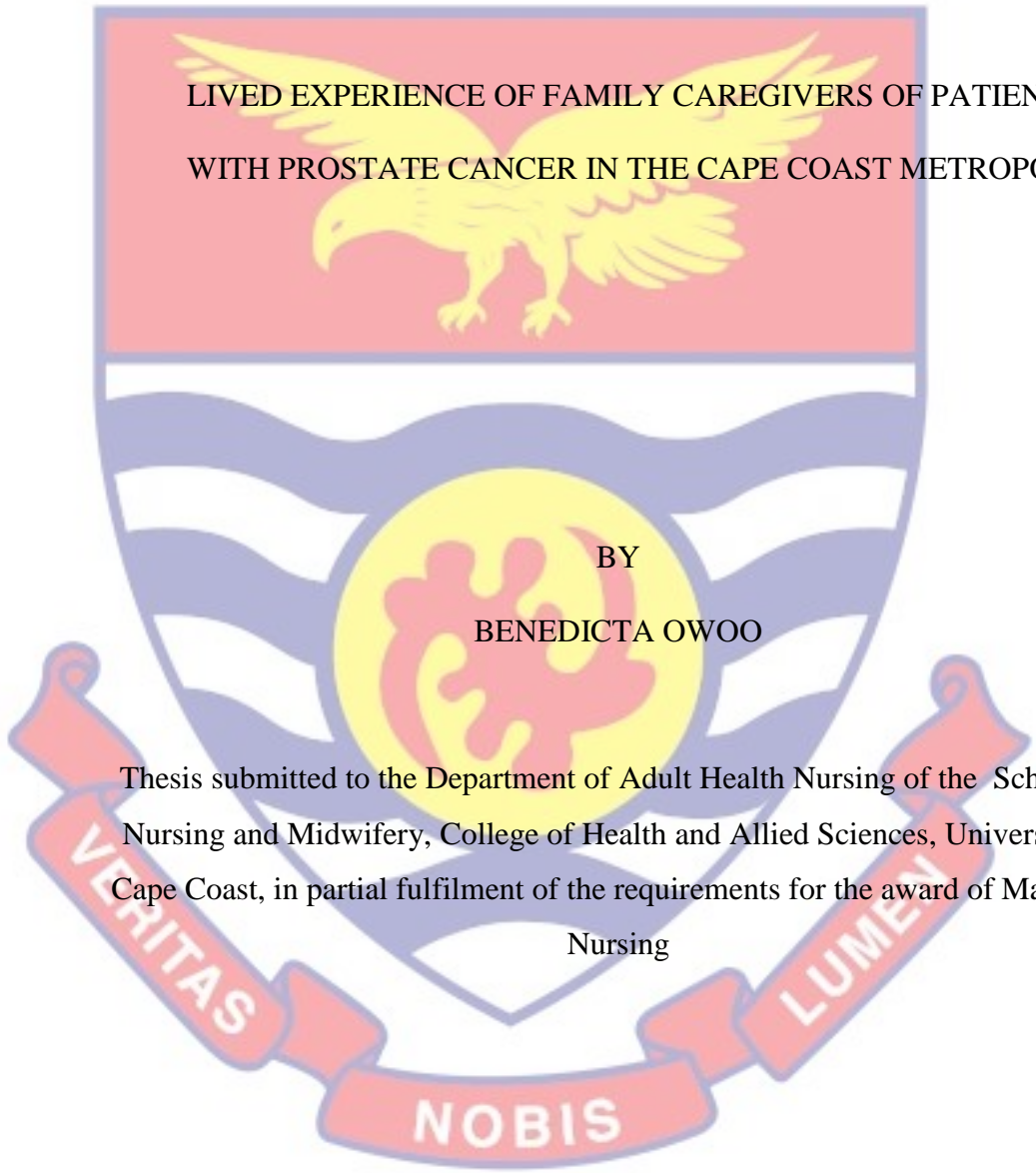


UNIVERSITY OF CAPE COAST



2019

UNIVERSITY OF CAPE COAST



LIVED EXPERIENCE OF FAMILY CAREGIVERS OF PATIENTS
WITH PROSTATE CANCER IN THE CAPE COAST METROPOLIS

BY
BENEDICTA OWOO

Thesis submitted to the Department of Adult Health Nursing of the School of Nursing and Midwifery, College of Health and Allied Sciences, University of Cape Coast, in partial fulfilment of the requirements for the award of Master of Nursing

JULY 2019

DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Candidate's Signature:.....Date

Name:

Supervisor's Declaration

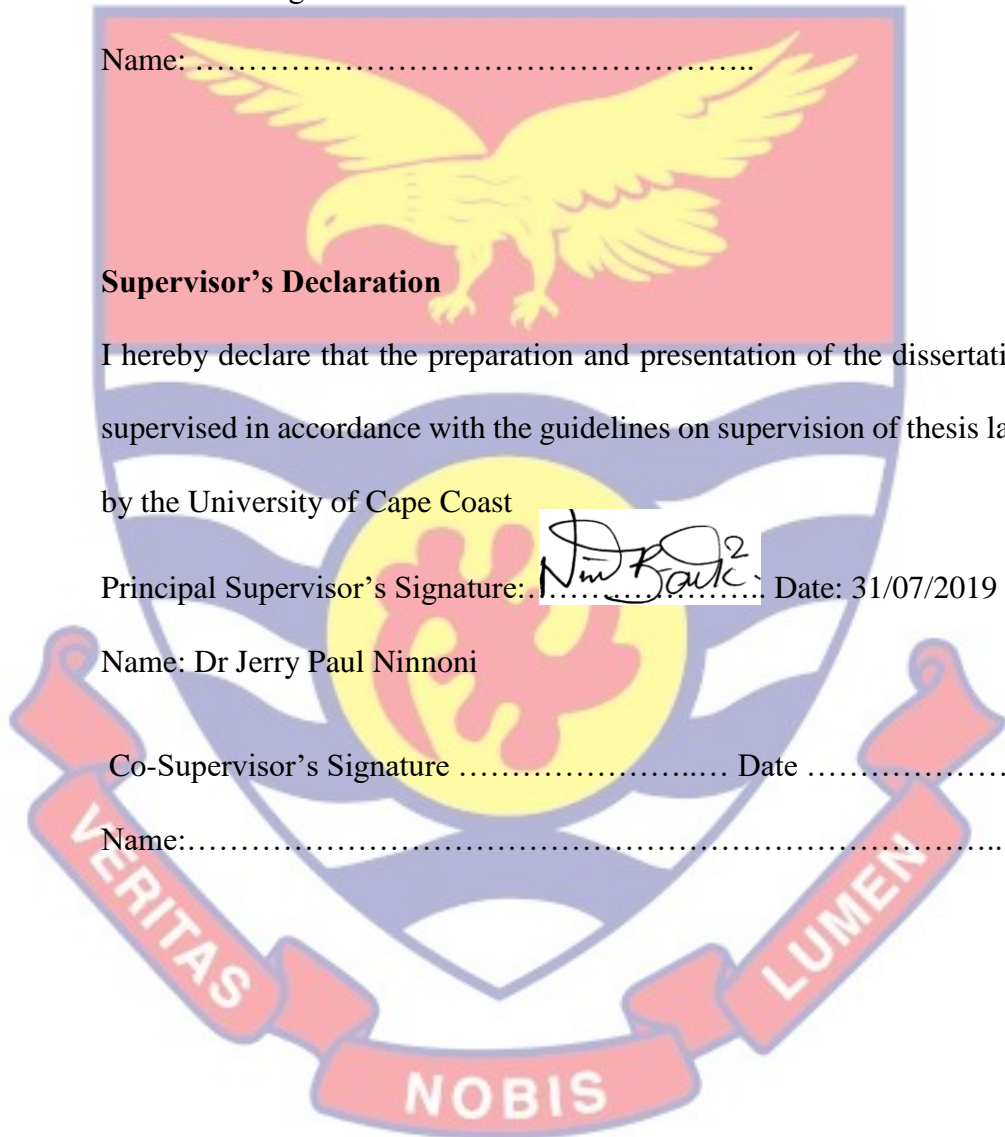
I hereby declare that the preparation and presentation of the dissertation were supervised in accordance with the guidelines on supervision of thesis laid down by the University of Cape Coast

Principal Supervisor's Signature:  Date: 31/07/2019

Name: Dr Jerry Paul Ninnoni

Co-Supervisor's Signature Date

Name:.....



ABSTRACT

Family caregivers play important roles in the overall well-being of people with prostate cancer. However, these roles are less recognized and often shrouded with challenges along with significant impacts on quality of life. This study explored the lived experience of family caregivers of patients with prostate cancer. The study adopted a qualitative approach using a descriptive phenomenological overtone. Twelve family caregivers of patients with prostate cancer were recruited. Four core themes emerged that described caregivers lived experience: the effects of caregiving; (these include physical impact, psychological impact and social impact), challenges confronting caregivers of prostate cancer patients, difficulties encountered within the healthcare environment and coping strategies adopted by family caregivers of prostate cancer patients. Data were analyzed using technique consistent with analyzing phenomenological data. The results showed that caregivers were faced with issues such as sleeplessness, fatigue, altered eating pattern, anxiety, inadequacy, “care as an obligation” hopelessness. Turmoil, loss of livelihood, role/role adjustment as well as lack of preparedness, lack of knowledge about the condition, misconception and financial constraints were also found as challenges. In an attempt to cope with these difficulties, family caregivers relied on support systems available and actively planned. In view of this, it can be concluded that caring for a loved one with prostate cancer is demanding, thus, posing a lot of concerns and worries to the family caregiver as they suppress their own needs in order to support their sick loved ones. The findings of this study can be used to guide clinical practice in the care of prostate cancer patients/family caregivers.

KEYWORDS

Coping

Family caregiver

Lived experiences

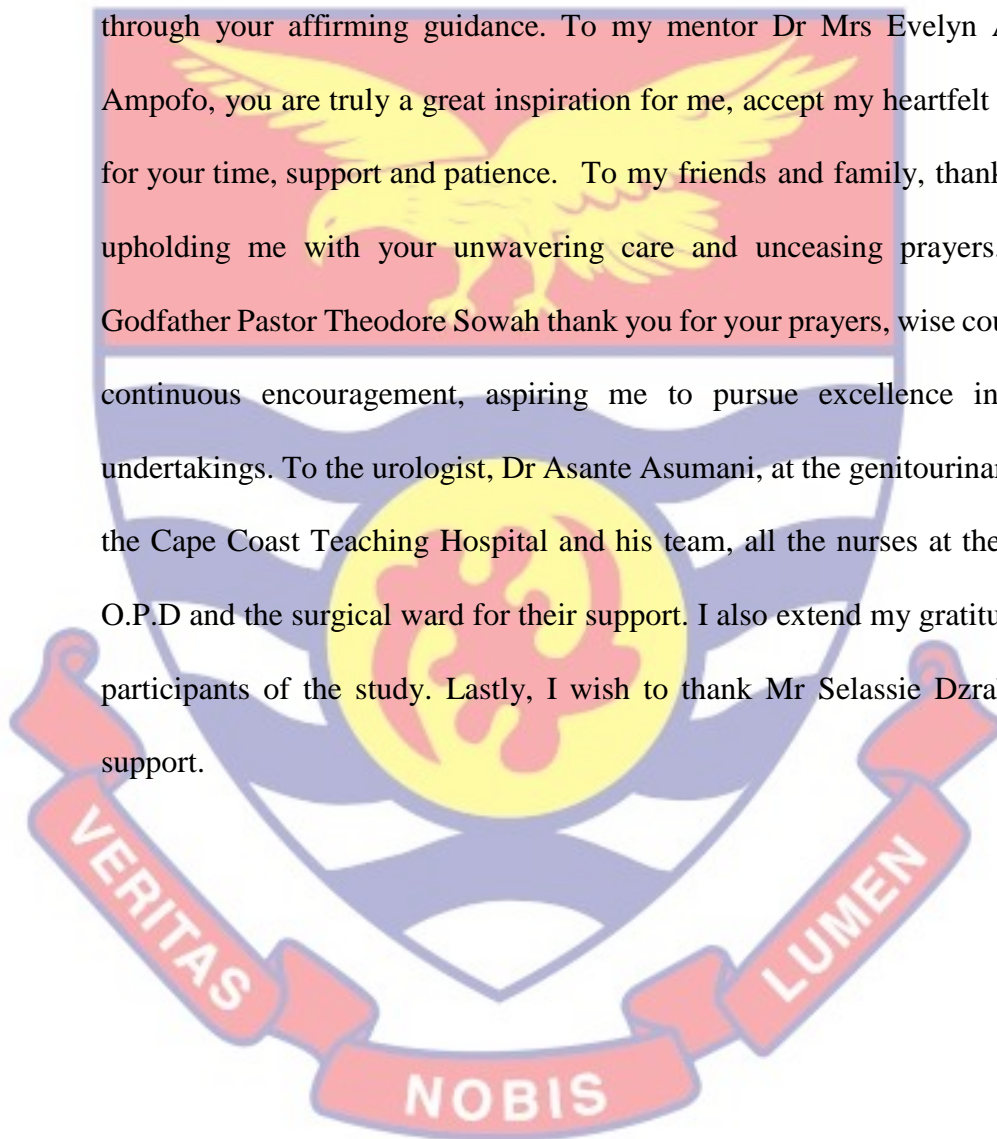
Patient

Prostate cancer



ACKNOWLEDGEMENTS

My first acknowledgement goes to the Author and Perfector of my faith, thank you for your surpassing goodness and faithfulness, bringing to completion, this thesis. To my supervisors, Dr Jerry Ninnoni and Dr Samuel Victor Nuvor thank you for investing your knowledge and wisdom in me through your affirming guidance. To my mentor Dr Mrs Evelyn Asamoah Ampofo, you are truly a great inspiration for me, accept my heartfelt gratitude for your time, support and patience. To my friends and family, thank you for upholding me with your unwavering care and unceasing prayers. To my Godfather Pastor Theodore Sowah thank you for your prayers, wise counsel and continuous encouragement, aspiring me to pursue excellence in all my undertakings. To the urologist, Dr Asante Asumani, at the genitourinary unit of the Cape Coast Teaching Hospital and his team, all the nurses at the surgical O.P.D and the surgical ward for their support. I also extend my gratitude to the participants of the study. Lastly, I wish to thank Mr Selassie Dzrah for his support.



DEDICATION

This work is dedicated to my late father, Mr Benjamin Owoo



TABLE OF CONTENTS

	Page
DECLARATION	ii
ABSTRACT	iii
KEYWORDS	iv
ACKNOWLEDGEMENTS	v
DEDICATION	vi
TABLE OF CONTENTS	vii
LIST OF TABLES	xiii
LIST OF FIGURES	xiv
LIST OF ACRONYMS	xv
CHAPTER ONE: INTRODUCTION	
Background of the Study	1
Overview of Prostate Cancer	2
Prostate Cancer Trends	5
Effect of Prostate Cancer on the Family Caregiver	7
Barriers Associated with Caring	9
Family caregiver Coping Strategies	10
Statement of the Problem	12
Purpose of the Study	15
Research Objectives	15
Research Questions	16
Significance of the Study	16
Delimitations	17
Limitations	17
Definition of Terms	18

Organization of the Study	18
CHAPTER TWO: REVIEW OF RELEVANT LITERATURE	
Introduction	20
Prevalence of Prostate Cancer	20
Prevalence in Terms of Married and Unmarried Couples	21
The concept of Caregiving and its conceptualization within the Ghanaian context	23
Caregivers Experiences of Caring for People with Prostate Cancer	25
Psychological Experience of the Family Caregiver	26
Physical Experience of Family Caregivers	28
Social Experience of Family Caregivers	29
Barriers to Caring for People with Prostate Cancer	33
Coping Strategies of Caregivers Caring for Prostate Cancer Patients	40
Theoretical Frameworks	43
Resiliency Model of Family Stress, Adjustment and Adaptation	43
Health Belief Model (HBM)	47
Transactional Model of Stress, Coping and Adaptation (Lazarus & Folkman, 1984)	52
The Quality of Life (QoL) Model Applied to the Family Caregiver	55
Conceptual Framework for the Study	57
Chapter Summary	61
CHAPTER THREE: RESEARCH METHODS	
Introduction	62
Research Design	62
The Rationale for the Design	65

Study Area	65
Population	66
Inclusion and Exclusion Criteria	66
Sampling Procedure	67
Data Collection Instrument	68
Pre-Testing	69
Data Collection Procedure	70
Data Storage	71
Data Processing and Analysis	72
Step one: Reading and re-Reading all Participants Verbatim Transcription	75
Step two: Extract Significant Statements	75
Step Three: Formulating Meaning	77
Step four: Formulated meanings are arranged in themes	78
Step Five: Results were incorporated into a rich and exhaustive description of the lived experiences	78
Step Six: Validation of the exhaustive description from the participants involved in the research	79
Step Seven: Incorporate any new or pertinent data obtained into the final study	80
Ethical Consideration	82
Methodological Rigor	83
The Use of Bracketing in this Study	85
Chapter Summary	88
CHAPTER FOUR: RESULTS AND DISCUSSION	
Description of Participants Demographic Characteristics	89

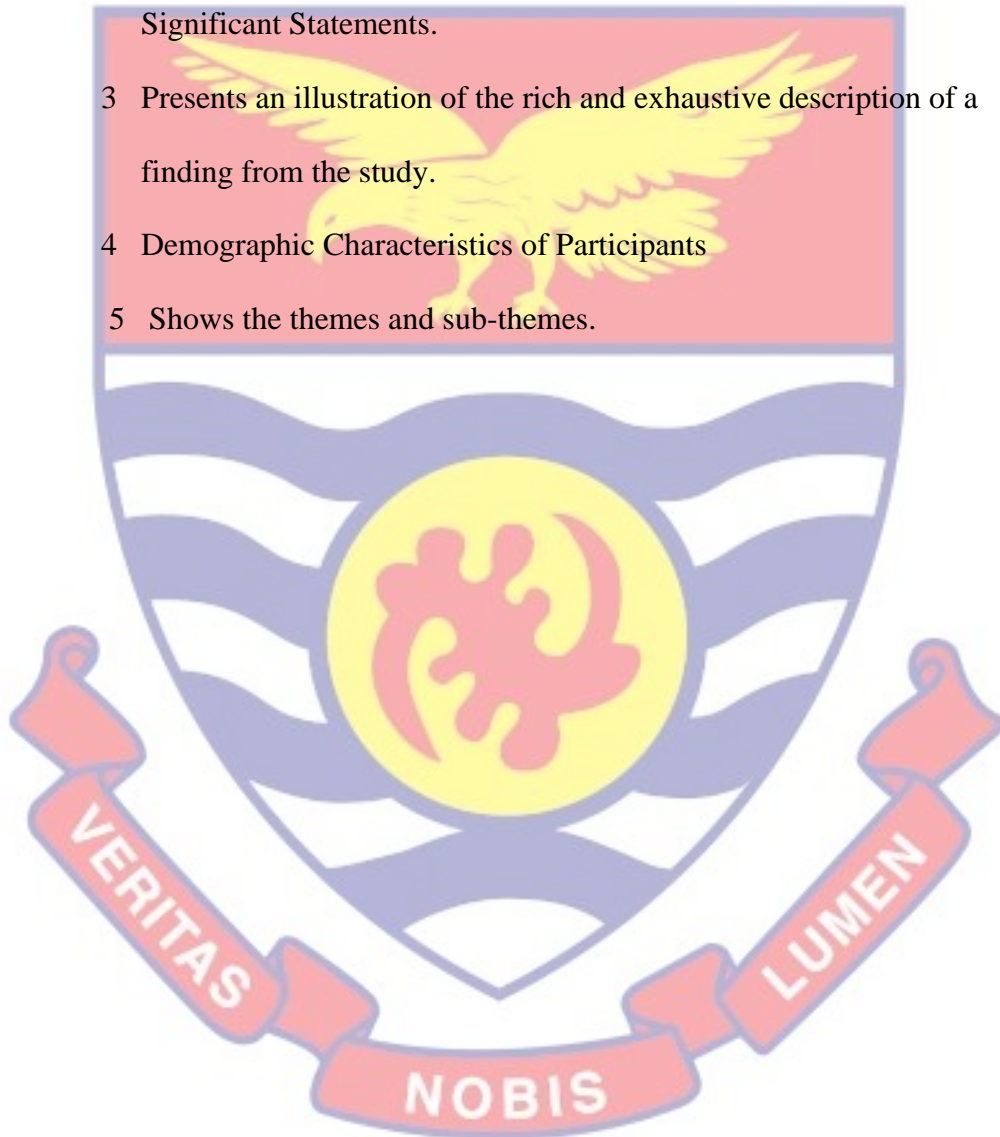
Key Findings from the Analysis	92
Difficulties encountered within the healthcare environment affecting the caregiver's role	92
Physical Impact of caregiving	93
Sleeplessness	93
Pain	96
Altered Eating Pattern	97
Worsening of Pre-existing condition	99
Fatigue	100
Psychological Impact	101
Anxiety	102
Empathy	104
Care as Obligation/ 'Giving Back'	104
Feeling inadequate	105
Hopelessness (halted life)	106
Uncertainty	107
Concealment	108
Social Impact	109
Sexual Concerns	109
Role /Role adjustment	111
Loss of livelihood	113
Grooming	114
Turmoil	115
Leisure activities	115
Challenges Confronting Caregivers of Patients with Prostate Cancer	117

Lack of Preparedness towards Caregiving Role	118
Lack of Knowledge about Condition and Treatment	119
Misconception about the condition	121
Financial constraint	122
Lacked knowledge about available resources	123
Communication concerns between caregivers and healthcare professionals	124
Difficulties encountered within the healthcare environment affecting the caregiver's role.	125
Lack of accommodation facilities	125
Poor Staff Attitude	126
Coping strategies used by family caregivers	128
Religiosity	128
Active Planning	130
Denial/Acceptance	130
Relaxation/ Listening to music	131
Support Systems	132
Medication abuse/ self-medication	135
Summary of Findings	135
Discussion of Findings	138
Demographic Characteristics of the Participants of the study	139
Effects of Caregiving	141
The Physical Impact of the Caregiving Role	141
The Psychological Impact of Caregiving	145
Social Impact of Caregiving on the Family Caregiver	151
Challenges confronting caregivers of patients with prostate cancer	154

Difficulties encountered within the healthcare environment affecting the caregiver's role	158
Coping strategies used by family caregivers	160
CHAPTER FIVE: SUMMARY, IMPLICATION, LIMITATION, CONCLUSION AND RECOMMENDATION	
Summary	165
Implications of Findings	167
Nursing Practice	167
Nursing/public education	168
Nursing Research	169
Conclusion	169
Limitations	170
Recommendation	170
REFERENCE	174
APPENDIX A: INFORMED CONSENT FORM	220
APPENDIX B: DATA COLLECTION INSTRUMENT	223
APPENDIX C: ETHICAL CLEARANCE	226
APPENDIX D: IRB ETHICAL CLEARANCE	227
APPENDIX E: CCTH ETHICAL CLEARANCE	228
APPENDIX F: INTRODUCTORY LETTER	229

