EXPERIENCES OF FAMILY CAREGIVERS OF ELDERLY BURNED PATIENTS
AT THE KOMFO ANOKYE TEACHING HOSPITAL, GHANA

BY

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DECLARATION

I declare that this thesis is my own work that was produced from research under supervision. This thesis has not been submitted in any form for any degree or diploma at any university or other institution of tertiary education. Authors and Publishers whose work have been utilised in this study have been duly acknowledged in the text and list of references.

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DEDICATION

This thesis is dedicated to Mr Gabriel Allotey for his colossal support.
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The writing of this piece of work has been made possible through the contribution of others. I cannot luster over without expressing my sincere thanks and deep appreciation to all those who have contributed in diverse ways to make this piece a reality.

It is the divine hand of the Lord that gave me the impetus to sail through this course and to Him I am particularly grateful.

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### TABLE OF CONTENTS

DECLARATION .................................................................................................................. i  
DEDICATION .................................................................................................................... ii  
ACKNOWLEDGEMENTS ................................................................................................... iii  
TABLE OF CONTENTS .................................................................................................... iv  
LIST OF FIGURES ............................................................................................................ vii  
LIST OF TABLES .............................................................................................................. viii  
LIST OF ABBREVIATIONS ............................................................................................. ix  
ABSTRACT ...................................................................................................................... x  

#### CHAPTER ONE

1.1 Background to the Study ...................................................................................... 1  
1.2 Problem Statement ............................................................................................. 6  
1.3 Purpose of the Study ......................................................................................... 10  
1.4 Research Objectives ......................................................................................... 10  
1.5 Research Questions ........................................................................................... 10  
1.6 Significance of the Study .................................................................................. 10  
1.7 Operational Definitions ..................................................................................... 11  

#### CHAPTER TWO

2.1 Theoretical Framework ....................................................................................... 12  
2.2 Overview of Burns: Definition, Causes and Incidence ..................................... 17  
2.4 Background Characteristics and Context of Caregiving .................................. 23  
2.5 Stressors Associated with Caregiving ............................................................... 27  
2.6 Coping Resources Associated with Caregiving ............................................... 35  
2.7 Outcomes of Caregiving .................................................................................... 37  
2.8 Summary of Literature Review ......................................................................... 39  

#### CHAPTER THREE

3.1 Research Design .................................................................................................. 42  
3.2 Research Setting .................................................................................................. 43  
3.3 Target Population ............................................................................................... 44  
3.4 Sample Size and Sampling Technique .............................................................. 45  
3.5 Inclusion Criteria ............................................................................................... 46  
3.6 Exclusion Criteria .............................................................................................. 46  
3.7 Data Gathering Tool .......................................................................................... 46  
3.8 Data Gathering Technique ................................................................................ 47  
3.10 Data Management ............................................................................................. 49  
3.11 Pilot Study ......................................................................................................... 49  

iv
3.12 Methodological Rigour .................................................................................... 49
3.13 Ethical Considerations .................................................................................. 51
CHAPTER FOUR .................................................................................................. 54
4.1 Socio-demographic Characteristics/ Background of Participants .................... 54
4.2 Context: Injury and Reactions of Caregivers .................................................. 57
4.2.1 Cause and Nature of Injury ........................................................................ 57
4.2.2 Confusion, Shock and Anxiety ..................................................................... 61
4.2.3 Devastation ................................................................................................. 66
4.3 Hospitalisation and Associated Stressors ......................................................... 70
4.3.1 Hospital Environment, Processes and Policies ........................................... 70
4.3.2 Caregivers’ Experiences ............................................................................. 75
4.4 Effects of Caregiving ....................................................................................... 94
4.4.1 Positive Effects .......................................................................................... 94
4.4.2 Negative Effects ........................................................................................ 96
4.5 Coping Strategies ........................................................................................... 97
4.5.1 Hope, Faith and Prayer .............................................................................. 97
4.5.2 Adjusting to the Situation .......................................................................... 101
4.5.3 Encouragement from nurses ..................................................................... 102
4.6 Support .......................................................................................................... 103
4.6.1 Support from One’s Family ....................................................................... 103
4.6.2 Support from Neighbours ......................................................................... 104
4.6.3 Support from Affiliated Religious Groups ............................................... 106
4.6.4 Support from workplace colleagues ......................................................... 106
4.6.5 Support from other Caregivers .................................................................. 108
4.7 Expected and Real Outcome of Injury ............................................................. 109
4.7.1 Recovery, Death, and Loss ........................................................................ 109
4.8 Summary of Findings ..................................................................................... 110
CHAPTER FIVE .................................................................................................. 113
5.1 Background of Family Caregivers ................................................................. 113
5.2 Context of Caregiving to Elderly Burned Patients ......................................... 117
5.3 Primary Stressors Associated with Caregiving to Elderly Burned Patients .... 122
5.4 Secondary Stressors Associated with Caregiving to Elderly Burned Patients .. 133
5.5 Resources Associated with Caregiving to Burned Elderly Patients ............... 137
5.6 Outcomes of Caregiving to Elderly Burned Patients ..................................... 141
5.7 Expected and Real Outcome of Injury ............................................................ 143
5.8 Summary ........................................................................................................ 144
CHAPTER SIX .......................................................................................................................... 145

6.1 Summary .......................................................................................................................... 145

6.2 Implications for Nursing Practice .................................................................................. 151

6.3 Implications for Nursing Education ................................................................................. 152

6.4 Implications for Policy ..................................................................................................... 153

6.5 Avenues for Further Research ......................................................................................... 154

6.6 Limitations of the Study .................................................................................................. 154

6.7 Conclusion ....................................................................................................................... 155

6.8 Recommendations ......................................................................................................... 156

6.8.1 Hospital ....................................................................................................................... 156

6.8.2 The Ministry of Health/ Ghana Health Service ............................................................ 157

REFERENCES ......................................................................................................................... 158

APPENDIX A: INTERVIEW GUIDE ...................................................................................... 192

APPENDIX B: CONSENT FORM .......................................................................................... 194

APPENDIX C: GENERAL PROFILE OF PARTICIPANTS ......................................................... 199

APPENDIX D: ETHICAL CLEARANCE .................................................................................. 201

APPENDIX E: APPROVAL LETTER FROM RESEARCH SETTING ........................................ 202

APPENDIX F: CERTIFICATE OF REGISTRATION AT KATH ................................................ 203

APPENDIX G: MAP OF KUMASI METROPOLIS ................................................................. 204

APPENDIX H: CODING FRAMEWORK .................................................................................. 205
LIST OF FIGURES

Figure 1: Seven Year Trend of Discharge and Mortality of Older Burned Patients 7

Figure 2: The Stress Process Model 12
LIST OF TABLES

Table 1: Themes and Sub-themes 53
LIST OF ABBREVIATIONS

K.A.T.H  Komfo Anokye Teaching Hospital

TBSA  Total Burned Surface Area

WHO  World Health Organisation

NHIS  National Health Insurance Scheme

NIH  National Institute of Health

RTA  Road Traffic Accident

SPM  Stress Process Model
ABSTRACT

The elderly population has been noted to be particularly at risk of being involved in burn injury and outcomes are usually related to significant morbidity and mortality rates resulting in increasing dependence on others. Despite this, there is limited exploration of their caregivers’ experiences. Thus, this study aimed at exploring and describing the experiences of family caregivers of elderly burned patients at the Komfo Anokye Teaching Hospital. The study was guided by the Stress Process Model and employed a qualitative exploratory-descriptive approach. Purposive sampling approach was used to recruit fourteen (14) family caregivers who rendered care to elderly burned patients from the time of admission until death. All the interviews were audio-taped and transcribed verbatim. Data was analysed using the principles of thematic content analysis as espoused by Miles and Huberman. Six major themes emerged; five of which were consistent with the Stress Process Model (injury and reactions of caregivers, hospitalisation and associated stressors, effects of caregiving, coping strategies and support) and the sixth (expected and real outcome of injury) was an additional theme. Burn injuries were noted to occur suddenly and associated with various emotional responses such as confusion, shock, devastation and anxiety among caregivers. The sudden occurrence of burn injuries was also associated with unplanned and urgent hospitalisation and unprepared entry into the caregiving role. These features represented the context of caregiving to older burned patients. Three males and eleven females were noted to undertake the caregiving role though all males indicated that it was a feminine role. In exploring the primary stressors associated with burns caregiving in the hospital, it was observed that participants faced several physical demands: waking up early so as to arrive at the hospital on time, providing hands on care and running errands (to purchase medications, dressing materials and feeds for the elderly burned patient). Though nurses took over care of the elderly burned patient, participants were still worried as nurses were unable to meet their
needs at all times especially at night. As the patient transitioned, they manifested symptoms such as pain, restlessness and impaired verbal communication which were identified to be sources of stress for caregivers. The primary stressors identified in this study led to the development of secondary stressors such as financial constraints and alteration in life patterns for caregivers. Despite these, the existence of various resources such as coping strategies (hope, prayer and adjusting to the new situation) and support from family, neighbours, affiliated religious groups among others were identified as means utilised by caregivers to mitigate the effects of the stress. At the end of the caregiving process, both negative effects (physical and emotional exhaustion) and positive effects (growth, feeling matured and meeting new people) were noted. The additional theme identified described the outcomes that participants had hoped for though the real outcome was recognised as double loss (death of the patient and loss of properties). As symptoms exhibited by the burned patient were reported to be distressing, it was suggested that further studies be done to identify the place of palliative care in burns management. Also, there is a need for a platform to enable caregivers to talk about their experiences. In addition, health professionals need to be aware of the emotional responses evoked by the occurrence of burns and offer assistance as the case may be. Furthermore, the National Health Insurance Scheme may require revision so as to absorb the costs associated with burns management.
CHAPTER ONE

INTRODUCTION

This chapter presents the background to the study and the problem to be explored. It also consists of the study’s purpose, objectives, significance and operational definitions of key words.

1.1 Background to the Study

Burn injury is a common type of traumatic injury causing considerable morbidity and mortality (Brusselaers, Monstrey, Vogelaers, Hoste, & Blot, 2010). Burns are among the most expensive traumatic injuries due to protracted periods of hospitalisation, intensive rehabilitation, and costly wound and scar treatment (Sanchez, Pererpez, Bastida, & Martinez, 2007). Injuries resulting from burns are more common in society than can be perceived (Muller, Pegg, & Rule, 2001). According to the World Health Organisation Injury Chart book, burns are a global public health problem, accounting for an estimated 195,000 deaths annually (Haagsma et al., 2015). Burns are the fourth (4th) most common type of trauma worldwide following road traffic accidents, falls and interpersonal violence (Peck, 2011). The majority of these occur in transitional countries and almost half occur in the W.H.O South-East Asia region (Othman & Kendrick, 2010).

In spite of increased education on burns prevention, burn injuries continue to present a significant social and fiscal burden through patient mortality, morbidity, and potential for long-term disability (Brusselaers, Hoste, Montrey, Colpaert, De Waele, Vandewoude, & Blot, 2004). Burn injuries are not specific to any given population or location. They affect every age group, ethnicity, and occupation. However, elderly persons and children have been cited as individuals with a high risk of being involved in burn injury (Bessey, Arons, & Dimagio, 2006; Mabrouk, Maaher, & Nasser, 2003; Peck, 2011).
The incidence of burn injury among elderly persons has been attributed to decreasing physical strength, impaired protective mechanism, poor vision, existence of multiple co-morbidities and decreased reaction time (Ho, Ying, & Chan, 2001). Some incidence of burn injuries among elderly persons have been attributed to abuse and neglect (Huang, Chang, Huang, & Tsai, 2008). In addition, Maghsoudi and Ghaffari (2009) have reported the existence of self-inflicted burns among elderly persons. The relatively atrophic skin of elderly persons makes the resulting burns deeper (Ho et al., 2001): thus, an estimated burned surface area ≥ 10 per cent is classified as severe burns but may be described as a minor burn among younger persons (Peck, 2011). The susceptibility of older persons to burn injury has been noted to be further accentuated by pre-existing medical conditions such as dementia which has been associated with increasing depth of the injury (Harvey, Mitchell, Brodaty, Draper, & Close, 2016; Klien et al., 2011).

Ageing as a process is associated with several changes that may result in increasing frailty (Clegg, Young, Illiffe, Rikkert, & Rockwood, 2013) and burn injuries are most likely to worsen pre-existing conditions and increase levels of dependence (Campbell, DeGolia, Fallon, & Rader, 2009; DeGolia, Rader, Peerless, Mion, Campbell, & Fallon, 2009). Age has been identified as an essential prognostic factor in burns care and is a major independent predictor in determining mortality associated with burns (Wearn, Hardwicke, Kitsios, Siddons, Nightingale, & Moiemen, 2015). Thus, it has been included in most prognostic scoring system of predicting survival after the occurrence of burn injury (Peck, 2011). It has further been specified that age, burn surface area and inhalational injury remain the mainstay of burn prognostication though their relative weighting varies between scoring systems (Sheppard, Hemington-Gorse, Shelley, Philp, & Dziewulski, 2011).

Physiologically, the skin is considered the largest organ of the body and serves as the first line of defense to infection (Al-Mousawi, Mecott-Rivera, & Herndon, 2009). Burn injuries do not only result in loss of this line of defense but may lead to hypothermia, hypovolaemic shock, renal
insufficiency (Al-Mousawi et al., 2009); depressed humoral and cell mediated immunity which makes the occurrence of infection higher (Jeschke, Barrow, & Herndon, 2004; Jeschke, Klien, & Herndon, 2004). In addition, the resultant effects of burns among elderly persons may include increased physical impairment, reductions in quality of life, loss of independence and death (Klien, Lezotte, Heltsh, Fauerbach, Holavanahalli, Rivara et al., 2011).

Burn care aims to enhance survival with minimal loss of function (Peck, 2011). The acute care phase commences with a period of specialised intensive care when wound care and surgical treatment are carried out in parallel. The care focuses on infection control, wound care, wound closure, circulation and nutritional support, elimination, pain management, and physical therapy (Evers, Bhavsar, & Mailander, 2010; Herndon, 2007). In recent times, over 50% of all patients with burns involving 80% of their total body surface area (TBSA) can survive, and the survival rate may be higher in adolescents and young adults (Esselman et al., 2007).

The process of ageing is however associated with several physiological changes which result in diminished functional reserves and decreased ability to adapt to burn injury (Keck, Lumenta, Andel, Kamolz, & Frey, 2009). The severity of the hypermetabolic response to burn injury has been noted to increase with age and may result in an exaggerated response to the injury among elderly persons (Jeschke, Barrow, & Herndon, 2009). Thus, clinical management of elderly burned patients remains a global challenge (Keck et al., 2009; Khadim, Rashid, Fogarty, & Khan, 2009) and some authors have argued that they should be classified as a part of a substantial category of patients who may not respond to treatment (Ismail, Long, Moiemen, &, Wilson, 2011).

Mortality rates are relatively high among elderly persons with burns (Mabrouk, Maher, & Naser, 2003) despite advances made in burns care leading to improved survival rates among younger persons (Metaxa & Lavrentieva, 2015). Mortality rates are even higher in transitional countries due to lack of specialised burn centres, resource constraints (human and material) and
Caregiving to Elderly Burned Patients

poor first aid management (Chaudhry, 2009). Even with similar burn size, Huang et al. (2008) argue that elderly burned patients suffer greater morbidity and mortality than younger patients. For instance, Tang et al. (2006) reported a mortality rate of 36% among burned elderly persons from his study in Shanghai. Also, Haik, Liran, Tessone, Givon, Orenstein, and Peleg (2007) identified a mortality rate of 35.3% among Israeli burned elderly persons with a survival rate of 99.6% among children. Furthermore, Chaudhry (2009) observed in his study that approximately 50% of the elderly persons died whereas low mortality rate (2.02%) was noted among burn injured patients aged 10 years and below. The mortality rate may be higher if the injury resulted from thermal source and is associated with inhalational injury (Chaudhry, 2009; Peck, 2011; Wearn et al., 2015).

Although some authors have argued that elderly persons have a likelihood of being discharged from a burn centre (Lionelli, Pickus, Beckum, Decoursey, & Korentager, 2005); others have indicated that they are likely to die within a year or two after discharge due to various complications such as multiple organ failure (Lundgren, Kramer, Rivara, Wang, & Heimbach, 2009). In this regard, Duke, Boyd, Reap, Randall, and Wood (2015) observed in their study which sought to investigate the long-term mortality among elderly burned patients in Australia that 180 (3%) died during the hospitalisation and 2498 (42%) died within a year after discharge.

Though mortality rates appear to be high among elderly burned patients, it is difficult to delineate when a burned patient entered the end stage (Mosenthal & Murphy, 2003; Peacock, Duggleby, Koop et al., 2014). However, the presence of an injury or functional impairments (resulting from underlying irreversible disease) that persists resulting in continuous care provision by others confirms the need for end of life care (National Institute of Health [NIH], 2004). Undoubtedly, the presence of burns in the elderly and its concomitant complications results in dependence on health professionals and family caregivers (Coventry, Grande, & Richards, 2005; NIH, 2004). This implies that in most instances, caregiving to the burned elderly patient may be
Caregiving to Elderly Burned Patients

geared towards end of life care which may be an indication that palliative care is an essential component of the therapeutic management process for elderly burned patients (Bayuo, 2018; Mosenthal & Murphy, 2003). Though health professionals may have received training in this regard, family members may not have been previously exposed to this form of care.

Familial caregiving to the elderly person as an experience is multidimensional. It involves responses to the stressors and changes in life patterns for the caregiver as the dependency needs of the frail elderly family member increases. Hence caregiving experiences may be multifaceted, presenting a combination of positive and negative elements resulting in unique experiences (Pierce, Steiner, Govoni, Thompson, & Friedeman, 2007).

Sundara (2011) has noted that family members may experience strong emotions immediately after the occurrence of the burn injury and this may continue throughout the hospitalisation period. The occurrence of a burn injury may also be associated with guilt feeling (Klienpill, 2006) and it has been described as a sudden life changing event which may leave limited time for family adjustment (Coffey, Everett, Miller, & Brown, 2011). Despite the sudden nature of the injury, family members are required to partake in the caregiving process (Sundara, 2011).

Family caregivers may not only participate in the provision of physical care needs but may also demonstrate an emotional connection with the care recipient (Peacock, Duggleby, & Koop, 2014). In addition, Penrod, Hupcey, Shipley, Loeb, and Baney (2012) have posited that family caregivers participate in decision making regarding the patient. Consequently, Coffey et al. (2011) have posited that undertaking these tasks can be emotionally challenging for the family caregiver as they may lack prior experience. Thus, they specify the need to offer support to family caregivers so as to assist them in their roles (Coffey et al., 2011). However, this can only be achieved by understanding the unique experiences that family caregivers of elderly burned patients face as they navigate through their roles. Specifically, there is a need to understand the
characteristics of family caregivers’ who provide care to elderly burned patients within the hospital, caregiving stressors, coping patterns and outcomes of the burns caregiving process. To this end, a theoretical model which takes into account these constructs will be beneficial to this exploration. Thus, the Stress Process Model (Pearlin, Mullan, Semple, & Skaff, 1990) will be used to explore the varied experiences of burns caregiving.

1.2 Problem Statement

Muller, Pegg, and Rule (2001) have specified that elderly persons constitute between 13% and 20% of total admissions to the burns unit in Australia. Data available from the Komfo Anokye Teaching Hospital (KATH.) in Ghana indicate that elderly persons constituted 12% (88 patients) of burns admissions from 2006-2009. During that period, fifty four (54) deaths were noted among elderly persons out of the recorded mortality of 96 (Agbenorku, Edusei & Ankomah, 2011). A recent retrospective study by Bayuo, Agbenorku, Amankwa and Agbenorku (2017) at K.A.T.H revealed that from 2008 to 2015, elderly persons (defined as persons aged 60 years and above) with burns formed 5 per cent of the overall 618 admissions noted. Over that same period, a total mortality rate of 67.7 per cent was noted among elderly persons. This implies that more than a half of the total number of elderly persons admitted with burn injury died; a feature which was absent from other age groups over the same period. Details of the yearly distribution (2008 to 2015) are presented in the line graph below:
As shown in figure 1, the years 2011 and 2015 recorded the highest number of admissions though mortality was generally high across all the years. An observation made from the line graph is that for every year (except in 2010 that no elderly person was admitted), the number of elderly persons who die are more than or exactly half of the number admitted. These mortality figures are likely to be more as there is no follow up system for discharged patients and as such long-term mortality rates could not be determined. Furthermore, a review of the 2016 in-patient statistics at the Burn Units of K.A.T.H revealed that a total of twelve (12) elderly persons were admitted with three (3) discharges and nine (9) deaths. Despite this trend as well as those noted in other studies, there has been limited focus on issues surrounding the outcome of care among elderly persons.

Globally, burn care studies have focused on the injured patients (Fox-Wasylyshun, El-Masri, & Williamson, 2005; Lee, 2001) with limited exploration of family caregivers’ experiences (Bäckström, 2013). In as much as Rabow, Hauser, and Adams (2004) have described caregiving as central to end of life care, Bäckström (2013) has argued that caregiving experiences remain minimally explored globally in the burn injured patient though significant strides have been made regarding caregiving research in conditions such as cancer and dementia. Also, Ghanaian studies relating to burns care have focused on the younger population with limited

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**Figure 1.** Seven Year Trend of Discharge and Mortality among Older Adults with burns at K.A.T.H

<table>
<thead>
<tr>
<th>Year</th>
<th>Discharged</th>
<th>Died</th>
</tr>
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<tbody>
<tr>
<td>2008</td>
<td>1</td>
<td>2</td>
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<tr>
<td>2009</td>
<td>1</td>
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<td>2010</td>
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<td>2011</td>
<td>2</td>
<td>5</td>
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<tr>
<td>2012</td>
<td>6</td>
<td>0</td>
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<tr>
<td>2013</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>2014</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>2015</td>
<td>4</td>
<td>3</td>
</tr>
</tbody>
</table>

**Source:** Bayuo et al. (2017)
exploration of the elderly population as well as caregivers for both groups. For instance, Adu and Koranteng (2015) studied a ten-year trend of burn injury in Kumasi, Ghana but the discussion of their study focused on patients aged 0 to ten (10) years. A similar trend was noted in the 2006-2009 epidemiological study by Agbenorku et al. (2011) as discussion focused on the paediatric population. Also, Bayuo, Agbenorku and Amankwa (2016) studied issues associated with burn injury survival among one hundred (100) survivors. However, the ages of the participants were within the ranges of 15 to 55 years.

Thus, globally and in Ghana, experiences of caregivers of burned patients appear blurred although they are active partakers in the management process and not mere passive observers (Yoo, Lee, & Chang, 2008). What family caregivers experience whilst participating in caregiving and the results of such events remain unclear. Consequently, it is difficult to determine what form of support to provide caregivers even though they may carry significant burden as a result of the caregiving (Waldrop et al., 2005).

Burns among elderly persons have been observed to increase frailty levels and as such they are dependent on formal and informal caregivers to have their needs met. Though formal care providers have received professional training and may be familiar with the caregiving process, family caregivers may not have been previously exposed to such events. Nevertheless, family caregivers partake in decision making and assist with meeting the care needs of the elderly burned patient.

Caregiving is commonly perceived as a chronic stressor, and caregivers may experience negative or positive psychological, behavioural, and physiological effects on their daily lives based on how well they cope. Coffey et al. (2011) observed that family caregivers may be under tremendous stress and health professionals are usually unable to support them; probably due to poor understanding of their experiences. Though family caregivers’ participation is essential in the therapeutic management process, they often go unrecognised by health professionals.
Caregiving to Elderly Burned Patients

Stressors that have been linked to caregiver wellbeing include the patient’s level of disability and the tasks and responsibilities necessary to address these needs. In addition to helping with activities of daily living and instrumental activities of daily living, caregivers may also participate in the provision of direct nursing care. An emerging area of research demonstrates that patient suffering also has an impact on the overall wellbeing of family caregivers (Hebert & Schulz, 2006). Suffering by the patient may evoke feelings of compassion among caregivers, or the sense of shared suffering with the patient, combined with a desire to alleviate or reduce suffering. However, caregiver burden may accentuate as the caregivers are often helpless and unable to resolve the patient’s suffering (Hebert & Schulz, 2006).

The experience of family caregivers to elderly persons is not a new phenomenon. Caregiving to elderly persons with burn injury is however in a distinctive perspective considering the nature of burn trauma which adds to the ageing process. In addition, Coffey et al. (2011) argue that unlike other chronic diseases such as dementia, the losses that result from burn injuries are sudden life changing events which may mean that caring for the burned patient is likely to be associated with unique experiences compared to other conditions that have gradual onset such as dementia.

Caregiving is an on-going process which suggests that stressors and coping patterns are likely to change as caregivers proceed through caregiving (Gott & Ingleton, 2011). Friedman, Harwood, and Shields (2002) therefore emphasise the need to understand these experiences of family caregivers. Thus, it is argued that if the specific stressors experienced by family caregivers, coping resources and outcomes are clearly understood, healthcare professionals will be more likely to identify ways of supporting them in their roles. This is essential as it has been indicated that the number of elderly persons will continue to increase steadily and the environment will continue to pose various risks to them in transitional countries (Ghana Population and Housing Census, 2010; United Nations, 2010).
1.3 **Purpose of the Study**

The purpose of this study is to explore and describe the experiences of family caregivers regarding caregiving to elderly persons with burns from period of admission to end of life phase at the Komfo Anokye Teaching Hospital in Ghana.

1.4 **Research Objectives**

The specific objectives were to:

I. illuminate the background characteristics of caregivers of elderly burned patients
II. uncover the context within which caregiving to an elderly burned patient occurs
III. identify primary stressors associated with caregiving to elderly burned patients
IV. discover secondary stressors associated with caregiving to elderly burned patients
V. ascertain coping resources associated with caregiving to elderly burned patients
VI. identify outcomes of caregiving to elderly burned patients

1.5 **Research Questions**

I. What are the background characteristics of family caregivers of elderly burned patients?
II. What is the context in which burns caregiving to elderly burned patients occurs?
III. What are the primary stressors associated with caregiving to elderly burned patients?
IV. What are the secondary stressors associated with caregiving to elderly burned patients?
V. How do family caregivers of elderly burned patients cope with caregiving?
VI. What are the outcomes of family caregiving to elderly burned patients who die?

1.6 **Significance of the Study**

Findings from this study will help to understand how family caregivers navigate through caregiving for elderly burned patients who die in a hospital setting. This is expected to help
researchers and clinicians develop strategies to support caregivers. In addition, findings generated from this study will prepare the platform for designing quantitative studies that will enable the development of an intervention to support family caregivers of burned patients. More specifically, findings from this study will contribute to the overall aim of developing palliative care guidelines for utilisation in burns care. Furthermore, the study findings may offer directions to health policy makers as it will offer insight into how well the current health system is meeting the needs of family caregivers of burned patients. Additionally, findings from the study will inform the Ministry of Health, Ghana Health Service and Nursing and Midwifery Council of Ghana to work collaboratively to lessen the burden on family caregivers of burned and other critically ill patients.

1.7 Operational Definitions

**Family Caregivers**: persons who participate in care provision to elderly burned patients from the time of admission till death.

**Elderly person**: an individual aged 60 years and above

**Burned patient**: An individual who has been involved in burn injury

**Caregiving**: care delivered by caregivers to elderly burned patients from the time of hospital admission till death.
CHAPTER TWO

LITERATURE REVIEW

This chapter presents the Stress Process Model and relevant literature in relation to the study. An overview of burn injuries and outcomes of burns management is provided after discussing the theoretical framework to enable the development of an in depth understanding of the nature of burns. Due to the paucity of studies regarding family caregiving in burns, studies associated with conditions such as dementia, cancer, heart failure and road traffic accident (RTA) will be discussed based on the constructs of the Stress Process Model. The databases used for this study included EMBASE, PsychInfo, ScienceDirect, Popline, CINAHL, HINARI and Google Scholar. The key terms used for the search included “burns”, “elderly caregiving”, “burns among older persons”, “dementia caregiving”, “cancer caregiving” and “end of life care”.

2.1 Theoretical Framework

The Stress Process Model developed by Pearlin, Mullan, Semple, and Skaff (1990) conceptualises caregiving experiences in terms of interactions between the caregiver, environment and context within which the caregiving occurred. As a process model, it focuses on the relationship among the elements posited to contribute to the overall caregiving experience. The model was developed after a study involving 555 unpaid caregivers of patients with dementia. Waldrop, Kramer, Skretny, Milch, and Finn (2005) argue that the Stress Process Model is the most popular theoretical framework applied to earlier investigations of family caregiving.

The Stress Process Model encompasses four domains which reflect the caregiver’s experiences: background and context, stressors, outcome of stress and mediators of stress or resources (Pearlin et al., 1990). This is shown below as figure 2.
The background and context factors usually arise from the social, economic, cultural and political environment in which the caregiver provides care (Pearlin et al., 1990). In addition, these factors describe the lifelong attributes of the individual that may impact the caregiving experience such as demographic characteristics of caregivers (age, gender, marital and employment status), illness trajectory and progression or decline in the patient (Judge, Menne, & Whitlatch, 2009). Thus, it represents the circumstances in which the caregiver operates and dictate what forms of resources may be needed and are available for use by the caregiver. Also, context represents the situation of the caregiving and nature of the disease requiring family caregiving. These factors have been noted to influence the extent to which the caregivers experience stress, sources of stress, types of resources available and the outcomes that emerge (Pearlin et al., 1990). Hence, it has been indicated that in order to fully understand the caregivers’ experiences, their background and context within which caregivers provide care need to be appreciated (Pearlin et al., 1990).
Pearlin et al. (1990) have described stressors as life events that impose demands on the individual and can exceed available resources thereby endangering health and well-being. In this model, the process of caregiving is viewed as a major source of stress that poses risk. The level of stress experienced by the caregiver is influenced not only by the actual demands and hardships but also by the subjective perceptions of the caregiving situation. Thus, if the caregiver perceives or appraises caregiving as stressful, there is an increased likelihood of negative outcomes. However, if caregiving is not viewed as such, positive outcomes are likely to emerge. Stressors have been noted to emanate from the context in which caregiving is provided. Pearlin et al. (1990) have further classified stressors into primary and secondary forms.

Primary stressors are the conditions, experiences, and activities that are problematic for caregivers and are directly related to the enterprise of providing care (Pearlin et al., 1990). Traditionally, primary caregiving stressors have been conceptualised as the care recipient’s symptoms or impairments (functional, behavioural, and cognitive) and the actual caregiving tasks required as a result (Pearlin et al., 1990). These tasks may vary at different phases of the caregiving process. Judge, Menne, and Whitlatch (2009) have described this form of stressor as an objective stressor.

Hull (1990) observed from an exploratory study that the patient’s symptoms, interactions with others, and concerns about his or her own well-being were the sources of primary stress for caregivers. Also, Schulz, Mckinnis, Zhang, Martire, Hebert, Beach, and Belle (2004) recognised that a caregiver’s perception of the patient’s suffering contributed to the development of depression and caregiver burden, indicating a strong association among these variables. In some instances, non-caregivers also experienced stressors comparable to those experienced by caregivers. For instance, Amirkhanyan and Wolf (2003) observed that non-caregiving siblings who visited the elderly frail person experienced depressive symptoms comparable to their
Caregiving to Elderly Burned Patients

caregiving siblings. This may mean that the perception of what the elderly frail person was experiencing played a major part in determining the stress they faced (Schulz et al., 2004).

Pearlin et al. (1990) have described the secondary stressors as ways that primary stressors influence and disrupt other areas of the caregiver’s life. These stressors vary and are uniquely individualistic (Zarit, Davey, Edwards, Femia, & Jarrott, 1998). It describes how stresses may drift from the caregiving process to other domains of the caregiver’s life, but does not involve the direct provision of care (Aneshensel et al., 1995). Herbert and Schulz (2006) have further described these as under-appreciated set of stressors as it appears to be unique to caregivers.

Some studies have indicated economic constraints and lifestyle interference as some secondary stressors that may be experienced by caregivers (Emanuel, Fairclough, Slutsman, & Emanuel, 2000). For example, when family members assume the caregiving role, they often relinquish or modify previous roles which may lead to significant changes in family dynamics, the marital relationship, and work responsibilities (Kramer & Lambert, 1999). Furthermore, transitioning from the home to the hospital has been described as a form of stressor which can pose some difficulties (Schulz, Belle, Czaja, McGinnis, Stevens, & Zhang, 2004). Schulz et al. (2004) have posited that hospital admission does not imply an end to family caregiving but rather, a continuation of care provision. In such situations, poor communication or negative interactions with the members of the health team may compound the experience of secondary stressors (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). In addition, family caregivers may be faced with decision making regarding care of the older adult: a task which they may not be prepared for (Azoulay et al., 2004). Tilden, Tolle, Nelson, and Fields (2001) observed that surviving family members experienced high stress levels associated with the decision to withdraw care and stress levels remained high up to six months following the death of the older person. Resources that emanate from the background and context are more focused on attenuating the secondary stressors so as to achieve either positive or negative outcomes (Pearlin et al., 1990).
Outcomes of caregiving refer to the consequences of the stress being experienced (Pearlin et al., 1990). The care of an elderly dependent person has generally been associated with negative outcomes; apparently due to the care needs (Hebert & Schulz, 2006). Though the bulk of research regarding family caregiving experiences has directed attention to negative outcomes, Hebert and Schulz (2006) argue that caregiving outcomes are not entirely negative. Hence, Nijboer, Triemstra, Tempelaar, Sanderman, and van den Bos (1999) suggest that positive outcomes may result from caregiving, even in the presence of caregiver burden. These positive experiences include sense of intimacy, self-esteem, growth, meaning and purpose (Nijboer et al., 1999). Kramer (2004) also identified positive and negative outcomes among caregivers of elderly persons with cognitive and physical impairments. In addition, some exploratory studies have identified either negative (Schulz, Beach, Lind, Martire, Zdaniuk, Hirsch, Jackson, & Burton, 2001) or positive outcomes (Enyert & Burman, 1999) among caregivers of people with a potentially life limiting illness. A meta-analysis conducted by Pinquart and Sorensen (2003) has established that family caregivers were under greater levels of stress, suffered higher incidence of depression and had lower general well-being, than their non-caregiving peers. These identified differences were particularly pronounced for spousal caregivers and women. These variations may indicate that positive or negative outcomes may be experienced by caregivers and in some instances; both outcomes may be experienced simultaneously.

