, 2023). Whereas HRQoL as a specific concept includes all aspects of health and is evaluated domain-wise. So, it can be considered "an individual's subjective assessment of his QoL in relation to physical, psychological and social domains of health" (Hand, 2016). However, WHO has used and defined term QoL to be used in field of health care.

2.4.1 Definition and Components

WHO has defined QoL as "an individual's perception of their position in life in context of culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is broad-ranging concept affected in complex way by person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment" (World Health Organisation, 2012).

Rice (1984) defined QoL "as a degree to which the experience of an individual's life satisfies that individual's wants and needs (both physical and psychological). Much of the debate about how QoL should be defined has centred around subjective versus objective approaches. Rice further defines objective QoL (OQoL) as degree to which specified standards of living are met by objectively verifiable conditions, activities, and activity consequences of an individual's life and subjective QoL (SQoL) as set of affective beliefs directed toward one's life". HRQoL is primarily concerned with those factors which fall within spheres of influence of health care providers and health care systems" (Németh, 2006).

2.4.2 Health Related Quality of Life

Since health is considered multidimensional concept, the HRQoL also incorporates all domains of physical, mental, emotional, and social functioning (Pietersma, de Vries & van den Akker-van Marle, 2014). HRQoL is dependent on one's health status and it focuses on the consequences of one's health status on QoL. Centre for disease control has defined HRQoL as "an individual's/group's perceived physical and mental health over time" (Centers for Disease Control and Prevention [CDC], 2022).

2.4.3 Measuring Quality of Life in Health Research

1. It may aid in providing high-quality and patient-centred care as it helps to assess patients' own perspective of their life quality.
2. QoL assessment can be beneficial in improving self-management skills by providing feedback to patients.
3. Measuring QoL can improve healthcare workers' awareness of patient concerns and patient-provider communication.
4. It can help to ascertain the burden of various preventable diseases, trauma and disabilities
5. It may provide novel inputs about the relation of HRQoL with various risk factors.
6. It will aid in keeping track of the progress of a nation in achieving its health objectives (Hand, 2016; Centers for Disease Control and Prevention [CDC], 2022).

2.4.4 Domains of QoL

WHO has divided QoL into four broad domains and 24 facets in total under these domains as discussed below:

Physical health: This domain includes facets associated with physical health and includes energy, pain, discomfort, sleep, rest, etc.

Psychological: This domain incorporates psychological aspects of health and QoL. Its facets are based on bodily image, negative and positive feelings, self-esteem, thinking, memory and concentration.

Independence level: It takes into consideration how independent a person is in his/her life. Facets of this domain consider mobility, ability to perform daily living activities, capacity to work and dependence on medicinal assistance.

Social relations: It includes the facets related to social as well as personal relationships. Environment: This domain takes into account the environmental component of QoL. It includes the availability of financial resources, access to health care, the environment of home, opportunities to learn new skills and recreational opportunities etc.

Spirituality/religion/personal beliefs: This domain has a single facet assessing religion/ spirituality/ personal beliefs (Ilić *et al.*, 2019).

2.4.5 Determinants of Quality of life

QoL is determined by a number of factors, which include physical health conditions, mental well-being, social conditions etc. Kivits et al performed secondary analysis of epidemiological data of HRQoL from 2 national surveys and revealed that the important determinants of QoL are main social indicators like living as couple, educational status, occupation and income per household, independent of age and gender (Kivits, Erpelding and Guillemin, 2013). Singh et al conducted a study to assess HRQoL among representative populations of South Asia (Singh *et al.*, 2017). This study revealed that HRQoL was significantly associated with age, gender, education, income, and employment status. In a study of Jordanian population by Matalqah et al it has been revealed that many physical and emotional factors like age, presence of chronic disease, and stress due to lower socioeconomic status were affecting HRQoL (Matalqah *et al.*, 2018). QoL also varies as per disease status as review conducted by Basavaraj et al has revealed that physical symptoms, drug therapy, psychological state of health, social support, using coping-strategies, level of spiritual wellness, and presence of psychiatric illness are important predictors of QOL in People Living with HIV/AIDS (PLHIV)(Basavaraj, Navya & Rashmi, 2010) . Similarly a study by Cho et al stated that HRQoL in patients with chronic hepatitis C is linked with age, gender, educational status, living type, employment, monthly income and presence co-morbidity (Cho & Park, 2017).

2.4.6 Measurement Tools to Access Quality of Life

There are various ways to assess HRQoL. This can be measured by using subjective measures as well as objective assessment tools. Selective tools may be required for the assessment of the QoL in different populations or different disease states (Kaur & Kaur, 2023). . HRQoL measures can establish the range of problems that affect patients, these can help to identify any ongoing problems that might get ignored otherwise. These can also be a predictor of treatment outcomes (Kaur & Kaur, 2023). HRQoL measures can help to calculate quality adjusted life years by combining them with measures of time in a particular health state. These measures of HRQoL can be classified as generic, disease-based tools and population-specific tools for measuring HRQoL (Pequeno *et al.*, 2020).

2.4.6.1 Commonly used QoL instruments

GENERIC INSTRUMENTS

Assessment of QoL-4D (AQoL-4D): Independent living, relationships, mental health and senses (Pequeno *et al.*, 2020).

Control, autonomy, self-realization and pleasure-16 (CASP-16): Control, autonomy, self-realization and pleasure (Hyde *et al.*, 2003).

EQ-5D and EQ-VAS: Mobility, self-care, usual activities, pain and discomfort, anxiety and depression. EQ VAS incorporates a Visual Analogue Scale. It captures the subjects' overall assessment about their health on a scale ranging from 0 (worst state of health imaginable) to 100 (best state of health imaginable) (Devlin & Brooks, 2017; Kim *et al.*, 2018).

CDC HRQoL-4 healthy days and CDC HRQoL-14 healthy days measures: CDC HRQoL-4 healthy days includes 4 survey-based questions to assess HRQOL. CDC HRQoL-14 Healthy

Days measures include four questions of CDC HRQoL-4 Healthy Days and five activity limitation questions, five additional healthy days HRQoL questions that are measuring recent symptoms of pain, depression, anxiety, sleeplessness, and vitality (Kaur and Kaur, 2023).

PROMIS patient-reported outcomes measurement information systemglobal health scale: Depression, anxiety, pain interference, physical function, fatigue, sleep disturbance, ability to participate in social roles and activities (Katzan and Lapin, 2018).

SF-36 medical outcomes study short form 36: Vitality, bodily pain, general health perceptions, physical functioning, mental health physical role functioning, emotional role functioning, social role functioning (Ware and Sherbourne, 1992).

World health organization QoL assessment (WHOQOL-100)12 and world health organization QoL assessment-abbreviated version (WHOQOL-BREF): Physical health, psychological, social relationships, and environment. world health organization QoL assessment-abbreviated version (WHOQOL-BREF) is a short version of WHO-QOL 100 (Ilić *et al.*, 2019).

DISEASE-SPECIFIC QUESTIONNAIRES

Asthma-specific HRQoL (AQLQ-J): It assesses the QoL of asthma patients across four domains of activity limitation, symptoms, emotional function and environmental stimuli (Ferreira *et al.*, 2005).

