UNIVERSITY OF GHANA

DEPARTMENT OF PSYCHOLOGY

COLLEGE OF HUMANITIES

PSYCHOSOCIAL PREDICTORS OF POSITIVE EXPERIENCES IN CAREGIVING AMONG FAMILY CAREGIVERS IN GHANA: A STUDY IN GREATER ACCRA REGION

BY

ANKRAH CHRISTIANA

(10232304)

THIS THESIS IS SUBMITTED TO THE SCHOOL OF GRADUATE STUDIES, UNIVERSITY OF GHANA IN PARTIAL FULFILLMENT FOR THE AWARD OF MASTER OF PHILOSOPHY DEGREE IN SOCIAL PSYCHOLOGY

JULY, 2017

DECLARATION

This is to certify that this thesis is the result of research carried out by CHRISTIANA ANKRAH towards the award of the MPhil Social Psychology Degree in the Department of Psychology, University of Ghana. Apart from references cited in this work, which have been duly acknowledged, this work has not been presented in part or in whole for any award in any other institution and I should be held accountable for any flaws associated with this work.

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CHRISTIANA ANKRAH

(STUDENT)

……

DATE

…… ……

PROF. PROF CHARITY S. AKOTIA	DR. JOSEPH OSAFO
(PRINCIPAL SUPERVISOR)	(CO-SUPERVISOR)
…….	……
DATE	DATE

DEDICATION

To my family and significant others, whose continuous assurance, support, and love made this thesis a reality.

ACKNOWLEDGEMENT

A big thank you to the Supreme Architect of the universe for the many blessings He continually surprises me with.

I take this opportunity to express my heartfelt gratitude to my principal and co-supervisor, Professor Akotia and Dr. Osafo for their guidance, constructive criticisms and the strong will to impact on the younger generation.

I am very grateful to my family, my husband (Mr. Yaw Ofori) especially, who has been very instrumental in my quest to pursue higher education.

To my research assistants (Francis, Deborah, Lilian, and Portia), I am highly indebted to you guys for the services offered.

This thesis would not have been possible without the participation of informal caregivers at their various homes; their experiences enriched the contents of the study. I am very pleased and humbled to have worked with them.

Finally, I really appreciate the love shown by colleagues, friends and significant others towards the completion of this programme.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ABSTRACT

Research on positive experiences of caregiving is steadily receiving societal attention. There have been theoretical propositions that values caregivers hold in life shape caregiving experiences. However, these propositions have not seen empirical study, especially within resource-poor contexts. The current study explored factors that shape the lived experiences among family caregivers within Ghanaian context. Data was gathered using a simultaneous mixed-method design with a survey of 120 conveniently sampled informal caregivers and individual interviews with 10 conveniently sampled informal caregivers all within Accra metropolis. Life values were measured with the Life Values Inventory (LVI) and caregiver experiences were measured using the Finding Meaning through Caregiving Scale (FMTCS). The quantitative data was analyzed using MANOVA and series of hierarchical multiple regressions and the qualitative data was analyzed using interpretive phenomenological analyses (IPA). Findings showed that informal caregivers experience complex sets of psychosocial stress and upliftment simultaneously. Factors which were found to affect the caregivers' experiences included conditions suffered by the care receivers, family situations, care receivers' own contributions and a surrendering attitude on the part of the caregivers. Male caregivers experience higher levels of negative aspects of care-giving than female caregivers while female caregivers experience higher levels of positive aspects of care-giving than male care givers. Other-focused values predicted positive experiences while self-focus values predicted negative experiences of caregiving. The findings are discussed within the context of developing psychosocial interventions to improve mental health among informal caregivers in Ghana and suggestions made for future research.

CHAPTER ONE

INTRODUCTION

1.1 Background of the Study

Family caregivers constitute substantial number of informal caregivers in low and middle income countries (LMICs). The reason has been attributed to the fact that majority of families cannot afford professional home care for their relatives who need care due to physical and or mental health challenges (Ae-Ngibise, Doku, Asante & Owusu-Agyei, 2015). Because of this, family members take it upon themselves to provide care for their sick relatives. Informal caregiving comes with several challenges and associated mental health consequences (Hamilton, 2014).

Challenges of caring for patients and relatives with chronic conditions have been well documented. This is especially so because research on the health and well-being among informal caregivers, for some time now has focused much attention on the negative outcomes (Knight & Sayegh, 2010). Attention to the positive experiences associated with the caregiving role among informal caregivers in general and family caregivers in particular has not received adequate attention (Farran, 1997). The various factors that shape positive experiences among family caregivers within a particular cultural context therefore needs further empirical examinations.

The current study examined the complexities and nuances that characterize informal caregiver experiences. In the current study, informal caregiving is conceptualized as family members and friends providing daily help and support their loved ones who are temporarily or permanently dysfunctional and therefore are not able to independently perform activities of

daily living. Using phenomenological research philosophy, the study explores the burden and positivity that characterises lived experiences of giving care among informal caregivers in Accra, Ghana. A phenomenological approach to caregiver research provides the researcher the opportunity for immersion into the life world of caregivers to uncover how the burden of caregiving co-exist with positive experiences (Petruzzo et al. 2017) in resource poor contexts.

1.1.1 The Burden of Informal Caregiving

Informal caregivers are mostly thrown into their caregiving role unexpectedly without any prior preparation and or anticipation. For most of them, they start the caregiving role with little or no knowledge about the condition their loved one is suffering from (Cheng, Mak, Ng, & Lam, 2015). Most of the conditions occur rapidly such as sudden strokes, dementia etc., the caregiving role coincides with the challenge of trying to make sense of the temporal or permanent loss of independent engagement of activities of daily living of their loved ones. They also do not receive income or remunerations and the family expect much from them when executing their roles. Because of this, informal caregivers are considered as one of the most vulnerable groups within the broader health and mental health discipline.

The burden of caregiving role has therefore been well-researched and the findings from the literature point to one direction. Many of the studies (e.g. Carbonneau, Caron & Desrosiers, 2010; Petruzzo et al. 2017) that report on the negative experiences of informal caregiving have used mainly the stress-adaptation model to explore the negative experiences that are associated with caregiving among informal caregivers or mostly family caregivers.

The studies exploring negative experiences associated with the caregiving role have reported that informal caregivers experience increased stress, depression, burden and identity loss because majority of them feel trapped in their caregiver roles. This line of studies has been

criticised for creating a one dimensional view of the caregiving experience, which does not provide a holistic understanding of the complex nature of caregiver role (Kramer, 1997).

With the dissatisfaction of the overemphasis on the negative experiences in caregiving, a different line of research appeared that sought to capture the positive experiences associated with informal caregiving role. Carbonneau et al. (2016) argue that the positive aspects of care should be considered when helping families since caregivers‘ support should not only reduce the difficulties they face but also enhance the positive aspects of their role.

1.1.2 Positive Aspect of Caregiving

The positive aspects of caregiving play a critical role in the caregiving experience. Nevertheless, there has been paucity of research studies that have examined the positive experiences associated with caregiving. The few studies that have focused on examining positive aspects of caregiving have tended to be exploratory and have also used small sample sizes (Chen & Greensberg, 2004).

These aspects of caregiving may contribute to maintain caregivers‘ involvement by buffering the impact of caregiving stress and burden on the caregiver‘s mental and physical health. There is ample evidence in literature to shows that negative and positive caregiving experiences can co-exist, and positive experiences can even compensate or buffer the negative effects of caregiving on life satisfaction (Kruithof, Post & Visser-Meily, 2015; Petruzzo et al. 2017). For instance, Petruzzo et al. (2017) reported that informal caregivers of patients with heart failure experience a mixture of burden and love.

Kramer (1997) at the early development of the debate argued for the consideration of positive aspects of caregiving for reasons including; (1) caregivers sometimes also want to share and discuss the gains in their caregiving experience; (2) identifying positive aspects of caregiving assists trained or professionals in working with caregiving systems; (3) positive aspects of

caregiving may be related to the quality of the care given to the care recipient; and (4) a focus on gains enhances the development of theories associated with caregiving.

Juxtaposing the burden research and the positive aspects of caregiving together shows that caregiving is characterized by complex and much nuanced experiences, where informal caregivers experience positive signs in the mixed negative experiences. The complex nature of the informal caregiver experiences should therefore reflect in research to holistically understand the phenomenon.

1.2 Statement of the Problem

Family caregivers constitute larger proportion of informal caregivers. This is because, caregiving for patients with chronic conditions always fall on the shoulders of family members for several reasons. For example, family members may engage in caregiving because they feel it is their responsibility, or they have a strong desire to do so, or there is no one else available (Peacock et al. 2009).

Family members are therefore mostly thrown into caregiver roles unexpectedly and so family caregivers always lack the requisite knowledge and skills to handle the person or the condition or both. This has sustained the interest in the negative experiences of informal caregivers in general and family caregivers in particular. These studies have uncovered that the combination of loss, the physical demands of caregiving and psychological distress often lead to negative changes in health-related quality of life for family caregivers (Peacock et al. 2009), thus providing support for the stress-adaptation model.

However, contrary to the stress-adaptation model, several studies have also shown that, in the midst of the stress and burden associated with caregiving, informal caregivers still experience some moments of upliftment and fulfilments. Therefore, a new research paradigm also emerged in the late 1900s that seeks to broaden knowledge of the experiences of caregivers to also include some positive experiences (Kramer, 1997).

In the area of mental health for instance, there has been a burgeoning interest in the positive aspects of caregiving (PAC). Adopting strength-based approach to caregiving experiences, these studies seek to unearth the positive aspect of the caregiver experiences that can be harnessed to plan for therapies and interventions to improve on the well-being of informal caregivers.

Being dominated by qualitative studies, the early studies on the positive aspects of caregiving showed that informal caregivers simultaneously experience fulfilment and stress in their caregiving role. The stress-adaptation model was unable to account for why informal caregivers report positive experiences and fulfilment whiles they are still experiencing high stress associated with the caregiving burden. This called for a new model or theory that could explain the concurrent experience of burden and upliftment to better account for the positive experiences among informal caregivers (Farran, 1997).

Existentialism perspective of humanistic psychology has therefore been to explain the new findings (Farran, 1997). The existential perspective of the positive aspects of caregiving explains that, in the midst of caregiving difficulties, informal caregivers have the ability to experience sorrow and happiness at the same time through the values they hold about life and the degree of choice or autonomy they exercise of the conditions (Farran, 1997).

Caregivers, particularly family members, spend a substantial amount of time providing care to ill relatives with little knowledge of how to deal with their condition (Kruithof et al. 2015; Petruzzo et al. 2017). Their lack of knowledge, support and guidance from health services to manage ill relatives at home results in the caregivers being unable to provide the required care (Petruzzo et al. 2017). Research shows that caregivers who receive educational support from health professionals were able to manage the needs of ill relatives, and as a result were less burdened by their condition (Kruithof et al. 2015). Evidence has also shown that many

caregivers who use religion as a social support network experience fewer burdens, are able to manage stressors and have a more positive attitude toward life (Farran, 1997; Petruzzo et al. 2017).

Family caregivers play a vital role in palliative care in sub-Saharan Africa where poverty, scarce healthcare resources and personnel, and late diagnosis render home-based care (HBC) the viable option for several chronically and terminally ill persons (Streid et al., 2014). Understanding the complexities of the family caregiver role in this context will aid in formulating culturally relevant support systems for these caregivers.

Even though the positive aspects of caregiving are increasingly receiving research attention, there are still further issues that need to be explored empirically to provide holistic understanding. For example, empirically studies that assess how values in life and degree of choice in caregiver role influence positive aspects of caregiving are scarce in the literature. Also, empirical studies examining positive aspects of caregiving within Ghanaian context is virtually non-existent. Also, this study therefore sought to explore the influence of life values on the positive aspects of caregiving among family caregivers within Ghanaian context.

1.3 Aim and Objectives

The main aim of the study was to examine positive experiences of caregiving among family caregiver in Ghana. Specific objectives of the study were:

1. To examine the values that family caregivers hold in life influence on positive experiences of caregiving.
2. To examine the values that family caregivers hold in life and their influence on the burden of caregiver informal experiences.

3. To assess how socio-demographic factors such as gender, age, conditions of care recipient and relationship with care recipient etc., affect the relationship between life values and positive aspects of care among the family caregivers.
4. To explore socio-cultural factors that shape positive experiences of family caregivers within the Ghanaian context.

1.4 Research Questions

Based on the objectives of the study, the following research questions were therefore raised:

1. How do values that family or informal caregivers hold in life influence the burden of their caregiving experiences?
2. How do values that family or informal caregivers hold in life influence positive aspects of their caregiving experiences?
3. How do socio-demographic factors such as age and gender etc. affect both burden and positive aspect of informal caregiver experiences?

1.5 Significance of the Study

Findings from the study provide valuable insight into the positive experiences of family caregivers in their caregiving roles. The findings show the complexities that characterises lived experiences of family caregivers in Ghana that is mixed with simultaneous experiences of stress and upliftment

The study also provides an understanding of how the values that family caregivers hold in life influence their caregiving outcomes. This helps in practice and theory with the development of interventions that draw on the strengths of the family caregivers and also insight adding to the knowledge of the literature on positive aspects of care.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter situates the current study within relevant literature concerning caregiving experiences, especially concerning the positive aspect of the caregiving experience. The two main models that will serve as the framework for the current study are first considered. The chapter is then proceeded with a review of related studies takes a critical look at the relevant studies in the light of the study objectives. A rationale that seeks to justification of the current study is discussed and then key variables of the study are highlighted. Hypotheses to be formulated and tested follow and then and a hypothesised model is constructed. Then various key terms are also operationally defined as applicable to this study.

2.2 Theoretical Framework

For the purposes of the current study, these two models (the Stress-Adaptation Paradigm and the Existential Perspective) were used as framework to explain the positive outcomes that caregivers experience in their caregiving role.

2.2.1 Stress-Adaption Model

Research on positive aspect of caregiving has been conceptualised as a chance finding that has provided a new perspective for looking at caregiver experiences. The stress-adaptation models have been drawn on to explain the dynamics of the caregiver roles and experiences for quite a while (Kramer, 1997). These models were first developed within the context of nursing care to explain the experiences of nurses in their care for chronically ill patients and the negative consequences associated with the caregiving role. The dominant theories within the field were the stress-adaptation and the role-strain theories.

These dominant models that have been used is the stress-adaptation or the stress-coping model that conceptualise caregiving experience as an oscillation between two distinct continua of being stressed up by the caregiving role or adapting to the role and being healthy. For instance, the Stuart Stress Adaptation Model (Stuart, 2009) assumes that care (originally as nursing care) assumes that (nursing) caregivers' health depends on their ability to adapt to their caregiving role and that inability to adapt produces negative experiences.

