

UNIVERSITY OF GHANA

COLLEGE OF HUMANITIES



**BURDEN OF CARE: PSYCHOSOCIAL EXPERIENCES OF CAREGIVERS OF OLDER
ADULTS LIVING WITH CHRONIC DISEASES**

BY

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DECLARATION

I hereby declare that this thesis is the result of research undertaken by MABEL YEBOAH DARFOUR towards the award of the MPhil. in Clinical Psychology Degree at the Department of Psychology, University of Ghana. All references within the study have been duly acknowledged.



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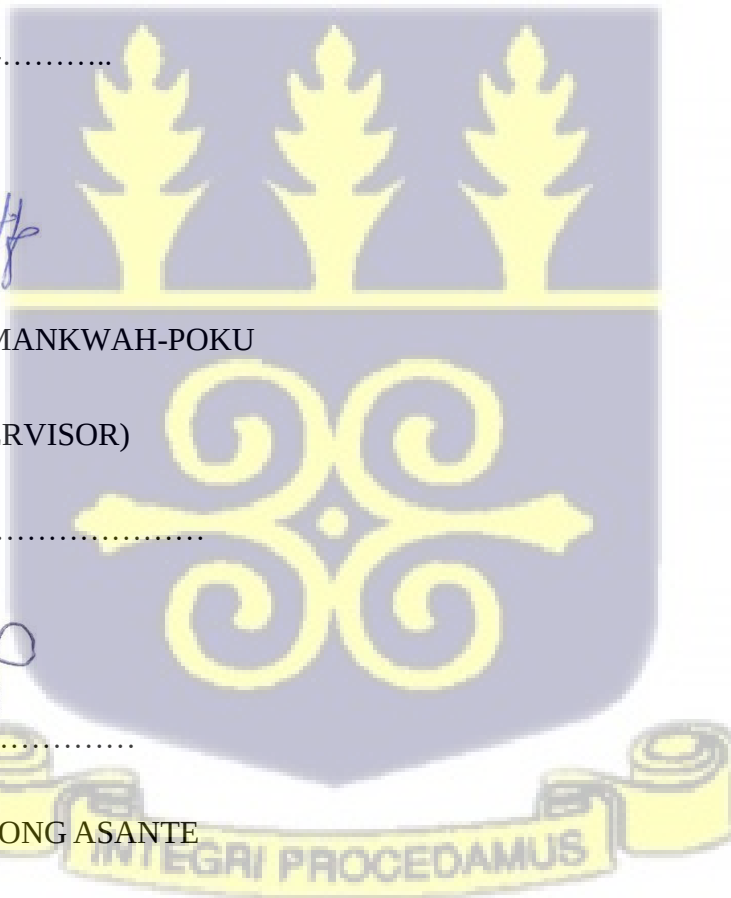
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DEDICATION

I dedicate this work to the Almighty God for giving me the strength, wisdom, and understanding to complete this thesis.

I also dedicate this thesis to my family, especially my parents, Mr. Emmanuel Darfour and Mrs. Angela Darfour for their unwavering support throughout the project. To my siblings, Caleb and Yaw I dedicate this to you for your love and support. To my beloved grandmother, Martha Fosu who inspired me to do this work, I dedicate it to you.



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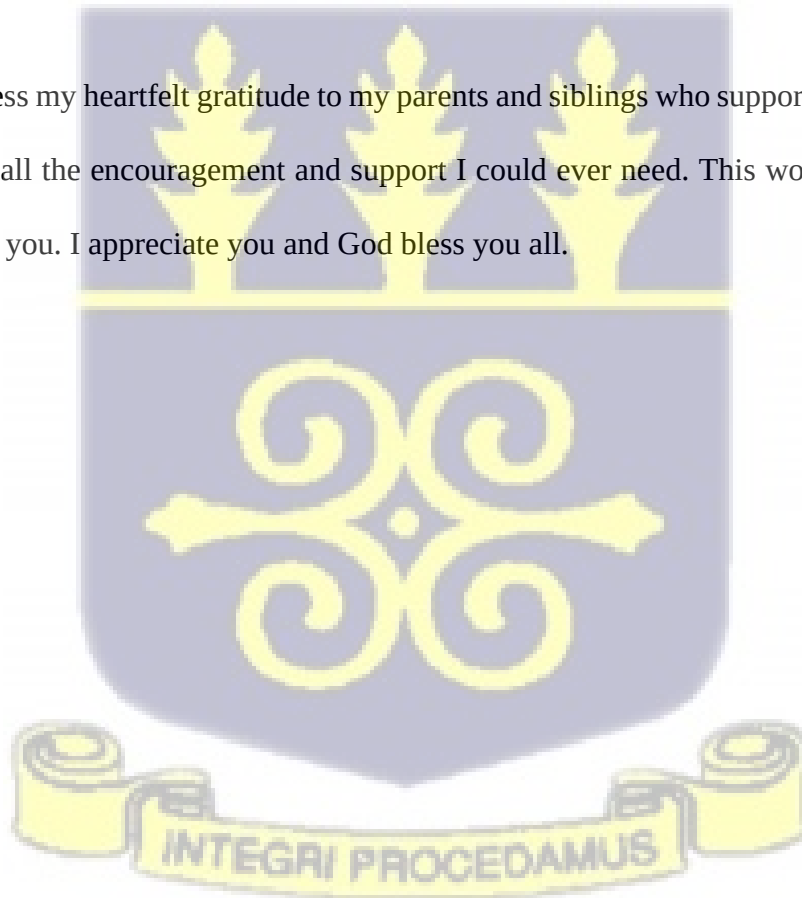
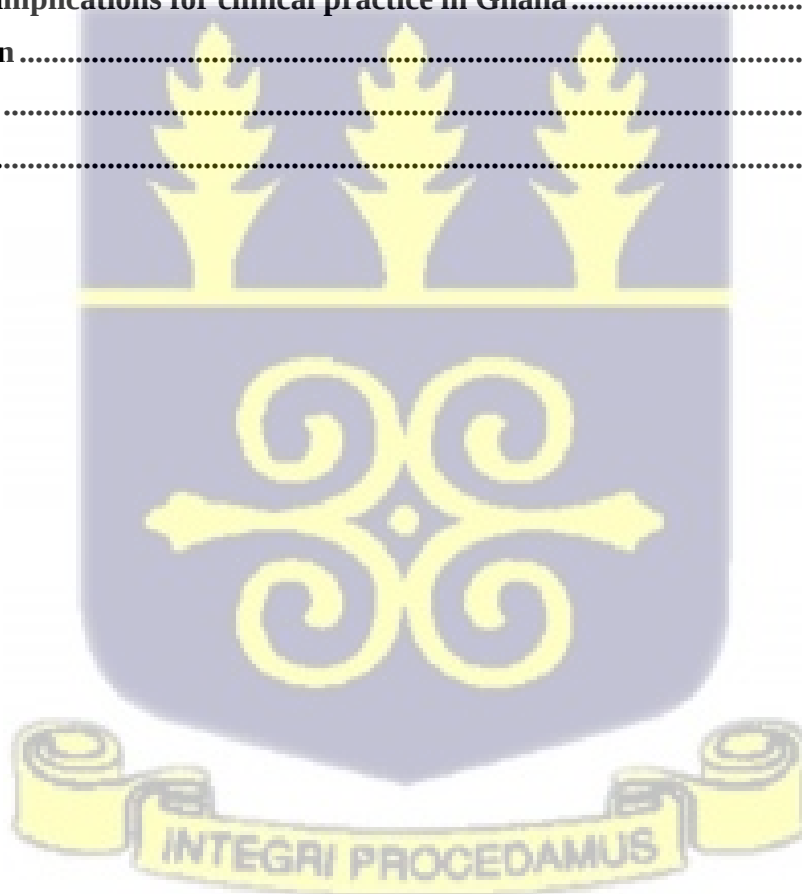


Table of Contents

DECLARATION	ii
DEDICATION	iii
ACKNOWLEDGEMENT	iv
ABSTRACT	1
CHAPTER ONE	2
INTRODUCTION	2
1.1 Problem Statement	13
1.3 Aims and Objectives of the Study	14
1.4 Relevance of the study	14
1.5 Organisation of the study	15
CHAPTER TWO	16
LITERATURE REVIEW	16
2.1 Theoretical Framework	16
2.1.1 Aranda and Knight's stress and coping theory (Aranda & Knight, 1997)	16
2.2.2 The Stress-Buffering Hypothesis of Social Support (Cohen & Wills, 1985)	20
2.2 Review of Related Studies	24
2.2.1 Psychosocial Experiences of caregivers of older adults with chronic diseases	25
2.2.2 Coping Strategies of caregivers	29
2.2.3 Relationship between spirituality, caregiver burden and wellbeing	31
2.2.4 Relationship between social support, caregiver burden and wellbeing	32
2.3 Rationale of the study	34
2.4 Research questions	35
2.5 Statement of Hypotheses	35
METHODOLOGY	37
3.1 Research Design	37
3.3 Research Setting	38
3.4 Population, Sample and Sample size Determination	39
3.5 Inclusion Criteria	39
3.6 Exclusion Criteria	40

3.7 Socio-demographic characteristics of participants	40
3.7 Measures.....	42
3.7.1 Demographic questionnaire.....	42
3.7.2 The Zarit Burden Interview- ZBI Revised 22-items (Zarit et al, 1980).....	42
3.7.3 Beck's Depression Inventory (Beck et al., 1961) BDI -II.....	43
3.7.4 Revised Berlin Social Support Scale (Roomaney et al., 2020) BSSS.....	43
3.7.5 The World Health Organization Wellbeing Index (World Health Organisation, 1998) WHO-5	44
3.7.6 Attitudes Related to Spirituality Scale (Braghetta et al., 2021) ARES.....	44
3.7.7 Semi-Structured Interview Schedule	44
3.8 Procedure	45
3.9 Ethical considerations	46
3.10 Data Analysis strategy	47
3.10.1 Quantitative Data Analysis	47
3.10.2 Qualitative Data Analysis	48
3.11 Trustworthiness of findings	48
CHAPTER FOUR.....	51
RESULTS.....	51
4.1 Findings of Phase I of the Study	51
4.1.1 Caregiving as a journey of Meaning and growth	52
Life of a caregiver	53
Caregiver responsibilities.....	55
Challenges of caregiving.....	56
4.1.2 Emotional Turbulence, Disruption of finances and social life	58
Emotional impact.....	58
Social impact	60
Financial impact.....	63
4.1.5 Finding Strength in Faith, Support and Adaptation	63
Self-care practices	64
Social support.....	66
4.1.6 Unmet Needs and the Quest for Recognition and Support	68
Training and support	68

<i>Emotional and psychological support</i>	70
4.2 Findings from Phase II of the Study	71
<i>Tests of normality</i>	71
<i>Reliability analysis</i>	71
CHAPTER FIVE	78
DISCUSSION	78
Overview	78
5.1 Discussion of qualitative findings	79
5.2 Discussion of quantitative findings	87
5.3 Points of convergence and divergence	96
5.4 Limitations/Recommendations for future studies	98
5.5 Theoretical implications of the study	99
5.5 Practical implications for clinical practice in Ghana	101
5.6 Conclusion	102
REFERENCES	104
APPENDICES	125



LIST OF TABLES

Table 1 Demographic characteristics of participants for the qualitative study	40
Table 2 Demographic Characteristics of participants of the quantitative study.....	41
Table 3 Themes and subthemes	52
Table 4 Descriptive statistics of constructs	72
Table 5 Correlation between Caregiver Burden and Wellbeing	73
Table 6 Mediation Analysis Showing the Impact of CB On Wellbeing Through Depression	74
Table 7 Moderation analysis of social support on the relationship between caregiver burden and wellbeing	75
Table 8 Moderation analysis of spirituality on the relationship between caregiver burden and Wellbeing	77



LIST OF FIGURES

Figure 1 Simple Slope Plot.....	75
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ABSTRACT

The population of older adults in Ghana is expected to grow in the coming years. With ageing comes its troubles and the need for caregivers to take care of the older adult population, especially those who may be burdened with chronic diseases. Caregiving for older adults tends to be strenuous and may lead to caregivers experiencing the burden of care, coupled with some psychosocial experiences that may negatively affect their well-being. This study used a concurrent mixed methods design to explore the psychosocial experiences and caregiver burden, the coping mechanisms and the needs of caregivers of older adults living with chronic diseases. Participants were recruited from two hospitals: the Ga East Hospital and Ghana Atomic Energy Hospital (GAEC) in the Ga East Municipality in the Greater Accra Region of Ghana. For the quantitative study, a total of 100 caregivers of older adults living with chronic diseases were purposively sampled and recruited for the study, and questionnaires were self-administered. For the qualitative study, 10 participants were purposively selected and interviewed using a semi-structured interview schedule. The quantitative data were analysed using Pearson r , hierarchical regression mediation analysis, while the transcribed qualitative data were analysed using reflective thematic analysis. The qualitative findings revealed that caregivers face negative social, emotional, and financial consequences, but self-care practices and social support offer relief. Caregivers also indicated the need for social support, support groups, and training avenues to care for their older relatives. The quantitative results showed that caregiver burden had a detrimental effect on their well-being, but depression was found to be the strongest predictor of poor mental health. The findings of the study highlight the need for the development of interventions and national policies that specifically address caregiver welfare.

CHAPTER ONE

INTRODUCTION

Ageing refers to the process whereby an individual experiences changes associated with their biological, psychological, and social functioning (National Institute of Aging, 2018; Bach, 2022). According to the National Institute of Ageing, older adults are individuals aged 65 years and older (National Institute of Health, 2024). Globally, the world's population is fast ageing. The World Health Organization (WHO), which has defined the older adult population as those aged 60 years and over, has stated that due to the population's rapid growth, there will be roughly 2.1 billion people in this age group by 2050, which is double the number reported in 2020 (1 billion people) (World Health Organization, 2022). Historically, the age considered as “old age” is usually defined by governmental policies that specify the chronological age that makes an individual eligible to enjoy certain exclusive services, such as pension benefits in Ghana or social security benefits in the United States (Teater & Chonody, 2019).

In Ghana, the older adult population is also set at age 60 years and over, as this is the official age for public service retirement (for most people) in the country and serves as the yardstick for defining older persons in Ghana (Braithwaite & Rosenberg, 2021). According to Essuman and Mate-Kole (2021), Ghana's older adult population, i.e. persons aged 60 years and over, ranked among the highest in Sub-Saharan Africa due to improved healthcare systems in the country, amongst other factors. They also stated that this population records a higher prevalence of chronic diseases and is highly susceptible to infections as well (Essuman & Mate-Kole, 2021).

The biological changes that usually occur as a result of ageing explain the decline in functioning and increased susceptibility to illnesses (Li, 2021; Guo, 2022). For instance, the immune

system's functioning slows down as a result of ageing, and there is a reduction in the production of B and T cells in the bone marrow and thymus, as well as the diminished function of mature lymphocytes in the secondary lymphoid tissues of the immune system which is attributed to ageing (Desdin-Mico et al., 2020; Lopez-Otin et al., 2023). This makes it difficult for older adults to respond to immune challenges as swiftly as young people do. This then leads to an increased risk of infections and diseases. Hence, ageing has been identified as a major risk factor for developing multiple chronic diseases such as stroke, cardiovascular diseases, cancer, and Alzheimer's disease (Maresova et al., 2019; Carrasco et al., 2022).

Even though research has shown that ageing is a risk factor for the development of chronic diseases (Carrasco et al., 2022), some researchers have argued that successful ageing exists among older adults (Urtama et al., 2019; Teater & Chonody, 2019). Successful ageing usually refers to how people are able to maintain a high quality of life as they grow older (Estebarsari et al, 2019). Some factors that influence successful ageing, according to Estebarsari et al. (2019), include increased social communication, heightened physical activity, lack of cognitive impairment, and limited medical status. Although some older adults are privileged to enjoy successful ageing devoid of chronic diseases, a good number of older adults are also saddled with chronic diseases, as research has indicated (Luo et al, 2019). Since ageing has been identified as a major risk factor for chronic diseases, it is of utmost importance to discuss what constitutes chronic diseases.

Chronic diseases are long-term health conditions that frequently result in long-term health restrictions and higher care requirements (Stacherl & Sauzet, 2023). Chronic diseases usually refer to diseases that last a year or more and usually require ongoing medical attention and limit daily activities or both (CDC, 2022). They are projected to become a recurrent cause of death in Sub-Saharan Africa by 2030 by the World Health Organization (WHO). The World Health

Organization (2022) posits that chronic illnesses include cardiovascular diseases, particularly heart diseases and stroke; chronic respiratory diseases; diabetes; and other conditions such as mental problems, visual and hearing impairment, dental diseases, bone and joint abnormalities, and genetic disorders. Literature shows that older adults are burdened with some of these chronic diseases (Trumble & Schneider-Crease, 2020; Sun & Li, 2023). Nutakor et. al (2020) asserted that chronic diseases such as stroke, hypertension, and diabetes affect people of all socioeconomic statuses, that are rich or poor, rural-urban dwellers, as well as older adults.

Hacker (2024) stated that the leading causes of morbidity and mortality are chronic diseases such as diabetes, heart disease, stroke, and cancer. However, hypertensive heart disease was the most reported chronic disease found among the older adult population in Lower-middle-income countries like Ghana (Wu et al., 2015). Also, many facets of an individual's life are impacted by chronic disease. These facets include the financial, psychological, and emotional strain of their condition, lifestyle changes, limitations in daily activities, and/or an increase in medical needs (Stacherl & Sauzet, 2023). These factors can have a serious negative impact on a patient's overall well-being. For this study, chronic diseases were limited to stroke, diabetes, hypertension, chronic kidney disease and cancer because multiple studies revealed the prevalence of such conditions among older adults in Ghana (Sarfo et al., 2018; Sanuade et al., 2019).

Chronic diseases become part of a patient's life and also endanger the patient's physical health and capacity to function, the patient's autonomy and independence, leading the individual to feel a sense of loss (Benkel et al., 2020). To mitigate this feeling of loss, older adults living with chronic diseases require caregivers to assist with their daily personal and medical needs. Older adults living with chronic diseases usually need help with emotional support, hospital rounds, drug

administration, personal chores, as well as mobility aids (Schulz & Eden, 2016). According to Jacobson (2023), a caregiver could be a family member or any important person who takes care of almost or all of a patient's needs. There are two types of caregivers, namely professional caregivers and informal caregivers (Cejalvo et al., 2021), with the main distinction being that professional caregivers are equipped with specific training about caregiving and receive compensation, whereas an informal caregiver has no professional training but may sometimes receive compensation for caring (Cejalvo et al., 2021). Most informal caregivers are family members.

Due to a sense of reciprocity that adult children have, which motivates them to take on the caring responsibilities of their elderly parents or relatives, the majority of informal caregivers for the elderly in Ghana are family members (Essuman & Mate-Kole, 2021). Also, according to Essuman and Mate-Kole (2021), there is an Akan proverb that translates to “if your parents take care of you for your teeth to erupt, you, in turn, take care of them till their teeth come off” (p. 5). Anderson and White (2017) also posited that children often used caregiving as a means to reciprocate the love their older adult parents or relatives showed them while growing up and found fulfilment. Additionally, they considered being caregivers of their older adult parents or relatives as a blessing or gift (Anderson & White, 2017).

Caregivers of older adults living with chronic diseases usually perform personal care tasks for the elderly, which include dressing and bathing, managing medications, cooking wholesome meals, aiding with mobility, scheduling doctor's visits, giving emotional support and company, while also handling house chores (Schulz & Eden, 2016). Caregivers are often exposed to a lot of stressors due to the tasks they perform, and if these stressors are not properly dealt with, they result in chronic stress and caregiver burden among caregivers (Faronbi et al., 2019). According to Cejalvo et al (2021) the type and severity of the disease of the care recipient, the variety of

roles to be performed by the caregiver, cognitive demands of caregiving, care permanence, and dependency are some determinants of the caregiver burden on informal caregivers, which leads to a reduction in their well-being.

Caregiver burden encompasses the persistent difficulty that results from the provision of care to a dependent, elderly person or relative with a disability that threatens the caregiver's physical and mental health, other family relationships, the caregiver's job, and the caregiver's financial situation (Kazemi et al, 2021). The domains of caregiver burden usually include financial strains, physical ill health, and emotional distress (Liu, 2020). Globally, the prevalence of caregiver burden ranges from 23.0% to 59.2% in different study populations (Loo et al., 2022). In Ghana, Okai (2019) asserted that the prevalence of Caregiver burden in terms of financial, physical, psychological, and social levels was 74.6%, 66.9%, 63.6%, and 51.7% respectively.

The concept of caregiver burden has been categorised into two, namely, objective and subjective burden (Cejalvo et al., 2021). Objective burden is described as changes caregivers initiate in certain domains of their lives to accommodate their care recipients, whereas subjective burden is defined as the reactions that caregivers emotionally attribute to the daily demands of caregiving (Cejalvo et al., 2021). Demanding caregiving responsibilities are frequently linked to poor health outcomes, such as anxiety, depression, physical disease, and poor sleeping habits. The ongoing difficulties of providing care can have a negative impact on the caregiver (Lopez-Anuarbe & Kohli, 2019; Bekui et al, 2022). Some of the outcomes of caregiving are considered the psychosocial experiences of caregivers in this study.

The term "psychosocial experiences" refers to an individual's subjective experiences, feelings, and perspectives about the things that impact their mood, cognitive behaviour, and social interactions (Zia et al, 2021). Negative psychosocial experiences, such as a decrease in social

interactions, poor psychological well-being, and loneliness usually result in depression and an increase in morbidity and mortality for caregivers as these experiences affect the way they cope with the burden associated with caregiving (Zwar et al., 2020). According to Kyei-Arthur et al (2022) however, positive experiences of caregiving, such as receiving gifts in the course of caregiving or even money from care recipients, can alleviate caregiver burden and burnout.

According to Dunkle et al (2014) a connection exists between caregiving and outcomes related to well-being, which is notably observed through the decline in caregivers' well-being during the early phases of their caregiving roles, the subsequent decline in their well-being as the demands of their care grow, and their recovery immediately after the death of their care recipients. This gives an insight into how strenuous caregiving demands impact well-being. Subsequently, Kokorelias et al. (2019) stated that a caregiver's psychosocial wellbeing and experiences consist of the caregiver's mental health, the caregiver's emotional wellbeing and social activities performed by the caregiver. Hence, psychosocial experiences used in the context of this study referred to depression, social support, spirituality, and the psychological well-being of caregivers of older adults living with chronic diseases in Ghana.

Even though some caregivers find caregiving rewarding and view it as a tool that helps them develop confidence and learn how to handle challenging situations, caregiving sometimes has a negative impact on a caregiver's well-being and usually causes psychological distress among caregivers (Schulz et al., 2020). Zheng et al. (2021) have also reported that psychological distress in caregivers has overwhelming consequences on caregivers, such as elevated symptoms of depression and anxiety, reduced physical health, a lower quality of life, as well as increased levels of perceived caregiver burden. Caregivers who often lack social support encounter a lot of difficulty in the course of caregiving and tend to isolate themselves or withdraw from pleasurable

activities. Such caregivers usually report depressive symptoms and negative affects (Schulz et al., 2020).