The European organization for research and treatment of cancer QLQ-C30 (EORTC QLQ–C30): Assesses QoL of patients with cancer by incorporating 9 multi-item scales including five functional scales (physical, role, cognitive, emotional, and social), three symptom scales (fatigue, pain, and nausea and vomiting), a global health and quality-of-life scale, several single-item symptom measures (Aaronson *et al.*, 1993).

Caregiver QoL index-cancer (CQoLC): A 5-point rating scale measuring QoL of family caregivers of the patients suffering from cancer across four domains of physical functioning, emotional functioning, family functioning and social functioning (Weitzner *et al.*, 1999).

Breast cancer chemotherapy questionnaire (BCQ): Assessing QoL of women undergoing adjuvant chemotherapy. The BCQ is comprised of 30 questions focusing on various aspects including loss of attractiveness, fatigue, physical symptoms, inconvenience, emotional distress, feelings of hope and support from other (Levine *et al.*, 1988).

POPULATION SPECIFIC QUESTIONNAIRES

Paediatric QoL inventory (Ped) oral health scale: Measures QoL in children with oral health problems and oral health QoL in children with other disorders in areas of physical functioning, role functioning, social functioning, emotional functioning (Atala-Acevedo *et al.*, 2020).

Child health and illness profile adolescent addition: Measures the QoL of adolescents in 6 domains with 20 subdomains. The domains are discomfort, disorders, achievement (of age-appropriate social roles), satisfaction with health, risks and resilience (Altshuler and Poertner, 2002).

WHOQOL-OLD: Measures the QoL in elderly in domains of sensory functioning, past, present and future activities, autonomy, social participation, death and dying and intimacy (Liu *et al.*, 2013).

Older PEOPLE'S QOL questionnaire (OPQOL): Measures QoL of elderly across dimensions of life overall, their health, independence, control over life and freedom, social relationships and participation, financial circumstances, home and neighbourhood, psychological and emotional well-being, culture and religion (Bilotta *et al.*, 2011).

2.4.7 Impact of Caregiving on Quality of Life

Caregivers often shoulder significant responsibilities such as daily care, medication management, pain control, and emotional support (Romito *et al.*, 2013; Lee *et al.*, 2018). These demanding tasks often result in physical exhaustion and psychological burden, leading to considerable psychological distress (Majestic and Eddington, 2019; Celik *et al.*, 2022). This distress, primarily manifested as anxiety and depression, is exacerbated by the unpredictable progression of the disease and the associated pain of the patient, yielding significant repercussions on the caregivers' quality of life (QoL) (Li *et al.*, 2018). Past research has indeed confirmed the prevalence of such distress among caregivers (Sklenarova *et al.*, 2015).

This psychological distress can considerably impinge on caregivers' QoL, affecting daily functioning and potentially instigating adverse impacts on family relationships, social interactions, and work productivity (Li *et al.*, 2018). This can precipitate a deterioration in overall QoL and induce negative psychological and physiological responses (Cui *et al.*, 2024). Additionally, psychological distress may mediate the relationship between the caregiving burden and QoL, depleting the caregivers' psychological resources and impacting their ability to cope, thereby intensifying the negative impact of the burden and diminishing their QoL (Cui *et al.*, 2024). Despite this, most previous research have primarily focused on the direct relationships between caregiving burden, psychological distress, and QoL, providing limited insights into the mechanisms through which caregiving burden influences QoL (Sklenarova *et al.*, 2015; Li *et al.*, 2018; Cui *et al.*, 2024).To rectify this, a comprehensive exploration of the mediating role of psychological distress between caregiving burden and QoL is necessary. Such an investigation could furnish practical guidance for targeted interventions aimed at alleviating psychological distress, enhancing caregivers' coping abilities, and ultimately mitigating the negative influence of caregiving burden on their QoL. Moreover, enhancing caregivers' psychological well-being could improve the efficacy and quality of caregiving services, ensuring more attentive and comprehensive support for patients (Northouse *et al.*, 2012).

2.5 Depression among Caregivers

Informal caregivers are persons, who provide day-to-day instrumental, financial, social and emotional support to a family member or a closely related person in need but not as occupation (Kleinman, 2010; Graessel *et al.*, 2014). Thus, caregiving is a burdensome, unpaid work and somewhat challenging task for the caregivers. It has been found to have a long-term effect on caregivers' physical or emotional health along with financial stress, anxiety and social isolation (Moss *et al.*, 2019). Studies in United States of America, also suggest, informal caregiving to be an important factor contributing towards developing depressive symptoms as well as poor physical health which may lead to suffering from impaired immune function and increased risk of mortality (Pinquart and Sörensen, 2003b). Relationship quality between the caregiver and care recipient is an immediate determinant of caregiving role to be burdensome or not. If the role of caregiving gets overloaded and conflict arises, that influences the caregiver's burden indirectly (Chakraborty, Jana and Vibhute, 2023). Gender differentials in burden of caregiving suggests that, the role of women in household activities and economic participation conflict with the role of caregiving and thus women caregivers used to have poorer relationship quality with care recipient which gradually works as a factor for developing poor physical and mental health (Gupta, Rowe and Pillai, 2009).Caregiver's general health also gets heavily affected by the type of disease afflicting the care recipient. Providing care to dementia or Alzheimer's patient shows significantly higher prevalence of depressive symptoms, especially among the female caregivers due to severe stress, inability to communicate and difficulty in coping with the behavioural problems of the care recipient (Cuijpers, 2005; Rote *et al.*, 2022).

Meta-analysis by Pinquart & Sorensen (2003) suggested that, the caregivers have lower levels of subjective well-being and poorer physical health than non-caregivers in United States and they were termed as "hidden patients". Poor physical health among caregivers is highly associated with poor mental health, lack of sleep or poor sleeping pattern, poor diet, anxiety and stress for increased medical expenditure for the care recipient etc (Pinquart and Sörensen, 2007; Abdollahpour *et al.*, 2014).

On the contrary, in some cases the effect of caregiving has been identified to have positive impact on mental health or does not add on stress when there exists a closely knitted emotional bond between caregiver and care recipient (Brown, 2007; Roth *et al.*, 2013), but it varies widely with type of care needed and health condition of the recipient. Even caregivers under specific situations and destressed conditions reported to have 18% reduced risk of all-cause mortality in comparison to non-caregivers (Chan, Vickers and Barnard, 2020).Emotional investment and responsibility towards a care recipient with disability, has been found to affect the mental health condition of the caregivers the most (Ory *et al.*, 1999). But even if the caregivers value the role of caregiving and not only be obliged to do it, they require external support to lead their own quality life (Chan, Vickers and Barnard, 2020).

2.5.1 Prevalence

The 2021 Behavioural Risk Factor Surveillance System (BRFSS) conducted by the CDC indicated that 20.65 % of respondents were primary caretakers for individuals with long-term disabilities (Centers for Disease Control and Prevention (CDC), 2021). This number is expected to increase in the coming decades, as an aging population creates a subsequent increase in the number of individuals living with chronic conditions (Liu, Heffernan and Tan, 2020). A major concern among these caregivers is their long-term mental health.

Insight into demographic factors contributing to higher rates of caregiver strain–often defined by a certain threshold on various depression index scales (Arai and Zarit, 2014; Liu, Heffernan and Tan, 2020)–has been the focus of many previous research efforts. However, these frequently sample homogenous disease categories (e.g., caregivers of individuals with Alzheimer's dementia), which impacts the ability for the findings to be generalized (Adelman *et al.*, 2014). Studies which are more comprehensive often suffer small sample sizes. Despite these shortfalls, several meta-analyses and secondary data analyses have made great strides in illuminating factors which are correlated with a higher frequency of caregiver distress. Past research largely validates the association that female caregivers, caregivers with lower educational attainment, or who lived with the care recipient, were at greater risk of experiencing depressive symptoms or distress (Adelman *et al.*, 2014; Monahan *et al.*, 2023).