With the increasing number of primary caregivers (and some nurses) reporting of positive experiences by caregivers, mainly in qualitative studies, the stress-adaptation models became deficient in adequately explaining this positive aspect of caregiving. The stress-adaptation model underwent a revision and the unified model of stress-health was developed to explain these positive experiences.

According to the unified model of stress-health perspective, the positive aspects of caregiving are understood to be part of the appraisal of the demands and adaptive capacities that mediate between the stressors (caregiving role) and caregiver well-being (increased risk of physical and psychiatric disease) (Tarlow, Wisniewski, Belle, Rubert, Ory & Gallagher-Thompson, 2004).

The unified model explains caregiving appraisal as the subjective evaluation made by the caregiver of his or her caregiving experience that weighs both the demands and benefits of caregiving, which may be either positive or negative (Tarlow et al. 2004). Thus, according to the mode, caregiving appraisal act as a mediator between caregiving role and caregiver experiences and therefore positive aspects of caregiving act to ameliorate the stresses of caregiving to help maintain the quality of life for individuals which can explain their positive experiences.

For example, the physically demanding work of assisting with activities of daily living (ADLs) by a family primary caregiver such as a spouse may be appraised to be an extension

of a long-lasting mutually reciprocal relationship. With such an appraisal, the unified model argues that, rather than being overwhelmed by the demands, the spousal caregiver experiences a sense of satisfaction and enhanced self-esteem because they are able to help someone they love. Thus, the caregiver‘s physical and mental well-being is maintained (Tarlow et al. 2004).

2.2.2 Existentialism Paradigm of Positive Aspects of Caregiving

The stress-adaptation models‘ inability to fully address the issue of how or why caregivers manage to do so well under difficult circumstances led some research to resort to Existentialism as an alternate theoretical view for exploring this issue. Existentialism is a philosophical perspective that addresses the complexities of individuals‘ experiences in and of life and the search for answers to such complex question as "What does it mean to exist or to be human?" (Farran, 1997, p.252).

Existential interpretations of life‘s circumstances and experiences have been found to have significant influence on psychological outcomes of individuals (Markman, Proulx & Lindberg, 2013). The existentialist paradigm has many assumptions about difficulties associated with being human. One of the main ideologies of existentialism is the idea that human beings do two important things alone – to be born or die (Farran, 1997). This has shaped many of the assumptions and explanations of existentialism as to why individuals might be able to bare a burden in good faith. For example, such assumptions include; that each individual, at some point in his or her lifetime experiences isolation at in an indifferent universe; each person suffers or despairs at some time in his/her life; and there are two things a person must do alone (Farran, 1997; Wong, 2013).

The existential perspective therefore acknowledges the fact that caregivers as human beings, have the potential to experience existential vacuum — times when one's goals are not met, times when there are feelings of nothingness, meaninglessness, anxiety, and isolation

(Markan et al. 2013). Thus, in the midst of difficulties of caring for a loved one, family caregivers have the power to experience this vacuum in their lives and still find reason to thrive. Thus, existential paradigm addresses the tremendous capacity that humans have to experience hope, to transcend and find meaning in the midst of difficult life experiences (Farran, 1997; Vos, Craig & Cooper, 2015).

The existential paradigm identifies tension between being free to make choices while at the same time assuming responsibility for what life sets before one, and the natural consequences of actions as explaining the way people deal with the challenges in their lives (Farran, 1997; Wong, 2013). Thus, according to this assumption, whether the caregiver role was a deliberate choice or forced on the individual makes a difference between experiencing positive outcome or negative outcome.

The tension between free choice and assuming responsibility is shaped by values one embraces and the choices one makes, as well as one's willingness to assume responsibility for right action and conduct (Ferran, 1997). The existential perspective therefore explains that the values of a caregiver in life and the extent of choice the caregiver had in assuming the caregiving role will influence their experience of positive aspect caregiving and finding meaning in life.

Based on the philosophy of Frankl (1963), existential psychologists identify and measure two distinct forms of meaning in life; provisional meaning and ultimate meaning. Provisional meaning refers to more short-term or transitory experiences that provide life with meaning, while ultimate meaning refers to a person's exploration of deeper meanings in life often associated with one's spiritual nature (Farran, Miller, Kaufman, Donner & Fogg, 1999).

2.3 Review of related studies

The concept of positive aspects of caregiving has been reported in the literature to be an integral part of the caregiver roles. The literature shows that positive experiences in the

caregiving role predict psychological outcomes and well-being among individual family caregivers. Positive aspect of caregiving has been reported to influence the stress experienced by caregivers as a result of the burden of caregiving. Caregivers who report of experience minimal positive experience in their caregiving role have also been found to report higher levels of negative psychological health including depression and anxiety.

For example, in a study to examine how positive aspects of care relate to the caregiving experience, Walker, Powers and Bisconti (2016) conveniently sampled 70 informal caregivers who provide a minimum of 8 hours of care for older adults (50 years or older) with chronic illness or disability. They found that positive aspects of caregiving were significantly related to burden, depression, identity loss and role captivity.

Thus, individuals who reported high positive experiences in their caregiving experience reported less burden, depression, identity loss and role captivity. They also found that positive aspects of caregiving moderated between burden and depression. Walker et al. (2016) thus, explained that caregivers who experience positive aspects of their caregiving role have learnt how to successfully cope with the challenges associated with their caregiving role and therefore have less of the bad (e.g. burden, depression, identity loss, role captivity and depression) and more of the good (e.g. joy, happiness, affection from care recipient).

In the Walker et al. (2016) study, positive experiences of care are projected as a single continuous construct. They therefore conceptualised positive experience as less experience of burden, depression, role captivity etc. Such conceptualisation of positive experience does not provide in-depth understanding of the actual positive experiences of the caregivers. Several other studies have also delineated the actual positive experiences as recounted by the caregivers. This line of studies has mainly come from those using qualitative methodology through the use of methods such as in-depth interviews (e.g. Gray, Hahn, Thapsuwan & Thongcharoenchupong, 2016; Peacock et al. 2009; Netto, Jenny & Philip, 2009) and dairy

recordings (e.g. Cheng, Mak, Ng, & Lam, 2015). These studies have showed several different dimensions of positive experiences among different family caregivers.

For instance, in a study to understand the experiences of caregivers with older people in relation to quality of life and stress management, Gray et al. (2016) conducted in-depth interviews with 17 family caregivers in Thailand. They reported that despite their participants reporting of many negative experiences such as emotional stress, financial struggles and worry, they also reported a number of positive experiences. The positive experiences they reported included experience of affection from care recipients and opportunity to show gratitude to the care recipient.

Some participants also recounted that in many instances, social support, in the form of encouragement from the wider community members put smiles on their face and helped them carry on with their caregiver roles. This supports earlier studies that have reported the influence of social support on caregiving gains for family caregivers of schizophrenic patients (e.g. Cheng & Greensberg, 2004). Gray et al. (2016) has therefore explained that the participants they studied showed signs of negotiating between the extremes of bliss and suffering. Therefore, if caregivers are made to understand suffering as part of life, it may help them manage their caregiving burden and stress better.

In an earlier study, Cheng et al. (2015) have also reported several dimensions of positive aspects of the caregiving experience. In a study to discover the positive gains as constructed by family caregivers of relatives, Cheng et al. (2015) sampled 57 primary caregivers of individuals with Alzheimer‘s disease in Hong Kong to provide diary recording of the positive aspects of their caregiving role over an 8-week period. Participants were tasked to record by describing their daily events and experiences in which positive experiences were achieved. Using thematic content analysis, Cheng et al identified ten (10) different themes showing different positive aspects of caregiving.

The diary records from participants showed that they; (i) have gained insights about Alzheimer and accepted of the condition, (ii) have had a sense of purpose and commitment to the caregiving role, (iii) experience feelings of gratification when the care-recipient was functioning relatively well, (iv) have mastered skills to handle the care recipient, (v) have increased patience and tolerance, (vi) have cultivated positive meanings and humour amidst difficult circumstances, (vii) letting go of things, such as when the care recipient's qualities had been lost or personal agenda had become unrealistic, (viii) developing a closer relationship with the care recipient, (ix) finding support, and (x) feeling useful helping other caregivers.

In a critical review of the qualitative literature on the positive aspects of caregiving in dementia, Lloyd, Patterson and Muers (2014) reported a strikingly consistency in the literature regarding positive experiences of caregivers of dementia patients. They reported of several studies reporting multiple positive experiences including role satisfaction, emotional rewards, personal growth, competence and mastery, faith and spiritual growth, relationship gains, sense of duty and reciprocity. They however observed subtle difference in different groups of carers in their positive experiences. For instance, adult child carers have been reported to seem to find personal growth as a particularly salient outcome. In contrast, spousal carers, particularly wives, tended to place a higher value on gains based in the dynamic of their relationship and on spiritual growth. Similar findings have also been reported in the literature among caregivers of cancer patients (Li & Loke, 2013).

Significant cultural differences have been observed in the positive experiences of caregiving. In exploring demographic group differences in positive aspects of caregiving, Roth, Dilworth-Anderson, Huang, Gross and Gitlin (2015) sampled 642 family caregivers to completed Positive Aspect of Caregiving scale in a wave 2 study examining resources for enhancing Alzheimer's caregiver health. They observed that African Americans reported

more positive attitude towards caregiving compared to Hispanics native Americans. As with many other studies, females were largely represented compared to males and the females also reported more positive attitude towards caregiving compared to males.

2.5 Statement of Hypotheses

Based on the theories and studies reviewed above, the following hypotheses were tested;

H1: Male caregiver will report higher negative experiences of caregiving than female caregivers.

H2: Female caregivers will report higher positive experiences of caregiving than male caregivers.

H3: Self-directed values will be associated with higher burden of negative caregiver experiences

H4: Self-directed values will be associated with low positive caregiver experiences

H5: Other-focused values will be associated with higher positive caregiver experiences

H6: Other-focused values will be associated with lower burden of negative caregiver experiences

2.6 Hypothesised Model

In the hypothesized model, life values will significantly predict caregiver experiences after controlling for demographic characteristics of the caregivers such as gender, age, education and years of caregiving. However, different life values will affect the caregiver experiences differently such that values that promote self-interest will increase negative caregiver experiences and reduce positive experiences and values that promote well-being of others will reduce negative caregiver experiences and increase positive caregiver experiences.

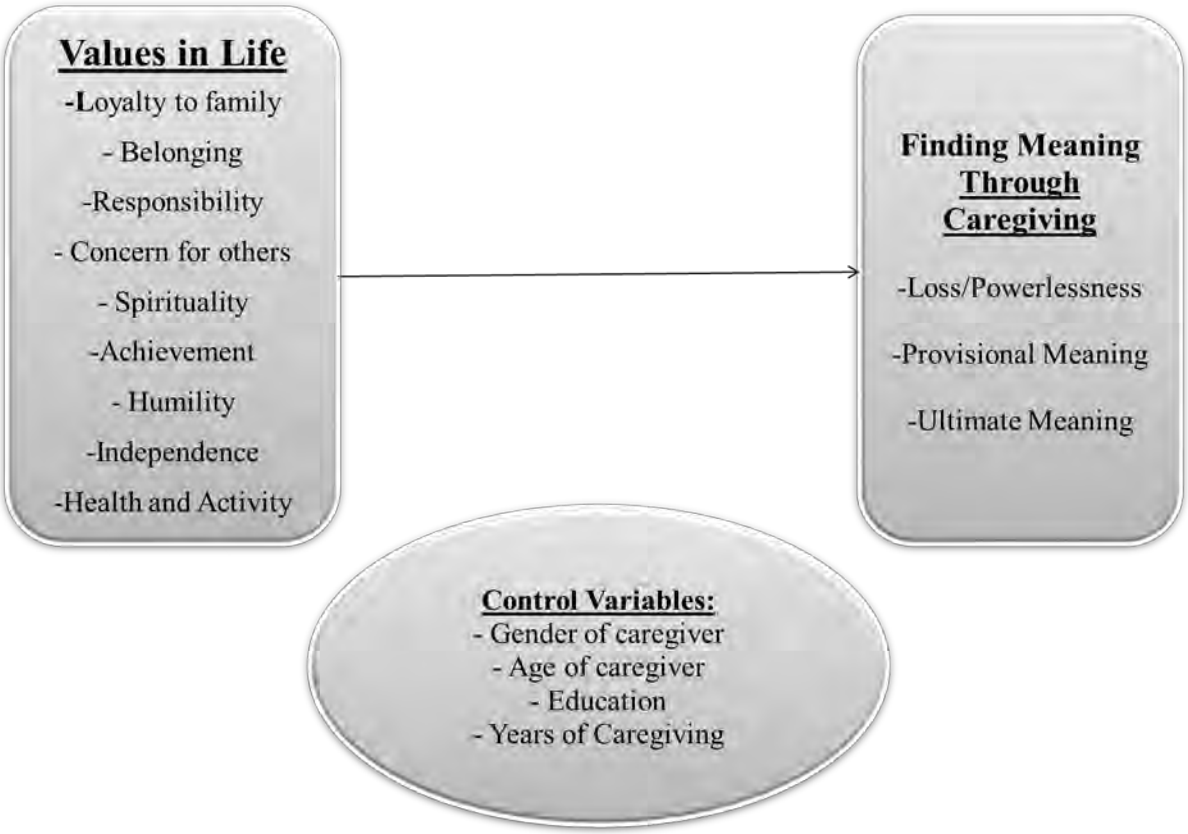

Figure 1: Hypothesized Model of Life Values as Predictors of Caregiver Experiences

2.7 Operational Definitions

1. Psychosocial factors in this study include stress, hopelessness and depression.

2. Informal caregiving is conceptualized as family members and friends providing daily help and support to their loved ones who are temporarily or permanently dysfunctional and therefore are not able to independently perform activities of daily living.

3. Life Values means deciding what is most important in life: scores on 9 subscales of the Live values inventory (Loyalty to family, Belonging, Responsibility, Concern for others, Spirituality, Achievement, Humility, Independence and Health and Activity).

4. Positive Aspect of Caregiving means getting satisfaction and benefits from giving care to a loved one: score on Finding Meaning Through Caregiving Scale (FMTCS).

CHAPTER THREE

METHODOLOGY

3.1 Introduction

This chapter contains the detailed methodological procedures that were employed in gathering and analysing data for the current study. The sections captured here are descriptions of the research design and approach, population of the study, sample size and sampling technique, description of measures, procedures for data collection, proposed data analyses and ethical issues of the study.