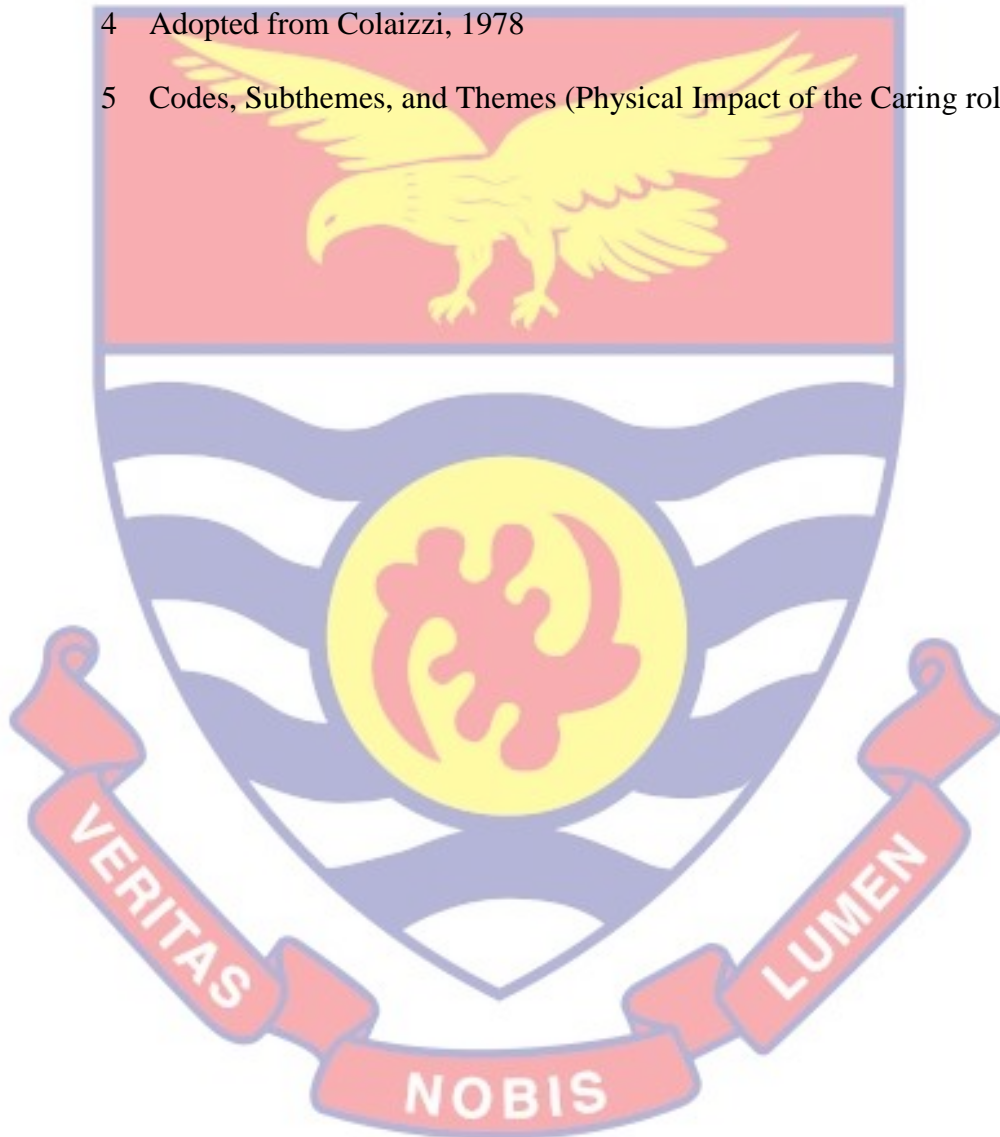
LIST OF TABLES

Table	Page
1 Example of the Process of Extracting Significant Statements/Phases from the Verbatim Transcripts.	76
2 Examples of the Process of Creating Formulated Meanings from Significant Statements.	77
3 Presents an illustration of the rich and exhaustive description of a finding from the study.	79
4 Demographic Characteristics of Participants	91
5 Shows the themes and sub-themes.	92



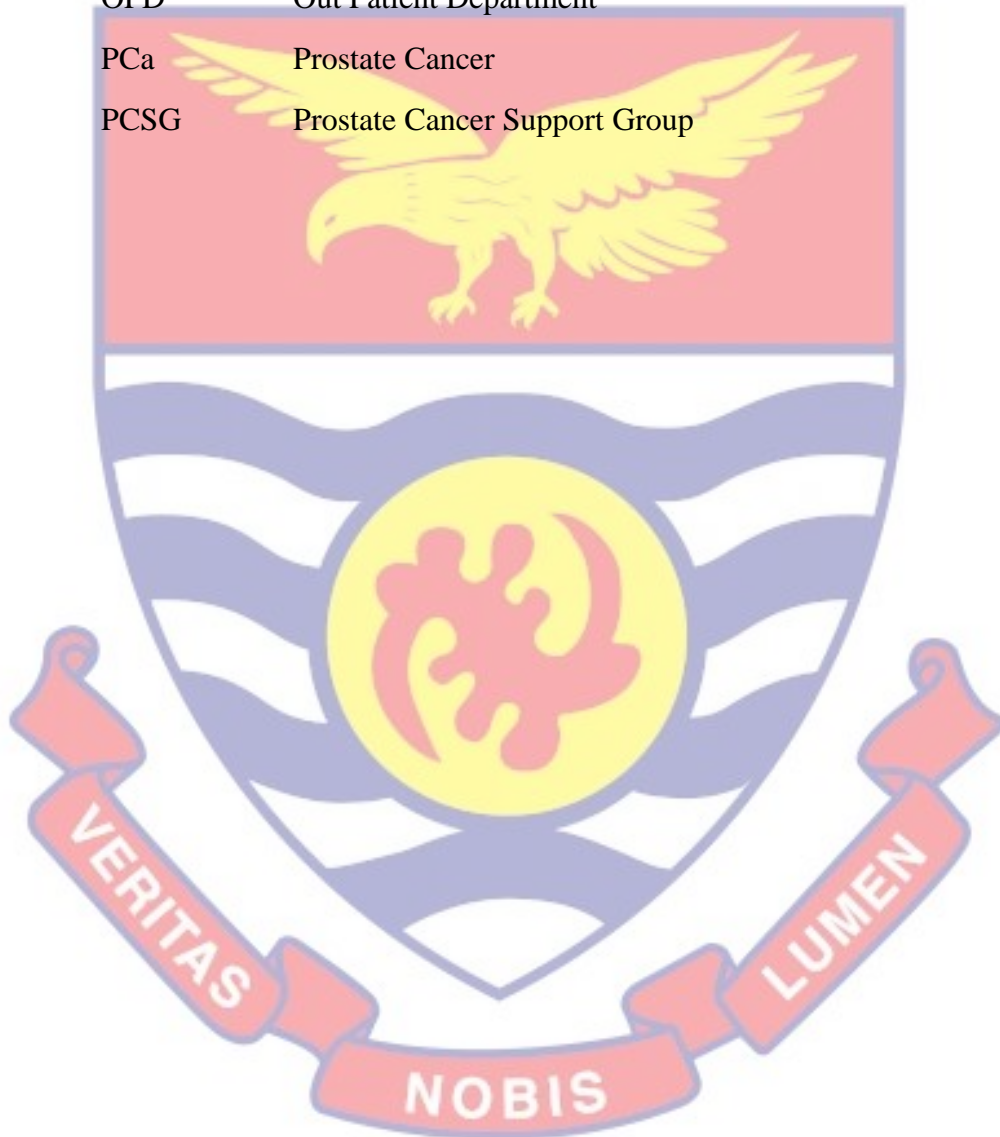
LIST OF FIGURES

Figure	Page
1 Health Belief Model	51
2 Quality of Life Model Applied to Family Caregiver	57
3 Conceptual Framework	60
4 Adopted from Colaizzi, 1978	74
5 Codes, Subthemes, and Themes (Physical Impact of the Caring role)	81



LIST OF ACRONYMS

AICR	American Institute for Cancer Research
CCTH	Cape Coast Teaching Hospital
DRE	Digital Rectal Examination
FCG	Family caregiver
OPD	Out Patient Department
PCa	Prostate Cancer
PCSG	Prostate Cancer Support Group



CHAPTER ONE

INTRODUCTION

Background of the Study

Caring is a phenomenon that has increased in importance during the past decade due to the increasing incidence of cancer. Providing care to cancer patients' is demanding. The complexity and uniqueness of care given to cancer patients vary depending on the type of cancer, stage of the illness, and type of treatment. The caring roles and responsibilities start when cancer is diagnosed and may extend for several years until the cancer is cured or takes the life of the individual. The family caregivers of patients with prostate cancer have many responsibilities (Waller, Girgis, Currow, Lambert, & Johnson, 2013) as they become the long-term care providers for these patients. They are expected to provide complex care at home with little resources, information, and support, yet, the healthcare system rarely addresses the challenging needs of these caregivers.

Globally, cancer is one of the major leading causes of death. The World Health Organization [WHO], (2018) report, showed that 9.6 million people died of cancer with 18.1 million new cases recorded annually. About 43.8 million people worldwide are living with cancer (WHO, 2018). Over the past 20 years, an increasing trend regarding cancer incidence and death has been evidenced worldwide, especially in low- and- middle-income countries (LMICs). In Sub-Saharan Africa, the incidence of cancer is growing rapidly and estimated to exceed 1 million by 2030 (O'Brien et al., 2013). Sub-Sahara Africa is projected to carry about 80 per cent of the global cancer burden by 2030 (Farmer et al., 2010). These

negative outlooks will place significant burdens on families and the nation as a whole.

It is estimated that by 2020, 10 million patients will die of cancer in Sub-Saharan Africa. Nigeria currently records the highest cancer death rate in Sub-Saharan Africa, accounting for about 10,000 cancer mortality and 250,000 new cases recorded yearly (Fitzmaurice et al., 2018). Global Cancer Incidence, Mortality and Prevalence [GLOBACAN],(2012) report estimated that 16,600 cases of cancer occurred annually in Ghana, yielding an age-standardized rate of 109.5 cases per 100,000 persons. Reports also showed that there were 10,160 new cancer cases recorded between 2000 and 2012 (WHO, 2018), with the Korle–Bu Teaching hospital (KBTH) recording 1,136 new cases of cancer in 2012. This was as a result of varying lifestyle, behavioural patterns, geographic and environmental factors (Bray, Jemal, Grey, Ferlay, & Forman, 2012). Delayed presentation to health facilities and deprived access to diagnostic technologies are also contributing factors (Marfo-Amankwah, 2016). Among cancers of the lung, colorectal, liver and stomach, prostate cancer is the second most common form of cancer affecting men globally (American Cancer Society, 2018).

Overview of Prostate Cancer

Prostate cancer is marked by an uncontrolled (malignant) growth of cells in the prostate gland. The prostate is the walnut-sized gland in men. Located just below the bladder and in front of the rectum. The prostate produces and stores fluid that helps to make semen, and is involved in regulating bladder control. Prostate cancer is one of the most common types of cancer found in men in the United State

and often begins without symptoms. In 2018, the American Cancer Society estimated that 164,690 men will be diagnosed with prostate cancer, 29,430 will die from the disease and 1 in every 9 men will be diagnosed with prostate cancer during their lifetimes. Prostate cancer can be slow-growing, such that many men die of other diseases before prostate cancer causes significant problems (American Cancer Society, 2018; Zanchetta et al., 2018). However, many prostate cancers are more aggressive and can spread outside the confines of the prostate gland, which can be deadly. The prostate cancer survival rate is greatly improved with early detection (American Cancer Society, 2018).

Although prostate cancer affects millions of men worldwide, adenocarcinoma prostate cancer is the most common (American Cancer Society, 2018). While treatment options and presentation of prostate adenocarcinomas are frequently studied, less is known about the other types of prostate cancers. These rare prostate cancers include prostate sarcomas, neuroendocrine tumours, small cell carcinomas, transitional cell carcinomas, and squamous cell carcinomas (American Cancer Society, 2018).

Furthermore, it is not yet known exactly what causes prostate cancer, however, some men are at higher risk than others for prostate cancer, and this may determine when to have a screening test done. Also, the risk increases with age, particularly after age 50 (American Cancer Society, 2018; Verhage & Kiemenev, 2003). Other risk factors may include: men of African American descent being twice likely as white men to develop the disease, having a family history of prostate cancer where a father or a brother was diagnosed with prostate cancer, particularly

if it is at a relatively early age (family history has been identified as a major risk factor) (Lessick & Katz, 2006), consumption of high-fat diet and/or obesity, smoking and living a sedentary lifestyle (American Cancer Society, 2018).

Also, prostate cancer frequently has no specific clinical symptoms. Although lower urinary tract symptoms may be present, these are neither specific nor sensitive enough to diagnose prostate cancer. Lower urinary tract symptoms are more specific to benign prostatic hyperplasia (BPH) and thus, not directly correlated to the presence of prostate cancer. But, if prostate cancer is present, lower urinary tract symptoms may also be present, especially if the prostate enlarges or intrudes into the urethral space. Lower urinary tract symptoms may include urgency, hesitancy, frequency, dysuria, weak stream, and urine leakage. In rare cases, men may experience certain symptoms when they have advanced prostate cancer (American Cancer Society, 2018). These symptoms are, however, also present in many men who do not have cancer. Some of these symptoms can include difficulty emptying the bladder, blood in the urine, and bone pains.

In a review article, Hamilton and Sharp (2004) determined that lower urinary tract symptoms were more prevalent in the presence of prostate cancer, yet the high prevalence of these symptoms among the general population decreases their predictive value. Therefore, there is no evidence that lower urinary tract symptoms are associated with localized prostate cancer and the presence of these symptoms are not sensitive or specific enough to aid in the diagnosis of prostate cancer. At present, there are no symptoms that are specific to the diagnosis of prostate cancer. Hence, rather than rely on symptoms, patients should have routine

prostate cancer screening, which includes a digital rectal examination (DRE), obtaining a blood sample to determine the presence of the prostate-specific antigen (PSA) or urine sample taken for new urinary (PCA3 and MDx Select) and blood (4K score and PHI test) biomarkers. If one or two of these screening examinations are abnormal, further investigation is carried out. Intervention at this stage allows prostate cancer to be detected early when it may be localized and treatment may cure or control the disease. Moreover, according to the American Cancer Society (2018), the treatment options for prostate cancer include; active surveillance, surgery, radiation therapy, cryotherapy, hormonal therapy, chemotherapy, vaccine treatment and prevention, and treatment of prostate cancer spread to bones.

Prostate Cancer Trends

Prostate cancer is a significant public health burden and a major cause of morbidity and mortality among men worldwide (American Cancer Society, 2018). A report by the American Institute for Cancer Research [AICR] showed that there were 1.3 million new cases recorded in 2018 (American Institute for Cancer Research [AICR], 2019). Australia, New Zealand, Northern, and Western Europe, and North America recorded the highest incidence rates. The report further revealed that there has been a dramatic increase in the age-adjustment incidence rates. This is due to an increase in the availability of screening for prostate-specific antigen in men at early stages. Also, the lifetime risk of developing the disease is one in six with the majority of these diagnoses occurring in men between the ages of 50 and 70 (Stefan, 2015). Currently, over 2.2 million men are living in the United States with prostate cancer and this number will greatly increase during the next half of

the century (American Cancer Society, 2018). In 2011, 240,890 new cases of prostate cancer were diagnosed in the United States (Torre, Siegel, Ward, & Jemal, 2016). Again, mortality due to prostate cancer continues to be on an upward trend (Fitzmaurice et al., 2018).

In Africa, reports on the incidence rate of prostate cancer are limited due to few population-based cancer registries in most parts of the continent (Adeloye, David, & Aderemi, 2016). However, an observation made in countries where registers exist such as Nigeria, South African and Zimbabwe showed that the rate of prostate cancer is on the increase (Chu et al., 2011). GLOBOCAN, 2012 reports released by the International Agency for Research on Cancer (IARC), revealed that prostate cancer (PCa) incidence and mortality rates in Africa were 23.2 and 17.0 per 100,000 respectively. Twenty per cent of this increase can be attributed to a change in the population age structure, size, and age-specific incidence rates owing to rapid population growth, and increasing life expectancy.

In Nigeria, an estimated prevalence of 127 per 100,000 was recorded in 1997, 182.5 per 100,000 in 2016 was recorded with estimated new cases of 6,236 and deaths of 5,098 per year (Adeloye et al., 2016). The Prostate Cancer Foundation report also revealed that in Benin the estimated number of new prostate cases per year was 255, while the estimated number of deaths was 210. Burkina Faso has an estimated number of new cases per year at 305 and deaths at 261 whereas Ivory Coast has an estimated number of new cases per year at 847 and deaths at 706 (Adeloye et al., 2016).

Similarly, in Ghana, reports have shown that prostate cancer is a leading cancer diagnosis and cause of cancer-related deaths among men. The high mortality rate has been attributed to late presentation and lack of screening for Prostate-specific antigen (PSA), due to poor access to healthcare facilities, culture/belief systems and ignorance (Arthur, Yeboah, Adu-Frimpong, Sedudzi, & Boateng, 2006). According to a report by Obu (2015), the death rate of prostate cancer is higher than all other cancers (breast, cervical and childhood cancer), with only a 17.7% survival rate. A global cancer database compiled in 2010 by the International Agency for Research on Cancer indicated that 921 new prostate cancer cases and 758 prostate cancer-related deaths were recorded every year in Ghana. Furthermore, It has been reported that Ghana has exceeded the global prostate cancer limits, with 200 cases out of 100,000 as against 170 worldwide (Obu, 2015). Thus, the government must intensify the fight against prostate cancer, because it was killing more people than cervical and breast cancers. The figures were alarming if six men out of nine diagnosed with prostate cancer die (Obiri Yeboah, 2018). As the numbers increase and the condition advances the need for caregivers increase.

Effect of Prostate Cancer on the Family Caregiver

Prostate cancer, however, does not only affect the men suffering from the disease but also the family caregivers. Even as one tries to render the best support to the client, studies have shown that there is a reciprocal relationship between men and their family caregivers. Whereas men's quality of life declines, caregivers' quality of life also decreases (Ofori, 2017; Wu & Harden, 2015). Family caregivers (FCGs) play a vital role in the direct care and support of patients with cancer

(Ferrell, 2017). Some of the roles played by the family caregiver are medication management, provision of personal hygiene needs, assisting with mobility, repositioning of the patient, paying off bills and facilitating appointments/ reviews with the client. They also assist with medical decision making and the provision of emotional support when clients are in distress (OncoLink, 2016). Family caregivers may be the spouse/partner, children, parents, extended families/relatives, close friends or loved ones (Sun et al., 2015).

The caring role has its negative consequences including physical exhaustion such as fatigue, insomnia, anorexia, and illness on the family caregiver in advanced prostate cancer (Blum & Sherman, 2010). Nonetheless, family caregivers of patients with prostate cancer sometimes report higher levels of cancer-related distress than are expressed by the patients themselves (Chambers, Pinnock, Lepore, Hughes, & Connell, 2011). They often fail to express their own needs and feelings while focusing on providing support for their relation with cancer. In such situations, these caregivers face the risk of succumbing to a wide spectrum of hidden, physical, social and psychological morbidities, as consequences of their caregiving (Sun et al., 2015). In the area of physical well-being, caregivers are tasked with the physical care of patient resulting in overall diminished health because of the strains of caregiving (Blum & Sherman, 2010). Literature suggests that higher caregiver burden is even associated with increased caregiver mortality risk (McConnell, Clarke, Butow, Smith, & Sharpe, 2004). The psychological impact of caregiving is most often addressed as anxiety, depression, distress, fears, and uncertainty. These emotions exist throughout the trajectory of initial diagnosis,

treatment, remission, recurrence, and end of life or during long-term survival (Kim, Baker, & Spillers, 2007). The social domain addresses the interaction between the patient and family and the impact of cancer on relationships. Similarly, the disease and treatment regimen, financially and sexually impact the caregiving role. Likewise, communication between patients, primary FCGs, other family members, and clinicians are also key elements of the family experience (Goldsmith, Wittenberg, Platt, Iannarino, & Reno, 2016)

Barriers Associated with Caring

Living in close relation to a serious illness like prostate cancer is physical, mentally, and emotionally draining. As the caregiver tries to balance the challenging role (providing personal hygiene needs, medication management, lifting, repositioning, paying bills and going for appointments or reviews etc.) of caregiving and personal life. The issue of barriers associated with caring also becomes a concern. Barriers that hinder the care given to patients with prostate cancer in Ghana include lack/poor access to healthcare, financial issues and lack of knowledge about the condition (Arthur et al., 2006). Similarly, variations in culture/beliefs systems and poor communication were also barriers identified (Arthur et al., 2006).

On the contrary, while some caregivers considered the caring role as a burden, others believe that the role provided positive emotions/ high satisfaction. The time spent together was described as "Precious time" which allowed for the expression of their love for the patient (Waller et al., 2013). This assertion is supported by a study conducted by Akpan-idiok and Anarado (2014) on the

perception of the benefits of caregiving to patients with advanced cancer. In their findings, family caregivers reported that caring for a patient with advanced cancer was rewarding as it provided satisfaction, closeness with the advanced cancer patient and a sense of fulfilment.

In the same view, a survey conducted by Nayak and colleagues revealed that out of 768 respondents, the majority is 654 (85.1%) of them had financial problems, 750 (97.7%) had lack of knowledge about the disease and 681 (88.6%) of the family caregivers lacked knowledge about symptoms management (Nayak, George, & Vidyasagar, 2018). These barriers may intend, affect the coping strategies and further impact the quality of life of the family caregiver. For instance, according to Berry and colleagues, in a study on supporting the supporters, findings revealed that family caregivers of cancer patients with financial concerns sought financial support from established support systems that offer financial navigation services, tailored towards assisting with financial aid (Berry, Dalwadi, & Jacobson, 2018). LeSeure and Chongkhamang, in their study, reported that the information given by family caregivers showed that, providing care for a cancer patient was very burdensome, requiring tremendous effort (LeSeure & Chongkham-Ang, 2015). The family caregiver thus develops strategies in order to cope with the situation.

Family caregiver Coping Strategies

In an attempt to balance life with the caring role, the family caregiver adopts different strategies in order to cope. This is however made difficult because they are faced with a wide range of unfamiliar task for which they are unprepared. The

family caregiver has no idea how to carry out their role, how much care the patient needs and how to use current resources (Given, Sherwood, & Given, 2011). Also, limited support from health caregivers, resulting in the neglect of their health and inadequate coping reactions (Given et al., 2011). Folkman and colleagues defined coping as a process of managing requirements and difficulties caused by the individual's inner and outer world, expending cognitive and behavioural efforts to solve personal and interpersonal problems and seeking to control and reduce stress (Folkman, Lazarus, Dunkel-schetter, DeLongis, & Gruen, 1986). In Ghana, a study that investigated the experiences of family caregivers of people with mental illness found that religious prayers served as a major coping strategy among family caregivers (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015). In the same vein, Ofori, (2017), also in a study on experiences of spouses of men with prostate cancer revealed that the women seek help from God and religious leaders as a way of coping. This is because they perceived their experiences as a test from God. However, little is known about the coping strategies of caregivers of people with prostate cancer in the Cape Coast Metropolis. Other studies have also proved that caregivers of cancer patients use different coping strategies when it comes to difficulties encountered during caregiving (Fitzell & Pakenham, 2010; Redinbaugh, Baum, Tarbell, & Arnold, 2003). This statement aligns with Strang and Koop, (2003), who reported that better coping was evident in family caregivers who can plan well and had knowledge about the patient's condition. Likewise, patient caregivers who showed a positive attitude toward the caring role are better able to cope. Other coping strategies reported included; staying positive, searching for

hope, getting their mind off a straining situation, and comparing their situation to the worst case of others (Nayak et al., 2018).

The importance of the role that family caregivers provide to the health care community and their impact on the care of men living with prostate cancer is undeniable. The need, therefore, remains to provide them with the best care possible. A desire to understand the needs of family caregivers of men with prostate cancer provided the catalyst for the development and execution of this study in the Cape Coast Metropolis.

Statement of the Problem

The rising case or prevalence of prostate cancer in Sub-Saharan Africa and in particular Ghana is well reported in the literature (Adeloye et al., 2016; Arthur et al., 2006; Obu, 2015; Oluwole, Rafindadi, Shehu, & Samaila, 2015; Yeboah et al., 2016) thus, the need for family caregivers. These family caregivers provide care and support to their loved ones during times of illness. The caregiving role has been played with little preparation and guidance from formal health care providers (Berry et al., 2018). Due to inadequate knowledge and skill, family caregivers may be unfamiliar with the type of care they must provide or the amount of care needed (Reinhard, Given, Petlick, & Bemis, 2008). As a result, they often neglect their health care needs to assist their family member, causing deterioration in the caregiver's health and well-being.