2.5.2 Measurement Tools for Depression

Careful assessment is an important part of evidence-based practice. Initial assessments of depressive symptoms can help determine possible treatment options, and periodic assessment throughout care can guide treatment and gauge progress (American Psychological Association, 2023).

Commonly used depression scales include:

Beck Depression Inventory: The Beck Depression Inventory (BDI) is widely used to screen for depression and to measure behavioural manifestations and severity of depression. The BDI can be used for ages 13 to 80. The inventory contains 21 self-report items which individuals complete using multiple choice response formats. The BDI takes approximately 10 minutes to complete. Validity and reliability of the BDI has been tested across populations, worldwide (BECK *et al.*, 1961; American Psychological Association, 2023).

Centre for Epidemiologic Studies Depression Scale: The Centre for Epidemiologic Studies Depression Scale (CES-D) was designed for use in the general population and is now used as a screener for depression in primary care settings. It includes 20 self-report items, scored on a 4-point scale, which measure major dimensions of depression experienced in the past week. The CES-D can be used for children as young as 6 and through older adulthood. It has been tested across gender and cultural populations and maintains consistent validity and reliability. The scale takes about 20 minutes to administer, including scoring (Saracino *et al.*, 2020).

EQ-5D: The EQ-5D is a standardized, non-disease specific instrument for describing and evaluating health-related quality of life. The instrument measures quality of life in five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It was introduced as a health-related quality of life measure by a group of European researchers, the EuroQol Group. Respondents can complete the questionnaire in under five minutes. There is a version for adults (age 16 and older) and the EQ-5D-Y for children/adolescents (8 to 15 years). The EQ-5D is available in a wide range of languages and is used worldwide (Devlin and Brooks, 2017).

Hamilton Depression Rating Scale: The Hamilton Rating Scale for Depression, abbreviated HDRS, HRSD or HAM-D, measures depression in individuals before, during and after treatment. The scale is administered by a health care professional and contains 21 items, but is scored based on the first 17 items, which are measured either on 5-point or 3-point scales. It takes 15 to 20 minutes to complete and score (Hamilton, 1960; Trajković *et al.*, 2011).

Montgomery-Åsberg Depression Rating Scale: The 10-item Montgomery-Åsberg Depression Rating Scale (MADRS) measures severity of depression in individuals 18 years and older. Each item is rated on a 7-point scale. The scale is an adaptation of the Hamilton Depression Rating

Scale and has a greater sensitivity to change over time. The scale can be completed in 20 to 30 minutes (Montgomery and Åsberg, 1979).

Children's Depression Inventory: The Children's Depression Inventory (CDI) is a modification of the Beck Depression Inventory for adults. The CDI is now on its second edition. It assesses depression severity in children and adolescents 7 to 17 years old. Two scales measure emotional problems and functional problems. Three separate ratter forms are available: one for parents (17 items), one for teachers (12 items) and a self-report (28 items). Administration time is between five and 15 minutes (Sun and Wang, 2015).

Quick Inventory of Depressive Symptomatology-Self-Report (QIDS-SR): The QIDS-SR measures the severity of depressive symptoms in adults 18 and older. There are 16 measures, selected from the Inventory of Depressive Symptomology (IDS, 2000). These symptoms correspond to the diagnostic criteria from the DSM-IV. Respondents use a 4-point Likert-type scale to assess their behaviours and mood over the course of the past week. It takes five to seven minutes to complete the report (Rush *et al.*, 2003).

2.6 Relationship between Care Burden, Quality of Life, and Depression

The interrelationship between care burden, quality of life, and depression among caregivers of hospitalized older adults has been widely documented in the literature. Care burden, often described as the physical, emotional, and financial strain experienced by caregivers, is a significant predictor of both quality of life and mental health outcomes (Liu, Heffernan and Tan, 2020).

Studies indicate that increased care burden is directly correlated with decreased quality of life. This is attributed to the substantial time and energy caregivers must devote to their duties, often at the expense of their own physical and emotional well-being. Research by Vitaliano et al.

(2003) highlights that caregivers frequently experience higher levels of stress, which can lead to physical health problems and a reduced ability to engage in social and recreational activities, thereby diminishing their overall quality of life (Vitaliano, Zhang and Scanlan, 2003).

Furthermore, the link between care burden and depression is well-established. Schulz and Sherwood (2008) found that caregivers of older adults are at a higher risk for depression compared to non-caregivers. The constant demands of caregiving, coupled with the emotional toll of witnessing a loved one's decline, contribute to significant psychological distress. This distress is exacerbated when caregivers lack adequate support systems or resources, leading to feelings of isolation and hopelessness (Schulz and Sherwood, 2008).

Quality of life and depression are closely interconnected in this context. Caregivers with lower quality of life are more prone to experiencing depressive symptoms, which in turn further reduce their quality of life, creating a vicious cycle. Pinquart and Sörensen (2003) emphasize that interventions aimed at reducing care burden, such as respite care and support groups, can improve both quality of life and mental health outcomes for caregivers (Pinquart and Sörensen, 2003b).

Overall, the literature underscores the need for comprehensive support systems for caregivers to alleviate care burden and improve their quality of life and mental health. By addressing these interconnected issues, healthcare providers can better support the well-being of both caregivers and the older adults they care for.

2.7 Context of Tertiary Health Institutions

Tertiary health institutions, often characterized by their provision of specialized medical care and advanced treatment options, play a critical role in the healthcare system (Singhal and Khadilkar, 2014). These institutions, which include teaching hospitals and large medical centres, are typically equipped with cutting-edge technology and staffed by highly trained professionals who offer comprehensive services for complex health conditions.

In the context of caregiving for hospitalized older adults, tertiary health institutions present unique challenges and opportunities (Akande *et al.*, 2022). The complexity of care required by older adults often necessitates prolonged hospital stays and intensive interventions, which can place significant burdens on family caregivers. According to research by McPherson et al. (2008), the high demands of caregiving in such settings can exacerbate caregiver stress and negatively impact their quality of life. The need for constant vigilance and frequent interactions with healthcare providers can lead to emotional and physical exhaustion among caregivers (McPherson, Wilson and Murray, 2007).

Furthermore, the environment of tertiary health institutions can influence caregiver experiences. Studies by Given et al. (2001) indicate that while these institutions offer access to high-quality medical care, they may also be associated with increased caregiver anxiety due to the perceived severity of the patient's condition and the complex healthcare processes involved (Given *et al.*, 1992). The advanced nature of care provided in tertiary settings often requires caregivers to navigate intricate healthcare systems, which can be daunting without adequate support and information.

Despite these challenges, tertiary health institutions also offer valuable resources that can mitigate caregiver burden. Access to multidisciplinary teams, including social workers, psychologists, and specialized nursing staff, can provide crucial support to caregivers. As noted by Duhamel (2005), the integration of family-centred care practices within tertiary health settings can enhance caregiver well-being by involving them in care planning and decision-making processes, thereby reducing feelings of isolation and helplessness (Doane and Varcoe, 2005).