Depression has been very prevalent among caregivers of older adults with chronic diseases, such that even spousal caregivers experience depressive symptoms (Monin et al., 2019). According to Lespine et al. (2022) the prevalence of depression among caregivers is very high. Depression among caregivers makes it more difficult for caregivers to provide the essential care that an ailing relative needs, which exacerbates their suffering and contributes to the medical and psychological problems caregivers face with a higher chance of suicide (Lespine et al., 2022). Caregivers with depression may also have difficulties sleeping, which may affect their well-being and performance of roles for their care recipients (Abeasi, 2020). In addition, Heffer & Willoughby (2017) posited that positive coping skills can be used to reduce negative outcomes such as depression and increase positive outcomes, thereby allowing individuals to handle difficult situations effectively.

The ideas and actions used to deal with stressful circumstances, such as stressful caregiving situations, both internal and external, are referred to as coping mechanisms (Algorani & Gupta, 2023). However, the different ways that people respond to stressors that they encounter are referred to as "coping styles". Coping styles are a collection of comparatively consistent characteristics that influence an individual's behaviour when faced with stress (Algorani & Gupta, 2023). Over time and in many contexts, these coping styles remain constant. The behavioural and cognitive attempts or efforts made by individuals to interpret and overcome challenges and difficulties are what are referred to as coping strategies (Kazemi et al., 2021). Coping mechanisms are, however, classified into four main categories.

The four main categories of coping mechanisms include: first, Problem-focused coping, which aims to address the specific issue that is generating the discomfort. It encompasses several strategies, such as planning, restrained coping, active coping, and suppression of competing activities (Algorani & Gupta, 2023). Second, emotionally focused coping; This approach seeks to lessen the bad feelings connected to the issue using acceptance, positive reframing, turning to religion, and comedy (Algorani & Gupta, 2023). Thirdly, meaning-focused coping; this approach deals with the use of cognitive techniques to ascertain and regulate the situation's meaning and lastly, social coping, or support-seeking, which is a stress-reduction strategy used when a person asks their community for practical or emotional assistance (Algorani & Gupta, 2023).

Even though employing a variety of coping mechanisms might be advantageous, individuals experiencing poor adjustment may find the use of various coping mechanisms challenging (Heffer & Willoughby, 2017). Kazemi et al. (2021) asserted that coping strategies play an essential role in controlling the psychological and physical burden on caregivers of stroke patients. Similarly, Akpan-Idiok et al. (2020) stated that acceptance, positive self-view, reprioritization, empathy, appreciation and family support are some coping strategies adopted by caregivers of older adults living with chronic diseases to ease the level of caregiver burden experienced during caregiving.

Social support has been identified as one of the protective factors needed for mitigating the negative psychosocial experiences of caregivers of older adults living with chronic diseases (George et al., 2020). Social support is categorized into two, namely perceived social support and received social support, where perceived social support refers to an individual's evaluation of the available social support and received social support is the actual and substantial social support available (George et al., 2020). In the context of informal family caregiving, received social

support is viewed in three forms, namely: emotional (i.e., providing caregivers with emotional needs such as love, empathy, caring, trust, etc.), tangible (i.e., providing financial aid, goods, etc.) and informational (i.e., offering advice or information that can be useful in the caregiving situation) (Bevan et al., 2019).

Perceived social support, however, refers to the degree to which caregivers believe that people around them are receptive to their needs and are available to help them (Hailey et al., 2022). The concept of perceived social support was further described by Hailey et al. (2022) as how people view friends, coworkers, and family in terms of being able to offer practical help during difficult situations. The protective role that social support plays in reducing caregiver distress and burden serves as an adaptive coping strategy for them. Also, social support may serve as a ‘buffer’, in providing caregivers with emotional and psychological support, which is considered a major factor in maintaining well-being and coping with health challenges (Hailey et al., 2022). This indicates that social support plays a huge role in the assessment of caregiver burden, and according to Kokorelias et al. (2019) caregivers’ psychosocial experiences are heavily impacted by social support. Besides social support, it has also been reported in multiple studies that individuals tend to use spirituality as a means of coping, especially in the Ghanaian context (Kyei-Arthur, 2022).

Furthermore, Adashek and Subbiah (2020) suggested that caregiver burden and caregivers’ coping mechanisms should be viewed from the cultural perspectives of the different cultural contexts they are presented to adequately address the problems of caregiver burden in relation to the culturally specific norms, beliefs, and practices that contribute to its experience. According to Dunfee et al. (2020), spirituality and religiosity are culturally supported coping strategies. Williams (2010) defined spirituality as an individual’s search for meaning, purpose, and significant

relationships in life, whereas religiosity is a formal construct of sacred belief, rooted in an institutional and community context that frequently entails service attendance, prayer and/or meditation, and devotion to shared practices and beliefs. In addition, spirituality is defined by Puchalski et al. (2018) as a dynamic and intrinsic facet of humanity through which individuals seek purpose, meaning, and transcendence, and experience relationships with family, self, society, nature, and/or the sacred and spirituality may be experienced through the practice of religion.

Religious coping refers to the use of religion and/or spirituality to deal with stressors, traumatic events, and adversities (Farinha et al., 2021). There are two forms of religious coping, namely, positive and negative religious coping. Positive religious coping refers to individuals having strong feelings in connection with God/transcendence and spiritual connection with others, whereas negative religious coping refers to feelings of spiritual discontentment with God/transcendence and attributing life events as punishments from God/transcendence and blaming God/transcendence (Dunfee et al., 2020). Some identified benefits of the use of religious coping include: positive feelings of cure and hope, an improvement in psychological, physical, and mental health, fulfilment with life, and a reduction in depressive symptoms, anxiety, and stress (Farinha et al., 2021).

Ghana is regarded as a highly religious country that accepts and tolerates individuals from a variety of spiritual backgrounds (Essuman & Mate-Kole, 2021). Occasionally, these religious and spiritual organizations offer their members social protection and aid in enhancing their social lives by connecting and engaging with like-minded individuals (Essuman & Mate-Kole, 2021). Studies in Ghana, such as that by Kyei-Arthur et al. (2022) posited that caregivers of older adults who associate religiosity and/or spirituality with caregiving demands reported pleasant experiences and blessings in their lives. This indicates that some caregivers draw strength,

resilience, and social support from their spiritual beliefs and the organizations that they belong to. Spirituality is also associated with better psychosocial outcomes, i.e., spirituality helps to decrease isolation among caregivers, provides comfort, and plays a role in healthy coping strategies that caregivers adopt in the caregiving process (Zheng et al., 2021).

Alquwez and Alshahrani (2020) asserted that seeking social support and using spiritual methods are psychological and behavioural efforts for dealing with distress associated with caring for persons living with stroke. In the context of caregiving, spirituality also serves as a resource that can be used to cope with the diseases of care recipients and helps in assigning new meanings to daunting caregiving demands and sufferings (Benites et al., 2021). According to Benites et al. (2021) studies that explore the experience of spirituality and the needs of family caregivers in the context of caregiver burden among caregivers of patients with chronic diseases are rare, and they also stated that spirituality is a multidimensional facet of the human experience. This makes it very relevant to investigate spirituality in the context of caregiving or caregiver burden, especially in a religious context such as Ghana.

The needs of caregivers, which have been grossly neglected by researchers, are also assessed in this study in light of an assertion made by Akgun-Citak et al. (2019) that a consideration of the needs of caregivers of older adults living with chronic diseases in the planning of interventions helps to address caregiver burden and promotes the health and well-being of caregivers. When caregiving needs are addressed, there will be significant improvements in caregiver health and well-being (Schulz et al., 2020). Consequently, it was imperative to examine the psychosocial experiences of Ghanaian caregivers who are taking care of older adults living with chronic diseases, specifically to identify the factors contributing to caregiver burden, assess the impact on their mental well-being, and their coping skills.

1.1 Problem Statement

In Ghana, family members or loved ones with disabilities, chronic diseases, or ageing-related issues are largely supported by caregivers. However, providing care frequently entails significant financial, emotional, and physical strains, which are made worse by societal standards, cultural expectations, and a lack of quality healthcare resources. The difficulties of caring and the absence of social support networks often result in significant levels of stress, anxiety, and depression among Ghanaian caregivers, particularly family members. Additionally, underreported psychological strain and an overwhelming sense of obligation may result from conventional and social beliefs that caregiving is a duty rather than a choice.

The psychosocial experiences of caregivers providing care for older adults living with chronic diseases in Ghana pose significant challenges, yet there is a paucity of research examining this specific phenomenon in the Ghanaian context in older adults living with chronic diseases (Kyei-Arthur & Cudjoe, 2020). With the increasing elderly population and rising burden of chronic diseases in Ghana (World Health Organization, 2022), it is crucial to understand the unique psychosocial challenges faced by caregivers in order to develop effective interventions and support systems. Even though caregiving for older adults with chronic diseases has been studied in other contexts (Faronbi et al., 2019; D'Amen et al., 2021; Tsai et al., 2021), the experiences of caregivers in Ghana may be influenced by several factors unique to the region (United Nations Department of Economic and Social Affairs, 2019).

Also, as stated earlier, globally, the prevalence of caregiver burden ranges from 23.0% to 59.2% in different study populations (Loo et al., 2022). In Ghana, Okai (2019) asserted that the prevalence of Caregiver burden in terms of financial, physical, psychological, and social levels

were 74.6%, 66.9%, 63.6%, and 51.7% respectively. Taking the prevalence rate of caregiver burden into consideration, it is imperative to inquire and/or explore caregiver needs that can lessen the burden of care and this necessitated this study.

1.3 Aims and Objectives of the Study

This study investigated how psychosocial experiences contribute to caregivers' experience of caregiver burden. Specifically, it assessed:

1. The psychosocial experiences of family caregivers of older adults with chronic diseases.
2. The coping strategies adopted by family caregivers.
3. The impact of caregiver burden on well-being.
4. The mediating effect of depression in the relationship between caregiver burden and well-being.
5. The moderating effect of spirituality and social support, in the relationship between caregiver burden and well-being.

The first two aims and objectives were explored qualitatively, whereas the last three aims and objectives were examined quantitatively.

1.4 Relevance of the study

This study will provide insight into the psychosocial experiences, caregiver burden and its impact on wellbeing, the coping skills and needs of caregivers of older adults dealing with chronic diseases in the Ghanaian context. The findings of this study will inform the development of tailored interventions and support systems that address the specific needs of caregivers in Ghana, which would enhance their well-being and quality of life. Findings from this study will help clinicians to better evaluate and understand the issues of caregiver burden that may arise in the

Course of Psychotherapy. The study will add to the limited literature in this area of study in the Ghanaian context. As Schulz et al (2020) asserted, the adverse effects of family caregiving on both caregivers and care recipients, when documented, would serve as an important first step in developing interventions and policies needed to address the needs of caregivers.

Furthermore, the Sustainable Development Goal (SDGs) 3 is targeted at achieving good health and well-being. Studies such as this will provide the information geared towards the realization of this goal through the identification and presentation of this health concern, which will lead to interventions being designed to help facilitate solving the problem.

1.5 Organisation of the Study

This section provides information about how the thesis is structured. It is presented in five chapters. Chapter one, as seen above, highlighted the background of the study, the problem statement, aims and objectives, as well as the relevance of the study. Chapter two outlines the literature review of the study, which comprises the theories underpinning this study as well as a review of related studies, the rationale of the study, the research questions and the study's hypotheses. Chapter three presents the method of the study, i.e., a detailed description of the research design, study area, population, sampling and sampling technique, measures, research procedure, data analysis, and ethical considerations are outlined. Chapter four presents the results of the study, highlighting the demographics of both the quantitative and qualitative data, and an extensive presentation of tables for the results gathered and explained in detail. The final chapter represents a discussion of findings, implications for clinical practice, theoretical implications, limitations, recommendations for future studies, and the conclusion of the study.

CHAPTER TWO

LITERATURE REVIEW

This chapter introduces the theoretical framework guiding the study and a review of related literature relevant to the present study. In addition, the chapter also highlights the rationale of the study and the statement of hypotheses.

2.1 Theoretical Framework

The theoretical frameworks underpinning this study are Aranda and Knight's stress and coping theory (Aranda & Knight, 1997) and The Stress-Buffering Hypothesis of Social Support Model (Cohen & Wills, 1985).

2.1.1 Aranda and Knight's stress and coping theory (Aranda & Knight, 1997)

Aranda and Knight's stress and coping theory for caregivers is a framework for understanding how caregivers experience stress and develop coping strategies to manage that stress. This theory suggests that caregiving can be a source of both positive and negative experiences, and the way caregivers cope with these experiences can impact their well-being.

The theory identifies four main components of caregiving stress:

1. The demands of caregiving: These are the physical, emotional, and social demands that come with providing care for someone else. Examples include managing medications, providing personal care, and navigating complex medical systems.
2. Caregiver resources: These are the personal, social, and financial resources that caregivers have at their disposal to help them manage the demands of caregiving. Examples include personal resilience, social support, and financial stability.
3. Appraisals: These are the subjective evaluations that caregivers make about the demands

of caregiving and their ability to cope with it. Positive appraisals can lead to a sense of mastery and control, while negative appraisals can lead to feelings of helplessness and hopelessness.

4. Coping strategies: These are the behaviours and strategies that caregivers use to manage the demands of caregiving and reduce their stress. Examples include problem-solving, seeking social support, and engaging in self-care activities.

The theory suggests that caregivers who have high levels of resources and positive appraisals are more likely to use effective coping strategies and experience less stress. On the other hand, caregivers who have low levels of resources and negative appraisals are more likely to use ineffective coping strategies and experience more stress. A revision of this theory by Knight and Sayegh (2010) however, posited that cultural values and ethnic differences in stress and coping include social support and coping styles rather than burden appraisals. Knight and Sayegh (2010) asserted that the role of cultural values in the model proposed by Aranda and Knight (1997) appeared to be smaller and more group-specific, with limited evidence in support of the initial idea that cultural values work by influencing the appraisal of caregiving as burdensome. However, they posited that cultural values and differences in culturally distinct groups tend to influence the choice and use of coping strategies by caregivers, the very nature of the coping strategies available to the caregiver, and the use and effects of social support in the course of caregiving (Knight & Sayegh, 2010).

Recent studies show that beyond burden appraisals, cultural factors play a significant role in the experience of caregiver burden as well as the coping strategies adopted by these caregivers and that social support is a big aspect of coping for these caregivers (Kokorelias et al., 2019; George et al., 2020; Kazemi et al., 2021).

Furthermore, Aranda and Knight's Stress and Coping Theory (1997) offers a framework for comprehending how people use different coping mechanisms to deal with stress while also considering the impact of environmental circumstances, personal resources, and social support.

This theory is instrumental when examining complex variables like depression, social support, spirituality, well-being, caregiver burden, and coping strategies. Each of these variables fits within the framework of Aranda and Knight's theory underpinning this study. Thus, the theory relates to each of the variables in the study in the following ways:

1. Depression: According to the stress and coping theory, depression is often an outcome when stressors, such as caregiving burdens, overwhelm an individual's coping resources. Depression can result from a prolonged inability to manage stress effectively or when stressors are perceived as uncontrollable or unmanageable. Therefore, depression in caregivers may indicate that their coping strategies are inadequate or require reinforcement through supportive measures.
2. Social support: One important external resource in the stress and coping paradigm is social support. It serves as a buffer, easing emotional pressure and assisting caregivers in managing stress. Social support offers both practical and emotional help that can improve self-efficacy, lessen feelings of loneliness, and promote healthy coping. It has been demonstrated that robust social support systems reduce caregiver stress, enhance mental health, and promote resilience.
3. Spirituality: Spirituality can be viewed as an internal coping resource. Spirituality gives many caregivers a feeling of connection, meaning, and purpose that aids in stress management. Spiritual activities or beliefs frequently provide consolation, uphold optimistic outlooks, and assist in evaluating the stress of providing care as tolerable

or even significant. In Aranda and Knight's model, spirituality contributes to a caregiver's ability to reframe stress and maintain hope and psychological resilience.

4. Well-being: In the stress and coping model, well-being as used in this study is an outcome variable that reflects the combined effects of stressors, social support, coping mechanisms, and individual stress assessment. The ability of a caregiver to manage stress using flexible coping mechanisms and accessible social and spiritual resources is a key indicator of their well-being. While low well-being may be a sign of extreme stress or a lack of coping mechanisms, high well-being implies effective coping.
5. Caregiver burden: Caregiver burden represents the primary stressor in this model, encompassing both the objective and subjective strain caregivers experience. The burden can vary based on factors like the level of care needed, the caregiver's relationship to the care recipient, and other life stressors. Aranda and Knight suggest that the degree of perceived burden influences how caregivers appraise their situation, which affects their coping responses and well-being outcomes.
6. Coping strategies: The model emphasizes the role of coping strategies in moderating the relationship between stress and outcomes like depression and well-being. Emotional regulation, problem-solving, and social support-seeking are examples of coping strategies. Maladaptive coping mechanisms, like avoidance or denial, can exacerbate depressive symptoms and caregiver burden, whereas adaptive coping mechanisms, like positive reframing and help seeking, tend to promote well-being and reduce depression.

Overall, Aranda and Knight's stress and coping theory and the revision made by Knight and Sayegh (2010) highlight the importance of understanding caregivers' unique experiences and

needs and provide a framework for developing interventions to support caregivers in managing the stress of caregiving. Also, Aranda and Knight's model illustrates how stressors, personal resources (e.g., spirituality), environmental resources (e.g., social support), and individual coping strategies interact to influence mental health and well-being outcomes among caregivers. By identifying which variables may mitigate or exacerbate stress, this framework can guide interventions that enhance coping resources and reduce caregiver burden.

2.2.2 The Stress-Buffering Hypothesis of Social Support (Cohen & Wills, 1985)

The Stress-Buffering Hypothesis of social support, proposed by Cohen and Wills (1985), suggests that social support plays a crucial protective role in buffering individuals from the negative effects of stress. According to the model, social support essentially "buffers" or lessens the negative effects of stress, especially in high-stress circumstances, by offering practical, emotional, or informational resources that improve a person's ability to cope. This model emphasizes the circumstances in which social support is most helpful, and as a result, it has become a fundamental framework in stress research, clinical and health psychology. The model posits that social support provides resources (emotional, informational, or practical) that help individuals cope more effectively, thereby reducing negative outcomes like anxiety, depression, and physical health issues. The factors that define the stress-buffering hypothesis of social support are as follows:

1. **Social Support as a buffer against stress:** The theory states that people benefit most from social assistance when they are under high levels of stress. Supportive relationships offer coping mechanisms in these circumstances, lowering the risk of physical and mental health issues brought on by stress.
2. **Types of social support:** According to Cohen and Wills (1985), many forms of social

support can aid in stress buffering, and each one offers unique resources to assist people in stress management. However, four types of social support were highlighted; first, emotional support i.e., expressions of empathy, compassion, trust, and love that make others feel appreciated and understood. Second, Informational support, this refers to advice, direction, or data that helps people solve problems or get a better knowledge of their circumstances. Also, Instrumental Support i.e., material aid, such as cash aid or work support. Lastly, appraisal support, that is feedback or affirmation that encourages people to view themselves or their circumstances more favourably.

3. Models of social support effects: Two potential effects of social support on well-being were proposed by Cohen and Wills which included the direct effects model and the buffering Model (Stress-Buffering Hypothesis). The direct effects model posits that, social support improves wellbeing at all stress levels. In other words, whether or not a person is under stress, social support is always helpful. However, the buffering model posits that social support is especially beneficial during times of high stress. When stress levels are high, social support becomes a powerful protective element, but in low-stress settings, its impact may be less noticeable.
4. Mechanisms for stress-buffering: Cohen and Wills proposed these mechanisms through which social support might buffer against stress. These mechanisms include; Enhanced appraisal of coping resources: Social support can boost an individual's perception of their ability to handle stressors by enhancing their appraisal of coping resources. This assistance changes the way people perceive their personal capabilities and the resources they have to deal with difficult situations. Individuals who receive reassurance, affirmation, or counsel from others tend to regard their situations as less dangerous and feel more suited to deal. Secondly, resource provision; resource provision refers to the real and practical assistance

provided by others that immediately alleviates the pressures associated with a stressor. This might involve physical aid, financial assistance, counsel, or other resources that help the individual manage their workload more effectively. This process reduces the impact of stress by decreasing demands, making stressful circumstances less severe and more tolerable with external assistance. Thirdly, the reduction of negative emotions: Social support also plays a crucial role in reducing negative emotional reactions to stress, such as anxiety, sadness, dissatisfaction and frustration. Individuals tend to feel understood, validated, and less isolated in their experience when they receive emotional support such as empathy, comfort, and reassurance.

In this study, caregiver burden, social support, spirituality, depression, well-being, and coping strategies were examined through the lens of Cohen and Wills' stress-buffering hypothesis of social support, each variable played a vital role in understanding how social support can mitigate the adverse effects of stress for caregivers. Thus, the theory relates to each of the variables in the study in the following ways:

1. Caregiver burden: According to the stress-buffering hypothesis, social support may help to mitigate the negative consequences of caregiver burden by providing both emotional and practical aid. The hypothesis predicts that caregivers with higher levels of social support will be less negatively impacted by caregiver burden since social support can lessen both the perceived intensity and real demands of caring.
2. Social support: The stress-buffering theory is centered on social support, which may act as a buffer between caregiver load and unfavorable health outcomes. Emotional support (offering empathy and understanding), instrumental assistance (assisting with chores), and informational support (advice and direction).

Emotional assistance may help caregivers reframe the burden as manageable, whereas instrumental support may lower real caring needs. Informational assistance may help caregivers feel more competent and educated, enhancing their assessment of coping resources and lowering stress.

3. Spirituality: Spirituality might be viewed as a coping resource that, when combined with social support, can help to reduce stress and caregiver burden. Many caregivers find that faith provides a sense of purpose, hope, and resilience, which can help them manage with difficulties. In line with the stress-buffering theory, spirituality may boost the effects of social support by providing a framework for individuals to positively interpret their caring role, therefore reducing feelings of burden and stress. Spirituality, for example, may help caregivers in finding purpose in their roles, therefore increasing resilience and emotional stability.
4. Depression: Depression frequently occurs when persistent stressors such as caregiver burden are significant, especially if coping resources and social support are limited. According to the stress-buffering hypothesis, social support may lessen the risk or severity of depression by lowering caregiver burden, offering emotional comfort, and reducing feelings of isolation. Depression might be considered an outcome variable in this study. Higher levels of perceived social support may be associated with reduced levels of depression among caregivers, since social support can lessen the emotional toll of caring stress while also improving general mood and mental health.
5. Wellbeing: Well-being serves as another outcome variable reflecting the positive impacts of effective stress buffering. Well-being encompasses both psychological

aspects (such as life satisfaction, happiness) and physical health outcomes. The stress-buffering hypothesis would predict that caregivers who receive high social support experience greater well-being, even in the face of caregiving stress. Social support helps buffer the strain by reducing negative emotions and fostering a sense of connectedness and purpose, which are essential for maintaining high well-being despite high caregiver burden.