Mediators or resources are personal, social and material assets that modify the causal relationships between stressors and outcomes (Pearlin et al., 1990). Resources are needed to enhance coping with caregiving as this will determine to a greater extent, the outcome of the process. These resources are essential factors in explaining individual variation in the effect of stressors on outcomes. Thus, Pearlin et al. (1990) propose that the social, financial, and internal resources available to manage stressful experiences moderate the relationship between stressors and outcomes. They further observed that resources can help explain the variability in individual
outcomes. In a study involving family caregivers of patients with terminal illness, Hull (1992) identified coping and social support as essential resources used to manage the stress of caregiving. In addition, Brinson (2001) interviewed six family caregivers providing end of life care to terminally ill patients and identified coping strategies of support, adaptive activities, spiritual means, and avoidance. Haley, LaMonde, Han, Narramore, and Schonwetter (2003) utilised the Stress Process Model in their quantitative study involving caregivers of older persons. The authors concluded that the magnitude of primary stressors faced by caregivers were less important than the psychosocial resource factors in predicting caregiver depression and life satisfaction. In particular, caregivers who had more positive appraisals of stressors and greater social support had lower levels of depression than caregivers without these resources.

In summary, the Stress Process Model considers caregiving as a process which involves interplay of various factors as the caregiver transitions. The ensuing section provides an overview of burns and offers an in-depth discussion of the condition.

2.2 Overview of Burns: Definition, Causes and Incidence

Burns are injuries caused by heat, electricity, radiation or corrosive substances to the skin; but can also directly injure the lungs and airways (Peck, 2011). Burns can occasionally affect muscles, bones and other internal organs (Stylianou, Buchan, & Dunn, 2015). Burn injuries usually result in breakdown of the skin. It ranges from minor to severe based on the extent of skin affected, anatomical site, depth of the injury, the age of the patient and the presence of co-existing disorders (Stylianou, Buchan, & Dunn, 2015). According to the World Health Organisation International Classification of Diseases version 10, burns are classified by site of injury [T20-T32]. In terms of aetiology, they are classified as those caused by exposure to smoke, fire and flames [X00-X09], contact with heat and hot substances [X10-X19], exposure to electric current
[W85-87], lightning [X33] and exposure to corrosive substances [X46, X49] (Othman & Kendrick, 2010).

Globally, Peck (2011) has noted that the incidence of burn injury severe enough to require medical attention was nearly 11 million; an incidence that he argued was higher than the combined incidence of tuberculosis and HIV infections and just slightly less than the incidence of all malignant neoplasms. Generally, flames have been reported as a major cause of burn injury (Groohi, Alaghehbandan, & Lari, 2002; Othman & Kendrick, 2010). Within a tertiary health facility in Ghana, Bayuo et al. (2016) observed from their study involving one hundred burned patients that flames resulting from gas explosion stood out as a major aetiological factor. This accounted for 84 (84%) of burn cases from 2013 to 2015. Aside flame burns, scalds (including steam) and contact burns have been identified as two major causes of severe burns (Brusselaers et al., 2010). In fact, some studies from Finland, Turkey, Spain and Slovakia have reported that scald injuries were more prevalent than flame burns; up to 63% (Aldemir, Kara, Girgin, & Guloglu, 2005; Barret, Gomez, Solano, Gonzalez-Dorrego, & Crisol, 1999) and this may indicate geographical variations regarding burn aetiology.

In the paediatric population, scalds clearly dominate accounting for 60% to 75% of all hospitalised burn patients, followed by flame and contact burns and children younger than two years are at high risk for scalds (Peck, 2011). The proportion of scalds is reported to be increasing over the years among paediatric populations (Othman & Kendrick, 2010). In terms of gender variation, flame burns have been noted to be prevalent in men, whereas scalds and contact burns are more frequent in women (Peck, 2011). This gender variation may be attributed to females’ increased involvement in domestic activities and the industrial involvement of males. Less frequent than flames, scalds, and contact burns are electrical burns, which were found to be generally more frequent than chemical burns (Othman & Kendrick, 2010). The great majority of
electrical burns are accidental, and especially in children and elderly persons, the majority of these accidents occur at home (Papp, 2009).

In terms of incidence of burns among elderly persons, Chang et al. (2005) observed that persons aged 65 years and above formed 8.5 per cent (94) out of the 1110 patients admitted with burns. Using the same age limits, Rao et al. (2006) noted that elderly persons numbered up to 63 in their study that sought to analyse aetiology and outcomes of burns among older adults. Pham et al. (2009) also observed that from 1991 to 2005, elderly persons with burns formed 14 per cent (23, 180) of the total 180, 401 burned patients admitted to various burn centres. Pham et al. (2010) further identified that from 1995 to 2007, older persons formed 8.6 per cent (23,794) of the total number admitted with burns. Literature consistently names flame and scald burns as the most common aetiology of burn injury among elderly persons (Lionelli et al., 2005; Rao et al., 2006; Pham, Klien, & Kramer, 2010). Chang et al. (2005) observed in their study involving 94 elderly persons that flame burns affected 73.4% followed by scalds which affected 14.9%. In similar lines, Wearn et al. (2015) also noted flame burns incidence of 40% followed by 26% elderly persons affected with scalds. Despite the incidence of flame burns among elderly persons, Chang et al. (2005) observed that a greater proportion of older females (32.3%) are affected by scalds as compared to males (6.3%) and this may suggest some gender differences in the occurrence of burn injuries.

By interrogating the mechanism of injury further, Wearn et al. (2015) noted that cooking related burns were most common followed by prolonged contact with the source of heat. In similar lines Klosova, Tymonova, and Adamkova (2005) also observed that burn injuries in the elderly are associated with domestic activities such as cooking and bathing. Huang et al. (2008) and Davidge and Fish (2008) also reported that the majority of elderly burns occur at home, most commonly in the kitchen followed by the bathroom and living room and this may provide a clue to why more elderly women are affected with scalds as compared to men. The systematic reviews
by Brusselaers et al. (2011) and Rybarczyk et al. (2017) also described the home to be a common place for the occurrence of most burn injuries among older persons. Additionally, a recent systematic review undertaken in the middle belt of Ghana has also described the home as a major site for the occurrence of burn injuries (Bayuo, Agyei, & Baffour, 2018). Thus, Bayuo and Botchway (2017) have suggested in their narrative review that domestic settings of the elderly may pose as a risk factor to their involvement in burn injuries and may provide clues for developing preventive strategies.

Mabrouk et al. (2000) have associated some cases of burn injury among elderly persons with collapse; which resulted in accidental falls into agents that led to burn injury. In addition, epilepsy and physical disability have been described as predisposing factors to burn injuries (Mabrouk et al., 2000). Furthermore, ageing has been associated with decreased sensation, reduced response time, decreased mobility, diminishing vision among others and these have been indicated to increase the intensity of burn injury in older people (Peck, 2011). The 2010 Population and Housing Census in Ghana have revealed that the prevalence of disability among elderly persons in Ghana is relatively higher as compared to other age groups in the country. The most common of these disabilities has been noted to be visual impairment and this can predispose elderly persons to burn injury. Mou, Griffith, Fong and Gowes (2013) have also argued that rural-to-urban migration, increased adaptation to western lifestyles such as monogamy and non-communal dwelling are exacerbating loneliness. These may put the elderly person in a difficult situation and this has been indicated to increase the incidence of burn injury among older persons (Bayuo & Botchway, 2017; Keck et al., 2009).

Further to the above, elderly abuse in the form of burning and neglect has also been reported (National Centre on Elderly Abuse, 2005). For instance, Peck (2011) noted that twenty-eight (28) patients aged 60 years or older who were admitted to the United States Army Institute of Surgical Research comprised neglected and abused older persons. However in Ghana, elderly
abuse usually goes unreported and data are rarely available regarding the incidence of elderly persons subjected to neglect and abuse. In addition, the lack of a National Burn Repository makes it difficult to obtain accurate data regarding the actual incidence of burn injury in Ghana; a feature common to most transitional countries (Peck, 2011).

### 2.3 Outcomes of Burn Management

Burn care aims to ensure survival with minimal loss of function and proceeds through resuscitative, acute and rehabilitative phases (Keck et al., 2009). Following burn injury in the elderly person, there may be lower physiological reserves and co-morbid disease such as hypertension and diabetes which may complicate their management (Pereira et al., 2002). Thus, management of elderly burned patients remains a great challenge for clinicians (Huang et al., 2008; Ismail et al., 2011).

Though improvements in the understanding of the pathophysiology of burns over the past decade has led to an increased probability of an elderly person being discharged alive (McGwin, Cross, Ford & Rue, 2003); Klein, Lezotte, Heltshe, Fauerbach, Holavanahalli, and Rivara (2011) have argued that elderly persons with burn injury are still more likely to die in the year or two following their discharge. In addition, Pham et al. (2009) reported that from 1991 to 2005, greater mortality rate was noted among elderly persons in the United States of America and it constituted a significant epidemiological problem in this category of persons. Elderly burned patients demonstrate slower recoveries, longer length of hospital stay and suffer more complications than their younger counterparts (Lumenta, Hautier, Desouches, Gouvenet, Giorgi, Manelli, & Magalon, 2008).

Taylor, Sen, Greenhalgh, Lawless, Curri, and Palmieri (2015) observed in their retrospective study that the maximum length of stay among patients who died was 270 days and 731 days among those discharged and this implies greater resource utilisation. Peck (2011) also
puts forward a cogent argument that majority of burn deaths (90%) occur in transitional countries; with slightly more than 7% occurring in high middle-income countries. Thus, it can be argued that despite the remarkable advances made in burns and critical care, limited improvement has been noted among elderly burned patients (Metaxa & Lavrentia, 2015).

Duke, Boyd, Rea, Randall and Wood (2015) observed in their study that older persons in the burn cohort had 1.4-fold higher all-cause mortality than elderly persons who were not burn injured. Also, 2498 (42%) elderly persons died after discharge whilst 3% (180) died on admission. This could mean that high mortality rates may be major outcomes of burn injury in elderly persons. This assertion is based on the fact that Duke et al. (2015) included a non-injured comparison group and a designated follow-up period which enabled the research team to evaluate the long-term mortality risk associated with burns among older persons. This comparative approach was not identified in most studies presented in this review. However, the studies have demonstrated similar findings that significant mortality rates remain a major outcome of burns among elderly persons. Aside burn injury in elderly persons leading to increased risk of mortality, it may result in worsening pre-existing health conditions, hamper good nutrition, reduce mobility and independence (Campbell, DeGolia, Fallon, & Rader, 2009; DeGolia et al., 2009). It also prevents affected persons from regaining their previous state of health (Mandell, Pham, & Klein, 2013). These clinical outcomes add on to the on-going frailty associated with ageing and increase the dependency needs of older burn injured patients (Clegg, Young, IJiffe, Rikkert, & Rockwood, 2013). In addition, it leads to the development of various complications which cause distressing symptoms to patients (Bayuo & Botchway, 2017). For instance, Brusselaers et al. (2010) noted that complications such as pneumonia and respiratory distress affected 45% elderly patients and this accounted for their deaths. The developments of infections, multi organ failure and septic episodes have also been reported (Jeschke et al., 2015; Yin et al., 2010).
Some studies have also observed gender differences regarding the outcomes of the burn injuries. For instance, Chang et al. (2005) noted that burned elderly women stayed longer in the hospital as compared to men. Despite the similar incidence of inhalational injury among both genders, the authors noted that mortality rates were higher among elderly women as compared to males even though women who died had smaller total burned surface area as compared to their elderly males (25.4% vs. 44.5%). Similarly, previous studies have also reported greater mortality rates among female elderly burned patients (McGwin et al., 2003; Muller, Pegg, & Rule, 2011). Though Thornton (2002) have reported that postmenopausal women tend to lose greater amounts of collagen which may contribute to slower healing rates, there is still a need for further research in assessing reasons for gender variability regarding burn injury outcomes. These outcomes may indicate that in most instances caring for the elderly burned patient may be geared towards end of life even though it has not received much attention (Mosenthal & Murphy, 2003).

The ensuing sections present a discussion of caregiving literature. However, due to the limited number of studies regarding burns caregiving, studies involving caregiving in conditions such as dementia, cancer and RTA are discussed using the constructs of the theoretical framework (Stress Process Model) discussed earlier.

### 2.4 Background Characteristics and Context of Caregiving

In order to understand family caregivers’ experiences, Pearlin et al. (1990) have specified the need to comprehend their background and context characteristics. The background characteristics reflect the demographic features of the caregivers and the context reveals the circumstances leading to entry into the caregiving role. Larsen and Lubkin (2006) have defined the caregiver as anyone who provides assistance to another in need; in this case, the older person. They further described the caregiver as one who provides care without pay and usually has personal ties to the care recipient. This may explain the reason why caregivers appear hidden in the healthcare system. Despite the roles they play, they receive no pay for their services but still
provide care, apparently because of their personal ties with the care recipient (Larsen & Lubkin, 2006).

Caregiving is conceptualised by Pearlin et al. (1990) as a career that embraces three stages to produce unique caregiving experiences. However unlike most careers, caregiving is unplanned, unexpected and not entered into by choice (Pearlin et al., 1990). The stages are role acquisition (usually precipitated by the onset of an illness), role enactment (performance of role related tasks) and role disengagement (follows death of the care recipient). As a career, Pearlin (1992) further posited that transitions may follow the sequence of residential caregiving, institutional placement and bereavement. Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) noted that each phase represents unique transitional experiences for the family caregiver. This is because each phase is associated with unique sources of stress and offers strategies for addressing these stressors. Also, it has been indicated that rapid transitions may occur between and within each stage of the caregiving career (Aneshensel et al., 1995).

During the role acquisition phase, the occurrence of an illness requiring caregiving is identified. Aneshensel et al. (1995) noted from their study involving dementia caregivers that during this period there is symptom recognition, diagnosis of the condition and assumption of the caregiving role. However according to Merrill (1997), in cases of traumatic events such as a fall, diagnosis played less central role as there was the need for sudden entry into the caregiving role. These variations may mean that different transitions may be experienced by caregivers providing care as the context within which care is required is different. Merrill (1997) has further argued that the extent of assuming the caregiver role in this phase is based on the relationship between the care recipient and the care giver. Thus, spouses and older children have been noted to be more involved in caregiving than distant relatives.
Another unique transition that occurs in this period is dealing with the reality of the diagnosis and impending loss (Pearlin et al., 1992). Family caregiving is often assumed to be provided to an ill or frail care recipient usually in their home for conditions such as dementia and cancer (Fast, 2005; Fast et al., 2005). This may last for years and even continue after institutionalisation of the care recipient (Kelley et al., 2000). As caregiving follows the illness trajectory and is required for protracted periods in these conditions, family caregivers have been noted to enter these roles before they self-define their status as caregivers. Although long-term care admission is necessary in the later stages of dementia, deciding to place a relative with dementia in a long-term care home can be distressing and complex for family caregivers (Chene, 2006). In relation to injuries such as RTA, family members have been noted to be in emotional tension as they assume the caregiving role. This emotional response to the injury was observed by Filho, Xavier and Vieira (2011) to be associated with the unexpected nature and sudden occurrence of the injury. The authors noted that the need for urgent hospitalisation was associated with depression, anxiety, sadness, fear, unawareness and these were further exacerbated by the physical traumas, economic difficulties and social implications. Thus, the authors suggest that family caregivers of RTA victims need professional support as they also suffer emotional injuries even as they care for their hospitalised relatives.

In the role enactment phase, the care recipient is usually placed in a health facility (Aneshensel et al., 1995). However, this could imply in-home care delivered by the caregivers. This usually requires adjustments in the personal and social life of the caregiver so as to meet the care demands of the care recipient. Even when the care recipient is placed in a health facility, provision of hands on care does not cease. The need for hospitalisation also presents unique transitions for the family as they adjust to the new setting and seek ways to continue providing care. The role disengagement phase is usually preceded by the death or cure of the care recipient
which marks a return to the caregiver’s normal way of life. However, the reality of a loss may have profound impact on the caregiver (Aneshensel et al., 1995).

Caregivers have been noted to be spouses, daughters or sons of the care recipient; with majority being females (Cohen, Pringle, & LeDuc, 2001). According to the United States National Alliance for Caregiving (2015), the typical family caregiver is a 46 year-old female with some college experience. However, Hebert and Schulz (2006) have noted that family caregivers are usually aged 18 years or older. Also, Brodaty and Donkin (2009) and Helmes and Pachana (2014) have reported that majority of dementia caregivers have no tertiary qualification. In the study by Santos et al. (2014) which sought to understand the experiences of family caregivers of traffic accident victims, it was revealed that caregivers were usually females with an average age of 40 years and presented as spouses, mothers and siblings of the care recipient. In similar lines, Filho et al. (2007) also observed that most family caregivers of persons involved in RTA were females who presented as spouses and siblings of the care recipient. Thus in both circumstances, caregiving appears to be rendered by a relative or a spouse.

Though it has been observed that it is less likely for males to undertake caregiving roles, Thompson, Tudiver, and Manson (2000) have argued that current demographic changes have allowed more males notably husbands and sons to take up caregiving roles. Romoren (2003) has also specified the existence of male carers who may undertake the same range of activities rendered by female caregivers. Male carers have been noted to experience caregiving differently as compared to their female counterparts; as men may not acknowledge the need for support, preferring to focus more on concrete tasks rather than emotional reactions to caregiving (Sanders, 2007). Thus, Yee and Schulz (2000) have suggested that female caregivers may experience more burden and psychological distress than males. In addition, male carers have been observed to be more likely to be in full time employment than female carers (Sanders, 2007).
Further to the above, a meta-analysis by Pinquart and Sörensen (2011) revealed caregiving differences among spouses, older children and children-in-laws. They noted that spouses were older but cared for younger care recipients, were of lower socio-economic status and less likely of being in full time employment. Spousal caregivers were also noted to provide greater levels of support which was consequently associated with higher depressive symptoms and greater financial burdens as compared to older children and children-in-law. Aside relations of the care recipient, Marks (1998) has argued that non-kin relations such as friends and neighbours can take up the caregiving role. Caregiving to a parent and parent-in-law have been noted by some authors to be associated with differences. For instance, Spitze, Logan, Joseph, and Lee (1994) identified the existence of greater distress when caring for one’s biological parent as compared to a parent-in-law. In relation to the caregiver-care recipient living situation, Goodman et al. (2004) has indicated that caregivers who live with the care recipients experience greater levels of burden as compared to those who live apart the care recipients. Smale and Dupius (2004) have suggested that this variation in burden levels may be related to the fact that co-residential caregivers tend to provide a greater number of hours of care and might experience more stress.

2.5 Stressors Associated with Caregiving

Caregiving is defined in the seminal work by Bowers (1987) as the meaning or purpose a caregiver attributes to behaviour rather than by the nature or demand of the behaviour itself. This would include observable behaviours, mental activities and shared understandings. Thus, a caring behaviour may have more than one purpose simultaneously. There is, however, an increasing recognition that the definition of caregiving is multidimensional and includes: level of physical and instrumental functioning, medical condition, frequency and number of tasks required of the primary caregiver, emotional dependency and the perception and interpretation of the caregiving process by both the caregiver and the care receiver.
Pearlin et al. (1990) have described caregiving as a career to which family members are insidiously drawn into. Thus, family members commence functioning as caregivers before they self-define in this role. While family caregiving has considerable rewards, including allowing caregivers to facilitate closure after death and helping them find meaning in their experiences (Stajduhar, 2003); it can be physically exhausting, difficult to recover from, and associated with emotional and financial burdens (Grande, Stajduhar, & Aoun, 2009). Unlike professional caregivers such as doctors and nurses, family members may not have experienced adequate preparation to undertake the caregiving career (Bevans & Sternberg, 2012).

Stress and emotional strain are frequently reported by family caregivers and these, in turn, are linked to a greater likelihood of carers reporting that their health has suffered and/or a lower quality of life (O'Sullivan, 2008). Care provision for a frail older person may result in considerable physical, emotional and behavioural strain on caregivers (McCurry, Logsdon, Teri, & Vitiello, 2007). These difficulties are exacerbated when caring for someone with other chronic conditions such as dementia (Mannion, 2008a).

Informal caregivers face varying levels of psychological, physical, spiritual, and financial distress at each transition phase and the end of life period is of no exception (Zivin & Christakis, 2007). A critical literature review by Yoo, Lee and Chang (2008) involving thirty five studies concluded that perceived burden levels and depression levels were relatively high among family caregivers at the end of life period; though a few positive experiences were noted. Over time, the range of end of life care services provided by informal caregivers is a well-documented combination of physical, practical, and emotional care (Hauser & Kramer, 2004; Rabow et al., 2004) that shift in focus and intensify over the course of the disease (Hebert & Schulz, 2006; Schumacher, Stewart, Archbold, Dodd, & Dibble, 2000; Soothill et al., 2001).

A phenomenological study by Ivey, Laditka, Price, Tseng, Beard, Lui, Fettermann, Wu, and Logsdon (2012) regarding experiences of family caregivers providing care to relatives in the
context of dementia at home revealed that, illness trajectory of care recipients served as a primary stressor to caregivers. Thus, caregivers specified that the changing symptoms and behaviours of care recipients influenced their daily life. These changes often increased hardships associated with caregiving. At advanced stages of dementia, when physical abilities and cognitive function diminished, the caregivers indicated the emotional difficulty that stressed them as well as the increased caregiver responsibilities. These negative experiences were also reported by participants in the study by McCurry et al. (2007). Though their study may be limited by the usage of a convenience sample, their conclusion substantiates findings by other studies (Schulz et al., 2003; Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Thus, it can be argued that stressors exist in the process of caregiving and the caregiver must respond to them by coping effectively or ineffectively. Hebert and Schulz (2006) have noted that in comparison with other forms of caregiving, dementia caregiving is associated with more primary stressors due to the prolonged duration of care and time consuming nature. Consequently, dementia caregivers have been cited to have greater emotional and psychological burden (Smale & Dupius, 2004). Primary stressors related to dementia caregiving have been associated with cognitive impairment, neuro-psychiatric abnormalities (such as agitation and delusions) and other behaviours that characterise the condition (Terri, 1997).

Generally, hospital admission has been noted to be stressful for family members (Klpenill, 2006). It may be even more difficult to endure the uncertainty associated with the hospitalised person’s condition (Engström & Söderberg, 2004). Additionally, attempts to undergo changes in relationship, roles and responsibilities may be demanding. The experience of transferring to residential care, has been shown for the older adults to have burdensome consequences of stress, depression, financial burden, loss of personal possessions, and loss of personhood ((Mitty & Flores, 2008) and these features may further compound the experience of primary stressors related to family caregiving. Additionally, although the transition to a health...
facility has been shown to initially relieve the burden of care, feelings of relief were transient and the more common experience was continued feelings of loss, failure, and guilt (Gaugler, Anderson, Zarit, & Pearlin, 2004; Strang et al., 2006).

Cerebro-vascular accident (stroke) has also been noted as a disease condition which requires family caregiving for longer periods. Hebert and Schulz (2006) have posited that stroke survivors are dependent on family caregivers for long term care. The significant aspect of caregiving to stroke survivors has been noted to be the sudden onset of the condition (Morris, Robinson, Raphael, & Bishop, 1991). Morris et al. (1991) further noted that the sudden and unexpected nature of stroke usually provided family caregivers with limited time for adjustment to the caregiving role. Consequently, the caregivers were poorly prepared for their roles, reported more stress and experienced greater emotional and psychological burden.

In relation to conditions that exhibit steady progression followed by a short-lived terminal phase such as cancer, caregivers have been noted to possess unique experiences and are also at a high risk of psychological morbidity (Hebert & Schulz, 2006). Hebert and Schulz (2006) further note that stressors that cancer caregivers face vary depending on the stage of the illness: diagnosis, treatment, remission and end of life phase. The authors indicated that after a diagnosis of cancer has been made, caregivers wanted information about the disease and its progression. Thus, lack of information became problematic for the caregiver and that served as a primary stressor. As treatment progressed, the caregiver became more focused on the needs of the care recipient and required support in meeting these needs. Hence, absence of support from health care professionals and the family burdened the caregiver. Though distress has been noted to decrease during stable remission, a sudden recurrence is more difficult (Northouse, Mood, Templin, Mellon, & George, 2000). As the cancer progressed to advanced stages, family caregivers were faced with uncertainty, fear and anticipatory grief (Northouse et al., 2000). Aside these, the existence of pain and its management have been reported as an issue among cancer patients that
stressed caregivers. Powe and Finnie (2003) have specified that family caregivers usually viewed pain as a manifestation of impending death or physical deterioration. In terms of pain management, Hebert and Schulz (2006) noted that fears of addiction and concerns about side effects contributed to stress experienced by family caregivers.

Severe congestive heart failure has been identified to be associated with the worst quality of life as compared to most cancers and other chronic conditions (Juenger et al., 2002) though Molloy, Johnston, and Witham (2005) have indicated that caregiving to patients with heart failure is limited as compared to other life limiting conditions. Mårtensson, Dracup, Canary, and Fridlund (2003) have suggested that family caregivers of patients with heart failure also experience stressors comparable to caregivers of patients with other chronic conditions due to their care needs. A meta-analysis by Pinquart and Sorensen (2003) revealed that higher levels of care recipient’s impairments were associated with greater stress levels for the caregiver. This feature is similar to that reported by other studies regarding family caregiving in cancer and dementia.

At the end of life period, Fulton and Epstein-Lubow (2011) have asserted that caregivers providing care in the home experienced the highest level of strain as compared to other caregivers as they are involved in total care provision and this could mean the existence of greater levels of stress at that phase. Grunfeld et al. (2004) have also observed the presence of elevated anxiety levels among caregivers of cancer patients at the end of life phase: levels higher than those experienced by the patients. Waldrop et al. (2005) have indicated that the intense management required as a cancer patient experienced decline in physical well-being presents as a form of stressor to family caregivers. This care encompasses assistance with activities of daily living (such as hands on care) and instrumental activities of daily living (such as running errands). They specified that these tasks intensified at the end of life period as the care needs increased in proportion with the physical decline. As a result, primary stressors associated with rendering
hands on care increased whilst quality of life of the caregiver diminished (Grunfeld et al., 2004). Furthermore, they noted that as cognitive decline set in, the caregiver had to take decisions on behalf of the care recipient. This task has been described as overwhelming for the caregiver as they did not know the wishes of the care recipient. This corroborates the assertions by Coffey et al. (2011) that end of life care provision is characterised by decision making which can be emotionally challenging for both formal and informal caregivers.

Further to the above, Schulz (2013) has indicated that accepting a patient’s prognosis to be poor may generate intense emotional responses and this might present as a primary stressor to the caregiver; in the same way the symptoms presented by the patient may stress the caregiver. In another study, Bevans and Sternberg (2012) noted that to receive the diagnosis of cancer is a significant stressor to the patient and the family and this is carried on throughout the caregiving career. In addition, the authors observed that being a witness to suffering may also present as a stressor to the caregiver.

Moreover, time needed to provide care has been noted to result in various adjustments among caregivers at the end of life period which serves as secondary stressors to family caregivers. For instance, Haley, LaMonde, Han, Narramore, and Schonwetter (2001) have observed that dementia caregivers in their study provided 75 hours of care per week for 49 months whilst cancer caregivers provided 115 hours per week for 14 months. Consequently, these hours allotted for care provision was associated with lower life satisfaction and higher depression among caregivers.

Peacock, Duggleby, and Koop (2012) utilised an interpretive phenomenological approach to study the lived experiences of caregivers who participated in care provision to a relative with dementia at the end of life period admitted to a long term facility. Their findings were organised according to the existential life world themes. Spatiality revealed a sense or lack of feeling welcome to provide end-of-life care in the facility and corporeality revealed feelings of
exhaustion. These may mean that within this context, caregivers had to continue providing care as they felt connected to the care recipient; even though they felt unwelcomed. In a similar study, Butcher, Holkup, Park, and Mass (2001) also employed a qualitative design to understand transitions that caregivers experience regarding placing a relative with Alzheimer’s disease in a special care unit. The authors noted that caregivers struggled with the decision to place their relative in a special care unit. The caregivers also verbalised feelings of anguish and guilt associated with their decision to place their relatives in a special care unit. However, throughout the decision making process, caregivers felt the need to remain connected with the care recipient and that involved frequent visitation and assistance with hands on care after placement in the special care unit. The latter findings affirm the findings by Peacock et al. (2012) in that, even after placement either in a long term facility or a special care unit, caregivers still felt the need to provide care as they experienced emotional attachment with the patient. It is worth noting that persons with Alzheimer’s disease may be catered for at home but injuries resulting from burns usually require immediate admission to a health facility. Thus, it is likely that transitions experienced by caregivers of patients with these conditions may differ.

In another study, Waldrop et al. (2005) studied 74 caregivers rendering care to relatives in hospice care using a qualitative in depth approach with the aim of understanding caregivers’ transition during end stage caregiving. The findings of the study revealed that end stage caregiving to cancer patients receiving hospice care was characterised by comprehension of terminality (recognition/ awareness that the care recipient was dying). This awareness emanated from the experience of receiving information regarding prognosis, observing progression of the disease and observing the patient’s personality change and role loss. The study further noted that the awareness enabled caregivers take on a new perspective with regards to death and dying. Development of this awareness could be related to the fact that hospice care is a specialised form of care for the terminally ill and as such plans of care are geared towards achieving peaceful
death. This feature is not likely to be obtained in other settings and these variations are likely to impact the transitions experienced by caregivers.

Burn victims and their families are faced with an unexpected, life changing injury and they do not have the necessary time to adjust to the trauma (Metaxa & Lavrentieva, 2015). The burned patient at the end stage experiences further functional decline which may have an impact on family carers (Murray, Kendall, Boyd, & Sheikh, 2005). As end of life care has not been clearly streamlined in burns care (Bayuo, 2018), it is difficult to ascertain when aggressive burns management should cease. Hence, aggressive management continues till the patient finally dies or survives (Mosenthal & Murphy, 2003).

Caring for a patient at the end of life involves both formal care provision (paid services by professional health workers) and informal care provision (Navaie-Waliser et al., 2002; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Penrod et al. (2012) indicate that family caregivers provide significant contribution at the end of life period and may require support as caregivers’ transitioned through their roles. More often, at the end of life period, healthcare professionals have focused more on the patients with limited consideration for what the family members may be experiencing (Fox-Wasylyshun, El-Masri, & Williamson, 2005). However, at the end of life period in burns, family members may have to face new challenges that may potentially be above and beyond their ability to adapt to; including financial difficulties, role changes and changes in overall health condition of the caregiver (Hwang et al., 2003). These features may have profound effects of caregivers as they transition through the process of caregiving. Unlike other chronic conditions such as dementia, the losses that result from burns and other traumatic injuries are sudden life changing events (Coffey et al., 2011). Family members are usually in crisis which is characterised by strong emotions immediately after the burn and this may continue, even as they take up the caregiving role (Sundara, 2011). These variations offer support for the need to explore burn caregivers’ experiences.
2.6 Coping Resources Associated with Caregiving

Despite the existence of various stressors in caregiving, there are mediators or moderators that assist caregivers in dealing with issues associated with the process. These can be described as coping resources or coping strategies (Nolan, Grant, & Keady, 1996). Smale and Dupuis (2004) have described coping to mean ways in which caregivers negotiate and mitigate the pressures and strains of caregiving. Pearlin et al. (1990) have suggested that while these factors cannot explain all of the differences between the stresses experienced by different caregivers, they may have a major explanatory role. The antecedent for coping can include the presence of a stressor that demands an emotional, cognitive, physiological, or behavioural response. In the context of the research, it can be stated that stress associated with caregiving will lead to coping by the caregiver. Thus, any analysis of coping will quickly lead on to the concept of stress, since stress is generally seen as the factor or set of conditions that is being coped with. Biegel and Schulz (1999) have described a sequential, cyclical model in which stressful situations begin when functional limitations of the care recipient and problem behaviours create a need for caregiving. The caregiver must evaluate the situation and decide if she or he can deal with the problems. A positive or benign evaluation leads to positive emotional responses and a sense of well-being. Alternately, an appraisal of the situation as stressful leads to negative emotional reactions (e.g., anxiety, depression); these reactions may interact with care recipient behaviours to create an escalation of negative outcomes.

Broadly, coping has been classified into problem-focused and emotion-focused coping strategies (Uren & Graham, 2013). Problem-focused coping strategies encompass strategies to define the problem, generate alternative solutions and take necessary actions to resolve the problem. Emotion-focused coping strategies are usually targeted towards decreasing emotional distress and include approaches such as avoidance, seeking social support and meditation. Studies have however shown that caregivers who used emotion-focused coping strategies had poorer
quality of life scores; though at a given period both approaches to coping might be used (Barbosa et al., 2011; Green & King, 2009; Myaskovsky et al., 2005).

In the study presented earlier by Waldrop et al. (2005), the central emergent theme noted regarding the transition was “comprehension of terminality”. This emerged as the caregivers received information regarding the decline in the care recipient’s health. To this end, it may mean that provision of information may have served as a resource that enabled caregivers cope with the decline in the care recipient’s health status.

Furthermore, Redinbaugh, Baum, Tarbell, and Arnold (2003) utilised a quantitative approach to study coping at the end of life period for cancer patients in hospice care. The authors asserted that lower levels of caregiver strains were noted among caregivers whose families have accepted the patient’s illness, defined the illness related problems in a more manageable way and felt capable of providing solutions to problems associated with end of life care. This is a feature Pearlin et al. (1990) described as an internal resource capable of enabling the caregiver to attenuate the effects of stress. In another study involving non-cancer caregivers, Wade, Borawski, Taylor, Drotar, Yeates, and Stancin (2001) noted that higher acceptance and lower denial of a child’s traumatic injury predicted lower levels of caregiver burden and distress. These findings may suggest that acceptance of an illness may be a coping strategy for caregivers. This may be related to the fact that acceptance of an illness allowed the caregiver become more aware of their grief and work at it instead of denying the reality of impending death (Redinbaugh et al., 2003). This assertion may offer some useful insights into the reasons behind escape-avoidance coping strategy leading to increased depression (Dunn et al., 2001). However, this could also mean providing carers with information regarding their relatives in a supportive environment (Waldrop et al., 2005). Furthermore, findings from a study by McCorkle and Pasacreta (2001) suggest that providing caregivers with adequate skill and knowledge made them feel capable of handling
issues related to caregiving. This is often associated with a sense of mastery and self-efficacy as it empowers caregivers to face the requirements hands on care.