3.2 Research Design and Approach

The study used a mixed-method phenomenological research (MMPR) design to collect both qualitative and quantitative data to answer the research questions (Mayoh & Onwuegbuzie, 2015). Studies exploring positive aspects of caregiving have largely used either quantitative or qualitative approaches. Some scholars, especially those advancing the positive aspect of caregiving (e.g. Walker et al. 2016) within the field have argued that combining qualitative and quantitative methods in a study provides opportunity for exploring caregiver experiences from different perspectives to enhance understanding of the lived experiences of caregivers.

Mixed-method approach also has the utility of addressing potentially complex psychological issues in diverse socio-cultural contexts (Braun & Clark 2013). Therefore, the study collected and analysed both qualitative and quantitative data, integrated the findings, and drew inferences about the questions raised in the study (Cresswell, 2014; Lucero et al. 2017).

Specifically, the study used the complementary or simultaneous mixed method design where both the qualitative and the quantitative data were collected and analysed simultaneously

(Mayoh & Onwuegbuzie, 2015). In mixed-method studies, the contribution and purpose of each component of the study needs to be explained (Cresswell, 2014). In this regard, Morse (2003) stated that the dominant method is denoted with capital letters (e.g. QUAN for quantitative and QUAL for qualitative) and the less dominant method denoted with small letters (i.e. qual for qualitative that is less dominant and quan for quantitative that is less dominant) and the two of them with a plus (+) sign. In the current study, both components of the study were independent of each other and therefore each of them is considered dominant. As explained by Morse (2003), the design is therefore complementary simultaneous QUAL + QUAN design.

The qualitative component of the study was based on a hermeneutic phenomenological method which made use of semi-structured in-depth individual interviews. Cresswell (2014) defined individual interview in qualitative research as involving collecting data through conducting intensive one-on-one interviews with respondents one at a time to explore their perspectives on a particular idea, program or situation (Cresswell, 2013). The interviews helped to explore the lived experiences of the caregivers in their caregiving roles. The main reason for choosing individual interviews ahead of other methods of gathering qualitative data such as focus group discussion was because of the ontological and epistemological foundation of the study.

Because the study rests on phenomenological philosophy, the qualitative component of the study basically explored the lived experiences of caregiving burden among the respondents (Bugental, 2013). This required entering into the _life-world‘ of the caregivers and delving deeper into personalized issues regarding their experiences of caregiving (Levitt et al. 2017; Smith, 2017). Phenomenological studies are characterized by double-hermeneutics where the researcher engaged with the caregivers to delve deeper into the private life of the respondents

to try to make sense of how they are making sense of their experiences (Smith, 2017). The only way of getting richer and better information from this encounter is through individual interviews as compared to other means of gathering qualitative data.

The quantitative component of the study used of cross-sectional survey to sample different categories of caregivers, mainly in terms of age, gender and condition of care recipient. The survey method involved administering questionnaires that to a large sample of the caregivers. The choice of survey technique was appropriate for this study because it allows for financial literacy to be investigated by using a large sample of the mental health caregivers. For caregivers with high levels of education, the questionnaire was self-administered and for the caregivers with low levels of education, the researcher or research assistants administered the questionnaire.

3.3 Study Setting

The study was conducted in Greater Accra Region, specifically within Accra Metropolitan Assembly. The choice of Greater Accra region is based on the high population of the region as indicated by the Ghana Statistical Service (GSS, 2013) census data. The region also has high incident of chronic physical and mental health conditions such as stroke, diabetes, dementia etc. (de-Graft Aikins et al. 2014). The region in general and the metropolitan in particular therefore has large number of family members giving care to their chronically ill patients.

These family caregivers span across diverse socio-cultural and economic backgrounds because of the cosmopolitan nature of the district due to diverse economic activities that draw people from all areas of Ghana. The district therefore served as a good place to conduct such a study that seeks to explore how socio-cultural and psychological factors shape caregiving experiences.

3.4 Population of the Study

The population of the study consisted of all informal caregivers such as family members within the district who are giving care to their chronically ill relatives. For the purposes of the study, the informal caregivers in the communities and health centres were sampled for the study. Institutionally based caregivers were not part of the study. The focus on community-based informal caregivers provided the context for exploring in-depth socio-cultural factors that shape their caregiver experiences.

3.5 Sample and Sampling Technique

Sampling procedures in mixed-method studies are very complex. Mayoh and Onwuegbuzie (2015) for instance argue that sampling participants for mixed-method study involves developing sampling framework that incorporates all sampling processes for both the qualitative and the quantitative part of the study. Developing the right sampling schemes for selecting participants ensures analytical generalization in the qualitative part of the study while also ensuring statistical generalization in the quantitative part of the study (Cresswell, 2014; Willig & Stainton-Rogers, 2017).

In the current study therefore, the parallel sampling technique was chosen as the framework for sampling participants. Onwuegbuzie and Collins (2007) defined parallel sampling as a way of selecting samples for a simultaneous mixed-method study that ensures that different samples are selected for different components of the study to ensure that no single participant takes part in both parts of the study. In the current study therefore, different group of informal caregivers were sampled for the qualitative component and different group sample for the quantitative component. This sampling strategy ensured that the study was free from difficulties associated with same participants having to take part in the survey and the personal interviews. Such a situation can result in fatigue or participant responses in one

component of the study affecting the other component of the study (Lucero et al. 2017; Mayoh & Onwuegbuzie, 2017).

In selecting different caregivers for each of the two components of the study, different sampling techniques were used. In both components of the study, the primary sampling technique was purposive. Purposive sampling technique was used because the researcher intentionally sampled the caregivers based on some specific inclusion criteria to yield rich and valuable information (Cresswell, 2014; Smith, 2015). But at some point, snow boiling and referrals were also used in locating some of the caregivers.

The main inclusion criterion for selecting participants was that the prospective participants should be informal caregivers with no formal training or education specific for caregiving. In this regard, caregivers who are based in or hired by institutions were excluded from the study. Another inclusion criterion was that the participants should have been giving the care for a minimum of one year. The one-year criterion was used because based on some earlier studies (e.g. Cheng et al. 2015; Gray et al. 2016), by one year, the caregiver would have experienced different faces of the caregiving role and therefore would provide very rich information.

Different sample size determinations were used in deciding how many caregivers were sampled for each component of the study. For the qualitative part, several factors were considered a guideline in determining sample size in qualitative research, especially for individual interviews. Factors such as the type of issue being explored, the kind of participants needed for the study, budget or resources available for the study, heterogeneity of the sample etc. (Cresswell, 2014; Mayoh & Onwuegbuzie, 2017).

However, in the current study, the criteria for sample size determination used for the qualitative part was the ample sample size for interpretative phenomenological analysis (IPA). Even though there is no specific answer to the number of samples needed for IPA, the

kind of in-depth analysis it requires ensures that, for rigour and richness, the smaller the sample the better (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015). In the current study, a sample of ten (10) caregivers were interviewed. The sample size of 10 is enough because it satisfies the suggestions by some scholars of IPA (e.g. Bugental, 2014; Heavey, Lefforge, Lapping-Carr & Hurlburt, 2017; Smith, 2014; 2014; Smith & Osborn, 2015) that a sample of 10 – 12 respondents is good for a rigorous interpretative phenomenological analysis. The characteristics of respondents interviewed are provided on table 1.

Majority of the caregivers were females. This reflects the pattern of caregiving in general where women are always left with taken care of family members who need care. The sample of caregivers in the study was relatively old with minimum age of 46 years and maximum age of 63 years. The sample is also relatively highly educated with almost half of them having tertiary education. The educational level of the caregivers interviewed is quite higher than the average caregiver in sub-Saharan Africa. All of them are taking care of their relatives.

Table 1: *Demographic Characteristics of Interviewed Caregivers*

Respondent	**Gender**	**Age**	**Education level**	**Occupation**	**Relationship with care receiver**	**Years of giving care experience**	**Gender of care receiver**	**Condition(s) of care receiver**
1	Female	63	Tertiary	Retiree	Husband	4 years	Male	Stroke
2	Female	59	No education	Unemployed	Daughter	7 years	Female	HIV/AIDS
3	Female	39	High school	Caterer	Father	2 years	Male	Diabetes/stroke
4	Male	50	Tertiary	Consultant	Wife	5 years	Female	Enlarged heart
5	Female	46	Tertiary	Teaching	Father	7 years	Male	Hypertension
6	Female	51	Tertiary	Teaching	Mother	7 years	Female	Stroke
7	Female	42	Basic Edu	Hairdresser	Father	4 years	Male	Dementia
8.	Female	46	High School	Trader	Nephew	5 years	Male	Diabetes
9.	Female	57	Basic Edu	Trader	Husband	6 years	Male	stroke
10.	Female	41	High School	Unemployed	Aunt	3 years	Female	Alzheimer‘s

For the quantitative part of the study, a sample size of one hundred and twenty (120) caregivers were surveyed. Using power of .80 and α of .05, the minimum sample size required to detect a medium effect was 103 nurses (see Table 2 in Cohen, 1992). The sample size of 120 was therefore deemed to be adequate to produce enough power. The demographic characteristics of the surveyed caregivers are provided on table 2.

Table 2: *Demographic Characteristics of Surveyed Caregivers*

Variable	**Category**	**Frequency**	**Percent**
Gender	Male	40	33.3
	Female	80	66.7
Marital Status	Married	44	36.7
	Divorced	2	1.7
	Separated	8	6.7
	Widowed	3	2.5
	Single	58	48.3
	Co-Habiting	5	4.2
Educational Level	No Education	4	3.3
	Basic Education	18	15.0
	High School	23	19.2
	Tertiary	75	62.5

The mean age of the participants was 37.58 years (SD = 13.11 years) with a minimum age of 21 years and a maximum age of 67 years. The mean years of caregiving was 3.43 years (SD = 2.61years) with a minimum years of 1 years and a maximum of 14 years.

As shown on Table 3.2, in terms of gender distribution, there were more females (66.7%) than male participants (33.3%). In terms of education, majority of them have tertiary education (62.5%) and the others have lower than tertiary education. Close to half of the caregivers (48.3%) are single and the more of them too are married (36.7%).

3.6 Measures

Different measures and instruments were used to gather data for the study. The qualitative data was gathered using semi-structured interview guide and the quantitative data was gathered using standard scales that were put together to form a questionnaire.

3.6.1 Interview Guide

A semi-structured interview was used for the individual interviews. For this, a semi-structured interview guide was developed to collect the data. The interview guide captured caregivers‘ experiences of the caregiving role and how the experience has shaped their lives.

3.6.2 Quantitative Measures

The quantitative component of the study adapted two scales for collecting the data; Life Values Inventory (LVI) and Finding Meaning Through Caregiving Scale (FMTCS).

The Live Value Inventory (LVI) was developed by Crace and Brown (1996) to assess individuals‘ values in life with regards to what the person considers important and worthy in order to examine how their values in life relate to roles they play in life (in this context, their caregiver role). The LVI is a 42-item inventory that identifies 14 distinct life values through factor analysis.

The 14 values the inventory identifies are; *Achievement, Belonging, Concern for the Environment, Concern for Others, Creativity, Financial Prosperity, Health and Activity, Humility, Independence, Loyalty to Family or Group, Privacy, Responsibility, Scientific Understanding,* and *Spirituality.*

Each of the values is assessed with 3 items measured on 5-point Likert scale ranging from 1 = almost never guides my behaviour to 5 = almost always guides my behaviour. Each value is scored by summing up the self-reported score on the 3 items. The lowest possible score on a value is 3 and the highest possible score is 15. Higher scores on a value indicate higher orientation to that value and vice versa.

The LVI has recorded Crobach alpha ranging between .68 to .88 among American sample and between .57 to .85 among Portugues sample (Almeida & Pinto, 2003). Sample items in the inventory include; respecting traditions of my family or group, appreciating the beauty of nature, living in harmony with my spiritual beliefs, being concerned with the rights of others etc.

The Finding Meaning through Caregiving Scale (FMTCS) was developed by Farran, Miller, Kaufman, Donner and Fogg (1999) to primarily assess positive aspects and ways that caregivers find meaning through their experience of caring for a person with dementia. The FMTCS has three subscales: Loss/Powerlessness, which identifies difficult aspects of caregiving; Provisional Meaning, which identifies how caregivers find day-to-day meaning; and Ultimate Meaning, which identifies philosophical/religious/spiritual attributions associated with the experience of caregiving. The FMTCS provides a useful measure for understanding the close relationship between both the difficult and positive aspects of caregiving and also may be used to identify a caregiver‘s strengths in clinical and research settings.

The FMTCS is a 43-item measure was derived from an initial measure of 135 items developed from caregivers‘ qualitative responses (Farran et al. 1991). The FMTCS is measured on a 5 point Likert scale ranging from 1 = strongly disagree to 5 = strongly agree. A higher score in a subscale indicates a higher experience and vice-versa. Sample items in the scale included ―I miss the communication and companionship that my family member and I

had in the past", –Caring for my relative gives my life a purpose and a sense of meaning" etc. The Cronbach alphas for the three subscales range between .88 to .91.

The Loss/Powerlessness (LP) subscale has 19-item subscale that combines three qualitatively derived themes and reflects caregivers' feelings of loss for their family member, feelings of loss concerning themselves, and feelings of powerlessness associated with caregiving. The Provisional Meaning (PM) has 19-items in the subscale that focuses on how persons find day-to-day meaning through caregiving with a focus on caregivers' values concerning positive aspects about life and caregiving, personal choices, and means by which caregivers find small pleasures in their current situation. The Ultimate Meaning (UM) subscale has 5-item that focus on a higher power or a religious/spiritual structure.

3.7 Procedures for Data Collection

The procedures for data collection involved first conducting a pilot study to assess the questionnaire and the interview guide before conducting the main study. The study started by obtaining an ethical clearance from the Ethic Committee for Humanities (ECH) of University of Ghana for approval to undertake the study. After that, an introductory letter was taken from the Department of Psychology to the study communities.

3.7.1 The Pilot Study

After the ethical approval is given, the pilot study was conducted. The pilot study served the purpose of establishing the psychometric properties of the scales to be used for the work and also to assess the ability of the interview guide to elicit the right responses. The pilot study involved conducting 3 interviews and surveying 15 caregivers. Through the pilot study, any challenge with the questionnaire and the interview guide were addressed before proceeding with the main study.

3.7.2 The Main Study

After the pilot study was completed, the main study was then carried out. Caregivers who took part in the pilot study were not included in the main study. Recruitment of participants for the study was then carried out. In the process of recruiting participants for the study, as when necessary, some surveys and interviews were conducted in the process of recruiting the participants. A total of three research assistants were trained.

The data collection for the main data took about three months, beginning in February and ending in somewhere April ending, 2017. Both the qualitative and the quantitative data collection process occurred concurrently. The researcher conducted all the individual interviews while the research assistants administered the survey instrument.

3.8 Ethical Considerations

High ethical standards were taken into consideration in the process of conducting the study. First of all, in seeking consent from the caregivers, the nature and purpose of the study was first explained to participants who were approached for the study. Those who agreed to participate were given the informed consent form to sign before taking part in the study.