6. Coping strategies: According to the stress-buffering hypothesis, social support can improve caregivers' coping strategies by providing both practical advice (instrumental support) and emotional encouragement. This model suggests that social support promotes adaptive coping (e.g., planning or seeking help) over maladaptive coping (e.g., avoidance), leading to better outcomes. This, in turn, would allow caregivers to handle their responsibilities more effectively and with less psychological strain.

Overall, this model predicts that caregivers with high levels of social support, spirituality, and efficient coping strategies would have lower levels of depression and better levels of well-being, even when the caregiver burden is high. This supports Cohen and Wills' stress-buffering hypothesis of social support, which states that social support protects individuals by increasing coping resources, offering practical and emotional comfort, and lowering negative feelings and outcomes.

2.2 Review of Related Studies

Caregivers of older adults with chronic diseases tend to experience a vast range of psychosocial experiences. Some of these psychosocial experiences have been highlighted by various researchers across the globe, a few from Africa, and very limited data in the study area from the Ghanaian

perspective. While some have focused on just exposing the challenges of caregivers using their psychosocial experiences, others have focused on how coping strategies play a role in their experience of caregiver burden. These studies have used different methodologies to assess the impact of caregiver burden on well-being.

2.2.1 Psychosocial Experiences of caregivers of older adults with chronic diseases

Several studies have investigated the psychosocial experiences of caregivers of older adults living with chronic diseases. A study by Price et al. (2020) conducted a scoping literature review using 27 studies to investigate the experiences and support needs of informal caregivers caring for people with multimorbidity. They reported that common challenges exist for informal caregivers of people with multiple chronic diseases (Price et al., 2020). Some of these challenges included the management of numerous healthcare teams, medical appointments, medications, and their side effects, as well as psychosocial challenges, which included high levels of psychological symptomatology and a decrease in social connectedness (Price et al., 2020). A study by Isac, Lee and Arulappan (2021) supported assertions made by Price et al. (2020) that a decrease in social connectedness contributes to caregiver burden and negative experiences, and they proposed that significant family and social support plays a huge role in the emotional well-being, physical and psychological states of caregivers.

Ploeg et al. (2020) conducted a qualitative study to assess the complexities of caregiving for community-living older adults with multiple chronic conditions who lived in Alberta and Ontario in Canada. The researcher interviewed caregivers of older adults (65 years and older) who were burdened with three or more chronic conditions. Their study revealed that caregivers' psychosocial experiences were influenced by the demands of caregiving, feeling socially isolated, staying committed to caring, and enjoying the benefits of caregiving. Some participants described the

caregiving process as exhausting, overwhelming, and stressful and mentioned experiencing feelings of depression, significant impairment in wellbeing, as well as the need for social support (Ploeg et al., 2020).

In a study conducted by Zhong et al (2020), they assessed social support and depressive symptoms in family caregivers of the elderly with disabilities in China. They also assessed caregiver burden as a potential mediator in the relationship between social support and depressive symptoms. Quantitative data were collected using a survey questionnaire. According to findings from their study, social support was negatively associated with depressive symptoms in family caregivers of aged people with disabilities and in caregiver burden, and caregiver burden partially mediated the relationship between social support and depressive symptoms (Zhong et al., 2020). This implies that caregiver burden can play a mediating role in the experiences of some of the psychosocial variables (social support and depression) affecting it; hence, assessing the moderating and mediating effects of some of these variables is very relevant in understanding caregivers' experiences.

In a systematic literature review conducted by D'amen et al. (2021) in Italy, 10 studies were assessed, with 3 being mixed methods, 6 qualitative and 1 quantitative study. The study examined the experiences of young and young adult family caregivers of aged persons with chronic illnesses. The selected studies were assessed using multiple databases such as Web of Science, PubMed, ProQuest - Psychology Database, Scopus, CINAHL Complete – EBSCOHost. Methodological appraisal and content analysis were used to assess the selected studies, and themes as well as sub-themes were identified. Findings showed that caregiving influenced the psychological state and social life of caregivers, but interestingly, there was a concurrent positive and negative impact of caregiving on caregivers (D'Amen et al., 2021). While other studies

reported feelings of improved self-image because of caregiving, others reported a decrease in self-image (D'Amen et al., 2021). However, some identified weaknesses of this study were that the studies used for the review included in their sample sizes young people but were unable to identify whether they were playing the role of primary or secondary caregivers, and these were confounding factors that probably affected the research, especially considering how significant caregiving activities and roles played affects the experience of caregiver burden on caregivers (Cejalvo et al., 2021). Secondly, in the selected studies, the illness of the care recipient was not stated as a factor influencing caregiving activities and role relationships. Hence, in this study, particular attention is given to the role of the caregiver, with special attention towards primary caregivers, as well as a specification of the illnesses of the care recipients of the caregivers were specified.

Tsai et al (2021) conducted a study in China among 328 aged caregivers to assess caregiver burden among aged people living with dementia. Quantitative data were gathered using a survey questionnaire. Caregiver burden was assessed using the Zarit Burden Interview schedule. Findings from their study showed that older caregivers of older patients with dementia experience a higher burden of care, especially when their care recipients' functional autonomy is hugely impaired.

Similarly, Rezaei et al. (2020) conducted a meta-analysis and systematic review of 25 articles to examine caregiver burden among caregivers of people living with chronic conditions in Iran. The meta-analysis method and the random effects model were used to analyse the data gathered. The STATA, version 14 was used to perform all the analyses. Findings revealed that caregivers of patients with chronic conditions experience high levels of burden, especially caregivers of patients who undergo dialysis, those with mental disorders, as well as patients with Alzheimer's disease (Rezaei et al., 2020).

In Nigeria, Akpan-Idiok et al. (2020) conducted a prospective cross-sectional study to investigate the burden of care and coping strategies among caregivers of cancer patients in Nigeria. In the study, 250 informal family caregivers of advanced cancer patients were assessed using the Zarit Burden Interview, a modified 17-item Coping Orientation to Problems Experienced (COPE) Inventory to survey. Results indicated that 46.19% of the sample size experienced severe burden, whereas 17.62% experienced insignificant or no burden, and 36.2% experienced moderate burden. They also stated that a strong relationship exists between the caregiver's burden level and coping strategies (Akpan-Idiok et al., 2020).

In Ghana, a study conducted by Agyapomah et al. (2023) sought to investigate caregiver burden amongst caregivers of aged persons with hypertension and/or diabetes mellitus in Kumasi, Ghana. The study purposively sampled 20 informal caregivers at a teaching hospital in Ghana. Participants were interviewed about their caregiving experiences, and the qualitative data were analysed using thematic analysis. Results indicated that aged persons with hypertension and/or diabetes mellitus had needs such as help with daily chores, drug administration, hospital assistance, etc., that placed a burden of care on the lives of their caregivers, which affected their work, health, and social lives. The study advocated for nurses to collaborate with informal caregivers in planning the care of aged persons with hypertension and/or diabetes mellitus (Agyapomah et al., 2023).

Abeasi (2020) conducted a study to explore depression and quality of life among caregivers of stroke patients and the role of social support in the experience of caregiver burden. A sample of 50 caregivers and 50 non-caregivers were recruited for the study, and depression, quality of life, and social support were measured. Findings revealed that the caregivers of stroke patients experienced significant depressive symptoms and a lower quality of life than non-caregivers.

A significant relationship between depression, quality of life, and social support was observed (Abeasi, 2020).

Kyei-Arthur et al. (2022) explored the positive experiences of primary and secondary caregivers of older persons in resource-limited urban settings in Accra, Ghana. The study adopted a phenomenological design and interviewed 31 family caregivers of older persons. Findings indicated that primary and secondary caregivers gained tangible and intangible gifts from providing care to older persons. The study also suggested that positive caregiving experiences will lessen caregivers' burden and burnout (Kyei-Arthur et al., 2022).

Furthermore, a similar study by Kyei-Arthur and Cudjoe (2020) sought to explore the challenges of primary and secondary caregivers of older adults and their coping strategies in the poor urban communities in Accra, Ghana. The researchers interviewed 31 caregivers in the Ga Mashie area about their caregiving experiences and coping strategies. Qualitative data were collected and analysed using thematic analysis. The results from the study showed that primary and secondary caregivers experienced the burden of care related to caring for the aged in terms of physical, economic, psychological and social burdens. In addition, the caregivers used spirituality and perseverance to cope with challenges they encountered in the course of caregiving. Their results also revealed that caregivers' challenges varied by type of caregiver, that is, whether the caregiver is primary or secondary (Kyei-Arthur and Cudjoe, 2020).

2.2.2 Coping Strategies of caregivers

Coping strategies refer to the behavioural and cognitive attempts made by individuals to interpret and overcome problems and challenges they encounter (Kazemi et al., 2021). Coping strategies work as mediators of stress that lessen the effects of stress on caregivers (Kyei-Arthur

& Cudjoe, 2020). Bassi et al. (2019) assessed the caregiving experience of 680 caregivers of patients with multiple sclerosis by examining tasks performed by caregivers, their coping strategies, and their psychological well-being. The study also examined the mediational role of coping strategies between caregivers' tasks and their well-being. Findings from this study revealed that caregiving tasks did not only negatively impact well-being, but they may also have a positive influence on well-being through the adaptive coping strategies that caregivers employed, such as positive reframing and supportive engagement (Bassi et al., 2019).

Agyemang-Duah et al. (2019) investigated the coping strategies or mechanisms adopted by caregivers of older adults in Ghana. They investigated the coping mechanisms that informal caregivers in rural and urban settings in Ghana used to overcome their caregiving challenges. They conducted in-depth interviews with 20 purposively sampled caregivers from the Kumasi Metropolis in the Ashanti Region of Ghana. Using thematic analysis, results revealed that six key coping mechanisms were used by these caregivers; i.e., spiritual coping, which included their faith in God, acceptance and encouragement, support from friends and family, reducing expenditure on activities unrelated to caregiving, borrowing from friends, and taking time off caregiving (Agyemang-Duah et al., 2019). The findings also revealed that through support, burnout among informal caregivers can be prevented (Agyemang-Duah et al., 2019).

An integrative review by Sabo and Chin (2020) investigated the self-care practices and needs of caregivers of older adults. The studies used for the review were conducted in six countries, which include: the United States, the United Kingdom, Spain, Brazil, and Canada. Studies used for the review focused on informal caregivers and caregivers who were younger than 50 years. Fifteen articles that met the inclusion criteria were used for the integrative review. Findings from the study revealed that social support, support resources, stress management, and physical activity were

recognized as self-care needs, whereas self-care practices included coping strategies, self-advocacy, prioritizing of self, activism, and legacy building (Sabo & Chin, 2020). Coping strategies were identified as a component of self-care practices that, when adopted, could lead to improvements in well-being and lessen or alleviate caregiver burden among caregivers of older persons with chronic illnesses.

2.2.3 Relationship between spirituality, caregiver burden and wellbeing

Adashek and Subbiah (2020) suggested that caregiver burden and caregivers' coping mechanisms should be viewed from the cultural perspectives of the different cultural contexts they are presented in to adequately address the problems of caregiver burden in relation to the culturally specific norms, beliefs, and practices that contribute to its experience. Dunfee et al. (2020) posited that spirituality and religion are culturally supported coping strategies.

Özdemir et al. (2020) assessed the psychosocial problems that family caregivers of palliative care patients encounter and their spiritual coping styles. A sample of 76 family caregivers was assessed using the Hospital Anxiety and Depression Scale and the Religious Coping Methods Scale. Findings showed that a weak positive association existed between anxiety and positive religious coping. No correlation existed between the negative religious coping scale and anxiety, depression, and the positive religious coping scale. There was also no association between the positive religious coping scale and the depression scale (Özdemir et al., 2020).

A study conducted by Alquwez and Alshahrani (2020) evaluated the impact of social support and spiritual coping on the quality of life and mental health of 123 informal caregivers of patients with stroke in Saudi Arabia. The study adopted a quantitative research design using the cross-sectional approach. The study revealed that participants of the study frequently used religious coping strategies other than existential coping strategies (Alquwez & Alshahrani, 2020). Findings

also revealed that participants gained higher social support from significant others and lower social support from friends (Alquwez & Alshahrani, 2020). Also, a larger number of the participants reported having mild to moderate depression, whereas more than one-third of the participants reported mild to severe anxiety. Overall, the results indicated that social support and spiritual coping significantly impacted the informal caregivers' quality of life and mental health (Alquwez & Alshahrani, 2020).

2.2.4 Relationship between social support, caregiver burden and wellbeing

Social support, caregiver burden and psychological well-being are related to the perceived health of caregivers of caregivers (Hernández-Padilla et al., 2020). A study was conducted by Hernández-Padilla et al. (2020) to analyse perceived social support, perceived health and caregiver burden among 225 family caregivers of individuals with Alzheimer's disease in Spain. The study also investigated perceived social support as a mediating variable between caregiver burden and perceived health, taking into consideration the gender of the caregivers. The study adopted a quantitative research method through the use of survey questionnaires. Findings from their study indicated that differences in perceived social support and perceived health were significantly higher in women than in men (Hernández-Padilla et al., 2020). The relationship between perceived health and family caregiver burden in women was mediated by perceived social support. This mediation was not observed among men used in the study. According to this study, family caregivers of Alzheimer's patients' mental health and caregiver burden are influenced by their perception of social support. However, the impact varies depending on the gender (Hernández-Padilla et al., 2020).

Another study conducted by George et al. (2020) assessed the relationship between caregiving and psychological distress and the moderating effect of social support in the relationship.

The study sampled 267,041 participants aged 45 years and above for the study from Australia and New South Wales. The quantitative research method was used for this study. The study also made use of the multiple regression analysis and moderation analysis methods to analyse quantitative data gathered from the research. Findings from this study indicated that the strength of the relationship between caregiver status and psychological distress was reduced to 40% for full-time caregivers and to 60% for part-time carers when a perception of social support exists in the relationship. This study also suggested the use of health campaigns in promoting the awareness of the existence of caregiver burden (George et al., 2020).

In Spain, a study was conducted by García-Torres et al. (2019), to investigate the predictive efficacy of the specific social support domains that contribute to the psychological or emotional well-being of cancer caregivers. A sample of 67 caregivers of cancer patients was used for the study. Instruments used for the research included a socio-demographic questionnaire, the Berlin Social Support Scale (BSSS) and the Hospital Anxiety and Depression Scale (HADS). Data were collected at two points in time. Time 1 (T1) was 30–45 days after diagnosis was made and Time 2 (T2) was 180–200 days after diagnosis was made. The researchers adopted the TRIPOD checklist for this study. Results from this research showed that there were statistically significant variations between the two evaluation points for the social support domains of protective buffering, support satisfaction, and perceived emotional support (García-Torres et al., 2019). Fewer sports and physical activity, greater support seeking, and less informational support at T1 were all predictive of anxiety at T2. In contrast, depression was predicted by less perceived support availability, which was what the logistic regression analysis used for the study indicated (García-Torres et al., 2019).

Studies done on social support in the study area looked at the moderating effects of social support in the relationships between caregiver burden and wellbeing, but these studies have mostly been conducted outside of the Ghanaian sociocultural context. Hence, the present study examined the moderating effects of social support in the relationship between caregiver burden and well-being among caregivers of older adults living with chronic diseases in the Ghanaian context.

2.3 Rationale of the study

Most of the studies done in the study area were done outside of the Ghanaian sociocultural context (Özdemir et al., 2020; Ploeg et al., 2020; Zhong et al., 2020) and may not account for the sociocultural differences that exist among the various sociocultural contexts hence the need to conduct more of such studies in the Ghanaian context to help develop interventions that meet the needs of caregivers in the Ghanaian society.

The literature review revealed a research gap that exists in the area of study. The methods used by existing studies were inadequate to highlight the lived experiences of caregivers of older adults living with chronic diseases. Methodologically, most of the studies conducted in the research area relied on the qualitative research design (Agyemang-Duah et al., 2019; Ploeg et al., 2020; Kyei-Arthur et al., 2022; Agyapomah et al., 2023) and a few relied on the quantitative research approach (Özdemir et al., 2020; Abeasi, 2020), but this study tends to fill the methodological gap using a mixed method design to obtain both an objective inquiry as well as a detailed and rich description of the phenomenon. This study, therefore, explored the experiences of family caregivers, investigated their psychosocial experiences in terms of spirituality, social support, depression, caregiver burden, wellbeing, and coping strategies. The study also examined the impact that caregiver burden, depression, spirituality, and social support have on caregiver

wellbeing, as well as the relationship between coping strategies and caregiver wellbeing, with the mixed methods approach.

Also, beyond exposing and exploring caregiver burden among caregivers of older adults living with chronic diseases, there were limited data or research studies that explored the needs of caregivers that could lessen the burden of care. Most of the studies done in the study area in Ghana mainly explored the experiences and coping strategies of caregivers of older adults living with chronic diseases (Abeasi, 2020; Kyei-Arthur & Cudjoe, 2020; Kyei-Arthur et al., 2022; Agyapomah et al., 2023). However, previous studies did not adequately take into account the needs of caregivers. This study, however, explored the needs of caregivers in the Ghanaian context. According to Adashek and Subbiah (2020) due to limited data in the study area, it is important to understand caregiving experiences from the perspectives of different societies/ethnicities and customs and the unique cultural norms used for discussing, approaching, and coping with patients with chronic diseases; and also posited that having this in-depth understanding will shape the development of personalised caregiving strategies to educate and empower caregivers.

2.4 Research Questions

1. What are the psychosocial experiences of caregivers of older adults living with chronic illnesses?
2. How do caregivers cope with the caregiver burdens they experience while taking care of older adults with chronic illnesses?
3. What will caregivers need in the course of caregiving that could reduce caregiver burden?

2.5 Statement of Hypotheses

1. There will be a significant negative relationship between caregiver burden and well-being.
2. Depression will mediate the relationship between caregiver burden and well-being.

3. Social support will moderate the relationship between caregiver burden and well-being such that at high levels of support, the effect of caregiver burden will be reduced.
4. Spirituality will moderate the relationship between caregiver burden and well-being such that at high levels of spirituality, the effect of caregiver burden will be reduced.



CHAPTER THREE

METHODOLOGY

This Chapter presents the method that was used for this study. It highlights the research design, study area, study population, sampling and sampling technique, measures, research procedure, data analysis, and ethical considerations.

3.1 Research Design

A mixed methods design was used for this study. A mixed methods research design (quantitative and qualitative) enables the researcher to make both an objective inquiry as well as get a detailed and rich description of a phenomenon (Schoonenboom & Johnson, 2017). A concurrent mixed method design was used, which allowed for both quantitative and qualitative data to be collected at the same time and within a shorter period of time (Bell et al., 2022). This approach was used because it allowed the researcher to use standardized questionnaires to gain quantitative data and the use of in-depth interviews to obtain qualitative experiences, to provide a detailed and comprehensive analysis of the research questions.

The concurrent approach was also used because it helped the researcher to objectively obtain multiple perspectives on the topic of caregiver burden and acquire more complete information for addressing the research questions over a shorter period of time. The quantitative method was used to examine the influence of caregiver burden on wellbeing amongst caregivers of older adults living with chronic illnesses as well as the psychosocial experiences they encounter in the course of caregiving whereas the qualitative method was used to explore in detail the nature of the experiences, the coping strategies employed by these caregivers and the resources that are available to help them to cope with caregiving.

A cross-sectional study design was used, and this also provided information about existing relationships between caregiver burden and the psychosocial experiences they encounter.

3.2 Research Setting

This study was conducted in the Ga East Municipality in the Greater Accra Region of Ghana. One of the sixteen (16) municipalities that make up the Greater Accra Region is the Ga East Municipality. It is located in the north of the region, between latitudes 5°36' and 5°47'N and longitudes 0°15' and 0°11'W. With a total area of 96 km², it is bordered on the west by the Ga West Municipality, on the east by the La-Nkwantanang-Madina Municipality, and on the north and south by the Akuapem South District and the Ayawaso West Municipality, respectively (Frimpong et al., 2022). The Municipality's capital is Abokobi, and the area is divided into two administrative zonal councils, that is, the Dome and Abokobi zonal councils (Ga East Municipal Assembly, 2018). Four main economic activities take place in the municipality, that is, industrial, commerce, service and agricultural activities (GSS, 2021). There are twenty health facilities in the municipality, but the Ga East Municipal Hospital and the Ghana Atomic Energy Commission Hospital are two major hospitals in the area that were used as research sites to gather data for the study. The reason behind the selection of these two hospitals as the study site was that they are notable hospitals in the municipality that make use of the national health insurance card; hence, the hospitals' facilities are accessible to individuals from all socioeconomic backgrounds. This research setting was used because it was the most suitable setting that provided the kind of participants needed for the study. The study sites also made accessibility to these participants very easy.

3.3 Population, Sample, and Sample Size Determination

The population for the study was caregivers of older adults living in the Greater Accra Region of Ghana who frequented the Ga East Municipal Hospital and the Ghana Atomic Energy Commission Hospital. A total of 100 caregivers of older adults living with chronic illnesses were sampled from the population for the quantitative study. This sample size was determined by Tabachnick and Fidell (2018) sample size calculation, $(N) = 50 + 8m$, where N is the sample size and m represent the number of independent variables or predictor variables. The number of predictor variables for this study was 4. Hence, the minimum sample size required for this study was 82. Therefore, a sample size of 100 was adequate for the study. For the qualitative aspect of the study, 10 caregivers were recruited using convenience and purposive sampling strategies.

These sampling approaches allowed the researcher to sample participants who were readily available and willing to provide information that would help achieve the objectives of the study. The sample size for the qualitative part of the study was appropriate as participants were assumed to have sufficient information, considering the aims of the study, sample specificity, quality of dialogue, guided theory and analysis strategy. Malterud et al. (2016) referred to this concept of sample determination as “information power” and recommended its use in the determination of sample sizes for qualitative studies instead of the concept of saturation.

3.5 Inclusion Criteria

The inclusion criteria for participants of the study were family caregivers aged 18 years and above who had a year or more experience in the provision of care for older adults living with chronic illnesses, specifically stroke, cancer, chronic kidney disease, diabetes and Hypertension. The age requirement for their care recipients was 60 years and above which made them suitable to participate in this study.

3.6 Exclusion Criteria

Individuals were excluded if they were professional caregivers (paid to provide care), family caregivers below 18 years, and family caregivers who had been providing care for less than a year to older adults with chronic illnesses.

3.6 Socio-demographic characteristics of participants

Data on the demographic characteristics of the participants were collated as part of the analyses for the qualitative and quantitative parts of the study. Socio-demographic characteristics of participants are presented in Table 1 and 2 are as follows:

Table 1

Demographic characteristics of participants for the qualitative study

Participant	Gender	Age of caregiver	Duration of care	Age of care recipient	Educational level	Religion	Type of Illness
P1	Male	26	3	78	Tertiary	Christian	Stroke
P2	Female	25	1	70	Tertiary	Christian	Cancer
P3	Male	30	7	66	Tertiary	Christian	Stroke
P4	Female	24	1	77	Tertiary	Christian	Stroke
P5	Female	26	2	69	Tertiary	Christian	Stroke
P6	Female	30	8	64	JHS	Muslim	Stroke
P7	Male	30	2	63	SHS	Christian	CKD
P8	Male	24	9	71	SHS	Muslim	Diabetes and Hypertension
P9	Female	26	5	74	Tertiary	Christian	Diabetes and Hypertension
P10	Female	22	2	65	Tertiary	Christian	Diabetes and Hypertension

Summary of the demographic characteristics of participants of the qualitative study are presented in Table 1. From the data presented in Table 1, the average age of participants providing care is 26.1 years. This relatively young age suggests that caregiving responsibilities are being undertaken by individuals in the early stages of adulthood. Majority of the participants (n=6) were females (60%) while the males (n=4) constituted 40% with an average duration of care provided is 3.8 years, indicating that participants are engaged in caregiving for extended periods.