Literature has reported that caregivers experience negative consequences as a result of the role they play (Kim & Given, 2008; Mazanec, Reichlin, Gittleman, & Daly, 2018; Nemati, Rassouli, Ilkhani, & Baghestani, 2018a). Some of these

challenges are psychological (increased tendency to cry, increased boredom, anxiety, and depression in late stages), physiological (tiredness, decreased appetite, changes in defecation, and decreased sleeping), and sociological (decreased interest in social issues, decreased interpersonal relationships, and decreased involvement in social activities) problems resulting in low quality of life (Rha, Park, Song, Lee, & Lee, 2015; Sercekus, Besen, Gunusen, & Edeer, 2014; Ugur, Elcigil, Arslan, & Sonmez, 2014). Other studies also indicated that when family caregivers were highly distressed, it affected the patient's long-term adjustment (Northouse, Templin, & Mood, 2001). Over time, a highly anxious family caregiver could increase the anxiety experienced by the patient (Badger, Segrin, Dorros, Meek, & Lopez, 2007). More so, distressed caregivers have more difficulty providing optimal patient care (Van Ryn et al., 2011), and administering medications to patients (Lau et al., 2010). These changes increase the likelihood that, the caregiver's health will suffer and subsequently, hinder their capacity to provide care.

In Ghana, men with prostate cancer are diagnosed late. This is due to late presentation to the healthcare facility and often at an advanced stage of the disease (Arthur et al., 2006) and low Prostate-specific antigen screening (Yeboah et al., 2016). Leading to a low detection rate, poor management, and increase mortality, accounting for 75% of deaths in men (Arthur et al., 2006). These may further be attributed to financial constraints, poor access to health care, culture/belief systems, and ignorance (Arthur et al., 2006). A study by Yamoah et al. (2012), showed that Korle- Bu Teaching Hospital recorded 20 advanced prostate cancer cases on

admission between February to April 2015. The caregivers of these patients were mainly family members (spouses, children, siblings, parents, cousins, aunts etc.) and are often unprepared for these caring roles due to various reasons.

Family caregivers may need information, emotional, social, and financial support from their families, friends and healthcare providers. Yet, attention has focused almost exclusively on improving patient outcomes (e.g., symptom management and quality of life). With less attention directed to the needs of family caregivers and the effect, the role has on them (Cochrane & Lewis, 2005).

Furthermore, several studies have been conducted in the area of prostate cancer but focused mainly on prevalence rates (Kimura & Egawa, 2018), treatment options (Cook et al., 2014; Siguenza, 2016), spousal support (Ofori, 2017), management (Yeboah et al., 2016), screening (Ogunsanya et al., 2017), knowledge/attitude (Amoah et al., 2018), factors influencing mortality (Obu, 2014a), age as a risk factor (Egote, Ossei, Quarshie, & Taylor, 2018), patient profile (Calys-tagoe et al., 2014), perception/attitude (Yeboah-asiamah, 2015) and incidence (Adeloye et al., 2016; Fitzmaurice et al., 2018; Obu, 2014b). However, family caregivers' experiences are often neglected. Also, in Ghana, research conducted on prostate cancer were in the Greater Accra (Asamoah et al., 2018; Calys-tagoe et al., 2014; Kyei, Klufio, Ayamba, & Mohammed, 2017; Obu, 2014b; Ofori, 2017; Otoo, 2010; Yamoah et al., 2012), Ashanti (Amoah et al., 2018) and Brong-Ahafo region (Egote et al., 2018; Yeboah-asiamah, 2015; Yeboah-Asiamah, Yirenya-Tawiah, Baafi, & Ackumey, 2017) where the main focus was on spousal experience, prostate cancer incidence, knowledge/attitude, perception, age at risk

and management of the condition. The majority of these studies employed a quantitative approach.

The only study that employed the qualitative approach is limited to spousal experience (Ofori, 2017) although significant others are caring for people with prostate cancer in Ghana. However, the knowledge retrieved from the studies conducted does not present a wider picture of the family caregiver experience in caring for patients with prostate cancer. Unlike the study which was limited to only spousal experience (Ofori, 2017). Little is known about the experiences of family caregivers of prostate cancer within the Cape Coast Metropolis. The present study will explore the experiences of family caregivers to include not only their spouses but relatives and significant others to enable a comprehensive understanding of their caring experiences.

Purpose of the Study

The purpose of the study was to explore the experiences of family caregivers of patients living with prostate cancer in the Cape Coast Metropolis.

Research Objectives

The study sought to achieve the following objectives;

1. To explore family caregiver experience of caring for people with prostate cancer.
2. To investigate barriers to caring for people with prostate cancer
3. To explore family caregivers coping strategies for people with prostate cancer

Research Questions

1. What are the experiences of caregivers caring for people with prostate cancer?
2. What are the barriers to caring for patients with prostate cancer?
3. What coping strategies do family caregivers of patients with prostate cancer have?

Significance of the Study

The findings of this study will give insight to health workers such as nurses, doctors, and clinical psychologists on exactly what family caregivers of patients with prostate cancer experience. This will encourage nurses to render holistic care to the client in addition to their family caregivers so that they can better understand the patient's condition.

The study findings intend to enable major stakeholder in the healthcare sector to design and develop protocols that can be applied to caring for patients with prostate cancer and their family caregivers. Equally, the outcome of the research will add to existing literature, as well as serve as a source of reference to other researchers who may wish to conduct studies in the same area.

The findings of the study will be very resourceful to the Ministry of Health, the Ghana Health Services, Cape Coast regional hospital and other stakeholders in their policy formulations. It is going to provide reasons for the establishment of prostate cancer support groups (PCASG) for family caregivers in Ghana. More so, in the area of culture results of the research intended to provide information regarding prostate cancer care needs of a culturally diverse population.

Delimitations

The researcher can gain first-hand knowledge about the experiences of participants through broad and open-ended inquiry (Rudestam & Newton, 2015), as data was collected through subjective and direct responses. The study was delimited to the physical, psychological and social experiences, as well as the barriers and coping strategies used by the family caregiver of people living with prostate cancer in the Cape Coast Metropolis.

Limitations

A major limitation associated with the present study was that the population consisted of exclusively family caregivers of prostate cancer patients. Thus, the findings may not necessarily be representative of caregivers of patients with other health conditions. However, the researcher was not interested in the generalization of finding, rather making meaning into experiences shared by participants. Likewise, the researcher's presence during data gathering which was often unavoidable in qualitative research can affect the responses of the participants. In an attempt to avoid this, the researcher ensured trustworthiness throughout the data collection process. Another limitation related to this study was that the process was time-consuming and labour-intensive (Creswell & Creswell, 2017) due to the copious amount of data that had to be analysed. Also, there were limitations linked to reliability and credibility. However, Patton argued that there were no straightforward tests that can be applied for reliability (Patton, 2002). Therefore, the researcher did her best in the interview phase to present data and communicate what the data reveals given the purpose of the study by ensuring rigour.

Yet, despite these limitations, the findings of this study provided an in-depth understanding of the experiences of family caregivers of men living with prostate cancer in the Cape Coast Metropolis.

Definition of Terms

Family caregiver: family caregiver may be the spouse/partner, children, parents, extended family/ relatives or friend.

Experience: anything the family caregiver goes through because of his/ her relations' disease or condition.

Patient: a person suffering from prostate cancer.

Quality of life: the family caregiver satisfaction with life condition, encircling the interaction of her physical, psychological, and social wellbeing.

Organization of the Study

This study was organized into five chapters. Chapter one consisted of the background to the study, the problem statement, the study objectives, research questions, the significance of the study, delimitations, and limitations of the study. Chapter two also dealt with a review of relevant literature. This was covered under the following: Experiences of family caregivers of patients with prostate cancer (physical experiences of the family caregiver of a patient living with prostate cancer; social impact of prostate cancer on the family caregiver; psychological experiences of family caregivers of patients living with prostate cancer). It will also look at the barriers in caring and the coping strategies employ during caring. Chapter three highlighted the methodological approaches used. It focused on the study area characteristics, and research design, population, sampling and sampling

size, study instrument, pre-test, the source of data, data collection, data management, and analysis as well as ethical considerations. Chapter four consisted of the findings and discussions. The chapter described and discussed issues such as the demographic background of the caregivers; psychological, social, physical experiences, barriers to caring as well as the coping strategies employed by the family caregiver. The last chapter covered the conclusion, a summary of major findings and recommendations of the study.



CHAPTER TWO

REVIEW OF RELEVANT LITERATURE

Introduction

This chapter focused on a review of literature relevant to the study. Areas covered under this section included the concept of caregiving and its conceptualization within the Ghanaian context, caregiver's experience of caring for people living with prostate cancer, investigated barriers to caring for people with prostate cancer and explored family caregiver coping strategies as they cared for people with prostate cancer. The chapter also included a conceptual framework for the study. Literature was retrieved from electronic databases such as ScienceDirect, PubMed, Wiley, SAGE, Google search and Google Scholar. The key terms used to retrieve relevant literature were caregiver, informal caregiver, experiences, prostate cancer, physical experiences, social experiences, psychological experiences, barriers, coping strategies and caring.

Prevalence of Prostate Cancer

Prostate cancer (PCa) is the second most commonly diagnosed malignancy and the leading cause of cancer mortality in men with significant public health burden (American Cancer Society, 2018). The incidence rate of prostate cancer in developed countries such as the United States, North America, Australia, New Zealand and Western and Northern Europe is reported to be the highest with a low mortality rate (Asamoah et al., 2018). This is likely due to the increase in Prostate-specific antigen screening and subsequent biopsies (Asamoah et al., 2018).

However, in Sub-Saharan Africa, the exact burden of prostate cancer remains largely unknown due to weak health systems, poor cancer registers (Adeloye et al., 2016) and a limited research environment with poor funding (Bello, 2017). As mentioned earlier, research has also established that high morbidity and mortality rate is due to late presentation to healthcare facilities in the advanced stage of the disease (Arthur et al., 2006; Bello, 2017; Yeboah et al., 2016).

Presently, a report in Ghana revealed that prostate cancer is the leading cause of death among men with a 17.7% survival rate (Obu, 2015). The report further suggests that six out of nine men diagnosed with prostate cancer die due to late presentation, lack of PSA screening, poor access to healthcare facilities, culture/belief systems and ignorance (Arthur et al., 2006; Yeboah et al., 2016). This increase has also increased the number of family caregivers as they automatically become the long-term caregivers of these men with little or no preparation.

Prevalence in Terms of Married and Unmarried Couples

Socioeconomic and demographic factors, including marital status, plays an important role in the prevalence of prostate cancer (Klaassen et al., 2015). Evidence shows that African American men with prostate cancer are less likely to be married (Gilligan, 2005). This supports the earlier works by Ross on the incidence rate of prostate cancer that shows similar findings (Ross et al., 1979). Also, findings from the earlier work of La Vecchia et al. (1993) is echoed in the current findings of Brown et al. (2018) in a study of social determinants of prostate cancer in the Caribbean: a systematic review and meta-analysis revealed that marriage was associated with a higher reported occurrence of prostate cancer.

Furthermore, Blumberg and colleagues also have reported that the social support extended by marriage is believed to promote health-seeking behaviour, leading to a greater chance of diagnosis (Blumberg, Vahratian, & Blumberg, 2014). Thus, without this social support, health-seeking reluctance may lead to delayed diagnosis and a higher risk of adverse outcomes. In contrast, a growing body of evidence explains that men with fewer sexual partners and subsequently lower rates of venereal disease, as well as men with a higher ejaculation frequency which are both likely conditions of a typical married life, could lower the risk of developing prostate cancer (Bae, 2015; Dennis & Dawson, 2002; Evans et al., 2010; Lian et al., 2016; Tyson et al., 2013). In view of the above, it is, therefore, appropriate to state that the social consequences of marriage might also include low prostate cancer mortality (Tyson et al., 2013). However, there are limited studies on the prevalence of prostate cancer among married and unmarried couples in Ghana. Other studies also examined the impact of marriage on the survival rate of prostate cancer patients (Abdollah et al., 2011; Gilligan, 2005)

A study conducted by Liu et al. (2018) on the impact of marriage on the overall survival of prostate cancer patients: surveillance, epidemiology and results (SEER) analysis revealed that marital status is a predictive factor for the survival of prostate cancer patients, as being married was associated with better outcomes. This finding is also mirrored in a study of marital status and prostate cancer by Tyson et al. (2013), who revealed that unmarried men (single, divorced, widowed and separated) have a higher risk of prostate cancer mortality compared to married men with similar age, race, stage and tumour grade. Others have also demonstrated

that marriage was a strong predictor of men seeking curative treatment as compared to their unmarried counterparts (Denberg, Beaty, Kim, & Steiner, 2005).

The Concept of Caregiving and its Conceptualization within the Ghanaian Context

The term “caregiving” is widely used and has been studied from a variety of perspectives, including nursing, sociology, and psychology (Mendez-luck, Kennedy & Wallace, 2009). Caregiving involves long-term caring for an individual with a chronic illness or physical disability or maybe intermittent and sporadic as in the case of caring for someone with an acute illness or an acute episode of a chronic illness (Scharlach et al., 2001). In the same vein, Stambor (2006) also viewed a caregiver as a person who attends to the needs of a dependent child or adult. Caregivers manage the physical, emotional, spiritual, and practical needs of another person while managing their own life, needs, family, and career.

Aboderin (2004) recounts that in Sub-Saharan Africa the foremost source of support has been the household and family. Kumado and Gockel (2003) also add that traditionally the family was the critical focus in the provision of support when members became old and were threatened by economic deprivation, disability and social isolation. Further, they point out that, the role of the family also extended to the provision of psychological stability and moral upliftment.

In this study, the term family is used to refer to both the nuclear unit and the extended family. In Ghana, there is often an abundance of support for the sick and their families (Kyei-Arthur, 2013). Moreover, Sackey (2005) adds that the care of the seriously ill may either result in family solidarity or magnify existing

dissensions and rancour within families, as the question of who takes care of the sick sometimes becomes extremely contentious. Thus, in times of ill-health members might be forced to quit their jobs, or relocate to provide care for ailing family members. However, there seems to be a decline in traditional family and kinship ties thereby impacting adversely on caring. Aboderin (2004) suggests that the shifts have been caused by a complex interaction between growing resource constraints and changing values as caring or providing for families can be difficult due to the rise in the cost of living.

All over the world, women are both providers and carers; they care for children, old people, the sick, the handicapped, and others who cannot look after themselves (Katbamna, Ahmad, Bhakta, Baker, & Parker, 2004). According to Songsore and McGranahan (2003), women also contribute to paying the health bills of members in most low-income households. Besides, the majority of family caregivers are generally likely to be women, in their role as mothers, sisters, daughters and wives (Kyei-Arthur, 2013). For instance, in the study by Ae-Ngibise et al. (2015) conducted in the Kintampo district, the majority of caregivers of patients with mental disorders were females. However, according to Van der Geest (2002), among the Kwahu (Akan) caring for the sick is the responsibility of the children, and in their absence, the wives can offer care. Similarly, a study by Sackey (2005) revealed that at least fifty per cent of elderly men are nursed and cared for by their wives. Songsore and McGranahan (2003), suggest that there are ideological and cultural barriers that prevent men from partaking in these activities. In contrast, a study by Sanuade and Boatemaa (2015) reported an approximately equal male to

female ratio for caregivers in Ghana, in their study of caregiver profiles and determinants of caregiving burden in Ghana.

The caregiving role could ultimately impact the physical and mental health of the caregiver because of inadequate community support systems. For instance, in the study by Sanuade and Boatemaa (2015), it was reported that less than five per cent of caregivers received financial, emotional, physical and personal care support. In contrast, a study by Kyei-Arthur (2013) revealed that caregiving was not related to physical and mental health among respondents in two communities in Accra (Ga Mashie and Agbogbloshie).

Caregivers Experiences of Caring for People with Prostate Cancer

The role of the family caregiver is significantly impacted by patient prognosis, stages of illness and goals of care (Glajchen, 2012). The impact on family caregivers may be negative or positive. These experiences may be influenced by other role demands (being employed, concurrently caring for other family members) and the availability of social, financial and training resources to support their caregiving roles (Van Ryn et al., 2011). While it may be said that family caregivers may experience powerful emotions (anxiety, fear, sadness, frustration and confusion) at the time of diagnosis and treatment, these experiences may equal or exceed those of the patient, such emotions may heighten as the illness advances and treatment becomes palliative (Edwards & Clarke, 2004; Hodgkinson et al., 2007). Stenberg and colleagues' review of the literature on the effects of caring for a cancer patient in the family found that the forms of problems that family caregivers have reported included physical health, social information needs, and

emotional burdens related to caregiving responsibilities (Stenberg, Ruland, & Miaskowski, 2010). The next section will further discuss three key areas, namely the psychological, physical and social experience of the family caregiver.

Psychological Experience of the Family Caregiver

Studies have emphasised that providing care to a family member or friend with cancer can affect the caregiver's overall psychological health. Ullrich et al. (2017) reported high anxiety levels and high depression levels in family caregivers of palliative cancer patients during home care. Similarly, through descriptive statistics and hierarchical multiple regression, Mosher, Bakas, and Champion (2013) study findings showed that, experiencing higher levels of distress and anger among family caregivers of patients with chronic illnesses are common, meanwhile, observing lower well-being among family caregivers are not unexpected since family caregivers have to provide various types of care and support for their patients. Similarly, in two meta-analyses of studies conducted in North America, Europe, Australia and Israel, by Hagedoorn, Sanderman, Bolks, Tuinstraand Coyne (2008); Hodges, Humphris, and Macfarlane (2005) on a study on couples coping with cancer, findings revealed that family members, particularly female partners, reported more psychological distress than the patients themselves for the reason that women performed many caregiving tasks and were involved in long hours of caregiving, and during this period there is worrying and pressure/exhaustion that accompanies the caring role.

Also, Walsh and friends hypothesized that the emotional response caregivers experience throughout the care situation triggers negative biological

responses (Walsh et al., 2018). At diagnosis, caregiver stress levels are elevated and the "fight or flight" response is initiated. While this response is beneficial in the short term, it is detrimental over an extended period. Caregivers experience chronic stress response (e.g., the release of glucocorticoids and catecholamines) as a result of prolonged treatment and disease progression of the patient. This prolonged response can negatively impact the caregiver's immune system and overall psychological health (Walsh et al., 2018). Equally, a study by Sercekus et al. (2014) on the experiences of family caregivers of cancer patients receiving chemotherapy reported that participants experienced such feelings as distress, sadness, shock, anxiety, weakness, irritability, guiltiness, hopelessness, depression and even fear of losing a loved one in the process of caregiving.

Likewise, it was found that caregivers who reported feeling burdened from providing care were 63% more likely to die within 4 years than caregivers who did not report emotional strain (Monin, Levy, Doyle, Schulz, & Kershaw, 2017). This correlates with other studies by Cappiello, Cunningham, Knobf, and Erdos, (2007); Carter and Chang (2000); Mellon & Northouse (2006); Morris, Grant, and Lynch, (2007), who also supported the above assertion that cancer caregiving stressful experience was associated with increased morbidity and mortality in caregivers. Also, in caring for the physical needs of the cancer patient, the caregiver experiences physical symptoms which are mostly ignored. Disregarding these symptoms have affected the quality of life of the family caregiver in diverse ways.

Physical Experience of Family Caregivers

Caregivers are tasked with the physical care of the patient, including complex symptom management. They often experience physical symptoms of their own, including insomnia, fatigue, and overall diminished health because of the strains of caregiving (Sun et al., 2015). Literature suggests that a higher caregiver burden is even associated with increased caregiver mortality risk (Glaser & Kiecolt-glaser, 2005). Family caregiving affects caregivers' physical health; the negative effects of caregiving on the health of caregivers have been established by many researchers in the past two decades. Caregiving has been associated with a decline in immune function (Glaser & Kiecolt-glaser, 2005; Murphy, Christian, Caplin, & Young, 2007), cardiovascular changes such as hypertension (Vitaliano & Katon, 2006), development and progression of many illnesses (Lovell & Wetherell, 2011), and increased mortality (Glaser & Kiecolt-glaser, 2005; Lovell & Wetherell, 2011; Waldrop, Kramer, Skretny, Milch, & Finn, 2005). Vedhara and Irwin (2005) in their study also posit that negative health effects of caring for a person with prostate cancer are caused by the lack of time to devote to self-care and negligence of protective health behaviours (such as maintaining a healthy diet, exercising routinely, keeping medical appointments, and getting adequate sleep) due to the caregiving burden.

Similarly, Li, Mak, and Loke (2013) study on spouses' experience of caregiving for cancer patients revealed that female spousal caregivers perceived higher level negative experience in caregiving such as lower mental health, lower physical health, poorer health-related quality of life, lower life satisfaction and

decreased marital satisfaction than male spousal caregivers. Furthermore, a study by Carter (2006), that investigated the brief behavioural sleep pattern among family caregivers revealed lack of adequate sleep as a challenge due to continuous worrying about the health of the patient, anxiety and depression (Glajchen, 2012). Given et al. (2011), in their study on support for caregivers of cancer patients also, reported that caregivers experience headaches and severe body aches as a result of the caregiving role.

In addition, a study conducted in China on fatigue influencing factors and coping strategies among cancer patients' spouses by Yao, Guo, Yuan, and Zhang (2017), revealed that Chinese cancer patients' spouses experienced higher levels of fatigue symptoms that were associated with considerable caregiving-related factors, such as medical expenses, education level, family income, support from other family members, caregiving time, and coping styles. In as much as, the caring role affects the caregiver physically, it also has a great toll on their social wellbeing.

Social Experience of Family Caregivers

The impact of caregiving on the social well-being of family caregivers was significant throughout the cancer trajectory (Kim & Given, 2008). The social structure and integrity of the family may be threatened when a member has a life-threatening illness like prostate cancer. Social well-being concerns of family caregivers of cancer patients may include possible changes in family roles; social support; communication; sexuality and intimacy; education; employment and leisure activities as well as a financial burden (Otis-Green & Juarez, 2012).

Nicholson (2009) defines social isolation as a state in which the individual lacks a sense of belonging socially, lacks engagement with others, has a minimal number of social contacts and they are deficient in fulfilling quality relationship. Others also defined social isolation as an objective and quantifiable reflection of the paucity of one's social contacts and the reduced size of one social network (Steptoe, Shankar, Demakakos, & Wardle, 2013). Literature suggests that social isolation can negatively impact the health of the family caregiver, despite having family support due to withdrawal from previous habits and lifestyles (LeSeure & Chongkham-Ang, 2015). There may be a feeling of increasing distress as a result of social isolation that will eventually impact the quality of life of both the patient and the caregiver.

The family caregiver mostly finds themselves so much involved in the care that, socialization is rare or non-existent. Brazil, Bainbridge and Rodriguez (2010), further argues that caregivers are faced with restrictions in their life as a result of the role they play leading to isolation. Also, Mosher, Champion et al. (2013), conducted a study on economic and social change among distressed family caregivers of lung cancer patients. Study findings revealed that seventy-four per cent of distressed caregivers experienced one or more adverse economic or social changes since the patient's illness. They found that the common changes included caregivers' disengagement from most social and leisure activities.

In the same view, Penner and McClement (2012) in their descriptive study on family members' experience of caring for patients with advanced head and neck cancer receiving tube feeding revealed that family caregivers had a diminished

social life as a result of their caregiving situation. The majority of the family caregivers reported that they no longer dined outside the home because of the patient's inability to ingest food orally. Also, their attendance at social functions had markedly decreased, and even when opportunities arose for them to go out or attend a social function, they chose not to attend because they did not want to leave their loved ones alone. These studies are in line with several other previous studies that determined that social aspects of caregivers' lives were adversely affected (Chindaprasirt et al., 2014; Stajduhar, 2013; Terakye, 2011).

Furthermore, Sercekus and colleagues, also determined in their study that, the family caregivers worked fewer hours and had to quit their jobs eventually due to the burden associated with caregiving (Sercekus et al., 2014). This is also supported by findings from Penner and McClement (2012) study, where a family member had to quit work or made another major lifestyle change due to caregiving, with others also reporting losing their main source of family income, losing most, or all of the family savings.