Also, the caregivers were made aware of the voluntary nature of the study, their right to withdraw at any point in time without explanation or penalty and were also assured of privacy and confidentiality. After the study, the researcher addressed any other concerns that participants will have about the study in the form of debriefing.

3.9 Data Analyses

Different analytical techniques were used in analyzing the data for different components of the study. The qualitative data was analyzed using thematic analyses and the quantitative data was analyzed using both univariate and multivariate statistical techniques.

3.9.1 Qualitative Data Analyses

For the qualitative component, the in-depth interviews analysed using interpretative phenomenological analyses (IPA). The IPA helps to explore deeper into narratives based on individuals‘ lived experiences (Smith & Osborn, 2015; Pietkiewicz & Smith, 2017). This therefore helped to understand the positive lived experiences of caregivers in their caregiving role.

The process of analysing qualitative interviews using IPA as suggested by Pietkiewicz and Smith (2017) were followed. For the start, all the interviews were audio recorded (with permission from participants) and transcribed for analyses. The first stage involved multiple reading of the transcripts and making notes to make sense of the broad themes within the narratives.

The next stage involved transforming the notes into emergent notes. At this stage, as suggested by Pietkiewicz and Smith (2017), the researcher depended more on her notes rather than the transcripts. Here, the aim was to transform the notes into emergent themes by formulating concise phrases that are slightly higher level of abstraction, which is a more psychological conceptualisation.

The third stage involved assessing relationships between the emergent themes and clustering the themes together. The themes are grouped together based on conceptual similarities and the descriptively labelling the clusters. At this stage, some themes that did not have enough evidence in the caregivers‘ narratives were removed. A higher level psychological abstraction was done on the clustered themes to get insight into participants‘ experiences of their caregiving role. Further detailed information is provided in chapter 4.

3.9.2 Quantitative Data Analyses

For the quantitative component, the data was analysed using hierarchical multiple regression to test the hypothesised model. This was however preceded by analysing the scales for validity using principal component analyses and for reliability using Cronbach alpha. Correlations between the study variables were then explored using Pearson Correlation co-efficient. Univariate and multivariate analyses were also conducted to explore the data. This was then followed by using multiple regressions to test for the model. Further detailed information on quantitative data analyses are provided in chapter 4.

CHAPTER FOUR

RESULTS

4.1 Introduction

This chapter presents detailed results and findings from the study. The results of the quantitative component of the study are presented first, followed by presentation of the findings from the qualitative component.

4.2 Results of Quantitative Component of the Study

The results of the quantitative part start with preliminary analyses of the data before testing the hypotheses.

4.2.1 Preliminary Analyses

The preliminary analyses were conducted, among other things to check for the assumptions and to prepare the data for testing hypotheses. The preliminary analyses included factor analysis, descriptive statistics, reliability and correlations matrix.

4.2.1.1 Factor Analysis

Factor analyses were conducted on all the scales that have sub-scales to assess underlying structures of the variables within the Ghanaian context. The factor analysis was conducted using the Principal Axial Factoring with varimax rotation. According to Tabachnick and Fidell (2007), all items that measure the same construct must load onto one factor. Factor loadings were set at .40 for all the scales. Assumption of sampling adequacy was tested using Kaiser-Meyer-Olkin (KMO) test and the number of factors to be extracted was determined using eigen values greater than 1 and scree plot (Pallant, 2010).

Life Values Inventory

Results of the factor analysis on the life inventory values are summarized in Table 4.1. First of all, sampling adequacy, tested using KMO test was found to be significant (KMO = .707, $\chi^2 = 2406.262$, $p < .001$). After inspecting eigen values of factors exceeding 1 and the scree plot, it was observed that the factors levelled out after the sixth factor. Six factors were therefore extracted.

This is different from the original scale that has eight sub-scales. The life values inventory among the sample used in this study however had six sub-scales. The six factors together accounted for a cumulative variance of 71.11%. The first factor, explained 26.55% variance, the second factor explained 18.50%, the third factor explained 10.001%, the fourth factor explained 6.540%, the fifth factor explained 5.05% and the sixth factor explained 4.47. The interpretations of the six factors are provided beneath Table 3.

Table 3: *Factor loadings based on a Principal Axis Factoring with Varimax Rotation for Life Values Inventory (N = 120)*

	Factors					
Items	**1**	**2**	**3**	**4**	**5**	**6**
Being liked by others	.588					
Being sensitive to others‘ needs	.639					
Being reliable	.643					
Being accepted by others	.613					
Helping others	.450					
Being concerned about the rights of others	.598					
Accepting my place in my family or group		.657				
Respecting the traditions of my family or group		.773				
Making decisions with my family or group in mind		.545				

Living in harmony with my spiritual beliefs	.744				
Believing in a higher power	.752				
Believing that there is something greater than ourselves	.794				
Having time to myself		.697			
Having quiet time to think		.624			
Being independent (doing things I want to do)		.470			
Having a private place to go		.589			
Having control over my time		.579			
Improving my performance			.511		
Challenging myself to achieve			.499		
Making money			.573		
Being wealthy (having lots of money, land, houses, cars)			.446		
Having financial success			.414		
Coming up with new ideas					.610
Creating new things or ideas					.801
Discovering new things or ideas					.725
Using science for progress					.652

Note: 1 = Belonging and concern for others, 2 = Loyalty to family or group, 3 = Spirituality, 4 = Independence and Privacy, 5 = Achievement and Financial Prosperity, 6 = Creativity and Scientific Understanding

Finding Meaning Through Caregiving Scale (FMTCS)

Factor analysis was also conducted on the Finding Meaning through Caregiving Scale (FMTCS) and the results are summarized in Table 4. Sampling adequacy tested using KMO test was found to be significant (KMO = .884, $\chi 2$ = 16504.457, $p < .001$). After inspecting eigen values of factors exceeding 1 and the scree plot, it was observed that the factors levelled out after the fourth factor and so four factors were extracted.

The original scale had three factors. However, in the current study a fourth factor was identified, where three items loaded perfectly with no double loading. The four factors together accounted for a cumulative variance of 70.32%. The first factor explained 25.02% variance, the second factor explained 19.30%, the third factor explained 14.43% and the fourth factor explained 13.57%. The interpretations of the four factors are provided beneath

Table 4: *Factor loadings based on a Principal Axis Factoring with Varimax Rotation for Finding Meaning Through Caregiving Scale (N = 120)*

	Factors			
Items	**1**	**2**	**3**	**4**
I miss not being able to be spontaneous in my life because of caring for my relative	.731			
I miss not having more time for other family members and/or friends	.743			
I miss not being able to travel	.761			
I wish I were free to lead a life of my own	.700			
I miss having given up my job or other personal interests to take care of my family member	.551			
I feel trapped by my relative‘s illness.	.651			
I wish I could run away	.565			
I feel that the quality of my life has decreased	.612			
I am sad about the mental and physical changes I see in my relative	.491			
I miss the little things my relative and I did together in the past.	.450			
I have no sense of joy		.698		
We had goals for the future but they just folded up because of my relative‘s condition		.760		
I have no hope; I am clutching at straws		.626		
Care-giving has made me a stronger and better person			.506	

I count my blessings	.715	
Caring for my relative gives my life a purpose and a sense of meaning	.734	
Even though there are difficult things in my life, I look forward to the future	.513	
Care-giving has helped me learn new things about myself	.597	
Every day is a blessing	.553	
This is my place; I have to make the best out of it.	.609	
Care-giving makes me feel good that I am helping	.428	
Talking with others who are close to me restores my faith in my own abilities	.432	
I start each day knowing we will have a beautiful day together	.599	
The Lord won‘t give you more than you can handle		.824
I believe in the power of prayer; without it I couldn‘t do this		.865
I believe that the Lord will provide		.839
I have faith that the good Lord has reasons for this		.614
God is good.		.770

Note: 1 = Loss/Powerlessness, 2 = Hopelessness/Desperation, 3 = Provisional Meaning, 4 = Ultimate meaning

4.2.1.2 Reliability of the Sub-scales

After running the factor analyses, reliability analysis of the sub-scales was computed using Cronbach alpha to test for the reliability of the items that measure each sub-scale. Tabachnick and Fidell (2007) asserted that the reliability level of the variables should be greater than .70 to be accepted as reliable. The results are summarized in Table 5.

Table 5: *Reliability Levels of the Scales and Sub-scales*

Variables	**No. Of Items**	**α**

Life Values	26	.89
Belonging Concern Others	6	.85
Loyalty Family	3	.88
Spirituality	3	.86
Independence Privacy	5	.80
Achievement Prosperity	5	.87
Creativity and Science	4	.78
Finding Meaning Through Caregiving	28	.84
Loss Powerlessness	10	.83
Hopeless	3	.77
Provisional Meaning	10	.88
Ultimate Meaning	5	.88

Observing from Table 5, with regards to reliability levels, the Cronbach alpha values of the scales and their sub-scales from the factor analysis ranged between $\alpha = .772$ and $\alpha = .896$. This means that all the scales and their sub-scales had high reliability levels.

4.2.1.3 Descriptive Statistics

Descriptive statistics was conducted to examine the distribution of scores on the variables among the participants in the study. The normality of the distribution of the data was also assessed using skewness and kurtosis values. Tabachnick and Fidell (2007) stated that the normality of a variable is determined when the values of skewness range between +1.00 and -1.00 and the values of skewness range between +2.00 and -2.00. The results of the descriptive statistics are provided on Table 6.

Table 6: *Descriptive Statistics (N = 120)*

Variables	**Min.**	**Max.**	**Mean**	**SD**	**Skewness**	**Kurtosis**
Belonging Concern Others	14.00	30.00	23.88	2.96	-.291	.235
Loyalty Family	6.00	15.00	11.40	2.16	-.271	-.595
Spirituality	3.00	15.00	13.03	2.31	-.532	1.996
Independence Privacy	9.00	25.00	16.78	3.29	.105	.001
Achievement Prosperity	10.00	28.00	21.89	3.59	-.551	.868
Creativity Science	6.00	20.00	14.76	2.83	-.145	-.014
Loss Powerlessness	17.00	50.00	30.71	7.22	.116	-.383
Hopeless	3.00	15.00	8.06	3.02	.538	-.445
Provisional Meaning	27.00	50.00	42.93	5.06	-.788	.284
Ultimate Meaning	7.00	20.00	17.73	2.99	-.681	1.585
Age	21.00	67.00	37.58	12.41	.530	-.862
Years of Caregiving	1.00	14.00	3.43	2.62	.673	1.738

Observing from Table 6, the skewness values range between -788 and .538 and the kurtosis values range between -.862 and 1.996. These values mean that the data is normally distributed with no outliers.

4.2.1.4 Correlation Matrix

The relationships among the variables were also examined using Pearson r to explore how the sub-scales in the study were related. The results of the correlation analysis are provided in Table 7.

Results from the correlation analysis shows that loyalty to family is positively related with provisional meaning (r = .212, p < .05) and negatively with both loss and powerless (r = -349, p < .01) and hopelessness (r = -229, p < .05).

Value for spirituality is positively related to ultimate meaning (r = .502, p < .01) and negatively with loss and powerlessness (r = -.187, p < .05). Value of belonging and concern for others is positively related with provisional meaning (r = .251, p < .05). Value for achievement is also related to both loss and powerlessness (r = -.287, p < .01) and hopelessness (r = -.306, p < .01).

Table 7: *Correlation among the Variables*

	1	2	3	4	5	6	7	8	9	10	11	12
1. Belonging and Concern for Others	1											
2. Loyalty to Family	.336**	1										
3. Spirituality	.297**	.199*	1									
4. Independence Privacy	.088	.433**	.042	1								
5. Achievement and Prosperity	.312**	.564**	.186*	.468**	1							
6. Creativity and Science	.189*	.283**	.131	.434*	.491*	1						
7. Loss and Powerlessness	-.061	-.349**	-.187*	-.123	-.287**	-.173	1					
8. Hopeless	-.022	-.229*	-.090	-.263**	-.306**	-.280**	.445**	1				
9. Provisional Meaning	.251**	.212*	.135	.117	.170	.012	-.058	-.120	1			
10. Ultimate Meaning	.082	.151	.502**	.103	.052	-.169	-.148	-.132	.527**	1		
11. Age of Caregiver	.087	-.124	.072	-.201*	-.128	-.081	.139	.160	.114	-.031	1	*
12. Years of caregiving	.150	.139	.208*	-.061	.143	-.017	-.066	-.106	.124	.165	.305**	1

** p< .05 , **p < .01*

4.2.2 Test of Hypotheses

After conducting all the preliminary analyses, the hypotheses in the study were tested. The hypotheses were tested in two parts: group differences were first tested and then predictors of caregiving experiences were examined.

4.2.2.1 Group Differences in Care-giving Experience

Group differences in care-giving experiences were first examined. Based on the factor analysis, four sub-domains of caregiving experiences (i.e. loss and powerlessness, hopelessness, provisional meaning and ultimate meaning) were assessed. The mean differences were compared based on gender (male caregivers vs. female caregivers) and educational status (i.e. basic education vs. High school education vs. Tertiary education).

A Two-way Multivariate Analysis of Variance (2-Way MANOVA) was therefore used to examine the group differences in care-giving experiences. MANOVA was used to compare the group differences because as argued by Tabachnick and Fidell (2007), MANOVA is the best test for examining mean differences when there are categorical independent variables and more than one continuous dependent variable that are theoretically related. Thus, instead of using ANOVA to analyse the variables one after the other and increasing type I error, MANOVA does all the different analysis at once and keeps type I error at its barest minimum.

MANOVA tests for both main effects and interaction effects between all the independent variables. In the current study, there were 2 categorical independent variables (gender and educational status) and four continuous dependent variables (i.e. loss and powerlessness, hopelessness, provisional meaning and ultimate meaning). Thus, MANOVA tested for gender differences, educational status as well as interaction between gender and education in care-giving experiences. The results are summarized in Table 8 and 9.

Table 8: *Multivariate Tests of Group Differences*

Effect	λ	F	Hypothesis df	Error df	p	η^2
Gender	.846	5.151	4.000	113.000	.001	.154
Education	.978	.630	4.000	113.000	.642	.022
Gender * Education	.981	.544	4.000	113.000	.704	.019

Table 8 shows that there are significant gender differences in care-giving experiences (λ = .978, F = 5.151, $p < .01$) with a small effect size (η^2 = .154). These findings show that hypothesis 1 is supported but hypothesis 2 is not supported.

Test of between subjects' effects are computed to examine the exact sub-component of care-giving experiences where the gender differences are found.