Financial instability has been identified as increasing caregiver burden and as such, having adequate financial resources may serve as a resource for coping. Schofield et al. (1998) have asserted that financial difficulties are often associated with poorer caregiver well-being. Another resource related to this is social support. Savage and Bailey (2004) posit that the amount and quality of social support available and utilised by caregivers helps to attenuate the burden of caregiving. However, Redinbaugh et al. (2003) have cautioned that it is the quality of the social support and not the quantity that helps to attenuate burden associated with caregiving. Studies have reported significant relationship between social support and caregiver burden based on caregivers’ perceptions of adequacy of support and their satisfaction with assistance received (Redinbaugh et al., 2003). Social support was also a key theme reported by participants in a study by Waldrop et al. (2005). This support was obtained from friends and members of the extended family who offered respite for caregivers. This break in caregiving allowed the caregivers’ time to overcome strains associated with the process. Waldrop et al. (2005) further reported the use of religious and faith practices as a coping resource. This was based on hope in a Spiritual Being; usually God.

2.7 Outcomes of Caregiving

Caregiving as a process usually ends in various outcomes. These outcomes can either be positive or negative based on how the caregiver appraised and responded to the situation. Generally, most studies using the Stress Process Model have measured outcomes based on levels of depression, anxiety and quality of life among caregivers (Cooper, Katona, Orrell, & Livingston, 2008; Kliszcz, Nowicka-Sauer, Trzeciak, & Sadowska, 2004). Schultz and Sherwood (2008) have asserted that caregiving has all the features of a chronic stress experience as it creates physical and psychological strain over extended periods.
Caregiving to Elderly Burned Patients

Approximately 32 per cent to 70 per cent of carers of patients with advanced cancer have been found to experience a high level of distress or symptoms which suggest depression (Dumont, Dumont, & Mongeau, 2008; Rivera, 2009). A longitudinal study conducted by Berg et al. (2009) among caregivers of stroke patients reported that the existence of depressive symptoms ranged from between 30-33% in the total study sample. Older age of patients and stroke severity were the main predictors of depression among the caregivers at the acute phase.

Despite the negative experiences, caregiving has also been indicated to be associated with positive experiences or outcomes; though this aspect of caregiving has been stated to have received less attention (Andren & Elmstahl, 2005). Hence, in a given caregiving situation, caregivers may experience either positive, negative outcomes or both. A systematic review by Mackenzie and Greenwood (2012) involving caregiving studies in stroke from 1999 to 2009 confirmed the existence of positive experience of meaning finding in caregiving and concluded that this enabled caregivers have a more balanced view of their roles. Similarly Cohen, Colantonio, and Vernich (2002) utilised a national sample of caregivers (289) from the Canadian Study on Health and Ageing to quantitatively determine positive aspects of caregiving to older persons living in communities. Employing a staged stepwise multiple regression, it was reported that 73% (211) of the total sample size identified at least one specific positive aspect of caregiving; 6.9% (20) could identify more than one positive aspect of caregiving. It was also detected that positive feelings were associated with lower burden scores and better self-assessed health.

Moreover, participants in the study by Ivey et al. (2012) also reported similar positive experiences in providing care to someone with dementia. This was described by the participants as feeling emotionally stronger and experiencing personal growth. Similarly, Hudson (2004) assert that at the end of life period, caregivers may experience personal growth through adversity, discovery of emotional strength, physical abilities and a deepening of the relationship with the
care recipient. Robinson, Fortinsky, Alison, Kleppinger, Shugrue, and Porter (2009) also reported from their study involving 4,041 participants in the Connecticut Long-Term Care Needs Assessment that caregivers rated their health better than non-caregivers and did not report more depressive symptoms or social isolation. Taking these points together, it can be said that caregiving may not always involve negative experiences or outcomes; and these may be linked to how the caregiver perceives the stressors identified in the process of caregiving as well as the resources available for coping (Pearlin et al., 1990). Wilkinson (2010) however argues that the extent to which positive experiences buffer the negative aspects still remains unclear.

2.8 Summary of Literature Review

The Stress Process Model developed by Pearlin et al. (1990) served as the theoretical basis for this study. The model emphasises the interplay between stressors associated with caregiving, coping resources and the outcome of these events within a particular context. By conceptualising caregiving as a career, Pearlin (1992) noted that it involves three phases; each with unique stressors and opportunities to address them. The review of relevant studies focused on caregiver background and context, stressors, resources and outcomes associated with caregiving. Though the current study focuses on caregiving in burns, caregiving in other conditions such as dementia, cancer, stroke and RTA were discussed due to the paucity of studies regarding caregiving in burns. Though family caregiving at various phases has been extensively researched in other conditions such as cancer, dementia and stroke, paucity of information exists in relation to burns caregiving.

With regards to caregiver background characteristics and context, it was revealed that though males are currently undertaking caregiving, it is most often assigned to females in the capacity of a spouse, daughter or a sibling. It was also observed that for conditions such as dementia and cancer, caregiving usually commenced in the home before institutionalisation.
Caregivers in this context have been noted to provide care for longer periods of time and their experiences reflect the illness trajectory. It was observed that for these conditions, there is a period of diagnostic investigation to confirm the diagnosis prior to commencement of the caregiving career. However, for conditions such as trauma, there was a need for urgent hospitalisation due to the nature of the injuries. Peacock et al. (2012), Waldrop et al. (2005) and Butcher et al. (2001) employed qualitative approaches to study dementia, cancer, and Alzheimer’s disease caregivers respectively. Waldrop et al. (2005) reported awareness by cancer caregivers about impending death within the hospice setting; Peacock et al. (2012) noted the need to be present with the patient in the long term care among dementia caregivers and Butcher et al. (2001) also specified caregiver challenges in decision making in the special care unit. These variations may be related to the context in which caregiving was carried out. Generally, various stressors have been noted with regards to caregiving. These stressors include patient’s symptoms with dementia cared for in the home (Ivey et al., 2012), hospital admission and uncertainty (Klienpill, 2006) and illness trajectory among cancer patients (Waldrop et al., 2005). In dealing with stressors, caregivers either used problem-focused or emotion-focused strategies. Though the use of the former has been associated with better outcomes, some studies reported caregivers relied on emotion-focused resources such as religious practices (Waldrop et al., 2005). Problem-focused resources included skill acquisition (McCorkle & Pasacreta, 2001) and acceptance which led to active problem solving at the end of life period (Redinbaugh et al., 2003). The outcomes noted in this review were both positive and negative experiences. Findings in this regard however appear inconsistent. Negative experiences were noted to be in the form of depression, anxiety and decreased quality of life. Depression was reported in both cancer (Rivera, 2009) and stroke caregivers (Berg et al., 2009). However, positive experiences such as meaning finding were noted from the systematic review by Mackenzie & Greenwood (2012) among stroke caregivers. Also
Ivey et al. (2012) reported positive experiences such as emotional strength among dementia caregivers. Similar findings were also reported by Hudson (2004).

These findings notwithstanding, the conditions presented here (such as dementia and cancer) are chronic conditions which progress over time. However, burns occur suddenly which leaves limited time for adjustment for the family and the need for caregiving may be sudden; a situation similar to that of stroke caregiving (Hebert and Schulz, 2006). Though it may be appropriate to manage patients with dementia or cancer at home, it might be inappropriate in burns. These may mean that caregiving in burns is most likely to occur in the hospital which might lead to unique experiences for the caregiver. Some studies presented here utilised interpretive phenomenology (Peacock et al., 2012; Ivey et al., 2012) and in-depth qualitative approaches (Waldrop et al., 2005) as paucity of studies were identified. In similar lines, this present study aimed to explore and describe the experience of caring for elderly persons with burns from time of admission till death. As research in this regard is limited, an exploratory descriptive approach would be beneficial. The next chapter presents the methods used in achieving the outlined objectives for the current study.
CHAPTER THREE

METHODOLOGY

This chapter presents the study’s methodology. The study’s design, research setting, target population, sample size, sampling technique, data gathering tool, data gathering technique, data analysis, data management, pilot study, methodological rigour, ethical considerations and expected outcomes will be discussed.

3.1 Research Design

Parahoo (2006) has noted that a research design is a plan, that specifies who, where and when data are to be collected and analysed. Burns and Grove (2009) have posited that an appropriate design must be chosen that is appropriate for the topic being investigated in order to answer the research questions. A research design can be qualitative or quantitative in nature (Cormack, 2000); both of which are guided by divergent philosophical, paradigmatic and methodological traditions. Quantitative research is largely a controlled and systematic process (Polit & Beck, 2010) aimed at producing empirical analysis of a topic of interest that may be generalized to a larger population (Parahoo, 2006). Qualitative research has been described as a systematic, subjective approach used to describe life experiences and give them meaning (Munhall, 2001).

As this study aimed to explore and describe the experiences of family caregivers regarding caregiving to elderly burned patients, the descriptive-exploratory design which is a qualitative approach was utilised for the study. The qualitative stance does not aim to generalise findings but considers the existence of unique and varied experiences of family caregivers regarding burns caregiving. Thorne, Kirkham, and MacDonald-Emes (1997) have specified that the descriptive-exploratory qualitative approach is appropriate to provide rich textual descriptions of human experiences. They further note that with this approach, the phenomenon of interest is explored
with participants in a particular situation and from a particular conceptual framework with the research question related to the meaning of the experience. Ontologically, this study is oriented towards the constructionist approach and seeks to comprehend the meaning of caring for elderly burned patients in the hospital (Ritchie et al., 2013). The epistemological stance is interpretive with the aim of understanding caregivers’ experiences from the perspective of those who have experienced the phenomenon of caring for elderly burned patients (Bryman, 2012).

3.2 Research Setting

This study was undertaken within the Kumasi Metropolis. Kumasi is the capital city of the new Asante State built from a voluntary unification of about a dozen city states. The Asanteman Traditional Council, the traditional governing authority of the old Asante Kingdom, was restored by the British Colonial Authority in 1935 and Kumasi became the seat of the Council though without political powers which were kept by the British Colonial Government with its seat in Accra (Boahen, 1992). Currently, the Kumasi Metropolis is the second largest and most populous city in the country; next to Accra (Population and Housing Census, 2010).

The Kumasi Metropolis is one of the thirty (30) districts in the Ashanti Region of the Republic of Ghana. It is located between Latitude 6.35°N and 6.40°S and Longitude 1.30°W and 1.35°E and elevated 250 to 300 meters above sea level. The Metropolis shares boundaries with Kwabre East and Afigya Kwabre Districts to the north, Atwima Kwanwoma and Atwima Nwabiagya Districts to the west, Asokore Mampong and Ejisu-Juaben Municipality to the east and Bosomtwe District to the south (Population and Housing Census, 2010). It is approximately 270km north of the national capital, Accra. It has a surface area of approximately 214.3 square kilometers which is about 0.9 per cent of the region’s land area. However, it accommodates about 36.2 per cent of the region’s population (Population and Housing Census, 2010). The largest ethnic group in the Kumasi Metropolis is the Asante (80.7%), a sub-group of the larger Akan
ethnic group. This is followed distantly by the Mole Dagbon (8.7%) and Ewe (3.6%). Almost all the other ethnic groups in Ghana can be found in the Metropolis (Population and Housing Census, 2010). The Ghana Statistical Services (2010) has indicated that the population of Kumasi Metropolis (1,730,249) represents 36.2 per cent of the total population of Ashanti Region (4,780,380). It comprises of 826,479 males (47.8%) and 903,779 females (52.2%).

In terms of tradition, the Population and Housing Census (2010) have noted that the celebrations of dead relatives through luxurious funeral rites have come to stay in the Metropolis.

In terms of health care, the metropolis has 136 healthcare facilities providing healthcare services to its residents with the largest being the Komfo Anokye Teaching Hospital (KATH). The Komfo Anokye Teaching Hospital (KATH) is the second largest hospital in Ghana. It is the main referral hospital for the Ashanti, Brong Ahafo, the Northern, Upper West and Upper East regions of the country. The hospital was built in 1954 and affiliated to the School of Medical Sciences (SMS) of the Kwame Nkrumah University of Science and Technology (KNUST). The hospital currently has 1000 beds, with an annual hospital attendance of about 679,050 patients made up of both out- and in-patients. The units dedicated to burns management include the Burns Intensive Care Unit (BICU) and ward D2C; with a bed capacity of six (6) each. Burn injured patients are initially admitted to BICU and transferred to the ward after being stabilised and inhalational injury has been ruled out. However, if special parts of the body (face, fingers and genitalia) are not involved, they are admitted to ward D2C. Clients with infected burn wounds are not admitted to the Burns ICU but to ward D2C.

3.3 Target Population

A population in research refers to those elements that make up the focus of the study that fit fixed criteria (LoBiondo-Wood & Haber, 2010). The target population for this study was
family caregivers who rendered care to an elderly person with burn injury at the Komfo Anokye Teaching Hospital, Kumasi.

3.4 Sample Size and Sampling Technique

Gerrish and Lacey (2010) have defined a sample as a subset of a target population, normally defined by the sampling process. Purposive sampling method was used to recruit participants for this study. This approach involved selecting individuals who have knowledge of the phenomena being studied or deemed potential information rich cases (Mapp, 2008). Thus, family caregivers who rendered care to burn injured elderly persons were expected to have the needed information required by this study and were invited to participate in this study. After ethical approval, the Admissions and Discharge Books of the two Burn Units were used to identify elderly burned patients who were admitted from January 2016. Contact numbers of next of kin were obtained from these books. Telephone calls were made and details about the primary caregiver obtained. Details of the study were made known to family caregivers and upon accepting to participate; a meeting was arranged with them at their own convenient time and venue. Also, family caregivers were identified when an elderly burned patient was admitted. After the death of the patient, the family caregiver was considered for participation in the study. However in this situation, the family caregiver was allowed sometime (two to three weeks) to deal with the reality of the loss before approaching them for possible inclusion in the study.

In both recruitment instances, the family caregivers were approached and invited to participate. The researcher provided details of the study and each participant was followed after a week to know their decision regarding participating in the study.
3.5 Inclusion Criteria

The establishment of exclusion and inclusion criteria according to LoBiondo-Wood and Haber (2010) increases the precision of a study and strengthens evidence produced. Participants included in this study met the following criteria:

- Family caregivers who rendered care to an elderly burned patient from admission to end of life period at the Komfo Anokye Teaching Hospital
- Family caregivers residing in Kumasi metropolis

3.6 Exclusion Criteria

Exclusion criteria included:

- Family caregivers who rendered care to an elderly burned patient whose final disposition was discharge
- Family caregivers who provided care intermittently to elderly burned patients

3.7 Data Gathering Tool

Qualitative research employs methods which allow researchers to collect data surrounding the experiences of people (Polit & Beck 2010). Considering the nature of the phenomenon understudy, an interview guide (Appendix A) was developed to facilitate the data collection process. The interview guide allowed in-depth exploration of caregiving experiences based on the constructs of the Stress Process Model whilst allowing other issues and concerns to emerge. The interview guide was designed to obtain information such as: background characteristics of the caregiver, experiences with health care professionals and organisations, transition to caregiving, caregiving stressors, coping resources and outcomes of caregiving. Aside the interview guide, the researcher also took note of facial expressions and body language and wrote field notes from these.
3.8 Data Gathering Technique

This refers to the process by which needed information will be obtained by the researcher. A semi-structured interview approach was used for data collection as it allowed flexibility in the pursuit of interesting leads and descriptions (Charmaz, 2006). The interviews took place at participants’ own convenient venue and time where recruited family caregivers were free to express themselves and talk about their experiences. Each interview lasted approximately 40-60 minutes. The researcher avoided the use of leading questions or jargons which may guide participants towards particular responses (Baumbusch, 2010). Permission was sought from participants to record interview proceedings. Oral consent was obtained prior to commencement and intermittently during data collection. Participants were informed to talk freely about what they felt comfortable with especially as the study aimed at capturing caregiving experiences from admission to end of life phase. Interviews commenced with a broad question that enabled participants to talk about their experiences. Intermittent breaks were provided so as to provide participants time to re-compose themselves. A reflexive diary was also maintained to keep track of all preconceptions at each phase of the study. The interviews centred on open ended questions and participants were allowed to express themselves; noting voice changes and general appearance.

Prompts and probes were used as follow up strategies that enabled the researcher clarify to issues and to obtain further in depth information. Iterative mode of questioning was used to ensure honesty during data collection. At the end of the first interviews, participants were informed that the data would be analysed and they will be contacted for a second interview. During the second interview, unclear issues from the initial interview were discussed with each participant. In addition, the interview transcripts were discussed with them to confirm if the interpretations were in line with their experiences. In four instances, participants got the
opportunity to indicate that the translation did not imply what they meant. Thus, they clarified these issues to reflect their experiences and their corrections accepted.

3.9 Data Analysis

Thematic analysis principles as espoused by Miles and Huberman (1994) was utilised in analysing data in this study. This proceeded through data reduction, display, drawing conclusion and verification. Data reduction refers to the process whereby the mass of qualitative data obtained such as interview transcripts, field notes, observations is reduced and organised, for example coding, writing summaries and discarding irrelevant data. Thus, at this stage, all interview proceedings were transcribed verbatim. Interviews that were conducted in the Akan language were transcribed with the assistance of a translator (without disclosing source of data) and these were discussed with participants to ensure that they were true representations of their descriptions. Field notes were also developed alongside. After completing the transcription in Microsoft Word 2010 and coding, they were exported to NVivo version 10 to commence creation of nodes; the main nodes created were named with the labels of the constructs of the Stress Process Model. At this stage, the interview transcripts had been read and re-read several times to obtain a sense of them. Discarding irrelevant data did not mean completely deleting them but they were stored on a separate sheet as they might be useful at a later stage. The second phase which is data display involved drawing conclusions from the mass of data. Miles and Huberman (1994) suggest that a good display of data, in the form of tables, charts, networks and other graphical formats is essential. This is considered as an on-going process, rather than just one to be carried out at the end of the data collection. Thus, sub nodes obtained from the data were placed accordingly under each applicable main node. The third stage involved drawing conclusions and verification.
3.10 Data Management

Ritchie, Lewis, Nicholls, and Ormston (2014) describe data management to mean the process of making qualitative data manageable; of labelling and sorting data according to a set of themes. NVivo version 10 was used to organise data obtained from the study. Recordings of interview proceedings and data analysis were kept in a password protected computer, only accessible to the researcher. Audio-recordings will be destroyed after five years from the time this study is completed and accepted.

3.11 Pilot Study

A pilot study may be described as a small scale or trial run of the larger study. It is used to assess the feasibility of a study, eliminate any potential problems and refine any methodological errors (Polit & Beck 2010). The methods employed in this study, such as audio-recording and data collection technique with the interview guide were piloted among three family caregivers of elderly burned patients to determine how useful they will be in generating caregivers’ experiences. Findings from this phase helped to correct some aspects of the interview guide. However, data from this phase were not included in the main study.

3.12 Methodological Rigour

Rigour according to Gerrish and Lacey (2010) refers to how strong a body of research is, in terms of confirming that all procedures have been followed judiciously and that the reader judges conclusions to be dependable or trustworthy. For this study the researcher used the framework developed by Lincoln and Guba (1985) as cited in Parahoo (2006) that seeks to establish methodological rigour in qualitative research. These included credibility, transferability, dependability and confirmability.

Credibility sought to address the issue of ‘fit’ between participants’ accounts and the representation of them by the researcher (Koch, 2006). Thus, credibility led the researcher to ask-
“How congruent are the findings with reality?” The researcher confirmed whether congruence existed between what participants described and what was generated from the narratives through member checking, prolonged engagement with family caregivers, and an audit trail. Member checking involved returning to family caregivers and consulting with them to determine whether descriptions given reflect their experience. Interviews conducted in “Akan” (a local language in Ghana) were translated into English with the aid of a translator so as to maintain the original meanings. These transcriptions were discussed with participants to ensure that they reflect caregivers’ experiences. Prompts and probes were also used during the interview process to enable participants clarify issues. Iterative mode of questioning was used to ensure that participants were being honest and revealing their experiences regarding caregiving. With regards to member checking, the research entailed interviewing caregivers and having follow up meetings with them to ensure that all data obtained reflect their unique experiences. In cases face-to-face meetings were impossible after the first interview; telephone calls were used as the means of discussion and this was recorded to aid in the analysis of data. Prolonged engagement was ensured by allocating adequate time for collection of data and prolonged immersion in the data so as to afford a richer breath of knowledge and description regarding burns caregiving experiences. The use of an audit trail also ensured credibility of this study. Detailed description of the research process has been provided to enable others judge the process. Memos available in Nvivo version 10 were used to design an audit trail and aid in recording decisions made at each phase of the study. Another strategy which was used in assuring credibility; and one that is part of the repertoire of skills of nursing is that of self- awareness. Considering the extent of literature review conducted and professional exposure to elderly burned patients, a reflexive field journal was maintained by the researcher to promote honesty and transparency.

Dependability concerns itself with the responsibility of researchers to substantiate that every part of the research is transparent, methodical and clearly documented (Tobin & Begley
2004). The quantitative synonym for this construct is reliability. Detailed description of each stage of the research process has been provided throughout the study. Also, developing an audit trail was useful here. This will enable external reviewers to judge the study’s dependability through a discussion of methodological and analytical decisions throughout the research (Koch, 2006).

Transferability/fittingness means that the research’s findings can ‘fit’ into other contexts outside the study situation and when readers regard findings as meaningful and find it applicable within their own contexts and experiences (Koch, 2006). To achieve this, there has been a detailed description of the research process so that others can evaluate the applicability of data to other contexts and settings.

Confirmability establishes the accuracy of data and the soundness of decisions and judgments in the sequence of the research process from the beginning to the end. The researcher ensured this throughout the process by accurate recording of data during the interview process, confirmation of descriptions by participants and on-going consultation with supervisors.

3.13 Ethical Considerations

Research is viewed as a scientific human endeavour that is organised according to a range of protocols, methods, guidelines and legislation (Gerrish & Lacey 2010). A proposal was submitted to the Institutional Review Board of the Nogouchi Memorial Institute for Medical Research for approval before the study commenced. After clearance (IRB00001276), permission was sought from the Head of Surgery Directorate of KATH to undertake the study. The study was registered at the Research and Development Unit of KATH.

Informed consent is the cornerstone of ethical research (Casssell & Young, 2002) and an important aspect of this is the quality of information provided to potential participants. The researcher provided the participants with a consent form detailing all information about the research in a clear and concise manner with personal explanation if required. Upon accepting to
participate in the study, each participant signed or thumb printed two copies of the consent form (one kept by the researcher and the other kept by the participant). However, for those who were not able to read, each item on the information sheet was explained to them in the presence of a witness before seeking their consent. In order to be sure that they had fully understood the study and their involvement, follow up questions were asked and if responses were satisfactory, they were allowed to confirm their participation by signing or thumb printing. However, if responses were unsatisfactory, further explanations were offered for participants to clearly understand the study and their involvement. Oral consent was sought prior to commencement of interviews.

Considering the nature of the study, the researcher incorporated a process of on-going consent or “process consent” (Dalton & McVilly, 2004) which meant that at every phase of the interview session the participant’s involvement was re-negotiated. This also implied that the participants were free to withdraw from the study at any point. This was made explicit on the information sheet and verbally reiterated at the time of the interview. The ethical principle of non-maleficence implied that no harm should come to participants (Cormack, 2000). The researcher was therefore mindful that the interview could bring up memories that could distress participants. In this instance, the interview was halted to enable participants re-compose themselves. If this was impossible, the interview was re-scheduled to a later date (two episodes of this were noted during the data collection phase). A clinical psychologist was contacted at K.A.T.H to offer counseling services to all participants when the need arose at no cost. This action emanated from the fact that re-collecting and re-living events surrounding end of life care may be stressful. In all, three participants were referred to the clinical psychologist for counseling at no cost. Participants were also informed of the need for a follow up meeting to discuss the findings.

The right to confidentiality is essential in research (Polit & Beck 2010) and this was ensured in this study. Participants’ identity has been concealed through the assignment of pseudo-names in data analysis and throughout discussion in the study. Interview proceedings and all data
related to this study have been kept in a password protected computer; only accessible to the primary researcher. Back up of all data relating to the study has been kept on an external hard drive and locked up in the researcher’s personal cabinet as well as password protected. These will be destroyed after five years following acceptance of the thesis. However, data for persons who decided to leave the study were destroyed immediately. Additionally, the translator recruited for the study did not know the identity of the participants as he only had access to voice recordings. The next chapter presents the findings.
CHAPTER FOUR

FINDINGS

The findings of the study are presented in this chapter and these have been organised into themes in relation to the Stress Process Model which served as the theoretical framework for the study. The socio-demographic characteristics are discussed as the background features of participants which imply that contextual factors are also discussed separately. The findings presented here represent the product of in-depth interviews with fourteen (14) caregivers as well as non-verbal cues recorded as field notes throughout the interview process. Six major themes were generated and have been presented here in relation to the Stress Process Model. Sub-themes were identified and categorised appropriately under the six major themes after coding of data.

4.1 Socio-demographic Characteristics/ Background of Participants

The process of purposive sampling resulted in recruiting fourteen (14) caregivers who rendered care to elderly burned patients at the Komfo Anokye Teaching Hospital (KATH) from admission to time of death. The socio-demographic characteristics correspond to background of participants in the Stress Process Model and are represented as such in this section. Also, it represents the response to the first research question which sought to illuminate the background features of caregivers who provided care to elderly burned patients in a hospital. Details of their socio-demographic features have been summarised in Appendix C.

From the data obtained, it was observed that more females (11) undertook caregiving roles to elderly burned patients as compared to males (3). The male caregivers in this study rendered care to male patients only as sons of the care recipient (2) and a brother of the care recipient (1). However, the female caregivers provided care to both male and female elderly burned patients as
sisters of the care recipient (2), daughters (4), fiancée (1), neighbour (1), spouse of the care recipient (1) and daughter in law (2).

In terms of education, most participants have had some level of formal education (Basic School- 4, Senior High School- 5, Diploma- 2 and Ordinary Level – 1). However, two (2) participants have had no formal education. In relation to employment, the majority of participants who provided care to elderly burned patients (13) were involved in some form of work as traders (6), artisans (5) and two (2) public servants. One (1) female participant who was initially noted as not having any formal education was unemployed.

The male caregivers were within the ages of 21 to 48 years whilst the females who took up the caregiving role were within the ages of 28 and 49 years. All participants in the study took on the caregiving role because they were related in some aspects to the elderly burned patient. The majority of participants were children of the care recipient (6). In addition, two (2) females provided care in the capacity of spouse and fiancée of the care recipient whilst one (1) female participant had to render care in the hospital because her male neighbour was involved in a gas explosion in her mother’s home. Furthermore, two female participants provided care as daughters in law to the care recipients. Also, two females provided care in the capacity as sisters to the elderly burned patients whilst one male participant provided care as a brother to the care recipient.

In terms of religious affiliations, majority of the participants were Christians (11) whilst the remaining three (3) participants were Moslems. Furthermore, nine (9) participants were married, two (2) were co-habiting and three (3) were single. The ensuing section presents the themes and sub-themes that were identified from the analysis in relation to the constructs of the Stress Process Model. The findings under each of the sub-themes are presented in turns.
Table 1

*Themes and Sub-themes in Relation to the Stress Process Model*

<table>
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<tr>
<th>SPM CONSTRUCT</th>
<th>THEME</th>
<th>SUB-THemes</th>
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<tr>
<td>Context</td>
<td>Injury and reactions of caregivers</td>
<td>• Cause and nature of injury</td>
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<td>• Confusion/ shock/ anxiety</td>
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<td>• Devastation</td>
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<td>• Helplessness and hopelessness</td>
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<td>Primary and secondary</td>
<td>Hospitalisation</td>
<td>• Hospital environment, processes and policies</td>
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<td>stressors</td>
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<td>• Caregivers’ experiences</td>
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<td>Outcome</td>
<td>Effects of caregiving</td>
<td>• Positive effects</td>
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<td></td>
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<td>• Negative effects</td>
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<td>Resources and mediators</td>
<td>Coping Strategies</td>
<td>• Hope/ faith/ prayer</td>
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<td>• Adjusting to the caregiving situation</td>
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<td>• Encouragement from nurses</td>
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<td>Resources and mediators</td>
<td>Support</td>
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<td>• Other caregivers in the hospital</td>
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<td>Additional theme</td>
<td>Expected and real outcome of injury</td>
<td>• Recovery, Death, and Loss</td>
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4.2  **Context: Injury and Reactions of Caregivers**

This theme describes the mechanism of the burn injury as well as caregivers’ responses to the injury occurrence. It describes the circumstances that led to the demand for caregiving so as to grasp the milieu within which caregiving occurred. The sub-themes identified were cause and nature of injury; confusion, shock and anxiety; devastation; helplessness and hopelessness. These are discussed with verbatim quotes from participants.

4.2.1  **Cause and Nature of Injury**

The causes of burns were varied and they included gas explosion, electricity, petrol and hot oil. It was observed that the injuries were events which occurred suddenly. Participants reiterated the fact that they did not have foreknowledge regarding the occurrence of the injury and did not expect the injury to have happened. In relation to the swift and sudden occurrence of the injury, participants mentioned that they had previously had an interaction (few minutes to hours) with the care recipient prior to the occurrence of the injury and that made them to doubt an injury had happened:

"It was sudden. I mean I had talked to her earlier before I left to my shop and she left to her stall. When I received the call I told the gentleman he should stop joking about issues like this. So I rushed to the place to see for myself and it was true. My sister was sitting on the floor with oil all over and could not get up. She was actually crying and I felt sad because how could this happen just after some few minutes we had talked. I was scared to even touch her not to talk about the other neighbours around. Her skin was all gone away and her clothes were burned as well"

Afia, 38 years (Sister)

In one instance, though the injury was identified to be of thermal source, its mechanism remained unclear as the caregiver could not establish any tangible link between the injury and the source:
“Hmmmmmm... [Pauses for some seconds] If I am asked how it occurred, I just do not know what to say. I have no idea how this thing happened. I knew she had some waist pains but she did not tell me she was going to see the pastor. All I know is that the pastor decided to pray for her and then all of a sudden there was fire but no one could tell where the fire came from. Some people were saying it was Holy Ghost fire but I did not believe it”

Matilda, 31 years (Daughter)

Even though participants noted that the injuries occurred suddenly, the occurrence of the injury made participants to reflect on incidents and interactions that had occurred prior to the injury. They re-examined these incidents and interactions to determine if they could have prevented the injury from occurring. Consequently for injuries that occurred in the homes, participants blamed themselves for being away the moment the injury occurred as they believed if they had been present, they could have averted the occurrence of the injury or attenuated its effects:

“You see it was so fast and quick and I was just wondering whether I could not have smelled the gas leaking previously or maybe it was there and I just brushed it aside. Ah...[pauses for some seconds] I remember the children told me it was leaking but I checked and it was okay so I left but I should have rechecked it again so that this accident would have been avoided. But you see for a small mistake of refusing to check this thing, the damage it caused was more horrible. If I were home may be I could have even smelled the gas and taken the cylinder out”

Mercy, 29 years (Daughter in law)

“You will not believe it because we had spoken not long ago. If I had been more careful at home all these things may have been avoided. In the end he died too and that was the most painful part of it all but in a way this could have been prevented easily because when the gas started leaking, we placed a wet cloth on it and it was okay so we all thought it was solved. Even the day it happened I was not at home but if I were there, I would have taken note of the leakage and prevented this altogether but things do happen ooooo... [sobs for some seconds and wipes the tears] ”

Esi, 28 years (Daughter)

Burn injuries were noted to occur with sounds that caused panic among persons present at the scene of the injury and those who heard from a distance. A participant shared the following:
“On our way back to the house, we parked the car at the usual place and started walking home. All we heard was a loud sound “woooooooom”. Though it startled us, we were okay because we thought it was from the refuse dump in the area because we usually hear that forms of sounds. But then we realised that there was smoke coming from the house and people screaming all over the place. We rushed there only to realise that the fire was from our house”

Kokui, 33 years (Daughter in law)

Another participant expressed:

“In the process of bringing the mast in front, the tip touched a high tension pole just as we had mounted our product stand. Immediately it touched the pole, he was shocked by the current and all we could hear was a booooom sound and he fell flat on the floor with the tent and mast falling over him and I am sure the way his head hit the floor, he sustained other injuries”

Afua, 49 years (Fiancée)

Though some elderly persons were able to escape from the scene after the injury to a safe place, it was noted that some victims were also trapped by the source of the burn injury which made them scream for assistance. Thus, some family members and neighbours attempted to rescue them from the source of the injury and also sustained varying degrees of burns in the process. After being rescued, participants came face to face with the burned elderly person with burned clothes:

“But the man went ahead to call another person who unknown to my mother was a driver and not qualified but my mother was inside. They took the cylinder to the kitchen and the driver said that the cylinder was overfilled and that was the main reason the regulator could not fit well. So they opened the top part of the cylinder to expel some of the gas out. Immediately, they fixed the regulator and lighted a match stick there in the kitchen. The whole kitchen was on fire which extended to other rooms. The driver escaped through the window but the old man could not and was trapped in the fire till other neighbours came to his rescue as my mother shouted for assistance and he was also screaming to be rescued”

Martha, 31 years (Neighbour)
One of the participants also narrated:

“So my husband rushed through the fire to rescue his father and smaller sister who had been caught up in the kitchen by the fire. It was then that my sister in law indicated that a stove had been put on already and he was working on another cylinder when the regulator just hit the floor and the gas leaked. So I think the fire that had been put on connected with the gas that has leaked and caused an explosion. I was not there though but from what I was told, am sure that was what caused the burns. I was really worried because my father in law was able and could do everything for himself and I just kept wondering if he would still remain the same seeing him with his body and clothes all burned by the fire”

**Kokui, 33 years (Daughter-in-law)**

The participants who arrived at the scene of injury also observed various changes in the burned elderly person which depicted the nature of the burn trauma. They indicated manifestations such as extensive burn wounds, swollen face, pain verbalised by the elderly person after the injury had occurred, inhaled products of combustion and changes in their personal features such as complexion. Some of the injuries were severe to the extent that participants could not recognise the burned elderly person after being rescued. Family members who rescued burned elderly persons were noted to have sustained varying degrees of the injury. However participants reiterated that in comparison, the injury that elderly persons sustained were more extensive than those of other rescuers:

“He was actually burned from head to toe... [sighs for some seconds] a dark skinned man suddenly looking all red and white and I am sure he even inhaled some of the smoke in the kitchen because anytime he coughed, there were black substances from his throat and his face was swollen. In comparison with what his daughter and son suffered, his was even worse. He was burned to the extent that I was unable to tell he was the one and when I realised he was the one, I shouted Jesus”

**Mercy, 29 years (Daughter in law)**

Another participant said:

“Shewas actually crying and I felt sad because how could this happen just after some few minutes we had talked. I was scared to even touch her. Her skin was all gone away and her clothes were burned as well. It was a sad thing to see and I stood there just wondering and not knowing what to do. It was even two male neighbours who helped her up from the floor”

**Theresa, 38 years (Sister)**
Furthermore, the injuries sustained by the elderly persons were in some cases accompanied by damages to properties such as houses and cars which appeared to heighten the intense emotions among persons who took on the caregiving role and other family members. However the focus of the individual who assumed the caregiving role was on the injured person with limited consideration for the damaged properties. Despite this, caregivers became more aware of the damages after the burned elderly person had been hospitalised as shown in the quotes below:

“When I received the call at my work place about the incident, there was nothing I could do but had to leave the work place immediately because my mother alone could not stand the sight of the old man getting burned not to talk about the house that is destroyed. I was visibly shaken. It was not easy at all for anyone of us. When I got there I just got some people around to help me send him to the hospital. I could not think straight and it was when I got back from the hospital that day that I realised that the explosion really damaged the house.”