Sexuality and affection also played a vital role when it comes to caregiving, especially in the case of spousal caregiving. Illness like cancer can change a partner into a patient; with changes in body image and sexual abilities. The caregiver may take enormous effort to maintain privacy and independence from the patient, while others welcome the change (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2010). In the case of prostate cancer, there may be erectile dysfunction after treatment resulting in the inability of the man to perform sexually. These men may thus, withdraw from sexual contact or sexual intimacy. In an attempt to ensure that

their partners do not worry about issues of sexuality/ affection, the caregiver gives up on sexual intercourse (Roth, Wadley, Temple, & Haley, 2009). In contrast, a study by Ervik, Nordøy and Asplund (2013) revealed that avoidance/ inability to engage in sexual intercourse was a source of worry to them. Some believed that it will result in their separation whereas others accepted their life without sexual intercourse. Another study reported that caregivers (spouse), as a result of the role they played perceived their partners as patients and not sexual partners (Hawkins et al., 2009). The issue of role adjustment is another vital social concern that cannot be ignored.

Cancer has a serious impact on the entire family and does not occur as an individual isolated experience. Family caregivers may experience conflict among their changing family roles and responsibilities, restrictions of their activities, strain in marital and family relationships, and struggle to maintain robust systems of social support (Ofori, 2017). More so, they may experience "role overload" when providing cancer care while taking on the patient's household or family responsibilities in addition to their own (Otis-Green & Juarez, 2014). Again, studies have shown that the caregiver role compelled spouses to take on many roles in the family that the patient once assumed, including home maintenance, paying bills and maintaining social connections (Chambers et al., 2011), and this was described as a burden by the caregivers. Additionally, Lopez and colleagues in their study also emphasized that family caregivers are put through the stress of having to break the bad news of the diagnosis, negotiate changes with family roles, childcare, household management and changes in occupation (Lopez, Copp, & Molassiotis,

2012). This was also evident in a study that revealed that family caregivers failed to adequately take care of their children because most of the attention and effort was directed towards taking care of the patient (Sercekus et al., 2014). Also, family caregivers reported that providing emotional support to their loved ones was an extremely difficult role to assume, while they dealt with their own emotions of providing care for a family member with an illness such as cancer (Penner & McClement, 2012).

Barriers to Caring for People with Prostate Cancer

The experience of caring for a family member with cancer is associated with several care-related problems as well as barriers making the caregiving role problematic. A study conducted by Roberts (2010) identified the eighteen most common barriers which confronted the caregivers of cancer patients. Some of these barriers were; poor knowledge of prostate cancer, lack of health insurance coverage, mistrust of the physician/health system, fear of cancer diagnosis which may lead to death and fear of testing procedures. In this study, the following areas under barrier will be discussed; lack of preparation towards caregiving role by family caregivers, loss of livelihood/financial concerns, lack of knowledge/education about condition and treatment, culture and communication problems between caregivers and health professional.

Preparedness is defined as a caregiver's perceived readiness for the caregiving role, which encompasses multiple domains, including the provision of physical care, emotional support, and instrumental support (Schumacher, Stewart, & Archbold, 1998). Given the intricate nature of the caregiving role, preparing the

family caregiver for the task ahead is very critical. This group needs specialized knowledge and skills to effectively perform the role. Yet available literature has revealed that many of these family caregivers receive little or no preparation at all for the task they are expected to assume. Thus, these family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, as well as receive little guidance from the formal health care providers (Mazanec et al., 2018). For these reasons, they may be unfamiliar with the type of care they must provide or the amount of care needed. Hence, provide care by trial and error and feared making a mistake (Mazanec et al., 2018). They may not know the resources available to them, how to access and best utilize these available resources (Mazanec et al., 2018).

In a study of 87 family caregivers during cancer treatment, increased caregiver preparedness was associated with decreased fatigue and mood disturbance, and was found to interact with mutuality (relationship quality) in buffering stress responses to high caregiver demands (Schumacher, Stewart, & Archbold, 2007). Similarly, Fujinami et al. (2015) reported a significant inverse association between preparedness and distress in 163 family caregivers of patients with lung cancer in an outpatient medical oncology setting. However, findings of Fujinami et al. (2015) contrasts that of Mazanec et al. (2018) who asserted in a study of Perceived Needs, Preparedness of Male Caregivers of Postsurgical and Emotional Distress Women with Gynecologic Cancer that emotional distress was not related to perceived preparedness, which infers that a nurse cannot assume that a prepared caregiver has less distress and vice versa. Similarly, a study by

Scherbring (2002) examined the preparedness of caregivers during the transition from hospital to home in a sample of 59 nonsurgical in-patients with cancer who had mixed diagnoses. The significant inverse relationship between preparedness and caregiver burden was reported to be constant from pre-discharge to one month post-discharge, and for every one-unit increase in preparedness, with burden score decreasing by about 17%.

Although, caring for a sick relative with a serious condition such as cancer can be to some extent fulfilling, it may also be costly especially in monetary terms. Cancer in the advanced stages may render its victims jobless, Yet, its management involves a lot of money. The responsibility for ensuring that the patient goes through treatment rests on the family, in most cases the family caregiver. This becomes a burden for the family caregiver. Limburg, Shaw, and McBride (2008) asserted that parents of children under 10 had the highest percentage of lost work and mothers whose children were diagnosed with leukaemia had the highest percentage of lost work at 92%. An increase in lost work was also noticed during palliative versus curative treatment of the disease including prostate cancer (Limburg et al., 2008). Also, a study by Miedema, Easley, Fortin, Hamilton, and Mathews (2008) found out that many of the interviewees asserted that, they were spending many thousands of dollars on equipment related to treatment for their children, such as feeding tubes, needles and medication. The out-of-pocket expenses (expenses for medical care that are not reimbursed by insurance) parents of a child with cancer incur are often related to the extra costs that parents must bear (Miedema et al., 2008), these were further revealed in a study by Cohn and

colleagues as travel, accommodation and drug expenses that served as a barrier in caring for cancer patients (Cohn, Goodenough, Foreman, & Suneson, 2003). As it often may result in a financial burden to family caregivers who may already feel the weight of economic hardship due to loss of income.

Similarly, Given and colleagues reported in their study that, caregivers of cancer patients took loans, sold their homes and used other financial resources to pay for the expensive cost of treatment that was not covered under health insurance (Given et al., 2011). Others also complained of even going bankrupt due to the expensive cost of treatment (Bradley et al., 2007). Other studies conducted by Brazil et al. (2010); Family Caregiver Alliance [FCA], (2016), revealed that caring for the ill loved one results in serious implications for the caregiver, including increased financial, emotional, and physical burdens resulting in the loss of employment. Similarly, findings from FCA, (2016), reported that as many as 70% of working caregivers reported suffering work-related difficulties, with 12% having to reduce work hours and 9% being forced to give up work completely. Equally, culture plays a significant role in caregiving.

Caregivers have become part of a triad of care, and effective caregiving and decision making requires that caregivers understand the course of the disease and the changing treatment goals. Knowledge about the condition and its management is one crucial area that has been neglected by healthcare providers especially nurses and physicians (Nemati et al., 2018a). Information on areas such as the cause, signs and symptoms, prevention, administration of medication at home to avoid medication errors and identifying adverse effects are very vital details that need to

be provided by healthcare professionals to improve quality of care and reduce caregivers' stress and uncertainty (Given et al., 2011)

In a study conducted by Sajjadi and associates, on the assessment of the common problems faced by Iranian family caregivers of patients with breast cancer, they proposed that failure of specialists in giving the required personal information and specialist knowledge about the patients' disease and the caregivers' health was major problems and needs faced by these family caregivers (Sajjadi, Rassouli, Abbaszadeh, Brant, & Majd, 2016). Although, most of the caregivers in Iran wanted to achieve more care-related information, however, due to the absence of certain educative and supportive centre for them, this need usually remained unmet (Sajjadi et al., 2016).

Also, another study by Travis, Bethea, & Winn, (2000), found that caregivers manage between one and fourteen medications daily, have difficulty keeping so many prescriptions filled, and often miss doses due to their work schedules. Their responsibility to monitor for adverse or toxic effects in family members who are not capable of reporting problems themselves is important in preventing dehydration brought on by vomiting and diarrhoea, and even more serious emergencies. Caregivers, therefore, need the education to recognize both classic and atypical adverse drug effects they may see as their family member's condition changes, and help in developing the critical thinking skills that would enable them to manage these potential problems.

Providing care to a sick family member is a tradition embedded in African culture. It is regarded as an age-old act of kindness, love and loyalty that binds

family members together (Asuquo, Etowa, & Adejumo, 2013). Cultural norms and values have a substantial effect on how caregivers perceive their own caregiving experiences and their roles as caregivers (Otis-Green & Juarez, 2012). However, culture in its way may also serve as a barrier that hinders the effective role of the family caregiver. A study by Kuan Lee Wai (2016) among Chinese speaking native in Canada, revealed that cancer is believed to be caused by having neglected or subjected the body to harmful habits. This belief among the Chinese can affect the care rendered by the family caregiver. This finding also mirrors the findings of a study conducted by Ho, Saltel, Machavoine, Rapoport-hubschman, and Spiegel (2004) among the North American cancer population who believe that unaccepted health behaviours cause cancer. Another study among the Chinese cancer population reported that cancer was perceived as retribution of having committed injustice to others (Lui & Ip, 2009). Others also believed that it is contagious (Lee & Bell, 2011). Such beliefs when upheld by one's community becomes very distressing to the family caregiver and patient, leading to isolation, and further reducing the social network (Cheng et al., 2013).

In Nigeria, Akpan-Idiok's study finding among the Nigeria cancer population showed that families refuse to seek help from outside for reasons of pride and not wanting strangers to be involved in their family matters (Akpan-Idiok, 2013). These findings were also reported in a study investigating the unmet needs and service barriers of Asian-American family caregivers, conducted by (Li, 2004). In contrast, a study on the impact of informal caregiving on older adults physical and mental health among Ghanaian, Indian and Russian caregivers by Lambert and

colleagues showed that caregivers received support mainly from outside the family household (Lambert et al., 2017). Further, in cultural contexts where there is an emphasis on maintaining stability and harmony in the family through members' adherence to predefined roles, it is conceivable that a serious illness that disrupts and redefines roles in the family will create tension among its members (Lee, 2007). This could be particularly distressing for the cancer patient and the family caregiver (spouse), as each adjusts to their new role in living with the illness.

Communication is another vital area across the healthcare setting that cannot be overlooked. It is described as challenging because it contributes to a major hindrance to the effective care provision by family caregivers (Stenberg et al., 2010). Communication with providers, physicians, nurses, social workers, pharmacists etc, may be difficult for family caregivers. Caregivers report not receiving quality information about their family member's care from providers. Many caregivers are unsure about how to interpret and use the information they receive. Finding out future treatment plans or expectations is an important area of family concern. There are concerns by families for lack of access to the needed care and support due to financial and eligibility barriers. Caregivers find themselves interacting with health care professionals in a variety of settings, all with very different, often conflicting, care goals or goals that add to the confusion and uncertainty for family members. Substantial evidence exists in the literature that caregivers have difficulty obtaining information from health care professionals, particularly physicians and nurses by Kimberlin, Brushwood, Allen, Radson, and

Wilson, (2004); Dyck, Wright, Zahlis and Shands's work (as cited in Reinhard et al., 2008).

A qualitative work by McWilliam, Brown and Stewart (2000) found that the positive communication experiences reported by breast cancer patients formed the foundations of a “working relationship” between patient and physician that was crucial to helping patients learn adaptive ways to live with breast cancer. Physician provision of information that was responsive to the needs of the patient along with caring and attentiveness to patient concerns, particularly their feelings of vulnerability, formed the core of positive experiences (McWilliam et al., 2000). Physicians who provided information that overwhelmed the patient was mistimed or was provided in an insensitive way served to undermine the relationship between patient and physician (McWilliam et al., 2000)

Coping Strategies of Caregivers Caring for Prostate Cancer Patients

Coping is the behavioural and cognitive efforts used by individuals as they try to minimize the effects of stress (Lazarus & Folkman, 1984). Coping can be adaptive, which reduces stress levels or maladaptive, which increases stress levels. Coping can also be reactive, leading to an action taken in response to the stressor, or proactive, leading to an action to minimize the effects of the future stressor. It can be influenced by personal characteristics such as age, gender, education, as well as social and environmental factors (Bliese, Edwards, & Sonnentag, 2017; Carver & Connor-Smith, 2010). Caregivers use coping strategies to adjust to changing life events and to manage the illness of the patient under their care (Cassidy & McLaughlin, 2015).

Measuring the efficacy of caregivers' coping involves identifying what coping strategies the particular caregiver uses. These strategies can range between problem-focused, and emotion-focused strategies (Lazarus & Folkman, 1984). There are positive aspects of each type of coping strategy. Couper et al. (2006) reported that caregivers using problem-solving strategies demonstrated lower levels of distress than caregivers who used emotion-focused coping strategies because emotion-focused coping strategies such as denial and avoidance lead to greater strain in coping (Kelly, Tyrka, Price, & Carpenter, 2008). Besides, greater caregiver strain is associated with maladaptive coping strategies that include avoidance, passivity, self-blame, and resignation (Redinbaugh et al., 2003). However, confidence in their coping abilities allows caregivers to demonstrate better psychological adjustment (Mazaheri et al., 2013). Descriptive research at the Medical Oncology Clinic by Karabulutlu (2014) study findings have it that, coping attitude used most frequently by family caregivers was active planning, and the least used coping attitude was avoidance/ isolation. Whereas, Subhashini (2014) also posits that, the frequently used coping strategies were seeking social support and planful problem solving followed by distancing oneself from the problem.

A review of a qualitative study by Mosher, Ott, Hanna, Jalal, and Champion (2015) revealed that maintaining a normal routine and turning to family and friends for support with symptom management, were also strategies adopted by the family caregivers often varied in their effectiveness. Whereas support from health-care professionals, complementary and alternative medicine was viewed to be more favourable. Similarly, several cognitive coping strategies were frequently reported

(i.e., changing expectations, maintaining positivity, and avoiding illness-related thoughts) as well as religious coping strategies. In a prospective cross-sectional study by Sajadian, RajiLahiji, Motaharinasab, Kazemnejad Eklily, & Haghightat, (2017), breast cancer patient caregivers' experiences were evaluated at Breast Cancer Research Center (BCRC), Motamed Cancer Institute (MCI), Tehran, Iran. Seven coping strategies emerged as coping strategies adopted by family caregivers. The most commonly used coping strategies after diagnosis included seeking social support, spirituality, and positive cognitive restructuring and the least used coping strategy was detachment. The most frequently used strategies six months after the diagnosis was seeking social support, spirituality, positive cognitive restructuring, and making changes and the least commonly used ones included wishful thinking, and keeping feelings to self-coping strategies. This is also consistent with Elanur (2014) findings that reported that the frequently used coping strategy among family caregivers was active planning and the least was avoidance and isolation.

According to Cancer.Net (n.d.), various coping strategies have been identified to enable the caregiver to cope with the condition their patients are currently facing. Some of these strategies include; Managing emotions, palliative and supportive care (care focused on reducing systems, improving quality of life and supporting patients), talking with a friend or family member about the condition, finding supportive information for your sick relation and hearing the Oncologist Perceptive. Eaton, Davis, Hammond, Condon and McGee (2011) in an exploratory research paper that investigated the coping strategies of families of hospitalized psychiatric patients and identified their positive and negative coping

strategies revealed findings that pointed to the fact that family members used more emotion-focused coping strategies than problem-focused coping strategies. The common coping strategies used by family members were communicating with immediate family, acceptance of their situation, passive appraisal, avoidance, and spirituality. The family members also utilized resources and support systems, such as their immediate families, mental health care professionals, and their churches. Religion or spirituality as a coping strategy in dealing with stress is well documented in the African literature on caregiving (Adams & Trinitapoli, 2009; Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Aziator, 2016; Bussing et al. 2014; Carrete & King, 2005; Ofori, 2017).

Theoretical Frameworks

Various researchers in their attempt to understand the caregiving role have conducted studies aimed at finding the possible link between experience, coping strategies, and barriers caregivers face in caring for prostate cancer patients. Some of the studies utilized theories such as the Quality of life Model Applied to the Family Caregiver, Resiliency Model of Family Stress, Adjustment and Adaptation, Transactional Model of Stress and Coping, The Stress Process Model, and The Health Belief Model (HBM) to explain the phenomenon. However, in this study, a few of the theories stated above are discussed in relation to the study, after which two was adapted to develop a conceptual framework that best fits the present study.

Resiliency Model of Family Stress, Adjustment and Adaptation

The Resiliency Model of Family Stress, Adjustment and Adaptation was developed out of the Family Stress Theory, a developmental theory borrowed from

family science which explores why some family systems adapt and even grows and thrives when faced with situational stressors or transitional events, while other family units deteriorate and disintegrate under similar circumstances (McCubbin & McCubbin, 2013). The theory is defined in nursing's metaparadigm of person, environment, health, and nursing. Family adaptation is described in the Resiliency Model for Family Stress, Adjustment, and Adaptation as the "outcome of the family's efforts over time to bring a fit at two levels: the individual to family, and the family to the community. This process ranges on a continuum from optimal nonadaptation to maladaptation" (McCubbin & McCubbin, 2013). The model is comprised of two distinct parts: The adjustment Phase and the Adaptation Phase. Each phase describes the family's ability to cope with illness, or stressors looking at the family strengths, resources, and coping/problem-solving abilities.

There were four assumptions within the original family stress model developed by Rueben Hill in 1949 (Figley & McCubbin, 2016). These were: unexpected or unplanned events which are usually perceived as stressful; events within the families, such as serious illness, and defined as stressful, are more disruptive than stressors that occur outside the family, such as war, flood, or depression; lack of previous experience with stressor events leads to increased perceptions of stress; and ambiguous stressor events were more stressful than non-ambiguous events (Figley & McCubbin, 2016).

McCubbin and McCubbin expanded on this original family stress model and created the Resiliency Model of Stress, Adjustment and Adaptation in 1989 (McCubbin & McCubbin, 2013). The expanded model included five propositions

that described relationships within the model itself. These propositions describe that in a family crisis:

1. The pileup of family demands (stressors, strains, transitions) is related to family adaptation, and this is a negative relationship;
2. Family typologies based on specific strengths of the family system (cohesion, adaptability, family hardiness, family time and routines) are related to family adaptation, and this is a positive relationship;
3. The family resources are related to family adaptation, and this is a positive relationship;
4. The family's positive appraisal of the situation is related to family adaptation, and this is a positive relationship, and finally
5. The range and depth of the family's repertoire of coping and problem-solving strategies when employed to manage a crisis are related to the level of family adaptation, and this is a positive relationship (McCubbin & McCubbin, 2013)

Nine aspects of resilient families dealing with a chronic illness situation have been identified. These include: balancing the illness with other family needs; maintaining clear family boundaries; developing communication competence; attributing positive meanings to the situation; maintaining family flexibility; maintaining a commitment to the family as a unit; engaging in active coping efforts; maintaining social integration; and developing collaborative relationships with professionals (Patterson, 2002).

In applying the model to this study, prostate cancer is viewed as a "family disease" as it affects not only the person diagnosed with cancer and their loved ones individually but also their relationships and family functioning (Rolland, 2005). Therefore, changes in one member of the family would provoke alterations to the (whole system) family. The model, lets us understand that the activation of resilience processes in the face of cancer diagnosis and treatment allows us to overcome daily stressors and to reach a new balance in family functioning. However, when a family struggles with the challenges posed by cancer, there is a risk of functioning chaotically and diverting its life course, this further translates into clinically significant levels of distress, a higher risk of developing psychosocial problems and low family cohesion.

It is therefore imperative that the clinician (nurse), assist the family unit to achieve resilience by providing adequate/relevant information on the condition, how to carry out medical routines at home, providing a comfortable environment for family members to ask questions, ensuring open communication, collaborative relationship and flexibility in treatment (Rolland & Walsh, 2006) helping them identify their strengths throughout the cancer trajectory to overcome the confusion, anxiety, frustration and anguish associated with the condition. This also helps the family to perceive their emotional state, change in family routines and strains as understandable and common to other families thereby achieving resilience (Walsh, 2003). This is mirrored in a qualitative study by Buchbinder, Longhofer and McCue (2009) in which fathers considered resilience as the need to adapt to change through stabilization of family life and incorporation of new family routines and rituals into

cancer care. Thus, allowing both the patient and their family caregivers to gain a sense of coherence thereby bouncing back and adapting successfully. An important reason for selecting this model is that it gives a useful indication to health professionals especially nurses on how to support the development of resilience in the moment of crisis among not only family caregivers but even patients. However, this model could not best fit the study because it lacked some components that are relevant to the current study

Health Belief Model (HBM)

The Health Belief Model was developed in 1950 by Rosenstock, Hochbaum, Kegeles, and Leventhal who were social psychologists working in the Public Health discipline (Rosenstock, 1974). The model was developed purposely to explain reasons why individuals either seek X-ray screening for tuberculosis (TB) or decline. The HBM is acclaimed to be among the pioneer and most influential models in the field of health promotion and education (Glanz, Rimer, & Lewis, 2002). The underlying factor was that health behaviour is determined by an individual's beliefs or perceptions concerning a condition and the fundamental strategies available to minimise its occurrence (Montano & Kasprzyk, 2015). Thus, the HBM views health behaviour change as a function of an individual's rational appraisal of the balance between the barriers to and benefits of action (Munro, Lewin, Swart, & Volmink, 2007)

At the initial stage, the model was made up of four main constructs: perceived susceptibility; perceived severity; perceived barriers and perceived costs. Perceived susceptibility explains an individual's subjective assessment of the risk

of contracting a disease or condition. The perceived severity also explains the seriousness and consequences associated with the condition. Factors that militate against and promote the adoption of intervention denotes the perceived barriers while the perceived costs imply the negative connotations and associated implications towards the compliance of the suggested intervention. According to Becker and Maiman (1975), the interaction of these four factors determines one's health-seeking behaviour. Between 1970 and 1980, the original model was altered and certain components that covered the individual's responses to symptoms and illness, as well as adherence to medical regimen, were added to it. Subsequent areas added to the model include perceived control and perceived threat, demographic characteristics that influence behaviour, cues to action (factors that stimulate people to seek health such as appealing communication, personal experience), illness behaviours, preventive health and health screening (Becker & Maiman, 1975). The HBM was purposely designed to explain and predict the uptake of TB X-ray screening. Currently, it is being used to predict general behaviours that respond to people's health.

The HBM has the following weaknesses. Firstly, it assumes that an individual's actions are rational. However, not all health actions and attitudes rest on rational choice. Secondly, the model also throws much light onto the negative side of actions that shape action taking such as discomfort and increasing morbidity associated with defaulting medical advice and pay less attention to the positive factors including motivations that can drive people to take the recommended

actions. Thirdly, the model does not consider other environmental factors that influence and modify individual behaviours.

In the context of this study, prostate cancer caregivers report having to negatively modify their lifestyles to meet caregiving demands (Stenberg et al., 2010) and they tend to prioritize the patient's healthcare needs over their own (Ross & Sundaramurthi, Thiruppavai Bevens, 2014), at a time when their stress levels are high, and they are most in need of good nutrition, exercise, relaxation, sleep etc. Prostate cancer caregivers have little time and possibly dwindling financial resources available to meet these needs. Instead, they go on with the care, often overwhelmed with psychological impairment, sleep disturbances, and deterioration in their physical health. This model could have been adopted for the current study because it emphasizes the determinants of an individual's readiness to take action and change his/her behaviour (s) for the preservation of his/her health. However, cancer caregiving, particularly as it becomes a major component of one's life, may well pose a perceived barrier to one's ability to take action in bettering or preserving one's health.