Table 9: *Tests of Between-Subjects Effects*

Source	Care-giving Experiences	Type III SS	df	MS	F	p
Gender	Loss and Powerlessness	140.747	1	140.747	3.789	.016
	Hopelessness	2.351	1	2.351	.263	.609
	Provisional Meaning	184.960	1	184.960	7.532	.007
	Ultimate Meaning	141.610	1	141.610	17.903	.000

Table 9 shows that male and female caregivers differ in their experiences of loss and powerlessness (F = 3.789, $p < .05$), provisional meaning (F = 7.532, $p < .01$) and ultimate meaning (F = 17.903, $p < .001$).

Table 10: *Mean Differences in Caregiving Experiences*

		Loss and Powerlessness	Hopelessness	Provisional Meaning	Ultimate Meaning
		M(SD)	M(SD)	M(SD)	M(SD)
Gender	Male	33.75 (7.25)	7.98 (2.99)	40.13 (4.79)	16.20 (3.72)
	Female	30.19 (7.20)	8.10 (3.05)	43.82 (4.97)	18.50 (2.00)
Education	Tertiary	29.95 (6.51)	7.64 (2.98)	43.00 (5.14)	17.69 (2.94)
	Non-tertiary	31.98 (8.20)	8.76 (2.99)	42.80 (4.97)	17.80 (3.09)

As shown in Table 10, comparing their mean differences, male caregivers (M = 33.75, SD = 7.25) experience higher loss and powerlessness compared to female caregivers (M = 30.19, SD = 7.20). Female caregivers experience higher provisional meaning (M = 43.82, SD = 4.97) than male caregivers (M = 40.13, SD = 4.79). Also, female caregivers experience higher ultimate meaning (M = 18.50, SD = 2.00) than male caregivers (M = 16.20, SD = 3.72).

These findings mean that male caregivers experience higher levels of negative aspects of care-giving than female caregivers while female caregivers experience higher levels of positive aspects of care-giving than male care givers.

4.2.2.2 Predictors of Care-giving Experiences

After examining the group differences in care-giving experiences, series of hierarchical multiple regression analyses were used to examine the factors that predict each of the four components of care-giving experiences after controlling for demographic characteristics (age, gender, years of caregiving and education). The demographic factors were controlled so that the unique effect of the predictors on each of the care-giving experiences can be examined (Pallant, 2010; Tabachnick&Fidell, 2007).

As argued by Tabachnick and Fidell (2007), the assumption of multicollinearity was examined before estimating the models. The assumption of multicollinearity was tested to show that the variables being included in the model do not measure the same thing (Pallant, 2010). The assumption of multicollinearity was assessed using Tolerance and variance inflation factor (VIF). The Tolerance values ranged between .244 to .909 and the VIF values ranged between 1.073 to 2.095 which indicates no multicollinearity (Pallant, 2010; Tabachnick&Fidell, 2007).

In testing for each of the four the hierarchical multiple regression models, the control variables (age, gender, years of caregiving and education) were put into the model in step 1. Gender was dummy coded (female caregivers = 1, male caregivers = 0) before being put into the model at step 1. The predictors, which were the 6 life values (Belonging and Concern for Others, Loyalty to Family, spirituality, achievement and prosperity and creativity and science) were then entered in step 2. The results are summarized on Tables 11, 12, 13 and 14.

4.2.2.3 Predictors of Loss and Powerlessness

The entire model predicting loss and powerlessness was found to be significant [$F (10, 110) = 5.526$, $p < .05$), explaining 28.8% ($R^2 = .288$) variance in feeling of loss and powerlessness in care-giving. In step 1, the effect of the control variables was significant [$F (4, 115) = 3.278$, $p < .05$), explaining 4.3% variance ($R^2 = .043$). Compared to male caregivers, females feel 8.1% less loss and powerlessness ($\beta = -.081$, $t = -2.869$, $p < .05$).

In step 2, life values significantly predicted feeling of loss and powerlessness in care-giving [$\Delta F (6, 109) = 6.257$, $p < .01$), explaining additional 25.5% ($\Delta R^2 = .255$) variance. A unit increase in the value of loyalty to family was found to reduce experiences of loss and powerlessness by about 27.6% ($\beta = -.276$, $t = -2.429$, $p < .05$). A unit increase in the value for independence and privacy increases experience of loss and powerlessness by about 13.9% (β

= .139, t = 3.267, p < .01) and a unit increase in the value for achievement and prosperity increases experience of loss and powerlessness by about 15.4% (β = .154, t = 3.255, p < .01)

Table 11: *Predictors of Loss and Powerlessness*

Model		**B**	**SE**	**β**	**t**	**P**
1	Age	.069	.068	.118	1.005	.317
	Years of Care-giving	-.278	.269	-.101	-1.031	.305
	Female	-1.232	1.419	-.081	-2.869	.017
	Tertiary	-1.229	1.667	-.083	-.738	.462
2	Age	.069	.068	.118	1.005	.317
	Years of Care-giving	-.278	.269	-.101	-1.031	.305
	Female	-1.232	1.419	-.081	-2.869	.017
	Tertiary	-1.229	1.667	-.083	-.738	.462
	Belonging and Concern for Others	.285	.236	.117	1.204	.231
	Loyalty to Family	-.924	.381	-.276	-2.429	.017
	Spirituality	-.429	.294	-.137	-1.456	.148
	Independence and Privacy	.304	.240	.139	3.267	.008
	Achievement and Prosperity	.310	.247	.154	3.255	.002
	Creativity and Science	-.262	.282	-.103	-.930	.355

Model 1: $R = .306$; $R^2 = .043$; Adjusted $R^2 = .009$; $\Delta R^2 = .043$; $F = 3.278$; $df1 = 4$; $df2 = 155$, $p < .05$

Model 2: $R = .534$; $R^2 = .288$; Adjusted $R^2 = .214$; $\Delta R^2 = .255$; $F = 5.526$; $\Delta F = 6.257$; $df1 = 6$; $df2 = 109$, $p < .01$

4.2.2.4 Predictors of Hopelessness

The entire model predicting hopelessness was found to be significant [F (10, 110) = 2.526, p < .05), explaining 18.8% (R^2 = .188) variance in experience of hopelessness in care-giving. In step 1, the effect of the control variables was not significant [F (4, 115) = 1.278, p = .283).

In step 2, life values significantly predicted experience of hopelessness in care-giving [ΔF (6, 109) = 3.257, p < .01), explaining 14.5% (ΔR^2 = .145) variance. A unit increase in loyalty to family was found to reduce experience of hopelessness by about 27.6% (β = -.276, t = -2.429, p < .05).

Table 12: *Predictors of Hopelessness in Caregiving*

Model		B	SE	β	t	p
1	Age	.069	.068	.118	1.005	.317
	Years of Caregiving	-.278	.269	-.101	-1.031	.305
	Female	-1.232	1.419	-.081	-.869	.387
	Tertiary	-1.229	1.667	-.083	-.738	.462
2	Age	.069	.068	.118	1.005	.317
	Years of Caregiving	-.278	.269	-.101	-1.031	.305
	Female	-1.232	1.419	-.081	-.869	.387
	Tertiary	-1.229	1.667	-.083	-.738	.462
	Belonging and Concern for Others	.285	.236	.117	1.204	.231
	Loyalty to Family	-.924	.381	-.276	-2.429	.017
	Spirituality	-.429	.294	-.137	-1.456	.148
	Independence and Privacy	.304	.240	.139	1.267	.208
	Achievement and Prosperity	-.310	.247	-.154	-1.255	.212
	Creativity and Science	-.262	.282	-.103	-.930	.355

Model 1: $R = .206$; $R^2 = .043$; Adjusted $R^2 = .009$; $\Delta R^2 = .043$; $F = 1.278$; $df1 = 4$; $df2 = 115$, $p = .283$; Model 2: $R = .434$; $R^2 = .188$; Adjusted $R^2 = .114$; $\Delta R^2 = .14.5$; $F = 2.526$; $\Delta F = 3.257$; $df1 = 6$; $df2 = 109$, $p < .01$.

4.2.2.5 Predictors of Provisional Meaning

The entire model predicting feeling of provisional meaning was found to be significant [F (10, 110) = 3.381, $p < .05$), explaining 29.6% ($R^2 = .296$) variance in feeling of provisional meaning in care-giving. In step 1, the effect of the control variables was significant [F (4, 115) = 3.003, $p < .05$), explaining 6.3% variance ($R^2 = .063$). Compared to male caregivers, females experience 25.5% more provisional meaning in care-giving ($\beta = .255$, $t = 2.819$, $p < .01$).

In step 2, life values significantly predicted feeling of provisional meaning in care-giving [ΔF (6, 109) = 4.876, $p < .001$), explaining additional 20.4% ($\Delta R^2 = .204$) variance. A unit increase in loyalty to family was found to increase feeling of provisional meaning by about 24.9% ($\beta = .249$, $t = 5.427$, $p < .001$) while a unit increase in the value for independence and privacy reduces feeling of provisional meaning by about 14.9% ($\beta = -.149$, $t = -3.444$, $p < .01$).

Table 13: *Predictors of Provisional Meaning*

Model		B	SE	β	t	p
1	Age	.078	.046	.192	1.687	.094
	Years of Care-giving	.087	.183	.045	.472	.638
	Female	2.724	.966	.255	2.819	.006
	Tertiary	1.426	1.135	.137	1.256	.212
2	Age	.078	.046	.192	1.687	.094
	Years of Care-giving	.087	.183	.045	.472	.638
	Female	2.724	.966	.255	2.819	.006
	Tertiary	1.426	1.135	.137	1.256	.212
	Belonging and Concern for Others	.316	.166	.185	3.899	.060
	Loyalty to Family	.414	.268	.249	5.427	.000
	Spirituality	.102	.207	.046	.491	.625
	Independence and Privacy	-.575	-.169	-.149	-3.444	.003
	Achievement and Prosperity	.173	.174	.123	.996	.322
	Creativity and Science	-.095	.199	-.053	-.480	.632

Model 1: $R = .308$; $R^2 = .095$; Adjusted $R^2 = .063$; $\Delta R^2 = .095$; $F = 3.003$; $df1 = 4$; $df2 = 115$, $p < .05$

Model 2: $R = .423$; $R^2 = .296$; Adjusted $R^2 = .204$; $\Delta R^2 = .201$; $F = 3.381$; $\Delta F = 4.876$; $df1 = 6$; $df2 = 109$, $p < .001$

4.2.2.6 Predictors of Ultimate Meaning

The entire model predicting feeling of ultimate meaning was found to be significant [F (10, 110) = 7.824, p < .001), explaining 41.8% (R^2 = .418) variance in feeling of ultimate meaning in care-giving. In step 1, the effect of the control variables was significant [F (4, 115) = 5.022, p < .01), explaining 6.3% variance (R^2 = .063). Compared to male caregivers, females are experience 34.0% more ultimate meaning in care-giving (β = .340, t = 3.879, p < .001).

In step 2, life values significantly predicted feeling of ultimate meaning in care-giving [ΔF (6, 109) = 8.40, p < .001), explaining additional 36.4% (ΔR^2 = .364) variance. A unit increase in loyalty to family was found to increase experience of ultimate meaning by about 21.3% (β = .213, t = 3.029 p < .01), a unit increase in value for spirituality also increases experience of ultimate meaning by about 52.7%% (β = .527, t = 36.620, p < .001), while a unit increase in the value for achievement and prosperity reduces feeling of ultimate meaning by about 13.7% (β = -.137, t = -2.355, p < .05) and a unit increase in the value for creativity and science reduces feeling of ultimate meaning by about 25.1% (β = -.251, t = -2.684, p < .01).

Table 14: *Predictors of Ultimate Meaning*

Model		B	SE	β	t	p
1	Age	-.019	.027	-.080	-.727	.469
	Years of Caregiving	.148	.105	.130	1.409	.162
	Female	2.146	.553	.340	3.879	.000
	Tertiary	-.280	.650	-.046	-.430	.668
2	Age	-.019	.027	-.080	-.727	.469
	Years of Caregiving	.148	.105	.130	1.409	.162
	Female	2.146	.553	.340	3.879	.000
	Tertiary	-.280	.650	-.046	-.430	.668
	Loyalty to Family	.334	.133	.213	3.029	.007
	Spirituality	.683	.103	.527	6.620	.000
	Independence and Privacy	.135	.084	.149	1.607	.111
	Achievement and Prosperity	-.231	.286	.137	-2.355	.013
	Creativity and Science	-.265	.099	-.251	-2.684	.008

Model 1: $R = .386$; $R^2 = .149$; Adjusted $R^2 = .063$; $\Delta R^2 = .149$; $F = 5.022$; $df1 = 4$; $df2 = 115$, $p < .01$; Model 2: $R = .646$; $R^2 = .418$; Adjusted $R^2 = .364$; $\Delta R^2 = .269$; $F = 7.824$, $p < .001$; $\Delta F = 8.40$; $df1 = 6$; $df2 = 19$, $p < .001$

4.2.3 Summary of Quantitative Findings

Findings from the quantitative analysis have shown that;

1. Male caregivers experience higher levels of negative aspects of care-giving than female caregivers while female caregivers experience higher levels of positive aspects of care-giving than male care givers.
2. Value for loyalty to family reduces experiences of loss and powerlessness and hopeless and increases experience of provisional meaning and ultimate meaning.
3. Value for independence and privacy increases experiences of loss and powerlessness and reduces experience of provisional meaning.
4. Value for achievement and prosperity increases experiences of loss and powerlessness
5. Value for spirituality increases experiences of ultimate meaning

4.2.4 Observed Model

The results of the quantitative findings are summarized on the observed model on Figure 2. As shown on the figure, in the final observed model, the factor analysis showed four different caregiver experiences. Two of them measure positive caregiver experiences (provisional meaning and ultimate meaning) and two of them measure negative caregiver experiences (loss and powerlessness and hopelessness). Factor analysis also identified six different values in life which are grouped into two based on their focal point of interest. In the final model however, only four life values had significant effect on caregiver experiences. Two of them measured values with self as the primary interest (i.e. self-focused values) and two of them measured values with other as the primary interest (i.e. other-focused values).

In the final model, after controlling for demographic factors (i.e. age, gender, education and years of caregiving experiences), the self-focused values (independence and privacy and achievement and powerlessness) were found to increase negative caregiver experiences (loss

and powerlessness and hopelessness) and decrease positive caregiver experiences (provisional meaning and ultimate meaning). The other-focused values (i.e. loyalty to family and spirituality) on the other hand were found to increase positive caregiver experiences and reduce negative caregiver experiences.