Table 2

Demographic Characteristics of participants of the quantitative study (N = 100)

Variable	Frequency	Percentage
Gender		
Male	39	39%
Female	61	61%
Age		
18-25	33	33%
26-35	52	52%
36 and above	15	15%
Duration of care		
1-3	69	69%
4-7	26	26%
7 – 10	5	5%

Table 2. above shows the demographic characteristics of the participants. The study included 100 participants. Of these, 39% were male, and 61% were female. The majority of participants were between 26-35 years old (52%), followed by 18-25 years old (33%) and 36 years and above (15%). In terms of tenure, 69% had 1-3 years of experience, 26% had 4-7 years, and 5% had 7-10 years.

3.7 Measures

3.7.1 Demographic questionnaire

A demographic questionnaire was developed to gather information on the family caregiver's personal information. Personal information assessed included the family caregiver's gender, age, level of education and religious affiliation. The data obtained on caregiving also included the age of the care recipients, the type of chronic illness of the care recipients, and the number of years of experience in the provision of care to the care recipients. Refer to Appendix 5.

3.7.2 The Zarit Burden Interview- ZBI Revised 22-items (Zarit et al, 1980)

The Zarit Burden Interview (ZBI-22) is a revised form of the original 29-item scale developed by Zarit et al. (1980). The ZBI is a 22-item self-reported scale that measures caregivers' personal, role strains and the perceived burden reported by caregivers of older adults. The ZBI also assesses the impact of caregiving on the financial situation, psychological well-being, and social life of caregivers. It is scored on a 5-point Likert scale ranging from 0 (Never) to 4 (Nearly Always). Total scores were obtained by summing up responses. Scores ranging from 0 to 20 indicated no burden or a mild burden of care; a score of 21 to 40 revealed a mild to moderate burden of care. Scores of 41 to 60 were interpreted as moderate to severe burden, and scores greater than or equal to 61 revealed severe burden. The Cronbach alpha of ZBI ranges from .85 and .93 (Al-Rawashdeh et al., 2016).

3.7.3 Beck's Depression Inventory (Beck et al., 1961) BDI -II

The BDI-II is a 21-item self-report scale that measures attitudes and symptoms of depression. It helps to assess the severity of depression. The BDI-II contains 21 items rated on a 4-point Likert scale ranging from 0 to 3, with a score of 0 indicating that a symptom is absent and a score of 3 indicating symptom severity. Symptoms assessed on the BDI-II include affective, cognitive, somatic and vegetative symptoms. Scoring the BDI-II was achieved by adding the scores for all 21 items. The minimum score achieved was 0, and the maximum score was 63. Higher scores on the BDI-II indicated a greater symptom severity. Scores ranging from 0–13 reveal minimal depression, 14–19 indicate mild depression, 20–28 indicate moderate depression, and scores of 29–63 indicate severe depression (Jackson-Koku, 2016). With a high internal consistency reliability, the BDI-II has a Cronbach's alpha of .81- .89, and good test-retest reliability (Lee et al., 2017).

3.7.4 Revised Berlin Social Support Scale (Roomaney et al., 2020) BSSS

The Revised Berlin Social Support Scale (BSSS) was developed to assess behavioural and cognitive factors of social support, and to evaluate quantity, function, and type of social support in both stressful and general circumstances. It is a 17-item measure rated on a 4-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree). The scale had two subscales: the perceived social support and the received social support. Scores are obtained either by summing up item responses or by generating the scale mean score (Schulz & Schwarzer, 2003). For this study, a scale mean score was generated and used to assess both received and perceived social support. With a high internal consistency reliability, the Cronbach's alpha of the BSSS is .89 (Roomaney et al., 2020).

3.7.5 The World Health Organization Wellbeing Index (World Health Organization, 1998) WHO-5

The World Health Organization Wellbeing Index (WHO-5) is a 5-item self-reported measure that assesses psychological well-being over the past two weeks. Items are rated on a 6-point Likert scale ranging from 0 (not at all) to 5 (all the time). The raw scores on the World Health Organization Well-being Index (WHO-5) range from 0 to 25 and are multiplied by 4 to give the final score, ranging from 0 to 100, with a score of 0 indicating very poor well-being and 100 indicating the best possible well-being (Topp et al., 2015). With high internal consistency and reliability, The WHO-5 has a Cronbach's alpha that ranges from .85–.91, and good test-retest reliability (Fung et al., 2022).

3.7.6 Attitudes Related to Spirituality Scale (Braghetta et al., 2021) ARES

The Attitudes Related to Spirituality Scale (ARES) is a scale that helps to investigate the influence of spirituality on different study populations. It measures the attitudes of individuals towards spirituality and their relationship with a transcendence. It is also an 11-item instrument that measures spirituality on a 5-point Likert scale ranging from 1 (totally disagree) to 5 (totally agree). A mean score was generated for this study to help assess scores for the level of spirituality of participants. The Attitudes Related to Spirituality Scale (ARES) has an excellent internal consistency at an alpha level of .98 (Braghetta et al., 2021).

3.7.7 Semi-Structured Interview Schedule

A semi-structured interview guide was developed and used to explore in-depth the subjective experiences of the family caregivers and the impact of caregiving responsibilities on their well-being. It helped to investigate family caregivers' use of coping strategies and access to resources and support services that enable them to deal with the challenging demands of caregiving.

The interview guide consisted of six sections: 1) The personal information of participants, 2) The caregiving situation, 3) The thoughts and experiences of caregivers about caregiving, 4) Psychological and social problems associated with caregiving, 5) How participants cope with the challenges of caregiving, and 6) Needs assessment and support services available to caregivers. Where necessary, further probing was done to seek further information and/or clarification of issues from participants.

3.8 Procedure

Ethical clearance was first obtained from the Ethics Committee for Humanities of the University of Ghana (Reference: 097/23-24). An introductory letter from the Department of Psychology with details about the purpose of the study and the researcher's details was then sent to the research sites (Ga East Municipal Hospital and the Ghana Atomic Energy Commission Hospital). After obtaining approval from the research sites, the researcher visited the sites to familiarize herself with the research sites. The researcher then recruited participants who met the inclusion criteria to participate in the study.

The data collection process then began by first explaining the study to the participant and obtaining written or oral consent from the participants. Participants were asked to carefully read the informed consent forms and decide whether they wanted to participate in the study and then sign the form. Translations were done orally in a local dialect (Twi) for participants who had difficulties reading the written informed consent form in English. Participants were informed of their right to withdraw from the study if they wanted to discontinue the process even after they had given their initial consent. After ethical issues were dealt with, data were collected from interested participants.

For the qualitative aspect of the data collection process, after contact was made with participants, interviews were scheduled in conducive environments devoid of distractions. Interviews lasted between 40-60 minutes, and were conducted using the semi-structured interview schedule, and they were audio recorded. The questions were translated into the local language for participants who did not understand English. A translation guide was developed that provided standardized wording and phrasing for each question in the local language. This ensured that all participants received the same meaning and intent of the questions, regardless of whether they were read in English or translated orally. This helped with uniformity and consistency in the study. Once participants had shared their traumatic experience/s, they received brief psychotherapy from the clinical psychologist on standby after the interview.

For the quantitative aspect of the study, it took participants about 15-30 minutes to complete the questionnaire as part of the data collection process. The purpose of administering the questionnaires to participants was explained before the data collection process began. Also, Participants for the qualitative study did not participate in the quantitative study. Participants who experienced extreme levels of stress while recounting their caregiving experiences were referred to a clinical psychologist for psychological intervention at the Ga East Municipal Hospital.

3.9 Ethical considerations

The study was conducted in line with the APA code of conduct that guides conducting research with human participants (APA, 2020). Ethical approval and clearance was obtained from the Ethics Committee for Humanities of the University of Ghana (Reference: 097/23-24). Interested participants were provided with information pertaining to the aims of the study, and informed consent was sought from participants interested in taking part in the study. The researcher ensured confidentiality, anonymity, voluntary participation, and minimizing harm. To ensure voluntary participation, participants were given the free will to participate in the study. In addition, the

researcher ensured that no form of physical or emotional harm was done to the participants, although there was a possibility of emotional distress for the participants involved. Hence, a clinical psychologist was on standby to offer psychological support if any participant needed psychological support during and after the study. Provisions were also made for participants to see the clinical psychologist at the Ga East Municipal Hospital in Accra if they experienced distress during the interview sessions that took place at the hospital. Furthermore, confidentiality was ensured by conducting the interviews in an environment free from distractions that served as a safe space for participants. In the analysis process, pseudonyms were used as a means of ensuring confidentiality and anonymity. The participants were also at liberty to withdraw from the study at any point in time if they so desired.

3.9 Data Analysis Strategy

3.9.1 Quantitative Data Analysis

The data were analysed using Jamovi statistical software. This software was used in analysing data because, despite its highly advanced analytical capabilities, it is straightforward, adaptable, and simple to use in comparison with the SPSS software (Ahmed & Muhammad, 2021). Three types of analyses were conducted. First, data analysis involved preliminaries that tested for internal consistencies of the instruments, skewness and kurtosis and descriptive statistics. Pearson product-moment correlation coefficient (Pearson r) was used to examine the relationship between the variables, i.e. caregiver burden (CB), depression (D), social support (Support) and wellbeing (WHO). Hierarchical Regression and Slope analyses were used to analyse the hypotheses. Regression was used to test Hypothesis 1. Mediation analysis was used to test Hypothesis 2, whereas moderation analysis was used to investigate Hypotheses 3 and 4.

3.9.2 Qualitative Data Analysis

The data was analysed using thematic analysis. Specifically, the Interview transcripts were analysed using Braun and Clarke's (2006) six steps for thematically analysing qualitative data.

These steps included; firstly, data familiarization, generation of initial codes, development of themes based on initial codes, review of themes, definition and naming of themes then writing of reports. Thematic analysis was used to help capture important details that related to the research questions and also to gain relevant themes that offered a better understanding and interpretation of the data obtained from the participants (Braun & Clarke, 2006). Thematic analysis was adopted for the purpose of this study because of its flexibility and its usefulness when dealing with participants as collaborators in a research paradigm (Braun & Clarke, 2006). After the data were transcribed, the transcripts were read over at least four times for familiarization. On the fourth reading, several codes were generated based on the responses that were identified from every participant. The generated codes were then categorised into subthemes and then into themes that explained common ideas. The various themes were also reviewed, re-defined and discussed in relation to the research questions.

Finally, based on the research analysis done, the researcher wrote a corresponding report highlighting research findings. In addition, general quotations made by participants that relate to the themes discovered were added to the report.

3.10 Trustworthiness of findings

Polit and Beck (2014) described trustworthiness of data as the most important criterion for assessing the measure of confidence in data obtained, methods used and interpretations of results to ensure the quality of any study. The trustworthiness of findings for this study was ensured using Shenton's (2004) recommendations. Shenton (2004) proposed four criteria that should guide

qualitative studies, which are: credibility, dependability, transferability and confirmability. In this research, trustworthiness was addressed through strategies aimed at enhancing credibility, dependability, transferability, confirmability and reflexivity. To ensure the credibility of results, at least a month's engagement and rapport building with family caregivers was done after establishing contact with them at the hospitals. This enabled them to build trust and confidence in the researcher and, therefore, decreased the likelihood of participants giving fabricated responses. Coded themes generated by the researcher were reviewed by supervisors to serve as a check to ensure that conclusions were based on participants' accounts and were devoid of researcher biases.

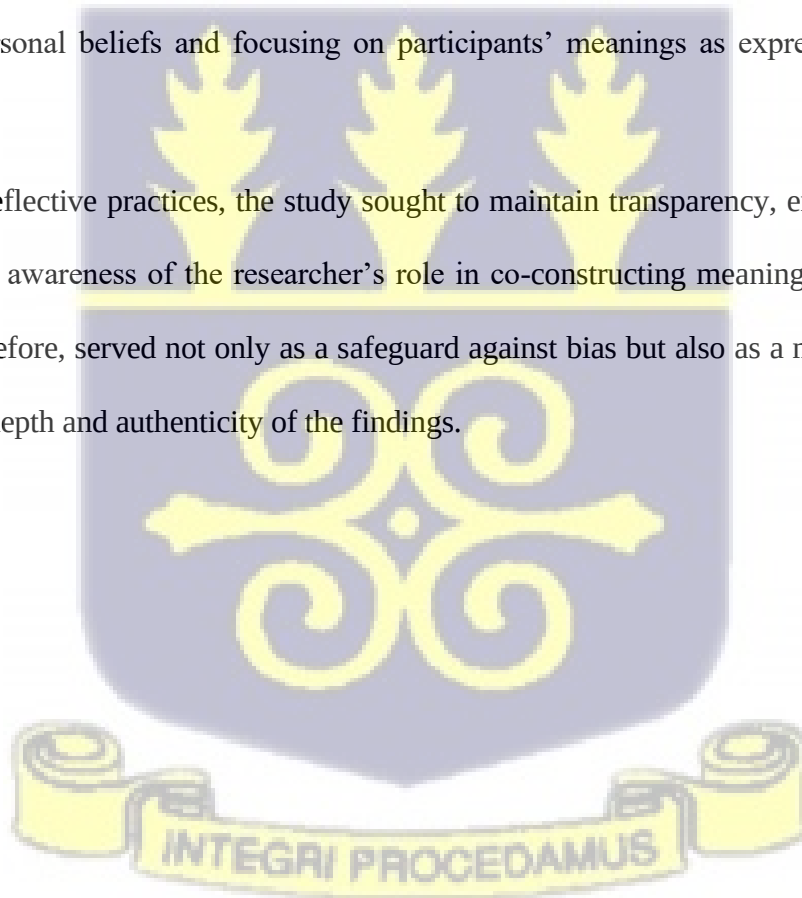
In ensuring the dependability of findings, all procedures used during data collection, which included interviews, transcriptions and discussions, were carefully documented. This also allowed for the provision of a detailed account of procedures followed during data collection and data analysis to enable replication of findings. For the Transferability of the qualitative findings, it was achieved by collecting enough detailed data to enable comparison with similar contexts. The study adopted a purposive sampling technique, which defined the sample of family caregivers of older adults dealing with chronic illnesses used and a description of the research context was also provided to allow judgment for whether it fits in other possible contexts or not (Guba, 1981). To promote confirmability, the researcher recorded responses of participants with a recorder and the data collected was manually transcribed by the researcher.

In reflexivity, a researcher examines how their personal background, including gender, culture, history, and socioeconomic status, as well as their biases and views, may have shaped how they interpreted the study (Cresswell, 2014). Reflexivity involves a continuous process of self-examination in which the researcher reflects on their own assumptions, experiences, and potential biases that could influence the research process and interpretation of data. In this study, the researcher

engaged in reflexivity throughout all stages of the research. The researcher reflected on personal motivations for studying caregiving, acknowledging possible biases stemming from, e.g., prior clinical experience, personal encounters with caregiving, or cultural understandings of family responsibility. To minimize these influences, the researcher maintained a reflexive journal to document thoughts, emotional reactions, and evolving interpretations after each interview. This process helped to separate participants' perspectives from the researcher's preconceptions.

During data analysis, regular peer debriefing sessions and consultations with a research supervisor were held to challenge assumptions and ensure that emerging themes were grounded in participants' narratives rather than personal expectations. The researcher also practiced bracketing, consciously setting aside personal beliefs and focusing on participants' meanings as expressed in their own words.

Through these reflective practices, the study sought to maintain transparency, enhance credibility, and demonstrate awareness of the researcher's role in co-constructing meaning with participants. Reflexivity, therefore, served not only as a safeguard against bias but also as a means of enriching the interpretive depth and authenticity of the findings.



CHAPTER FOUR

RESULTS

This chapter presents the results of the two distinct phases of the study: one qualitative (referred to as Phase I) and one quantitative (referred to as Phase II). The qualitative findings are discussed first, followed by an examination of the quantitative results. Consequently, the results from each study are detailed below.

4.1 Findings of Phase I of the Study

As stated earlier, the qualitative data from the participants were analysed using thematic analysis as suggested by Braun and Clarke's (2006) six-stage analysis of qualitative data. Four major themes emerged from the analysis: 1) *Caregiving as a journey of meaning and growth*, 2) *Emotional turbulence, disruption of financial and social life*, 3) *Finding strength in faith, support and adaptation*, and 4) *Unmet needs and quest for recognition and support*. Verbatim quotations are provided to illustrate each theme and subtheme extracted from the data. Table 3 highlights the themes and subthemes that emerged from the data.

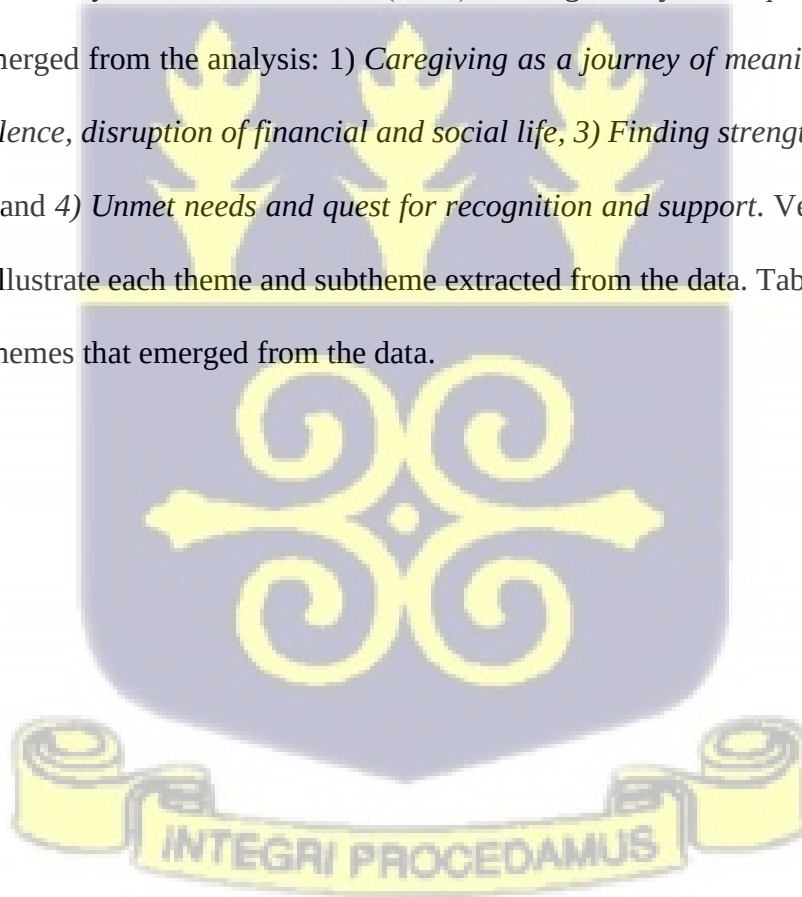


Table 3
Themes and subthemes

Theme	Subthemes
Caregiving as a Journey of Meaning and Growth	Life of a caregiver Caregiver responsibilities Challenges of caregiving
Emotional turbulence, disruption of finances and social life	Emotional impact Social impact Financial impact
Finding Strength in Faith, Support, and Adaptation	Self-care practices Social support
Unmet Needs and the Quest for Recognition and Support	Training and support Emotional and psychological support

4.1.1 Caregiving as a Journey of Meaning and Growth

The above theme emerged as one of the major themes in the study. The theme encompasses the diverse experiences of family caregivers for family members who have chronic diseases. Three subthemes made up this theme: *life as a caregiver*, *responsibilities of caregivers* and *challenges in caregiving*. These subthemes are discussed in the following paragraphs.



Life of a caregiver

Prior to becoming caregivers, all the participants described their lives as happy and devoid of any stress or restrictions. It was evident that the participants could live their lives as they desired. Thus, the participants, before becoming caregivers, were very sociable, outgoing and moderately happy individuals who lived their lives with freedom. For instance, one participant who was taking care of his 78-year-old grandfather described himself before caregiving as follows: *“I wasn't the kind of person that was restricted. I could go out anytime I want. I could come back anytime I want. So, before being a caregiver, I was happy”* (Participant 1, Male).

Another participant highlighted her life before caregiving in this quote *“I was living life, I didn't really have much worries as a young lady, I was just like, trying as much as I could to like, realize my dreams, and do what I liked, basically enjoy life”* (Participant 5, Female).

Upon assuming caregiving responsibilities, all participants reported experiencing an overwhelming shift in every aspect of their lives. The weight of caregiving responsibilities gradually took over their personal time, social interactions, and professional aspirations, creating a sense of confinement and isolation. Many described feelings as though their lives had lost the diversity of experience; they once enjoyed turning their once lively routines into a repetitive cycle of care tasks, which left little room for anything else. Social relationships, which were once a source of joy and emotional support, began to dwindle. One participant explained that:

My life is like, monotone, if I should say it that way, it's just like one way. You can't really do much, I can't do some of the things I would like to do, I can't like, go out, stay out late, you know, you have, I have to be home early to make sure that everything is going on, and as the one who is like, financially supporting the house now, I can't even spend money the way I'd want to spend money (Participant 5, Female).

Emotionally, the impact was devastating. Caregivers often expressed feelings of guilt, not only for moments when they felt frustrated or overwhelmed but also for desiring a break from their caregiving duties. These emotions were compounded by the physical exhaustion that many caregivers experienced. One participant stated that:

One time I felt overwhelmed and I began to shed tears, I had to move away from her and not cry in front of her because I don't know what she is even going through and I am feeling all sad about it. I felt guilty that I was crying and there was no one for me to turn to and say I am crying so help me out. (Participant 2, Female).

The relentless demands of caregiving meant sleepless nights, chronic fatigue, and in some cases, deterioration in their own health. Some participants highlighted as follows: *“So, I don't get time to rest. So, I wake up very tired and I usually have back pains and headaches”* (Participant 1, Male) Another stated that *“Because I have been taking care of my dad, I usually have backpains, I feel embarrassed when my friends come over and I am not really myself like I am no longer who I used to be”* (Participant 4, Female).

Thus, caregiving became an all-consuming responsibility, robbing them of their sense of self. Many participants expressed a loss of personal identity, as their roles in their personal lives were overshadowed by the singular identity of being a caregiver. They no longer had time to pursue their own hobbies, dreams, or even basic self-care, which led to feelings of resentment, helplessness, and a sense that they were simply existing rather than truly living. A participant had this to say: *“But physically, it's tiring because you have to carry him here, carry him there, bath him, you're not getting enough sleep, but you still have to do whatever you have to do for him the next morning”* (Participant 1, Male).

This transformation left caregivers with a sense of grief, not only for the life they once had but also for the person they used to be.