Overall, the literature underscores the need for targeted interventions and support systems within tertiary health institutions to address the unique needs of caregivers of hospitalized older adults. By leveraging the resources and expertise available in these settings, healthcare providers can improve both patient and caregiver outcomes.

2.8 Conclusion

The literature review has provided a comprehensive examination of the relationship between care burden, quality of life, and depression among caregivers of hospitalized older adults within the context of tertiary health institutions. Through empirical studies and methodological considerations, several key insights have emerged.

Firstly, the multifaceted nature of care burden—encompassing physical, emotional, and financial dimensions—has been clearly articulated. Measurement tools such as the Zarit Burden Interview have been highlighted as effective means to quantify this burden. The literature consistently shows that higher levels of care burden significantly impact caregivers' quality of life, reducing their physical, psychological, social, and environmental well-being.

Quality of life, an essential component of caregiver health, is influenced by a range of factors including personal, social, and environmental aspects. Commonly used instruments like the SF-36 and WHOQOL-BREF have been pivotal in assessing these dimensions. The review underscores the dual impact of caregiving on quality of life, noting both the challenges and the potential for positive experiences.

Depression among caregivers is prevalent, with numerous studies documenting its association with care burden. Risk factors such as a personal history of depression, lack of social support, and the severity of the patient’s condition have been identified. Measurement tools like the Beck Depression Inventory are crucial for assessing depressive symptoms and understanding their consequences on caregivers' health and caregiving abilities.

The interconnections between care burden, quality of life, and depression are evident. Increased care burden negatively affects quality of life, which in turn exacerbates depressive symptoms. Conversely, a better quality of life can mitigate the negative impacts of care burden, highlighting the importance of supportive interventions.

The context of tertiary health institutions introduces unique challenges and opportunities for caregivers. These institutions, while providing advanced medical care, also impose complex demands on caregivers. However, the resources and multidisciplinary support available in these settings can alleviate some of the caregiver burdens.

In summary, this literature review has elucidated the intricate relationships between care burden, quality of life, and depression among caregivers of hospitalized older adults in tertiary health institutions. The findings underscore the necessity for comprehensive support systems and targeted interventions to enhance caregiver well-being.

2.9 Empirical Table

Authors/ Year/Title	**Aim of study**	**Research Design/Sample Used**	**Conclusion**	**Limitations**
Cui, P., Yang, M., Hu, H. *et al.* (2024) The impact of caregiver burden on quality of life in family caregivers of patients with advanced cancer: a moderated mediation analysis of the role of psychological distress and family resilience.	This study aims to probe the mediating effect of psychological distress on the relationship between caregiver burden and QoL, as well as the moderating effect of family resilience.	A multi-centre, cross-sectional study was conducted in the oncology wards of five tertiary hospitals in Henan Province, China, between June 2020 and March 2021. 290 caregivers were recruited using convenience and purposive sampling techniques	The study corroborates psychological distress's mediation between caregiver burden and QoL and family resilience's moderation between psychological distress and QoL. It underscores the need for minimizing psychological distress and bolstering family resilience among caregivers of advanced cancer patients.	Firstly, being a cross-sectional study, it cannot establish causal relationships. Secondly, it is possible that the caregivers who participated in the study were more proactive, potentially leading to an overestimation of family resilience's role and introducing response bias. Future longitudinal studies might explore the moderating effects of family resilience on caregiver burden and QoL at different stages
Cheng WL, Chang CC, Griffiths MD. *et al*. (2022) Quality of life and care burden among family caregivers of people with severe mental illness: mediating effects of self-esteem and psychological distress	This study aims to investigate the impact of caregiver burden on the quality of life of family caregivers of patients with severe mental illness.	A multi-centre cross-sectional survey was conducted. Family caregivers of people with schizophrenia, major depressive disorder, and bipolar disorder were recruited using convenience sampling. In total, 459 dyads of caregivers and PWMI were recruited for this study.	The findings indicated that caregivers' psychological health and care burden influenced their QoL. Interventions that target family caregivers' self-esteem and psychological distress may attenuate the effect from care burden, and further improve their QoL.	The present study provided no evidence of causal relationships because it utilized a cross-sectional study design. Second, all the variables used in the present study were assessed using self-reports. Therefore, the findings are likely to be biased because of factors such as social desirability and common method variance. Future studies using different methods to collect data should be conducted to

				corroborate the present study's findings.
Chakraborty R, Jana A, Vibhute VM (2023). Caregiving: a risk factor of poor health and depression among informal caregivers in India- A comparative analysis	To identify how health condition varies within caregivers and a comparative analysis of how in similar socio-economic background health condition varies between caregivers and non-caregivers.	A comparative analysis of how in similar socio-economic background health condition varies between caregivers and non-caregivers. 72,250 individuals were interviewed.	Caregivers are more susceptible to depression and poor self-rated health compared to non-caregivers irrespective of their socio-economic characteristics, only the magnitude of vulnerability varies.	Whether caregiving role is responsible for onsetting the depressive symptoms or poor health outcome, could not be analysed with only cross-sectional data. Due to limitation of data, comparative analysis among the caregivers, according to the type of disease of the care recipient could not be done in this research
Monahan Z, Shores D, Mack A. *et al.* (2023). Prevalence of depression among caregivers based on the condition and relationship of care recipient	To Investigate the rates of depression among caregivers whose care recipients had different conditions, such as mental illness, chronic respiratory conditions, or were their live-in partners.	a cross-sectional analysis using the 2021 Behavioural Risk Factor Surveillance System (BRFSS) conducted by the Centres for Disease Control and Prevention (CDC) to determine rates of depressive disorders among caregivers and associations between demographic and relational aspects of the care recipient.	Our findings add to previous research showing that specific groups of caregivers are at higher risk for caregiver stress. Future qualitative research may elucidate underlying causes of depression among caregivers. Analysis into the risk factors for depression among caregivers is vital in providing effective therapeutic options for the caregiver.	Results were based on self-reported survey data, which are susceptible to social desirability bias. Diagnoses of depression may also be over or under reported across several demographic variables, which may confound results.
Liu Z, Heffernan C, Tan J. (2020) Caregiver burden: A concept analysis	The purpose of this paper was to provide clarity surrounding the concept caregiver	An electronic search of MEDLINE, CINAHL, Health Source Nursing/Academic Edition and Academic	A definition of caregiver burden was developed. Tools to measure caregiver burden were identified. The findings from this analysis can be used	Caregiver burden may vary across caregivers caring for patients with different diseases or at different stages. Therefore, it is recommended that future

	burden.	Search Complete (ASC) of EBSCO, China National Knowledge Infrastructure (CNKI) and Google Scholar were searched with a limit of 10 years and published in the English or Chinese language.	in nursing practice, nursing education, research and administration.	studies focus on specific types of disease or illness to obtain a more accurate understanding of the concept of caregiver burden as it relates to disease and the status of patients' conditions.

CHAPTER THREE

MATERIALS AND METHODOLOGY

3.1 Participants

3.1.1 Participant Selection

The study population comprise caregivers of hospitalized older adults at University of Benin Teaching Hospital, Edo state Nigeria. Caregivers who provide unpaid, primary care to older adults (aged 60 and above) admitted to various wards will be considered for inclusion.