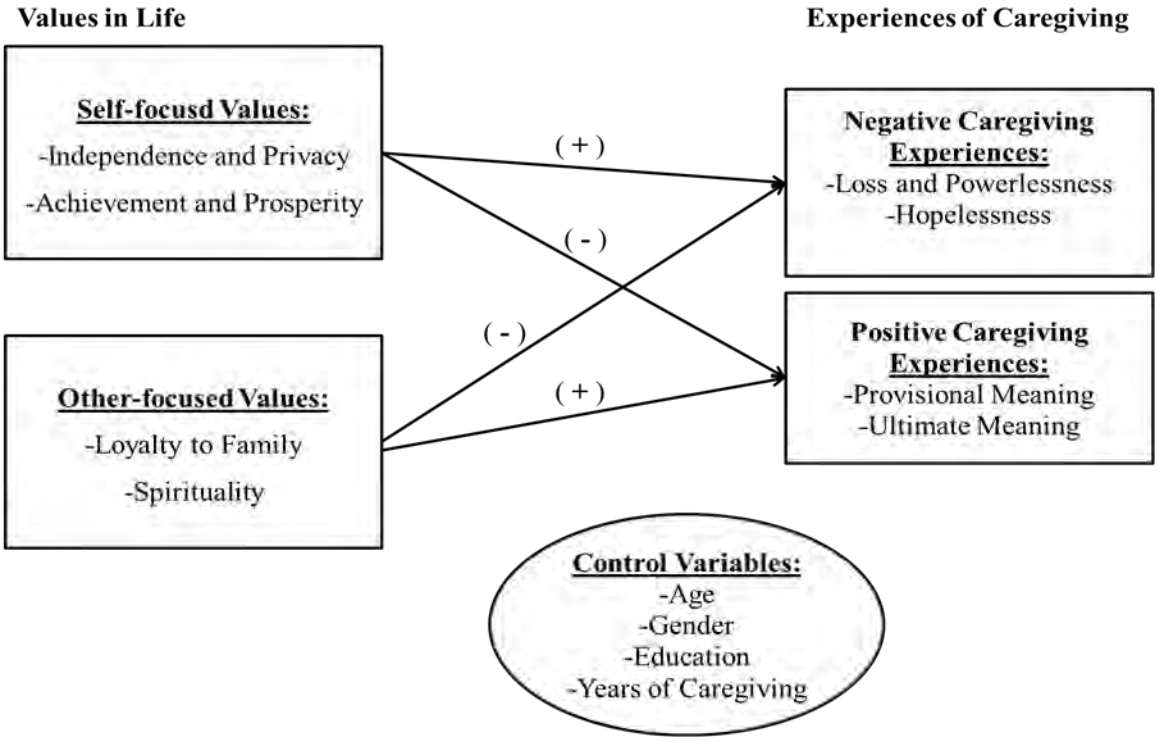

Figure 2: Observed Model of Life Values as Predictors of Caregiver Experiences

4.3 Results of Qualitative Component of the Study

The qualitative component of the study explored the lived experiences of the caregivers within the context of their caregiving role. Fundamentally, the objective was to explore how they experience their role as caregivers and the factors that affect how they experience their caregiving role. The findings are therefore presented under two main organizing themes: (i) how the caregivers experience their caregiving role and (ii) the factors that influence their caregiving experience.

4.3.1 How do the Caregivers Experience their Caregiving Role?

The first objective of the qualitative part was to explore how the caregivers experience their caregiving role. The findings from the interpretive phenomenological analysis showed that the caregivers experience sudden or drastic change in life that comes with new illuminations and are filled with both good and stressful outcomes.

Sudden or Drastic Change in Life:

The caregivers experience a kind of a sudden and drastic change in life that they had not prepared for. For some of them, the sudden change was experienced in two-fold because of the caregiving role and their transition into a new phase of life.

> *"I am taking care of my husband. I started this role just a month after I retired from work. I retired in October and started this role in November" (Female, 63years)*

> *Right now I am old and have finished childbearing so I am supposed to rest. Just when I thought of resting and now this.....(Female 59 years)*

> *hmmm...my life has changed drastically. Now I work from morning till evening when I retire to bed. There is nothing sweet in my marriage life anymore. As we used to help each other, now everything is on my shoulder..... (Male, 50years)*

Retiring from work is found to be a very critical period in life that comes with a lot of psychosocial adjustment. In the case of women, studies have shown that they face several challenges during their retirement phase of life. Therefore, taking up a caregiving role on retirement means that there is a double burden of adjusting to both the retirement and caregiving roles simultaneously. This creates a situation where the caregivers are not well-prepared for the role added to their new status;

> *very well said, initially I didn't know anything about caregiving to elderly people who are ill. All I knew was to take care of little children. It was really hard for me when I started. There was nobody around to teach me what to do (Female, 63years)*

> *....you see, I never thought this was going to happen at this time of my life and it did. I had not planned for it so I did not know what to do (Female, 46years)*

The suddenness with which the caregivers assume their caregiving role makes them least prepared for it. Consequently, they experience several psychosocial stressors trying to adjust.

Social life Affected:

The major area where respondents experience sudden stress is within their social life context. They indicated that all of a sudden every social activity they used to engage in came to halt. The social activities affected range from visits to family and friends, attending religious activities, travelling to stigma.

> *...oh yes. Am not able to go and visit friends or other family members.....For the past 3 yrs. I have not been able to visit my old mother at Kumasi. Anytime I plan going then a different situation crop up (Female, 63 years)*

Its only market and funerals I sometimes go and even with that one I don't keep long.....Because of the situation I can't even go church as often as I used to go. I cannot travel and leave her and the children alone here (Female, 51 years)

We are all very sociable and like people. Now nobody comes to us because of her condition. It worries her and me so much and sometimes I will be in the room and cry all day (Female, 59 years)

No, no, and no. not anymore.....I used to be the church secretary for 8 good years. I love to help the church to grow but now due to the situation I only go to church for the first service which is a two-hour programme.....sometimes I even I go late to give my offering (Female, 39 years)

Sometimes, it gets so stressful that some of the caregivers begin to blame themselves for the relative's condition:

I do get worry that I even feel I failed her in life (Female, 59years)

However, the experiences of their caregiving role are not all stressful or sad stories. They indicated their caregiving roles were also filled with lots of positive experiences and moments of upliftment and enlightenments.

New Realizations in Life:

They begin to find meaning in ordinary things and they become appreciative of the little things they have always taken for granted:

I have come to realised that whenever I give offering to do the work of God, I get more blessings (Female, 61 years)

These days I do pray a lot.....each morning, the moment I wake up from bed, I lie on the floor flat and roll seven times just to praise God for letting us see another day. So now I count my blessings each day (Female, 63 years)

Sometimes I do ask myself is it this man who is lying down like this. Now what I mostly say is that if you are not sick you have to thank God the moment you wake up from bed (Female, 58 years)

This work is not easy at all....sometimes it makes to see certain things about you that you did not know....About three months ago we travelled to a hospital at the Eastern Region called St. Dominic's at Akwatia. They admitted her for a whole month. I could not leave her there alone so I had to come back and ask some neighbours to take care of her children. There was not even a place for me to sleep so there was a kiosk that other caregivers had rented. We were about five sleeping in there...I never even knew I could sleep at such places (Female, 59 years)

Gains from Care-giving

Apart from the new realizations that the care-givers come to, they also experience some positive moments in the midst of their difficulties. Sometimes the experience comes with forming new relationships with other caregivers and some even develop the interest of devoting their time to helping other new caregivers:

There was nobody around to teach me what to do. So what happened is whenever we go to the hospital for treatment or review, the other caregivers there talks about their experiences and I listened carefully. I took some advice from them and it really helped me. Even now should I have the time I would voluntarily go round to teach caregivers what to do with their patients (Female, 63 years)

For some of them too, they found company in the presence of the care receiver, someone they can chat and laugh with sometimes:

> *But in all I am happy to have my daughter and her children here. They are keeping me company because I used to be alone (Female, 59 years)*

> *.....when she is happy we talk and laugh. She is very sociable and like people (Female, 51 years)*

Apart from that, some of them also develop new passion for what they do:

> *Eeehhh..... hmmm now I wish my husband is back on his feet to continue his previous life, so I do everything with passion for him to get well again (Female, 63 years)*

4.3.2 What factors affect their Caregiving Experience?

The first objective has shown that the caregivers experience a mix of burden and upliftment simultaneously in very complex ways. The second objective explored the factors that shape the burden or the upliftments that the caregivers experience. Findings from the interpretive phenomenological analysis showed several factors that influence the experiences of the caregivers. These factors include the conditions the care receiver is suffering from, family tensions, contributions from the care recipients themselves and a _surrendering attitude‘ on the part of the caregivers.

Conditions Suffered by Care receiver;

The findings showed that the conditions that the care receivers suffer from influence the caregiving experience profoundly. Specifically, conditions that are stigmatizing (e.g. HIV/AIDS) were realized to increase burden of the caregivers because of the attitudes of other people towards the care recipients and the caregiver:

.....Now nobody comes to her because of her condition (HIV/AIDS). It worries me so much and sometimes I will be in the room and cry all day (Female, 59 years)

Also, co-morbid conditions that happen successively or simultaneously and conditions that deteriorate also put lots of burden on the caregivers:

My husband had been managing kidney problem, but he used to go to the hospital alone with the driver. Then along the line he started suffering from diabetes. ...he was managing it but about a week to my retirement, he paralysed just like that.... it was stroke (Female, 63 years)

I do everything I can for him.....but it looks like he is deteriorating every day. Sometimes I don't even know what to do and I ask myself why this condition is like this (Female, 58 years)

...and every now and then she complains of new sickness. So we have been going to the hospital all the time (Female, 63 years)

Family Situation

Findings from the study also showed that the family situation affect their caregiving experience a lot. This comes as a result of either the tensions within the family or family loyalty and love. The family tensions were usually observed to be between spousal duties and filial responsibilities:

I will say we sometimes disagree to agree. Other times too he doesn't understand and feels I have neglected him. But you can't say because of that you will not take care of your father. There are times when he would want me to follow him to a party or program but I do tell him I can't go and that one brings about quarrel (Female, 46years)

...like I said earlier, a lot of people come here that sometimes I have to prevent them from entry because he needs to sleep for me also to get some rest. Some family members misconstrued me thinking I don't want them to see their relative. But you cannot please everybody (Female, 63 years)

For the past 3 yrs. I have not been able to visit my old mother at Kumasi. Anytime I plan going then a different situation crop up. When I think of it, it weighs me down (Female, 59 years)

However, when there is family loyalty, caregiving becomes a continuance of care for relatives and therefore come with fewer burdens. Also, family loyalty ensures that caregiving decisions are taken as a family and everybody contributes to ease the burden:

It's my other daughters and their husbands. They have been giving me money every month. That is what I used to take care of the house. I also use some for medicine whenever we go to the hospital for treatment or review. We visit the hospital every two weeks (Female, 58 years)

...oh yes. She is my daughter so I can't say I will not take care of her. And if I don't do it, who will? I didn't give birth to her like this, it is sickness that has cramped her (Female, 59 years)

oh...it is my father who is not well and I am taking care of him. I started this role about three years ago. We had no option than one of us moving from our husbands' home and coming to take care of him. I and my siblings are five and we are all married and living in our husbands' homes. We are four girls and one boy. The boy is our last born and he lives with our father but he too because of his work he doesn't

get time for him. So we all decided and I agreed to stay here and take care of him (Female, 39 years)

Care receiver contribution

The care receivers themselves were also found to influence the caregiving experience a lot. Most of the caregivers indicated that the care receivers can sometimes be very stubborn and fight with them to make the issue even worse:

...there are other times too she would insult me the whole day and would not want me to do anything for her nor her children. She sometimes packs her things and her children and will vanished from the house. She will go away for about a week before they will come back... The only thing she can do for herself is to talk and insult me as if I am the cause of her illness (Female, 59 years)

I have been using my pension pay and my children are also helping a lot. All his wealth is in his name so I find it difficult getting access to his money. If I need money for the house, he has to be taken to the bank. Even his close friend has advised him to transfer some into my name, but he would not do it. Even though he is ill he is very stubborn (Female, 63 years)

Some of them also indicated that their care receivers sometimes wish for death to come for them and that makes them very sad and not know what to do:

She is always wishing that she dies and go away....when it happens like that I become so sad that I don't know what to do (Female, 59 years)

Sometimes too the care receivers would be driving healer shopping and force the care givers to be taking them from one healer to another:

There are times that she thinks her sickness has some spiritual connotations so we do go to spiritual camps for healing but there is no any improvement (Female, 58 years)

Surrendering Attitude on the Part of Caregivers

The study further found that certain psychosocial characteristics about the caregivers themselves influence their caregiving experiences. For instance, some of them indicated that they surrender everything to God and hope for the best. That helps to put their minds at ease so that they can have some peace:

For me, I do whatever I can and I leave the rest to God....If I add thinking to this, I will die soon and there would be no one to take care of her..... (Female, 59 years)

...But I trust God for his recovery so I have left everything to Him.... (Female, 63 years)

4.3.3 Summary of Findings

Findings from the qualitative part of the study show that:

1. The caregivers experience complex sets of psychosocial stress and upliftment simultaneously. These come in the form of adjusting to sudden life changes that they are not prepared for, co-occurrence of caregiving with other critical life adjustments, shrinking social life, new perspectives about life and some psychosocial gains
2. Different factors were found to affect the caregivers‘ experiences. These included conditions suffered by the care receivers, family situations, care receivers‘ own contributions and a surrendering attitude on the part of the caregivers

CHAPTER FIVE

DISCUSSION

5.1 Introduction

The current study examined lived experiences of family caregivers about their caregiving roles in Ghana. In this chapter, the findings from the qualitative and the quantitative components are discussed separately. The quantitative findings being discussed first followed by the qualitative findings. The practical and research implications of the findings in the current study are discussed. The chapter also presents some limitations of the current study and recommendations made for future research.

5.2 Discussion of Quantitative Findings

The quantitative component of the study examined how different values in life shape both positive and negative caregiving experiences. The quantitative findings are divided in two for the purposes of the discussion: gender differences in caregiver experiences and life values as predictors of caregiver experiences within the Ghanaian context.

5.2.1 Gender Differences in Caregiver Experiences

The first objective of the quantitative part examined differences in the four caregiver experiences among male and female caregivers. Findings from the study showed that male caregivers in the study experienced higher loss/powerlessness and hopelessness compared to the female caregivers. Also, the female caregivers experience higher provisional meaning and ultimate meaning compared to the male caregivers. This means that the male caregivers experience higher levels of negative aspects of caregiving than female caregivers while

female caregivers experience higher levels of positive aspects of care-giving than male care givers.