Martha, 31 years (Neighbour)

“But I hoped that he would get better with time and unfortunately he died and the car was damaged beyond repair as well and I think after the electric shock, the whole place was on fire too. We did not think that he would die and we hoped he would get better. Life was more important so we did not even see the damaged car. It was after he had been admitted that we even realised the car was also spoilt”

Yaa, 41 years (Spouse)

4.2.2 Confusion, Shock and Anxiety

This sub-theme describes reactions of family caregivers to the occurrence of the burn injury and further elucidates the context in which caregiving occurred. Following the occurrence of the injury it was observed that participants experienced various reactions. Participants were confused as a result of the unexpectedness of the injury and the damage it had caused to the elderly person and properties. In addition, they could not believe that within a short frame of time, an explosion or a fall could have resulted in such extensive injury. Participants were lost in thoughts and could not immediately come to terms with the injury that had occurred. Participants
also asked themselves several questions which appeared rhetorical as they had no answers to them and could not understand the entire situation:

“Looking at all that happened I think I was confused and just could not think straight. I mean how could this happen so suddenly and quickly. It was just something else seeing his clothes on fire plus the house too. So many things were running through my mind and could not even move an inch. It was like I felt frozen at one place and I kept asking myself what at all is this too? How did this happen so suddenly?”

Michael, 48 years (Brother)

“It was not like I was far away. I had spoken with her that morning and we were supposed to go to church later that day. How else could I explain this because I never saw this coming? If not I would have even advised her not to fry anything that day. I see these things in movies but I never thought it could happen to me so suddenly and not knowing what to do. We got to the hospital before I realised what was happening and it was not a dream after all but very real. I was just wondering how she slipped and fell into the hot oil.”

Theresa, 38 years (Sister)

One contributory factor to the confusion observed among the participants was whether an error on their part had resulted in the injury. The experience of confusion was such that participants did not know what to do. They felt lost and attempted to establish links between any previous clues and the injury:

“I kept asking myself if I saw this coming at all but I did not. I just did not know what to do. I was moving my legs but honestly I did not know in which direction they were even going and I was not even sure what I was doing or saying. Maybe I was saying some useless things but I was so confused at what I saw”

Ishmael, 23 years (Son)

“Some of these things do happen and I was wondering if I was the cause as I wanted to cook immediately the cylinder was filled and brought home. I was buying some items when I received the phone call and I told them to stop joking because I had just left the place. I got there and it was true. That was so sudden and I was just confused and till today I have no idea where I placed the items I had purchased at the shop”

Akosua, 40 years (Daughter)

In addition to being confused, it was observed that participants were shocked at the occurrence of the injury. They were shocked at the changes that had suddenly occurred in the appearance of the elderly person such as charring and pain verbalised by burned elderly person.
The observed changes in the elderly persons frightened the participants. They were scared to go close to the burned patient and could only do this after the wounds had been dressed and covered at the hospital:

“Everything was like a shock to me. I had spoken to her that morning and we really had plans for the day then out of nowhere, she fell into the oil. I was just shocked when I realised that the gentleman who called was telling the truth after all and not playing games with me. I was totally lost when I came to face to face with my sister who was burned. There was nothing I could do to help her because I have never seen anything like this before. People talk about things like this but I never knew it was near me and it could happen to my sister. I never dreamt something like this could happen and when it did, I was totally lost. I was really scared with the wounds I saw and I just could not get close to her because I have never seen anything like that before”

Theresa, 38 years (Sister)

“In fact he was really burned and I was afraid of getting close to him. But after the doctors and nurses covered the wound, I could go close to him. He looked so big with all the bandages that had covered his entire body. He could not even move his leg not alone his hands. I felt sad inside and for a while, I did not know what to do. He is my older brother and in fact I do not know how I behaved but I woke up in a long chair after I had seen him. It was shocking to me”

Michael, 48 years (Brother)

Also, the participants were shocked at the extent of damage caused to properties. In some instances, it was noted that damaged properties were not limited to that of the elderly person only but to other possessions which belonged to other persons. Thus, participants were both terrified at the injury to the elderly person and properties that were damaged:

“I was there when it happened and I wish I was not even there because I have never seen anything as terrible as that before. The sound with which the cylinder exploded whilst my father was working on it was very loud that I thought it was a car tyre but it was not. When I rushed there, I saw my dad on the floor screaming and he looked so black. Charlie, it was a sad one for me seeing him like that and the kitchen and other parts of the house burning as well”

Kwabena, 21 years (Son)

“Within some few minutes, the room was burned too and it even got to the neighbouring rooms just within some few minutes Hnnnnnnnn [sighs heavily]. It was like all our hard work and toil had just been destroyed by the fire”

Agatha, 35 years (Daughter)
In addition, participants expressed anxiety at the scene of injury. They were worried and expressed concern about the consequences of the injury and whether the elderly person might return to his or her previous state of good health. They were also anxious about damaged properties and associated financial loss. Two participants shared their concerns:

“Uhmm... [stammers for some seconds] i felt like I was in an unknown land after I heard the sound. It was then I noticed that his clothes were on fire. I was startled, frightened and could not speak for a while when I saw my senior brother in this state. It was like the world had come to an end for me because he did not look like he would be as he used to be”

Michael, 48 years (Brother)

“You see it is all loss of money because there was a rented room nearby and this fire destroyed some part. We are in Ghana and the landlord held us to also contribute something to rebuilding his house”

Akosua, 40 years (Daughter)

Apart from being anxious about the occurrence of the burn injury, participants were also anxious about going to the hospital. This is because they had heard several stories about the hospital such as only critically ill patients are brought to KATH and this made them nervous about the outcomes of the elderly burned person. For most of the participants, it was their first time of coming to the hospital and did not know what to expect. This made them anxious as expressed by two participants:

“I have heard many stories about the place that it is usually people whose illnesses are so terrible who are brought there. So I realised that he was also in a terrible state but did not think for a moment that he would die with it. I was worried because he was really burned by the fire and the shock too was bad”

Mercy, 29 years (Daughter in law)

“This one was different because I have never been with a family member at Gee [KATH] and I was just wondering how it would be. I have heard stories that people who are brought here are very sick and most of them die. In fact when they told us an ambulance is coming to pick us to Gee [KATH] I felt that his condition was really bad”

Michael, 48 years (Brother)
People who were present at the scene of the burn injury were not the only ones who were anxious and distraught. The participants who received the news via phones were also confused, shocked and stunned comparable to those who were at the scene of the injury. They were terrified about the news of the injury. These participants had to halt all their activities and quickly make it to the place where the elderly burned patient had been taken to (hospital) or to the home of the burned patient. The participants treated the news about the injury as a matter of urgency based on what they were told via the phone. They were highly uncertain and anxious about the state in which to find the burned elderly patient. This intense feeling of uncertainty reportedly appeared to be the impetus that moved the participants to halt all their activities upon hearing the news and to rush to the hospital or scene of injury:

“Eiiiiiiiiiiiiiiii I felt terrible and very sad because of what my mother told me on the phone. When I received the call at my work place about the incident, there was nothing I could do but had to leave the work place immediately because my mother alone could not stand the sight of the old man getting burned not to talk about the house that was destroyed. I was visibly shaken. It was not easy at all.”

Martha, 31 years (Neighbour)

“I was at Adum in my phone shop when my auntie called that the cylinder at home had exploded whilst she was cooking but had gone out to buy magi cube from the shop in our area. She only got there and realized the kitchen was on fire and my father was the only one there. I just shouted before I could know that was what I did. Ahhhhhhh, auntie said my father’s clothes were on fire. I was afraid and had to rush out immediately to the house and later to the hospital”

Ishmael, 23 years (Son)

In the case of one participant who rendered care to an elderly burned patient in the capacity of a neighbour, it was noted that the confusion, shock and anxiety were further exacerbated by dealing with the family of the elderly burned patient. She was not sure how the family of the injured man would receive the news of the injury and the need for hospitalisation:
“I mean it was not like we saw this thing coming and we never dreamt such an incident would occur. Even if it was another family member of ours, things would have been easier but this man was a neighbour and not related to us in anyway. How were we going to inform his family members or break the news to them?”

Martha, 31 years (Neighbour)

It was also found that a female participant who rendered care in the capacity of a daughter had feelings of remorse in addition to the confusion, shock and anxiety. Her feeling of remorse was because she left her elderly father alone to attend to his personal needs although she knew he was not capable of doing so. Thus, she had hoped to remedy the situation by caring for her injured father and in so doing, to ask for his forgiveness. However, her father remained on mechanical ventilation and could not verbally express himself throughout the hospitalisation period until his death:

“Eiiii, it was scary for me so I had to leave my fiancé’s place to come to the hospital that night to see my father. He could not talk or respond to calls and he remained this way till he died. It was difficult to accept that I never had the chance to talk to my father or He could not open his mouth to also talk to me till he died. It was really terrible for me because I really wanted to tell him how sorry I was for leaving him that night. It was like I was mad walking about aimlessly because I never thought something like that could happen so suddenly.”

Esi, 28 years (Daughter)

4.2.3 Devastation

In addition to the confusion, shock and anxiety that most participants experienced, it was observed that some participants were also devastated by the sudden events of injury. The participants were overwhelmed because they were unprepared to handle the consequences of the injury and they indicated that the repercussions were unbearable. Although they reflected profoundly on the events, they had many unanswered questions. Regarding the injury, they reiterated that due to the sudden occurrence, they were unprepared. They wished they could have averted the situation. Memories of the wounds they had observed on the elderly injured persons and the seemingly resounding screams of the burned patients continued to frighten and distress them as it was the first time they had reportedly experienced such events. The devastation that
lingered on was such that the participants who were present during the injury wished they had been absent. In addition, some participants lost appetite and could not be themselves because of the state in which they saw the injured elderly persons:

“In fact it was not an easy time for me and my family and it was not like I had an option in this situation. I felt burdened with these turn of events though. It was really a big work for me because I was just unprepared at this time to handle these events with all the big wounds and the pain that made him scream. I mean if I had seen this coming I would have taken every step to prevent it but we are humans after all”

Kokui, 33 years (Daughter in law)

“I have never seen anything as terrible as this I mean the wounds and all that. It was not a good sight at all and I wish I were not even there when it occurred. It was really frightening and sad seeing him like that but I could not even go close. It was a day I felt very, very sad. With all the pain, he was screaming here and there and shouting too and as for the wounds I just could not stand it at all. I had never seen anything as frightening as the wounds I saw on that day and I just wished I were not there”

Michael, 48 years (Brother)

The feeling of devastation experienced by participants was also due to the separation of the elderly person from other members of the family following the injury. This was because the elderly persons who got injured were performing some important activities for participants before their injury. The activities included taking care of their children or running their businesses in their absence. In addition, the participants felt so closely tied to the older persons that their hospitalisation and absence from home made them feel devastated. They rationalised that they had no option but to accept the hospitalisation because the injuries to the older persons were severe as one participant expressed:

“I have a drinking spot in the village that my mother usually took care of when I came to Kumasi and she did it so well and kept the money safely as well. I really loved her but after getting burnt, I had no one reliable to take care of the spot and I missed her presence a lot not to talk of the children who she took care of during vacations. I really thought she would get well and come back but it is all in the hands of God”

Matilda, 31 years (Daughter)
Another participant expressed with despair:

“He was my father and I had stayed with him all this while. He was not the type who got sick and he was always strong but this burns made him stay in the hospital. Anytime I entered his room, it was empty without him”

Kwabena, 21 years (Son)

4.2.4 Helplessness and Hopelessness

After the injury had occurred, the participants felt helpless as they could not do anything to reverse what had happened. They lacked strength to intervene and had to call for assistance in order to rescue the elderly person from the injury. In situations where the elderly person was trapped in the fire, the participants stood helpless without knowing what to do. After the elderly person had been rescued from the fire, the participants who had basic first aid knowledge said they forgot what they had to do and felt completely lost. There was seemingly nothing they could do to reverse what had happened to the older persons and that made them feel helpless:

“In fact I did not think I would also one day encounter such an incident. It was just too much to bear just within a day. You see I even forgot about the fact that I am a nurse at that instance. It was scary and I stood there helpless because I could not even recollect my first aid tips not alone think about what to do. It was my husband who gathered courage and went through the smoke and fire to rescue him. Even after bringing him out of the fire, I did not know what to do or say”

Kokui, 33 years (Daughter in law)

“It felt like I was not myself because I was speechless upon seeing what had happened. It was unexpected and too sudden for me. I just could not do anything until I heard someone shouting for more water. I just could not figure out what to do and was just standing there. All I could hear myself saying was Jesus, Jesus, Jesus”

Yaa, 41 years (Spouse)

The participants’ inability to foresee the advent of the injury made them feel helpless. They re-echoed that they had no option and did not know what to do but to accept the situation. In addition, the participants felt the burned older persons might not be able to return to their previous states of health even if they got well:
“There are things that you just cannot do anything about. If it should happen it will happen and it is the will of God. I wished I could have seen it coming so that it was prevented but it did not happen that way because we are humans. Since the family left everything in our care, we had no option but to take full responsibility for what has happened. My mother was so shocked that she was just not able to even go to the hospital. So as the older child, I just had to take up that role in addition to my regular job. I was just imagining how soon he would get better but I was just concerned if he would have been okay at all”

Martha, 31 years (Neighbour)

Another participant who was distraught said:

“But there was no option and no one to handle it and that falls on me, the daughter in law. I was not prepared in anyway and everything was just too sudden and quick. But you see even if I were not ready, I still did it. It was not something I had planned or budgeted for at all but it happened and there was no way I could turn back the hands of time or reverse the situation. I just had to live with it like that. We came to the hospital in a rush without even locking our doors”

Mercy, 29 years (Daughter in law)

The participants’ feeling of helplessness and hopelessness were not only due to the burned elderly person but also to damaged property. As the fire blazed on and neighbours used water to prevent the spread of the fire, the participants reiterated that they wished they could have done more to bring the fire under control but there was nothing they could do and had to look on as properties were destroyed in addition to the injuries sustained by the elderly persons. In some instances, doors had to be forcibly broken to rescue the older person and other family members from the fire. The participants had wished that they could have done this without further damage to property:

“The neighbours had to break the door to rescue him from the smoke after we had quenched the fire small. But the fire was still on and we tried to put it off after the neighbours got him out. It was terrible scene and we were all working hard to put the fire off completely. It did not even occur to us to call fire service because it was too sudden to think”

Esi, 28 years (Daughter)

Furthermore, it was observed that participants’ feelings of helplessness and hopelessness were also because they did not know the course the injury would take after the elderly person had
been rescued from the source of injury. They only saw the wounds and were oblivious of the prognosis as indicated in the words of this participant:

“I saw the wounds very well and I wished I were not even there because it was terrible... [pauses for a while] I initially thought that these are just wounds that would have healed in no time but it was more than that. We got to the hospital and they were doing so many things and I just kept asking myself if it was all because of the wounds. It was not easy at all”

Michael, 48 years (Brother)

4.3 Hospitalisation and Associated Stressors

This theme describes the primary and secondary stressors faced by caregivers and it sought to achieve the third and fourth objectives for this study. The sub-themes identified were hospital environment, processes and policies and caregivers’ experiences.

4.3.1 Hospital Environment, Processes and Policies

This sub-theme describes caregivers’ involvement with the hospital environment and further describes the setting of the caregiving. Following the occurrence of the burn injury there was a need for hospitalisation of the burned elderly person. In this instance, the hospitalisation was urgent and unplanned. This need for urgent hospitalisation was related to the nature of the burn injury which did not permit care at home. This required some participants to accompany the patient to the hospital and in some circumstances, the participants met with the patient at the hospital (those who were informed on phone). The need for unplanned and urgent hospitalisation was also related to the extent and nature of wounds that participants witnessed that made them rush the burned patient to the hospital with the assistance of others:
“Well he did not marry after his wife died and had no children. It is not like there was someone around because all our siblings are out of the country. So I was the right person to be by his side whilst he was at Gee [KATH]. Actually, there was no one to do it better than myself, his senior brother. It happened so fast for me to even pack my things into the ambulance. I have not done this before but this time I had to do it because he is my only brother. The wounds were really bad and it was not something we could handle at home so straight the hospital. We had to rush and everything happened in a rush too”

Michael, 48 years (Brother)

“That was why he invited me to join this promotion activity so I can be by his side. Moreover, when the injury occurred, I was the only female around. So after the other men rescued him from the fire and sent him to the hospital, I had to remain and be by his side. I stayed there and joined him to Gee too. I think he was really burned because everyone who saw him said we should hurry up and go to the hospital. I just could not stand the wounds and the way he was screaming so we rushed to the hospital. I mean the way things happened, I could not prepare myself at all. There was no time to even pack things to the hospital because it happened outside the house. I did not see this coming and was just not ready for it at all”

Yaa, 41 years (Spouse)

Some elderly burned patients were initially seen at the nearest health facility for first aid and referred to KATH for specialist management as the initial point of call did not have the expertise to manage the extensive burn injury. However, the news of coming to KATH did not go well with these participants as they hoped the first point of call could manage the injury. They felt disappointed having to leave the first point of call as they noted that the patient only had wounds which could be managed easily without any knowledge of the on-going physiological perturbations. Thus, coming to KATH was a new experience and participants were worried about how things would go. Participants also reiterated that they had heard several stories about the hospital and that contributed to their experience of anxiety:

“I know that patients who are brought to Gee are usually seriously ill ones who are dying. So when we were asked to come to Gee, I realised my sister was not in good condition. She even asked the nurse whether she was been referred because she was going to die. But the nurse only said it was all to help her get better. I thought they would just cover the wounds and we would have gone back home but we were later informed that we had to come to Gee [KATH] because they cannot help us much”

Theresa, 38 years (Sister)
“But after some few hours there, the staff said his condition was beyond what they could handle so they called the ambulance to bring him to the bigger hospital here in Kumasi. It was my first time coming to Gee [KATH] and I did not know how it will be because I heard so many things about this place. In fact I did not want to come at all but I had to because of his state. I really thought the first hospital could have handled the situation”

Matilda, 31 years (Daughter)

Upon arrival at the Accident Emergency Unit of KATH, participants had to go through various processes before and after admitting the burned patient. They recounted that it was tiring process as they had so many places to go as well as things to purchase in order to complete the admission process. Some participants had to wait for several minutes before securing a bed for the burned patient. During the waiting period, they stayed with the patient in the car that had conveyed them to the hospital. However, after the patient had been sent to an appropriate triage code, participants were asked to wait outside even though they wanted to be present and witness whatever was happening:

“When we arrived at the emergency unit, we had so much to do before she was finally given a bed in the unit. I was moving here and there to give information, buy bed sheet, strip [glucose strips], water and other things after she was taken to the Red area. Even after giving her a bed I was asked to go out and that I will be called when I was needed. I really wanted to be by her side because she is my only sister and most of the hospitals I have been to, I was allowed to even sleep by my relative.”

Theresa, 38 years (Sister)

“When we got to Accident Emergency Unit they said there was no bed so we should wait for some time before they got us a bed. All these while, I was with him in the taxi and seeing all the wounds. But you see after getting him a bed I was told to wait outside.

Kwabena, 21 years (Son)

Furthermore, participants reported that the hospital environment was unfamiliar. The unfamiliarity with the hospital environment was apparently associated with participants’ first time experience in the hospital. Some participants wished that the burned patient be seen immediately by the medical team but this was achieved after a hospital card had been obtained. In addition it was observed that it was difficult for participants to identify the variations among health
professionals such as doctors and nurses. Thus all males were identified as doctors and females
were identified as nurses:

“When we got to Gee [K.A.T.H] with my father, it was afternoon so I thought things
would go faster but I had to here and there before he was sent to some place. He had to
wait a while before the doctor came and he also asked so many questions. I could not even
identify who the nurses were and who the doctors were. So I called all the men who came
to him doctors and called the females too nurses. There were so many places to go and
many things to do like pay money, buy drugs outside the hospital and buy food. I was so
tired after all these but I felt okay because my father was receiving medications”

Mercy, 29 years (Daughter)

“I have heard of the Kufour Emergency before but I have never been here. I entered and I
did not know what to do. A bed was brought for my husband to lie on and then I had to go
to a desk for a card. I just wanted them to start giving my husband some medications but
they were waiting for the card. He did not have health insurance so I had to pay for
everything to be done. I just could not find my way out of here”

Yaa, 41 years (Spouse)

The setup of the hospital was also described as complex and participants indicated
difficulty in navigating their way through the hospital to the extent of getting lost. Also, the units
in the hospital were noted to have some policies such as strict visiting time and unavailability of
stay-in facilities for caregivers as one participant noted:

“As for getting lost at the Kufour Emergency, it happened to me on several occasions
especially when I had to go to the area they sold the dressing materials. Sometimes I end
up in some offices before I get directed to the correct place. The place was really big with
small, small offices. I really got lost several times and I later got the place he was and I
was told visiting was over. Can you imagine that? They did not provide a place for us to
sleep and then when I turned up late because I got lost, I was not allowed to see my
husband”

Afua, 49 years (Fiancée)

The participants were worried about the lack of waiting area. In some places, a waiting
area was available but there were no seats thus caregivers had to stand or sit on the floor:

“And you know where we were sitting, some place at the Kufour Emergency. There are
no seats there and we had to sit on the cemented floor unless you have the strength to
stand for long hours. If you want to sleep, you place a cardboard on the floor and sleep on
it.”

Ishmael, 23 years (Son)
Following the hospitalisation of the elderly burned patient, there was a need for a caregiver. In this instance, the caregiving entry was sudden and unplanned. Despite the sudden entry into the caregiving role, some nuances were noted among those who had previously undertaken the caregiving role and those undertaking it for the first time. It was observed that the former category of caregivers were mentally prepared whilst both categories of caregivers were physically unprepared. Mental preparation involved making up one’s mind to adjust to the new role. It was observed that though their previous experience did not make caring for the elderly burned patient any easier, it gave them an idea of what a caregiver was expected to do. In some instances, they noted significant variation between their previous and current experiences. Some participants had to commence their caregiving role as soon as the injury occurred as they were at the scene of injury. Thus, they had to accompany the elderly burned patient to the health care facility even though they felt intense emotional response to the occurrence of the burn injury. Similarly for other participants who were not at the scene of injury, they were filled with mental images of how the care recipient looked till they saw the patient and commenced the care giving role within 24 hours of the injury occurrence:

“After she was given a bed at the hospital, I felt at ease because I knew she would get better. I even wanted to go home but was given some papers to go and buy medications. Though I was frightened initially, after she was admitted and the nurses covered the wounds, my sister felt okay and I was okay too. I could not go anywhere and had to remain in the hospital to take care of her too. I was not really ready for this but I made up my mind to do whatever it takes to see my sister survive so we could go home together. Yes, my auntie fell ill and because I was very close to her I remained by her. She was admitted to the hospital in our hometown because her blood pressure was high. For her I was not scared at all because it was only blood pressure problem. She was discharged home after some few days. I slept by her side throughout the period she was in the hospital but this was different and it was a sad one seeing my sister in this way”

Theresa, 38 years (Sister)
Another participant had this to share:

“As I sat in the car to the hospital, I was just imagining what my neighbour looked like. If he really looked like what I was told on the phone, then it was terrible. But I guess it was even more than they had described on the phone to me after I saw him. I had never taken care of anyone at the hospital and I was really unsure what would happen. I was just not ready for this at all but I had to do it anyway”

Martha, 31 years (Neighbour)

The caregiving role was described as a female’s work by all the male participants but there was no one available and as such, they had to take on the responsibility of providing care in the hospital. They felt it was a female’s work because women are usually involved in caring for others in the homes and as such they were best suited for this. In addition, none of the male caregivers had previously undertaken the caregiving role. Thus, they entered the role with an expectation that the care recipient would get better as soon as possible so that they could resume their usual life patterns. Some participants expressed:

“Hmmmnnnnn... [stammers briefly] I have never done this before because it is usually the women who do that so I felt like I was been a mother to my brother as the same time his junior brother. I had to get him all sorts of food, water, juice, buy medications and dressing materials which are usually done by the women. But like I said I did not have any option and I hoped he will get well soon so that I could also return to my usual way”

Michael, 48 years (Brother)

“Ah but it is the females who do this work and the men work to bring money to support them but like I said earlier on, our siblings are out of the country and I just had to do this because after all he is my brother. I just did not know what to expect and it was worse when we entered the Kufour Emergency and the doctors and nurses were asking so many questions. They were mentioning certain things I did not understand and then I realized that this was going to be a big work. My prayer was that my father got better as soon as possible so that we could leave this place but he died less than a week after we came here”

Kwabena, 21 years (Son)

4.3.2 Caregivers’ Experiences

This sub-theme describes what participants went through as a result of taking up the caregiving role in the hospital. These descriptions highlight the primary stressors they
encountered as well as how these stressors affected the caregivers (secondary stressors). The ensuing section reflects the primary stressors identified in the caregivers’ experiences.

The participants felt the need to render care to the burned elderly persons. This was because they had no option than to do so for, there was no one to care for the injured elderly person. In some instances, the participants felt they were the best persons to provide care and would not allow anyone to do so:

“Immediately the mast touched the pole, he was shocked by the current and all we could hear was a booooom sound and he fell flat on the floor with the tent and mast falling over him. He was rushed immediately to the Duayaw Nkwanta hospital for medical attention. But after some few hours there, the staff said his condition was beyond what they could handle so they called the ambulance to bring him to the bigger hospital here in Kumasi. I had no option than to join him here”

Afua, 49 years (Fiancée)

“It was not I really wanted to do this but I felt really sorry for leaving him that night so when the issue of who would remain in the hospital came up, I accepted it immediately. I did this so that when he woke up from the machine, I would have been the first person to see and talk to him so he could forgive me for leaving him alone that night”

Esi, 28 years (Daughter)

As the elderly burned patients were admitted to the various units in the hospital, caregivers were faced with the physical demands of in-patient stay. These demands served as primary stressors for caregivers as they were related to the direct demands of patient care. In-patient stay required caregivers to wake up early so as to arrive at the hospital at a specific time within the day. Consequently, caregivers who stayed far from the hospital needed to leave home early so as to arrive at the hospital on time. Participants noted that even when they arrived earlier than the stipulated time, they had to stay behind the gates till it was time for them to be opened before they could enter and see the care recipient. This pattern continued till the patient died. Thus, longer period of in-patient stay implied prolonged duration of visit:
Caregiving to Elderly Burned Patients

“This one is not like staying here for like a day or two. I actually stayed by his side for three months before he died. All this while, I had to wake up as early as 3am, bath and prepare to come here. I leave the house at 5am from Mampong to here. I stay till evening before I go back home”

Esi, 28 years (Daughter)

“I did not want to miss any visiting time and so I come here as early as 5:30am so that I could enter the ward as soon as the gates are opened. Other than that I will miss seeing my father till afternoon or unless I am called to make payment but sometimes I got here and the gates are locked and I had to wait till they are opened”

Matilda, 31 years (Daughter)

The participants mentioned that at the Emergency Unit, they provided more hands-on care such as maintaining oral hygiene, feeding and cleaning patients where there were no burns. However, they reported that upon transferring the patients to the Burns ICU, the hands-on care was taken over by the nurses; they were not offered the opportunity to provide it any longer. The participants indicated that they wished they had been allowed to provide care to their patients as they felt obliged to do so:

“When we came to Kufour Emergency [Accident Emergency Unit], I had to come early enough to clean the areas that were not bandaged like his face, brush his teeth and change the diaper before feeding him but after he was taken upstairs and was given one room, the nurses just did not allow me to do anything for him.......... not even feeding him. So I just sat and watched them and when the time was over, I packed my items and left the place. I just wished I was still the one brushing his teeth for him or feeding him but by the time I get there, the nurses would have already brushed his teeth and waiting to feed him”

Esi, 28 years (Daughter)

However, two male participants were happy when the nurses in the Burns ICU took over the care of their patients. They believed the nurses had been trained for these tasks and they could perform them better. They felt relieved when the nurses took over those aspects of care and were thankful to them. Also, they had more time to interact with their patients when they came late:

“I was very happy when I arrived the first day at the ICU and the nurses had brushed his teeth and were ready to feed him. It was like part of my job had been taken off my head. I just kept thanking the nurses I met there over and over again”

Kwabena, 21 years (Son)
In addition to the hands-on care which some participants provided initially, their activities were running errands to purchase medications, dressing materials and obtaining prescribed diets for their patients. They described these activities as tiring and stressful since they required physical exertion such as climbing a fleet of stairs and walking long distances. Occasionally, participants were unable to obtain prescribed items in one place and that required more walking. Sometimes, the money budgeted for buying items was not adequate and participants had to go home for more money before they could purchase the needed items. One participant recalled a situation where she was too exhausted to climb the stairs and used the elevator. She got stuck in the elevator due to power outage:

“It was really hectic and tiring. One person taking care of three people and I had to go and work in my unit as well because I was not on annual leave by then. So every morning, I would come and see all three of them, buy medications, dressing materials and get them food. For my father in law, he was intubated and he had a nasogastric tube so I had to go to B4 to collect milk for him. I was in the hospital most of the time and I slept in the hospital throughout the period. It was really tiring and there was one time I felt too tired to climb the stairs to B4 and used the lift. I am sure the lights went off and we got stuck in the lift for about 3 minutes before the lights came back on.”

Kokui, 33 years (Daughter in law)

As the caregivers were not allowed to stay with their patients, they needed to have a reliable means of communication; these were their mobile telephones. On some occasions their telephones went off so they had to walk around the entrance of the Emergency Unit and frequently ask staff if they were needed. There was no designated place for caregivers to charge their telephones. They therefore had to be within easy reach to respond promptly when needed. Thus, some participants had to stay within the hospital premises until evening:
“Even after giving her a bed I was asked to go out and that I will be called when I was needed. I really wanted to be by her side because she is my only sister and most of the hospitals I have been to. I was allowed to even sleep by my relative. But here, it was different and there were so many places to go: buy medications, bandages for dressing and pay for some items. Because I was not allowed to be with my sister, the nurse took my telephone number and told me to make sure I was always around but sometimes my phone went off and there was nowhere to charge it. So I used to walk around the entrance of the Kufour emergency”

**Theresa, 38 years (Sister)**

However, continuously staying on the hospital premises was difficult for participants as they needed to combine their usual work with the caregiving role. Some caregivers therefore came to the hospital earlier to ask for things that might be needed for the day. After purchasing them, they went to work and returned in the afternoon. However, as the patients transitioned to their final stages, some participants indicated that they wanted to be around their patients throughout the day. This was not possible due to the hospital policy on visiting hours. Some participants had these to say:

“It was like having two jobs but no pay. I had to be here and there and it was a really tiring time for me. I will wake up early and come and sort issues out here so that I can leave for work. It was difficult for me so it got to a point I just had to take my annual leave from work”

**Martha, 31 years (Neighbour)**

“It was even more difficult than running my own business. I was just not familiar with this place but still had to come. People are so busy running to save lives. I would leave the house at 5am and stay at the gate till 6:30am when the security man would open the door for us to enter. The Emergency entrance was another difficult place even though I had my father in here. After seeing him in the morning, I would sit at the usual place and wait to be called to go and buy medications or bandages for dressing but I realised it was not helping me because I had to go to work so I came there in the mornings and made the purchases before leaving for work.”

**Agatha, 35 years (Daughter)**

Some caregivers opted to sleep in the hospital at night to be able to see their patients at the least opportunity. However, this was difficult for them as the hospital lacked accommodation facilities for caregivers. These participants had to sleep on the floor or on chairs and adapt to sleeping outside which was a huge sacrifice for them. Although they were worried and feared
falling ill under such circumstances, they did not have any option and lived with the hope that the elderly burned patient would get better quickly and leave the hospital. On some occasions, they wondered how long the caregiving in the hospital would last so as to resume their normal way of life. Two participants expressed their sentiments:

“It was painful and difficult for me. I have not done this before but had to still do it. I slept in the hospital premises throughout his stay till he died. I usually slept at the main OPD because there are chairs there and the place was free at night. I really left everything behind at home and the shop to make sure he was okay at the hospital”

_Ishmael, 23 years (Son)_

“During the night it was easier to enter the unit because there were really few visitors. That was one trick I learned so I decided to stay here and sleep at night at the ground floor. At least I got to see my father most of the time in the night but I still had to wake up early so that I could bath and get ready for work after seeing my father. It was not comfortable at all but I had to do it for the sake of my father. I knew I might fall sick and I did fall sick too.”