3.1.2 Inclusion Criteria

I. Primary caregivers of hospitalized older adults (aged 60 and above) at UBTH.
II. Caregivers aged 18 and above.
III. Caregivers who have been providing care for at least one month.
IV. Caregivers who provide consent to participate in the study.

3.1.3 Exclusion Criteria

I. Caregivers who are unwilling to participate or unable to provide informed consent.

3.2 Materials

3.2.1 Apparatus/Instruments

Caregiver Strain Index (CSI): The caregiver strain index, developed by M. Terry Sullivan in 2002, is a widely utilized tool in research to measure the strain experienced by caregivers. The CSI comprises 13 dichotomous (yes/no) items, encompassing various domains such as physical strain, emotional strain, financial burden, and social disruption. Each item is scored 1 for "yes" and 0 for "no," with a total possible score ranging from 0 to 13. Higher scores indicate greater levels of strain.

In a study by Sullivan et al. (2002), the reliability and validity of the CSI were examined using Classical Test Theory (CTT). Their findings demonstrated that the Cronbach's alpha values typically fall within the 0.86 to 0.90 range, indicating high reliability. Reliability testing with the test-retest method revealed that the scores for caregiver strain showed no significant difference between the two separate times they were tested (T_1 and T_2), with a T_1-T_2 correlation coefficient of 0.88 ($p < 0.001$) for the total CSI scores (Sullivan, 2002).

The Caregiver Strain Index (CSI) was selected to assess the strain experienced by caregivers of hospitalized older adults due to its established validity and reliability, making it a robust tool for identifying caregivers who may need additional support (Sullivan, 2002).

WHOQOL-HIV BRIEF: The WHOQOL-BRIEF provides a comprehensive evaluation of quality of life across multiple dimensions, reflecting the complex interplay of physical, psychological, social, and environmental factors affecting caregivers. Its relevance extends to both HIV and non-HIV caregiving contexts, making it adaptable for diverse research populations. The WHOQOL-HIV BREF comprises **31 items** structured across six key domains:

Physical Health: Assesses pain, fatigue, energy levels, and overall physical functioning.

Psychological Health: Covers self-esteem, emotional well-being, and mental clarity.

Level of Independence: Evaluates the ability to perform daily activities, dependency on medical aids, and work capacity.

Social Relationships: Focuses on personal relationships, social support, and satisfaction with social interactions.

Environment: Includes financial resources, healthcare accessibility, safety, and home environment.

Spirituality/Religion/Personal Beliefs: Explores the influence of beliefs and spirituality on coping and quality of life.

The tool also contains two general questions assessing overall quality of life and general health satisfaction.

Scoring Methodology

Responses are recorded on a **5-point Likert scale** ranging from 1 (very dissatisfied/very poor) to 5 (very satisfied/very good).

Scores for each domain are transformed into a scale ranging from 0 to 100, where higher scores indicate better quality of life.

The use of WHOQOL-HIV BREF allowed for a detailed assessment of caregivers' quality of life across multiple domains, providing insights into the potential impact of caregiving burden. The multidimensional nature of the tool ensured a holistic understanding of caregivers' experiences, aligning with the study's aim to explore the relationship between care burden, quality of life, and depression.

Reliability and Validity

The WHOQOL-HIV BREF has been shown to have high reliability and validity across diverse populations, ensuring that the data collected is robust and credible for analytical purposes (Hsiung *et al.*, 2011).

By including this instrument, the study was able to generate comprehensive data to explore the intricate dynamics of caregiving, offering a basis for targeted interventions to improve caregivers' well-being.

3.3 Methods

3.3.1 Research Design

This study employs a cross-sectional research design to investigate the relationship between care burden, quality of life, and depression among caregivers of hospitalized older adults.

3.3.2 Sampling Technique

A convenience sampling technique was used to recruit participants. Caregivers were approached in various wards of UBTH, and those meeting the inclusion criteria and willing to participate were included in the study.

3.3.3 Sample Size Calculation

The study was conducted among caregivers of hospitalized older adults in the University of Benin Teaching Hospital (UBTH), Benin City.

The minimum sample size was calculated using the Slovin sample size Formula.

n = N/(1 +Ne^2)

Where

n= sample size N = Population size of caregivers of hospitalized older adults in UBTH which totalled to 100.

e = Margin of error (set at 0.05)

The calculated minimum sample size for this study was:

n= $100/1+100(0.05)^2$

n=80.

Therefore, the minimum sample size required for this study was approximately 80 participants.

3.3.4 Procedure for Data Collection

Data was collected from caregivers of older adults in the University of Benin Teaching Hospital (UBTH), specifically from the Geriatric Ward and older adults in Wards C1, A4, and A1. After obtaining informed consent, participants were provided with questionnaires to complete in a comfortable and private setting within the hospital premises.

The data collection process utilized a structured questionnaire to gather information on participants' age, gender, educational level, and other relevant sociodemographic details. The WHOQOL-BREF instrument was employed to assess the quality of life of the caregivers, alongside the Caregiver Strain Index (CSI) to evaluate caregiving burden. These tools, originally developed in English, were administered without cross-cultural adaptation to the local setting, which may have impacted the caregivers' comprehension and interpretation of the questions.

While the researcher was present to clarify and assist with questionnaire items, the accuracy of interpretations and responses could be influenced by linguistic and cultural nuances that were not fully addressed. Participants were encouraged to ask questions if they encountered difficulties or required further explanations.

3.3.5 Ethical Consideration

Ethical approval for this study was sought and obtained from the Ethical and Research Committee of the University of Benin Teaching Hospital (ADM/E/22/A/VOL.VII/14865432037). Written informed consent was obtained from all participants after explaining the study's purpose, procedures, potential risks, and benefits.

3.3.6 Data Analysis

Descriptive statistics (mean, standard deviation, frequencies, and percentages) was used to summarize demographic data.

Inferential statistics of Spearman rho was conducted to explore the relationship between care burden and quality of life, and between care burden and depression. Significance was set at $p < 0.05$.

Data was analysed using the Statistical Package for Social Sciences (SPSS) version 27.

CHAPTER FOUR

RESULTS

4.1 Sociodemographic variable of the respondents

A total of 80 participants were recruited for this study. The respondents had a mean age of 37.56 ± 11.36 years, with ages ranging from 20 to 60 years. The majority of participants were female (73.8%), and 61.3% were married. Regarding educational background, 68.8% had attained tertiary education, while 31.3% had secondary education.

When asked about their health status, 31.3% described it as neither poor nor good, while 26.3% reported it as good, and 22.5% rated it as very good. A significant majority (72.5%) did not consider themselves critically ill, while 27.5% did. Additionally, 48.8% of respondents attributed health concerns to stress, while 51.2% did not identify any specific health issues.