The HBM proposes that individuals may experience barriers that prevent them from engaging in healthy behaviours. It is possible that, particularly when the burden is greatest such as during acute treatment, caregiving may be a perceived barrier, both psychological and practical, to maintaining healthy behaviours. For example, the time demands of active caregiving may prohibit the caregiver from exercising, eating properly, or participating in stress reduction activities; the stress of active caregiving may make individuals more susceptible to self-medicating with

alcohol, drugs, and/or food. However, once the acute demands of active caregiving are over, cancer caregiving may be more protective of their health. Studies that examined health promotion behaviours in cancer caregivers (focusing on physical activity) conducted by Beesley, Price, and Webb (2011), stated that caregivers' level of physical activity was decreased as a result of the caregiving role, this was further buttressed by finding from Willette-Murphy et al. (2009), who found that those caregivers with lower levels of physical activity exhibited more problems with sleep.

Furthermore, caregivers of cancer patients are sure to commit resources to care for their relatives with prostate cancer if they perceive that not doing so has more adverse consequences. Also, if resources are readily available such that caring for relatives with prostate cancer will not weigh serious socio-economic consequences on the individual or family (thus, if there are no barriers), then it is more likely that caregiver will commit time and other resources to care for their relatives with cancer. Information from healthcare professionals, the media and others could also serve as cues to action which would either cause individuals to care for their relatives with cancer or refuse to do so.

Socio-demographic (modifying) variables such as age and marital status can also influence whether individuals will care for their relatives with prostate cancer or not. For example, married people might not be able to make time to care for their sick relatives as they must attend to their familial duties. With age also, too young or too old relatives might not be able to care for cancer patients because they might not have the strength to do so. According to a study by Akpan-idiok and Anarado

(2014), on the caregiver perception of benefits of caring for patients with advanced cancer revealed that majority of the participants within their active/productive years (30-50) were more negatively affected as a result of the role they played, implying that they had more responsibilities such as attending to their works, social lives and other family needs in addition to the caregiving role. In contrast, the findings of Antoni et al. (2010) revealed that younger (caregivers in their productive years) caregivers experience greater benefit and less stress as compared to older caregivers.

However, the model lacks a certain component of barriers, experience and coping relevant to the present study

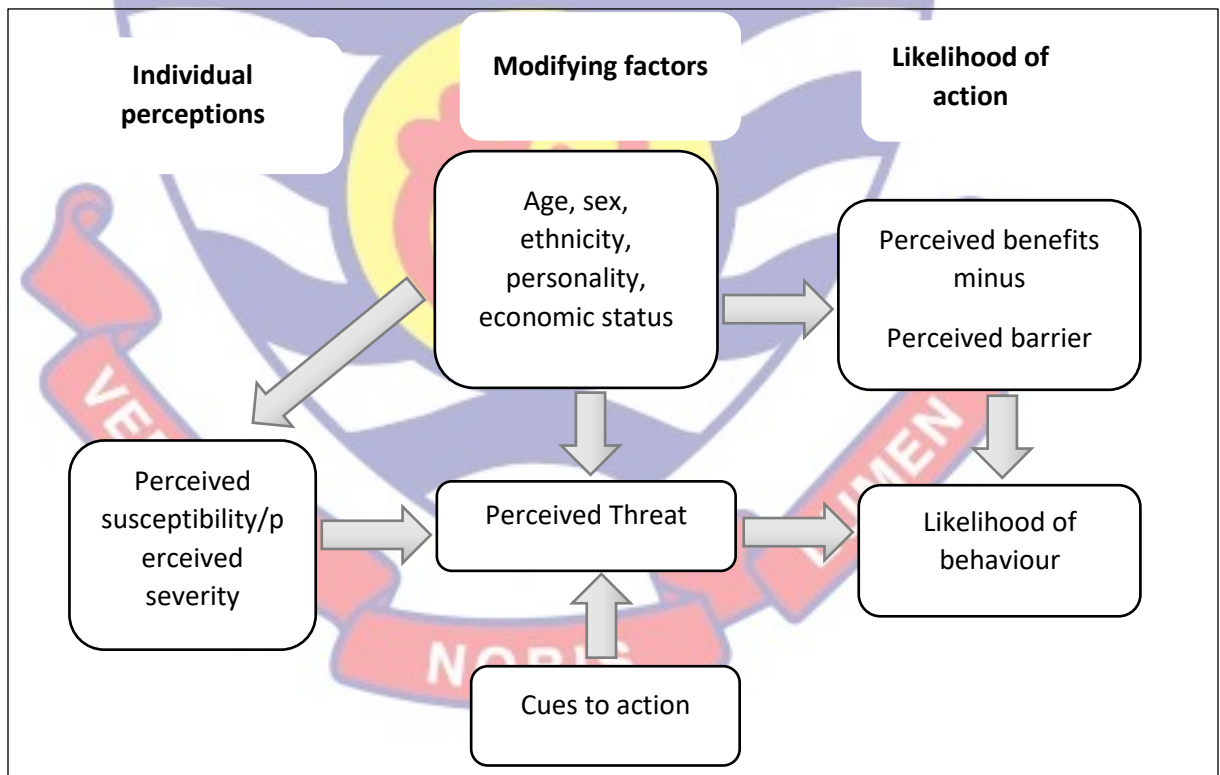


Figure 1: Health Belief Model (Rosenstock, 1974)

Transactional Model of Stress, Coping and Adaptation (Lazarus & Folkman, 1984)

The Transactional Model of Stress, Coping and Adaptation is a framework for evaluating the processes of coping with stressful events. The transactional model emerged in the 1960s and has helped tremendously shape the direction of research on stress and coping. Psychological stress refers to a relationship with the environment that the person appraises as significant for his or her well-being and in which the demands tax or exceed available coping resources (Lazarus & Folkman, 1984). Krohne (2002) affirms that this definition points to two processes as central mediators within the person-environment transaction: cognitive appraisal and coping. Cognitive appraisal is an individual's evaluation of what is happening for their well-being and coping is an individual's effort in thought and action to manage specific demands (Lazarus, 1993). An appraisal is based on the idea that emotional processes (including stress) are dependent on actual expectancies that persons manifest concerning the significance and outcome of a specific encounter (Krohne, 2002). He added further that, this concept was necessary to explain individual differences in quality, intensity, and duration of an elicited emotion in environments that were objectively equal for different individuals. When faced with a perceived or potentially stressful event, we engage in cognitive processes that involve a primary and secondary appraisal.

A primary appraisal is an evaluation of the meaning and significance of the situation, whether its effect on one's well-being is positive, irrelevant, or negative (Wood, Wood, & Boyd, 2007). Krohne (2002) states that within the primary

appraisal, three components are distinguished: goal relevance describes the extent to which an encounter refers to issues about which the person cares. Goal congruence defines the extent to which an episode proceeds following personal goals. Type of ego involvement designates aspects of personal commitment such as self-esteem, moral values, ego-ideal, or ego-identity. Lazarus and Folkman (1984) reveal that an event appraised as stressful could involve harm or loss, threat and challenge. Explaining further, harm or loss refers to the (psychological) damage that has already occurred. The threat is believing an event is demanding and will put us at risk for damage (anticipation of harm).

Challenge results from demands that a person feels confident about mastering. Challenges question how we learn or gain confidence from an experience. When people appraise a situation as involving threat, harm, or loss, they experience negative emotions such as anxiety, fear, anger, and resentment (Lazarus & Folkman, 1984). An appraisal that sees a challenge, on the other hand, elicits positive emotions such as excitement, hopefulness, and eagerness (Wood et al., 2007). In the present study, the individual (based on his preparedness for the role and other factors) appraises the newly assumed role of caregiving to determine whether it is a threat to his/her environment or not. Among other things will be determining whether the role will affect the caregiver's daily routine, work schedule or social life.

Secondary appraisal involves coping options available to the individual. A secondary appraisal is a cognitive evaluation of available resources and options before deciding how to deal with a stressor (Wood et al., 2007). Three main

questions are asked during the secondary appraisal. "What options are available to me?" "What is the likelihood that I can successfully apply the necessary strategies to reduce stress?" "Will this process work, will it alleviate my stress?" In an attempt to answer these pertinent questions, the individual evaluates internal or external coping options as well as more specific resources to create a more positive environment. Available resources include physical (health, energy, stamina), social (support network), psychological (skills, morale, self-esteem), material (money, tools, equipment), and time. Thus, it may become a reappraisal of the stressor and our coping resources.

According to Krohne (2002), three secondary appraisal components are distinguished: blame or credit, coping potential and future expectations. He further explains that blame or credit results from an individual's appraisal of who is responsible for a certain event. Coping potential means a person's evaluation of the prospects for generating certain behavioural or cognitive operations that will positively influence a personally relevant encounter. Future expectations refer to the appraisal of the further course of an encounter for goal congruence or incongruence. Inadequate resources to deal with the stressor during secondary appraisal results in high stress levels but sufficient resources during secondary appraisal leads to minimal or insignificant stress levels as the individual will make use of available coping responses.

This model conceptualizes coping efforts along two dimensions, that is, problem-focused and emotion-focused coping strategies. Problem management strategies, which will be more adaptive for changeable stressors, are directed at

changing the stressful situation. These include active coping, planning problem solving, information seeking, and use of social support. Emotion-focused coping efforts, which are more suitable when the stressor is unchangeable, are directed at changing the way one thinks or feels about a stressful situation. These include seeking social support, venting of feelings, avoidance, and denial (Mselle, Evjen-Olsen, Moland, Mvungi, & Wankuru Kohi, 2012).

In the context of the study, the coping aspect of the model was adopted, where the coping strategies adopted by the prostate cancer caregivers were examined under the two dimensions described in the above model, namely the problem-focused and the emotion-focused. The type of coping strategy adopted by the family caregiver depends on the experiences encountered which may be psychological physical or social. Emotion-focused coping efforts are more suitable when the stressor is unchangeable. They are directed at changing the way one thinks or feels about a stressful situation whereas, Problem-focus coping, is more adaptive for changeable stressors. They are also directed at changing stressful situation. The adaption of this model provides a broader understanding of the coping strategies used by the family caregiver.

The Quality of Life (QoL) Model Applied to the Family Caregiver

The QoL model was originally referred to as the conceptual model of pain and quality of life (Ferrans, 1996). It was initially developed to produce a theory that describes the areas of quality of life in clients with cancer, precisely to explore the experiences of pain and fatigue and its relationships to QoL. A theoretical model to show the relationship between the nursing process and the dimensions of quality

of life was developed by (Padilla & Grant, 1985). In 1986 Ferrel Wisdom and Wenzl used Padilla and Grant model as a conceptual framework to develop and test the quality of life instrument (Ferrell, Wisdom, & Wenzl, 1989). Then, the instrument was revised and used to gather data on the relationship between pain and QoL (Fagernäs & Odame, 2013). From the two studies conducted, a conceptual model known as the City of Hope emerged. This model illustrated the influence of pain on the dimension of quality of life. The Model supports that quality of life has four dimensions: physical wellbeing, psychological well-being, social well-being and spiritual well-being. Other models also emerged from the first original model, one of such models is the Quality of Life Model Applied to Family Caregivers in 2001 by Ferrell.

The physical wellbeing domain refers to the physical functioning of the caregiver. The assumption is that certain health problems accompany physical functioning and these are: fatigue, sleep disruption, function, nausea, appetite, constipation, aches or pain. The social wellbeing domain explains the interaction of the caregiver with the patient and others. Isolation, role adjustment, financial burden, roles/relationships, affection/sexual function, leisure activities, burden and employment are the variables under social wellbeing. Psychological wellbeing is the emotional functioning of the caregiver who may experience anxiety, depression, helplessness, difficulty coping, fear, uselessness, loss of concentration, control and distress. Spiritual wellbeing refers to the spiritual impact of caring for a relative with cancer. It involves meaning, uncertainty, hope, religiosity, transcendence and positive change. All four domains interact to determine the overall quality of life of

a family caregiver. In applying this model to the study, the researcher is allowed to assess the needs of these hidden patients (family caregivers) in order to come up with evidence-based interventions to meet those needs. Three areas were considered out of the four discussed above namely the physical, psychological and social.

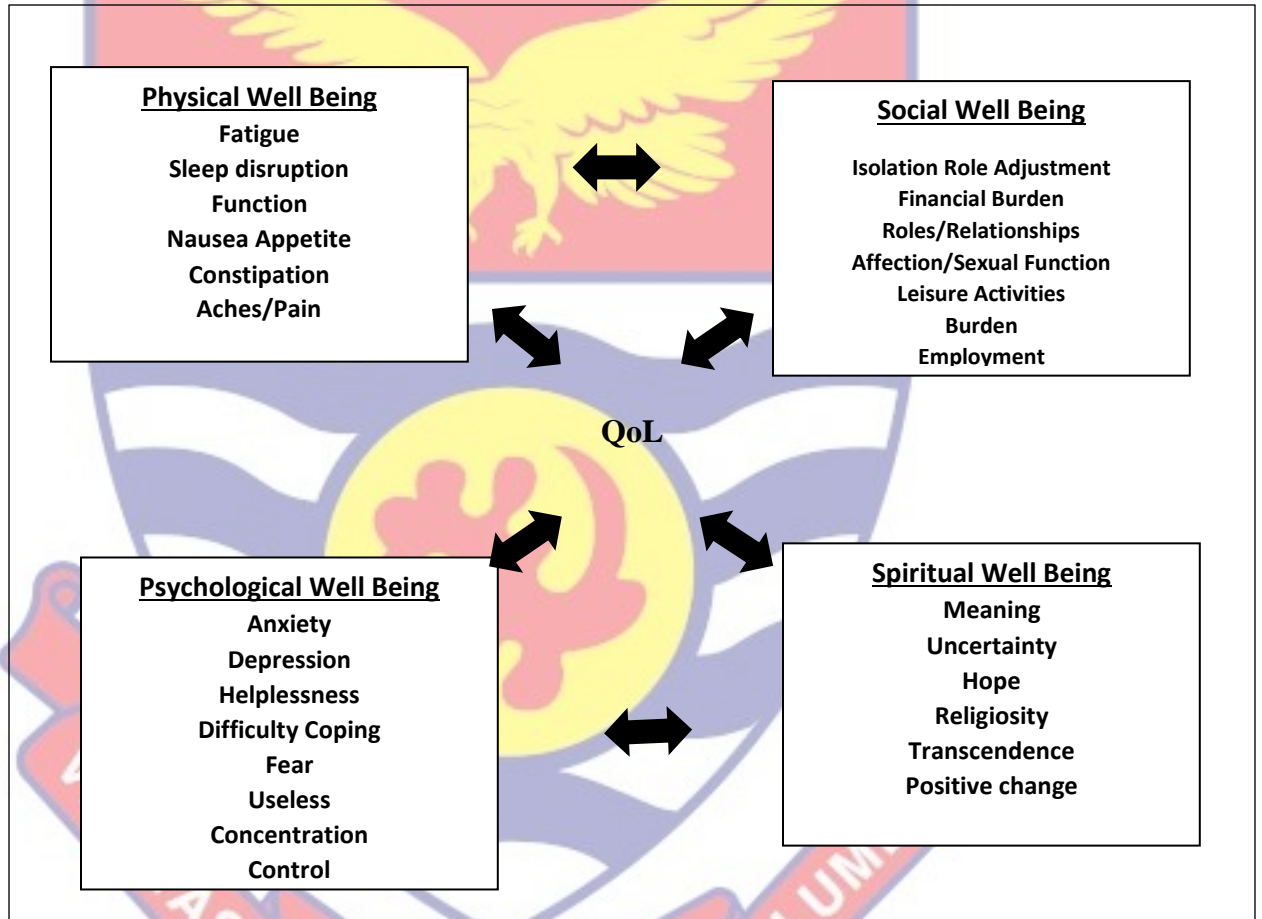


Figure 2: Quality of Life Model Applied to Family Caregiver (Ferrell, 2001)

Conceptual Framework for the Study

The conceptual framework for the study was adapted from Ferrell's 2001 (as cited by Ofori, 2017), Quality of Life Model Applied to the Family Caregiver and the Transactional Model of Stress, Coping and Adaptation by Lazarus and Folkman

(1984). The transactional model of Stress and Coping and the Quality of life model were chosen because they make it possible to elicit the experiences, coping strategies and barriers associated with the caring role from family caregivers whose relations are living with prostate cancer. The Transactional Model of Stress and Coping and the Quality of life model applied to the family caregiver describe the experiences, coping strategies and barriers that fit into the context of this study through review of related literature, hence, its adaption.

This model looked at the family caregiver experiences under three areas; namely the physical, social and psychological. The spiritual aspect of the model was omitted because it was captured under the coping strategies adopted by the caregiver. The physical experience domain refers to the physical functioning of the caregiver. It is assumed that certain health problems accompany physical functioning and these are fatigue, sleep disruption, anorexia, appetite, constipation, aches or pain. The social experiences domain describes the interaction of the caregiver with the patient and others which include isolation, role adjustment, financial burden, roles/relationships, affection/sexual function, leisure activities, burden and employment. The psychological experiences may be anxiety, depression, helplessness, fear, uselessness, and loss of concentration. These experiences can influence the quality of life of the caregiver as well as the coping strategies that the individual will adapt.

It also looked at the coping strategies employed by these family caregivers namely the problem- focus and emotion-focus coping as discussed by Lazarus and Folkman in their stress and coping model. Emotion-focused coping includes;

seeking emotional support, religious asylum, denial, avoidance, distancing, venting anger, acceptance, alcohol use and selective attention whereas problem-focused coping involves defining the problem, generating, evaluating an alternative solution, learning new skills to manage stress and active planning. These coping strategies adopted by family caregivers influence the quality of life either positively or negatively. Positive outcomes such as improved mood, better relationship satisfaction, personal growth, competence and mastery, better subjective well-being, and even better cognitive functioning and lower mortality (Brown & Brown, 2014). A study conducted by Li and Loke (2014), showed that caregivers reported feelings of being rewarded, personal growth, and finding meaning, personal satisfaction and discovery of personal strength, and improved their relationship, not only with the care-receiver but also within other relationships. Negative outcomes may also include, increase in the risk for mortality, psychological distress, psychiatry problems and an increase in the risk for chronic conditions such as Hypertension and Diabetes (Li & Loke, 2014).

Finally, the barriers that affect the provision of care by the family caregiver may include culture, financial problems, fear of addiction, lack of knowledge about the disease, conflict among family members and communication problems. These barriers could also influence the kind of coping strategies adopted by the individual family caregivers which will further affect the quality of life. This aspect of the framework was developed by the author in an attempt to provide a complete description of the phenomenon. Using this developed construct (Figure 3), the

researcher seeks to examine how caring for the prostate cancer patient may affect the family caregiver under the stated dimensions.

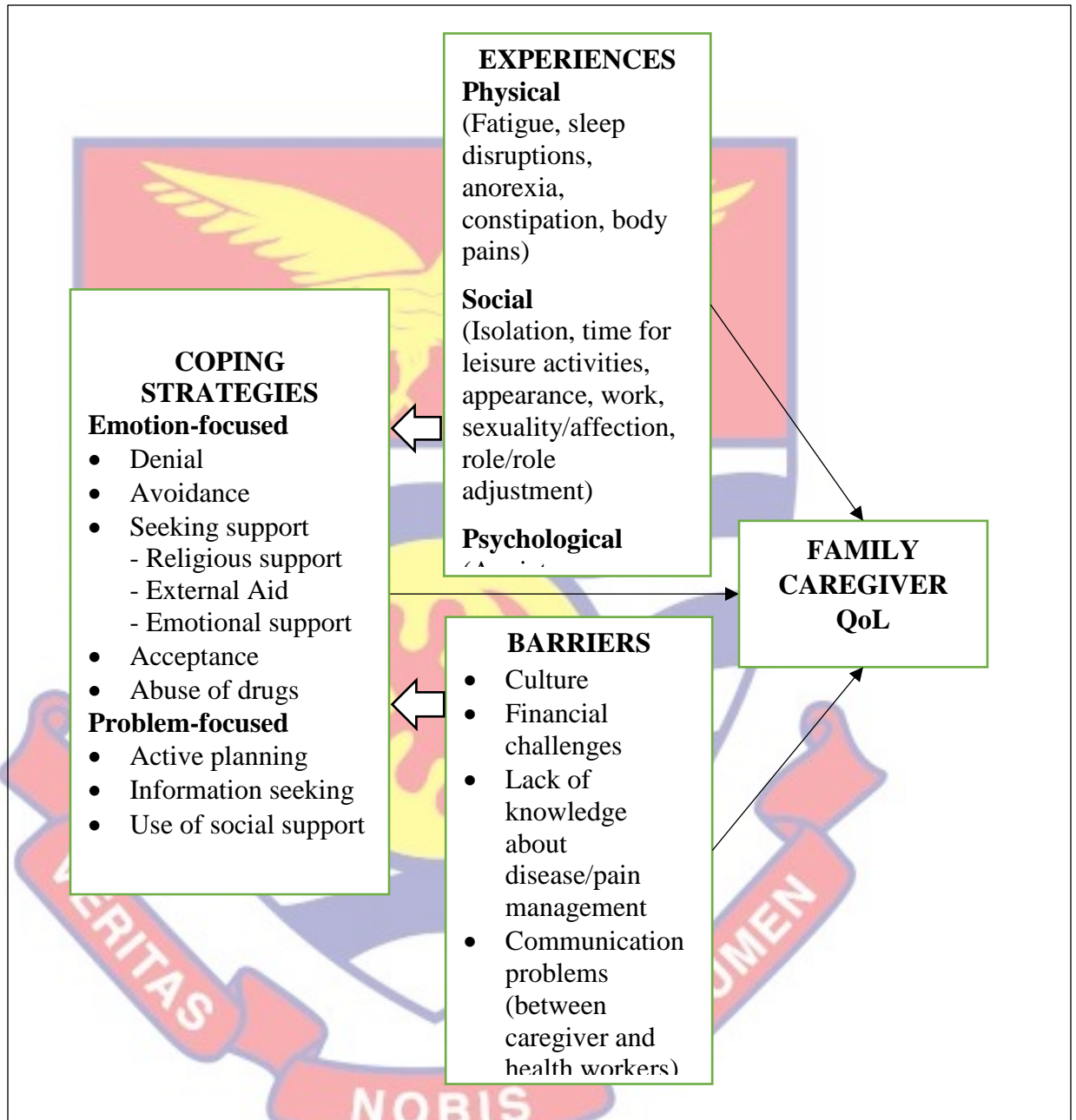
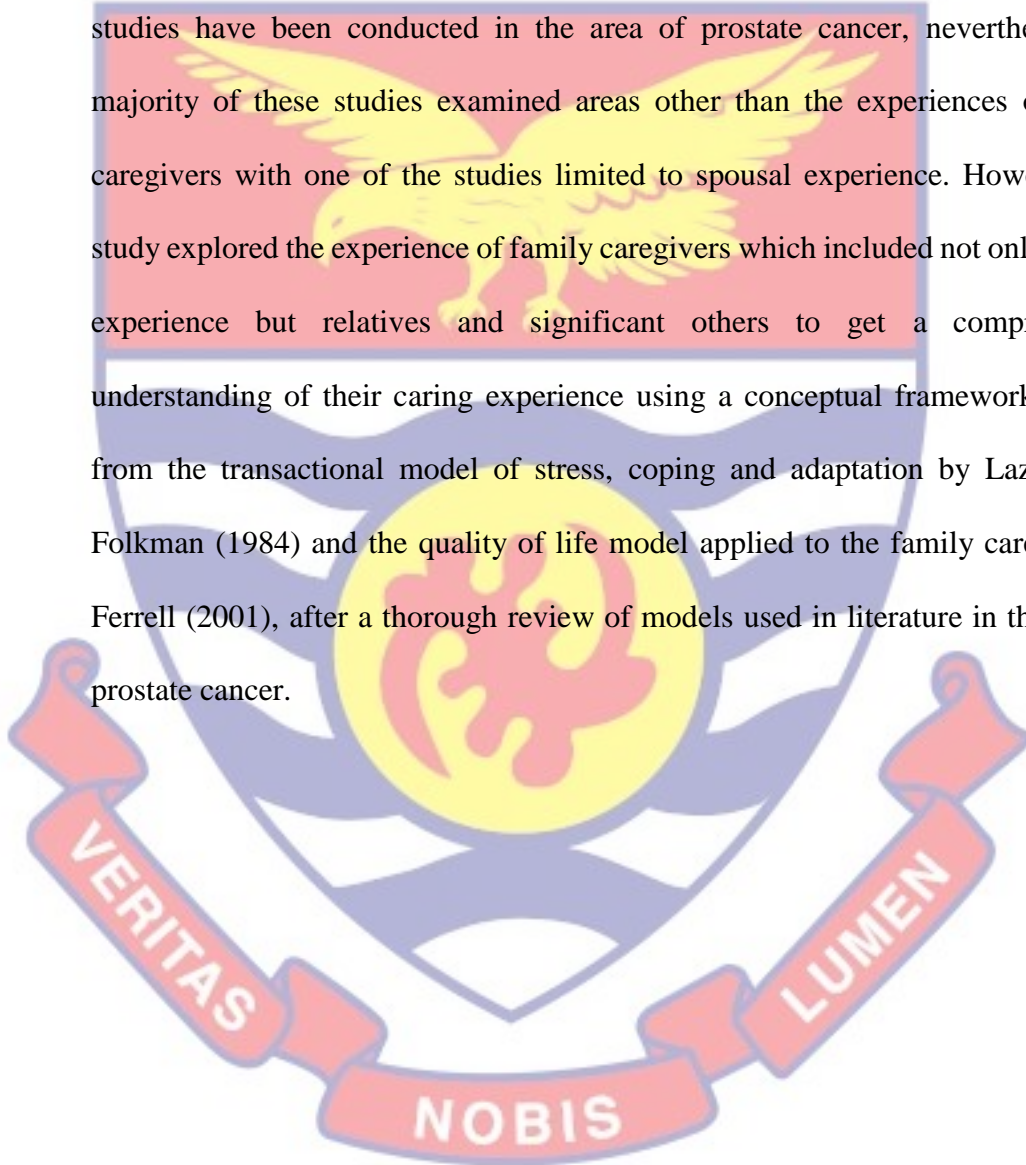


Figure 3: Conceptual Framework

Source: Adapted from the Quality of Life Model Applied to the Family Caregiver (Ferrell, 2001) and the Transactional Model of Stress, Coping and Adaptation (Lazarus & Folkman, 1984).