Caregiver responsibilities

The participants made mention of their caregiving responsibilities, highlighting the complex and varied nature of the roles they perform. These duties included not only routine domestic tasks such as cleaning, cooking, and managing the household, but also more specialized care tailored to the specific health needs of their care recipients. This added layer of responsibility significantly increased their workload, contributing to elevated levels of stress and fatigue. A 25-year-old female participant who is taking care of her 78-year-old auntie with breast cancer explained the variety of responsibilities she performs for her in the quote below.

So, on a daily basis we ensure that she eats well, we cook for her, we wash for her, we sometimes bath her especially for the first week after her chemotherapy, we do everything for her so cleaning washing even sometimes using her phone to be answering calls for her. We do basically everything. So, after the first week of her chemo and radiation she becomes sort of an invalid, and was unable to care for herself and that is the time she needs me the most. So that's the time I take care of her by doing basically everything for her. But then after the first week of the chemo she is actually able to bath herself but for the cooking we are trying to reduce it for her so we cook for her most of the time (Participant 2, Female).

Another participant who is responsible for caring for her 77-year-old father with a stroke described her responsibilities as basically doing everything for her father. She shared that

So, when I wake up, I have to give him food, give him his medicine, take him outside for fresh air because he insists. He wants it outside. Bring him back when he gets tired of it.

Take him again. We help him use the loo because he doesn't want to use pampers. I don't know if it's because his ego is too much. So, I take him to the loo, bring him back and then attend to his basic needs. He needs water and all that stuff. (Participant 4, Female)

Many participants were responsible for transporting the care recipient to medical appointments and ensuring they received timely and appropriate medical attention. This included keeping track of medical schedules, administering medications as prescribed, and coordinating with healthcare professionals. They highlighted the need to monitor the care recipient's overall health and well-being, often acting as mediators between the care recipient and healthcare providers. In some cases, caregivers had to manage complex medical regimens, assist with physical therapy, and respond to medical emergencies, illustrating the depth of their involvement in both the physical and emotional care of those they supported. Despite these challenges, participants expressed a strong sense of duty, compassion, and dedication in fulfilling their caregiving roles. One participant had this to say.

So, I always take to her hospital appointments and make sure she eats the right food all the time. I also help her to take her medications and make sure she's eating healthy foods like I earlier mentioned. So basically, foods that are suggested by the dietician (Participant 9, Female)

Challenges of caregiving

The majority of the participants shared various challenges they encountered in their caregiving roles. A significant issue highlighted was the uncooperative behaviour of the care recipients. Participants noted that the care recipients often resist following their guidance, particularly when it comes to adhering to medication schedules. In some cases, care recipients even refuse to take their prescribed medications, stating that they need a break or "holiday" from their medications.

This defiance adds some level of difficulty to the caregivers' efforts to provide consistent and effective care. The excerpt below reveals the experiences of one participant.

Sometimes, she doesn't want to take her medications. She usually says the medications are too much for her. And she wants a holiday. That's the stuff she was saying. She wants a holiday. Like, today, let's take it off. I'll be like, okay, fine. But, you know, she's supposed to be taking her medications. And then, you're going to be stressed. When she does that, it becomes a challenge for me. (Participant 8, Male)

Another participant also stated that: *“so he usually does not listen to the doctors and do whatever he wants so taking care of him becomes really challenging and difficult”* (Participant 1, Male).

It was evident among the participants that caring for a loved one who consistently resists guidance and medical advice creates a deep emotional burden. In some cases, the participant's patient's refusal to follow dietary and treatment recommendations had led to serious health complications, worsening the caregiver's sense of responsibility and guilt. For instance, in the case of a 26-year-old caregiver of a 74-year-old grandmother with diabetes, the situation had escalated to the point where the patient faced potential amputation, which the caregiver believes could have been avoided if earlier advice had been heeded. The inability to persuade the patient to make healthier choices has left the caregiver feeling powerless, despite attempts from family members and the medical team. The emotional toll is immense, as the caregiver feels stuck, questioning whether their efforts are sufficient and fearing the possible outcomes. She exclaimed in the quote below:

She does not listen to anything. Sometimes she just wants to eat what she wants to eat whatever she wants. She does not care whether it will be bad for her or not. It makes it

really challenging. Especially now and with her foot situation. I am really suffering to take care of her. Everyone close to her has also spoken to her but to avail. That is very overwhelming (Participant 9, Female).

4.1.2 Emotional turbulence, disruption of finances and social life

This theme reflects the impact of caregiving on family caregivers. Three subthemes made up this theme: emotional impact, social impact, and financial impact. Direct quotes from participants are included to reinforce the narratives in the following paragraphs.

Emotional impact

Caregiving appeared to be an emotionally draining experience for the family caregivers. Caregiving for elderly parents with terminal illnesses is often described as a physically, emotionally, and mentally taxing experience. The participants reported the profound emotional toll it could have on them, especially those who saw themselves as the primary source of care. All the caregivers expressed feelings of deep exhaustion. For instance, in the case of one participant, the responsibility of caring for two ailing parents weighs heavily on her, particularly following her father's mild stroke. She experiences a profound sense of isolation, often crying privately to shield her parents from the depth of her exhaustion and sadness. She said:

There are days that I cry like I said earlier, it is just not easy. I cry most times, I am tired but I can't also give up because they are my parents and I have to do it for them not for my sake, also, I need my dad to live longer (Participant 10, Female).

Another participant also expressed himself in the quote below:

Filled with anxiety. Yes, I'm filled with anxiety and fear. Because, certainly every day she keeps deteriorating, like you see changes in her and not for the better. So, it's quite

bothering and scary. I am mostly sad all the time. Because my mother is sick (Participant 7, Male).

In addition to the emotionally draining experiences of caregiving, the participants also conveyed deep feelings of frustration. These frustrations seemed to stem primarily from witnessing the progressive deterioration of the health of those under their care. Many caregivers expressed that the slow decline in the well-being of their loved ones, especially in cases of terminal illness, fostered a profound sense of helplessness. This sense of hopelessness aggravates their emotional burden, as they often feel powerless to stop or alleviate the suffering of their care recipients. In some cases, the relentless toll of the disease on the care recipients leads caregivers to feel that death might offer a more merciful end to their suffering. Though painful to admit, some caregivers revealed that they sometimes wished for the care recipient's passing as a means of relieving not only their own distress but also the suffering of their loved. One participant expressed that below:

And when I look at my mother, I wish there was something I could do to take her pain away. Sometimes I even wish she would just die especially with this current critical state that she is in so that she'd be free from the pain (Participant 6, Female).

The emotional toll of caregiving was to such an extreme that in the case of some participants, it led to suicidal ideations. The constant stress, physical exhaustion, and mental burden associated with providing care overwhelmed such individuals, causing feelings of hopelessness, isolation, and despair. The emotional strain of constantly attending to the needs of others, often without adequate support or respite, compounded their sense of helplessness. Over time, the pressure of being responsible for another person's well-being became too much to bear, and thoughts of suicide emerged as an escape from the unrelenting demands of caregiving. This situation underlines the

significant psychological risks associated with caregiving, particularly when individuals lack the necessary emotional and social support systems. They said:

I mean there are sometimes where I felt suicidal at a point that in death there is not going back so when I die why should I experience the things I go through? I won't face the challenges I am facing so why don't I die and then leave everything? But I realized that there is a greater purpose for me rather than to die or cut my life short so we are still pushing forward (Participant 3, Female).

“There are times i feel like ending it all because her situation is not getting better, my life is at a standstill and my money keeps going” (Participant 3, Male).

Social impact

Socially, the impact of caregiving on the caregivers was equally profound, significantly altering their personal lives. All the participants expressed that caregiving had led to substantial social restrictions, limiting their ability to engage in regular social activities. This withdrawal from social life created a sense of isolation and disconnect from their community and social networks. The caregivers often felt as though their roles had confined them to their homes, leading to a reduced sense of personal freedom and emotional fulfilment. Some participants explained their new lives in the quotes below.

And then, in a social way too, I feel I'm more excluded from the social life because I'm mostly at home. Because if I'm living home, I think I have to go through so much before I go. I feel I'm supposed to be around in case of anything. And how she will make you feel even when you're going out. It's very bad. (Participant 8, Male).

Another stated that: *“I cannot even go anywhere again. No social events whatsoever. I have to always be with her at the hospital”* (Participant 4, female).

Furthermore, the participants reported that caregiving had negatively impacted their relationships with other people, leading to feelings of isolation and emotional strain. Many participants expressed that the time and energy required for caregiving left little room for maintaining social connections, which in turn strained their relationships with friends. As a result, participants expressed a sense of loss, as caregiving not only limited their social lives but also impacted their chances of building or nurturing intimate partnerships. This isolation heightened the emotional toll that caregiving already placed on their well-being, leaving them feeling. One participant had this to say:

I am very limited to social activities, I don't go anywhere as I said earlier, no family or friendly events, financially I am very drained up because every money I make goes into my mother's medical bills and drugs, emotionally I am very broken; On personal relationships yes. It has really suffered but I humbly call people who can help me perform my duties for my mum if I have to go out urgently but my mum needs me, I get sibling around who can fill in for me till I return (Participant 6, Female)

It should be noted that caregiving had a significant negative impact on the education of some participants. A large proportion of the participants were students, and as such, they were juggling the dual responsibilities of caregiving and pursuing their studies. The demanding and time-consuming nature of caregiving often left little time and energy for their academic obligations, resulting in a decline in their performance, missed deadlines, and, in some cases, absenteeism from classes. Many participants reported difficulty focusing on their studies and maintaining the balance needed to excel academically. One participant shared her ordeal in the quote below:

I have to make sure I balance this 50-50. Take some time for my school stuff. And then a little for social life. And another 50 for her. Because I have to make sure she's fine. You know? That she's fine all the time. Also, with school? Most of the time, our lessons are online. So, when there's a situation where they're doing online, I'm at home. And I'm in class online. Then she'll call you. Like, hey. Like, what's up? I'm in the class. So, let's do this after maybe two hours. She'll end up calling you again. Within a few minutes, she'll call you multiple times. And that distracts sometimes (Participant 8, Female)

Another participant also said that: *“Because of her situation I am usually unable to focus in class and I almost failed a course because of that”* (Participant 6, Female).

For the participants who were employed, caregiving responsibilities also had adverse effects on their professional lives. The constant need to attend to their caregiving duties led to frequent absences from work, reduced productivity, and, in some cases, conflicts with their employers or colleagues. Balancing caregiving with employment often required compromises, such as working fewer hours or taking unpaid leave, which impacted their financial stability. These dual burdens strained their ability to effectively manage both responsibilities, ultimately affecting both their educational and professional trajectories. Some participants had this to say:

when I go to work, sometimes you would have to leave the workplace just to come and see her. Because she might be facing an attack or something. So, immediately she calls you that maybe she can't breathe or she can't do this. You would have to let everything slide and come check on her (Participant 7, Male).

“Like I said earlier my work has really suffered. Currently I have even taken leave off work. When the foot issue started, I couldn’t even concentrate at work. It was really bad”
(Participant 9, Female).

Financial impact

Many of the participants expressed that caregiving had placed a significant financial burden on them. The costs associated with caregiving are reported to be high, primarily due to the need for specialized diets, medications, and frequent hospital visits. These expenses have created a substantial strain on the caregivers’ personal finances, making it difficult for them to maintain financial stability. As a result, their overall financial well-being has deteriorated, with some caregivers reporting a sharp decline in their financial reserves and a reduced ability to manage their daily living expenses. The following quotes depict how caregiving has negatively impacted the finances of caregivers.

Okay, let me start with financial. Financially, I've already mentioned that I'm the primary source of income for the house now, because my mom has also stopped working to take care of him when I come to work. So, there's no money coming, and my dad's age, he's a pensioner, as you'd call it, a pensioner, so it's really draining my financial life (Participant 5, Female).

“Financially it is very draining and we spend a lot on medical bills mostly from my small money and some small contributions from others hmm” (Participant 9, Female).

4.1.5 Finding Strength in Faith, Support, and Adaptation

This theme emerged as one of the major themes in the study. The theme includes the diverse coping mechanisms used by family caregivers for family members who have chronic or terminal diseases. Two subthemes made up this theme: *self-care practices* and *social support*. These subthemes are discussed in the following paragraphs

Self-care practices

All the participants revealed that they engage in self-care practices as a coping mechanism to manage the demands of their caregiving responsibilities. A prominent and widely adopted form of self-care was relaxation, such as watching movies, which allowed them to temporarily escape the stresses of caregiving and engage in a leisurely activity. Additionally, participants emphasized the importance of having adequate rest, highlighting that proper sleep and relaxation play an important role in improving their mental and physical well-being. These practices help them maintain a balanced approach to their caregiving duties, ensuring they remain resilient and effective in their roles. Some participants had this to say: *“Oh, so sometimes I watch Netflix. Okay, not sometimes, most of the times, it's either Netflix or I listen to music just to take my mind of”* (Participant 5, Female). Another stated that: *“I just sleep a lot to get some relief from the daily activities”* (Participant 9, Female).

Some of the participants mentioned that they take walks as a coping strategy to manage the demands of their caregiving responsibilities. These walks, whether short or long, provide them with a valuable opportunity to step away from the often-intense environment of patient care. As they walked, they found that it helped clear their minds, allowing them to release some of the stress and mental fatigue that builds up throughout the day. Additionally, the physical activity not only improves their mood but also refreshes their energy levels, preparing them mentally and emotionally for the next set of caregiving tasks. This practice serves as a simple yet effective form of self-care, helping them maintain focus and balance in a challenging work environment. A quote by one participant indicated this:

Sometimes I leave her in the room and go for walks to clear my head. To ensure that I can give her the care that sometimes she needs. To ask myself if what I am doing is it right, to ensure that

at least I can give her the care that she needs. Because sometimes, you are overburdened, you are tired and everything, sometimes too when you make an outburst to them you make them feel lonely and sad so there are sometimes you need to take walks to clear your head to make sure you are sound and emotionally well to take care of them (Participant 2, Female)

Spiritually, a few participants highlighted that they engage in prayer as a key coping strategy to manage the challenges of their caregiving roles. For these individuals, prayer serves as a source of comfort and strength, allowing them to find peace amidst the physical and emotional demands of their job. By turning to their faith, they sought guidance, patience, and resilience to continue providing care, especially during times of stress or when faced with difficult situations. This spiritual practice not only helps them cope with the pressures of caregiving but also fosters a sense of purpose and connection, as they believe they are fulfilling a higher calling through their work. One participant shared how her spirituality has contributed to her coping strategies in the quote excerpt below:

I would say first, God. I would say, God was my strength. Because I would have left him a long time. If that strength wasn't there. So, I think God and my Christian upbringing. Caring for people, love people. And he was my grandfather too. So, I can't just get up and say that, no. I can't do this. I'm going. It wasn't an option. So, spiritually, God was there for me (Participant 1, Female).

A smaller number of participants reported engaging in unhealthy coping strategies, particularly drinking, as a way to manage the stresses associated with caregiving. They acknowledged that while they recognized the potential harm of such behaviours, they found that alcohol temporarily alleviated feelings of being overwhelmed. These participants described caregiving as emotionally taxing and mentally exhausting, and resorting to drinking provided them with a form of escape

or relief from the constant pressure and responsibilities they faced. This emphasizes the importance of addressing mental health and providing healthier coping mechanisms for caregivers to prevent reliance on maladaptive strategies like substance use. One said: *“Alcohol. Besides alcohol, there is nothing. Yes. Because it takes my mind off something. And no, that's not what I used to do. But that's what I had to solicit to. I hope you understand me”* (Participant 7, Male).

Social support

Social support was reported as one of the major coping strategies, providing essential, emotional and practical relief to caregivers. This support primarily manifested in the form of family assistance, where other family members occasionally stepped in to share caregiving responsibilities. When caregivers needed a break from the demanding nature of their roles, these family members would temporarily take over, allowing the primary caregivers a chance to rest and recover, even if just for a short period. While these temporary respites may not last long, they play a crucial role in alleviating the ongoing pressure that caregivers experience daily, offering them moments of respite and emotional relief. This type of support also highlights the importance of a strong family network in managing the mental and physical challenges associated with caregiving, even if the assistance is intermittent.

Well, sometimes, some family members come and assist so that I will be able to go to school. So, I cook and do everything for her and then I tell them that okay when it is this time, they should give her medication. But there are some that when they come you don't really see what they are doing, yes. Currently the family is there to support me when they see that I am overwhelmed with the activities and I am the only one caring for her and they see that I am very tired. Then they come home and come and help her (Participant 2, Female).

Another form of support that caregivers often receive comes in the form of verbal encouragement from friends and family members. A participant stated that: *“Sometimes my aunties encourage me and tell me that it shall be well. This helps me to navigate the situation”* (Participant 3, Male).

These words of affirmation serve a dual purpose. First, they provide caregivers with the emotional boost needed to persevere through the challenges of their roles. Hearing that they are doing a good job reminds them that their efforts are seen and valued, which helps to reduce feelings of isolation and burnout. Second, these words of encouragement reinforce a sense of purpose and pride in their work, allowing caregivers to feel appreciated for the positive impact they are making. This emotional support can be incredibly uplifting, helping caregivers to stay motivated and maintain a positive outlook, even in difficult circumstances. Consequently, these affirmations from loved ones play a crucial role in sustaining caregivers’ mental and emotional well-being, enhancing their overall capacity to care for others. Some participants had these to share: *“We usually receive support from family and prayers. Some even offer prayers. Oh, some of them offer money and encouragement. Sometimes people from church come to the hospital to talk to us”* (Participant 9, Female). Another stated that: *“I usually receive support from family especially my older brothers and some words of encouragement and motivation”* (Participant 10, Female).

Notably, care recipients with children or relatives living abroad tend to experience greater financial relief, as these individuals are often in a better position to provide consistent and substantial financial aid. This additional support can significantly alleviate the pressure on caregivers, enabling them to focus more on the well-being of the care recipient and less on financial strain. Such assistance is necessary to ensure a sustainable and effective caregiving environment.

Especially, like, they are family. They call to check out, like, how are you? How is grandma? How are things going? And then, sometimes through financial support. Like, they bring some cash, you know. Yeah. And also, some words of advice. Like, just to make you have stable money and be able to perform your duties or responsibilities that are given (Participant 8, Male).

4.1.6 Unmet Needs and the Quest for Recognition and Support

Another major theme that emerged from the data is the needs of caregivers. The subthemes include *training and support*, *professional assistance* and *the provision of mental health services*.

Training and support

Most participants highlighted the need for training to equip them with the necessary skills to deliver high-quality care through telemedicine. They emphasized the importance of structured, comprehensive training programs that would not only familiarize them with telemedicine technologies but also enhance their caregiving abilities. Participants pointed out that such training would enable them to handle caregiving tasks more effectively, leading to improved care recipients' outcomes. Additionally, they expressed a desire for training that covers both technical aspects of caregiving and best practices, ensuring they feel confident and competent in their roles. Some participants expressed that *"I think caregivers need some sort of training"* (Participant 5, Female). Another stated that: *"A lot of information should be out there, a lot of training should be out there for caregivers to know what they're actually getting themselves into and how they should sometimes even manage a situation"* (Participant 5, female).

In terms of support, many participants emphasized the importance of various forms of assistance that would enable them to effectively carry out their responsibilities as caregivers to the elderly. Several caregivers specifically mentioned the need for physical support, such as having access to a personal trainer or a reliever who could assist with physically demanding tasks

associated with caring for older adults with chronic diseases. These tasks often include lifting, transferring, and providing general mobility support, which can be physically strenuous and, over time, lead to caregiver fatigue or injury. Some participants stated as follows:

Probably if we were two or three or four, you get me? I'll say this because right across my street, my friend's mom was also having diabetes. The woman had diabetes, and she's already suffering from a stroke. Since she has five to six people taking care of her, it ups her spirits. So maybe that will help (Participant 7, Male).

Social support emerged as a need for caregivers, who frequently expressed the absence of organized support groups and associations in Ghana. These groups could provide a vital space for caregivers to share their experiences, challenges, and successes, creating a network where they can give and receive emotional support. The lack of such networks left caregivers feeling isolated and without a structured means to cope with the emotional demands of their role. One participant had this to say:

So for example what I mean by support networks is having people experiencing the same thing that you are also experiencing and then you know that if this is happening to my patient or auntie, you will be like someone has experienced this before and the person did this so let me also try that remedy, but we don't really have that we are waiting to experience it and try a lot of things before you get to the remedy (Participant 2, Female).

Additionally, caregivers expressed a strong desire for greater community connections, which they believe could be fostered through regular social gatherings and community events. These gatherings would not only reduce feelings of isolation but also help build a sense of belonging and solidarity among caregivers. By connecting with others who face similar challenges, caregivers

could develop a support system that nurtures both their emotional well-being and resilience. This indicates a need for initiatives that create communal spaces and opportunities for caregivers to connect, which could significantly improve their overall quality of life.

Emotional and psychological support

The need for mental health services and counselling was strongly emphasized, as caregiving responsibilities frequently result in significant emotional stress and burnout. Caregivers often face intense physical, emotional, and mental demands, which can lead to feelings of exhaustion, helplessness, and even depression. Many caregivers reported experiencing anxiety and frustration due to the challenging nature of their roles, which often involve long hours and limited time for personal well-being. Therefore, they highlighted the importance of having access to psychological support services, such as counselling and mental health resources, to help them cope with the pressures of caregiving. A participant had this to say:

Maybe, what can I say, maybe free therapy. It would be nice to talk to somebody who understands what you are truly going through. But nobody will understand you. To many, it's just like, oh, his mother is sick, he's taking care of his mother, he's doing this, he's doing that. (Participant 7, Male).

These services would provide caregivers with a safe space to express their feelings, manage stress, and receive guidance on how to maintain their own mental health while supporting others. Access to such support could ultimately enhance caregivers' resilience, improve their quality of life, and enable them to provide better care to those they support.

4.2 Findings from Phase II of the Study

This aspect of the study was the quantitative phase of the study. The Jamovi software was used to analyse the quantitative data. This section presents a preliminary analysis of the data.

Tests of normality

Regression analysis requires that the data to be analysed be normally distributed. Normality of the data obtained for this study was determined by using the absolute values of the skewness and kurtosis of each latent construct. As noted by Tabachnick and Fidell (2007), data is normally distributed if the absolute values of the skewness and kurtosis of the variables are between -1 and $+1$. This analysis was performed in Jamovi, and the results showed that all the latent constructs had absolute skewness and kurtosis values between -1 and $+1$, indicating a normal distribution in the data set, as shown in Table 4.

Reliability analysis

The reliability of the research instruments was assessed by calculating the Cronbach alpha coefficient, a measure of internal consistency. While all instruments used in this study possessed established psychometric properties, it is customary in social science research to determine the Cronbach alpha coefficient when applying a scale in a new context or study. Therefore, the reliability of instruments measuring caregiver burden, depression, social support, well-being and spirituality was computed. All the scales exhibited Cronbach alpha coefficients exceeding the acceptable threshold of .70 (Nunnally, 1967). The mean (SD) of the variables, Caregiver Burden, Depression, Social Support, Wellbeing, and Spirituality (Spirit) are presented in Table 4. The reliability for each measure was high, with Cronbach's alpha values ranging from .80 to .97.