Table 4.1: Sociodemographic variable of the respondents

N=80

Variable	**Category**	**Frequency**	**Percentages**
Gender	Female	59	73.8
	Male	21	26.3
Marital status	Married	49	61.3
	Single	24	30.0
	Separated	7	8.8
Educational level	Primary	-	-
	Secondary	25	31.3
	Tertiary	55	68.8
How is your health	Poor	16	20.0
	Neither poor nor good	25	31.3
	Good	21	26.3
	Very good	18	22.5
Do you consider yourself critically ill	No	58	72.5
	Yes	22	27.5
If there is something wrong with you, what do you think it is	Nil	41	51.2
	Stress	39	48.8
	Min	**Max**	**Mean ±SD**
Age	20	60	37.56± 11.36

4.2 Descriptive statistics on caregiver strain index and WHOQOL-HIV BREF

The caregiver strain index mean score of the respondents was 10.35± 1.65. The Domain 1- Physical health, Domain 2- Psychological health, Domain 3- level of independence, Domain 4- Social relationships, Domain 5- Environment, Domain 6- Spirituality/Religion/personal beliefs and the Total Quality of life score of the respondents were 10.35± 1.65, 14.48± 2.37, 15.38± 2.97, 12.70± 2.90, 12.26± 2.68, 25.85± 4.36, 14.01± 2.81 and 94.68± 9.88 respectively as shown in table 2

Table 4.2: Descriptive statistics on caregiver strain index and WHOQOL-HIV BREF

Variable	Minimum	Maximum	Mean± SD
CSI	6	13	10.35± 1.65
WHOQOL-HIV BREF			
Domain 1-Physical health	10	20	14.48± 2.37
Domain 2- Psychological health	10	23	15.38± 2.97
Domain 3- level of independence	7	19	12.70± 2.90
Domain 4- Social relationships	7	20	12.26± 2.68
Domain 5- Environment	18	37	25.85± 4.36
Domain 6- Spirituality/Religion/personal beliefs	9	20	14.01± 2.81
Total Quality of life	77	133	94.68± 9.88

4.3 Spearman statistics examining the relationship between the care burden and the psychological and total quality of life of the respondents

Spearman statistics was done to examine the relationship between some selected variables. The findings revealed there was no relationship between care burden and the total quality of life of the respondents (rho=-0.027, p=0.814). There no relationship between care burden and the psychological health of the respondents (rho=-0.196, p=0.081) as shown in table 3.

Table 4.3: Spearman statistics examining the relationship between the care burden and the psychological and total quality of life of the respondents

Variable	**Rho**	**P**
Care burden* Total QOL	-0.027	0.814
Care burden * Psychological health	-0.196	0.081

4.4 Hypothesis Testing

1. There will be no significant relationship between care burden scores and overall quality of life scores among caregivers of hospitalized older adults

   Test: Spearman rho

   Alpha level: 0.05

   Observed p value: 0.814

   Judgement: Since the observed p value is greater than 0.05, the null hypothesis is therefore NOT REJECTED.

2. There will be no significant relationship between care burden scores and levels of depression among caregivers of hospitalized older adults

   Test: Spearman rho

   Alpha level: 0.05

   Observed p value: 0.081

   Judgement: Since the observed p value is greater than 0.05, the null hypothesis is therefore NOT REJECTED.

CHAPTER FIVE

DISCUSSION, CONCLUSION, RECOMMENDATIONS AND IMPLICATIONS

5.1 Discussion

This study assessed the relationship between care burden, quality of life (QoL), and depression among caregivers of hospitalized older adults at the University of Benin Teaching Hospital (UBTH). The findings provided insights into the caregivers' experiences, with implications for interventions aimed at improving their well-being.

The study revealed that caregivers had a moderate overall QoL, with a mean score of 94.68 ± 9.88 on the WHOQOL-BREF scale. Among the domains, the highest mean score was observed in spirituality/religion/personal beliefs (25.85 ± 4.36), while social relationships had the lowest mean score (12.26 ± 2.68). These findings are consistent with reports by Hwang and Kim (2024), who noted the protective role of spiritual beliefs in coping with caregiving stress. The low scores in social relationships align with studies like Yao et al. (2024), which attributed this to the time demands of caregiving, leading to social isolation.

The moderate QoL scores could also reflect the dual burden of caregiving responsibilities and the personal health challenges reported by some respondents. For instance, 31.3% of participants rated their health as neither poor nor good, and 27.5% considered themselves critically ill. This underscores the need for targeted interventions to improve caregivers' health and social support systems.

The study found a negative but non-significant relationship between care burden (mean CSI score = 10.35 ± 1.65) and overall QoL (rho = -0.027, p = 0.814). Although this contrasts with the significant associations reported by Pacheco Barzallo et al. (2024), the discrepancy might be due to differences in the population and the moderate burden reported in this study.

A possible explanation for the non-significant relationship could be the reliance on coping mechanisms, such as spirituality, as evidenced by the high scores in the spirituality domain. Additionally, the caregivers' relatively young mean age (37.56 ± 11.36) and higher education levels (68.8% had tertiary education) may have contributed to better adaptability and resilience, mitigating the impact of caregiving burden on QoL.

Although depression levels were not explicitly quantified in this study, the findings revealed indicators of psychological strain. For example, the mean score for psychological health (15.38 ± 2.97) was relatively low compared to other QoL domains, suggesting the mental health challenges caregivers face. These results align with findings from Yao et al. (2024), who reported a high prevalence of depression among caregivers, emphasizing the psychological toll of caregiving.

The relatively low psychological scores highlight the urgent need for mental health support services for caregivers. Interventions such as counselling and stress management programs could help alleviate the psychological strain experienced by this population.

The study also found a negative but non-significant relationship between care burden and psychological health (rho = -0.196, p = 0.081). This finding is consistent with studies like Hwang and Kim (2024), which suggested that the relationship between caregiving burden and depression could be influenced by contextual factors, including caregivers' coping strategies and social support networks.

The non-significant relationship observed in this study may also reflect the moderate care burden reported by respondents. Moreover, cultural and societal norms that value caregiving roles might have contributed to reducing the psychological impact, as caregivers may perceive their responsibilities as fulfilling rather than burdensome.

Overall, this study highlights the complex interplay between caregiving burden, QoL, and psychological well-being among caregivers of hospitalized older adults. While the moderate levels of care burden and QoL scores suggest that most caregivers are managing their responsibilities relatively well, the low social and psychological health scores point to areas requiring targeted interventions.

Future research should consider longitudinal designs to better understand the dynamics of caregiving burden over time. Additionally, qualitative studies could provide deeper insights into the coping mechanisms and support systems employed by caregivers, offering a foundation for designing effective interventions.

5.2 Conclusion

This study examined care burden, quality of life (QoL), and psychological well-being among caregivers of hospitalized older adults. The findings indicated no significant associations between care burden and QoL or psychological health. Caregivers reported moderate levels of burden, with challenges particularly noted in the social relationships and psychological health domains. Despite these challenges, high scores in the spirituality/religion/personal beliefs domain suggest that coping mechanisms, such as spiritual practices, may play a role in maintaining caregiver well-being. These findings underscore the need for interventions targeting social support and mental health services for caregivers.

These findings highlight the complex and multifaceted nature of caregiving, emphasizing the need for targeted interventions. Support systems should aim to enhance caregivers' mental health, social networks, and overall well-being. Interventions such as counselling, stress management programs, and access to community resources may help reduce caregiver strain and improve their QoL. Future research should focus on exploring these relationships further, incorporating longitudinal studies and qualitative approaches to better understand caregivers' experiences and coping strategies.

5.3 Recommendations

Based on the findings, the following recommendations are proposed:

1. **Implementation of Support Programs:** Healthcare institutions should provide psychosocial support, including counselling services and caregiver support groups, to help alleviate caregiver stress.
2. **Respite Care Services:** Initiatives such as temporary relief care should be made available to reduce the continuous strain on caregivers.
3. **Caregiver Education:** Educational programs on stress management, effective caregiving techniques, and available healthcare resources should be introduced.
4. **Policy Formulation:** Stakeholders should consider policies that provide financial and social support to caregivers, recognizing their role in the healthcare system.
5. **Conduct Regular Assessments:** Routine assessments of caregivers' quality of life, mental health, and care burden should be carried out to identify at-risk individuals and provide timely interventions.