Chapter Summary

In summary, this chapter describes the experiences of family caregivers of patients with prostate cancer, the barriers they encounter and the coping strategies adopted. Following the review of available literature, it was found out that several studies have been conducted in the area of prostate cancer, nevertheless, the majority of these studies examined areas other than the experiences of family caregivers with one of the studies limited to spousal experience. However, this study explored the experience of family caregivers which included not only spousal experience but relatives and significant others to get a comprehensive understanding of their caring experience using a conceptual framework adapted from the transactional model of stress, coping and adaptation by Lazarus and Folkman (1984) and the quality of life model applied to the family caregiver by Ferrell (2001), after a thorough review of models used in literature in the area of prostate cancer.



CHAPTER THREE

RESEARCH METHODS

Introduction

This chapter shows the methodological steps in the data gathering process from participants to answer the research questions. It includes the following sub-sections: Introduction; Research design; Study area; Population; Sampling procedure; Data collection Instruments; Data collection procedures; Data processing and analysis and Summary of the chapter.

Research Design

A research design is a framework or guide used for the planning, implementation, and analysis of a study (Driessnack, Sousa, & Mendes, 2007). It serves as the work plan details of what needs to be done to complete a research project by ensuring that the results obtained answers the research question (Williams, 2007). In this study, a qualitative phenomenological descriptive approach was used to collect study data and to provide a response to the research question posed earlier. The approach leads to an exhaustive description of the lived experiences of family caregivers of patients with prostate cancer, further leading to a more effective way of addressing the needs of this group.

Researchers, however, have a choice of three basics methods to choose from when carrying out a study (Polit & Beck, 2006). The researcher may use a quantitative research method to test hypotheses, make predictions and ultimately describe an event by using figures. This method enables the researcher to use numbers in statistical tests to ensure that, the results have a statistical relationship,

and uses numbers to explain their findings. The researcher may also choose to employ a mixed method in which a combination of quantitative and qualitative methods may be used to completely describe an event. Adopting this approach provides a more complete understanding of a research problem than either approach alone. Other researchers may also choose to use a qualitative research method to describe the kind/quality of a subject while interpreting and attempting to understand the event. This method enables the researcher to use texts to explain their findings.

Thus, in comparing the merits and drawbacks of especially quantitative and qualitative research, Carson (2005) states that quantitative (or positivist) research was viewed as the research 'gold standard for so long because of the inherent generalizability of results from such research which was viewed as true science. However, later on, researchers discovered that generalizability is not always the complete picture of a research 'story'. Therefore, choosing the qualitative approach over the rest had the strongest merit since it provided rich and substantial data during the data collection leading to a rich and broad-scale understanding in the areas, which remain unexplored or underexplored in qualitative procedures due to the limitation of the deductive approach to data collection. Englander (2012), further puts forth that the notion of generalizability is malleable and sometimes misunderstood when comparing research methods, and smaller, more descriptive in-depth studies (such as those evidenced in many qualitative research studies). This may help to increase the understanding of rarely studied groups or phenomena

than surface-level, quantitative studies, no matter the quantitative study's sample size.

Phenomenology was selected among the other approaches such as Ethnography, Narrative inquiry, Case study and Grounded theory (Rahman, 2017) because It enables researchers to put aside their perceptions of a phenomenon and give meaning to a participant's experiences. More so, exploring the experiences of others enables previously unavailable insights to be discovered. Also, it focuses on the lived experience within a particular group and its fundamental goal is to arrive at a description of a particular phenomenon (Creswell & Creswell, 2017). Within the phenomenological research methodology, there are two dominant approaches: the descriptive approach and the interpretive approach. While interpretive phenomenology "aims to give individuals in particular contexts a voice and understand how they make sense of their experience" Larkin and Thompson (as cited in Ritchie, Lewis, Nicholls, & Ormston, 2014 p 271). The descriptive approach was viewed as a way of reaching true meaning through penetrating deeper and deeper into reality (Spinelli, 2005). Hence, the selection of descriptive phenomenology as the methodology guiding this study was a purposeful means of extracting key findings of the experiences of family caregivers of patients with prostate cancer. Colaizzi (1978) further affirms that descriptive phenomenology requires a focus on a 'lived' experience and a rich, detailed, and exhaustive description of the universal essence of the experience of participants.

The Rationale for the Design

The researcher used a qualitative descriptive phenomenological approach to explore the experiences of family caregivers of patients with prostate cancer because the experience is subjective, therefore, using this approach will be appropriate in exploring the individual lived experiences of the family caregivers (Davidson, 2002). This method further offers flexibility; allowing for more freedom during the interview to explore the experiences of these family caregivers (Jacob & Furgerson, 2012). Consequently, providing in-depth and rich information on the phenomenon being studied. Another strength that comes with choosing this approach was that it produced a detailed account of participants' feelings, opinions, experiences, and interprets the meanings of their actions (Denzin, 2013). Similarly, it provided a holistic understanding of the human experience in specific settings, allowing the researchers to discover the participants' inner experience (Strauss & Corbin, 2008). However, beyond the above strengths mentioned, some weaknesses were evident. One notable criticism was the lack of generalizability of qualitative findings but the focus of this study was not to generalize the study findings to a wider context but to give a holistic description of participants lived experiences.

Study Area

The study area is the location where the research was carried out (Burns & Grove, 2011). The study was conducted at the Genito-urinary unit of the Cape Coast Teaching Hospital. The Cape Coast Teaching Hospital was established on 12 August 1998 and converted to a teaching hospital in 2014. The hospital is the biggest in the Central region receiving many referral cases from Cape Coast and

beyond. It serves as a facility for medical students from the University of Cape Coast and a Centre of learning for several health professionals. The hospital has several units which include a Genito-urinary unit for the management of cancer cases. This study area was selected because the Central region and for that matter, Cape Coast has no other hospital that sees prostate cancer patient apart from the Cape Coast Teaching Hospital. Also, per the researcher knowledge on existing literature, no study on prostate cancer has been undertaken in the Central region.

Population

Study population refers to the total number of people or elements that fit the criteria for the study (Korb, 2012). The study targeted family caregivers (spouse, parents, children, siblings, cousins, aunties, loved ones and friends) who provided care to prostate cancer patients.

Inclusion and Exclusion Criteria

As part of the inclusion criteria for the study, family caregivers who provided the most assistance (family caregivers who spent much time caring for the patient) to the prostate cancer patients were selected (spouse, children, parents, siblings, cousins, aunties friends and loved ones). Likewise, family caregivers who were involved in the care of prostate cancer patient for at least (8) hours and more, provided care for 6 months and above, and are aged ≥ 18 years (the age considered as maturity stage according to the 1992 constitution of Ghana) and were willing to participate. The study, however, excluded bereaved family caregivers who no longer cared for patients living with prostate cancer.

Sampling Procedure

Sampling as described by LoBiondo-Wood and Haber (2010) is a process of selecting a portion of the population to represent the entire population. In this study, a purposive sampling technique was adopted in selecting participants as it involves identifying and selecting participants or groups of individuals that were especially knowledgeable about or experienced with a phenomenon of interest as stipulated by Creswell and Plano Clark (2017). Also, considering the willingness to participate and the ability to communicate experiences and opinions in an articulate, expressive, and reflective manner (Bernard, 2002). These caregivers were targeted at the Genito-urinary clinic as they came with their relations with prostate cancer for review, others were also met on the surgical ward, both through the prostate cancer patients.

In a qualitative study, the data gathered is of great value to the researcher however, there are no hard or fast rules about how to determine the sample size. The sample size usually must be 'large' enough to obtain data to sufficiently describe the phenomenon of interest and address the research questions thus; the goal is to attain 'saturation' as emphasized by Glaser and Strauss (2017). Creswell, (2014) nevertheless, recommends 5- 25 participant. So, in this study, both Creswell (2014) and, Glaser and Strauss (2017) recommendation was taken into consideration to determine saturation. The hospital, however, could not provide accurate data on the total number of prostate cancer patients who visit the Genito-urinary unit in a month so, a sample size of 10-12 participants was selected for the study with saturation in mind. Data saturation refers to the point in the research

process when no new information was discovered in data analysis, and this redundancy signals to the researcher that data collection may cease (Faulkner & Trotter, 2017). This indicated that further data collection would yield similar results. Hence, with this knowledge in mind, at the point of twelve (12) participants, the researcher identified no new information suggesting point of saturation.

Data Collection Instrument

Different methods are used to collect data in qualitative research; the most common were interviews, focus group discussions, observational methods and document analysis (Creswell & Creswell, 2017). The study adopted the semi-structures face to face in-depth interview method. This method reflects confidentiality while allowing for an elaboration of feelings, thoughts, and experiences on the research questions (Creswell, 2014). It also allows the researcher to gain first-hand knowledge about what participants experience through broad and open-ended inquiry using direct and personal responses.

Its flexible nature allows the participants to express themselves freely as well as the researcher to probe into specific areas of interest (Kusi, 2012). Additionally, it enables direct interaction with the participants, whose responses could be recorded and later cross-checked for accuracy (Khan, 2012). However, twelve participants were interviewed to reach saturation

The interview guide was divided into four sections. Sections A was on the demographic data of the participants (age, sex, highest educational level, occupation, religion and the relationship with the patient). Section B explored family caregivers' experiences of caring for patients with prostate cancer, section

C investigated barriers to caring for people with prostate cancer, whereas, section D explored family caregivers coping strategies as they care for people with prostate cancer. The construct from the conceptual framework and the research objectives guided the development of the interview guide, using open-ended questions with probes.

Pre-Testing

A pre-testing allows the researcher to conduct a small study to test research protocols, data collection instruments, sample recruitment strategies, and other research techniques in preparation for a larger study (Hassan, Schattner, & Mazza, 2006). Burns and Grove (2011) similarly accentuate that, pre-testing allows the researcher to amend possible errors before applying them to the actual sample. During the pre-testing, the researcher had the opportunity to pretest the instrument by administering it to a few participants before administering it to the main study participants to fine-tune the instrument (Ofori, 2017). Pre-testing the interview guide aided the development of the needed skill for qualitative data collection as a novice researcher. In this study, the pilot test was conducted with two participants at the Cape Coast Teaching Hospital. After the pretest, two questions under section B of the guide were merged.

The question that was merged into the other was "Do you know the name of cancer your relative is suffering from?" And the question into which it was merged was "Please kindly tell me about your relation's condition". It came to the researcher's notice that upon asking the second question the first question was answered. Also, two questions under section D were omitted. These questions were

"What are the resources you have used so far to help you get through this situation?"
Would you like to share a saying that describes this experience?" The two questions were omitted because, again, the first question was embedded in a previous question asked and the second question was not well understood by the participants hence the participants found it difficult to provide an answer to it.

Data Collection Procedure

Given the number of cases identified within the criteria of this research, initial contact was made with the prostate cancer patients at the consulting room of the Genito-urinary unit. Patients who met the inclusion criteria were recruited at the consulting room by the doctors. The doctors then directed the patient to the researcher in the consulting where the researcher was provided with a seat. Patients who agreed to participate in the research were provided information about the study. They were asked to identify who they considered their family caregiver and contact information of these family caregivers were retrieved. The researcher contacted the family caregivers on the telephone and an explanation of the importance of the study was provided.

The interview was then scheduled and conducted at their convenient venues, date and time. The interviews were conducted in the homes of participants, and within the hospital premises at the hospital snack bar/eatery and outside some of the wards since their relatives were on admission. Each participant was given a consent form to read and sign/thumbprint, those who did not have the literacy ability were assisted, and all misunderstandings clarified about days/week before the interview. In instances where participants could not read English, the researcher

herself translated in Twi to ensure that the participants understood everything written on the consent form. The data collected lasted between March and April 2019.

In the process of the interview, all information elicited was recorded onto an audiotape with the consent of the participants, and then later transcribed. The researcher probed and redirected responses when necessary to focus on the interview, and also to get in-depth rich responses to questions posed. Participants were informed ahead of time about further interview sessions/phone calls for clarifications when necessary. Transcription was done concurrently with the interview.

Maxwell (2013) posited that research data was irreplaceable so having a backup tool like an audio recorder for data management is essential, thus, the researcher kept records on experiences in a field diary as well as copies of the recorded interviews and transcribed files in an electronic mail/hard disc. The nonverbal communications of the participants, participants' mannerisms and anything vital to the study such as participant crying, laughing, feeling of sadness, anger, and moodiness during the interview were recorded in a field diary and dated to help the researcher understand the data generated during transcription. The interview was face to face and it lasted between 40- 50 minutes.

Data Storage

Data storage/management is a term that describes the organization, storage, preservation, and sharing of data collected and used in a research project (Wiggins et al., 2013). The main purpose of data management in a qualitative study is to

“store data for maximal efficiency in retrieval and analysis” by Padgett (as cited in Ofori, 2017 p 34). The researcher kept records of the date, time and place where the interviews were conducted prior to data collection. Participants were identified by pseudonyms after interviews have been conducted, transcribed verbatim and saved up in a word document. Hard copies of the document labelled with the pseudonyms were kept in a file separately for everyone for easy retrieval. The demographic information and consent forms were also kept separately and these were accessible to only the researcher and her supervisors. Also, the recorded tape, transcribed data and field notes were kept in a cabinet with the key accessible to only the researcher. The transcribed data was backed up electronically on a hard disc and electronic mail to prevent data loss. Information will be discarded after five years

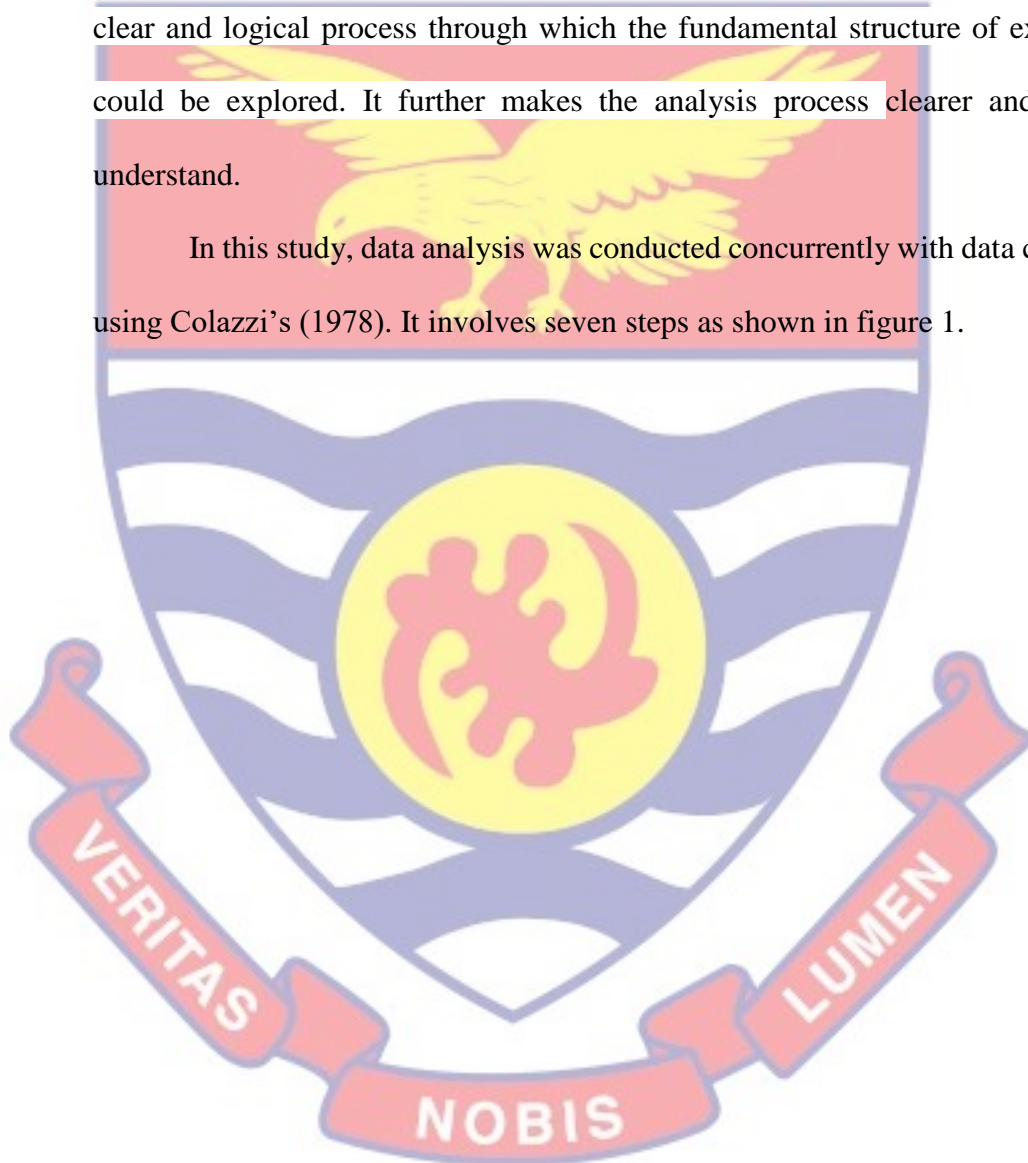
Data Processing and Analysis

Data analysis is the process whereby the researcher seeks to reduce and make sense of vast amounts of information often from different sources so that impressions that shed light on the research question can emerge (Savenye & Robinson, 2005). The generated data were analyzed using thematic analysis for the reason that it was an independent and reliable qualitative descriptive approach for identifying, analyzing, and reporting patterns (themes) within data (Braun & Clarke, 2006).

Following the review of some descriptive phenomenological data analysis methods and techniques described by Colaizzi (1978), Englander (2012), Braun & Clarke, (2006) and Giorgi (2009), the researcher chose to use Colaizzi’s approach

as the analysis frame for this study, as this method of data analysis is rigorous and robust, and thus ensures the credibility and reliability of its results. It also allows the researcher to reveal emergent themes and their interwoven relationships. Again, the approach was specifically tied to descriptive phenomenology thus, providing a clear and logical process through which the fundamental structure of experience could be explored. It further makes the analysis process clearer and easy to understand.

In this study, data analysis was conducted concurrently with data collection using Colazzi's (1978). It involves seven steps as shown in figure 1.



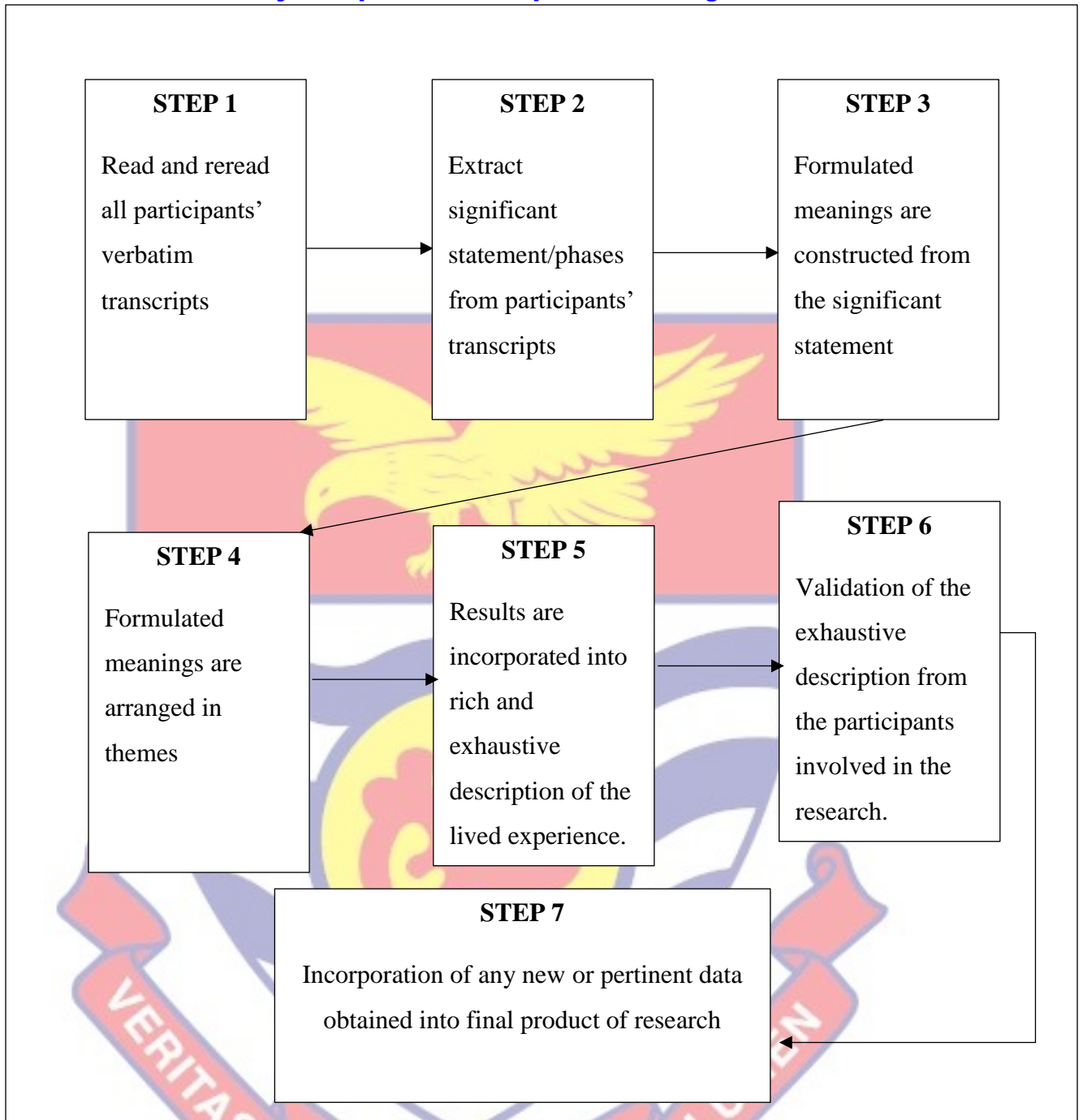


Figure 4: Adopted from Colaizzi, 1978

The recorded interviews were transcribed verbatim immediately at the close of each interview day. Each recorded interview was carefully listened to several times and transcribed. Most of the interviews were conducted in Fante, one participant spoke English and another Ga language. The interviews conducted in Fante and Ga language were translated into English by the researcher herself before

transcribed. Transcription was done by the researcher herself by listening to the recorded interviews sentence by sentence from the tape. At a point, the tape is paused and rewind to get a clear picture of what the participant was saying. The statement was then written down after clarity has been achieved. This continued until all the interviews have been transcribed, taking about four (4) hours for each recorded interview to be transcribed. The interviews, transcription and analysis covered the period of March to May 2019.