So far, the literature on gender differences in caregiving has been complex and dynamic. While some earlier studies (e.g. Miller & Cafasso, 1992) have reported no significant gender differences in caregiver experiences, more recent studies (e.g. Lin et al. 2012; Sharma et al. 2016) have reported consistent gender differences in caregiver experiences. Majority of these findings point to female caregivers experiencing higher levels of stress and caregiver burden compared to male caregivers. For example, Lin et al. (2012) have reported that female caregivers experience more negative experiences and this was found to be more pronounced among wives. Sharma et al. (2016) in a systematic review have also reported that female caregivers have been found to experience higher burden than male caregivers.

Several reasons have been attributed to why male caregivers have better psychological well-being than female caregiver in most studies. For example, there is ample evidence to show that more women are engaged in caregiving more than men and that woman spend more time in caregiving more than men (Lin et al. 2012). Also, women have been found to provide care for more critical physical and mental health conditions compared to those provided by men. Sharma et al. (2016) nevertheless argued that with the changing times and norms, the significant female burden over male caregivers are likely to change as more men assume caregiving in more critical physical and mental health conditions for extended hours as well.

This prediction is in line with the findings from the current study. The reason that may account for the male caregivers reporting high negative experiences in the current studies may be deeply seated in shape gender role differences in Ghana. Traditional gender role ideologies are deeply held in Ghana and are found to still persist even among individuals with higher levels of education (Akotia & Anum, 2012). These traditional gender role ideologies

allocate care in general and caregiving for patients in particular to women (Ae-Ngibise et al. 2015; Mwinituo & Mill, 2006; Sanuade & Boatemaa, 2015). Therefore, men who are engaged in caregiving in the Ghanaian context do not only have the stress associated to caregiving to deal with but also caregiving may challenge their masculinity in general.

Several studies in Ghana (e.g. Adinkrah, 2012) show masculinity are very important in driving male experiences in the Ghanaian context to the point that some men even contemplate suicide when certain issues disgrace their masculinity. Therefore, males engaged in caregiving in Ghana might be facing a psychosocial challenge to adjusting to their new perceived ―feminine role" while also dealing with the stress that comes with caregiving. Female caregivers on the other hand do not face the socio-cultural pressures of caregiving because that forms part of their traditional gender roles (Drah, 2014). They are therefore only left with the stress and burden associated with providing care to deal with, something which they had been socialized to do. Thus, in Ghanaian context, deeply held traditional gender role ideologies might explain why the male caregivers recorded higher negative experiences.

5.2.2 Life Values and Caregiver Experiences

The quantitative component also examined how life values influence caregiver experiences. The findings from multiple regression analysis showed that the life values affect caregiver experiences. Findings from the study showed that high levels of loyalty to family reduces the experiences of loss and powerlessness, hopelessness, increases experience of provisional meaning and ultimate meaning. Also, value for independence and privacy increases experiences of loss and powerlessness; and reduces experience of provisional meaning. Value for achievement and financial prosperity increases were found to increase experiences of loss and powerlessness. Lastly, value for spirituality increases experiences of ultimate meaning.

Putting these findings together, the study has shown that holding communal values (i.e. loyalty to family) protect caregivers from negative experiences associated with caregiving. The communal values also give the caregivers positive experiences in their caregiving role. These findings can be accounted for by the fact that loyalty to family is consistent with the collective nature of the Ghanaian culture. Collectivism ensures that individuals value their relations and put the interest of others ahead of their own personal interest. For this reason, giving care to a sick relative is seen as a natural role that individuals are obligated to do.

This finding is consistent with previous studies (e.g. Knight & Sayegh, 2010; Knight, et al. 2002; Youn, et al. 1999) that have reported that cultural values shape caregiving experiences profoundly. For instance, Knight and Sayegh (2010) have reported in other collectivistic cultures that familyism values reduce the burden of caregiving. Thus, holding values for family loyalty and providing care to a sick relative is conceptualised with the values of responsibility, love and care and therefore are in line with cultural values.

However, holding values that are not consistent with the cultural values can lead to increased burden. For example, holding self-directed values in a collectivistic culture is seen as not in line with the culture and as such does not sit well with caregiving (Knight & Sayegh, 2010). This might explain why values that are meant for self-fulfilment were found to be associated with higher burden and low positive experiences. For instance, holding self-directed values in life (e.g. independence and privacy, value for achievement and financial prosperity) increases caregiver stress and reduces the positive experiences associated with caregiving. This might be explained with the fact that individuals who value independence and privacy might see caregiving role as too intrusive and invasion of privacy. Also, valuing achievement and financial prosperity means that individuals need the freedom of movement to move about and work to achieve their objectives (Crace & Brown, 1996).

However, caregiving comes with several other things such as restricted movement, reduced income due to reduction in hours of work, increased expenditure etc. This means that individuals who value self-fulfilment goals but are caught up in caregiving are forced to give up on all these things and that may lead to the feeling of loss and powerlessness to pursue their values or their goals. This also means that having self-directed values make adjusting to caregiving role very difficult and takes long time. This is in line with Walker et al's. (2016) argument that positive experiences of caregiving come about after caregivers have learnt how to successfully cope with the challenges associated with their caregiving role and therefore have less of the bad (e.g. burden, depression, identity loss, role captivity and depression) and more of the good.

The study found further that having a value of spirituality is associated with higher experience of ultimate meaning. Value of spirituality means that individuals subscribe to the idea of a higher power that has control over everything in life. In most religious groups, God is the higher power that people believe has control over everything. Therefore, valuing spirituality means learning to put hope and trust in God to take care of difficult situation. Therefore, individuals who have spirituality are able to surrender the burden of caregiving to God to take care of the situation and therefore lift some amount of burden from their shoulders. A surrendering attitude also came up in the qualitative part of the study to be critical to the mental well-being of caregivers. This finding is in line with several studies that have reported that religiosity and spirituality buffer caregiver burden (Delgado-Guay et al. 2013).

5.3 Discussion of Qualitative Findings

The qualitative aspect of the study sought to explore the dynamics of the lived experiences of caregivers in Ghana. Two specific objectives were examined; the study first examined how

caregivers experience their caregiving role in Ghana and secondly explored the factors that shape their caregiving experiences. The findings are discussed based on these two areas.

5.3.1 Lived Experiences of Caregivers in Ghana

Findings from the study showed that the caregivers experience complex sets of psychosocial stress and upliftment simultaneously. These come in the form of adjusting to sudden life changes that they are not prepared for, co-occurrence of caregiving with other critical life adjustments, shrinking social life, new perspectives about life and some psychosocial gains.

The stressors caregivers faced were found to be related to the fact that caregiving roles come very sudden and therefore they are not well-prepared for. Among all the caregivers interviewed, the assumption of their caregiving role took approximately a month for them to take on the role. For many of them, they were already going through some significant phase in their lives which itself required long period of psychosocial adjustment. For instance, for some of them were retiring, had married not long, had started a new work etc.

Suddenly, when they have not finished readjusting to their new life, caregiving role also comes to compound the burden. Now the caregivers have to face the difficulties of physically and psychosocially adjusting to the caregiving role, while at the same time either letting go of the other state in their lives (as in the case of the woman who was coming on retirement but never got the rest she needed) or adjusting simultaneously to both situations (as in the case of a woman who had to move from the husband‘s place to come live with the father, thus adjusting simultaneously to caregiving and marital life).

Apart from the burden of double or simultaneous psychosocial adjustment, the care givers also experience restrictions in their movement and attendant reduction in their social world. Most social activities become restricted including attending religious activities, funeral, marriage ceremonies, travelling and in extreme cases even visiting family and friends. This

was found to put a lot of stress on them because it pills up boredom in them as a result of doing the same thing over and over again at the same place with the same individual, not knowing when it will end. This also came up in the quantitative findings when quest for independent and privacy was associated with high levels of loss and powerlessness.

However, the care givers also experience some positive outcomes. They get new perspectives about life which helps them to see life completely differently from what they used to. Most of them indicated that they were now appreciating the little things in their lives that they have always taken for granted. They appreciated the gift of life, their ability to move and do things independently for themselves. They realized the value of a smile especially when their care receivers are happy and smiling.

These new realizations come with several psychosocial gains that enhance their psychological well-being. Some of them indicated that they find company in their care receivers in the midst of the boredom and they chat and laugh sometimes. They are also able to identify the people around them who truly care. They see those who visit them often even though they are unable to pay back the visit. They also learn to be dependent on God and submit to Him. These findings are somehow consistent with other studies who have examined lived experiences of caregivers (Kramer, 1997; Lyod et al. 2014; Mohammed, 2015; Petruzzo et al. 2017).

5.3.2 Factors that shape Lived Experiences of Caregivers in Ghana

The second objective concerned the examined factors that were associated with the lived experiences of the caregivers. Findings from the study showed that different factors were found to affect the caregivers‘ experiences. These included conditions suffered by the care receivers, family situations, care receivers‘ own contributions and a surrendering attitude on

the part of the caregivers. There are elements of each of these factors that affect the positive and negative experiences of the care givers.

Some of these factors, such as the family situation is very complex and affect the caregiving experience in nuanced ways. For example, family loyalty is reported to reduce care giver burden compared to taking care of a non-relative. This was observed in the quantitative part of the study as loyalty to family was associated with low levels of negative experiences and high levels of positive experiences. However, there are instance of tensions as caregiving crosses family boundaries. For example, women who are taking care of their husbands were recounted of experiences tensions with the relatives of the husband. Daughters who take care of their fathers also recount of tensions with their husbands.

This means that family factors shape live experiences of caregivers in much nuanced ways. Wives usually experience these family tensions when they are providing care to either their husbands or parents. Also, mothers who provide care to their married daughters also face such tensions from their son-in-laws. These findings are in line with previous studies (e.g. Lin et al. 2012; Sharma et al. 2016) that have explored gender dimensions of care giver burden and report that wives experience highest form of burden of caregiving compared to the other groups. The current study has shown that substantial amount of the caregiving burden among wives come from tensions that cross family boundaries.

The study shows that the care givers themselves also shape lived experiences of caregiving profoundly. The current study finds that sometimes the care receivers refuse to help the caregivers in caring for them. This is evident in the retiree wife whose sick husband refuses to transfer some funds into her name so that she can access it and use to take care of him. She therefore has to rely on her retirement income in taking care of the sick husband. There are some care receivers who also find difficulties in accepting their chronic conditions. They

healer shop and put pressure on their caregivers to take them from one healer to another. Thus, the care receivers constitute major factor that shape lived experiences of caregiving.

The study also found that a surrendering attitude on the part of the caregivers protects them from the severity of the caregiver burden. Learning to surrender to God, to take care of the situation means that the caregivers can come to terms with their roles in the caregiving experience and not add to the burden of thinking when the care receiver is going to be healed. This finding was also observed in the quantitative part of the study when value of spirituality was found to be associated with high levels of ultimate meaning.

The current study makes contribution to literature in the sense of how methodological innovation contributes to understanding informal or family caregiver experiences in resource-poor contexts. The use of the mixed-method approach has brought to bear how family caregivers go through simultaneous experiences of stress and upliftment. The present thesis has therefore increased understanding in terms of factors that shape both negative and positive experiences of family caregivers in Accra, Ghana.

5.4 Implications of the Study

The current study has shown that the caregiver experience is marked simultaneous experiences of burden and upliftment in their caregiving role. These experiences are influenced by several factors. The findings have several implications on improving mental health among caregivers in low and middle income countries.

First of all, findings in the current study show that male caregivers experience high levels of negative experiences of caregiving while female caregivers experience higher levels of positive experiences of caregiving. The implication of this finding is that male caregivers constitute at risk population of caregivers in contexts where there is a deep seated socio-cultural emphasis on gender roles. This means that mental health interventions for caregivers

in Ghana should pay attention to men who are providing care to relatives with physical or mental chronic conditions.

Secondly, the findings from the quantitative part showed that the values that the caregivers hold in life significantly influence their caregiving experience. Specifically, other-oriented values, such as loyalty to family and value for spirituality increase positive experiences in caregiving while self-focused values such as value for independence and privacy increase negative experiences and reduces positive experiences as well. Based on this finding, it is recommended that mental health interventions targeted at family caregivers should pay attention to the values that the caregivers hold in life. Thus, caregivers who hold self-focused values in life are more at risk of suffering higher burden of caregiving stress.

Furthermore, the qualitative part has shown that tensions between spousal duties and filial responsibilities increases burden of caregiving experiences. This was mainly observed among caregivers who provide care either to their spouses or married women who provide care to their parents. For instance, spousal caregivers are found to face tensions from the relatives of care receivers while not getting time for their own families. Mental health interventions for caregivers should therefore target the tensions within the family space so that the burden can be reduced.

Again, it was observed from the conduct and attitudes of some care receivers compound the experiences of caregiving. For instance, there are instances where the caregiver needs the care receiver‘s help in providing care. This is evident in the narrative of the retiree whose husband is not willing to transfer some of his wealth into her name so that she can access it to help the husband. It is therefore recommended that mental health interventions should also focus on the care receiver factor so that they can help make the caregiving less burdensome.

Last but not the least, another implication of the study is the fact that a surrendering attitude on the part of the caregiver helps in reducing worry and ensuring peace of mind. Surrendering the worries to a higher power reduces the burden of too much thinking. This was also evident in the quantitative part of the study where value for spirituality increased ultimate meaning among the caregivers. It is therefore important that mental health interventions for caregivers focus on helping caregivers access their spiritual sides to their advantage.

5.5 Limitations of the Study

The current study has some limitations that should guide interpretations and applications of the findings from the study.

First of all, the characteristics of the sample of respondents used could have affected the study outcome. The sample in the study was relatively highly educated with most of them attaining tertiary education. This is not a characteristic reflection of the educational level of most informal and family care givers in Ghana. This may have been because of the use of convenience sampling technique. The participants with relatively high education were more willing to participate partly because of their knowledge of the relevance of the research. Consequently, those with higher education were sampled more.

Secondly, the study was mainly done in urban areas within the capital city of Accra. Apart from that, most participants were selected from caregivers who visited health centres with their care receivers. Because of this, caregivers who are providing care at homes in poor communities, slums and rural areas were not captured in the current study.

These means that the any attempt to generalize the findings to all family caregivers in Ghana should be done with caution.

5.6 Suggestions for Future Studies

Based on the limitations in the study and the field experiences of the researcher, the following suggestions are made for future studies:

First of all, the researcher observed on the field that some caregivers lost their care recipients after several years of caregiving. This raised the question of how caregivers readjust their lives after the demise of their care recipients, but this was beyond the scope of the current study. It is therefore recommended that future studies should consider researching into how former caregivers adjust back into routine life after losing their care recipients.

Secondly, it is suggested that future study should consider examining the factors that give rise to family tensions within the context of caregiving, especially between spousal duties and filial responsibilities. Understanding these factors would help making the family space safer for caregivers within the contexts of the interface of nuclear and extended families.