5.4 Implications for Further Studies

The findings of this study highlight areas for future research:

1. **Longitudinal Studies:** Investigating the long-term effects of caregiving on quality of life and mental health would provide deeper insights.

2. **Larger Sample Sizes:** Future studies should involve more participants to improve statistical power and generalizability of findings.
3. **Exploration of Interventions:** Research should evaluate the effectiveness of specific interventions, such as counselling or respite care, in reducing caregiver burden.
4. **Comparative Studies:** Comparing caregivers across different healthcare settings and cultural contexts could provide a broader understanding of caregiving dynamics.
5. **In-depth Qualitative Research:** Detailed interviews with caregivers may uncover nuanced experiences and coping strategies not captured in quantitative studies.

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APPENDIX 1

INFORMED CONSENT

Title of the Study: RELATIONSHIP BETWEEN CARE BURDEN, QUALITY OF LIFE AND DEPRESSION AMONG CAREGIVERS OF HOSPITALIZED OLDER ADULTS IN A TERTIARY HEALTH INSTITUTION

Researcher: MISS ABIEYUWA EHIOZEE

Supervisor: DR (MRS) O.S. KUBEYINJE

Financial Sponsorship: This research project is self-sponsored.

Contact Phone Number: 09016623805

Purpose of the Study: You are invited to take part in the research aimed at helping us determine the relationship between care burden, quality of life, and depression among caregivers of hospitalized older adults at the University of Benin Teaching Hospital (UBTH). This study seeks to analyse how caregiving responsibilities impact your mental and physical well-being.

Participants: As a caregiver of a hospitalized older adult at UBTH, you can participate in this study if you meet the inclusion criteria, which includes being aged 18 years and above and actively involved in the care of the hospitalized older adult.

Procedure: Self-report questionnaires will be administered to assess your quality of life and care burden. The prevalence and severity of depression will also be measured using a standardized scale. Statistical analyses will be employed to assess the correlation between care burden, quality of life, and depression levels.

Benefit of Participation: This study will provide you the opportunity to gain insights into how caregiving responsibilities may affect your quality of life and emotional well-being. It may also help you better understand your own levels of care burden and depression, guiding you towards strategies for improving your overall health and well-being.

Risks of Participation: The procedures for this study involve self-reported assessments that pose no physical risk or harm.

Cost/Compensation: There is no cost or compensation for this study apart from your highly esteemed time and compliance.

Contact Information: If you have any questions or concerns about this study, you can contact the named investigator (project student) on the stated phone numbers.

Voluntary Participation: Your participation in this study is voluntary. You have the right to withdraw from the study at any point if you feel uncomfortable, even after initially consenting to participate.

Confidentiality: All information gathered in this study will be kept completely confidential. No reference will be made in written or oral material that will link you to this study.

Participant Consent: I understand that the study has been clearly explained to me, and I fully comprehend the study process. I am willing to participate in the study.

____

Participant’s signature and date

____

Witness’s signature and date

____

Researcher’s signature and date

APPENDIX 2

WHOQOL-HIV BREF

Domain 1	(6-Q3) + (6-Q4) + Q14 + Q21 ☐ + ☐ + ☐ + ☐	Raw Score	Transformed score	
Domain 2	Q6 + Q11 + Q15 + Q24 + (6-Q31) ☐ + ☐ + ☐ + ☐ + ☐			
Domain 3	(6-Q5) + Q20 + Q22 + Q23 ☐ + ☐ + ☐ + ☐			
Domain 4	Q17 + Q25 + Q26 + Q27 ☐ + ☐ + ☐ + ☐			
Domain 5	Q12 + Q13 + Q16 + Q18 + Q19 + Q28 + Q29 + Q30 ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐ + ☐			
Domain 6	Q7 + (6–Q8) + (6-Q9) + (6-Q10) ☐ + ☐ + ☐ + ☐			

ABOUT YOU

Before you begin, we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**? Male / Female

How old are you? _________________ (age in years)

What is the highest **education** you received? None at all / Primary / Secondary / Tertiary

What is your **marital status**? Single / Married/ Living as married / Separated / Divorced / Widowed

How is your **health**? Very Poor / Poor / Neither Poor nor Good / Good / Very Good

Do you consider yourself currently ill? Yes / No

If there is something wrong with you, what do you think it is? _____________________

Please respond to the following questions if they are applicable to you:

What is your **HIV serostatus**? Asymptomatic / Symptomatic / AIDS converted

In what year did you first **test positive** for HIV? ____________________

In what year do you think you were infected? ______________________

How do you believe you were infected with HIV? (Circle one only):

Sex with a man / Sex with a woman / Injecting drugs / Blood products / Other

(specify)________________

Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions**. If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks.** For example, thinking about the last two weeks, a question

might ask:

		Not at all	A little	A moderate Amount	Very much	Extremely
11(F5.3)	How well are you able to concentrate	1	2	3	4	5

You should circle the number that best fits how well are you able to concentrate over the last two weeks. So you would circle the number 4 if you were able to concentrate very much. You would circle number 1 if you were not able to concentrate at all in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4 (F50.1)	How much are you bothered by any physical problems related to your HIV infection?	1	2	3	4	5
5 (F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
6 (F4.1)	How much do you enjoy life?	1	2	3	4	5
7 (F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5
8 (F52.2)	To what extent are you bothered by people blaming you for your HIV status	1	2	3	4	5
9 (F53.4)	How much do you fear the future?	1	2	3	4	5
10 (F54.1)	How much do you worry about death?	1	2	3	4	5

		Not at	A little	A moderate	Very much	Extremely

		all		amount		
11 (F5.3)	How well are you able to concentrate?	1	2	3	4	5
12 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
13 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
14 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
15 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
16 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
17 (F51.1)	To what extent do you feel accepted by the people you know?	1	2	3	4	5
18 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
19 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
20 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
21 (F3.3)	How satisfied are you with your sleep?	1	2	3	4	5
22 (F10.3)	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
23 (F12.4)	How satisfied are you with your capacity for work?	1	2	3	4	5
24 (F6.3)	How satisfied are you with yourself?	1	2	3	4	5
25 (F13.3)	How satisfied are you with your personal relationships?	1	2	3	4	5

26 (F15.3)	How satisfied are you with your sex life?	1	2	3	4	5
27 (F14.4)	How satisfied are you with the support you get from your friends?	1	2	3	4	5
28 (F17.3)	How satisfied are you with the conditions of your living place?	1	2	3	4	5
29 (F19.3)	How satisfied are you with your access to health services?	1	2	3	4	5
30 (F23.3)	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
31 (F8.1)	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	1	2	3	4	5