Table 4
Descriptive statistics of constructs

	Caregiver Burden	Depression	Social Support	Wellbeing	Spirituality
Reliability	.92	.80	.97	.91	.95
Mean	50.84	12.63	52.84	12.38	44.14
Standard deviation	15.36	5.98	15.01	5.31	8.37
Skewness	-0.20	0.38	-0.52	0.21	-.98
Kurtosis	-.90	-0.04	-1.12	-0.81	.97

Relationship between Caregiver Burden (CB) and well-being

The first hypothesis proposed that “There will be a significant negative relationship between Caregiver Burden (CB) and well-being” To test this, a Pearson product-moment correlation analysis was conducted. The results revealed a significant negative relationship between CB and well-being [$r(233) = -.60, p < .001$]. The results suggested that the first hypothesis be retained (see Table 5).

Table 5*Correlation between Caregiver Burden and Wellbeing*

Variables	1	2	3	4	5
1.Caregiver burden	-				
2.Depression	.63***	-			
3.Social Support	-.55***	-.53***	-		
4.Wellbeing	-.60***	-.60***	.60***	-	
5.Spirituality	.08	.17	-.07	-.07	-

Note: * $p < .05$, ** $p < .01$, *** $p < .001$

The mediating role of depression in the relationship between caregiver burden and wellbeing

The second hypothesis predicted that “Depression will mediate the relationship between caregiver burden and wellbeing” To test this, A mediation analysis was performed to assess the mediating role of Depression in the link between CB and Wellbeing. The results (see Table 6) revealed that the total effect of CB on Wellbeing was significant ($\beta = -.128$, $t = -7.51$, $p < .001$). With the inclusion of the mediator (Depression) the impact of CB on Well-being still remained significant ($\beta = -.324$, $t = -3.83$, $p < .001$). The indirect effect of CB on well-being through Depression was also significant ($\beta = .246$, $t = -3.43$, $p < .001$). This indicates that the relationship between CB and Wellbeing is partially mediated by Depression. In essence, the results partially support Hypothesis 2, showing that the effect of caregiver burden on well-being is partially mediated by depression.

Table 6*Mediation Analysis Showing the Impact of CB On Wellbeing Through Depression.*

Total Effect(a->b) -c		Direct Effect(a->b) -c'		Indirect Effects(a*b)				
Coefficient	p-value	Coefficient	p-value	Coefficient	SD	T Value	P-values	CI(95%) (LL;LU)
-.128	<.001		H2: CB->Wellbeing - >Depression	.246	.02	-3.43	<.001	-.125; -.034

The moderating role of social support (SS) on the relationship between caregiver burden and well-being

The third hypothesis predicted that there would be a moderating effect of social support (SS) on the relationship between caregiver burden and well-being. To verify this assertion, a moderation analysis was conducted using CB, SS as predictors of well-being. The results revealed a significant negative correlation between CB and well-being. ($B=-0.09$, $SE=0.02$, $Z=-3.84$, $p<.001$), indicating that higher caregiver burden was linked to lower levels of well-being. SS, on the other hand, was found to be positively correlated with well-being ($B=0.20$, $SE=0.02$, $Z=8.27$, $p<.001$). This suggests that increasing levels of SS could be associated with increasing levels of well-being. The results of the interaction effect (CB*SS) were also significant ($B=-.01$, $SE=.00$, $Z=-3.94$, $p<.001$). In light of this, the third hypothesis was accepted. The negative results of the interaction term suggest that Social Support serves as a buffer which helps diminish the effects of Caregiver Burden. Thus, as the levels of Social Support increase, the levels of Caregiver Burden decrease.

Table 7

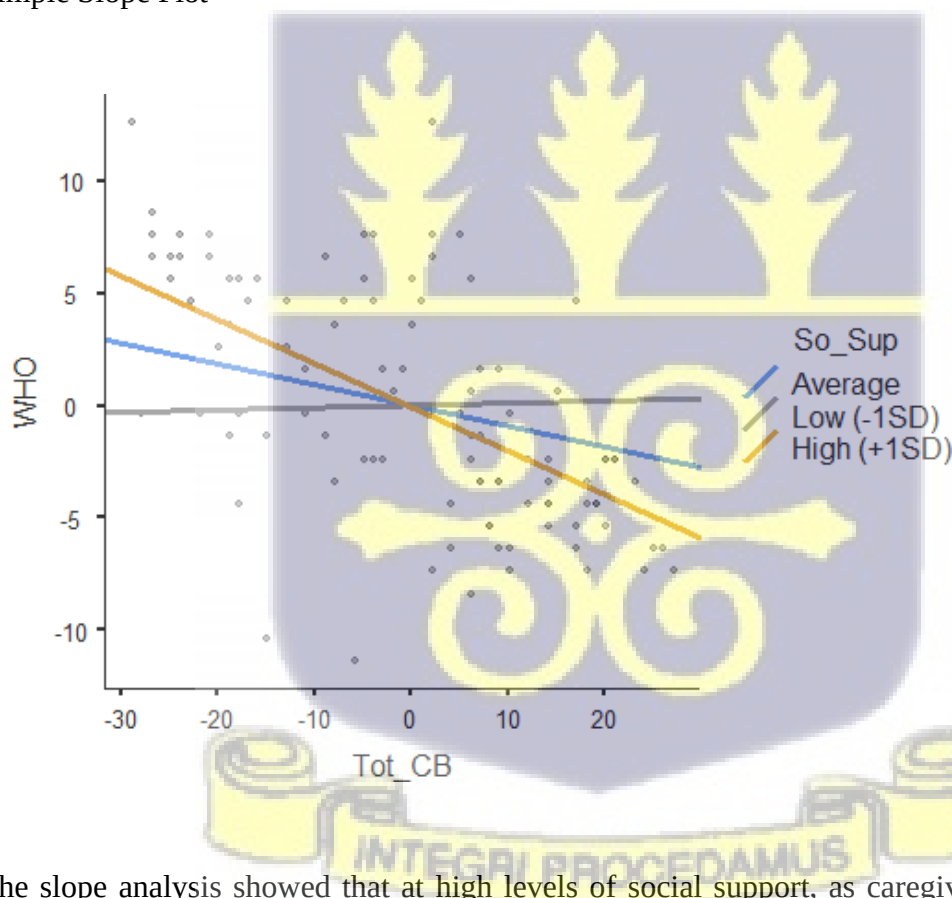
Moderation analysis of social support on the relationship between caregiver burden and wellbeing

Predictor	B	SE	95% CI (Lower)	95% CI (Upper)	Z	P
Caregiver Burden	-0.09	0.02	-0.14	-0.05	-3.84	< .001
Social support	0.20	0.02	0.15	0.25	8.27	< .001
Caregiver burden * social support	-0.01	0.00	-0.01	-0.00	-3.94	< .001

Note. *B* = unstandardised coefficient; *SE* = standard error; *CI* = confidence interval.

Figure 1

Simple Slope Plot



The slope analysis showed that at high levels of social support, as caregiver burden increased, well-being also increased, showing that social support provided the caregivers enough resources to buffer the negative impact of the caregiving burden.

The moderating role of spirituality in the relationship between caregiver burden and well-being

The Fourth Hypothesis predicted spirituality would moderate the relationship between caregiver burden and well-being. To test this hypothesis, a moderation analysis was conducted, including caregiver burden, spirituality, and their interaction term as predictors of well-being. The results (see Table 7) revealed a negative significant relationship between CB and well-being, in that, higher levels of caregiver burden were associated with lower well-being [$B=-0.21$, $SE=0.02$, $Z=-8.26$, $p<.001$]. However, spirituality did not significantly predict well-being, [$B=-0.02$, $SE=0.05$, $Z=-0.41$, $p=.684$]. Furthermore, the interaction term (CB * Spirituality) was also not significant, [$B=-0.00$, $SE=0.00$, $Z=-0.67$, $p=.504$]. These findings indicate that spirituality does not moderate the relationship between caregiver burden and well-being. Thus, hypothesis 4 was not supported.



Table 8

Moderation analysis of spirituality on the relationship between caregiver burden and wellbeing

Predictor	B	SE	95% CI (Lower)	95% CI (Upper)	Z	P
Caregiver Burden	-0.21	0.02	-0.25	-0.15	-8.26	< .001
Spirituality	-0.02	0.05	-0.13	0.07	-0.41	.684
Caregiver burden * Spirituality	-0.00	0.00	-0.01	0.00	-0.67	.504

Note. *B* = unstandardised coefficient; *SE* = standard error; *CI* = confidence interval.



CHAPTER FIVE

DISCUSSION

This chapter presents the discussion, limitations and recommendations for future studies, and the implications of the study. The chapter ends with the main conclusions from the study's findings.

Overview

The study was conducted to explore the experiences of family caregivers of older adults living with chronic diseases, using the mixed-method approach. The qualitative study explored the psychosocial experiences of caregivers of older adults living with chronic diseases (1), the coping strategies adopted by family caregivers (2), and the needs of family caregivers (3) while the quantitative study investigated the relationship between caregiver burden and wellbeing (4), the role of depression in mediating the relationship between caregiver burden and wellbeing (5), the role of social support in moderating the relationship between caregiver burden and wellbeing of caregivers (6) and the role of spirituality in moderating the relationship caregiver burden and wellbeing (7). For the qualitative part of the study, findings showed that caregivers experience negative social, emotional and financial consequences as a result of caregiving. Also, self-care practices and social support offered relief to these caregivers. For the quantitative part of the study, findings indicated that there was a significant negative relationship between caregiver burden and well-being. Also, depression partially mediated the relationship between caregiver burden and well-being. In addition, social support moderated the relationship between caregiver burden and well-being such that at high levels of social support, the effect of caregiver burden was reduced. However, spirituality did not moderate the relationship between caregiver burden and well-being.

5.1 Discussion of qualitative findings

The qualitative study identified a wide range of duties performed by caregivers, highlighting the complexity and diversity of their caregiving roles. These duties entailed not only routine domestic tasks such as cleaning, cooking, and managing the household but also more specialized care tailored to the specific health needs of their care recipients. Caregivers shared that they often had to assist with personal hygiene, including bathing and cleaning, as many care recipients were unable to perform these activities independently. Research has shown that caregiving roles include not only routine household duties but also extensive healthcare responsibilities such as managing medication, assisting with mobility, and providing personal care (Schulz & Eden, 2016; Stacherl & Sauzet, 2023). This mirrors the study's findings of caregivers engaging in both domestic and specialized care for their recipients.

The role of caregivers often extends into activities such as personal hygiene, which can be very challenging. For instance, assisting with bathing, cleaning, and personal grooming has been reported in many caregiving contexts as both emotionally and physically taxing (Schulz et al., 2020). This is especially pronounced when the care recipient is unable to perform these tasks independently, such as elderly individuals or those with chronic diseases. The need for caregivers to manage such tasks can stem from limited access to formal healthcare services and trained personnel in the home environment, which is often seen in low-resource settings like Ghana (Akgun-Citak et al., 2019).

In many Ghanaian households, the expectations surrounding caregiving are heavily influenced by cultural norms, where the family, especially women, is considered the primary unit responsible for providing care to the sick and elderly. Studies by Osei (2016) and others posit that in the absence of sufficient social welfare systems, the burden of care falls predominantly on family

members, who may have limited formal training or support in handling specialized healthcare tasks. The caregiving responsibilities, thus, expand from traditional domestic roles into more demanding health-related duties, as reflected in the findings of the study.

Moreover, the strain on caregivers is further enhanced by economic constraints. Caregivers may lack access to essential resources, including healthcare services, making it necessary for them to take on a bulky percentage of tasks to compensate for the absence of formal care support (Darkwah, 2014). This dynamic, often referred to as “informal caregiving,” is common in many low- and middle-income countries (LMICs), like Ghana, where formal long-term care systems are either non-existent or underdeveloped (Agyapomah et al., 2023).

Several academic studies posit that the health impacts of caregiving on caregivers of older adults living with chronic diseases in settings like Ghana are very severe (Akpan-Idiok et al., 2020; Agyapomah et al., 2023). The scope of caregiving, particularly when it involves both domestic and health-related tasks, can lead to physical and emotional exhaustion. A study by Gyasi et al. (2020) found that the intensity of caregiving is associated with heightened stress levels and mental health challenges among caregivers. Additionally, the physical demands of assisting care recipients with personal hygiene tasks like bathing can result in musculoskeletal strain, as noted in research on caregiving burden (Schulz & Eden, 2016). This was consistent with findings from this study, as participants reported having challenges with their health due to performing caregiving roles such as caring for care recipients, managing medications, bathing them, etc.

The transition from a generally content life to one overwhelmed by caregiving responsibilities is a phenomenon well-documented in academic literature, such as (Faronbi et al., 2019; Cejalvo et al, 2021), particularly in studies on caregiver burden and role strain. Caregivers often experience what is known as role engulfment, where caregiving responsibilities consume

other aspects of their identity, leading to emotional, physical, and social strain. Studies consistently highlight that caregiving can lead to profound shifts in personal well-being and social life. Shikimoto et al. (2018), for example, conceptualized caregiver stress as resulting from role strain, where caregivers experience emotional distress due to the cumulative demands of caregiving. These responsibilities can interfere with their personal life, resulting in social isolation, emotional exhaustion, and in some cases, depression (Schulz et al., 2020). The findings from the study corroborate these observations, as participants reported how caregiving responsibilities overtook their personal time, social interactions, and professional goals. The sense of confinement and loss of personal freedom described by the participants mirrors what Liu et al. (2019) identified as role captivity, where caregivers feel trapped in the caregiving role with little opportunity to escape or find personal fulfilment outside of their responsibilities.

The experience of social isolation due to caregiving duties has also been predominantly identified by several studies (D'Amen et al., 2021). These studies have shown that caregivers often report a reduction in social activities and interactions as their responsibilities increase (Chappell & Dujela, 2015; Hernández-Padilla et al., 2020). This social withdrawal is compounded by the emotional toll of caregiving, with many caregivers feeling emotionally and physically drained, making it difficult to engage in social or recreational activities. In Ghana, where the extended family is traditionally relied upon for support, this social isolation might be even more pronounced for caregivers who do not receive adequate help from other family members (Essuman & Mate-Kole, 2021; Agyapomah et al., 2023). While the cultural expectation is that caregiving is a shared responsibility, the reality is that one person, usually known as the primary caregiver, often bears the majority of the burden, which exacerbates feelings of confinement and isolation as identified in the present study.

The conflict between caregiving responsibilities and professional aspirations is another significant challenge caregivers face, especially in settings with limited forms of support systems. Many caregivers in the study reported that their professional goals were sidelined or abandoned due to the demands of caregiving, which was consistent with findings made by other studies (Abeasi, 2020). Also, Kyei-Arthur and Cudjoe (2020) noted that caregivers often have to scale back on work or leave employment altogether, leading to economic strain and reduced career satisfaction. In Ghana, the lack of formal caregiving structures and reliance on family members may intensify these struggles. Formal institutions and services for respite care are limited, pushing caregivers to make significant personal and professional sacrifices (Agyemang-Duah et al., 2019; Kyei-Arthur et al., 2022).

In the Ghanaian context, caregiving is often embedded in cultural and familial expectations, where caregiving is seen as both a duty and an obligation, particularly for women (Oppong, 2019). The social expectation is that family members, often female, will assume caregiving roles without necessarily having the emotional or financial support to do so. This adds a layer of cultural pressure that intensifies the feeling of isolation. Furthermore, the healthcare infrastructure in Ghana, particularly in rural and semi-urban areas, is often inadequate, increasing the burden on family caregivers to fill gaps in healthcare provision (Gyasi et al., 2020). This further limits their ability to balance caregiving with personal aspirations.

The feeling of monotony and loss of diversity in life experiences, as reported by caregivers in the study, has been explored in the literature as part of the *role overload* caregivers experience. According to Lespine et al. (2022), caregivers often feel that their lives become consumed by caregiving tasks, which can lead to a sense of monotony and a lack of fulfilment in other areas. This monotonous routine is often worsened by the 24-hour nature of caregiving, where there is

little to no respite. In the Ghanaian context, this is especially problematic, as caregiving is often done without formal support systems, leaving family caregivers with little opportunity for breaks or personal time.

It should also be noted that this overwhelming sense of confinement and isolation, as highlighted in the study, is also closely linked to mental health issues among caregivers. Studies have shown that caregivers are at higher risk of developing anxiety, depression, and other mental health challenges due to the prolonged stress and emotional strain associated with caregiving (Lopez-Anuarbe & Kohli, 2019; Stacherl & Sauzet, 2023). It was not surprising, therefore, that in the present study, some of the participants reported incidents of suicidal ideation due to the strain caused by caregiving. In Ghana, where mental health services are not easily accessible and mental health stigma remains high, caregivers might be reluctant or unable to seek the psychological help they need, and this further affects their sense of confinement and emotional distress.

All the participants revealed that they engage in self-care practices as a coping mechanism to manage the demands of their caregiving responsibilities. This included relaxation such as watching movies, taking walks and having enough rest. To some, their spiritual lifestyle contributed to their coping mechanisms. A few participants reported unhealthy coping strategies, such as drinking alcohol. This finding supports the importance of self-care practices in managing the emotional, physical, and psychological demands of caregiving. The use of self-care as a coping mechanism among caregivers is consistent with global literature, which highlights that caregivers often resort to various strategies to maintain their well-being amid stress and burnout risks (Sabo and Chin, 2020).

In the Ghanaian context, where caregivers face high or increased workloads and limited resources, the need for effective coping strategies becomes even more essential (Abeasi, 2020). The present findings indicate that caregivers engage in healthy practices such as relaxation, walking, and spiritual activities, which support the coping strategies highlighted by Lazarus and Folkman's Transactional Model of Stress and Coping. This model suggests that individuals manage stress through both problem-focused (directly addressing stressors) and emotion-focused (managing emotional responses) coping mechanisms. Relaxation, walks, and spiritual lifestyles are emotion-focused coping strategies which help caregivers alleviate stress by promoting a sense of calm and mental respite.

The mention of alcohol consumption as an unhealthy coping strategy is also reflective of global trends where high-stress environments sometimes push individuals toward detrimental behaviours. In the area of caregiving and health, especially in low-resource settings such as Ghana, caregivers are often susceptible to burnout due to high stress. For instance, in a study by Ankrah et al. (2021), it was found that a significant portion of healthcare workers in Ghana reported stress levels that often led them to unhealthy habits, including substance use. Alcohol, though offering temporary relief, poses long-term health risks, and this can exacerbate stress and emotional instability.

Social support was also reported to be an effective coping mechanism by family caregivers. Family support was reported to be very effective, together with words of encouragement from friends and family. Family members sometimes offer temporary help to the caregivers by engaging in some of the responsibilities so that the primary caregivers can have time to rest. Financial support was also mentioned to be an important coping mechanism. The finding that social support is an effective coping mechanism for family caregivers corroborates

well with the broader literature on caregiving, particularly in the context of low- and middle-income countries (LMICs) like Ghana, where the care system often lacks sufficient formal support structures (Agyemang-Duah et al., 2019; Bassi et al., 2019).

In Ghana, the socio-cultural importance of extended family relationships plays a pivotal role in caregiving. The collectivist nature of Ghanaian society means that caregiving is not solely the responsibility of an individual, but often shared among relatives (Osei-Tutu & Dzomeku, 2016). In this context, family members offering temporary help to the primary caregiver, as indicated in the finding, allows caregivers to take essential breaks, reducing the risk of caregiver burnout. Words of encouragement and emotional support from friends and family are significant for caregivers. The psychological burden of caregiving can be overwhelming, particularly in cases involving chronic illness or disability. As noted by Lloyd et al. (2014), emotional support helps caregivers maintain a sense of personal control and optimism, which is essential for effective coping. In the Ghanaian context, such encouragement is often tied to cultural and religious practices. The strong role of religion in Ghana means that faith-based encouragement, prayers, spiritual advice, and communal religious practices are often woven into the social support caregivers receive (Agyemang-Duah et al., 2022).

Financial support as a coping mechanism is especially important in Ghana, where caregivers may face economic challenges due to limited access to social security and healthcare coverage. According to a study by Kusi et al. (2020), caregiving in Ghana often comes with direct and indirect financial costs, including lost income opportunities due to the time spent providing care. The reliance on out-of-pocket payments for healthcare services, as opposed to comprehensive insurance schemes, exacerbates this financial strain. Therefore, financial support from family members can alleviate some of the economic pressures associated with caregiving, making it a

vital form of social support.

With regard to the needs of caregivers, the findings suggest the urgent need for training to equip them with the necessary skills to deliver high-quality care. They stated the importance of structured, comprehensive training programs that would enhance their caregiving abilities. The caregivers pointed out that such training would enable them to handle caregiving tasks more effectively, leading to improved care recipients' outcomes. Participants stated that training in caregiving strategies is necessary to deliver quality care to the elderly. Older adults often require more personalized care and support, which presents additional challenges when care is delivered remotely. Studies have shown that when caregivers are equipped with the right skills, they are better able to manage elderly patients' complex needs, leading to improved health outcomes (Chappell & Hollander, 2013; Adashek and Subbiah, 2020).

In the Ghanaian context, elderly patients are often cared for by family members or informal caregivers, many of whom lack formal healthcare training (Agyemang-Duah et al., 2019). As the healthcare system evolves, it has become crucial that these informal caregivers receive training in how to care for elderly patients. Such training could cover topics like understanding geriatric health, effective communication with elderly patients, and managing the emotional aspects of remote caregiving. This is further complicated by the limited availability of formal caregiving services, meaning that family caregivers often shoulder the entire burden. Without respite care or professional assistance, caregivers can experience burnout, which may manifest as anxiety, depression, or physical health problems (Zwar et al., 2020).

This study's findings posit that caregivers not only require practical support but also need access to mental health services and counselling to cope with the emotional toll of caregiving. The psychological burden is even more pronounced in cases where caregivers have to manage the care

of elderly persons with cognitive impairments, such as dementia, which is an increasing concern given the ageing population in Ghana (Gureje et al., 2010). Unfortunately, mental health services remain underdeveloped in Ghana, and many caregivers may lack awareness or face stigma when seeking such support (Osei, 2016).

The findings of this study resonate with studies conducted in other low- and middle-income countries where traditional family structures are under strain due to economic pressures, urbanization, and the migration of younger family members (Akpan-Idiok et al., 2020). As a result, the elderly may be left in the care of fewer family members, increasing the stress on those who remain.

5.2 Discussion of quantitative findings

The quantitative part of the study assessed certain specific objectives, and these are discussed in relation to the results in this section. To begin with, the study examined whether there will be a significant negative relationship between caregiver burden and well-being. Results from the analysis indicated that there was a significant negative relationship between caregiver burden and well-being. This finding is similar to what has been previously reported by studies globally (Lopez-Anuarbe & Kohli, 2019; Bekui et al, 2022). This is an indication that caregivers in Ghana often perform caregiving roles that result in significant emotional, physical, and financial negative effects on their well-being. These roles put a strain on the individual as well as the individual's resources, and this directly affects their overall well-being and functioning (Cejalvo et al., 2021). Caregivers reported feelings of stress and depressive symptoms, which contributed to the negative relationship between caregiver burden and well-being. Also, caregivers may feel constantly overwhelmed by their caregiving responsibilities, and this significantly affects their well-being.