In analyzing the data gathered, the researcher adhered to Colaizzi's seven steps as much as possible. The steps and action taken are described below.

Step one: Reading and re-Reading all Participants Verbatim Transcription

All recorded interviews were transcribed verbatim. Each interview took between 4 to 5 hours to be transcribed. Transcripts were read several times to be familiarized with the data. By so doing a deeper understanding and a sense of 'feel' for what was described by the participants was achieved. Reading and re-reading through the transcribed files and 'not' taking note of statement that may help for the next stage immediately also helped the researcher to truly 'see' experiences of the participants in the transcribed documents. After all the reading have been completed the researcher then moved on to step two, described next.

Step two: Extract Significant Statements

At this stage of the analysis, significant statement and phrases were identified and extracted from the transcribed document that pertains to the experiences, barriers and coping strategies employed by family caregivers of prostate cancer patients. By the end of step two, a list of significant statements

(codes) has been identified from the transcribed data. An experienced researcher was also made to read and re-read the transcribed data and extract statements for each that he believed were related directly to the study in a process of peer debriefing after the purpose/ relevance of the study has been explained. A comparison of extracted statements was made, and in the end, a consensus was reached. Step illustrated in table one below.

Table 1: Example of the Process of Extracting Significant Statements/Phases from the Verbatim Transcripts.

Significant Statements	Transcript Number	Page Number
<u><i>I normally have body pains and feel weak. In the mornings, waking up from bed is very difficult because I experience pains all over my body because of the frequent lifting and changing of position with no one to assist me. He is very heavy as you see him there like that.</i></u>	1	8
<u><i>Mostly, when he is in pain, he makes the hm hm. hm, sound so I quickly go in there to find out what the problem is. He will tell me that he is tired of sleeping for a long time in a particular position. In this case, I have to try to do some turnings or sit him up in bed, the next minute he will call again for you to assist him to assume another position. Because of that, I cannot sleep as my mind is mostly on him throughout the night.</i></u>	1	9
<u><i>I was always thinking about him. Even my colleagues at work, even told me that I've suddenly lost weight</i></u>	2	18
<u><i>I realized that when I am stressed up due to the workload at home combined with my job, I start experiencing headaches.</i></u>	2	22
<u><i>Sister, even after cooking I cannot eat, I'm always worried and afraid because I don't know what this is leading to anymore.</i></u>	6	54

Step Three: Formulating Meaning

After the completion of comparative analysis as described in step two, the process of understanding the meaning behind each significant statement/phrase was undertaken, toward creating a formulated meaning unit from each significant statement. Each underlying meaning was coded in one category as they reflect an exhaustive description. Step illustrated below in table two

Table 2: Examples of the Process of Creating Formulated Meanings from Significant Statements.

Significant Statement	Formulated meanings
<u><i>“I normally have body pains and feel weak. In the mornings, waking up from bed is very difficult because I experience pains all over my body because of the frequent lifting and changing of position with no one to assist me”.</i></u> (Transcript 1, page 8)	Caregiver realizes that the laborious nature of the caring role has resulted in bodily pains and weakness
<u><i>“In this case, I have to try and do some turnings or sit him up in bed, the next minute he will call again for you to assist him to assume another position. Because of that, I can't sleep as my mind is mostly on him throughout the night”.</i></u> (Transcript 2, Page 9)	The caregiver stated that the constant waking up at night to assist the patient result in sleeplessness
<u><i>“Even my colleagues at work, they even told me that I've suddenly lost weight”</i></u> (Transcript 2, Page 18)	Caregiver have noticed that she has lost weight; even colleagues from work due to the difficult nature of the role,
<u><i>“When I am stressed up due to the workload at home combined with my job, I start experiencing headaches”</i></u> (Transcript 2, Page 22)	The caregiver realizes that combining her job with the caring role was very stressful resulting in headaches
<u><i>“Sister, even after cooking I can't eat, I'm always worried and afraid”</i></u> (Transcript 6, Page 54)	Caregiver experienced anorexia due to persisting worrying over the patient's health

Step four: Formulated meanings are arranged in themes

Based on the guidance of Colaizzi (1978) the researcher undertook the difficult task of grouping formulated meanings together into thematic clusters. From this process, four dominant themes emerged. They were: 1) Effects of caregiving (Physical impact, psychological impact and social impact on the family caregiver) 2) Challenges confronting family caregivers of patients with prostate cancer 3) Difficulties encountered within the health care environment affecting the family caregivers' role 4) Coping strategies used by family caregivers of patients with prostate cancer. Represented in figure two below

Step Five: Results were incorporated into a rich and exhaustive description of the lived experiences

At this stage of the analysis, all themes were defined into an exhaustive description under the main phenomenon "Experiences of family caregivers of patients with prostate cancer". Thereafter, the researcher sought an expert researcher who reviewed the findings in terms of richness and completeness to provide sufficient description and to confirm that the exhaustive description reflects the experiences of the family caregivers of patients with prostate cancer. Finally, a validation of this exhaustive description was confirmed with the researcher's supervisors. The exhaustive description "statement" (Spinelli, 2005) of the experience represents key findings from this study; it is included in its entirety in 'Findings' in Chapter four. However, table three gives an illustration of this step.

Table 3: Presents an illustration of the rich and exhaustive description of a finding from the study.

Sleeplessness	(Physical Impact)Subtheme
<p>Sleeplessness was a major concern reported by most of the participants. Participants stated that sleeplessness resulted from staying awake to constantly checking on the patient in case they needed something or assistance. Others could not sleep due to persistent worry about the outcome of the patient’s condition and how to overcome the financial burden. One participant, however, reported that she slept well</p>	<p>Exhaustive Description</p>
<p>Participant could not sleep because the patient may need assistance in one way or the other.</p>	<p>Patients’ Quote</p>
<p>Participant has insomnia because the patient was in severe pain</p>	<p><i>“At night I always have my mind on him, with the little noise from his room, I wake up to go find out if everything is all right. So, I can’t sleep well”</i> Grace</p>
<p>Participant has insomnia because the patient was in severe pain</p>	<p><i>“Since this whole condition started, he is not able to sleep, so as the caregiver, I also find it difficult to sleep because if he is in pain or needs something and I’m fast asleep, I don’t know what will happen. Apart from that, things he used to do on his own, he is no longer able to do them without assistance so I must stay up and help”</i> Mercy</p>

Step Six: Validation of the exhaustive description from the participants involved in the research

This step typically involves a return to research participants for member-checking of created profiles of their experiences, and verification that what the researcher described, accurately reflects their experience with the phenomenon

under investigation. Participants' views on the study results were obtained directly via phone calls. This step was done by the main researcher as she took approval from the participants in advance during the first interviewing. Eventually, all participants showed their satisfaction toward these results which entirely reflect their feelings and experiences. Again, a peer de-briefer reviewed the exhaustive description as well, as suggested by Lincoln and Guba (1985). The peer de-briefer was requested to read the exhaustive description of the experience of study participants and the final themes and compare his understanding of elements shared in these documents to the information in participants' information profiles. This additional verification step was done to enhance the trustworthiness of the study findings.

Step Seven: Incorporate any new or pertinent data obtained into the final study

At this point, a new theme that emerged, which did not fit into the existing category at the initial stage was added to the study. A new theme that emerged was *'Difficulties encountered within the healthcare environment affecting the family caregiver's role'* with *"Lack of Accommodation Facilities"* and *"Poor Staff Attitude"* as subthemes

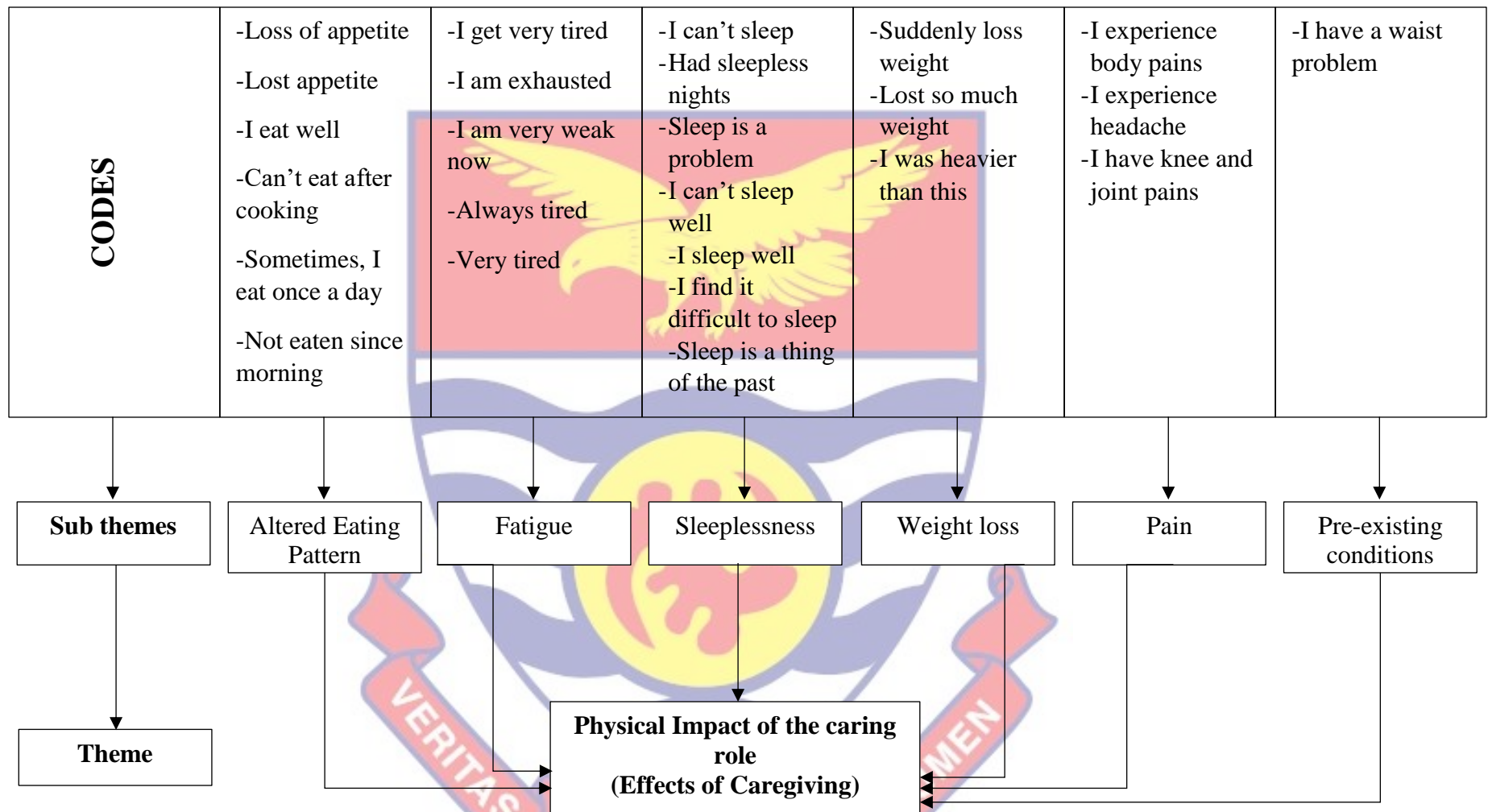


Figure 5: Codes, Subthemes, and Themes (Physical Impact of the Caring role)

Ethical Consideration

Ethical approval was sought from the Institutional Review Board (IRB) of the University of Cape Coast. Copies of the ethical approval letter and an introductory letter from the School of Nursing and Midwifery, University of Cape Coast was sent to seek permission from the Cape Coast Teaching Hospital. The hospital, after reviewing the proposal for the study, provided a letter to be sent to the Head of Surgical Sub-BMC and Head of the Urology Department/ Clinic to ensure that all assistance need was provided. The researcher was then introduced to the specialist in charge of Urology, where the purpose and relevance of the study were provided. A place within the consulting room was provided where the researcher took a seat to explain the purpose, objectives and benefits to prostate cancer patients and also to reach their family caregivers.

Upon reaching these family caregivers on phone and some within the hospital premises, the purpose, objectives, benefits and potential risks of the study were explained to the participants verbally and in the consent form, and also, participants were allowed to ask questions for clarification. This was done days/week before the actual interview to allow time for participants to decide whether or not to participate. Only participants who consented to participate in the study were offered a consent form to sign/thumbprint. Participants were assured of confidentiality and privacy of any information provided, this was done by making them aware that the data provided was only going to be used for academic purposes, and only the researcher and two supervisors will have access to the data. Participants were also informed of their right to withdraw at any time during data

collection and were assured that it was not going to affect the care their patients received at the hospital.

The anonymity of participants was ensured by assigning pseudonyms to the participant during the recruitment. The pseudonyms were used when the participants were being quoted in the findings chapter. Privacy was ensured during the interview. Participants were informed that data and other study documents such as consent forms, audiotapes and transcripts would be kept under lock and key for at least five years after the study. The sheet containing demographic data and other identifiable information is being kept separately from transcripts under lock and key. Participants were informed that appropriate ethical clearance would be sought if the data has to be used in future for any other purpose.

Methodological Rigor

Since this study was not quantitative, nor grounded in post-positivist thought, trustworthiness is the terminology used to describe the rigour of the research process. Usage of this term was suggested by Englander (2012), who asserted that the term validity is the realm of post-positivist researchers, and therefore, it is deemed inappropriate as a descriptive term for qualitative investigation. Rigour is therefore described as the extent to which the findings of the research can be trusted. The trustworthiness of the study was, therefore, achieved through four main criteria namely credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985).

Credibility refers to the true value of the data and interpretations of the data or findings of the study; this was achieved by ensuring that contact was maintained

with participants to verify if the findings of the study are true to their experiences. By using member checking, "which was achieved by getting agreement from the participants on the emerged results through phone calls (Creswell, 2014). Also, an experienced researcher was made to review the finding and compare with participants information profile to ensure that information from participants was accurately presented

Transferability involves the ability of the research to yield similar results when repeated in other settings or group; this was achieved by recruiting a nominated sample. These are family caregivers of prostate cancer patients within the Cape Coast metropolis involved in the care for about 6 months and more, at least 8 or more hours in a day, above 18 years and have agreed to participate in the study.

Dependability refers to the consistency and stability of the findings of the research; it was achieved by keeping an audit trail, code and recoding of the data by another researcher after which it was being compared for commonalities and also peer examination. The audiotape, transcribed data and findings were also cross-checked by my supervisor

Confirmability refers to establishing that the collected data represents the information participants provided. It was established, through the verification of results with participants, and using their own words in generating the description of their experiences. Also, documenting the researcher's preconceptions before the onset of the study by means of bracketing, thus, eradicates any bias inherent in the researcher believes and attitudes (Creswell, 2014).

The Use of Bracketing in this Study

Phenomenology in qualitative research have different approaches, amongst these several approaches are descriptive and interpretive which remains the classical approaches that guide most qualitative research. In this study, the descriptive phenomenological approach based on the work of Husserl was selected to explore the lived experiences of family caregivers of patients with prostate cancer within the Cape Coast metropolis. This method was selected because according to Husserl, to understand the lived experiences of participants, descriptive phenomenology is the best approach. Freeman (2011) further asserted that understanding cannot be conceived as a fixed meaning but how the meaning is generated and transformed. Giorgi (2011) concurs by stating that to discover meaning in the data one needs an attitude open enough to let unexpected meanings emerge. This assertion is what Husserl termed bracketing, phenomenological reduction or Epoche.

Bracketing is therefore termed as a methodological device of phenomenological inquiry that requires deliberate putting aside one's own belief about the phenomenon under investigation or what one already knows about the subject before and throughout the phenomenological investigation (Carpenter, 2007). It was further described as a means of demonstrating the validity of the data collection and analysis process (Ahern, 1999). Bracketing again is defined as holding in abeyance those elements that define the limits of an experience when the nurse is uncovering a phenomenon about which he/she knows a great deal (Ray, 1994). It is therefore imperative that as a novice nurse researcher and a clinical

nurse of about eight years of practice, an effort is made to put aside repertoires of knowledge, beliefs, values and experiences to accurately describe the life experiences of participants.

Bracketing was ensured right from the research literature review, data collection, and analysis since they are all sequentially related. To begin with, a reflexive diary was kept throughout the research process which was used to write down thoughts, feelings, and perceptions, allowing the researchers to re-examine her positions on issues raised that might affect the research process. This strategy was concurred by Wall, Glenn, Mitchinson and Poole (2004) who suggest that using a reflexive diary is helpful to develop bracketing skills and facilitate decision making during the progress of a phenomenological investigation.

The next strategy adopted was during the literature review. The researcher did some groundwork through the literature review to gain a better understanding of the lived experiences of family caregivers of cancer patients in general, this helped to develop the research proposal to kick start the study. Even though the knowledge gained through the process of a literature review may inevitably affect the researcher preconceptions on the topic, however, literature required for the development of the proposal was what was more important at the beginning stage. Most of the literature review for the actual study was done during data collection based on the information given out by participants. Van Manen (2016) supports this by postulating that a research method is a way of investigating certain kinds of questions, why the questions and the way one understands the questions, as important starting points.

During data collection, the research questions were not pre-determined; instead, followed the cues of the participants (Ray, 1994). A semi-structured interview guide and face to face technique were used to collect data. This guide consisted of open-ended questions that were developed in advance and by prepared probes (Morse & Richards, 2002). The interviewer had a set of questions on an interview schedule, but the interview was guided by the schedule rather than dictated by it; the interviewer probed freely on interesting areas that came up from participants' interests or concerns (Lindlof & Taylor, 2002). Again, the researcher asked focusing but not leading questions about the experiences and listen carefully to the participants. Example of a question asked "Please kindly tell me about your relations condition", a follow-up question was "How do you think your caring role has affected you?" The researcher promoted bracketing by participants somehow because she realized that the knowledge of her being a nurse which the participants were aware of made it difficult for some of the participants to frankly express their feelings/opinion on the phenomenon under investigation, this agrees with the assertion held by Caelli (2001) who suggested that both researchers and participants should attempt to put aside their assumptions about the phenomenon because these can facilitate the description of the primordial experience; particularly in cases where the participants probably know that the researchers also have similar knowledge to the participants concerning the phenomenon under investigation.

At the point of data analysis, the information generated may be distorted and filtered; thus, this may affect the validity of the study. To avoid this Polit and Beck (2006) suggests that Colaizzi's data analysis method is employed as it is the

only phenomenological analysis that calls for the validation of results by returning to study participants. Therefore, to ensure that participants' experiences were correctly described, Colaizzi's method of analysis was used to analyse the data in the present study. This procedure helped the participants to ascertain if their answers to any of the questions needed to be rectified, and also, ensuring that the researcher has not misinterpreted the data.

Chapter Summary

The chapter described the methodology of the study, the research design, the study area, population, sampling procedure, data collection and instrument, data collection procedure, data processing and analysis, ethical consideration and methodological rigour. A major limitation to the present study is that it consisted of only family caregiver of prostate cancer patient thus; the findings were not representative of caregivers of patients with other health condition. In addition, the study was conducted in Cape Coast; however, the research provided insufficient data to conclude on the culture/national differences in caregiver's experience. Again, findings revealed that all respondents were Christians, thus, it is likely that family caregiver experiences might differ among different religions.

CHAPTER FOUR

RESULTS AND DISCUSSION

This chapter presents the findings generated after the analysis of data gathered from participants on their experiences of caring for patients with prostate cancer. The study sought to explore the lived experiences of family caregiver of patients with prostate cancer. The findings are presented according to the objectives of the study. Four themes that emerged from the data were: the effects of caregiving (physical impact, psychological impact and social impact), challenges confronting caregivers of prostate cancer patients, difficulties encountered within the healthcare environment affecting the family caregivers' role, a new theme that emerged from the study, and coping strategies used by family caregivers of prostate cancer patients. These major themes and their sub-themes are presented with verbatim quotations from the participants using pseudonyms. A background description of the participants in the study is also provided. In total, there are four (4) themes and thirty-three (33) sub-themes.

Description of Participants Demographic Characteristics

The study participants were twelve (12) in number and aged between 27 – 67 years (see table 4 below). The family caregivers included six (6) spouses and six (6) children of the patients. The number of years of marriage by spouses were between 10- 30 years with children. Two of the participants had children before marrying their husbands. And some of the patients also had children before marrying their present spouses. These spouses had between one to five children with their present spouses. The six children who took up the caring role were five

females and a male. Four females out of those five were married with children whereas one was not married but in a serious relationship. The male was also not married but in a relationship. All participants were Ghanaians and Christians. Two participants were government workers on retirement. One participant was a seamstress, four were petty traders, two were farmers and three were professionals of which one is a mental health nurse awaiting posting, a teacher and a secretary. The duration of care was between 6 months - 2 years. Most participants preferred to speak Fante which was their native language. However, other participants also spoke several other languages such as English, Ga and Twi. Four of the interviews were completed in the participants home. Eight took place within the hospital premises. Five of the patients of these caregivers were on admission and the rest were at home. Nine of the participants were sole caregivers whereas three had assistance occasionally from others/family members. The residential location for these family caregivers within the Cape Coast Metropolis varied between urban and rural settlements.