Did someone help you to fill out this form? ________________________________

How long did it take to fill this form out? ________________________________

Do you have any comments about the assessment? ________________________________

____

____

____

THANK YOU FOR YOUR HELP

APPENDIX 3

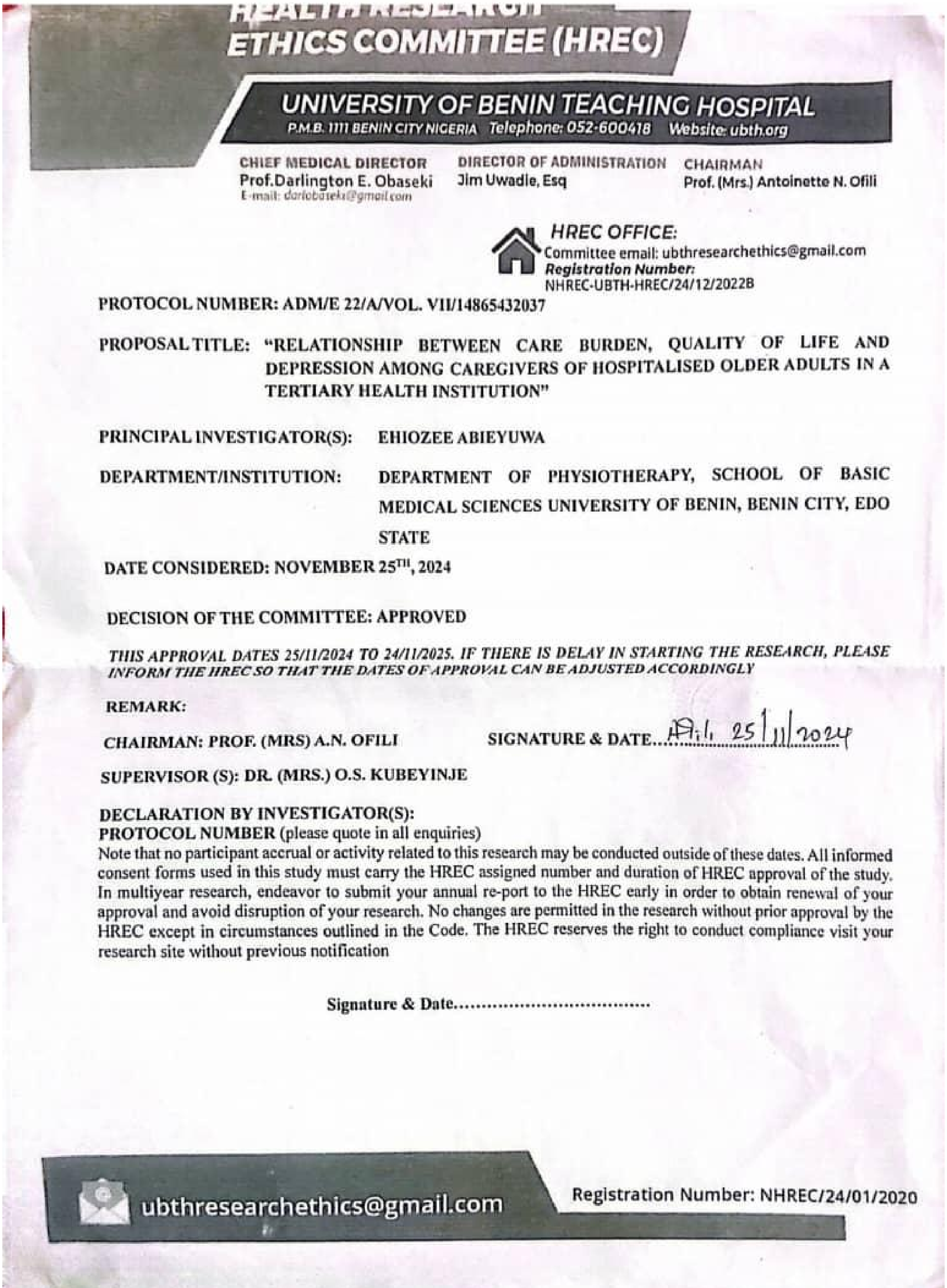
CAREGIVER STRAIN INDEX

The caregiver strain index; I am going to read some things out that other people have found difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g., because the person you care for is in and out of bed or wanders around at night).		
It is inconvenient (e.g., because helping takes so much time or it’s a long drive over to help).		
It is a physical strain (e.g., because of lifting in and out of a chair; effort or concentration is required).		
It is confining (e.g., helping restricts your free time or cannot go visiting).		
There have been family adjustments (e.g., because helping has disrupted your routine; there has been no privacy).		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation).		
There have been other demands on your time (e.g., from other family members).		
There have been emotional adjustments (e.g., because of severe arguments).		
Some behaviour is upsetting (e.g., because of incontinence; the person you care for has trouble remembering things, or does things that bother you).		
It is upsetting to find the person you care for has changed so much from their former self (e.g., he/she is a different person than he/she used to be).		
There have been work adjustments (e.g., because of having to take time off).		
It is a financial strain.		
Feeling completely overwhelmed (e.g., because of worry about the person you care for; concerns about how you will manage).		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

APPENDIX 4

ETHICAL APPROVAL



ETHICS COMMITTEE (HREC)

UNIVERSITY OF BENIN TEACHING HOSPITAL
P.M.B. 1111 BENIN CITY NIGERIA Telephone: 052-600418 Website: ubth.org

CHIEF MEDICAL DIRECTOR	DIRECTOR OF ADMINISTRATION	CHAIRMAN
Prof.Darlington E. Obaseki E-mail: darlobaseki@gmail.com	Jim Uwadie, Esq	Prof. (Mrs.) Antoinette N. Ofili

HREC OFFICE:
Committee email: ubthresearchethics@gmail.com
Registration Number:
NHREC-UBTH-HREC/24/12/2022B

PROTOCOL NUMBER: ADM/E 22/A/VOL. VII/14865432037

PROPOSAL TITLE: "RELATIONSHIP BETWEEN CARE BURDEN, QUALITY OF LIFE AND DEPRESSION AMONG CAREGIVERS OF HOSPITALISED OLDER ADULTS IN A TERTIARY HEALTH INSTITUTION"

PRINCIPAL INVESTIGATOR(S): EHIOZEE ABIEYUWA

DEPARTMENT/INSTITUTION: DEPARTMENT OF PHYSIOTHERAPY, SCHOOL OF BASIC MEDICAL SCIENCES UNIVERSITY OF BENIN, BENIN CITY, EDO STATE

DATE CONSIDERED: NOVEMBER 25TH, 2024

DECISION OF THE COMMITTEE: APPROVED

THIS APPROVAL DATES 25/11/2024 TO 24/11/2025. IF THERE IS DELAY IN STARTING THE RESEARCH, PLEASE INFORM THE HREC SO THAT THE DATES OF APPROVAL CAN BE ADJUSTED ACCORDINGLY

REMARK:

CHAIRMAN: PROF. (MRS) A.N. OFILI **SIGNATURE & DATE**........25/11/2024

SUPERVISOR (S): DR. (MRS.) O.S. KUBEYINJE

DECLARATION BY INVESTIGATOR(S):
PROTOCOL NUMBER (please quote in all enquiries)
Note that no participant accrual or activity related to this research may be conducted outside of these dates. All informed consent forms used in this study must carry the HREC assigned number and duration of HREC approval of the study. In multiyear research, endeavor to submit your annual re-port to the HREC early in order to obtain renewal of your approval and avoid disruption of your research. No changes are permitted in the research without prior approval by the HREC except in circumstances outlined in the Code. The HREC reserves the right to conduct compliance visit your research site without previous notification

Signature & Date..................................

ubthresearchethics@gmail.com Registration Number: NHREC/24/01/2020