The qualitative part of the study found that before becoming caregivers, the caregivers were generally happy about their lives. However, upon assuming caregiving responsibilities, all the caregivers reported experiencing a profound and overwhelming shift in every aspect of their lives. The weight of caregiving responsibilities gradually took over their personal time, social interactions, and professional aspirations, creating a sense of confinement and isolation. Many described feelings as though their lives had lost its meaning, turning their once vibrant life routines into a monotonous cycle of care tasks, which left little room for anything else. This finding is consistent with Aranda and Knight's stress and coping theory (Aranda & Knight, 1997), which conceptualizes caregiver burden as a primary stressor that exerts a cumulative impact on mental and physical health outcomes. According to this model, persistent exposure to the demands of caregiving, such as managing the care recipient's health needs, navigating financial constraints, and coping with emotional exhaustion, depletes the caregiver's psychological resources and leads to reduced well-being. The results from this study suggest that caregiving, although often perceived as an expression of love and duty, may simultaneously function as a chronic stressor that undermines caregivers' quality of life.

From a psychosocial perspective, this negative relationship may be explained by the imbalance between caregiving demands and the available coping resources. As caregivers assume multiple responsibilities without adequate institutional or social support, they may experience heightened levels of strain, fatigue, and frustration. Over time, this accumulated stress erodes their emotional stability, disrupts social relationships, and contributes to feelings of helplessness, all of which adversely affect well-being. The emotional toll is often compounded by limited opportunities for self-care and the societal expectation to remain resilient and devoted, particularly within collectivist cultural contexts such as Ghana, where caregiving is traditionally viewed as a moral obligation. Empirical studies conducted in similar settings have reported comparable

outcomes, demonstrating that caregivers with higher burden scores tend to report lower levels of psychological and physical well-being (Anderson & White, 2017; Cejalvo et al., 2021). The present finding, therefore, reinforces the notion that caregiving in the context of chronic illness is a double-edged role, providing meaning and purpose on one hand, while exerting significant stress and compromising well-being on the other. Findings from the qualitative phase of the study corroborated this finding from the quantitative phase of the study, as caregiver burden has a significant negative relationship with well-being.

Also, this study examined the objective that depression will mediate the relationship between caregiver burden and well-being. Depression is one of the major challenges associated with caregiving, especially caregiving for older adults living with chronic diseases (Abeasi, 2020). The results from the analysis indicated that depression partially mediated the relationship between caregiver burden and well-being. This finding is consistent with other studies where depression has been found to mediate the relationship between caregiver burden and wellbeing (Zhong et al., 2020). Caregivers tend to experience depressive symptoms when caregiver burden is overwhelming (Lopez-Anuarbe & Kohli, 2019). The quantitative findings of this study revealed that depression significantly mediates the relationship between caregiver burden and overall well-being among caregivers of older adults living with chronic diseases. This result suggests that the psychological distress associated with caregiving burden translates into diminished well-being primarily through depressive symptomatology. In essence, the extent to which caregiving burden affects the caregiver's general well-being depends largely on the presence and severity of depressive symptoms. This finding aligns with previous studies which have established that high caregiving burden often precipitates emotional exhaustion and psychological strain, leading to elevated risks of depression (Lopez-Anuarbe & Kohli, 2019). Depression, in turn, compromises both subjective and psychological well-being by reducing motivation, impairing coping capacity,

and increasing feelings of hopelessness and fatigue (Zhong et al., 2020). Within the context of this study, the mediating effect of depression reflects the psychological pathway through which caregiving responsibilities translate into poorer health and life satisfaction outcomes. Theoretically, this result lends support to Aranda and Knight's stress and coping theory (Aranda & Knight, 1997), which posits that caregiver stressors such as role overload, emotional demands, and financial strain contribute to negative mental health outcomes, which then mediate the overall impact on well-being. According to this model, depression operates as a key stress response linking objective stressors (care burden) to subjective outcomes (well-being). The current study's findings affirm this, illustrating that the caregiver's emotional state serves as an essential mechanism explaining the relationship between burden and well-being. Furthermore, in the Ghanaian cultural context, where caregiving is viewed as a familial obligation and an act of filial piety, caregivers may suppress expressions of distress to fulfil expected social and moral roles. This cultural restraint, however, may contribute to internalized stress and undiagnosed depressive symptoms, thereby intensifying the negative impact of caregiving burden on well-being. The limited availability of mental health support and the stigma associated with emotional difficulties may also exacerbate the mediating role of depression. Consequently, caregivers are likely to experience a progressive decline in psychological well-being as the burden intensifies without corresponding emotional relief or support. Also, the presence of depression as a partial mediator implies that interventions focusing solely on the practical or physical aspects of caregiving may not be sufficient. Addressing caregiver well-being requires an integrated approach that simultaneously targets emotional health.

Overall, the quantitative results demonstrate that while caregiving burden has a direct negative impact on well-being, its indirect effect through depression is particularly critical. This emphasizes the need for holistic caregiver support programs that recognise mental health as a

central component of caregiving outcomes. By acknowledging depression as a mediating mechanism, policymakers and practitioners can design interventions that not only reduce the practical burden of caregiving but also promote caregivers' emotional and psychological well-being.

In addition, the study further examined whether social support moderated the relationship between caregiver burden and the well-being of caregivers of older adults living with chronic diseases. The quantitative analysis demonstrated that social support significantly moderated this relationship, such that at higher levels of perceived social support, the negative impact of caregiver burden on well-being was reduced. This finding also suggests that social support serves as a protective factor or buffer, mitigating the adverse psychological and emotional effects of caregiving stress. Thus, social support was an effective coping mechanism for caregivers in alleviating their burden. Social support is widely recognized in caregiving literature as a critical factor in buffering the stress associated with caregiving responsibilities. For instance, according to Chappell and Dujela (2015), social support can mediate the negative effects of caregiving stress, improving emotional well-being and preventing burnout. This outcome aligns with the stress-buffering hypothesis (Cohen & Wills, 1985), which posits that social support functions to reduce the harmful effects of stress on health and well-being by enhancing coping capacity and promoting emotional resilience. According to this framework, social support provides caregivers with practical assistance, emotional reassurance, and a sense of belonging, all of which can help them better manage the demands of caregiving. Consequently, caregivers who perceive strong support from family, friends, or community networks are less likely to experience the detrimental effects of caregiving burden on their overall well-being.

Empirical studies across various cultural contexts have consistently confirmed the moderating role of social support in caregiving outcomes. For instance, Bevan et al. (2019) and

Hailey et al. (2022) reported that caregivers with higher levels of social support demonstrated better psychological adjustment and lower stress levels compared to those with minimal support. The findings of the present study are therefore consistent with this broader body of research, reinforcing the notion that social support serves not only as a coping resource but also as a critical determinant of caregivers' mental health and life satisfaction.

Within the Ghanaian sociocultural context, the significance of social support is particularly noteworthy. Family networks, religious communities, and neighborhood associations traditionally provide emotional and material assistance to individuals facing stressful circumstances. Family support, in particular, is crucial in Ghana, where extended family systems are still prevalent. This finding is also supported by studies in other African settings that highlight the reliance on familial networks for both emotional and physical relief in caregiving contexts (Oppong, 2019). The results are also consistent with previous studies done in the area globally such as Isac, Lee and Arulappan (2021) and Price et al. (2020) who posited that a decrease in social connectedness contributes to caregiver burden and negative experiences and they also proposed that significant family engagement and social support plays a huge role in the emotional wellbeing, physical and psychological states of caregivers. However, with ongoing changes in family structure, urbanization, and the growing burden of chronic diseases among older adults, such informal support systems are increasingly strained. Therefore, the finding that social support moderates the relationship between caregiver burden and well-being highlights the importance of strengthening both formal and informal support mechanisms to sustain caregivers in their roles.

Practically, this result highlights that interventions designed to reduce caregiver burden should not only focus on the individual caregiver but also on enhancing their social environment. Encouraging participation in caregiver support groups, community-based programs, and faith-based initiatives can foster shared experiences and collective coping. Moreover, integrating

structured social support interventions into health and social service delivery can promote caregivers' psychological resilience and improve their overall quality of life.

In sum, the moderating effect of social support found in this study affirms its critical role as a buffer in the caregiving stress process. By reducing the intensity of the relationship between burden and well-being, social support emerges as a central mechanism through which caregivers can maintain emotional balance and sustain their caregiving roles over time. Strengthening and institutionalizing social support systems should therefore be a priority in efforts aimed at promoting caregiver well-being within ageing populations.

Furthermore, the study assessed the role of spirituality in moderating the relationship between caregiver burden and well-being. Spirituality has been identified in several studies as an effective form of coping for caregivers of older adults living with chronic diseases (Dunfee et al., 2020). The qualitative phase of the study revealed that caregivers adopted spiritual coping to help alleviate their stress and promote well-being. However, the quantitative part of the study did not support this assertion, and this may be due to several factors pertaining to participant characteristics, etc., that might have accounted for this difference in the results. The study explored whether spirituality would moderate the relationship between caregiver burden and well-being among caregivers of older adults living with chronic diseases. Contrary to expectations and findings from several previous studies, the results did not reveal a statistically significant moderating effect of spirituality on this relationship. This implies that, although spirituality remains an important aspect of caregivers' lives, it did not significantly alter the strength or direction of the association between caregiver burden and well-being within the present sample.

This finding contrasts with earlier empirical evidence that has highlighted spirituality as an important coping mechanism for caregivers facing the emotional and physical demands of caring

for chronically ill older adults (Dunfee et al., 2020; Farinha et al., 2021). In such studies, spirituality was found to buffer the negative effects of stress, often by providing caregivers with a sense of meaning, acceptance, and emotional regulation. The lack of a moderating effect in the current study, therefore, warrants closer consideration of contextual, methodological, and interpretive factors that may explain this outcome.

One possible explanation may lie in the homogeneity of spiritual orientation among participants. In the Ghanaian context, spirituality and religiosity are pervasive cultural values that are widely shared across the population. Consequently, the limited variability in spirituality scores could have restricted the ability to detect significant moderating effects statistically. When most participants report high levels of spirituality, the potential buffering differences between high and low spirituality groups become minimal, thereby obscuring its role as a moderator.

Another plausible explanation relates to the distinction between spiritual belief and functional coping. Although many caregivers may identify as highly spiritual or religious, spirituality may not always translate into effective coping behaviors in the face of sustained caregiving stress. For instance, some caregivers may rely on spirituality primarily for acceptance rather than active problem-solving, which may not be sufficient to offset the impact of high burden on well-being. In such cases, spirituality may function more as a source of comfort than as a protective mechanism against stress-related decline in well-being.

Additionally, the result may reflect changing caregiving realities in contemporary Ghanaian society. As family structures evolve and the burden of care intensifies, traditional spiritual or faith-based sources of strength may be increasingly challenged by the practical and emotional demands of caregiving. The absence of formal institutional support may also lead caregivers to experience overwhelming feelings that spirituality alone cannot alleviate. Thus, while

spirituality remains an important aspect of personal meaning and motivation, it may not independently buffer the psychological impact of caregiver burden without complementary social and emotional support systems.

Theoretically, this finding suggests that spirituality, although a valuable internal coping resource, may not consistently operate as a moderator within Aranda and Knight's stress and coping theory (Aranda & Knight, 1997) or the stress-buffering framework (Cohen & Wills, 1985) in all contexts. Its effectiveness may depend on how it interacts with other psychosocial resources such as social support, coping efficacy, and emotional resilience. In this study, it is possible that these other factors played a more dominant buffering role in shaping caregivers' well-being.

In summary, while spirituality did not significantly moderate the relationship between caregiver burden and well-being in this study, its role as a personal and cultural resource should not be underestimated. The finding emphasizes the need for a more nuanced understanding of spirituality, one that distinguishes between spiritual beliefs, practices, and their practical application in coping with stress. Future research may benefit from employing more sensitive measures of spirituality or exploring its indirect effects through other mediating or interactive pathways.

This finding does not corroborate with studies such as Kyei-Arthur et al. (2020) and Dunfee et al. (2020) that posited that spirituality can serve as a buffer or influence the relationship between caregiver burden and wellbeing. Rather, it corroborated with studies like Özdemir et al. (2020) that suggested that no relationship existed between negative religious coping and negative

psychosocial outcomes like depression and anxiety, hence spirituality does not serve as a buffer in the relationship between caregiver burden and wellbeing in the present study.

5.3 Points of convergence and divergence of qualitative and quantitative findings

Caregiver burden studies have been conducted in various sociocultural contexts around the world. Caregivers of older adults living with chronic diseases have reported diverse negative and positive psychosocial experiences, which have shaped their experience of the burden of care. This study employed a mixed-methods design to ascertain the comprehensive experience of caregiver burden. The points of convergence and divergence of findings from this study are discussed in subsequent paragraphs.

The qualitative aspect of the study revealed the nature of the psychosocial experiences of caregivers of older adults living with chronic diseases in depth. It also explored their coping strategies and needs. From the findings of this aspect of the study, caregivers expressed how the burden associated with caring for their elderly relatives has a negative influence on their well-being. Specifically, caregivers stated how caregiving roles such as bathing, caring and carrying care recipients, as well as helping with hospital rounds, take a physical, psychological and social toll on their wellbeing. Similarly, the quantitative part of the study highlighted that caregiver burden has a significant negative relationship with well-being. This reveals that both the qualitative and quantitative parts of the study supported the idea that caregiver well-being is negatively influenced by caregiver burden, specifically for caregivers of older adults living with chronic diseases. This is consistent with previous studies in the area of caregiving for older adults with chronic illnesses (George et al., 2020; Rezaei et al., 2020).

Also, the qualitative part of the study explored the coping mechanisms of the caregivers. It was seen that, caregivers used various coping strategies to cope with the caregiving situation.

The most popular and consistent form of coping strategy amongst caregivers in this study was identified to be social support. Social support was also reported to be an effective coping strategy by family caregivers. Family support was reported to be very effective, together with words of encouragement from friends and family. Family members sometimes offer temporary help to the caregivers by engaging in some of the responsibilities so that the primary caregivers can have time to rest. Similarly, it was found from the quantitative study that social support was significant in moderating the relationship between caregiver burden and well-being, such that at high levels of support, the effect of caregiver burden was reduced. Thus, the qualitative and quantitative aspects of the study supported the idea that social support is an effective coping mechanism for caregivers in alleviating their burden.

Furthermore, the qualitative part of the study revealed that caregivers used spiritual methods to cope with their caregiving situation. It is important to note that some studies suggest that spirituality as a coping strategy is significant in the Ghanaian cultural context, where religion plays a significant role in daily life activities (Kyei-Arthur et al., 2022). However, the hypothesis from the quantitative study did not find any significant impact of spirituality on caregiver wellbeing, but the qualitative study provides a different perspective on the role of spirituality, which is consistent with studies by Osei-Tutu et al. (2020) and Kyei-Arthur et al. (2022). For many, turning to their faith-based practices not only gives them a sense of purpose but also a psychological outlet during times of intense stress. Spirituality and religious practices have been associated with lower levels of anxiety and better mental health outcomes, as noted by Rosmarin and Leidl (2020).

It is important to note that both results from the qualitative and quantitative parts of the study, whether ideas converged or diverged, presented a comprehensive analysis of the nature of

caregiver burden experienced by caregivers of older adults living with chronic diseases, and addressed the objectives of this study.

5.4 Limitations/Recommendations for future studies

The study has some limitations that need to be addressed. Ghanaian cultural norms regarding family caregiving and the role of caregivers may have affected the participants' willingness to fully express their psychosocial burdens. Some caregivers may have viewed their roles as a duty or obligation and therefore downplayed the emotional and psychological impacts of caregiving, leading to a potential underestimation of the true burden of care. They may have also felt that truly expressing themselves was like complaining about their role and, therefore, may have downplayed some of their experiences.

Furthermore, participants, particularly in the qualitative interviews, might have been influenced by social desirability, especially when discussing sensitive issues related to caregiving, stigma, or the treatment of older adults with chronic diseases. This could have led them to underreport negative experiences or emotional difficulties. Again, there is a possibility of selection bias, as caregivers who volunteered to participate may have been those with either more pressing burdens or those who were more willing to share their experiences. This could result in overrepresentation of certain psychosocial experiences, neglecting those of caregivers who may not have been able to participate due to time constraints, work demands, or emotional stress. Hence, future studies should be longitudinal studies to make room for participants who may be time-constrained, busy with work schedules, etc., in order to get a diverse group of participants.

The sample size may have been limited in the quantitative phase due to the difficulty of accessing a larger population of caregivers, leading to the inability to generalize the findings.

The results may reflect only the experiences of those in specific settings or communities and may not be representative of all caregivers in Ghana. While qualitative methods provide in-depth insights, the relatively small number of participants may limit the ability to generalize findings across a broader population of caregivers. It is therefore recommended that future studies should expand the sample size to get the views of a relatively larger sample.

Gender roles play a significant part in caregiving responsibilities; therefore, future research should explore the differences in psychosocial experiences between male and female caregivers to understand how gender dynamics affect caregiving outcomes and inform gender-sensitive interventions. Furthermore, including the experiences of the older adults living with chronic diseases in future studies would offer a more holistic view of the caregiving relationship. Understanding both sides of the caregiver-care recipient dynamic could lead to more effective policies and support systems that address the needs of both parties.

5.5 Theoretical implications of the study

The findings of this study, guided by Aranda and Knight's (1997) stress and coping theory, contribute valuable theoretical insights into understanding the psychosocial experiences of caregivers in Ghana. This theory frames caregiving as a dynamic process with both positive and negative outcomes, depending on how caregivers perceive and cope with the stressors they face. Through a mixed-method approach, this study offers a holistic understanding of caregivers' experiences, uncovering the unique interplay of stressors, coping mechanisms, and cultural factors specific to the Ghanaian context.

The use of Aranda and Knight's stress and coping theory in this study reveals its applicability in diverse cultural settings. Previous applications of the theory have largely been within Western contexts. By employing this theory in the Ghanaian caregiving landscape, this study extends its

relevance, suggesting that cultural norms, familial obligations, and socioeconomic conditions influence caregivers' experiences and coping strategies in significant ways. For instance, traditional values of extended family support systems may either alleviate or compound caregiver stress, depending on the circumstances, highlighting the importance of culture in shaping caregiving dynamics.

One of the core premises of Aranda and Knight's theory is that caregiving involves both positive and negative experiences. The study's findings, particularly from qualitative interviews, corroborate this premise by illustrating that some caregivers derive a sense of bonding and emotional satisfaction from providing care, but also experience considerable emotional, physical, and financial strain. The mixed-method approach, which quantifies levels of stress, anxiety, and depression alongside qualitative narratives, highlights the bidirectional nature of caregiving, reaffirming that coping mechanisms play a critical role in determining whether caregiving leads to burnout or resilience.

The theory suggests that coping strategies, whether problem-focused (e.g., seeking support, using healthcare services) or emotion-focused (e.g., reframing challenges positively) are crucial to caregivers' well-being. This study's exploration of coping strategies in Ghana provides theoretical insight into how culturally specific practices such as communal living, spirituality, and reliance on extended family support networks play an essential role in caregivers' ability to cope with stress. These findings suggest that, while caregivers in Ghana may use globally recognized coping strategies, they also rely on unique, culturally bound approaches that contribute to their overall psychosocial well-being.

While Aranda and Knight's theory emphasizes the individual caregiver's coping mechanisms, this study's mixed-method design uncovers the need for broader structural support

from health systems. Quantitative findings may show high levels of caregiver burden (e.g., in terms of financial and time commitments), and qualitative data may reveal caregivers' frustrations with inadequate support infrastructure. These findings imply that beyond individual coping, systemic interventions are crucial to mitigating the negative psychosocial effects of caregiving in low-resource settings like Ghana. This highlights an area where the theory could be expanded to include the role of systemic and institutional factors in alleviating caregiver burden.

5.5 Practical implications for clinical practice in Ghana

The study highlights the significant psychosocial burden faced by caregivers. This points to the need for national policies that specifically address caregiver welfare. Such policies could include financial support, tax relief, or stipends for caregivers, especially those providing care for long-term chronic diseases. These measures will help reduce the financial stress that caregivers experience, which often exacerbates their emotional and physical burden.

The findings revealed that caregivers often lack the skills and knowledge necessary to provide effective care for older adults with chronic diseases. The government should therefore introduce standardized caregiver training programs within healthcare facilities, teaching essential skills for handling the medical, emotional, and mental health needs of aged patients. This policy could be implemented through healthcare institutions and community health centres, ensuring caregivers are adequately equipped to manage their responsibilities.

Furthermore, the integration of caregiver support services into primary healthcare settings can be a critical policy direction. This includes the creation of counselling services for caregivers, as well as routine psychological evaluations, to help them manage the emotional toll of caregiving. Policies could mandate the establishment of support groups, mental health services, and respite care programs to ease the psychosocial burden.

The burden on caregivers is exacerbated by inadequacies in healthcare services and infrastructure. Policymakers should focus on expanding access to community-based health services, ensuring chronic disease management programs are available close to caregivers' homes. Strengthening community outreach programs can relieve caregivers from having to frequently travel long distances to access healthcare, reducing their physical and financial burdens.

There is a need for policies that integrate caregivers into Ghana's social protection system, providing them with access to social security benefits and health insurance coverage. These policies should also include provisions for caregivers to receive time off or respite without risking their employment or income, recognizing the crucial role they play in the health system. National awareness campaigns on the challenges faced by caregivers and the importance of psychosocial support can influence policy priorities. These campaigns can educate the public, including policymakers, about the need for more comprehensive support for caregivers, leading to legislative changes aimed at improving their quality of life.

5.6 Conclusion

The study on the burden of care and psychosocial experiences of caregivers of older adults living with chronic diseases in Ghana highlights several key challenges and opportunities for policy interventions. Drawing from both qualitative and quantitative data, the findings highlight that caregiving is a complex, multifaceted experience shaped by the intersection of cultural expectations, caregiving roles, and limited formal support systems.

The results collectively demonstrate that while caregiving for older adults is often motivated by deep familial obligation, love, and cultural duty, it also puts significant emotional strain, physical exhaustion, and financial hardship on caregivers. These outcomes indicate the dual nature of caregiving as both a valued social responsibility and a potential source of personal

vulnerability. From the study, it was gathered that caregivers' experiences reflect ongoing negotiations between resilience and stress, altruism and fatigue, connectedness and isolation.

Interpreting these findings through the lens of the study's objectives, it becomes evident that the burden of care is not merely an individual challenge but a structural and societal issue. The study affirms that caregiver well-being is closely tied to contextual factors such as access to healthcare resources, social support networks, and the availability of respite services. It also reinforces the need to view caregiving within the broader framework of ageing and health policy, where the well-being of older adults cannot be sustainably improved without addressing the conditions under which their caregivers operate. The study's insights have important implications for both practice and policy. Interventions aimed at reducing caregiver burden

This research also contributes to the growing body of knowledge on ageing and caregiving within the African context, particularly in Ghana, where cultural expectations deeply influence caregiving practices. By exposing the lived realities of caregivers, this study calls for a shift from viewing caregiving solely as a private family responsibility to recognizing it as a shared social concern deserving of attention and policy response.