Future studies are also suggested to examine lived experiences of caregivers in other at risk locations such as rural areas, poor communities, slums and prayer camps and other non-orthodox care centres such as prayer camps.

5.7 Conclusion

The current study sought to examine the experiences of caregivers in Accra, Ghana using a concurrent mixed-method phenomenological research design. The quantitative component of the study examined how values caregivers hold in life affect both their negative (measured as loss/powerlessness and hopelessness) and positive (measured as provisional meaning and ultimate meaning) experiences of caregiving. The qualitative part explored the lived experiences of the caregivers.

Findings from a sample 120 ~~surveyed~~ respondents for the study showed that value of loyalty to family and spirituality increased provisional and ultimate meaning. Also, value of independence and privacy as well as achievement and financial prosperity increased loss and powerlessness. Male caregivers reported high levels of loss and powerlessness and hopelessness while female caregivers reported higher provisional and ultimate meaning.

Findings 10 in-depth interviews showed that that the caregivers experience complex sets of psychosocial stress and upliftment simultaneously. These come in the form of adjusting to sudden life changes that they are not prepared for, co-occurrence of caregiving with other critical life adjustments, shrinking social life, new perspectives about life and some psychosocial gains. Also, the study showed further that different factors were found to affect the caregivers‘ experiences. These included conditions suffered by the care receivers, family situations, care receivers‘ own contributions and a surrendering attitude on the part of the caregivers. There are elements of each of these factors that affect the positive and negative experiences of the care givers.

The implications of these findings within the context of improving mental health among family caregivers are discussed. The limitations of the study as also discussed with suggestions for future studies recommended.

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APPENDICES

ETHICS DOCUMENTS

UNIVERSITY OF GHANA
ETHICS COMMITTEE FOR THE HUMANITIES (ECH)
P. O. Box LG 74, Legon, Accra, Ghana

21st December, 2016

My Ref. No.....

Ms Christiana Ankrah
Department of Psychology
University of Ghana
Legon

Dear Ms. Ankrah,

ECH 054/16-17: PSYCHOSOCIAL PREDICTORS OF POSITIVE EXPERIENCES IN CAREGIVING AMONG FAMILY CAREGIVERS IN GHANA: A CASE STUDY IN GREATER ACCRA REGION

This is to advise you that the above reference study has been presented to the Ethics Committee for the Humanities for a full board review and the following actions taken subject to the conditions and explanation provided below:

Expiry Date:	13/06/17
On Agenda for:	Initial Submission
Date of Submission:	17/10/16
ECH Action:	Approved
Reporting:	Quarterly

UG/ISSER/ECH VALID UNTIL 13 JUN 2017 APPROVED DOCUMENT

Please accept my congratulations.

Yours Sincerely,

Rev. Prof. J. O. Y. Mante
ECH Chair

CC: Dr. Maxwell Asumeng, Department of Psychology

APPENDIX B

FACTOR ANALYSIS SUMMARY TABLES

Finding Meaning through Caregiving Scale

Sub-scales in Current Study	Items in original scale
1 = Loss/Powerlessness	3, 4, 6, 7, 11, 12, 13, 14, 17, 18
2 = Hopelessness/Desperation	8, 10, 15
3 = Provisional Meaning	21, 22, 25, 29, 30, 31, 34, 35, 37, 38
4 = Ultimate Meaning	39, 40, 41, 42

LIFE VALUES INVENTORY

Sub-scales in Current Study	Items in original scale
1 = Belonging and Concern for Others	2, 4, 12, 16, 18, 32
2 = Loyalty to Family or Group	10, 24, 38
3 = Spirituality	14, 28, 42
4 = Independence and Privacy	9, 11, 25, 37, 39
5 = Achievement and Financial Prosperity	1, 2, 6, 15, 20, 34
6 = Creativity and Scientific Understanding	5, 13, 19, 33

APPENDIX C

UNIVERSITY OF GHANA

DEPARTMENT OF PSYCHOLOGY

CAREGIVER EXPERIENCES QUESTIONNAIRE

Please your consent is required to take part in a study that examines the experiences of caregiving roles in Ghana. The study is for academic purposes and so participation is strictly voluntary with no associated penalty should you decline to participate. Your privacy and confidentiality are assured as you will not be required to provide any personally identifying information. If you need any further clarification, you can reach the researcher on (**put your phone number here)**

Should you choose to participate, you will be required to fill this questionnaire that examines your values in life and the experiences of your caregiving role. Please fill out each the pages until the end where it is stated **—END OF SURVEY**. Specific guidelines and instructions are provided to guide you. Please do well not to skip any of the questions. There is no right or wrong answer, only respond according to how the items reflect your personal experiences.

Please sign if you consent to participate

_____ _____

Signature Date

A. CAREGIVER DEMOGRAPHICS

Gender: 1. Male [ ] 2. Female [ ]

Age (in years):_____

Marital Status: 1. Married [ ] 2. Divorced [ ] 3. Separated [ ]

4. Widowed [ ] 5. Single [ ] 6. Co-habiting [ ]

Educational level: 1. No Education [ ] 2. Basic Education [ ]

3. High School [ ] 4. Tertiary [ ]

Occupation: _____

Relationship with care recipient? _____

How long have you been taking care of your relative?

_____

B. CARE RECIPIENT DEMOGRAPHICS

Gender: 1. Male [ ] 2. Female [ ]

Age (in years):_____

Marital Status: 1. Married [ ] 2. Divorced [ ] 3. Separated [ ]

4. Widowed [ ] 5. Single [ ] 6. Co-habiting [ ]

Educational level: 1. No Education [ ] 2. Basic Education [ ]

3. High School [ ] 4. Tertiary [ ]

Condition suffering from: _____

C. LIFE VALUES INVENTORY

The values we hold in life guide our behaviours and decisions by dictating what is important and valuable to us. On the following pages is a list of beliefs that guides people's behaviour and helps them make important decisions. Read each one and then choose a response (1-5) that **best describes** how often the belief guides **your** behaviour. If a belief in being healthy almost never guides your behaviour, circle 1. If being healthy almost always guides your behaviour, circle 5. If the best answer for you is between 1 and 5, circle the number 2, 3, or 4 that **most accurately** describes how this belief guides your behaviour.

Read each item carefully and circle only one response. Usually your first idea is the best indicator of how you feel. Answer every item. There are no right or wrong answers. Your choices should describe your own values, not the values of others.

1 = Never Guides My Behaviour, 2 = Almost Never Guides My Behaviour 3 = Sometimes Guides Behaviour, 4 = Almost Always Guides My Behaviour, 5 = Always Guides My Behaviour

Value	***Never***	***Almost Never***	***Sometimes***	***Almost Always***	***Always***
1. Challenging myself to achieve	1	2	3	4	5
2. Being liked by others	1	2	3	4	5
3. Protecting the environment	1	2	3	4	5
4. Being sensitive to others' needs	1	2	3	4	5
5. Coming up with new ideas	1	2	3	4	5
6. Having financial success	1	2	3	4	5
7. Taking care of my body	1	2	3	4	5
8. Downplaying compliments or praise	1	2	3	4	5
9. Being independent (doing things I want to do)	1	2	3	4	5
10. Accepting my place in my family or group	1	2	3	4	5
11. Having time to myself	1	2	3	4	5
12. Being reliable	1	2	3	4	5
13. Using science for progress	1	2	3	4	5

14. Believing in a higher power	1	2	3	4	5
15. Improving my performance	1	2	3	4	5
16. Being accepted by others	1	2	3	4	5
17. Taking care of the environment	1	2	3	4	5
18. Helping others	1	2	3	4	5
19. Creating new things or ideas	1	2	3	4	5
20. Making money	1	2	3	4	5
21. Being in good physical shape	1	2	3	4	5
22. Being quiet about my success	1	2	3	4	5
23. Giving my opinion	1	2	3	4	5
24. Respecting the traditions of my family or group	1	2	3	4	5
25. Having quiet time to think	1	2	3	4	5
26. Being trustworthy	1	2	3	4	5
27. Knowing things about science	1	2	3	4	5
28. Believing that there is something greater than ourselves	1	2	3	4	5
29. Working hard to do better	1	2	3	4	5
30. Feeling as though I belong	1	2	3	4	5
31. Appreciating the beauty of nature	1	2	3	4	5
32. Being concerned about the rights of others	1	2	3	4	5
33. Discovering new things or ideas	1	2	3	4	5
34. Being wealthy (having lots of money, land, houses, cars)	1	2	3	4	5
35. Being strong or good in a sport (being athletic)	1	2	3	4	5
36. Avoid credit for my accomplishments	1	2	3	4	5
37. Having control over my time	1	2	3	4	5
38. Making decisions with my family or group in mind	1	2	3	4	5
39. Having a private place to go	1	2	3	4	5

40. Meeting my obligations	1	2	3	4	5
41. Knowing about math	1	2	3	4	5
42. Living in harmony with my spiritual beliefs	1	2	3	4	5

D. CAREGIVING EXPERIENCES

This part of the questionnaire examines your lived experiences of your caregiving role; the good, the bad and all others. Read each one and then choose the response (SA = Strongly Agree, A = Agree, UN = Undecided, D = Disagree, SD = Strongly Disagree) that **best describes** how you often feel in your caregiving role. Read each item carefully and circle only one response. Usually your first idea is the best indicator of how you feel. Answer every item. There are no right or wrong answers. Your choices should describe your own values, not the values of others

ITEMS	**SA**	**A**	**UN**	**D**	**SD**
Loss/Powerless Subscale (LP)					
1. I miss the communication and companionship that my family member and I had in the past.	1	2	3	4	5
2. I miss my family member‘s ability to love me as he/she did in the past	1	2	3	4	5
3. I am sad about the mental and physical changes I see in my relative	1	2	3	4	5
4. I miss the little things my relative and I did together in the past.	1	2	3	4	5
5. I am sad about losing the person I once knew	1	2	3	4	5
6. I miss not being able to be spontaneous in my life because of caring for my relative	1	2	3	4	5
7. I miss not having more time for other family members and/or friends	1	2	3	4	5
8. I have no hope; I am clutching at straws	1	2	3	4	5
9. I miss our previous social life	1	2	3	4	5
10. I have no sense of joy	1	2	3	4	5
11. I miss not being able to travel	1	2	3	4	5
12. I wish I were free to lead a life of my own	1	2	3	4	5
13. I miss having given up my job or other personal	1	2	3	4	5

interests to take care of my family member					
14. I feel trapped by my relative‘s illness.	1	2	3	4	5
15. We had goals for the future but they just folded up because of my relative‘s condition	1	2	3	4	5
16. I miss my relative‘s sense of humour	1	2	3	4	5
17. I wish I could run away	1	2	3	4	5
18. I feel that the quality of my life has decreased	1	2	3	4	5
19. My situation feels endless.	1	2	3	4	5
Provisional Meaning (PM)					
20. I enjoy having my relative with me; I would miss it if he/she were gone	1	2	3	4	5
21. I count my blessings	1	2	3	4	5
22. Caring for my relative gives my life a purpose and a sense of meaning	1	2	3	4	5
23. I cherish the past memories and experiences that my relative and I have had	1	2	3	4	5
24. I am a strong person	1	2	3	4	5
25. Caregiving makes me feel good that I am helping	1	2	3	4	5
26. The hugs and –I love you” from my relative make it worth it all.	1	2	3	4	5
27. I‘m a fighter	1	2	3	4	5
28. I am glad I am here to care for my relative	1	2	3	4	5
29. Talking with others who are close to me restores my faith in my own abilities	1	2	3	4	5
30. Even though there are difficult things in my life, I look forward to the future	1	2	3	4	5
31. Caregiving has helped me learn new things about myself	1	2	3	4	5
32. Each year, regardless of the quality, is a blessing	1	2	3	4	5
33. I would not have chosen the situation I‘m in, but I get satisfaction out of providing care	1	2	3	4	5
34. Every day is a blessing	1	2	3	4	5
35. This is my place; I have to make the best out of it.	1	2	3	4	5
36. I am much stronger than I think	1	2	3	4	5
37. I start each day knowing we will have a beautiful day together	1	2	3	4	5
38. Caregiving has made me a stronger and better person	1	2	3	4	5

Ultimate Meaning (UM)					
39. The Lord won't give you more than you can handle	1	2	3	4	5
40. I believe in the power of prayer; without it I couldn't do this	1	2	3	4	5
41. I believe that the Lord will provide	1	2	3	4	5
42. I have faith that the good Lord has reasons for this	1	2	3	4	5
43. God is good.	1	2	3	4	5

Ten-Item Personality Inventory-(TIPI)

Here are a number of personality traits that may or may not apply to you. Please write a number next to each statement to indicate the extent to which you agree or disagree with that statement. You should rate the extent to which the pair of traits applies to you, even if one characteristic applies more strongly than the other.

1=Disagree strongly, 2=Disagree moderately, 3=Disagree a little, 4=Neither agree nor disagree, 5=Agree a little, 6=Agree moderately, 7=Agree Strongly

No.	Item							
1	I see myself as extraverted and enthusiastic	1	2	3	4	5	6	7
2	• I am more reserved an quiet	1	2	3	4	5	6	7
3	I am more open to new and complex experiences	1	2	3	4	5	6	7
4	• I am more conventional and uncreative	1	2	3	4	5	6	7
5	I see myself as dependable and self-disciplined	1	2	3	4	5	6	7
6	• I see myself as more disorganised and careless	1	2	3	4	5	6	7
7	I see myself as very critical and quarrelsome	1	2	3	4	5	6	7
8	I see myself as very sympathetic and warm	1	2	3	4	5	6	7
9	I see myself as anxious and easily get upset	1	2	3	4	5	6	7
10	I see myself to be very calm and emotionally stable	1	2	3	4	5	6	7

END OF SURVEY

Thank you for your participation. If you would like some more information about this study and its findings, please include your contact details and I would be pleased to send you the information.

Name:

Contact number:

Email address:

Table 3.3: Sample Questions in the Interview Guide

- Can you please tell me how you came to assume your caregiving role? Probed into issues such as:

i. when the caregiving role started,

ii. was someone taking care first,

iii. did the caregiver or the care receiver move etc

- Are there some challenges you face in your caregiving role?

a. Probed into challenges in areas such as

i. Challenges in marriage

ii. Challenges in work

iii. Challenges in religious activities

iv. Challenges in social life

v. Challenges in finances etc

b. Also probed into how the caregiver is managing or dealing with each of the challenges

• Despite these challenges, are there some good experiences or moments in your caregiving role?

a. Probe into good experiences in areas such as:

i. Human interactions

ii. Spiritual growth or upliftment

iii. Positive outlook in life

• How has your caregiving role shaped you as a person?

a. Probe into areas such as how the caregiving role has influenced:

i. Behaviour (actions)

ii. Emotions (affect)

iii. Cognition (thinking)