_Matilda, 31 years (Daughter)_

Meeting the physical demands of in-patient stay also required caregivers to take rapid decisions. Some decisions were related to deciding whether to use the money available to buy dressing materials or medications. At the end of life phase, some caregivers were required to take decisions whether the patient should be placed on mechanical ventilation or not. However, for one patient who was intubated on the day of admission, the decision that had to be taken by the caregiver was related to withdrawing the patient from life support which the female caregiver noted that it was a really huge decision for her even though she was told her father had died:

“Sometimes there money available was just not enough so I had to choose whether to use it to buy medications or dressing materials or food. But you see, the two are important but I usually chose the dressing materials because I cannot stand seeing my husband with soaked bandages and the smell is really bad”

_Yaa, 41 years (Spouse)
“It was difficult to accept that I never had the chance to talk to my father or He could not open his mouth to also talk to me till he died. When I was asked if the machine should be put off, I felt like the end has come. My father never talked to me from the time he was brought to the hospital till he died. I told the doctors to hold on a while before removing the machine because I hoped there was something else that could be done to make him recover”

Esi, 28 years (Daughter)

In addition to meeting the physical demands of caregiving, the participants in this study were faced with several concerns that acted as primary stressors for the caregivers. The participants were concerned about their own health and well-being as they travelled on daily basis to the hospital and had to sacrifice their comfort to focus solely on the patient. Some participants had to go hungry in order to save money to purchase dressing materials and medications for the care recipient:

“I mean I was always traveling from Mampong to Gee [KATH] and it was like putting myself at risk of being involved in accident but I had no option at all because I just had to be here and be by my father’s side. I just prayed and hoped that everything will be okay on the road.”

Esi, 28 years (Daughter)

“I could not go to work frequently at this time because I had to remain by my father’s side. Sometimes, I had to go hungry without even realising it. Sometimes too, I had to go hungry so that I could save the money to buy medications because if the medications were not bought, he would just be lying there like that”

Kwabena, 21 years (Son)

Due to the demanding nature of caregiving required, some participants mentioned that they fell ill as they provided care and yet had to continue in the caregiving role as they perceived that their illness was ‘better’ than that of the older burned patient on admission, as this participant expressed:
“My skin color even went bad and I lost weight as well all with the hope that he would get better but he died after three months. Can you imagine how difficult and painful it is (pauses and wipes off tears for a while)… remains silent for a few seconds)There were no seats there and we had to sit on the cemented floor. If you want to sleep, you place a cardboard on the floor and sleep on it. I fell sick two times with malaria but I still remained in the hospital because at least I could still move about better than him”

Yaa, 41 years (Spouse)

As participants stayed in the hospital, they expressed concern about their families at home even though they were constantly in touch with them on telephone. Concern for the family was not limited to the participants who stayed on the hospital premises. The participants who lived at home but commuted daily to the hospital and back home mentioned that because they left home early, they had to delegate the care of their children to other members of the family or older siblings among their children. They expressed worries about what happened in their absence:

“I called my older daughter frequently to see what was happening at home but sometimes I got scared especially when I knew their father was not around. You know children and how they can behave at times. I just prayed and hoped that nothing bad happened to them but I was really worried what might happen to them”

Akosua, 40 years (Daughter)

Participants also expressed concerns about the elderly burned patients. They indicated that although the nurses took over the hands-on care of the patients, there were occasions when they were unable to provide care, especially at night. This was a source of worry for participants. Thus, they wished they were present with the patient. For some care needs of the patients such as pain relief, the caregivers were not qualified to provide them as these required a professional to do so. For such care needs, the caregivers constantly reminded the nurses and doctors on duty. In some instances, these needs were not met although the patients persistently complained; this was a source of worry for participants as shown by the quotes:
“I really wanted to sleep by my sister because she always complained that in the middle of the night when she needed water or she felt pain, she would call but no one came around. But I was told the rule did not permit me to sleep over. Though I felt hurt by not being able to assist my sister this way, I had to abide by the rules there. So anytime I came to visit her, I would tell the nurses that my sister was in pain in the night but there was no one around. I hoped they would solve it but I came the following day and it was the same story”

Theresa, 38 years (Sister)

“He sometimes wanted to drink tea or water but he would call and call but no one would come around. So he just had to keep quiet. Occasionally, some of them heard him or checked on him frequently so they knew what he needed”

Yaa, 41 years (Spouse)

It was also observed during visiting hours that some family members took pictures of the elderly burned patient unknown to the staff on duty. Participants expressed that they could not stop the person who took the pictures but wished the nurses had seen this incident and stopped the one as the pictures were circulated in the community:

“Some of the nurses too were not vigilant because the day his second wife visited, she took photos and it was all over the community. I could not stop her but I wished the nurses had seen it so they stopped her. I was very worried because the pictures were all over the community and I was not okay with it. I could not complain to the nurses too because I was afraid what the family members would say and I wished the nurses saw it themselves”

Martha, 33 years (Neighbour)

Aside the patient’s own symptoms which stressed participants, it was observed that the symptoms they observed among other patients in the Burn ICU and Accident- Emergency Unit added on to their experience of primary stress. The main symptom was the extent and nature of the burn wounds as well as their screams and cries resulting from burns associated pain:

“Anytime I entered the ICU and saw other patients in the unit, I felt like they were also suffering. I could hear some of them crying and some in bed throughout the time I was there. It was really sad. Though I really wanted to see my father, I sometimes felt sad going there. I saw some wounds when I had gone to see my father and I just could not stand it. I just rushed into my father’s room. How can a human being’s skin go off like that”

Agatha, 35 years (Daughter)
Caregiving to Elderly Burned Patients

“I gathered courage before going to the ICU because some of the things I saw there was really sad. Children and adults getting burned and it was really sad to see things like that and I heard some of them screaming too. It was a sad experience”

Michael, 48 years (Brother)

Further to the above, it was observed that some forms of therapeutic regimen or treatment modalities were sources of stress for the participants. For caregivers who provided care to elderly burned patients on mechanical ventilation, it was identified that the sight ventilator and the endotracheal tube made them feel the critical nature of the injury. In addition, participants noted that the sound produced by the monitoring gadgets and ventilators in the unit were worrying and that appeared to prevent them from staying long enough with the patient though they wanted to. In some instances, the monitoring gadgets were not related to the care of the elderly burned patient but were used in caring for other patients. However, the sounds from these gadgets were still disturbing to participants:

“The machine he was put on to help him breathe was big and I am sure you saw it because I remember you very well. It was big with so many writings I could not understand. There was a tube too in his mouth which looked scary and I was wondering what it was doing there. The machine was making some sounds that frightened me and I did not know what the sound meant. Sometimes the nurses came into the room when they heard the sound and did something but I did not understand and I stood there watching”

Yaa, 41 years (Spouse)

“He could not talk and he did not open his eyes. There was a machine on him through his mouth and it was making noise frequently. So even though I wanted to see my father frequently, the machines around him scared me. Some whitish things were also connected to his chest and I was wondering what all these things were doing on my father. I could come with hot water to clean him up but when I see the machines, I panic and leave soon afterwards. Even when his machine was not making any sound, the patient next to him also had another machine that was making noise too”

Kokui, 33 years (Daughter)

In addition to the sounds from the gadgets, it was identified that seeing the burned patient after wound dressing was disturbing as they had been packed with dressing materials such as cotton and gauze which made them look big and mobility was limited:
“But after the doctors and nurses covered the wound, I could go close to him. But he looked so big with all the bandages that had covered his entire body. He could not even move his leg not alone his hands. It was like crucifixion. Though I could get closer to him, I felt worried and sad inside and for a while, I did not know what to do”

Afia, 38 years (Sister)

Throughout the caregiving period in the hospital, all participants indicated that they needed information regarding the progress of the patient and to be told exactly what was happening at any particular moment. Participants specified that they actually asked questions but the responses were not satisfactory. In some instances, there were no verbal responses at all even though they presented questions to the health care providers. However, some caregivers interpreted the non-verbal responses (facial expressions) to mean the health care provider was busy with other patients. Furthermore, the speed with which care was rendered in the Emergency Unit and Burns ICU was identified to make participants feel lost and disturbed even though they were present with the patient:

“From the time of admission till he died, I had so many questions but I asked sometimes and no answers were given. I thought the staffs were busy with work or something. So I kept my questions to myself but I really wanted to know how things were going”

Afua, 49 years (Fiancée)

“Some of the nurses were really good but others I asked questions but they did not have answers to them. Everything was happening so quickly that it was really difficult to get someone to sit with and discuss all that was happening. I thought the nurses and doctors were really busy saving lives so I kept all my questions to myself”

Kwabena, 21 years (Son)

Participants noted that they needed avenues to express issues they were experiencing and needed to communicate with the health care professional to understand what was happening. Though they indicated this was absent in the Accident Emergency Unit, occasionally they had this need met after the patient had been transferred to the Burns ICU for continuity of care:
“Even when they did not answer me, I kept asking them whenever I came around. But when we moved upstairs, the doctors and nurses were really encouraging and it was helpful and they communicated well with me and other family members who came”

Matilda, 31 years (Daughter)

The feeling of being lost experienced by participants increased at the end of life period when the elderly burned patient required resuscitation. Participants who were present at the time of resuscitation were reportedly frightened and terrified at the turn of events and the gadgets that were being used. However, even when they were asked to wait outside, they still felt the need to remain there to watch what was happening but they were not allowed to do so. Some also lost their way as the exited the unit:

“The machine on him sounded and before i realised the nurses had pulled a big wheel and there was one nurse who was hitting his chest. I was so confused and did not know what was happening. Everyone looked busy and I could hear them shouting. They asked me to wait outside but I said I wanted to be present and see all that they were doing. So I stayed and watched what was happening until they informed me that my father had died”

Kwabena, 21 years (Son)

“I was confused and lost when one nurse shouted that he is dying. They all rushed into the room and started doing so many things. So many machines were moved to his room and I was wondering what was happening. I got out of the room because I was asked to wait outside but did not know whether to stay there or move out. Before I realized where I was at the place we usually bought the dressing bandages”

Kokui, 33 years (Daughter)

Participants also wished they had information regarding the prognosis of the patients. Although they believed the health care professionals knew the patients would die, they kept it from them and even when they perceived it, the health professionals could not affirm it. When they asked questions about the progress of the patients, the responses were not straight forward. Thus, they felt the health professionals had limitations in their work since issues relating to mortality were out of their control. Participants felt that with their years of experience and continuous clinical practice, health professionals should be able to forecast poor outcomes:
“Oooo for those we met at that time, they were really encouraging and spoke well to us and we did not encounter any issue with them but I wished they have offered more explanations to me and wished they had told me that my father was actually in a critical condition. Because I really did not understand what was happening till he finally died. The news of his death actually hit me badly because I least expected it and really hoped he would come alive so I could apologise for leaving him alone.”

Ishmael, 23 years (Son)

“The first time I saw his wounds in the ICU then I realised how terrible they were. He was just not breathing well too and he could hardly recognise anybody. He also did not want to eat at all and that was not how he was previously. I asked questions but the nurses told me anything is possible as God has the final say. I really felt they were hiding something from me because I really wanted to know whether he would have survived or not”

Martha, 31 years (Neighbour)

“Sometimes too communication has to be straight forward because I am sure the staff realised he was not going to make it but they kept writing all sorts of expensive medications for us to purchase. I know such things are difficult to tell but they have worked long in the hospital to know if someone would survive or not”

Yaa, 41 years (Spouse)

As the patient approached death, participants who identified the patient’s changing state indicated that they longed to have provided hands on care to the care recipient but were not allowed to do so. This is because they felt a longing to be physically present with the patient as they were unsure what might happen later. This was however not possible due to the strict visiting hour policy enforced by health professionals and security personnels. Thus, participants occasionally devised other strategies such as deceiving the security staff or pay a token to gain entry and see the patient’s condition for themselves. Even if they were not allowed to participate in care provision, merely seeing the patient made them feel satisfied:

“Oooo I forgot to tell you that sometimes, I would intentionally buy water and tell the security man that I had been called to bring them to my brother. In that way, I got inside with the water so that I could see what was happening to my brother.”

Afia, 38 years (Sister)
“Because I want to come to his place frequently, sometimes I even tell the security men that I have been called even when I have not been called so I can just go in and see what is happening. Even if I don’t feed him, I got to see that he was okay before leaving. On some occasions, I had to pay some small token to the security men before I was allowed to enter”

Akosua, 40 years (Daughter)

At the end of life period, concern for the patient increased as participants could not comprehend the needs of the patient due to difficult verbal communication. Thus, they had to use their judgment to assess what the patient needed. Participants experienced much difficulty as they did not know exactly what the patient needed. Consequently, it became guess work for them and they felt even more concerned about whether the health professionals understood the patient. In addition, participants indicated that the older burned patient’s inability to recognise them as they used to in the initial phases of the illness stressed them:

“At some point, I just did not know what he wanted because he was just rolling in bed. Sometimes I took a bottle of water but he refused and when I talked too, he could not answer me in the way he used to answer. Ah……. I knew I was losing my brother. He just could not talk well and I was wondering how the nurses understood what he really wanted. I spoke with him so many times but he could not even understand what I was saying and could not even identify me as his sister”

Afia, 38 years (Sister)

“In fact for the first three days we were there, she was able to talk well and eat as well. But thereafter, she could not talk well and even when she spoke, it was not clear and we could not understand it. She could not even recognise me, her sister oooooo neither could she recognise her children when they came around. How else can this be explained if not the fact that she was dying slowly. Moreover, I know that when a sick person begins to behave in this manner, their heart is troubled and they want to give up so I knew my sister was dying. I saw her wounds too on one of the dressing days and realised how terrible my sister’s condition was. After the bathing too, the entire body was bandaged except her face. I felt sad within me for seeing my sister in this situation. I asked one of the nurses around why my sister was behaving that way but he said they had inserted something into the neck and that made her talk that way but I felt my sister was dying slowly. It was really hurting that my sister could not recognise me and she could not recall my name too. Can you imagine how painful it will be for your sister to do this to you? I felt hopeless after seeing all these things and this continued till she finally died

Theresa, 38 years (Sister)
Furthermore, as the patients transitioned into their final stages, the patients’ refusal to eat stressed them. This was because the patients had never behaved in that manner. Although, caregivers were unaware of the transitions going on with the patient, they could perceive there was something wrong:

“I kept wondering what would happen next to him. I did not know whether he was dying slowly or not. He was not eating even when I brought his favourite food. My brother has never rejected my food and this time, he just could not eat my food. There I felt sad for what my brother was going through and I felt some way that there was something happening to him.”

Afia, 38 years (Sister)

“My dad always enjoyed the food I prepared for him but just this time, he refused [pauses and wipes tears from eyes]. I just knew something was wrong but I just did not know what was happening”

Esi, 28 years (Daughter)

In addition to the above transitions, it was observed that the burned elderly patients became restless as they got to the end of life. The restless state of the patients was a source of worry to participants as the patients had to be tied to the bed. The participants noted that the restless states of the patients could not be adequately managed by the health professionals as the patients kept moving the limbs in bed. Despite the patients’ restlessness, caregivers were asked to continue to purchase food and medications for them. The participants who rendered care to patients on mechanical ventilators were worried about the patients’ unresponsiveness to touch or communication. The caregivers noted that the patients could not respond to their touch and voice even though they wished to have verbally communicated with them:

“When I arrived all the machines on her had been removed and my sister was tossing her head side to side and she was restless and could not talk at all. I was wondering what the nurses and doctors were doing about it because anytime I complained to them, they said they were doing their best but I just could not see what they were doing. I was hopeless but I was asked to bring food, juice and some medications.”

Theresa, 38 years (Sister)
“My dad’s hands had been tied to the bed at the time I got there because he was just not stable in bed. His arms were tied because he wanted to pull the tube out. But it was later removed and I had hoped that he will get better soon and come home.”

Kwabena, 21 years (Son)

“He could not talk and when I talked he did not respond to anything I said. I wondered if he ever heard what I was telling him. Even when I touched him, he did not move his hand. It was like he died before the day the doctors told me he was dead.”

Yaa, 41 years (Spouse)

At the end of life period, participants who were present at the scene of resuscitation in the ward specified that there was no information. Even when they asked, they were told to exit the place:

“I really wanted to know what was happening but they were all busy working on my sister. I just sat outside waiting for them to finish so I could ask them questions but there was no one coming around.”

Theresa, 38 years (Sister)

After the death of the elderly burned patients, participants had to settle huge hospital bills before the death certificates were signed. After they had settled the bills, they were informed the doctors who were to sign the death certificates were not around. Thus, they had to wait for hours or go back to the hospital later for the certificates. Participants found this worrying as they felt they were not being treated well after the loss of their patients:

“Even after he died, I had to inform the family to come and pay the hospital bills and it was not small money and I was wondering why we had to pay such money even when he had health insurance. But you see he was dead and we were told that if the bill is not settled, no one would sign his certificate so we had no option than to pay. I really thought immediately after payment, the doctors would sign the paper but I waited and they never came. I came the following day and it was the same story. I got angry because it was not nice at all”

Michael, 48 years (Brother)

As a result of caregivers’ experiences with hospitalisation, it was observed that these primary stressors drifted to other domains of the caregivers’ life. In the ensuing section, caregivers’ experiences with secondary stressors are presented.
Participants who commuted to the hospital on daily basis indicated that transportation fares were a burden for them. Lack of money for transportation implied that the caregiver might miss a visit. Participants also indicated that the expensive medications they purchased drained the financial reserves of the family. Aside purchasing medications, participants also noted that the cost of dressing materials drained their finances as dressing change had to be undertaken three times or more within the week. It was found that if dressing materials were not purchased, wound care was not rendered and so participants had to ensure that the dressing materials were readily available. Thus, some participants mentioned that they had to starve in order to save enough money to purchase dressing materials. Participants were also concerned about the accommodation expenses at the Burns ICU. All these expenses drained the financial reserves of the caregiver and the family as whole. This was a source of worry for all participants:

“Look, coming from Mampong every morning was not a small thing. I mean in and out for the three weeks was huge money but I had to be here every day too. Sometimes when I am called from work, I needed to pick a taxi so I could get there on time. My father remained the same way from the first day till he died. He did not open his eyes or his mouth to even say a word. But we kept buying expensive drugs and because of that we still had debts to settle even three months after burying him”

Esi, 28 years (Daughter)

“I was hopeless but I was asked to bring food, juice and some medications. As for the medications, we purchased till she died and they were all expensive ones too. I wished the doctors had even told us plainly that she would not get better as that could have helped us cut down costs. Some of the medications cost as high as 35 million old Ghana cedis. The cheapest one we bought was even 20 million and this was on the day she died. Even that medication was not used and we had to return it and that helped us to offset some bills at least. The dressing material for dressing change was 200 cedis so you can calculate the total cost for her three week stay in the ward not forgetting the accommodation fees as well which was also 200 cedis everyday.”

Theresa, 38 years (Sister)

At the end of life, the desire and hope for patients’ survival made participants purchase various medications for use for their patients. However, these medications were either partly used
or were not used at all. Some participants reportedly became bankrupt to the extent that some doctors had to go to the pharmacy as surety for the pharmacy to provide the medications:

“I really thought things would improve as he started taking those expensive medications so that we could go back home but it did not get any easy for us. As the days went by he was just getting bad and there was a time he could not even recognise me. Even when I spoke, he could not recognise and it was difficult to even understand him. I just did not know what he wanted and it was a hard time for me as his sister. Sometimes, I just did not know what to say to relatives at home. I kept wondering what will happen next to him. But the doctors were always telling us to buy medications for him and they were expensive too”

Afia, 38 years (Sister)

“The medications I bought on the day he died were so expensive but you see, the nurses only used one and that was all; he died ooooooo. But the medication had been opened and it could not be returned. So you see, he died and the medications became useless but it cost plenty money too”

Yaa, 41 years (Spouse)

Participants reiterated that as a result of caregiving and constant demand for their presence in the hospital, they had to put several things in their lives on hold so as to meet the requirements of caregiving in the hospital. Lifestyle changes were also noted to occur in the lives of participants as they could not participate in their usual social activities. This required participants to undergo a process of adjustment to the new demands such that significant components of their lives such as eating and sleeping patterns changed. For participants who stayed in the hospital with their patients, it was found that other activities of daily living such as bathing changed significantly. Also, due to the demands of caregiving, participants usually slept late but had to wake up early in order to be at the hospital premises on time. The participants who stayed in the hospital at night also noted that they had to wake up early and prepare for the activities ahead:

“My entire life really changed within that time and sometimes I even forgot about certain important things. There was a time I was almost knocked down by a car because I could not hear the honking of the car. I just could not think straight at times. We expected that he would survive so that we could send him back to his relatives but in the end he died. After all these struggles here and there, he died in the end leaving us with huge financial burden.”

Martha, 31 years (Neighbour)
“I could not watch my favourite football matches any longer because I was always there just to see how my brother was faring. It was not an easy one for me the first three days we came here but gradually, I got used to the whole thing”

Michael, 48 years (Brother)

“I usually got home late but still had to wake up early so I could come here on time. It was tiring for me because I just could not do anything when I got home. Even sleeping became difficult because I was wondering what was happening to him in the hospital so I decided to stay in the hospital at night. After sleeping on the floor, I bathed outside too so I had to wake up early to avoid anyone seeing me whilst I was bathing. Even when going to the toilet, I had to pay but in my house, this I can go there anytime I felt like it”

Yaa, 41 years (Spouse)

For the family caregivers who stayed in the hospital at night, they indicated that even to access the lavatory, there was a need to pay a fee. One male participant recalled a day he experienced loose stools and that required him to visit the lavatory more than ten times in the day. He recounted the cost he had to pay and noted that it reduced the amount of money he had reserved to pay for dressing materials. For some female participants, they had to go to the extent of borrowing from other family caregivers around:

“I do not know what I ate that day but I was just running and each time I got to the toilet, I had to pay. By the time I realised, I had even used some part of the money for dressing materials. I just pleaded with the nurses to manage the materials I got for my fathers”

Ishmael, 23 years (Son)

“Sometimes things got hard that I borrowed money from other people I met whilst at the hospital and I paid them whenever I got money from other family members”

Akosua, 41 years (Daughter)

Due to the demands of caregiving, participants had some challenges in their work. For one female participant who was a nurse in a district hospital, there was the need for repeated requests for permission at the work place. Meanwhile, at the end of life there was a need for her constant presence at the hospital. Thus, she had to take her annual leave as she felt too tired to work productively after seeing the patient:
"I kept asking permission so I could see how he was doing at the hospital. But the permission became too much and the nurses kept calling me to the hospital. I just took my annual leave so that I could make sure I was around all the time. It was difficult juggling these two things at the same time and tiring too."

Martha, 31 years (Neighbour)

For the traders who also functioned as family caregivers, they left their wares in the care of a colleague but indicated that they were unable to render proper accounts to them afterwards. Thus, they preferred locking up their goods and personally overseeing it whenever they had the opportunity to. This required packing the items to and fro which required physical strength as well as losing customers to other traders in the area. Some female caregivers who traded in vegetables indicated that their goods got spoilt and that resulted in another financial loss. Some of the traders even slept behind their wares and one participant recounted an incident that she lost her purse whilst asleep in the market:

"I came to the hospital before going to the market and sometimes I leave the market to attend to my husband at the hospital. I usually left my products with a friend but sometimes she was too busy with her items that she was not able to account for my items she sold. Sometimes I slept off whilst in the market and even lost my money bag one day."

Yaa, 41 years (Spouse)

"Sometimes I had to lock the fruits and vegetables so I could attend to him but I get back tired and not able to trade again so I just go home. The following morning, some of the items would have gone bad and I lost money."

Akosua, 40 years (Daughter)

4.4 Effects of Caregiving

This theme refers to the outcomes of stressors being experienced by the caregiver. The effects noted in this study have been classified into positive and negative effects.

4.4.1 Positive Effects

Participants indicated that they met new people and made new friends who gave them words of encouragement during the caregiving process. Some participants indicated that they are
still in contact with the friends they made and communicate occasionally. Through meeting new people, the caregivers indicated that they also acquired new information they did not know about the hospital and life in general:

“Some of the people I met there were really good people and they were very helpful. Though I lost my fiancé, I got some friends too. Well, they cannot replace my fiancé but at least, it was good to have them around. Last Christmas, one of them even called to find out how I was doing and I was really happy to hear from her. You see the suffering we went through, I think we are the best people to talk about these things amongst ourselves because it was not easy for any of us. We talked and talked till we fell asleep in the hospital. I really learnt about things I did not know about the hospital and some of the people I met there were very experienced. As soon as I shared my problems with them, they gave me suggestions. ”

Afua, 35 years (Fiancée)

Participants indicated that they felt a sense of maturity as they had come face to face with death issues and survived. In addition they were able to take some decisions they considered as bold ones such as withdrawing the patient from the ventilatory support system. Also, they considered the news of the death as a huge one that they had to endure when they were told especially as it was their first time experience:

“I have never seen anything like that before... [long pause]I just saw my brother die. It was like I saw death. After this, I felt like I had understood life better and could handle issues with better understanding. In fact I made it through that moment when the nurses informed me that my brother was dead and I had to agree for them to remove the machine that was helping him breathe. Initially when they told me, I felt like he was not dead because his chest was still moving until the nurses paused the machine and I realised he was really dead. It was my first time facing such an issue of death and having to take him off the machine. I did not know where I got the strength from to remain in the room for them to take off the machine and they covered him. I stood there all these while looking on. But ever since then, I think nothing really disturbs me in this life.”

Michael, 48 years (Brother)

Participants also stated that it was a great opportunity to demonstrate their love to someone they loved dearly. Thus, they felt experienced and understood in depth what it meant to love. Participants mentioned feeling personally fulfilled with what they went through as they saw it as a test of their commitment to the patient and a demonstration of affection. They felt elated that they were able to remain by the patients’ side until death without giving up:
“There were no seats there and we had to sit on the cemented floor. If I wanted to sleep, I placed a cardboard on the floor and sleep on it. I fell sick two times before he finally died. After all these troubles, then he died at the end. But at least, though it is a painful one, I feel happy within myself that I was by his side and that proved the love I had for him. I felt like I have really grown up.”

**Afua, 35 years (Fiancée)**

In addition, participants who were Christians felt they had experienced spiritual growth as they understood Christianity better. One participant compared her situation with that of Job in the Bible. They felt that the problem had improved their walk with God as they were able to journey through the caregiving process but lost the patient at the end:

“I prayed, yes I prayed that he would make it but he died. God knows best so all thanks to him. I think I understand things better now and this has drawn me closer to God because I became a prayerful person with some periods of fasting. It is like the story of Job in the Bible”

**Martha, 31 years (Neighbour)**

### 4.4.2 Negative Effects

Despite the positive effects described above, some negative outcomes were also noted. Participants observed that they were exhausted at the end of the caregiving process. This exhaustion had both physical and emotional dimensions. Physical exhaustion was related to the physical demands of providing care in the hospital. Emotional exhaustion was related to the patient symptoms, nature of the injury and other experiences that the caregiver underwent which caused periodic sleeplessness. In addition, coming face to face with death was a source of emotional exhaustion for participants who witnessed it:
“Well for me, I really wished the man would have survived so that we send him back to his relatives. This has been an opportunity to know this hospital because if not for this incident, Gee [KATH] was not a place I will even want to come to. I met some really wonderful people as well. However I felt really burdened by the turn of events and I have still not overcome it. It was really a tiring time for me and fell ill once with malaria during the process. I saw his wounds and the way he was behaving before he died and they were very disturbing to me. I still remember some these things.”

Martha, 31 years (Neighbour)

“After his death hmmmmm, because of the way I saw his wounds and the pain he experienced, I am unable to sleep at night. Sometimes I sleep and wake up suddenly but cannot sleep again because I picture my husband and all that he went through with the wounds all over his body. I also feel sad and pain within myself that such an incident happened to him”

Yaa, 41 years (Spouse)

Participants indicated that they experienced flashbacks occasionally with images of the patient they cared for as well as other patients:

“Though I had lost her, I knew her suffering was over. In fact, I had to rest in the house for over three weeks before I could resume working in my shop. On some nights, I had to even stay in the hospital and had to sleep outside the hospital gate on the floor so that I could wake up early to visit my sister. I saw other patients too with burns and it was scary. Occasionally, I remember my sister and shed some tears and hope she is resting in the bosom of Our Lord. I remember what my sister went through and I ask so many questions that I don’t even have the answers to. And yes I saw some patients too with very terrible wounds and I could not forget about these things. Sometimes when I am alone, I remember them and I cry”

Theresa, 38 years (Sister)

4.5 Coping Strategies

This theme refers to resources that modified the relationship between stressors and outcomes of the caregiving process.

4.5.1 Hope, Faith and Prayer

From the onset of the injury, participants hoped that the burned patients would get well soon and be discharged as they perceived that the burn injury was limited to the wounds that they
saw. This form of hope appeared to be the force that drove participants to continue purchasing items needed for the patient care. They felt that no matter the extent of the injury, the patient would still survive and get discharged home as soon as possible for them to also resume their usual routines. Thus they were surprised when the patient spent longer periods on admission. Participants who rendered care to patients placed on mechanical ventilation had hoped that they would recover from that phase successfully. Furthermore, participants hoped that for all the struggles they went through, they would have been repaid with an early discharge of the patient:

“Hmmm, from day one to day three after he had been admitted, I felt hope because considering the extent and the fact that he had been intubated, I thought he was going to die soon but after three days he had very stable vitals. Because of that, any medication the doctors wrote, I just got it instantly for them to use because I felt he would make it. On the sixth day, his HB was low the temperature was swinging to the extent that he recorded 40.6 degrees Celsius. Moreover the ventilator settings were changed and he was moved to a mode that would deliver 100 per cent oxygen to him and I was wondering why he was keeping long in the ICU but I realised that if it were not necessary, the doctors would have allowed us to go home”

Kokui, 33 years (Daughter in law)

“It was a tiring activity but she was my sister so I had to endure with the hope that she would get better and come back home. My sister occasionally requested for her favourite food (fufu with green leafy soup) and I had to prepare it and bring it to her and feed her as well. I encouraged her a lot whilst she could talk well. In the mornings, I came around to visit her and talk with her. I used to bring her food for the nurses to feed her and the nurses were good. I had to buy dressing materials too for the nurses to bath her and it was on one of the dressing days that I saw how the wounds were really looking like but I had hope that they were just wounds that would heal in no time at all. I was really hoping that after all the struggles, my sister would have gotten better soon but it did not happen like that”

Theresa, 38 years (Sister)

The inner urge to work towards achieving recovery of the older burned patient was identified as a resource. The presence of hope made participants believe in a positive outcome. Thus, they were prepared to go the extra mile so as to achieve recovery. As the Emergency Unit has been associated with dealing with complicated health care issues, participants held the view that so long as they had arrived there, there were better chances of the patient surviving. Thus, in the face of increased emotions and stress regarding the caregiving process, hope took the
Caregiving to Elderly Burned Patients
caregivers through the period. At the end of life period when participants noticed the transitions
of the older burned patient, they were hopeful that the situation would improve:

“I had to be running up and down to buy drugs, pay for blood, buy dressing materials
with the hope that he would get better. Even when his diet changed, I had to climb that
high building three times a day to collect the milk for him”

Yaa, 41 years (Spouse)

“As for Gee [K.A.T.H], I know it is seriously sick patients who come here and because it
is such a big place, I knew they would be able to do something to help my father. So
anytime they wrote medications, I made sure it was bought. We borrowed money just to
make sure that he received his medications continuously”

Ishmael, 23 years (Son)

“As soon as I am called to buy any medications, I just left immediately if only I have the
money available. Even the day they were pressing his chest, some medications were
written and I purchased them but they only used some and I was informed my fiancé had
died”

Afua, 49 years (Fiancée)

Furthermore, it was observed that participants had hope in the expensive medications they
purchased even though these drained their financial reserves. They believed that as the
medications were costly, they had to be potent enough to aid rapid recovery of the burned patient.
Thus, they continued to purchase these medications until the patient was pronounced dead.
Participants who perceived the patient was dying described this as “false hope” as they knew the
outcome but wanted to push to the end as anything could happen:

“I really thought things would improve as he started taking those expensive medications
so that we could go back home but it did not get any easy for us. As the days went by he
was just getting bad and there was a time he could not even recognise me. Even when I
spoke, he could not recognise and it was difficult to even understand him. Even then I was
still buying those expensive medications because I really felt that anything expensive is of
good quality”

Matilda, 31 years (Daughter)

“I am sure the staff realised he was not going to make it but they kept writing all sorts of
expensive medications for us to purchase and I was buying them because I really had hope
and the nurses were saying the medications were good too so I kept buying them”

Martha, 31 years (Neighbour)
Throughout the caregiving journey, participants noted that strength from God allowed them to undergo the caregiving journey. Participants indicated that it would have been difficult if they had not relied on God for strength and guidance. They described this sort of strength as being able to go on despite the hardships and reality they were faced with. Thus throughout the caregiving journey they maintained their faith in God but wished that the recovery would be faster:

“There are things that you just cannot do anything about. If it should happen it will happen and it is the will of God. I think God gave me strength to go through this whole thing. I just see God as my source of strength through this period because all that happened was so shocking and frightening: losing a neighbour and your house at the same time and still coming to take care of him in the hospital really requires supernatural strength”

Martha, 31 years (Neighbour)

“In fact it was not easy for me and the family as well. I hoped he will get better with time but he died. God really supported us through this time because can you imagine losing a brother and spending all these money as well. If not for God, it would have been just not possible. The entire family also helped take care of some of the financial issues too”

Afia, 38 years (Sister)

The belief and faith expressed by participants were also associated with the performance of various religious practices. These religious practices included praying and fasting with the hope for an expedited recovery. It was noted that anytime they visited the patient, they prayed with them. Also, participants were always in the mood for silent prayers and singing songs with the patient:

“As early as 2am, I would wake up and pray continuously and sometimes fasted all with the hope that my husband would get better. Even after I left his room, I still continued praying and would sing some songs by his side because he really liked music”

Yaa, 41 years (Spouse)
“It was not like I did not believe in prayers but we all did pray and in that situation, the family members had to pray on our behalf whilst I took care of him. God is everywhere so He would definitely answer us. Coming to this hospital was filled with prayers and fasting periods because of our faith in God”

Michael, 48 years (Brother)

4.5.2 Adjusting to the Situation

In addition to the hope and faith practices, it was observed that participants adjusted to the entire hospitalisation situation which was noted as a coping strategy. Participants reiterated that they had no option and even though they felt helpless, they got used to the change in their life patterns. It was noted that this process of adjustment was an on-going process for participants. Adjusting to the situation was noted to be preceded by acceptance of the circumstances. Thus, participants accepted that fact that the burned elderly person required the support of a caregiver prior to adjusting to the situation. Even though coming to KATH was a first time experience for participants, they were able to learn and navigate their way through:

“I never thought this would happen but it did so you just accept it. My father in law was intubated as soon as we got to the hospital. Providing care to them in the hospital was another job like I stated earlier on. It was difficult I must say but I just had to adapt. When the blisters on my husband’s wound and that of my father in law were broken, I realised the extent of the injury was terrible and huge. It was my own family I was taking care of at the hospital. The family was also supportive just that no one volunteered to come and stay by them in the hospital. I just had to adjust to the whole situation”

Kokui, 33 years (Daughter in law)

Another participant expressed:

“It had happened and there was nothing I could do because there had to be someone by her. I just had to do it. I had a lot of things to learn so I just prepared myself to move here and there. I just took it like that and it was tiring but I got used to it and lived with it because whether I liked it or, it had happened already”

Theresa, 38 years (Sister)

After the death of the care recipient, participants also adjusted to the situation by coming to terms with the loss and accepting the situation through weeping and seeing the mortal remains of the patient which confirmed that the end had come:
“It was difficult accepting the fact that he is dead and gone but I had to accept it. I stood by his body crying till the nurses carried his body away. It was a difficult thing for me because I never really saw this coming. I just cried that day till I realised that he was no more with me because he had died”

Afua, 49 years (Fiancée)

4.5.3 Encouragement from nurses

Participants reiterated that they occasionally received words of encouragement from nurses. This form of encouragement was based on keeping the hope of the caregiver alive as nurses were unsure of the outcomes. Thus, participants were encouraged to continue purchasing medications as well as keep visiting the patient. In addition participants were occasionally asked questions about how they felt and that provided an avenue of release for them. However, this was not always available even though participants wished for continuous interactions with the nurses:

“She was good because she encouraged me a lot. Even you were there too……. I remember you very well because you were always asking questions and asking me to tell you if there was anything bothering me. The nurses were okay most of the time because they allowed me to talk about what was bothering me. I think what they told me made me to really continue buying those medications, I mean the expensive ones”

Matilda, 31 years (Daughter)

“As for the doctors and the nurses, they were really encouraging and it was helpful and they communicated well with us but for some questions, they appeared not to have answers to. I understand that because life is in the hands of the Almighty God, it is not easy to say whether someone will die or not”

Esi, 28 years (Daughter)

When participants were shocked and sad due to the occurrence of the injury, nurses encouraged them to be strong in order to support the elderly burned patients:

“I felt sad inside and for a while, I did not know what to do. He is my older brother and in fact I do not know how I behaved but I woke up in a long chair after I had seen him. It was shocking to me. What the nurses told me was that later on they beg me; I should hold myself together so as to be able to support my brother and that really encouraged me a lot”

Michael, 48 years (Brother)

“Some of the nurses there were really encouraging and they spoke nicely to me. My brother even mentioned one particular nurse who was always by his side but I wonder
why not all of them could behave that way. Just hearing some of the encouraging words were helpful even though I knew my brother was ill but it really helped me”

Afia, 38 years (Sister)

4.6 Support

In addition to the resources described above, it was evident that various forms of support were available for caregivers throughout their journey and this served as a form of resource.