Therefore, addressing both the immediate and long-term needs of caregivers, Ghana's healthcare system can improve the well-being of caregivers and the older adult population alike. A comprehensive policy framework that recognizes and supports the critical role of caregivers is necessary. It should promote sustainable caregiving practices through education, accessible healthcare services, and social protection measures, ultimately reducing the burden of care and enhancing the psychosocial well-being of caregivers in Ghana.

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APPENDICES

Appendix 1: Ethical Clearance



UNIVERSITY OF GHANA

ETHICS COMMITTEE FOR THE HUMANITIES (ECH)

P. O. Box LG 74, Legon, Accra, Ghana

My Ref. No: ECH/097/23-24

January 30, 2024

Mabel Yeboah Darfour
Department of Psychology
University of Ghana
Legon

ETHICAL CLEARANCE (ECH 097/ 23-24)

The Ethics Committee for the Humanities (ECH) conducted a full-board review and approved your protocol titled:

BURDEN OF CARE: PSYCHOSOCIAL EXPERIENCES OF CAREGIVERS OF AGED PERSONS LIVING WITH CHRONIC ILLNESSES

PRINCIPAL INVESTIGATOR: **MABEL YEBOAH DARFOUR**

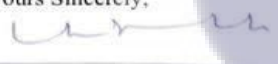
Please note that the final review report must be submitted to the Committee at the completion of the study. Your research records may be audited at any time during or after the implementation. Any modification of this research project must be submitted to ECH for review and approval prior to implementation.

Please report all serious adverse events related to this study to ECH within seven (7) days verbally and in writing within fourteen (14) days.

This certificate is valid until January 29, 2025. You are required to submit annual reports for continuing review.

Please accept my congratulations.

Yours Sincerely,


Professor C. Charles Mate-Kole
ECH Chair

Cc: Professor Adote Anum, Department of Psychology, UG
Dr. Margaret Amankwah-Poku, Department of Psychology, UG
Professor Kwaku Oppong Asante, Department of Psychology, UG

Tel: +233-303933866

Email: ech@ug.edu.gh

Appendix 2: Introductory letter by the Head of Department of the Psychology Department

 **UNIVERSITY OF GHANA**

DEPARTMENT OF PSYCHOLOGY
SCHOOL OF SOCIAL SCIENCES
COLLEGE OF HUMANITIES

PSYC 2/33/03

January 12, 2024

Ref. No.:

The Medical Director
Ga East Municipal Hospital
P. O BOX WY1895
Kwabenya.

Dear Sir/ Madam,

LETTER OF INTRODUCTION
MISS MABEL YEBOAH DARFOUR - 10937542

The above-named student is an MPhil Clinical Psychology student at the Department of Psychology in the University of Ghana.

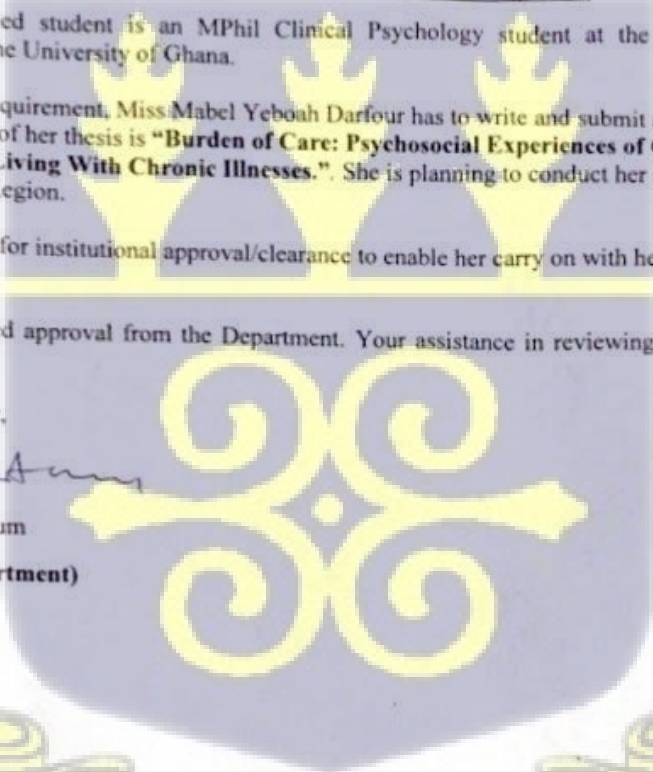
As part of the requirement, Miss Mabel Yeboah Darfour has to write and submit an original thesis. The title of her thesis is **"Burden of Care: Psychosocial Experiences of CareGivers of Aged Persons Living With Chronic Illnesses."** She is planning to conduct her study in the Greater Accra Region.

She is applying for institutional approval/clearance to enable her carry on with her research work.

She has received approval from the Department. Your assistance in reviewing her proposal is appreciated.

Yours faithfully,


Prof. Adote Anum
(Head of Department)


INTEGRI PROCEDAMUS

P. O. Box LG 84, Legon, Accra, Ghana | Tel: +233 (0) 50 914 4101
Email: psychology@ug.edu.gh | www.ug.edu.gh



Appendix 3: Study Consent form

UNIVERSITY OF GHANA



Ethics Committee for Humanities (ECH)

Official Use only

Protocol number

PROTOCOL CONSENT FORM

Section A- BACKGROUND
INFORMATION

Title of Study:	Burden of Care: Psychosocial Experiences of Caregivers of Aged Persons Living with Chronic Illnesses.
Principal Investigator:	Mabel Yeboah Darfour
Certified Protocol Number	

Section B- CONSENT TO PARTICIPATE IN
RESEARCH

General Information about Research

The aim of this study is to investigate the psychosocial experiences of caregivers of aged persons living with chronic illnesses (chronic mental illnesses and chronic medical conditions). The nature of the burden of care, social support and wellbeing will be investigated.

If you agree to be part of the study, you will be asked to fill some sets of questionnaires that assesses your burden of care, social support and wellbeing. An interview session will be included if you are interested thus it is not mandatory as only 10 of such interviews are needed. For the

quantitative aspect of the study, it will take approximately 20 minutes to complete the questionnaire. Participants will be given a pencil or pen to fill in their responses to the questionnaire. However, for the qualitative part of the study, the interviews will last for approximately 30-40 minutes. If you agree to participate in the interview session after filling the questionnaire, a different day will be scheduled for the interview. Interviews will be recorded and stored safely.

Benefits/Risks of the study

There are no direct benefits to participants. The results may help to improve knowledge on how best to help caregivers. There are minimal risks associated with your participation in this study. I will take every precaution to ensure and maintain your safety and confidentiality. A Clinical Psychologist will be contacted to be on standby to provide help to participants who would experience emotional challenges throughout the research process.

Confidentiality

The identity and privacy of participants will be protected. No personal identifiable information will be collected in the research process. Alpha-numeric code names (eg. AG 1) will be used to identify participants instead of their names. All research-associated documents and audio recordings will be stored in a safe place. Audio recordings will be stored using a zip file with a password for protection. This will help to prevent loss and theft of the data. Information collected will only be shared with my supervisor. Hence, confidentiality will be guaranteed.

Compensation

Participants would be compensated with 10.00 Ghana cedis as refreshments upon successfully filling the questionnaire and/participating in the interview. Participants who do not complete all the questionnaires or do not stay to complete their interview sessions will not receive any amount.

Withdrawal from Study

Participation in this study is voluntary and participants have the right to withdraw at any time without any consequences. If you feel uncomfortable or become uninterested in the study, you can withdraw from the research at any point in time. Also, If the researcher discovers that a participant does not fully meet the criteria for participating in the research, the researcher will end the individual's involvement.

Contact for Additional Information

For further inquiries and concerns pertaining to the research, participants can contact the researcher. The contact details of the researcher are as follows:

Name: Mabel Yeboah Darfour

Institution: University of Ghana-Department of Psychology

Address: P.O. Box LG 84, Accra, Legon

Email: mydarfour001@st.ug.edu.gh

Telephone: +233 558359438

Your rights as a Participant

If you have any questions about your rights as a research participant in this study you may contact the Administrator of the Ethics Committee for Humanities, ISSER, University of Ghana at ech@ug.edu.gh or 00233- 303-933-866.

Section C- PARTICIPANT AGREEMENT

"I have read or have had someone read all of the above, asked questions, received answers regarding participation in this study, and I am willing to give my consent to participate in this study. I will not have waived any of my rights by signing this consent form. Upon signing this consent form, I will receive a copy for my personal records."

Name of Participant

Signature or mark of Participant

Date

If participant cannot read and or understand the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Name of witness

Signature of witness / Mark

Date

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual and a psychologist will be recruited to assist participants who may be stressed out.

Name of Clinical Psychologist: Mr. Samuel Wiafe

swiafe2010@gmail.com

Contact: 0247969265

Name of Person who Obtained Consent

Signature of Person Who Obtained Consent

Date



Appendix 4: Interview Schedule

INTERVIEW SCHEDULE FOR CAREGIVERS OF OLDER ADULTS LIVING WITH CHRONIC ILLNESSES.

Questions with probes

1. Tell me about yourself

- a. What is your relationship with your care recipient?
- b. How long have you been caring for the patient?
- c. How did you come to be the primary caregiver of the care recipient?

2. Tell me about the caregiving situation

- a. Tell me what caregiving responsibilities you perform for the care recipient?
- b. How often do you need to assist your care recipient?

3. Tell me about your thoughts and experiences about caregiving.

- a. How would you describe your life in general before you became a caregiver?
 - b. Tell me about your expectations about caregiving before you became a caregiver?
- c. How would you describe your life in general now that you have become a caregiver?
 - d. Do you receive support for taking care of your care recipient? If yes, what type of support do you receive?
 - e. Do you face any challenges while taking care of your care recipient? If yes, kindly elaborate on the challenges and how they impact your daily routine and overall well-being?

4. Tell me about any psychological and/or social problems and experiences associated with caregiving for you.

- a. Have you ever received any form of psychological support for your role as a caregiver?
 - i. If yes, what kind of psychological support did you receive.
 - ii. Was it a recommendation/or referral by the hospital or self-referral.
- b. In what ways have the condition of your care recipient affected your own life- emotionally, socially, financially etc.

5. Tell me how you cope with the challenges you face while providing care for your care recipient.

- a. Have you faced any difficulties balancing caregiving responsibilities with other aspects of your life, such as work or personal relationships? How did you cope with that?

b. Can you share any circumstances where you felt overwhelmed by the responsibilities of caregiving? How did you cope with those feelings?

c. Have you encountered any obstacles in accessing resources or support services for both yourself and your care recipient? How do you overcome these obstacles?

d. Do you have a support network in place to help you during particularly challenging times? If so, how do they assist you?

e. What self-care practices do you prioritize to maintain your physical and mental well-being while providing care?

6. Tell me what you think you will need in providing care for your care recipient.

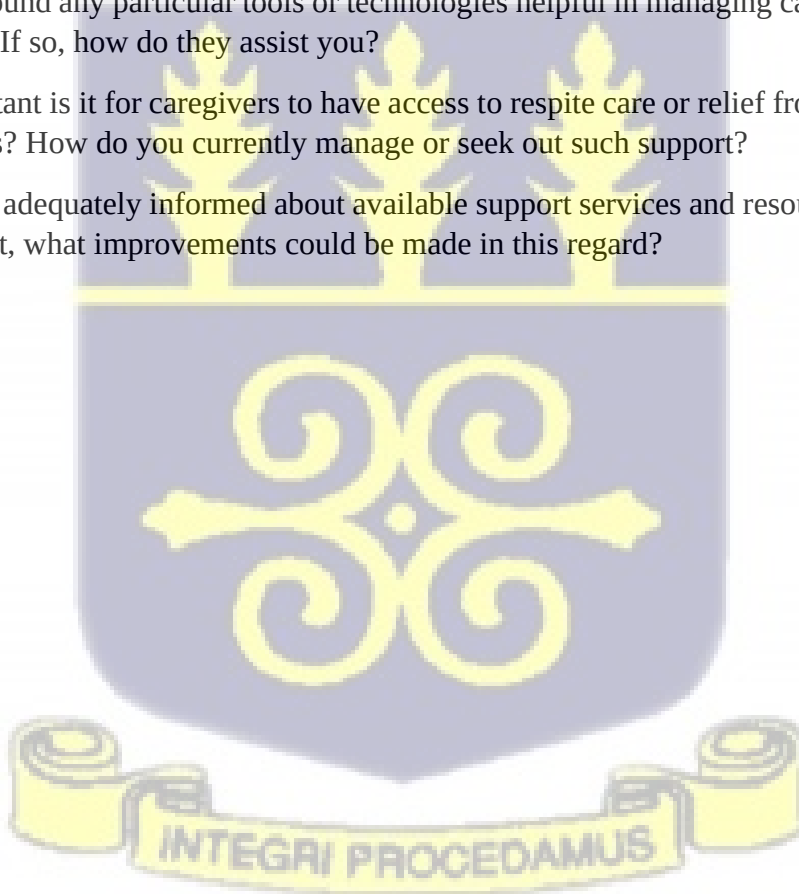
a. Do you think you are lacking anything that when obtained will make your caregiving more efficient?

b. In your experience, what types of assistance or services are most beneficial for caregivers?

c. Have you found any particular tools or technologies helpful in managing caregiving responsibilities? If so, how do they assist you?

d. How important is it for caregivers to have access to respite care or relief from their caregiving duties? How do you currently manage or seek out such support?

e. Do you feel adequately informed about available support services and resources for caregivers? If not, what improvements could be made in this regard?



Appendix 5: Questionnaire

QUESTIONNAIRE ONE

Experiences of caregivers of aged persons living with chronic illnesses.

This research seeks to explore the psychosocial experiences of caregivers living with chronic illnesses. Your name or personal identifiable information will not be required in this survey. Kindly, answer the questions sincerely based on what you do and know. There are no right or wrong responses and responses you will give will be kept confidentially. It will take about 30 minutes to complete this questionnaire. Please note that participating in this research is voluntary and you are free to withdraw from participation at any time.

Thank you for your time and participation.

SECTION A

Demographics

1. What is your gender?

Male 0 Female 1

2. What is your age? Please specify

3. Are you the primary caregiver to your care recipient?

Yes 0 No 1

4. How old is your care recipient? Please specify

5. What illness is your care recipient living with? Please specify

6. How long have you been providing care for the care recipient? Please specify

7. What is your religious affiliation?

Christian Muslim Other Specify _____
0 1 2

8. What is your level of education? Please specify

9. Do you have children of your own you care for?

Yes 0 No 1 If Yes, please specify how many

10. Do you get support from other family members? Yes 0 No 1

SECTION B

ZARIT BURDEN INTERVIEW FOR ASSESSING CAREGIVER BURDEN

The following is a list of statements that reflect how people sometimes feel when taking care of another person. After reading each statement, indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings.

Statements	Never	Rarely	Sometimes	Frequently	Nearly Always
1. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0	1	2	3	4
2. Do you feel embarrassed about your relative's behaviour?	0	1	2	3	4
3. Do you feel angry when you are around your relative?	0	1	2	3	4
4. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?	0	1	2	3	4
5. Are you afraid what the future holds for your relative?	0	1	2	3	4
6. Do you feel strained when you are around your relative?	0	1	2	3	4
7. Do you feel that you do not have as much privacy as you would like because of your relative?	0	1	2	3	4
8. Do you feel that your social life has suffered because you are caring for your relative?	0	1	2	3	4
9. Do you feel uncomfortable about having friends over because of your relative?	0	1	2	3	4
10. Do you feel that you have lost control of your life since your relative's illness?	0	1	2	3	4
11. Do you wish you could just leave the care of your relative to someone else?	0	1	2	3	4

12. Do you feel uncertain about what to do about your relative?	0	1	2	3	4
13. Do you feel that you should be doing more for your relative?	0	1	2	3	4
14. Do you feel you could do a better job in caring for your relative?	0	1	2	3	4
15. Overall, how burdened do you feel in caring for your relative?	0	1	2	3	4
16. Do you feel that your relative asks for more help than (s)he needs?	0	1	2	3	4
17. Do you feel that because of the time you spend with your relative that you do not have enough time for yourself?	0	1	2	3	4
18. Do you feel your relative is dependent upon you?	0	1	2	3	4
19. Do you feel your health has suffered because of your involvement with your relative?	0	1	2	3	4
20. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on?	0	1	2	3	4
21. Do you feel that you will be unable to take care of your relative much longer?	0	1	2	3	4
22. Do you feel that you do not have enough money to care for your relative in addition to the rest of your expenses?	0	1	2	3	4

SECTION C

BECK'S DEPRESSION INVENTORY

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applies to you. Do not spend too much time on any statement.

1. I do not feel sad.	0
-----------------------	---

I feel sad.	1
I am sad all the time and I can't snap out of it.	2
I am so sad and unhappy that I can't stand it.	3
2. I am not particularly discouraged about the future.	0
I feel discouraged about the future.	1
I feel I have nothing to look forward to.	2
I feel the future is hopeless and that things cannot improve.	3
3. I do not feel like a failure.	0
I feel I have failed more than the average person.	1
As I look back on my life, all I can see is a lot of failures.	2
I feel I am a complete failure as a person.	3
4. I get as much satisfaction out of things as I used to.	0
I don't enjoy things the way I used to.	1
I don't get real satisfaction out of anything anymore.	2
I am dissatisfied or bored with everything.	3
5. I don't feel particularly guilty.	0
I feel guilty a good part of the time.	1
I feel quite guilty most of the time.	2
I feel guilty all of the time.	3
6. I don't feel I am being punished.	0
I feel I may be punished.	1
I expect to be punished.	2
I feel I am being punished.	3
7. I don't feel disappointed in myself.	0
I am disappointed in myself.	1
I am disgusted with myself.	2
I hate myself.	3

8. I don't feel I am any worse than anybody else. I am critical of myself for my weaknesses or mistakes. I blame myself all the time for my faults. I blame myself for everything bad that happens.	0 1 2 3
9. I don't have any thoughts of killing myself. I have thoughts of killing myself, but I would not carry them out. I would like to kill myself. I would kill myself if I had the chance.	0 1 2 3
10. I don't cry any more than usual. I cry more now than I used to. I cry all the time now. I used to be able to cry, but now I can't cry even though I want to.	0 1 2 3
11. I am no more irritated by things than I ever was. I am slightly more irritated now than usual. I am quite annoyed or irritated a good deal of the time. I feel irritated all the time.	0 1 2 3
12. I have not lost interest in other people. I am less interested in other people than I used to be. I have lost most of my interest in other people. I have lost all of my interest in other people.	0 1 2 3
13. I make decisions about as well as I ever could. I put off making decisions more than I used to. I have greater difficulty in making decisions more than I used to. I can't make decisions at all anymore.	0 1 2 3
14. I don't feel that I look any worse than I used to.	0

I am worried that I am looking old or unattractive.	1
I feel there are permanent changes in my appearance that make me look unattractive.	2
I believe that I look ugly.	3
15. I can work about as well as before.	0
It takes an extra effort to get started at doing something.	1
I have to push myself very hard to do anything.	2
I can't do any work at all.	3
16. I can sleep as well as usual.	0
I don't sleep as well as I used to.	1
I wake up 1-2 hours earlier than usual and find it hard to get back to sleep.	2
I wake up several hours earlier than I used to and cannot get back to sleep.	3
17. I don't get more tired than usual.	0
I get tired more easily than I used to.	1
I get tired from doing almost anything.	2
I am too tired to do anything.	3
18. My appetite is no worse than usual.	0
My appetite is not as good as it used to be.	1
My appetite is much worse now.	2
I have no appetite at all anymore.	3
19. I haven't lost much weight, if any, lately.	0
I have lost more than five pounds.	1
I have lost more than ten pounds.	2
I have lost more than fifteen pounds.	3
20. I am no more worried about my health than usual.	0
I am worried about physical problems like aches, pains, upset stomach, or constipation.	1

I am very worried about physical problems and it's hard to think of much else.	2
I am so worried about my physical problems that I cannot think of anything else.	3
21. I have not noticed any recent change in my interest in sex. I am less interested in sex than I used to be.	0
I have almost no interest in sex.	1
I have lost interest in sex completely.	2
	3

SECTION D

MULTIDIMENSIONAL SCALE FOR PERCEIVED SOCIAL SUPPORT

Please read each statement and circle a number 1, 2, 3, 4, 5, 6 or 7 which indicates how much the statement applies to you. Do not spend too much time on any statement.

Statements	Very Strongly Disagree	Strongly disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
1. There is a special person who is around when I am in need.	1	2	3	4	5	6	7
2. There is a special person with whom I can share joys and sorrows.	1	2	3	4	5	6	7
3. My family really tries to help me.	1	2	3	4	5	6	7
4. I get the emotional help and support I need from my family.	1	2	3	4	5	6	7
5. I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7

6. My friends really try to help me.	1	2	3	4	5	6	7
7. I can count on my friends when things go wrong.	1	2	3	4	5	6	7
8. I can talk about my problems with my family.	1	2	3	4	5	6	7
9. I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7
10. There's a special person in my life who cares about my feelings.	1	2	3	4	5	6	7
11. My family is willing to help me make decisions.	1	2	3	4	5	6	7
12. I can talk about my problems with my friends.	1	2	3	4	5	6	7

SECTION E

THE WHO-5 WELLBEING INDEX

This assesses the subjective quality of life and general wellbeing of participants. Please read each statement and indicate how often you experience the feelings listed by circling the number that best corresponds to the frequency of these feelings. Do not spend too much time on any statement.

Statements	All of the time	Most of the time	More than half the time	Less than half the time	Some of the time	At no time
1. I have felt cheerful and in good spirits.	5	4	3	2	1	0
2. I have felt calm and relaxed.	5	4	3	2	1	0
3. I have felt active and vigorous.	5	4	3	2	1	0
4. I woke up feeling fresh and rested.	5	4	3	2	1	0
5. My daily life has been filled with things that interest me.	5	4	3	2	1	0

SECTION F

ATTITUDES RELATED TO SPIRITUALITY SCALE

Please read each statement and circle a number 1, 2, 3, 4, or 5 which indicates how much the statement applies to you. Do not spend too much time on any statement.

Statement	Totally Disagree	Disagree	Neither Agree nor Disagree	Agree	Totally Agree
1. I believe in something sacred or transcendent (God, a higher force).	1	2	3	4	5
2. Meditation, prayer, readings and/or contemplation are practices that I use (at least one of them) to connect with a spiritual force beyond myself.	1	2	3	4	5
3. I have witnessed facts/situations that have led me to believe that there is something beyond the material world.	1	2	3	4	5
4. My faith or spiritual beliefs sustain me on a daily basis.	1	2	3	4	5
5. My spirituality helps me have a better relationship with others.	1	2	3	4	5
6. My spirituality influences my physical and mental health.	1	2	3	4	5
7. My spirituality encourages me to help others.	1	2	3	4	5
8. I believe in continuity after death.	1	2	3	4	5

9. My spiritual beliefs and values guide my day-to-day actions.	1	2	3	4	5
10. My faith or spiritual beliefs give meaning to my life.	1	2	3	4	5
11. Spiritual practices (e.g., praying, fasting, meditation or other) help maintain or improve my physical or mental health.	1	2	3	4	5