4.6.1 Support from One’s Family

Participants obtained support from their families in meeting the needs of the burned elderly patient. This support basically included financial support and frequent calls to follow up on the state of the patient as well as the caregiver. This form of support was noted to exist from the time of admission till death and was constantly available for participants:

“God really supported us through this time because can you imagine losing a brother and spending all these money as well. If not for God, it would have been just not possible. The entire family also helped take care of some of the financial issues too and they always called to check up how I was faring and the old man too”

Kokui, 33 years (Daughter in law)

“I think the urge to see them get better really drove me on. It really gave me some strength to move on. Also, I knew he was not going really going to make it though I had hope along the way. My family was also supportive in some ways like raising funds for the medical bill and they were always calling to find out what was happening”

Kwabena, 21 years (Son)

Occasionally, participants who stayed in the hospital premises were visited by other family members and this opportunity was utilised to visit the burned patient:

“Because I was always in the hospital, some of the family members came around on weekends to visit us. Anytime they came, we went to see him together and we talked and talked about so many issues”

Michael, 48 years (Brother)
Another form of familial support was noted to exist in taking charge of participants’ activities in their absence at home. Thus some family members were involved in taking care of participants children as well as operating their businesses in their absence:

“In my absence, there were other family members who were taking care of my child. In the mornings when I left home, they bathed the child and took them to school and it was really helping me a lot”

Afia, 38 years (Sister)

Family members were also identified to support caregivers with religious practices such as prayers and fasting:

“We all prayed and fasted, I mean the family did that too because God is everywhere and could hear us. So I did mine here and they did theirs too at home. Some of them were going to prayer camps for prayers too because we really wanted him to survive and live so that we could return him to his relatives”

Martha, 31 years (Neighbour)

“I wished this had not even occurred at all but it did happen and there was nothing that prayer could not solve. I called my sister and she really prayed with me most of the time. She even fasted but I could not do that so I prayed a lot”

Afua, 49 years (Fiancée)

In addition, participants received various forms of encouraging words from family members even though the caregiving process was tough:

“Sometimes when I spoke with the people at home and they tell me everything will be fine, I felt like they could really see what was happening here and I was okay. If not I wondered how I could have gone through this hard time”

Kwabena, 21 years (Son)

4.6.2 Support from Neighbours

Aside the family, it was identified that participants obtained support from their neighbours. This form of support was identified to be at the point of injury were neighbours were
involved in extinguishing the fire, rescuing the older person from the source of the burn injury
and assisting with conveying the patient to the hospital:

“I lived with him when these frequent power fluctuations commenced. But this night I had
left to visit my fiancé soon before the lights went off. When the lights went off, he did not
switch off his gadgets and left them on. In the middle of the night when the lights came
back on whilst he was sleeping when the room caught fire. As to what exactly set the room
on fire, I have no idea. He could not talk or open his eyes by the time he was saved by the
neighbours”

Esi, 28 years (Daughter)

Another participant shared this experience:

“So they opened the top part of the cylinder to expel some of the gas out. Immediately,
they fixed the regulator and lighted a match stick there in the kitchen. The whole kitchen
was on fire which extended to other rooms. The driver escaped through the window but
the old man could not and was trapped in the fire till other neighbours came to his rescue
and took him to the hospital.”

Martha, 31 years (Neighbour)

In addition, some neighbours visited the patient and the caregiver at the hospital. Also,
they provided some financial support to help participants offset the cost of hospitalisation:

“My neighbours were very helpful too because anytime they visited us in the hospital, the
even gave me some money too. I remember the first time we came to the hospital with my
father and the money I had was not enough, they added some to it and I was really happy
with what they did”

Ishmael, 23 years (Son)

One participant reiterated that her neighbour plied the hospital’s route to his work place
and as such her means of transportation was always assured as she got the opportunity to join him
every morning in his car:

“The man who was staying in my area used to pass through Gee [KATH] to the Soldier
line so I joined him and it really helped me save some money and got to the hospital on
time. I just had to wake up early and join him”

Theresa, 38 years (Sister)
4.6.3 **Support from Affiliated Religious Groups**

Members of some religious groups were also noted to be supportive as they frequently called to check on the patient and the caregiver and also offered words of encouragement. Furthermore, some members visited participants at the hospital to offer various words of encouragement. For a participant who cared for a neighbour at the hospital, it was observed that the church helped to raise funds to help the family offset the cost of hospitalisation:

“My family members were mostly also looking for money to finance the care and that really helped me feel quite relaxed whilst I was there. The church also supported us with prayers and regular visitation to my mom as well and they called me often to find out how things were going in the hospital. I was really happy when some of the presbyters from my church visited me at the hospital. The church actually took offering for us on Sunday and it really helped us”

**Martha, 31 years (Neighbour)**

In addition, members of some churches and mosques also supported the participants in prayers so as that the injured person would have an expedited recovery:

“Our families were also supportive in some ways like raising funds and the nurses at the hospital were also helpful. But you see they are not in your shoes though they show sympathy so they cannot feel what you are feeling. At least their sympathy helped. Our church members also called frequently and supported us in prayers because we all prayed for a quick recovery but God has His own ways”

**Kokui, 33 years (Daughter in law)**

4.6.4 **Support from workplace colleagues**

Further to the sources of support described earlier, it was observed that participants also obtained various forms of assistance from colleagues at the workplace. This form of support involved colleagues taking over some of participants’ tasks at the workplace so that they could attend to the needs of the elderly burned patient at the hospital. This meant that these participants could report to work late or close from work earlier than the usual time or taking a prolonged break to visit the hospital:
“In fact it was not an easy time for me and my family and it was not like I had an option in this situation. I felt burdened with these turn of events though. It was really a big work for me because I was just unprepared at this time to handle these events. I had to wake up very early in the morning and come to the hospital till evening. But my colleagues at work really understood such that they covered up for me and did some of my work so I was able to get to work late and even close early.”

Kokui, 33 years (Daughter in law)

“My colleagues were very helpful. They were really doing some of my work because I got to work so tired such that I hardly did anything but they covered up for me and I was really grateful for what they did”

Martha, 31 years (Neighbour)

For participants who worked as traders, they were able to leave their wares in the care of their colleagues so they could visit the hospital. However these participants noted that this form of support did not last as their colleagues could not render proper accounts of items sold:

“My friend in the market was taking care of my items in my absence but I realised that she was busy with hers too and she was not able to really sell mine. I don’t blame her because we all had to eat”

Theresa, 38 years (Sister)

“I was not happy with it at all but it was my sister so I just had to do it like that. Coming here was like closing my shop because I could not get anyone to open it and sell the items there until my friend volunteered to do that for me”

Afia, 38 years (Sister)

It was noted that some colleagues at the work place were familiar with some personnel at KATH and referred the participants to them for assistance. Participants who obtained this form of support reiterated that it helped them to go through the processes involved at the various units of the hospital. Also, the participants contacted these personnel anytime they encountered difficulties with care in the hospital. As these personnel had authorisation into any part of the hospital at any time, they visited the burned patients occasionally and updated the caregivers on the patients’ progress. It was observed that some of these personnel (who were nurses themselves but were working in other units in the hospital) had to be with the night nurses on some occasions as the nurses slept on duty and were unable to respond to the needs of the patients:
“I really wanted to know his condition but the staffs were too busy to respond to my questions and there were so many machines in that room that were making all sorts of noise that startled and frightened me. I had to go and sit outside for a while until I was called to buy some medications. Luckily my friend at work called his friend too at the Emergency Unit who assisted me though later in the day. Thereafter, every morning I would come with porridge and wait till visiting time is over and then go and wait outside. I was called occasionally to buy dressing materials and medications.

Martha, 31 years (Neighbour)

“Even urine, I had to empty and report the values to the nurses on duty. So usually in the evenings, I had to let some male nurses friends of mine come and stay with the nurses on duty so that they could keep an eye on my father in law especially because he was in a critical condition. The nurses would tell me to buy coconut juice but the following day I come and meet the juice sitting there. Though the nurses were encouraging, the burns care was not good because for a burns ICU that cannot handle a blocked central venous catheter is not an ICU at all and I am sure he was in pain as well. Your nurses there need a lot of training”

Kokui, 33 years, (Daughter in law)

4.6.5 Support from other Caregivers

Peer support from other family caregivers was identified to exist as a form of support especially for participants who stayed on the hospital premises. Participants noted that the existence of this support allowed them an opportunity to discuss issues with other caregivers to obtain advice as well as encouragement:

“Sometimes I slept off till it was time to see him in the afternoon. I got some new friends whose relatives too were on admission so we talked a lot and occasionally they gave me some money to support him. We understood ourselves and they spoke well with me”

Mercy, 29 years (Daughter)

Occasionally, some participants and other caregivers teamed up to pray as well as fast together:

“We used to wake up as early as 3am and then prayed for our sick relatives to get well soon so we left the hospital because it was not comfortable there at all. On some days too we fasted together and prayed as a group”

Agatha, 35 years (Daughter)
“It was like a family here because we prayed together and on Sunday mornings, we had church service at the main OPD. It was really helpful to me because I got the opportunity to pray.”

Afua, 49 years (Fiancée)

Some participants also reiterated that they were able to obtain loans from other caregivers to purchase medications or dressing materials:

“Sometimes I went hungry because I needed to make sure my brother got all the medications that were written by doctors. Because if you don’t buy it, he will just be lying there and nothing will be done for him. Sometimes I slept off till it was time to see him in the afternoon. I got some new friends whose relatives too were on admission so we talked a lot and occasionally they gave me some money to support my brother.”

Michael, 48 years (Brother)

4.7 Expected and Real Outcome of Injury

This is an additional theme that was identified from the analysis but not a part of the constructs of the Stress Process Model.

4.7.1 Recovery, Death, and Loss

At the beginning of the caregiving journey, participants were expectant of achieving recovery within the shortest possible time. This was because participants viewed the injury to be associated with wounds only. Thus they expected that as the wounds healed, the burned elderly person would get better:

“In fact it was not easy for me and the family as well. I really thought it was just the wounds and I hoped he would get better soon so we all returned to our own lives. But after sometime, the wounds on his face were healing well but he was not getting better. Even some of the wounds on his body were healing well but he was not getting better”

Yaa, 41 years (Spouse)

“Honestly, I got lost sometimes. There were so many activities happening at the same time and you can hear some noise from the machines in the room which was very scary. It was a tiring activity but she was my sister so I had to endure with the hope that she would get better and come back home as soon as possible”

Theresa, 38 years (Sister)
Despite this expectation, the older person died which appeared worrying for participants:

“Well it got to a stage that I realised that I was losing my brother. I noticed that his infusions were not going as normal, he was growing too fat and could not sleep as he used well. I left my work and family to take care of my brother but he died at the end. It is a moment in my life that I cannot forget because I lost a lot of things. I really wanted to sleep by him too because he complained that anytime he called during the night, no one came to see him even when he screamed”

Michael, 48 years (Brother)

“We expected that he would survive so that we could send him back to his relatives but in the end he died. After all these struggles here and there, he died in the end leaving us with huge financial burden. I mean you are already aware that sleeping in the BICU for a day is 200 cedis not mentioning the medications, dressing materials and food and even the funeral expenses”

Martha, 31 years (Neighbour)

Some participants felt that they had wasted their time to care for a patient who died in the end as they hoped for a recovery. In addition, due to the damages to properties such as vehicles and houses, participants felt they had suffered a double loss:

“My father died, his house got burned and I still feel guilty for leaving him alone that night. I never got to say sorry to him and it still hurts me until today. I still felt tired even after he died. Sometimes I sleep at night and wake up suddenly because I remember the incident and begin to cry. Only if I was there, I believe I would have noticed this problem and solved it.”

Esi, 28 years (Daughter)

“There are things that you just cannot do anything about. If it should happen it will happen and it is the will of God. I think God gave me strength to go through this whole thing. I just see God as my source of strength through this period because all that happened was so shocking and frightening: losing a neighbour and your house at the same time and still coming to take care of him in the hospital really requires supernatural strength because it felt like I had wasted my time counting all these losses.”

Martha, 31 years (Neighbour)

4.8 Summary of Findings

The study identified the existence of male and female caregivers providing care to elderly burned patients at the Komfo Anokye Teaching Hospital. Despite the existence of both categories
Caregiving was observed to be associated with females. Burns were noted to occur suddenly with limited time for adjustment though caregivers were rapidly drawn into the caregiving role. The context of burns caregiving was associated with several emotional responses such as shock, helplessness, hopelessness and devastation. These emotional responses were directed towards the burned patient and the aftermath of the injury such as damage to property.

Despite these emotional responses, participants still provided care. Several aspects of the caregiving and hospitalisation processes were noted to be sources of stress for caregivers. It was observed that the need for urgent hospitalisation, unfamiliar environment, cumbersome processes at the hospital and complex hospital set up with lack of waiting and sleeping areas for caregivers were sources of primary stress. Additional sources of primary stress were noted to be associated with running errands, decision making, the extent of wounds, poor pain management and concern for the patient, family and caregivers’ own well-being. As the patients transitioned to the end of life period, the experience of primary stressors were compounded by the symptoms of the elderly burned patients such as restlessness and inability to communicate verbally.

Furthermore, participants also witnessed other patients’ symptoms such as the nature of the wounds and this also served as primary stressors. Some groups of equipment and how they function were also cited as sources of stress and these included the sound from gadgets such as monitors and the colossal size of the mechanical ventilators. Some of the primary stressors participants experienced brought about financial constraints. Due to the need to be constantly present in the hospital, they also experienced some changes in their life schedules. Furthermore, the strict visiting periods established by the hospital and the desire to witness the progress of the elderly burned patients made some participants resort to live on the hospital premises. In so doing, they had to sleep on floors or chairs, bath early in the open and pay to use the lavatory services. These served as secondary stressors for participants.
Despite these sources of stress, the existence of resources was acknowledged. For instance, participants had hope and engaged in prayer and other faith practices. Also, they adjusted to their new roles as caregivers and received encouragement from nurses. In addition, various sources of support were noted. This included support from other family members, neighbours, the affiliated religious group, workplace colleagues and other caregivers. At the end of the caregiving and the hospitalisation period, positive and negative outcomes were noted. Positive outcomes were associated with the experience of personal growth through a difficult period and some participants were satisfied to have been able to demonstrate their love to the elderly burned patient. Negative outcomes were observed to be associated with physical and emotional exhaustion from the stresses of caregiving. An additional theme was identified outside the constructs of the model used to inform this study. This theme described participants’ expected outcomes of hospitalisation of the burned elderly persons as well as the actual outcomes. All the participants had hope of quick recovery but in the end they experienced double losses (death of patient and loss of property). The ensuing section presents a discussion of the study findings in relation to the reviewed literature.
CHAPTER FIVE
DISCUSSION OF FINDINGS

This chapter discusses the key findings of the study in relation to literature and taking into consideration the constructs of the Stress Process Model. The study set out to explore and describe the experiences of caregivers of elderly burned patients from time of admission till death at the Komfo Anokye Teaching Hospital. Specifically, the objectives of the study were to:

I. illuminate the background characteristics of family caregivers of elderly burned patients
II. uncover the context within which caregiving to an elderly burned patient occurs
III. identify primary stressors associated with caregiving to elderly burned patients
IV. discover secondary stressors associated with caregiving to elderly burned patients
V. ascertain coping resources associated with caregiving to elderly burned patients
VI. identify outcomes of caregiving to elderly burned patients

Through the interview process, five major themes emerged which were consistent with the Stress Process Model: injury and reactions of caregivers, hospitalisation and associated stressors, effects of caregiving, coping and support. An additional theme that emerged from the study was expected and real outcome of injury.

5.1 Background of Family Caregivers

Background features of caregivers have been described as the lifelong attributes of the individual such as demographic information that may impact the caregiving experience (Judge, Menne, & Whitlatch, 2009).

Caregivers have been noted to be spouses, daughters or sons of the care recipient; with majority being females (Cohen, Pringle, & LeDuc, 2001). In the current study, it emerged that most caregivers were related in some aspects to the care recipient. Thus there were sons,
daughters, spouse, brother, fiancée, and daughters in law of the elderly burned patient. This finding is in line with previous studies that close relations usually played the role of a caregiver to an elderly person; and it offers support to the premise that ones’ family or relation is the appropriate resource to be relied on (Azoulay et al., 2004; Barker, 2002). In most countries, spouses are often the first in line to assume the caregiving role; however if there is no spouse, children of the elderly person assumed the role and may share it with their spouses as well (Wolff & Kasper, 2006). Meanwhile, Mou, Griffith, Fong and Gowes (2013) have posited that rural-to-urban migration, increased adaptation to western lifestyles such as monogamy and non-communal dwelling are exacerbating loneliness and adversely affecting the availability of immediate family members to provide care to elderly persons with burns. This may imply that as the family system gradually undergoes changes, the availability of immediate family members’ especially older children to offer assistance to ageing family members may be adversely affected.

Despite the predominance of family members as caregivers, studies have shown that a significant proportion of community dwelling frail elderly persons receive assistance from neighbours and friends (Barker, 2002). Estimates have suggested that between 5 per cent and 10 per cent of these elderly persons regularly receive informal assistance from this category of non-kin caregivers (Nocon & Pearson, 2000). Barker (2002) has indicated that this form of non-kin caregiving relationship is naturally occurring and built out of remarkable acts of sharing and kindness between people. Contrary to Barker’s assertion, in the current study, a woman had to become a caregiver to the elderly burned patient (who was her neighbour) not on humanitarian grounds but was forced by the attitudes of the man’s family to take full responsibility for the injury of the elderly man which occurred in her home. This raises some concerns regarding the neglect of the burned elderly person by the family.

In relation to the gender of caregivers, the United States National Alliance for Caregiving (2004) has indicated that the typical family caregiver is a 46 year old female with some college
experience. Previous studies have affirmed that more females are likely to assume caregiving role to elderly persons as compared to males (Barker, 2002; Waldrop et al., 2005). Despite this, Thompson, Tudiver, and Manson (2000) have argued that current demographic changes have allowed more males notably husbands and sons to take up caregiving roles and this is reflected in the current study as three males took up the caregiving roles as sons and a brother of the care recipient. Though Romoren (2003) has affirmed that the existence of male carers who may undertake the same range of activities rendered by female caregivers, it was observed that male caregivers in the current study described caregiving as a feminine responsibility as females are involved in caring for others in the home. In similar lines, family caregiving has been described as a predominantly female activity despite changes in social structure and norms (Barker, 2002). This may be related to the societal and cultural demands that allow females to assume the caregiving role (Sharma, Chakrabarti, & Grover, 2016). Additionally, this is more likely to occur in societies and cultures such as Ghana, which endorse the traditional value of the woman as the natural caregiver (Prince, 2004).

Allison et al. (2003) have noted that women have historically undertaken the care of relatives, as they were most usually the ones available to fulfil this role, frequently being at home. The typical dementia caregiver has been noted to be a middle-aged or older female child or spouse of the person with dementia (Brodaty & Donkin, 2009). Similarly, the typical cancer caregiver has been described as a female aged 55 years or older (Honea, Brintnal, Given, et al., 2008). Within the context of road traffic accidents, Filho et al. (2007) and Santos et al. (2014) also observed that caregivers were typically females who presented as spouses, siblings or mothers of the care recipient. Taken together, these findings indicate that females play significant caregiving roles no matter the disease condition even though opportunities exist for males to assume such roles. As the caregiving role has been described as a predominantly feminine work, Simpson et al. (2004) have argued that men are likely to feel isolated in this role and perceived by others as
performing outside of normative roles. This may indicate the need for further research in exploring experiences of male caregivers rendering care in the hospital as it can enable the development of strategies that can be instituted to support them.

In terms of education and employment, it was observed in the current study that most participants have received some form of formal education and are involved in various forms of employment. In similar lines, Yeandle and Buckner (2007) also noted that several caregivers undertake caregiving roles alongside paid employment and have indicated that a growing elderly population has been indicated to mean that more people of employment age will make decisions about combining work and caregiving.

Though Greenhaus and Powell (2006) have argued that male caregivers are more likely to be employed than their female counterparts; it was observed in the current study that most participants (males and females) were in various forms of employment. This may represent changing roles of females in the Ghanaian society that permits them to take up paid employment alongside their usual caregiving duties. According to Arksey and Glendinning (2008), the main stimulus for combining both roles is financial security. This is particularly important as being admitted to the hospital is associated with financial obligations and being in employment may place participants in a position to offer financial assistance. Despite this assertion, some studies have observed that playing the dual role may be associated with negative consequences such as lower earnings due to repeated absence at work (Carmichael & Charles, 2003; Heitmueller & Inglis, 2004) as well as poor physical and emotional health due to stress of caregiving and job related issues (Evandrou & Glaser, 2004). This assertion is of particular interest to the current study as it was noted that majority of participants were traders and artisans, thus in the informal sector; and not government employment where they may have enjoyed some leave periods and still receive salaries on monthly basis. As majority of participants practiced their own craft,
absence at the place of work may mean not obtaining proceeds that day resulting in acquiring lower earnings.

Religion has been postulated to assist individuals in their caregiving efforts (Nightingale, 2003) and as such a caregiver’s religious affiliation play a part in enabling them cope with the demands of caregiving (Fry, 2001). Thus in the current study, participants were observed to belong to either the Christian or Islamic religion. Dilworth-Anderson, Boswell, and Cohen (2007) noted in their qualitative study that religious beliefs helped participants through the caregiving journey as they obtained strength to endure the demands of caregiving. Further studies are however warranted in determining the variability among various religious affiliations and its effects on caregiving.

5.2 Context of Caregiving to Elderly Burned Patients

Context in the Stress Process Model considers the situation of the caregiving and nature of the disease requiring caregiving. Thus, it represents the circumstances in which the caregiver operates (Pearlin et al., 1990).

Caregiving is conceptualised by Pearlin et al. (1990) as a career that embraces three stages to produce unique caregiving experiences. However unlike most careers, caregiving is unplanned, unexpected and not entered into by choice. The stages are role acquisition (usually precipitated by the onset of an illness), role enactment (performance of role related tasks) and role disengagement (follows death or cure of the care recipient). For conditions such as dementia and cancer, Pearlin (1992) has posited that transitions may follow the sequence of residential caregiving, institutional placement and bereavement. However in the current study, it was observed that burn injuries occurred suddenly and were unplanned or unexpected events which required immediate hospitalisation of the burned elderly person. This corroborates with the findings of Coffey et al. (2011) as they noted that the occurrence of burns is a sudden life changing event which may leave
limited time for family adjustment. Thus, this is unlikely to follow the sequence described by Pearlin (1992) as residential caregiving could not occur in relation to the occurrence of burn injuries: entry into the hospital implied commencement of caregiving role. This discrepancy may be associated with the differing nature of the conditions as dementia may not require sudden hospitalisation when it is diagnosed.

Aneshensel et al. (1995) have noted that for chronic medical conditions such as dementia, there is a need for symptom recognition and diagnosis prior to assumption of the caregiving role. However Merrill (1997) has suggested that in traumatic cases, diagnosis played a less central role as there was an urgent need for a caregiver after symptoms have been recognised. Waldrop et al. (2005) have argued that the onset of the patient’s illness and illness trajectory shaped transitioning of caregivers of persons with cancer. They further specify that in some situations, the onset of the symptoms were sudden whilst others were gradual; thus allowing the caregiver to adjust to the demands of caregiving in the latter instance. Thus, even though Pearlin et al. (1990) have described caregiving as a sudden occurrence in the role acquisition phase, caregivers of burned patients are more likely to experience entry into caregiving more suddenly than dementia or cancer caregivers as the latter may have some time prior to assumption of the caregiving role. Moreover elderly burned patients cannot be cared for in the home due to the nature of the injury which requires urgent hospitalisation. Thus, caregivers of burned elderly persons may miss the aspect of residential caregiving and move suddenly to caregiving in the hospital. This may also imply that for caregivers of burned elderly persons, the role acquisition and role enactment phases occurred almost simultaneously as the burned patient was hospitalised soon after the injury had occurred.

In addition to the sudden entry into the caregiving role, it was noted in the current study that the occurrence of the burn injury evoked various emotional responses and it characterised the role acquisition and enactment phases. Thus, participants reflected on preceding events to the
burn injury and some played the self-blame game as a result. Furthermore participants were confused, anxious and shocked due to the occurrence of the injury, symptoms of the burned elderly person, coming to the hospital and damage to properties. Despite the existence of these intense emotions, participants assumed the caregiving role. These emotional responses to the injury were also observed by Filho, Xavier and Vieira (2011) to be associated with the unexpected nature and sudden occurrence of RTA. They noted that the need for urgent hospitalisation was accompanied by depression, anxiety, sadness, fear, unawareness and these were further exacerbated by the physical traumas, economic difficulties and social implications. Thus, they suggest that family caregivers of RTA victims need professional support as they also suffer emotional injuries even as they care for their hospitalised relatives. Similarly, as sudden occurrence of RTA can be likened to burn injuries, caregivers of burned elderly persons may require professional support as they exhibit comparable emotional response to the injury.

Findings from a systematic review and meta-synthesis by LeSeure and Chongkham-ang (2015) showed that various emotional responses such as emotional devastation, fear, panic, denial and shock also characterised the context of cancer caregiving. These responses reportedly occurred after the diagnosis of cancer was made by the physician. However caregivers of elderly burned patients in the current study manifested these emotions before arriving at the hospital. This may be a characteristic feature of burn trauma.

Further to the above, it was observed in the current study that participants were devastated due to injury occurrence, unprepared to handle the consequences of the injury and felt separated from the older person. This implied that the burn injury in itself served as a form of stressor prior to taking up the caregiving role; this augments the need for professional support for the caregivers. Separation from the elderly burned person due to the need for urgent hospitalisation could be explained by family ties between caregivers and care recipients. In addition, it highlights the role elderly persons’ play in families. Participants reminisced about who would run their
Caregiving to Elderly Burned Patients

businesses or cater for their children during vacation; roles that the elderly usually played. In relation Peacock, Duggleby and Koop (2014) have indicated that caregivers do not only participate in the provision of hands on care, they also demonstrate an emotional connection with the care recipient.

Another contextual feature worth noting is that most burn injuries resulted in damage to properties. This evoked feelings of helplessness and hopelessness and further heightened the emotional responses in the caregivers. In addition, it was observed in the current study that participants did not know the course of the injury which contributed to feelings of helplessness. The intense emotions were such that some participants got perplexed and did not know what to do although some had first aid ideas. This might be the reason why Sundara (2011) has posited that family members may experience strong emotions immediately after the occurrence of the burn injury and this may continue throughout the hospitalisation period. Although Sanders (2007) has suggested that male caregivers may not acknowledge the need for support, preferring to focus more on concrete tasks rather than emotional reactions to caregiving; findings from the current study point to the fact that both male and female caregivers experienced comparable emotional reactions to the injury occurrence. This implies that gender may play a less central role with regards to response to burn injury occurrence.

Also, the feeling of remorse was noted in the current study as expressed by one participant as she left her elderly father to attend to his needs whilst she also left home. In similar lines, Klienpill (2006) has asserted that the occurrence of a burn injury may be associated with guilt feeling. Also, caring for a patient with RTA has been noted to be associated with guilt feeling (Azevedo & Santos, 2006). Generally, across all cultures in the world, there is a common understanding and expectation that older children are morally obligated to care for ageing parents (Theixos, 2013). Due to parental, societal, and moral expectations, the resultant guilt carries with it the potential of shame which is distinguished from guilt as the public acknowledgment of the
transgression (Harstade, Roxberg, Andershed, & Brunt, 2012). Morally, caregivers may feel responsible and thereby think that their actions may have contributed to a negative outcome in the institutionalisation of their parents and resulted in overwhelming feelings of remorse and guilt arising from a perceived violation of a moral or social standard of familial obligations (Tilghman-Osborne & Cole, 2010). In bereavement, guilt is considered an “emotional reaction in grieving when one has failed to live up to expectations to the deceased” (Li, Stroebe, Chan & Chow, 2013, p. 156). These feelings of guilt and associated feelings of anxiety and depression may have a significant impact on the well-being of family members, especially women (Ferguson, Lawrence, & Matthews, 2000). This is likely to occur in the instance of this study participant who left her elderly father on his own. Thus, Gonyea, Paris and Zerden (2007) have argued that the challenge for clinicians is to help guilt-ridden caregivers to revise their evaluative standards so as to engage in self-forgiveness and self-acceptance. This also specifies the need to establish psychosocial counselling services for family members of burned patients to enhance their recovery from guilt and remorse. This is especially important as the setting in which this study was undertaken may lack a well-developed hospice programme which may have offered professional counselling services to caregivers. Meleis’s theory of nursing transitions proposed that assisting people in managing life transitions is a central role for nursing (Meleis, Sawyer, Im, Hilfinger Messias, & Schumacher, 2000). However, if families are not enrolled in hospice care, they may not have direct access to health care providers.

Despite the existence of these emotional features, participants in this study took active part in the caregiving process. This affirms the findings by Yoo, Lee, and Chang (2008) that caregivers are active partakers in the caregiving process and not mere passive observers. The participants in this study undertook varying range of activities such as meeting self-care needs and running errands to purchase medications and dressing materials. Considering the emotional response to the injury and the range of activities that participants performed, Coffey et al. (2011)
assertion becomes important here. They maintain that caregivers may be under tremendous stress and health professionals are usually unable to support them; probably due to poor understanding of their experiences.

As elderly burned patients were admitted to and died in the hospital, caregivers’ role disengagement may be said to have occurred in the hospital. This period reportedly generated feelings of sadness and loss among participants. Similarly, Filho et al. (2007) have indicated that sadness among caregivers of persons with RTA was exacerbated by the loss of the patient. Considering the foregoing, it is evident that the context of burns caregiving to elderly burned persons is wrought with various emotional responses from role acquisition phase till disengagement. This calls for the need for support for these caregivers irrespective of their gender.

It was found in the current study that admission of the elderly burned patient led to most participants’ first time experience with caregiving. Thus, the hospital environment was described as both unfamiliar and complex to the extent that some caregivers could not navigate their way through the hospital. This was further compounded by occasional lack of beds and poorly resourced waiting areas (absence of seats). However it was observed that participants who had previously experienced caregiving in other contexts appeared to be mentally prepared for the caregiving journey whilst both first time carers and those with previous experience were physically unprepared for the daunting tasks. This may be due to the nature of burn trauma which has been observed to occur suddenly, leaving limited time for adjustment and preparation for entry into the caregiving role (Coffey et al., 2011).

5.3 Primary Stressors Associated with Caregiving to Elderly Burned Patients

Primary stressors are the conditions, experiences, and activities that are problematic for caregivers and are directly related to the enterprise of providing care (Pearlin et al., 1990).
Traditionally, primary caregiving stressors have been conceptualised as the care recipient’s symptoms or impairments (functional, behavioural, and cognitive) and the actual caregiving tasks required as a result (Aneshensel et al., 1995).

In this study, participants described the physical demands they faced. They included waking up early so as to arrive early at the hospital, providing hands on care and running errands (to purchase medications, dressing materials and feeds for the elderly burned patient). In relation to conditions such as dementia and cancer, it has been noted that caregivers assisted the care recipients in meeting their care needs at the initial stages of the disease and this may change as the disease progressed (Waldrop et al., 2005). According to Schulz (2000), dementia caregivers in the home provided assistance by being available when needed; supervising prescribed treatment; evaluating significance of changes; providing structure to the care receiver’s daily routine; normalising this routine within the bounds of impairment; and assisting in the activities of everyday living, including transportation, grocery shopping, house-work, preparing meals, managing finances, arranging and supervising outside services, giving medicine, assisting the individual with getting in or out of bed or a chair, dressing, bathing, toileting, feeding, and help with continence and diapers. The performance of these activities physically stressed caregivers. However as burned elderly persons were hospitalised immediately and caregivers may miss the residential aspects of caregiving, some differences are evident in what caregivers were expected to do in their roles.

Though some studies have described hands on care as sources of primary stress (Smale & Dupuis, 2004; Waldrop et al., 2005), it was observed in the current study that participants’ inability (notably females) to continually provide this care was rather problematic for them. This variation may be attributable to the fact that most forms of dementia and cancer caregiving occur in the home whilst burns caregiving to elderly persons occurs almost entirely in the hospital. Thus, disruptions in family processes are likely to be more pronounced in the latter and
participants may want to make up for these changes by being able to meet the physical needs of the burned elderly patient as most participants specified feeling separated from the burned patient. Aside participating in the provision of hands on care, it was observed in the current study that participants wished to be physically present with the burned elderly person continually; apparently due to the feeling of separation. However this was impossible due to strict visiting-hour policy at the hospital. Thus some participants opted to sleep in the hospital premises so as to get close to the burned patient with the least available opportunity and some went to the extent of deceiving the security men (gate keepers) or paying a token in order to gain entry into the Accident Emergency Unit.

Peacock et al. (2012) have argued that caregivers may experience a feeling of being an outsider as the care recipient transitions to the care home or hospital due to the fact that others take over the provision of hands on care and this leads to the experience of physical separation between caregivers and care recipients. This experience may be related to filial obligations that family members have towards elderly persons and inability to meet these obligations may be associated with feelings of failure (Chappell & Kusch, 2007). Though nurses took over care of the elderly burned patient, participants were still worried as they were unable to meet their needs at all times especially at night. This appeared to strengthen the desire to be always physically present with the burned patient but this was impossible due to regulations at the hospital.

In addition to the above, caregivers found the aspect of running errands to purchase medications, dressing materials or collect feeds from other unit as stressful. This may be related to participants’ unfamiliarity with the hospital environment and the physical exertion required to completing those tasks. In relation, Edwards and Scheetz (2002) have suggested that performing these tasks are associated with financial burden. The authors’ assertion may offer some insights into the complaints of stress among the participants in the current study since making purchases imply financial disbursements.
Furthermore, participants were faced with the need to make difficult decisions regarding some aspects of the elderly burned patient’s care which stressed them. This included decisions regarding apportioning the financial resources available, decision to place the elderly burned patient on mechanical ventilation or not as they transitioned to the end of life period and decision to withdraw ventilatory support. Penrod et al. (2012) have posited that caregivers usually participate in decision making regarding the patient and this has been described as an emotionally challenging activity (Coffey et al., 2011). Azoulay et al. (2004) have also argued that family caregivers may not be ready for this task even though they are required to do it and this places them under undue stress. A contributory factor to this may be related to caregivers’ inability to determine the choices of the burned elderly person. Tilden, Tolle, Nelson, and Fields (2001) reported from their study that surviving family members reported high stress levels associated with the decision to withdraw care and stress levels remained high up to six months following the death of the elderly person. This finding may specify the need to allow caregivers some time to avoid taking decisions in a rush.

In the current study, participants were concerned about their own well-being, the patient’s well-being and the well-being of the family at home. Hull (1990) also reported participants’ concerns for their own well-being as sources of primary stress among cancer caregivers. In the current study, it was observed that the frequent visits that participants made to the hospital and prioritising the needs of the patient were the main sources of concern when it comes to their own well-being. Although these activities may be associated with a sense of duty to provide care, Smale and Dupius (2004) have argued that caregivers concerns for their own needs may often be perceived as shameful and selfish. Thus, caregivers are unlikely to talk about these concerns as they maintain sole focus on the care recipient and this has been highly linked to the development of caregiver burden (Smale & Dupius, 2004).
Regarding concerns for the patient, participants reiterated the fact that even though nurses took over hands on care of the patient, there were occasions they were unable to provide them; especially during the night. This is because nurses on night shift may be having naps and unable to respond to the needs of the elderly burned patient. Scott, Rogers, Hwang, and Zhang (2006) have noted that the unique challenges of the critical care environment is the need for specialised and demanding nursing and assessment skills, rapid decision making, as well as enhanced organisational and motor performance skills. Furthermore, because burns critical care department nurses provide 24-hour care to patients who are often in an unstable condition, such nurses must not only perform accurate clinical assessments but must remain highly vigilant and respond swiftly to subtle changes in a patient’s condition and this specifies the need for nurses to take restorative napping (Scott et al., 2006). Fallis et al. (2011) have also suggested the need for health care organisations to identify barriers that adversely affect night nurses’ napping behaviours so as to reduce fatigue and increase vigilance. Despite these assertions, some authors have noted that the issue of napping during night shift still remains controversial (Alspach, 2008) and appears to be receiving much attention (Rogers, 2004; RCN, 2012). In as much as napping may prevent fatigue, it may raise some quality of care issues especially if the patient is in need or requires assistance whilst the nurse naps. This may mean that nurses need to have a nap schedule so as to ensure that at every period of the night shift, there is someone available to attend to the burned patients. Additionally, there may be a need to improve nursing staffing levels in the Burn Units of the Komfo Anokye Teaching Hospital so as to ensure that adequate number of staffs is available in a given shift. However, this may require political intervention as Ghana currently has a good number of unemployed Registered Nurses waiting for financial clearance to commence work.

Further to the above, findings from the current study revealed that the symptoms exhibited by the elderly burned patient as well as other patients were additional sources of primary stress. These symptoms are extensive burn wounds, moaning, groaning and persistent complaints of pain.
by the patient. As the patients transitioned into the end of life phase, symptoms such as impaired verbal communication, restlessness and refusal to eat were observed by participants who were seemingly helpless and hopeless. Relieving these symptoms appeared to be impossible and the participants were worried if the health professionals really understood the non-verbal communication cues of the patient. In a recent qualitative exploration in the same setting, Bayuo (2018) noted that nurses felt powerless in the face of these symptoms as they were unable to relieve the symptoms. In part, Bayuo (2018) has attributed this difficulty to poor application of palliative care tenets in burns care though death has been noted as a major outcome for elderly persons in transitional countries (Bayuo & Botchway, 2017). Ray, Karlekar, Crouse, Campbell et al. (2017) have also posited that no current literature describes the intersection of palliative care and burn care or integration of palliative care in this area of care. Thus, they suggest that palliative care in burns may need to focus on pain and other symptoms in burn intensive care unit, address special needs of the critically ill burned patient, their families, and clinicians.

The principles of palliative care encompass excellent communication, pain and symptom management, goals of care, bereavement, and spiritual support, usually for patients who are at the end of life with chronic ailments (Mosenthal and Murphy, 2003). Conversely, burns care is focused on acute care of the critically injured, where decisions and care are provided to rapidly cure the patient and prolong life, often no matter the cost in suffering and resources. If the patient dies it is often suddenly, leaving little room for the application of the traditional notions of palliative care. Thus, it appears the place of palliative care in caring for the severely injured burn patient is ill defined and these patients are often subjected to aggressive burns management till they die (Coffey et al., 2011). This may imply the need to develop palliative care guidelines to be used in burns care as Ismail et al. (2011) have asserted that palliative care guidelines and protocols have been well developed in disease conditions such as cancer but these are not directly transferable to burns care as the burned patient has needs which might vary from other patients.
This is particularly important as a recent narrative review has shown that aside high mortality rates among elderly burned patients, they face distressing symptoms which cannot be relieved by traditional burn care principles (Bayuo & Botchway, 2017). As noted in an earlier study, these distressing symptoms affect the patient as well as health professionals (Bayuo, 2018) and the current study has also revealed that informal caregivers are affected.

Furthermore, pain management has been noted to be a major challenge in our setting and contributing factors have been noted to include lack of pain assessment tools and pain management protocols (Bayuo, Munn, & Campbell, 2017); limited availability of appropriate pain medications and financial constraints (Bayuo, Agbenorku, & Amankwaa, 2016) and poor attitudes towards opioids (Bayuo & Agbenorku, 2015). Thus there has been a clarion call to improve pain management in the burned patient as poorly managed pain adds on to the already established deleterious hypermetabolic state (Bayuo, Munn, & Campbell, 2017; Bayuo, Agbenorku, & Amankwaa, 2016). Similarly, within the context of cancer caregiving, Powe and Finnie (2003) have specified that family caregivers usually viewed pain as a manifestation of impending death or physical deterioration. This implies a need to maintain adequate pain relief for all patients no matter their condition. It is worth noting, however, that differences exist in the nature of burns and cancer pain which may need to be taken into consideration in the management process.

A unique source of primary stress in this study was noted to be associated with some family members or visitors taking photographs of an elderly burned patient whilst on admission. This was identified in the words of a participant who rendered care in the capacity of a neighbour and her source of worry was that the pictures were spread via social media to the community members. This act cast a slur on the reputation of her family, being blamed in the community for causing harm (inadvertently though) to an elderly neighbour. Although she could not stop them, she had hoped that the nurses would have seen it and prevented the visitors from taking the
photographs. This raises concerns regarding nurses’ vigilance, quality of care as well as legal issues as the patient’s consent was not sought prior to taking the photograph or sharing it with community members. The act of sharing photographs have been noted to have permeated societal fabric and several news items in Ghana and beyond have indicated the tendency of members of the public and health professionals to take pictures of accident victims and post these on social media such as Facebook, Whatsapp and Twitter. Gerdelman (2013) have argued that taking, posting and sharing unauthorised images of patients does constitute an abuse. In India, it has been reported that an accident victim died because of delay in receiving assistance as persons who passed by were interested in taking snap shots of him rather than helping him to the hospital which was closer to the scene of injury (timesofindia.com; Feb 2, 2017). Thus in some countries such as Malawi, United States and United Kingdom, health professionals are very likely to lose their professional license for taking and sharing patients’ pictures without their consent or allowing others do it (Ventola, 2014). Additionally, there may be a need to educate family members about these issues as well as their implications so as to enable them avoid it altogether.

Bevans and Sternberg (2012) have posited that caregivers of cancer patients receiving allogeneic haematopoietic stem cell transplantation (HSCT) are faced with several stressors from the procedure as it takes some weeks of hospitalisation followed by three to four months of intense outpatient management. Similarly it was observed in the current study that some forms of burn care treatment modalities were sources of stress for the caregivers. These treatment modalities included mechanical ventilation and burns wound care after which burned patient looked colossal. Also the sound from the cardiac monitor used to assess various vital parametres was identified to be a source of primary stress. In some instances these gadgets were not related to the care of the elderly burned patient but other patients also on admission. This was further compounded by poor information flow: thus participants did not know the usefulness of the gadgets. In relation, Schulz (2006) has also noted that lack of information regarding treatment
modalities and progression of cancer was a source of stress to participants after a diagnosis has been made. The health care team however, cannot be blamed unduly in this case because probably they were oblivious to the fact that the caregivers were scared of the sounds emanating from the machines. The caregivers may not have complained about their fears to them. As the use of ventilators and cardiac monitors cannot be avoided in the hospital, there is a need to provide caregivers with information regarding the role of these gadgets in the treatment process. Furthermore, as sounds from these gadgets can prompt the health care team of an impending complication, their volumes cannot be turned off but education provided to the caregivers regarding the meaning of these sounds may be helpful in attenuating their stress levels.

Schulz (2013) has argued that receiving the news of a patient’s poor prognosis may generate intense emotional responses which might present as a stressor to the caregiver in the same way, seeing the symptoms presented by the patient may stress the caregiver. In this study, the participants wished they had been told exactly what was happening to the patients. Though some participants noted the changing state of the burned patient, they still wanted confirmation of their observations from the health professionals. Findings from the study by Waldrop et al. (2005) among 74 cancer caregivers indicated that end stage caregiving was characterised by “comprehension of terminality” (recognition/ awareness that the care recipient was dying). This awareness emanated from the experience of receiving information regarding prognosis, observing progression of the disease and observing the patient’s personality change and role loss. They further noted that the awareness enabled the caregivers to take on a better perspective with regards to death and dying. The burned patient at the end stage experiences further functional decline which may have an impact on family carers (Murray, Kendall, Boyd & Sheikh, 2005). As end of life care has not been clearly streamlined in burns care (Mosenthal & Murphy, 2003), it is difficult to ascertain when aggressive burns management should cease. Hence, aggressive management continues till the patient dies or survives (Mosenthal & Murphy, 2003) though
functional decline experienced by the patient serves as a form of stress to health professionals and family members (Bayuo, 2018; Bayuo & Botchway, 2017). Despite these, there is a need for ongoing communication between caregivers and health professionals so as to update caregivers of the state of the burned patient especially as participants reiterated their need for information but rarely had it met. Hospice care has been specially designed for end of life care and operates with a philosophy of providing honest and tactful communication with caregivers. However burns management lacks this approach to care and requires further research to determine the exact place of palliative care in its management. Also, there may be a need to develop palliative care guidelines specific to burns management (Bayuo, 2018).

Although McClement, Fallis, and Pereira (2009) found in their study that the experience of having a family member undergo resuscitation is stressful, it was observed in the current study that participants’ wished to stay and observe the resuscitation process. However the participants were asked to exit the room: a feature that was noted to be a source of stress. This variation may be associated with lack of information regarding the actual state of the burned elderly person which made participants still want to be physically present. Family presence during resuscitation continues to remain controversial in most settings, and an increased emphasis on family centered care (Davidson et al., 2007) in conjunction with families exercising their rights to be present during resuscitation (Myers, Eichhorn, & Guzzetta, 1998) have led to a revisiting of the issue. Accordingly, Walker (2008) has indicated that increased research attention is being directed toward the practice of allowing family members to bear witness to resuscitation efforts in hospitals. Also various professional organisations such as Emergency Nurses Association (ENA; 1993), American Association of Critical Care Nurses (2004), Canadian Association of Critical Care Nurses (CACCN; 2005), European Federation of Critical Care Nursing Associations, European Society of Paediatric and Neonatal Intensive Care, and European Society of Cardiology Council on Cardiovascular Nursing and Allied Professions have released various statements in
support for the practice (Fullbrook et al., 2007). Furthermore, Jabre et al. (2013) have specified that family presence during resuscitation was associated with positive results on psychological variables and did not interfere with medical efforts or result in conflicts. Despite the benefits, family presence during resuscitation continues to remain a controversial issue. Fleming (2003) and Searight & Gafford (2005) have suggested that cultural factors may have a role in this as they may influence reactions to be present or absent during resuscitation. For instance, Badir and Sepit (2005) observed in their study among Turkish critical nurses (N = 409) that 83% of the sample (n=231) did not feel it was necessary to invite family members to be with the patient during resuscitation, and 69% (n=192) did not want family members present. In relation to the current study, though participants wished to be present, health professionals did not permit them to do this. Moons and Norekval (2008) however noted that nurses in Ireland and United Kingdom possessed more positive attitudes towards family presence during resuscitation and actually encouraged family members to do so. These differences may mean that further research is warranted in exploring this issue further within the Ghanaian context.

This study showed that when the elderly burned patient died, participants were worried about the huge hospital bills they had to settle. Even when they had settled the bill, completing the death certificate was another arduous task that stressed participants. This was because the policy at KATH indicates that relatives were required to settle all outstanding debts before the death certificate was completed. The participants in this study had to visit the hospital severally before the death certificate could be completed. This raises some concerns, in that, the caregivers were in a period of grief due to the death of the burned patient and they were stressed further by delays in completing the death certificate. This finding is unique to this study as the Stress Process Model terminates with the death or cure of the patient with no consideration for what happened after that period. This implies that after the death of the patient, some situations or experiences still existed that stressed participants.
In summary, this section has described forms of primary stressors faced by caregivers of elderly burned patients and compared these with literature. Traditionally, primary caregiving stressors in the Stress Process Model have been conceptualised as the care recipient’s symptoms or impairments (functional, behavioural, and cognitive) and the actual caregiving tasks required as a result. However, the findings from this study have revealed that there were several aspects of care that appeared problematic for caregivers. This may be related to the fact that the Stress Process Model has previously been applied to caregiving in the home with patients with various chronic conditions such as cancer and dementia. Thus, its application to burns caregiving within the hospital context may reveal other stressors related to caregiving, the suddenness of burn injuries as well as hospitalisation. As some persons with dementia and cancer may require hospitalisation, there may be a need to utilise the Stress Process Model at this phase of care as this will capture caregiving within the hospital setting. Thus, findings from this study appear to have extended our understanding of stressors associated with caregiving in the hospital. For instance, after the death of the elderly burned patients, the experience of primary stressors was not over as the participants had to continue to commute to the hospital to complete processes required to obtain the death certificates.

5.4 Secondary Stressors Associated with Caregiving to Elderly Burned Patients

Pearlin et al. (1990) have described the secondary stressors as ways that primary stressors influence and disrupt other areas of the caregiver’s life. These stressors vary and are uniquely individualistic (Zarit, Davey, Edwards, Femia & Jarrott, 1998). These are the stresses that may drift from the caregiving process to other domains of the caregiver’s life. Herbert and Schulz (2006) have described these as under-appreciated set of stressors. Some studies have clearly indicated economic constraints and lifestyle interference as some secondary stressors that may be experienced by caregivers (Emanuel, Fairclough, Slutsman & Emanuel, 2000). In similar lines, Waldrop et al. (2005) have noted that cancer caregivers were also faced with financial strains. In
relation to the current study, it was observed that the process of caregiving and hospitalisation drained the financial reserves of the family. This was because participants had to transport themselves to the hospital, purchase dressing materials and medications and pay to access the lavatory whilst in the hospital. After the death of the elderly burned patient, family members had to settle hospital bills and they described this as huge. Though they described some of the medications as expensive, they still purchased them. Lai (2012) has described financial constraints associated with caregiving as a significant factor in the development of caregiver burden in both males and females. This highlights the need to re-consider health care costs for burns in particular, as most forms of caregiving to the elderly burned patient occurs in the hospital. Also, there may be a need to re-structure the National Health Insurance System (NHIS) in supporting burned patients and their families. It is worth noting that accommodation expenses and dressing materials for burned patients are not covered by the NHIS. Similarly, some essential medications such as higher order antibiotics required for the management of the burned patient are not covered by the scheme and these have to be paid for by the family directly. In the case persons who survive the injury Bayuo, Agbenorku and Amankwaa (2016) have reiterated that they are faced with financial constraints as the family’s finances are depleted due to their care needs. Health care financing has been described as a primary necessity and access to health care largely depends on the finances available. Thus, the World Health Organisation has itemised health care financing among the essential needs of every country.

In its report, ‘Health Financing in Ghana at a crossroads’, the World Bank argues that the NHIS Basic Benefit Package (BBP) is financially unsustainable, and asks the Government of Ghana to consider cost-sharing if it is to continue providing the comprehensive Basic Benefit Package (BBP). The report further recommends the use of co-payments for some covered services and sections of the populations (who are able to pay) as a strategy for increasing NHIS revenue and directing utilisation towards more cost effective services. However, it does not say which
services or medicines should attract co-payment. A systematic review by Qingyue, Liying and Beibei (2011) observed that one of the purposes of cost sharing is to change the utilisation of services or prescription drugs for the enrollee of public or private health insurance schemes. However, compared with people in insurance scheme without cost sharing, the introduction of cost sharing decreases the utilisation of most kinds of medical services. This may not be beneficial for the elderly burned patient as burn injuries have been noted to require urgent admission and it would be difficult to ascertain the forms of services to be included or excluded in their care. Elderly persons aged 70 years and above are exempted from paying NHIS premiums. They however have to pay a fee to be registered with the Scheme. Meanwhile, this exemption package does not consider the expenses associated with trauma care. Thus, more innovative strategies may be needed to re-design the current NHIS, taking into consideration the diverse population groups in Ghana.

In addition to financial constraints, it was also observed in the current study that participants experienced lifestyle interference as they maintained sole focus on the patient at the hospital. Participants were unable to take part in their usual social activities. They slept in the hospital in chairs or floors and could not eat well. Consistent with these findings, previous studies have noted that caregivers experience a sense of a disruption in normal life due to their caregiving roles (Stajduhar & Davies, 2005; Stajduhar, 2013; Wennman-Larsen & Tishelman, 2002). In this regard, Vukicevic et al. (2016) have specified that disruption in the caregiver’s life could be prevented by offering respite services to enable caregivers take intermittent breaks. Meanwhile, Kristjanson et al. (2004) found that the existence of a night respite care service enabled caregivers to sleep better and avoid caregiver fatigue. Furthermore, Pinquart and Sorensen (2011) observed that because spouses are most likely to live with the care recipient, they tend to provide more hours of care and find less respite which led to the development of caregiver burden. This may be particular true for residential caregiving as the caregiver lives with the care recipient. However,
caregiving to the elderly burned patient appears to occur almost entirely in the hospital and there may be a need for caregivers to negotiate with other family members so as to take occasional respite whilst other family members also continued with the caregiving at the hospital.

Kramer and Lambert (1999) have noted that when family members assume the caregiving role, they often relinquish or modify previous roles which may lead to significant changes in family dynamics, the marital relationship, and work responsibilities. Similarly, Waldrop et al. (2005) identified work related conflict among cancer caregivers. In relation to the current study, it was observed that one participant persistently requested for permission to be absent to the extent that other members of staff complained about it. This continued until she decided to commence her annual leave thereafter. Participants who worked as traders also reiterated that leaving their wares with colleagues was associated with poor accounts being rendered; thus they packed their wares to and fro in between visiting the elderly burned patient at the hospital. Combining work with caregiving in the hospital was identified as a difficult task for participants. Meanwhile a school of thought contends that being in employment and working as an unpaid caregiver is associated with unique benefits and combining these roles may not be problematic if both roles do not interfere with each other (Plaisier et al., 2015). However for most family caregivers, there is a greater likelihood for a spill over effect from caregiving into work or vice versa (Arno et al., 1999). This interference may be a contributing factor why a participant in this study had to persistently obtain permissions from the work place. Also, traders in the study noted that they slept whilst in the market; a feature which may represent the interference of caregiving demands in their work. Consequently these conflicts have been noted to result in poor well-being and the development of caregiver burden (Evandrou & Glaser, 2003; Fredriksen and Scharlach, 2006). Thus further research is warranted in determining forms of respite services for burn caregivers so as to ensure that lifestyle disruptions are reduced to the minimum.
5.5 **Resources Associated with Caregiving to Burned Elderly Patients**

Resources or mediators are personal, social and material assets that modify the causal relationships between stressors and outcomes (Aneshensel et al., 1995). Resources are needed to enhance coping with caregiving as this will determine to a greater extent, the outcome of the process. Thus, despite the existence of various stressors in caregiving, there are mediators or resources that assist caregivers in dealing with issues associated with the process. Smale and Dupius (2004) have described these resources to mean ways in which caregivers negotiate and mitigate the pressures and strains of caregiving.

Biegel and Schulz (1999) described a sequential, cyclical model in which stressful situations begin when functional limitations of the care recipient and problem behaviours create a need for caregiving. The caregiver must evaluate the situation and decide if she or he can deal with the problems. A positive or benign evaluation leads to positive emotional responses and a sense of well-being. Alternately, an appraisal of the situation as stressful leads to negative emotional reactions (e.g., anxiety, depression); these reactions may interact with care recipient behaviours to create an escalation of negative outcomes. In relation to the current study, it was observed that participants accepted and adjusted to the need for caregiving but not the patient’s condition. However this was associated with lack of options for caregivers. Also after the death of the elderly burned patient, caregivers adjusted to the situation by coming to terms with the loss amidst crying and visualising the mortal remains of the patient as traditionally practiced in Ghana. Wade, Borawski, Taylor, Drotar, Yeates and Stancin (2001) have suggested that that higher acceptance of a child’s traumatic injury predicted lower levels of caregiver burden and distress. This was associated with the fact that a caregiver who accepted the child’s injury was unlikely to deny the existence of the problem and may be able to work towards achieving treatment objectives. Redinbaugh et al. (2003) have also suggested that acceptance of the situation may allow the caregiver to be more conscious of their grief and actively work towards its resolution.
and this may explain why caregivers who practice escape-avoidance experience greater burden (Dunn et al., 2001). Waldrop et al. (2005) have asserted that in order to enable caregivers adjust in this sense, there is a need for honest communication as it makes them aware of what was happening at a given time. This is particularly of interest as the current study noted participants’ information needs were hardly met especially at the end of life period and that brings under scrutiny how well participants adapted to the caregiving situation.

Waldrop et al. (2005) noted that cancer caregivers utilised religious and faith practices as a coping resource. This was based on hope in a Spiritual Being; usually God. In similar lines, it was observed in the current study that participants expressed hope in God and were engaged in faith and religious practices such as prayers and fasting. Religion and hope in God has been noted to be intertwined sources of inspiration and strength (Santos et al., 2014). They further describe faith as one of the factors that helps in emotional control and determines the action, as the family finds strength in God to solve problems, highlighting mainly prayer as a means. Religion and faith practices have been described as a major source of emotional support as it is perceived as a way to relieve internal conflicts and foster acceptance of the situation experienced by the family caregivers (Santos et al., 2014). Lee (2001) has also suggested that religious and spiritual practices may be associated with decreased depression and increased life satisfaction. Despite these assertions, Hebert et al. (2007) noted in their systematic review that evidence for the effects of religion and spirituality remain unclear as the preponderance \( n = 71, 86\% \) of studies found no or a mixed association (i.e., a combination of positive, negative, or non-significant results) between religion/spirituality and well-being. These mixed findings may represent the multifaceted nature of religion and the diversity of caregiver outcomes. Thus, further research is warranted in this regard to assess the impact of religion on burns caregiving outcomes in Ghana.
Aside hope in God, participants in this study expressed hope in expensive medications they purchased and hope for an expedited recovery. Thus even though participants were worried about the financial burden associated with purchasing expensive medications, they had hoped that these medications could expedite the process of recovery. Even at the end of life period, participants still had hope in the medications and continued purchasing them till the patient died. Consistent with the findings of this study, Kolata and Pollack (2008) have noted that expensive cancer medications such as Avastin generated hope among cancer patients and caregivers even as it prolongs life for some few months. It is however important to educate family members about the extent to which these medications can help their patients in order to prevent disappointment. This may be necessary especially in this instance in which these medications are not covered by the NHIS and increases the financial burden experienced by families of burned patients; a phenomenon which has been described as the “high cost of dying” (Scitovsky, 2005). At the end of life period, drug treatment goals have been noted to shift to symptom control and quality of life and as such changes in drug utilisation are expected (Curtis, 2008). Such a shift in treatment goals from preventative and curative care to symptomatic care will impact the drug therapy used during the end-of-life period, requiring changes to the types, formulations, administration routes and doses of medications used. Specialised palliative care services may oversee such changes for those patients; however, limitations in access to palliative care services mean that end-of-life care for many patients is managed outside of these specialised services (Curtis, 2008). Health professionals in trauma and burns care have been noted to be poorly prepared to meet the palliative care needs of patients in their care and that means that aggressive treatment may continue till death (Mosenthal & Murphy, 2003) which may be more expensive. Thus, although having hope in these medications may be helpful, participants may become disappointed if the expedited recovery they wished for is not realised. This strengthens the argument for assessing the
place of palliative care in burns care as it is likely to allow focus on improving the burned patient’s/ family’s quality of life rather than attempting to prolong it (Bayuo, 2018).

In this study, participants received encouragement from nurses which served as sources of comfort for them. Although this resource was not available all the time, caregivers appreciated it whenever it occurred. In line with this finding, Theis et al. (2003) have asserted that nurses can provide information, encouragement, and a supportive presence to allay caregivers’ worries and fears. As nurses maintain constant and continuous contact with patients and family members, they stand the greatest opportunity of encouraging family members as well as alleviating their worries.

In addition to the above, it was noted in the current study that various sources of support was available to caregivers as they provided care to elderly burned patient. The sources are family, neighbours, affiliated religious group, work place colleagues and other caregivers.

Support from the family was in the form of financial contribution, frequent calls, visitation, taking charge of participants’ duties at home and participating in religious activities such as fasting and prayers. Support from neighbours also took the form of assisting with the hospitalisation process, financial contribution and visitation. Support from the affiliated religious group took the form of financial contribution, visitation and engagement in various religious practices. It was also noted that workplace colleagues provided support in the form of taking over some aspects of participant’s work and introducing participants to other colleagues in the hospital who assisted them with the hospitalisation processes. Support from other caregivers was noted to include financial assistance in the form of loans and teaming up to pray and fast. Similarly, social support was identified as a key theme reported by cancer caregivers in a study by Waldrop et al. (2005). This support was obtained from friends and members of the extended family who offered respite for caregivers. This break in caregiving allowed the caregivers’ time to overcome strains associated with the process. Burleson and MacGeorge (2002) have defined social support as the
“verbal and nonverbal behavior produced with the intention of providing assistance to others perceived as needing that aid” (p. 374). Social support has also described as an “interpersonal transaction” through which people address emotional concerns (Goldsmith, 2004, p. 3). Thus, availability of social support from friends, family and co-workers has been described as a major resource in caregiving literature (Brinson, 2001). Tang (2009) has asserted that greater levels of emotional support from social networks enhanced caregivers overall quality of life. Other studies have also found that perceived satisfaction of social support from family and/or friends predicts lower levels of caregiver strain and burden (Bainbridge et al., 2009), depression, (Gaugler et al., 2009), and psychological distress (Daly et al., 2009). Similarly Haley, LaMonde, Han, Narramore, and Schonwetter (2003) have indicated that greater social support from family and friends are associated with lower levels of depression. Despite these benefits, Redinbaugh et al. (2003) have cautioned that it is the quality of the social support and not the quantity that helps to attenuate burden associated with caregiving. Thus in relation to findings from the current study, participants still experienced financial burden despite the various sources of financial assistance.

5.6 Outcomes of Caregiving to Elderly Burned Patients

Caregiving as a process usually ends in various outcomes. These outcomes can either be positive or negative based on how the caregiver appraised and responded to the situation (Pearlin et al., 1990). Thus in this study, both positive and negative outcomes were noted. Generally, most studies using the Stress Process Model have measured outcomes based on levels of depression, anxiety and quality of life among caregivers (Cooper, Katona, Orrell & Livingston, 2008; Kliszcz, Nowicka-Sauer, Trzeciak & Sadowska, 2004).

In the current study, participants experienced physical exhaustion due to physical demands of caregiving in the hospital and this manifested as tiredness. In addition, emotional exhaustion was noted and this was related to the patient symptoms they observed, nature of the injury and
subsequent death of the elderly burned patient. The aspect of this finding that corroborates with those of Schulz (2008) is that caregiving is associated with physical strain. In similar lines, approximately 32 per cent to 70 per cent of carers of patients with advanced cancer have been found to experience high levels of distress at the end of the caregiving journey which suggests the existence of physical and emotional exhaustion (Dumont, Dumont & Mongeau, 2008; Rivera, 2009). Bayuo (2018) observed that nurses also experienced emotional exhaustion due to the nature of the extensive wounds they observed as well as the patients’ symptoms. This exhaustion was heightened as the patient transitioned to the end of life period and further compounded by lack of avenues for release after the patient had died. This finding is similar to what was noted in the current study which may suggest that being witnesses of burn trauma and its associated symptoms represent significant sources of emotional stress in burns caregiving (Cronin, 2001; Greenfield, 2010; Hettiaratchy & Dzewulski, 2004). This may be particularly essential as participants in the current study noted that they occasionally experienced flashbacks of the caregiving and hospitalisation experiences. Further to this, some participants indicated that they experienced sleeplessness on some occasions. This finding is in line with those of Hepburn, Lewis, Sherman, and Tornature (2003) as they observed sleeplessness to be an associated aftermath issue of caregiving.

Despite the negative experiences presented above, some positive outcomes were noted in the current study. Some participants indicated they were able to meet new people and make friends in the hospital. Also, participants specified feeling matured due to the fact that they were able to take some bold decisions and came face to face with issues surrounding death. In addition, they experienced spiritual growth as God gave them strength to journey through the process. Similarly, Ivey et al. (2012) reported positive outcomes in providing care to someone with dementia in the home. This was described by the participants as feeling emotionally stronger and experiencing personal growth. At the end of life period, Hudson (2004) has asserted that
Caregivers may experience personal growth through adversity, discovery of emotional strength and physical abilities. These features demonstrate personal maturity and may mean that even in the presence of caregiving stressors; caregivers may still experience some positive outcomes. In the current study that some participants felt personally fulfilled and satisfied by being able to go through the caregiving journey. Also, some participants (spouse and fiancée) indicated they were able to demonstrate their love to the elderly burned patient. Hudson (2004) has argued that caregiving usually led to deepening of relationship with the care recipient. This may also mean that though dementia and burns differ significantly, caregivers may still experience positive outcomes of caregiving in both instances. Wilkinson (2010) however argues that the extent to which positive outcomes buffer the negative aspects still remains unclear and this may explain why both positive and negative outcomes may exists concurrently. This offers directions for further research in the area of understanding how positive experiences can help attenuate negative experiences.

5.7 Expected and Real Outcome of Injury

This succinct section discusses an additional theme that was discovered in the study but not a part of the Stress Process Model. Though participants expected expedited recovery within the shortest possible time (due to the fact that they associated the injury with only the existence of wounds) the elderly burned patient died in the end. This was a source of worry for participants and they felt they had wasted their time in some instances in the face of double loss (death of the elderly burned patient and loss of property). A contributing factor to this may be associated with poor communication links between participants and health professionals as it has been argued that honest and open communication may allow caregivers to have a balanced view of the possible outcomes of the injury (Dunn & Mosenthal, 2007; Mosenthal & Murphy, 2003).
5.8 Summary

In summary, this chapter has presented various discussions regarding the experiences of caregivers of elderly burned patients. Though the Stress Process Model has been mostly applied to caregiving in chronic conditions such as dementia, it appears useful in acute conditions such as burn injuries. Despite this it was noted that the Model tended to favour caregiving in the home than in the hospital as it does not take the setting of the hospital or stressful incidents that occurred after the death of the care recipient into consideration. Thus, further studies are warranted in situating the Stress Process Model in various settings: home, nursing homes, hospitals among others.
CHAPTER SIX

SUMMARY, CONCLUSION, IMPLICATIONS AND RECOMMENDATIONS

This chapter summarises the study and presents its implications for nursing practice, research, education as well as issues for policy considerations. In addition, the study’s limitations are discussed. Also, recommendations are presented to serve as a guide for improving service delivery to elderly burned patients as well as supporting family caregivers in their roles.

6.1 Summary

The study explored the experiences of family caregivers of elderly burned patients who died at the Komfo Anokye Teaching Hospital. The study was guided by the Stress Process Model developed by Pearlin et al., (1990). An exploratory-descriptive qualitative approach was utilised and purposive sampling method used to recruit fourteen (14) caregivers who rendered care to elderly burned patients from admission till period of death. The data collection approach was driven by a semi-structured interview style with an interview guide. Interviews were audiotaped, transcribed and analysed concurrently using Miles and Huberman (1994) approach to thematic analysis. Though themes that emerged from the study were in line with the constructs of the Stress Process Model, an additional theme was identified which reflects expected and real outcome of the burn injury.

In exploring the background of caregivers, it was observed that most caregivers were related in a way to the care recipient. Thus, there were sons, daughters, spouse, brother, fiancée, and daughters-in-law of the elderly burned persons. However, one participant had to render care to a neighbour who was injured in her mother’s apartment. The majority of the participants were females and the male caregivers also described caregiving as a feminine role. In terms of
education and employment, it was observed in the study that most participants had received some form of formal education and was involved in various forms of employment. Also, all participants were noted to belong to either the Christian or Islamic religion; though Christians formed the majority.

The context of caregiving to the elderly burned patient was observed to be characterised by the sudden and unexpected nature of burn injury occurrence. This was noted to lead to sudden hospitalisation of the elderly burned person. In addition to the suddenness of the caregiving role it was noted that the occurrence of the burn injury evoked a myriad of emotional responses which characterised the role acquisition phase. Thus, during participants reflections of events preceding the injury, some played the self-blame game. Furthermore, participants were confused, anxious and shocked due to the occurrence of the injury, symptoms of the burned elderly person, going to the hospital and vast damage to property. Despite the existence of these intense emotions, participants assumed the caregiving role. Also, it was observed in that participants were devastated due to injury occurrence, unprepared to handle the consequences of the injury and felt separated from the older persons. This implies that the burn injury in itself served as a form of stressor prior to taking up the caregiving role and underscores the need for professional support for these caregivers. Separation from the elderly burned person due to the need for urgent hospitalisation could be explained by family ties between caregivers and care recipients. In addition, it reflected the role elderly persons play in families as participants reminisced about who would run their businesses in their absence or cater for their children during vacation. Another contextual feature worth noting is that most burn injuries resulted in damage to properties which accompanied some elderly burned patients. This accentuated the feelings of helplessness and hopelessness and further increased their emotional responses. In addition, it was observed in the current study that participants did not know the course of the injury which contributed to feelings of helplessness. These intense emotions were to such an extent that some participants did not
know what to do even though some had first aid ideas. Some participants had guilt feelings throughout their caregiving role and blamed themselves for the injuries to the elderly persons. Since the elderly burned patients were admitted to hospital and died while on admission, the caregivers’ role disengagement could be said to have occurred in the hospital. It was noted in the current study that admission of the elderly burned patients led to most participants’ first exposure with caregiving as well as the hospital environment. Thus, the hospital environment was described as both unfamiliar and complex and some caregivers had difficulty navigating through the hospital setting. Although participants who had previous experience with caregiving in other contexts appeared to be mentally prepared for the caregiving role, both first time carers and those with previous experience were physically unprepared.

In exploring the primary stressors associated with burns caregiving in the hospital, it was observed that participants faced several physical demands including waking up early in order to arrive at the hospital in good time, providing hands-on care and running errands (to purchase medications, dressing materials and feeds for the elderly burned patient). Even though previous studies have noted that the performance of hands-on care increased the risk for caregiver burden, the current study found that participants were rather stressed for not being able to participate fully in the delivery of hands-on care. When nurses took over care of the elderly burned patients, participants worried because they were unable to meet their patients’ needs at all times, especially at night. The participants strongly desired to be present with the burned patients all the time. The desire to be physically present with the burned elderly persons was continually expressed by participants apparently due to feelings of separation. However, this was impossible due to the strict visiting-hour policy at the hospital. For this reason, some participants resorted to sleeping on the hospital premises so as to be close to the elderly burned patients at the least opportunity. Some participants went to the extent of deceiving the security men, the gate-keepers at the hospital
whilst others paid them a token (bribery) in order to sneak into the hospital at any time to see their patients.

Furthermore, participants were faced with the need to make certain difficult decisions regarding some aspects of the elderly burned patients’ care which stressed them. These included decisions concerning financial resources and use of mechanical ventilation as patients transitioned into the end of life period. During caregiving, participants expressed concern about their own wellbeing, their patients’ wellbeing and the wellbeing of the family members at home. It was observed that the frequent trips to the hospital and prioritising the needs of their patients in lieu of their own were the main sources of concern in relation to caregivers’ well-being. With regards to concern for the patients, participants reiterated the fact that even though nurses took over the hands-on care of the patients, there were occasions they were unable to provide them especially during the night. This was because nurses on night shift may be sleeping and unable to respond to the needs of the elderly burned patients. Furthermore, the symptoms exhibited by the elderly burned patients as well as other patients on the wards were sources of stress for participants. These symptoms were the extensive burn wounds and persistent complaints of pain by the patients. As the patients transitioned into the end of life phase, symptoms such as impaired verbal communication, restlessness and refusal to eat were observed by participants. It was noted that relieving these symptoms appeared almost impossible and participants worried if the health professionals understood the non-verbal communication cues of the patients. A unique source of primary stress in this study was associated with some family members or visitors taking photographs of one elderly burned patient whilst on admission. This happened when a participant had to care for a neighbour who got injured in her house. Her concern was about the spread of the pictures throughout the community and the gossips that accompanied the news. Although she could not stop the act she had expected that the nurses would have been vigilant enough to have seen and prevented the visitors from taking the photographs. In addition, it was observed that
some forms of therapeutic regimen or burn care treatment modalities were sources of stress for
the caregivers. These treatment modalities included mechanical ventilation and burns wound care
which made burned patient looked big. Also, the sound from cardiac monitors used to assess
various vital parameters was a source of primary stress. In some instances, these gadgets were not
being used to care for the elderly burned patients but other patients on admission. This was further
compounded by poor information flow hence participants did not know the usefulness of the
gadgets. Particularly, caregivers wished they had known the real outcome of the injury from the
onset of admission but this was far-fetched. At the end of life period, it was observed that
participants wished to stay and observe the resuscitation process. However, they were asked to
leave the room and wait outside; this was another source of stress to caregivers. When the elderly
burned patients died, participants were worried about the huge hospital bills they had to settle.
When they had settled the bills, completing the death certificate was another arduous task that
stressed participants. This was because the policy at KATH indicated that relatives were required
to settle all outstanding debts before the death certificates were completed and participants in the
study had to visit the hospital several times before the death certificates were completed.

Secondary stressors were also explored in this study. It was observed that the process of
caregiving and hospitalisation drained the financial reserves of the families. This was because
participants had to commute to the hospital, purchase dressing materials and medications and pay
to use the lavatory whilst in the hospital. After the death of the elderly burned patients, family
members had to settle huge hospital bills. In addition, it was found that participants experienced
lifestyle disruptions as they focused solely on the patients. Participants were unable to participate
in their usual social activities. Family caregivers slept in the hospital, on chairs or floors and
could not eat well. One participant persistently requested for permission to be absent from work
to the extent that other members of staff complained about it. She was forced to request for her
annual leave. Participants who worked as traders reiterated that leaving their wares with
colleagues led to poor accounts being rendered. They packed their wares to and fro, whilst visiting the elderly burned patient at the hospital. Combining work with caregiving in the hospital was identified as a difficult task for participants.

The study findings showed that various resources enabled caregivers to deal with the stresses of caregiving. Participants ultimately accepted and adjusted to the caregiving and hospitalisation. However, this was fraught with lack of options for caregivers. Also, after the death of the elderly burned patients, caregivers adjusted to the situation by coming to terms with the loss amidst crying and viewing the mortal remains of the patients. Participants expressed hope in God and were engaged in faith and religious practices such as prayers and fasting. Participants expressed hope in the expensive medications they purchased as they felt they were efficacious in expediting recovery of the elderly burned patients. Participants also received words of encouragement periodically from nurses. Other forms of support available to participants were from participants’ family, neighbours, affiliated religious group, work place colleagues and other caregivers. The forms of support were mainly financial and spiritual support.

The study also explored the outcomes associated with caregiving. These outcomes were either negative or positive. The negative outcomes were in the form of physical and emotional exhaustion. Physical exhaustion was the physical demands of caregiving in the hospital which manifested as tiredness. Emotional exhaustion was related to the patients’ symptoms they observed, the nature of the injury and death of the elderly burned patients. Some positive outcomes were also noted in the current study. Some participants indicated that they were able to meet new people and make friends in the hospital. Also, participants mentioned feeling mature since they were able to take some difficult decisions and coming face to face with issues concerning death. In addition, they experienced spiritual growth as God reportedly gave them strength to go through the process of caregiving. Some participants felt personally fulfilled and
satisfied by being able to go through the caregiving process. Other participants (spouses and fiancée) indicated that they were able to demonstrate their love to the elderly burned patients.

The additional theme obtained was expected and real outcome of injury. Although participants expected expedited recovery due to the fact that they associated the injury with only the existence of wounds, the elderly burned patients died in the end. This was a source of worry for participants and they felt they had wasted their time as well as experiencing double losses being, death of the elderly burned patient and loss of property.

6.2 Implications for Nursing Practice

Findings from the study have some implications for nursing practice; notably burns nursing. Considering the sudden occurrence of burn injuries, unexpected entry into caregiving and the emotional response to burns, there is a need for empathic communication with caregivers and other family members. In addition, nurses may need to create avenues that will allow caregivers express themselves and communicate openly about their concerns and worries. Also, nurses can take a lead role in educating caregivers about the need for respite services and encourage them to discuss the option with other family members.

In addition as participants wished to participate in the delivery of hands on care, nurses may need to negotiate with caregivers so they can feel part of the care delivery process. This may mean assisting caregivers to acquire skills that can enable them perform some hands on care such as mouth care. In some instances nurses can collaborate with family caregivers in meeting the physical needs of the elderly burned patient. However there should be clear limits to what caregivers can do. In addition, nurses may take a lead role in orienting caregivers to their new roles regarding caring for a burned patient. This may help participants in the adjustment process and help mitigate the problem of unpreparedness.
In relation to sleeping during night duty, there could be scheduling among nurses on duty so as to enable staff take their naps in turns rather than taking it together. This will allow nurses to meet the needs of the burned patient even at night. Additionally, there may be a need to improve staffing levels of nurses in the Burn Units as this can boost the overall manpower available during various shifts. Also, nurses in the burn unit may need to be vigilant and monitor visitors when they come around so as to prevent them from taking photographs of burned patients.

The study also revealed several aspects of the injury that served as stressors and this included watching the patient’s wounds, sounds from the gadgets and sight of some gadgets such as the ventilator. In addition participants did not know the course of the injury. This implies that nurses need to provide education to caregivers and family members regarding the injury trajectory and treatment regimen or modalities. The importance of various treatment modalities instituted needs to be discussed with caregivers to prevent fear and enhance their participation in the caregiving process.

At the end of life phase where resuscitation is required, nurses may need to assess the circumstances to allow caregivers to remain or exit the place. Nurses can ask caregivers if they prefer to remain at the scene of the resuscitation or not. As caring for the elderly burned patient may require application of palliative care tenets, burn care nurses may need to seek opportunities to enhance their skills in rendering palliative care to burned patients.

6.3 Implications for Nursing Education

Education in nursing is the central part of nurses’ strength of knowledge to impact care for patients. Aside nurses offering education to caregivers and family members, findings from the study offer some ideas regarding nursing education. Curricula for programmes such as emergency nursing, critical care nursing and burns nursing may need to consider adding palliative care modules to their training. In addition, the palliative care modules at the basic nursing level may
need to consider a shift from solely limiting palliative care to cancer management. This may help students acquire essential skills in rendering palliative care in trauma situations. Furthermore, the palliative care specialty programme at the Ghana College of Nurses’ and Midwives may need to consider establishing palliative care in trauma so as to make palliative care accessible to elderly burned patients. If possible, palliative care in burns may be developed as a sub-specialty programme at the college.

6.4 Implications for Policy

Considering the experiences of caregivers at the initial phase of the hospitalisation, it is necessary that relevant stakeholders in the hospital develop policies to establish protocol that can enable patients go through the admission process smoothly. Also, the strict visiting time at the hospital needs further re-consideration by management. In addition, policies are needed to ensure that the burn unit is strengthened so that all services can be obtained at the same venue rather than caregivers’ having to travel to and from the unit. Furthermore, a policy change is required with regards dressing the burned patient only after dressing materials have been purchased by family members.

It was also noted in the study that the process of signing the death certificate was a stressful one for caregivers. Thus, policies are needed to allow doctors complete the death certificate as soon as death has been confirmed so as to allow caregivers collect it as soon as they complete payment of hospital bills. Further to this, policies are needed to increase the coverage of the NHIS to include some aspects of burns care. This is to reduce the financial burden on families of burn patients. Also, a burns fund may need to be developed in the hospital to offer financial support to families who may not be able to afford burns care.
6.5 **Avenues for Further Research**

Based on the findings of this study, further studies are warranted among caregivers of other age groups with burns such as babies, neonates and young adults to assess if their experiences may differ or align with findings of this study. In addition, further research is needed in understanding when aggressive management of the burned patient should cease or if it should continue alongside palliative care till end of life period. This also implies that further research is needed in the development of palliative care guidelines for use in burns care as it has been noted that guidelines in other disease states such as cancer cannot be applied to burns care.

Also, further research is needed in understanding the experiences of male and female caregivers in other trauma contexts such as RTA to assess how it differs or aligns with that of burns. In addition, the effects of religion on caregiving outcomes require further inquiry within the Ghanaian context. Further to this, family presence during resuscitation requires further research to enable development and enactment of policies to support caregivers and family members during end of life periods. Opportunities also exist in determining how positive experiences attenuate negative experiences among caregivers as well as exploring the impact of hope on caregiver outcomes. The area of respite services for burn caregivers is also an area warranting further research to enable the development of services that can enable caregivers to take intermittent breaks from caregiving.

6.6 **Limitations of the Study**

Findings from the study may be limited in some ways. Firstly, findings may be unique to the setting in which caregiving was undertaken though they may be transferable to similar settings. Additionally, the study focused on family caregivers who rendered care to elderly burned patients and as such, the findings may reflect experiences of this cohort of caregivers though
opportunities exist in exploring the experiences of other caregivers such as those of paediatric burned patients.

6.7 Conclusion

In conclusion, the study explored caregivers’ experiences of rendering care to elderly burned patients from admission till death at the Komfo Anokye Teaching Hospital, Kumasi. The Stress Process Model developed by Pearlin et al. (1990) served as the theoretical framework for this study. The study revealed that most caregivers are females and related in several aspects to the care recipient. The nature of the burn trauma appeared to define the context of the caregiving. Thus the unexpected and sudden nature of the injury led to unprepared hospitalisation with various emotional responses such as confusion, shock, anxiety, helplessness and devastation. The sources of primary stressors were varied with some aspects related to the caregiving required and others related to the hospitalisation. At the end of life period, the symptoms of the elderly burned patient such as restlessness and impaired verbal communication were sources of primary stress. Participants were also stressed from the some treatment modalities such as mechanical ventilation that they observed. These stressors drifted into the lives of caregivers and led to secondary stressors such as draining their financial reserves and work related conflicts. Despite these issues, participants obtained support from various sources such as family, neighbours and church. In addition, caregivers had hope in God and practiced various religious beliefs that enabled them to cope with caregiving. At the end of the caregiving journey, both negative (physical and emotional exhaustion) and positive outcomes (personal growth, demonstration of love and feeling fulfilled) were noted.

Despite the usefulness of the Stress Process Model in meeting the study’s objectives, an additional theme reflecting expected and real outcome of injury was noted which indicates that the model reflects only outcomes of the caregivers and not those of the patient. Also some
stressors were noted to be related to caregiving and others related to hospitalisation. In addition, some stressors were noted to occur after the death of the elderly burned patient. Thus, the Stress Process Model may need to integrate outcomes of the patient with those of the caregivers to become a comprehensive model.

6.8 Recommendations

Based on the findings of the study, the following recommendations are put forward for:

6.8.1 Hospital

- The processes of admission need to be made less cumbersome for family members so as to enable them go through it easily.
- Directional signs are needed at vantage points to allow family members navigate their way easily through the hospital. Family members need to be provided with information regarding how to locate the information desk in the Accident Emergency Unit so as to contact personnel there at any point in time
- Sleeping places for caregivers need to be constructed so as to prevent caregivers from sleeping on floors and chairs as they journey through caregiving
- Music may be needed in the unit so that caregivers may not need to concentrate on sounds from the gadgets
- Appropriate avenues of release for family members need to be developed in the hospital to enable family members talk about their concerns and worries
- The cost of hospitalisation at the Burn Intensive Care Unit needs to be reviewed so as to reduce the financial burden on family members.
- There is a need for training collaboration between the Komfo Anokye Teaching Hospital and hospitals, clinics and health centres at the periphery to enhance capacity building in burns management
There is a need to install call light in patient rooms to enhance their calls to nurses especially during the night shift.

Authorities at the Komfo Anokye Teaching Hospital need to increase the number of beds available especially at the triage area to allow for quick admittance of patients.

Health professionals need to identify who they are and their designation to patients and relatives so that they can properly addressed. Though the use of name tags have improved in the hospitals, some patients and caregivers may still not be able to read it and that specifies the need for health professionals to introduce themselves.

There is a need to collaborate with appropriate governmental agencies to recruit more nurses as the acuity levels of elderly burned patients appears to be high.

There is a need to establish psychosocial counselling services for family members of burned patient to enable them overcome feelings of guilt and remorse.

6.8.2 The Ministry of Health/ Ghana Health Service

The Ministry of Health/ Ghana Health Service may need to consider innovative ways of integrating palliative care into trauma programmes so as to enable practitioners develop skills that will allow them meet the palliative care needs of persons with burns.

The Ministry of Health/ Ghana Health Service needs to increase the number of persons trained in burns care to offer specialist care to burned patients.

The National Health Insurance Scheme (NHIS) needs to be reviewed to absorb the cost of burns management.

There is a need to collaborate with health facilities in stepping up health promotion activities in the area of preventing the occurrence of burn injuries.
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Caregiving to Elderly Burned Patients


Caregiving to Elderly Burned Patients


Caregiving to Elderly Burned Patients


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Caregiving to Elderly Burned Patients


Caregiving to Elderly Burned Patients


Kliszcz, J., Nowicka-Sauer, K., Trzeciak, B., & Sadowska, A. (2004). The level of anxiety,
depression and aggression in nurses and their life and job satisfaction. *Medycyna pracy*, 55(6), 461-468.

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Caregiving to Elderly Burned Patients


Mandell, S. P., Pham, T., & Klein, M. B. (2013). Repeat hospitalization and mortality in older adult burn patients. *Journal of Burn Care & Research, 34*(1), e36-e41.


Papp, A. (2009). The first 1000 patients treated in Kuopio University Hospital Burn Unit in Finland. Burns, 35(4), 565-571.


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Caregiving to Elderly Burned Patients
APPENDIX A: INTERVIEW GUIDE

A. BACKGROUND CHARACTERISTICS AND CONTEXT

1. How old are you?......................
2. Sex.................................
3. Marital Status.............................
4. Religion.................................
5. Employment Status........................ Specify..........................
6. Level of education........................
7. How did the burn injury occur?
8. How did you feel about the occurrence of the burn injury?
9. How did you become a family caregiver?
   a. Probes:
      i. Have you previously been a family caregiver? Specify capacity in which 
         you were a caregiver
      ii. What is your relationship with the care recipient?
      iii. How prepared were you to handle the role?
         1. Specify preparations undertaken if any
10. How did you feel about becoming a caregiver?
    a. What changes did you notice after been a caregiver?
    b. What were your expectations about being a family caregiver?

B. STRESSORS AND TRANSITIONS

11. How was it like providing care in a hospital from admission till death?
    a. Probes:
       i. What did you do as a caregiver?
       ii. How did you recognise the changing state of the care recipient?
       iii. What did you experience as you provided care?
       iv. What support did you require and was it available?
       v. What did you perceive as problematic or rewarding?
       vi. How about the nurses, doctors, ward environment, other family members 
           and the client?

C. COPING RESOURCES/ MEDIATORS

12. What can you describe as things that enabled you to handle your caregiving role?
Probes
i. Resources in the hospital?
ii. Family/friend resources?

13. Was there anything that made the process of caregiving difficult for you?

Probes
i. Within the unit care was provided?
ii. How about the family?
iii. The care recipient?

D. OUTCOME OF CAREGIVING

14. How was it like after the death of the care recipient?

a. Probes:
   i. Outcomes of caregiving: positive and negative?

15. Is there any other information you would like to share?
APPENDIX B: CONSENT FORM

Title: Experiences of Family Caregivers of Elderly Burned Patients at the Komfo Anokye Teaching Hospital

Principal Investigator: Jonathan Bayuo (Mr)

Address: School of Nursing and Midwifery- University of Ghana
Legon

General Information about Research
I am a second year MPhil (Nursing) student at the University of Ghana conducting a study in the above named area. This study is for academic purposes and it seeks to understand your experiences as a caregiver whilst caring for an older person with burns from admission till death. Care provision has been noted to be associated with various forms of experiences and varying outcomes. Thus, the study aims to describe these experiences so as to help the health care team assess what forms of support can be implemented to help other caregivers of older persons with burn injuries in the future. You have been invited to participate in this study because you took active part in caring for an older person with burns (aged 60 years and over) at KATH. Your details were either obtained from the Admission and Discharge books of ward D2C or Burns ICU of the Komfo Anokye Teaching Hospital or you recently participated in caregiving at any of the above mentioned units of KATH. It is not compulsory for you to participate in this study. If you agree to participate, you will sign or thumbprint two copies of this form (one will be kept by you and the other with me). Thereafter, an interview will be scheduled with you at your own time and chosen venue which is expected to last between 40 to 60 minutes. Before
the interview begins, your consent will be sought again regarding your participation in the study and if you agree, the interview will begin. Your permission will be sought and interview proceedings audio recorded.

Possible Risks and Discomforts
This study is not intended to expose you to any form of harm either physically or psychologically. However, you will have to offer your time in order for the interview to be answered. Thus, intermittent breaks will be offered as and when necessary. In addition, if you have any challenges during the data collection, you may take a break and continue later. Also, if recollecting your experiences as a caregiver evokes strong emotions evidenced by crying, the interview will be halted for a while to allow you re-compose yourself. However, if this is impossible, the interview will be re-scheduled. In case you will need professional assistance, you will be referred to the psychiatry unit of Komfo Anokye Teaching Hospital to meet Dr. Steve Wemakor for counselling at no cost. Furthermore, if after the interview you feel there are issues you need to talk about which are outside the domain of this project, you will be referred to a palliative care physician specialist (Dr. Esinam Agbeko) at the Komfo Anokye Teaching Hospital for professional assistance. At any point in time, that is before and after completion of data collection you will need their services, please feel free to contact me and make the necessary arrangements. Please note that you will not be charged for these services.

Possible Benefits
You may not benefit directly from the study; however, the findings that are gathered from this research will enable the healthcare professionals to know how to support family caregivers of older burned clients.
Confidentiality

Your name or identity will not be noted during the audio recording. However, a coding system to identify each participant will be developed and used by me. In addition, details of your experiences will not be disclosed to the psychologist in case you are referred to him. However, if the information might be needed to enhance your management, your permission will be sought before disclosing it. Data collection and analysis will be carried out by the primary researcher with ongoing consultation with supervisors. The research assistant will only ensure that you have signed or thumb printed appropriately before the interview commences. All transcripts will be coded and as such any source of information will be known only by me and in some cases authorised personnel such as my supervisors. Also, all information pertaining to this study such as audio recordings and transcripts will be stored in a password protected computer, accessible only by me. In the final write up of the thesis, pseudo-names will be used when providing verbatim quotes.

Compensation

No amount of compensation can pay for the information you will provide. However as a sign of appreciation, you will be given a University of Ghana brooch. This will be given to you at the end of the data collection.

Voluntary Participation and Right to Leave the Research

Your involvement in this research is voluntary. Nothing will be demanded from you if you decide to leave the study. You may choose to leave withdraw from this study at any point, only that you have to inform the researcher if you wish to withdraw. As soon as you withdraw, all information belonging to you will be destroyed.
Contacts for Additional Information

Kindly contact the under listed if you have any questions. You may also use the same contact in case you incur any injury related to the research.

Name: Jonathan Bayuo
Tel: 0209266925

Dr. Patience Aniteye (Supervisor)
Tel: 0244681352

Prof. Pius Agbenorku
Tel: 0244599448

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant, you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.ug.edu.gh

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title *(Experiences of family caregivers of elderly burned patients)* has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

__________________________  ____________________________
Date                                                        Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:
I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

_______________________                  _______________________
Date                                      Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

___________                              _______________________
Date                                      Name Signature of Person Who Obtained Consent
APPENDIX C: GENERAL PROFILE OF PARTICIPANTS

<table>
<thead>
<tr>
<th>PSEUDONYM</th>
<th>AGE</th>
<th>SEX</th>
<th>MARITAL STATUS</th>
<th>RELIGION</th>
<th>EDUCATION BACKGROUND</th>
<th>OCCUPATION</th>
<th>RELATIONSHIP TO PATIENT</th>
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<tr>
<td>Afia</td>
<td>38</td>
<td>F</td>
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<td>Christian</td>
<td>Basic School leaver</td>
<td>Trader</td>
<td>Sister</td>
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<td>Single</td>
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<td>Diploma</td>
<td>Public servant</td>
<td>Daughter</td>
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<tr>
<td>Mercy</td>
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<td>F</td>
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<td>Christian</td>
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<td>Trader</td>
<td>Daughter-in-law</td>
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<tr>
<td>Esi</td>
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<td>Christian</td>
<td>None</td>
<td>Unemployed</td>
<td>Daughter</td>
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<tr>
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<td>Islam</td>
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<td>Trader</td>
<td>Daughter-in-law</td>
</tr>
<tr>
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<td>Christian</td>
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<td>Fiancée</td>
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<tr>
<td>Michael</td>
<td>48</td>
<td>M</td>
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<td>Christian</td>
<td>Ordinary Level</td>
<td>Artisan</td>
<td>Brother</td>
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<td>Daughter</td>
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<tr>
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<td>Occupation</td>
<td>Relation</td>
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<tr>
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<td>35</td>
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<td>Trader</td>
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<tr>
<td>Yaa</td>
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<td>Christian</td>
<td>None</td>
<td>Trader</td>
<td>Spouse</td>
</tr>
</tbody>
</table>
APPENDIX D: ETHICAL CLEARANCE

NOGUCHI MEMORIAL INSTITUTE FOR MEDICAL RESEARCH
Established 1979
A Constituent of the College of Health Sciences
University of Ghana

INSTITUTIONAL REVIEW BOARD

Phone: +233-302-016438 (Direct)
+233-289-522574
Fax: +233-302-502182/515202
E-mail: irir@noguchi.mimcem.org
Teles No: 2556 UGL GH

My Ref. No: DF22
Your Ref. No:

18th November, 2016

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824
IRB 00001276
NMIMR-IRB CPN 044/16-17
IORG 0000908

On 18th November, 2016, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) conducted expedited review and approved your revised protocol titled:

TITLE OF PROTOCOL: End of life care experiences of family caregivers of older burned clients at the Komfo Anokye Teaching Hospital

PRINCIPAL INVESTIGATOR: Jonathan Bayuo, MPhil Cand.

Please note that a final review report must be submitted to the Board at the completion of the study. Your research records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 17th November 2017. You are to submit annual reports for continuing review.

Signature of Chair: 
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)
APPENDIX E: APPROVAL LETTER FROM RESEARCH SETTING

Mr. Jonathan Bayuo  
Burns Intensive Care Unit  
Directorate of Surgery  
Komfo Anokye Teaching Hospital  
Kumasi  
Ghana.

Dear Sir,

RE: APPLICATION TO CONDUCT RESEARCH ON END OF LIFE CARE EXPERIENCE IN BURNS MANAGEMENT AT KATH.

In response to your application letter dated 12th December 2016, requesting for permission to conduct a research on “END OF LIFE CARE EXPERIENCE IN BURNS MANAGEMENT” at the Komfo Anokye Teaching Hospital in Kumasi.

I wish to communicate the acceptance of your application to you. I am by this letter permitting you to conduct the said study in respect to the understated conditions.

You are required to submit a photocopy of the approval letter from the KNUST Committee of Human Research Publication and Ethics or any accredited Institutional Review Board to the Department of Surgery.

Clinical data to be obtained from the Department of Surgery must remain confidential throughout your study. The data should be used solely for this research.

You are required to communicate the outcome of this study to the Department of Surgery.

Wishing you successful in your clinical investigations.

Yours faithfully,

[Signature]

Dr. Christian Kofi Gyasi-Sarpong  
Head, Department of Surgery
APPENDIX F: CERTIFICATE OF REGISTRATION AT KATH

KOMFO ANOKYE TEACHING HOSPITAL
RESEARCH AND DEVELOPMENT UNIT (R & D)
CERTIFICATE OF REGISTRATION

REG. NO: RD/CR17/005

This is to certify that

Prof/Dr/Mrs/Mr/Ms. Jonathan Beyong

has registered his/her proposed study titled End of life care experiences in burn management

with the Research and Development Unit.

Date: 5th January, 2017

Name of issuing officer
Mr. Juliet Amede Ato Frimpong

Signature

Receipt No K/16/0162162

**This certificate does not constitute ethical clearance for the conduct of the study but proof of registration of study with KATU. Ethical clearance from the Committee of Human Research Publications and Ethics (CHRP&E) is required to conduct the study.**
APPENDIX G: MAP OF KUMASI METROPOLIS

Source: http://www.ghanabooksjwp.com/apps/photos/photo?photoid=113429022
<table>
<thead>
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<th>THEME</th>
<th>SUB-THEME</th>
<th>CODE</th>
<th>DESCRIPTION</th>
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<tr>
<td>Injury and reactions of caregivers</td>
<td>Cause and nature of injury</td>
<td>CNJ</td>
<td>This describes the how the burn injury occurred and its characteristics</td>
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<td></td>
<td>Confusion/shock/anxiety</td>
<td>CSA</td>
<td>These describe the emotional responses to the occurrence of the burn injury</td>
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<td></td>
<td>Devastation</td>
<td>D</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helplessness and hopelessness</td>
<td>HH</td>
<td></td>
</tr>
<tr>
<td>Hospitalisation and associated stressors</td>
<td>Hospital environment, processes and policies</td>
<td>HEPP</td>
<td>It describes the setting where caregiving occurred and further elucidates the context of the caregiving as well as some stressors</td>
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<td>Caregivers’ experiences</td>
<td>CE</td>
<td>It describes how participants journeyed through the caregiving process</td>
</tr>
<tr>
<td>Effects of caregiving</td>
<td>Positive effects</td>
<td>PE</td>
<td>It describes the positive outcomes associated with caregiving</td>
</tr>
<tr>
<td></td>
<td>Negative effects</td>
<td>NE</td>
<td>It describes the negative outcomes associated with caregiving</td>
</tr>
<tr>
<td>Coping Strategies</td>
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<td>Adjusting to the</td>
<td>ADJ</td>
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<tr>
<td>caregiving situation</td>
<td>ENC</td>
<td>These describe how participants coped with the demands of caregiving</td>
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<tr>
<td>---------------------------</td>
<td>------------------------------------------</td>
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<tr>
<td>Encouragement from nurses</td>
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<table>
<thead>
<tr>
<th>Support</th>
<th>FAM</th>
<th>These describe the sources of support for family caregivers</th>
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<tr>
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<td>Neighbours</td>
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<tr>
<td>Affiliated religious groups</td>
<td>ARG</td>
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<tr>
<td>Colleagues at work</td>
<td>COL</td>
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</tr>
<tr>
<td>Other caregivers in the hospital</td>
<td>OCH</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Expected and real outcome of injury</th>
<th>RDL</th>
<th>This describes the outcome that participants had hoped for regarding the burned patient and real outcome they witnessed.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Recovery, Death, and Loss</td>
<td></td>
<td></td>
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</table>