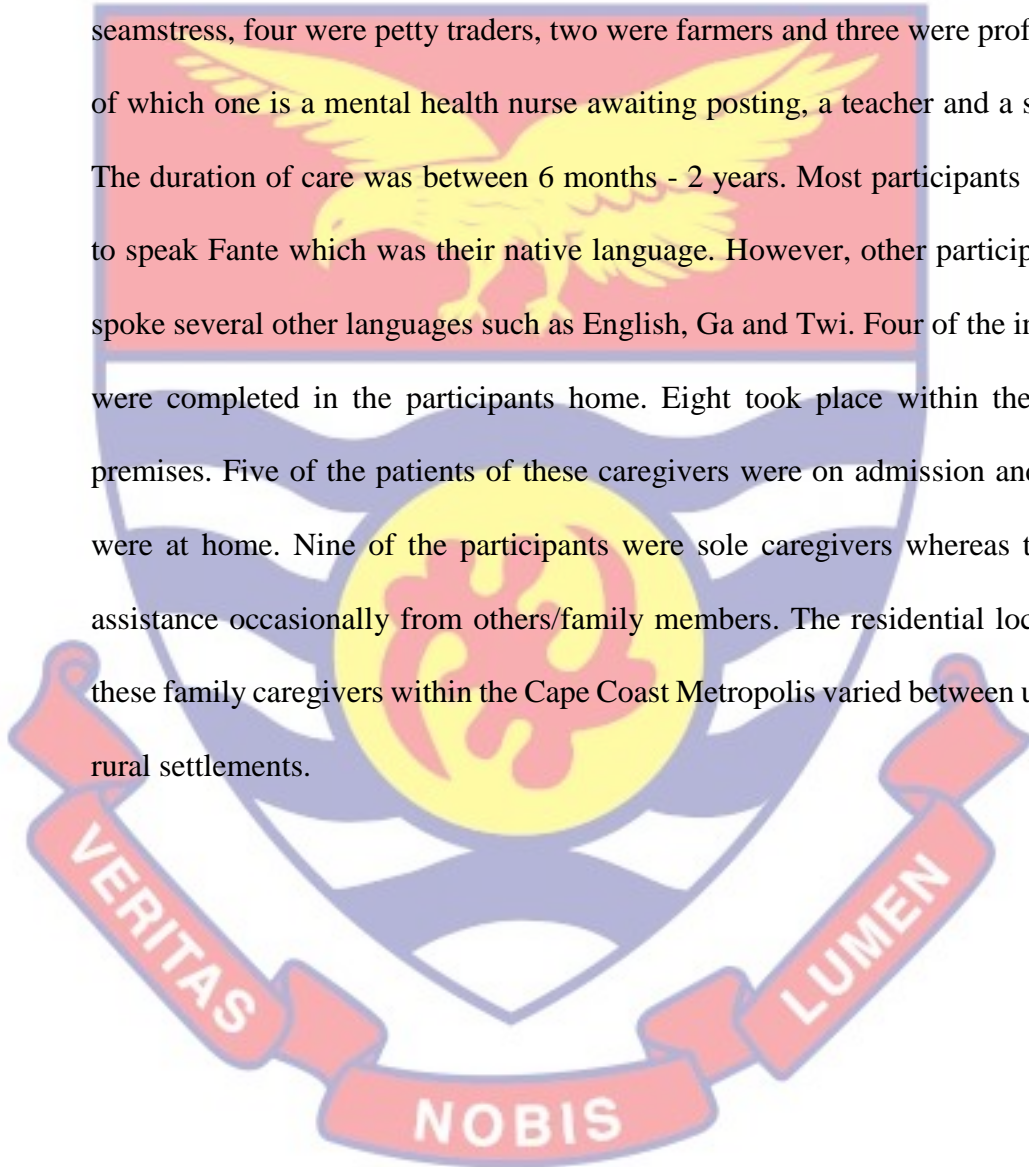


Table 4: Demographic Characteristics of Participants

Pseudonyms	Age	Sex	Marital status	Religion	Educational level	Relations hip to patient	Duration of Care	Occupation
Love	38 yrs	Female	Married	Christian	JHS	Father	2 years	Seamstress
Peace	36 yrs	Female	Not Married	Christian	Tertiary	Father	1 year	Secretary
Grace	29 yrs	Female	Married	Christian	Tertiary	Father	1 year	Nurse (Awaiting postings)
Joy	58 yrs	Female	Married	Christian	Primary	Husband	1 year	Trader
Mercy	67 yrs	Female	Married	Christian	Tertiary	Husband	2 year	Retired
Forgive	62 yrs	Female	Married	Christian	Tertiary	Husband	1 year	Retired
Favour	41 yrs	Female	Married	Christian	SHS	Father	1 year	Trader
Humble	62 yrs	Female	Married	Christian	Illiterate	Husband	1 year	Farmer
Passion	60 yrs	Female	Married	Christian	Illiterate	Husband	1 year	Farmer
Kindness	64 yrs	Female	Married	Christian	Tertiary	Husband	2 years	Trader
Hope	27 yrs	Male	Not Married	Christian	Tertiary	Father	6 months	Teacher
Faith	40 yrs	Female	Married	Christian	Illiterate	Father	1 year	Trader

Key Findings from the Analysis

This section will present the main findings that emerged from the analysis

Themes and sub-themes.

There were a total of 4 themes and 33 sub-themes that emerged from the study results.

Table 5: Shows the themes and sub-themes.

Effects of Caregiving	
Physical Impact	Sleeplessness Altered eating pattern Fatigue Weight loss Pain Worsening of Pre-existing condition
Psychological Impact	Anxiety Inadequacy Uncertainty Hopelessness (Life halted) Concealment Empathy Care as obligation/ “Giving back”
Social Impact	Sexual concerns Role /Role adjustment Grooming Turmoil Loss of livelihood/income
Challenges confronting caregivers of prostate cancer	Lack of preparedness Lack of knowledge about condition and treatment Misconception about the condition Lack of support (resources, government) Financial constraints Communication concerns
Difficulties encountered within the healthcare environment affecting the caregiver’s role.	Lack of accommodation facilities Poor staff attitude
Coping strategies used by family caregivers	Religiosity Active planning Denial/Acceptance Relaxation/listening to music Support systems (Emotional/Physical/ Financial) Seeking knowledge on the condition Medication abuse

Source: Field survey (2019)

Research has documented that the work of family caregivers can be very laborious, and this adversely affects caregiver health in diverse ways. In response to the first research question “**what are the experiences of family caregivers of patient with prostate cancer?**” *“Effects of caregiving” was a major theme that emerged with physical, psychological and social impact as subcategories, and this is represented below.*

Physical Impact of Caregiving

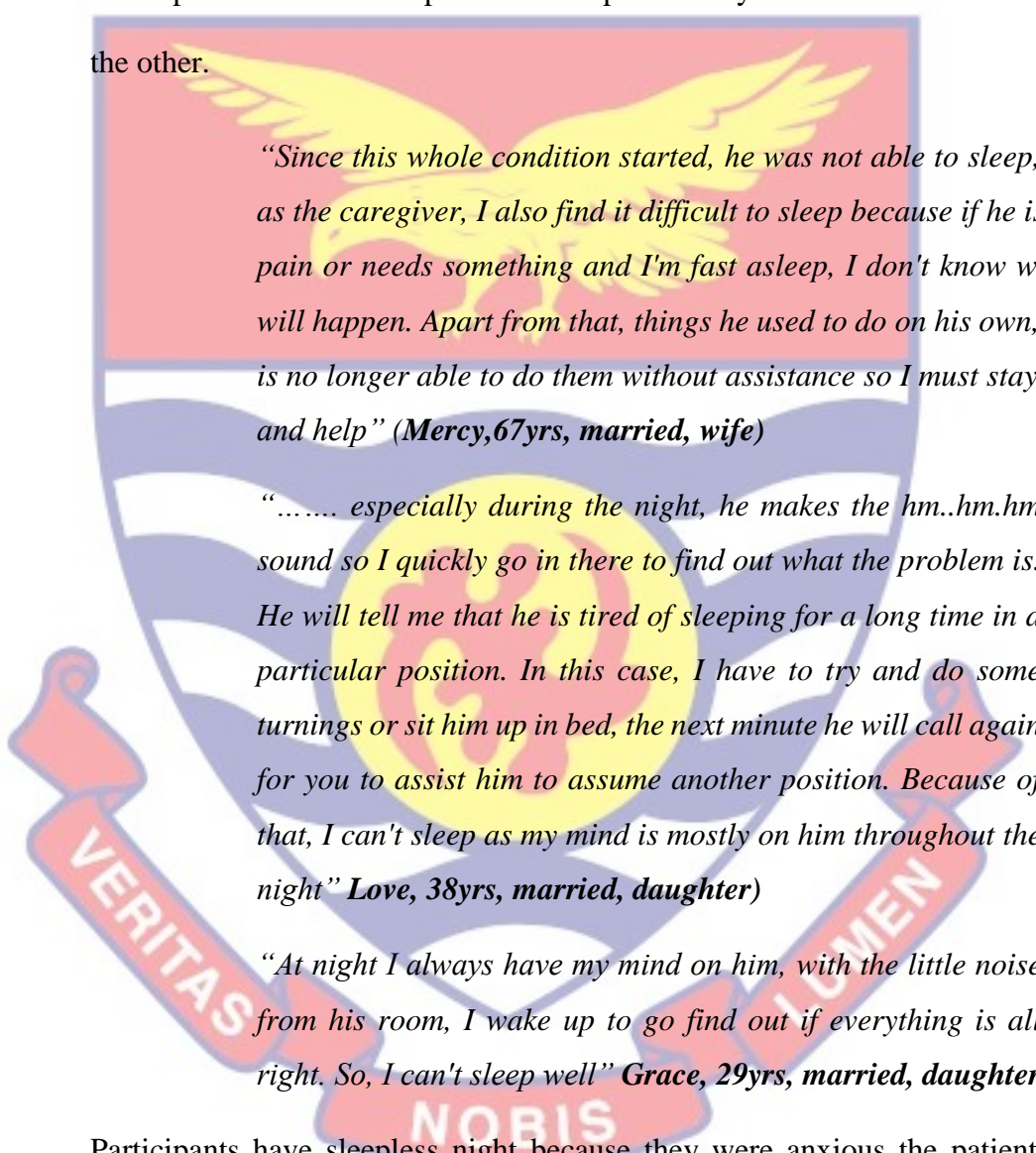
The family caregivers shared their experience of the physical impact of the role they played. They mentioned that caring for a relation with prostate cancer was a very difficult task which resulted in a lot of physical exertion, especially when it involves constant washing/cleaning to do away with the stinging smell from leaking of urine due to urine urgency, lifting and changing of patients position, checking on patients from time to time especially at night, accompanying the patient to hospital and managing medications. However, the degree of impact was dependent on the severity of the condition and whether or not the patient was bedridden. Most of the participants stated that they suffered physical problems such as, sleeplessness, pain, altered eating pattern, fatigue, weight loss, and worsening of other pre-existing conditions.

Sleeplessness

Sleeplessness was a major concern reported by most of the participants. Participants stated that sleeplessness resulted from staying awake to constantly check on the patient in case they needed something or assistance. Others could not

sleep due to persistent worry about the outcome of the patient's condition and how to overcome the financial burden. A participant, however, reported that she slept well

Participants could not sleep because the patient may need assistance in one way or the other.



“Since this whole condition started, he was not able to sleep, so as the caregiver, I also find it difficult to sleep because if he is in pain or needs something and I'm fast asleep, I don't know what will happen. Apart from that, things he used to do on his own, he is no longer able to do them without assistance so I must stay up and help” (Mercy, 67yrs, married, wife)

“..... especially during the night, he makes the hm..hm.hm sound so I quickly go in there to find out what the problem is. He will tell me that he is tired of sleeping for a long time in a particular position. In this case, I have to try and do some turnings or sit him up in bed, the next minute he will call again for you to assist him to assume another position. Because of that, I can't sleep as my mind is mostly on him throughout the night” Love, 38yrs, married, daughter)

“At night I always have my mind on him, with the little noise from his room, I wake up to go find out if everything is all right. So, I can't sleep well” Grace, 29yrs, married, daughter

Participants have sleepless night because they were anxious the patient was in severe pain

“As for sleeping, hmmm it is a problem. I am not able to sleep. At night when we go to bed, he won't sleep for you to also sleep.

He constantly complains of pain, turning and tossing on the bed. Sometimes this continues till morning, to about 3:00 am before you find him sleeping then I am also able to get some sleep. Sister, I am suffering. It is not easy at all” **Passion, 60yrs, married, wife**

“Because of the situation, I can’t also sleep as the pain is too much for him to bear and also the pain makes him grind on his teeth which you could hear so loudly” **Forgive, 62yrs, married, wife**

“Because sometimes he complains of feeling pains in his genitals. I have to wake up and give him pain killers that were prescribed. I can only go back to bed when he is better” **Hope, 27yrs, unmarried, son**

Participants could not sleep due to the anxiety and persistent worrying about the patient’s health and how to overcome financial burden.

“Sleep is a thing of the past, at the moment what I do best is worry, and worrying deprives you of your sleep. When I’m constantly worrying about his health, how to raise money for the medical bills, buy medications and pay for laboratory investigations how can I sleep? Currently, the life we are living, hmmm... it is only God” **Humble, 62yrs, married, wife**

“I’m not able to sleep at all, especially when the old man is in so much pain and we were not receiving any feedback from the hospital and doctors as to when the surgery will be done coupled with the stress of this pregnancy, and the thought that probably the doctors have seen something that may result in an unexpected occurrence during the surgery. How can I sleep?” **Faith, 40yrs, married, daughter**

Others however reported being able to sleep well without any worries at all.

"I can sleep well. I don't have any problems with sleep. He knows I usually get tired so when I sleep, he does not bother me" **Joy, 58yrs, married, wife**

Participant does not live with the patient but goes home to her immediate family after rendering the care needed for the day. However, she reported having a sleepless night despite the exhaustion hence took sedatives to enable her to sleep.

"I always find myself very tired and exhausted. At night I find it difficult to sleep, so, to enable me to have some good sleep to regain my strength for the more difficult task the next day I sometimes take sleeping pills. I usually get them from the pharmacy" **Favour, 41yrs, married, daughter**

Pain

Still, in answering the first research question, Pain was a category that emerged under the physical impact. It is an unpleasant sensual experience associated with actual or potential damage. In this study, participants shared their experience of pain in three different ways, namely body pains, waist pain and headache. The experience of pain according to participants was a result of the physical support including helping patients with daily activities, managing patient's disease and medical appointments. Others also took ill due to the nature of the role they play.

"Sometimes I even fall sick and have to go to the pharmacy to get myself some medications. I normally have body pains and feel weak. In the mornings, waking up from bed is very difficult because I experience pains all over my body due to the frequent lifting and changing of position with no one to assist me. He is very heavy as you see him there like that" **Love**

“Madam, hmm, as we speak now, I have knee and waist pain. Sometimes I even want to give up. Because I am already tired of everything. My son used to bring him for reviews but I had to come today because he is a teacher and he needs to go to work....” Joy, 58yrs, married, wife

“I realized that when I am stressed up due to the workload at home in managing my dad’s condition combined with my job, I start experiencing headaches” Peace, 36yrs unmarried, daughter

Altered Eating Pattern

Whether the caregiver was able to eat well or not was another issue that comes up. The family caregivers shared their experience on how the caring role has affected their eating habits. Most caregivers reported eating once a day or not eating at all, and rather taking in drinks due to loss of appetite. This was as a result of the increased workload making it impossible for them to make time for food. Others also mentioned that their inability to eat well had resulted in weight loss. Whereas, others attributed the weight loss to constantly worrying about the patient. Others, however, mentioned that they eat well.

Participants not able to eat well due to loss of appetite for food

“Hmm sometimes immediately you try to put some food in your mouth, he will call you to assist in easing himself. So, what happens is that you end up not able to continue with your food. I have to then get some drink since I’ve suddenly lost appetite” Love, 38yrs, married, daughter

“My eating pattern, hmmm, I need to make sure my dad is served, and my girl too is served, by the time I’m done I would have even lost appetite. What happens is that, after preparing breakfast, I may

decide that oh let me wash these few things, then before I know its lunchtime, I get their food ready, and something else comes up again, so I sometimes I end up eating once and mostly in the evening” **Grace, 29yrs, married, daughter**

Participant not able to eat well due to persistent worrying about patients’ health

“Sister, even after cooking I can't eat, I'm always worried and afraid because I don't know what this is leading to anymore”
Forgive, 62yrs, married, wife

“Yes, I haven’t eaten anything since morning but I want him to eat something and recover quickly. I’m not worried about me but more worried about him. Because I believe that if he is okay, I will also be fine” **Faith, 40yrs, married, daughter**

Participant attributed the weight loss to the inability to make time for food

“Since I started caring for my dad, I've lost so much weight. I wake up at night, especially with my little girl also with me, I need to wake up very early and do some of the chores for the day otherwise she would not allow me when she wakes up. I will prepare their (my little girl and dad) food, wash and so on, hence not able to make time to eat” **Grace, 29yrs, married, daughter**

“Sometimes it is difficult to eat because I’m not able to make time but I try to make sure I take in something since I don't want to lose weight as my colleagues at work were already complaining that I have lost too much weight” **Peace, 36yrs, unmarried, daughter**

Participant attributes increase workload to inability to make time to eat

“Sometimes I eat once a day because there is too much to be done and by the time, I realize it is already time for dinner” Favour, 41yrs, married, daughter

Participants, however, did not have any problem with her eating habit

“I eat very well; I do not have a problem with food” Joy, 58yrs, married, wife

Participant had lost weight due to worrying about the patient condition.

“Madam I am scared and always worried because of the condition, I was heavier than this, look, I have lost so much weight since this condition started. I have changed” Joy, 58yrs, married, wife

Worsening of Pre-existing condition

Studies have reported that the caring role was associated with the development of chronic conditions in some family caregivers as well as worsening of pre-existing conditions. In this study, one participant stated that she had a waist problem that had become worse due to the demands of the caring role. Another also mentioned that she took ill and had to get herself some treatment. However, none of the participants mentioned that they have developed conditions such as hypertension/ diabetes mellitus or having such conditions that had grown worsened as reported by other studies.

“Caring for my husband is not easy, I have a waist problem and I find myself always very tired. The waist problem was there but was not as serious as it has become now, and it is all because of the role I currently play” Forgive, 62yrs, married, wife

Fatigue

Fatigue within this context is a subjective feeling existing at one point in time on a continuum from wariness to complete exhaustion resulting from physical, emotional and mental activities. Most of the participants expressed a feeling of severe exhaustion as a result of physical activities. The degree of exhaustion was dependent on whether the caregiver lived with the patient in the same house or if he/she is the sole caregiver of the patient

Participant reported extreme exhaustion due to caring for her dad (patient) and her little girl

“I find myself working throughout the day, You, know how urine is, if I don't constantly wash the clothes and clean the room, no one can even sit there. So, I'm always cleaning urine especially with my little girl around crawling, touching and inserting things into her mouth. Hmm, it is not easy for me at all. My day is full of activities. Activity after activity (from morning till evening) so I get very tired. Caring for children is hectic and adding a sick person to it becomes even worse....” Grace, 29yrs married, daughter

The participant is the sole caregiver of a patient who is bedridden and dependent on her to meet personal care needs

“He is also very weak now; he can't do anything for himself. So, if I'm working on him, he can't even help me in any way, I will have to do everything all by myself it is not easy by the time I'm done coupled with other house chores, I am very exhausted” Joy, 58yrs, married, wife

Participant experiences increase exhaustion due to the laborious nature of the caring role

*Always tired and exhausted. For instance, today I had to wake up at 4 am and prepare everything for him for the children to take care of him, then rush down to the hospital to get his card and things ready and also join the queue so that we can see the doctor on time. So, I had to take the lead to secure the place while he joins later. By the time we get home, hmm” **Mercy, 67yrs, married, wife***

*“Hmm, my major problem is the toilet. if he goes to the toilet, I have to make sure I go for it afterwards to take it to the mains to discard it. For the bathing I have a big basin in my kitchen, he sits in the basin and I clean him up. After which I pour out the water. Then I go ahead to do other things for the day such as cooking, washing etc. Doing these things are not easy, I have waist pain and I find myself exhausted at the end of the day” **Forgive, 62yrs, married, wife***

*“Because of the role I play currently, I find myself always tired, coupled with lack of sleep. Sometimes, some things need to be done, but because of the exhaustion, I'm not able to do them” **Humble, 62yrs, married, wife***

Psychological Impact

The second subcategory under the main theme "Effects of Caregiving" is the psychological impact of the caring role on the family caregiver. The participants described how the caring role affected them psychologically. Findings showed that participants experienced such feelings as anxiety, uncertainty, helplessness, hopelessness, concealment, and saw the care as an obligation/ "giving back".

Anxiety

Caring for a relation with prostate cancer was described as a very difficult task with a persistent feeling of anxiety. Most of the participants demonstrated lots of worry in three areas, especially due to the financial burden, change in patient's physic and news of cancer/treatment.

Participant experienced anxiety following the news of cancer

"At the beginning when I was told that he has cancer, it got me very worried. I find myself always thinking about him. It's the only thought I have all day (Na ayem shieshi3 wohopaa) I was always scared" **Peace, 36yrs, unmarried, daughter**

"I was scared when I heard he has prostate cancer. My heart skipped a beat because it is a condition that kills. It also brings along pain and debt" **Mercy, 67yrs, married, wife**

"I was very frightened when I was told he has prostate cancer and also when the catheter was inserted that day, he could not pass urine. I have seen how people who have the condition suffer and what they go through. For me when the rubber was inserted, I thought it will stay in forever so it got me very scared" **Forgive, 62yrs, married, wife**

"The day I heard that he has cancer, it got me worried because some people say it is infectious, others also say it kills its victims within a short time" **kindness, 64yrs, married, wife**

Participant was scared and worry upon hearing the news of cancer but was later relieved when she heard that something can be done about it

“I felt someway upon hearing that he could not pass urine (Me nipadwapoyee me bribi). And later became more afraid when I heard he had prostate cancer. Because I had no idea that there is a condition that can make someone not be able to urinate. As human as we are if you can’t urinate then it is a big problem. But when I realised that something could be done about it. I was relieved” **Love, 38yrs, married, daughter**

Participant experienced anxiety over the future financial burden

“I worry a lot about finances. Especially when it comes to settling medical bills and purchasing medications” **Favour, 41yrs, married, daughter**

“Also, money was another major problem that made me very worried. It was our prayer that God will send help so that we can fort the medical bills and other things” **Kindness, 64yrs, married, wife**

“When we were first told about the condition and treatment. It got me very scare and worried especially about the cost of treatment. After doing all the laboratory investigations requested, the doctor said every month we will have to pay 400gh cedis for medications and 200gh cedis for injections, making a total of 600gh cedis per month...for 2 years” **Faith, 40yrs, married, daughter**

Participants were anxious because of the patient’s change in body image

“It has even turned him into an old man at this tender age”

Mercy, 67yrs, married, wife

“As for worrying, hmmm, it is one thing I do best, especially when the limbs got swollen and he starts experiencing severe pain. It gets me very worried” Humble, 62yrs, married, wife

“When we got married this was not how he was and all of a sudden, everything has changed. He has changed” Passion, 60yrs, married, wife

“He's walking changed, he was now drawn more to the affected side of the waist and that made me very worried” Forgive, 62yrs, married, wife

Empathy

Empathy describes the family caregiver's capacity to understand or feel what the patient is experiencing from within. Three of the participants described how they felt anytime they found their patients in pain or discomfort.

“Anytime he is in pain, I feel very sorry for him, I also kind of experience the pain he is going through” Joy, 58yrs, married, wife

“I also go through the same pain” Mercy, 67yrs, married, wife

“I felt pity for him because he was going through a lot of pain” Forgive, 62yrs, married, wife

Care as Obligation/ ‘Giving Back’

Most of the caregivers in this study described the experience as "Giving back" or Care as an obligation. They believe that these patients had cared for them in the past, thus it is their responsibility to also care for them now that they are not in the position to care for themselves. By so doing they are honouring their spouses and fathers.

As three daughters stated

“I cannot leave my dad and go and sit home doing nothing. He took care of me, so, now that he needs me, I can't turn my back on him. The bible even tells us to honour our father and mother. So, will continue to do this and see what God has for me” **Love, 38yrs, married, daughter**

“If I were the one in his position now, he will be the one to take care of me and I know he will gladly do it. So, if the tables have turned and he is now not well, I am his child I must take care of him” **Grace, 29yrs, married, daughter**

“It does not affect me much, because even if it does, I know I'm suffering for my dad so it is not an issue” **Favour, 41yrs, married, daughter**

As said by one spouse

“He has taken care of our children; we live in our own house with about ten extra rooms rented out. So, he has tried for us, I can't leave him now” **Joy, 58yrs, married, wife**

A son mentioned

“Initially my siblings decided to hire someone to assist me but I told them that I can do the job because I know what my dad has done for me thus, it is time to also take care of him” **Hope, 27yrs, unmarried, son**

Feeling inadequate.

Providing quality care depends on the caregiver's knowledge, experience and personal capability, and every caregiver has a certain capacity that cannot be exceeded. The inability to provide proper care and satisfy the unreasonable

concerns of the patient makes the caregiver feel inadequate. Participants reported that not being able to please the patient and settle medical expenses on time for treatment to commence was very worrying and frustrating. Partly because of their inexperience and lack of a previous encounter with care-related problems.

“Most of the times. Especially when he starts complaining about things, he becomes very difficult to please and everything isn't good enough. It is very difficult to bear” **love, 38yrs, married, daughter**

“Sometimes not being able to raise the money for medical expenses, coupled with the old man in so much pain is unbearable. And yet, not know what to do” **favour, 41yrs, married, daughter**

Hopelessness (halted life)

Participants reported a feeling of hopelessness, indicating that because of their caring role, their life and plans revolved around the patient. Their life has come to a halt, knowing that they are trapped and until the patient recovers, they cannot do anything about their situation

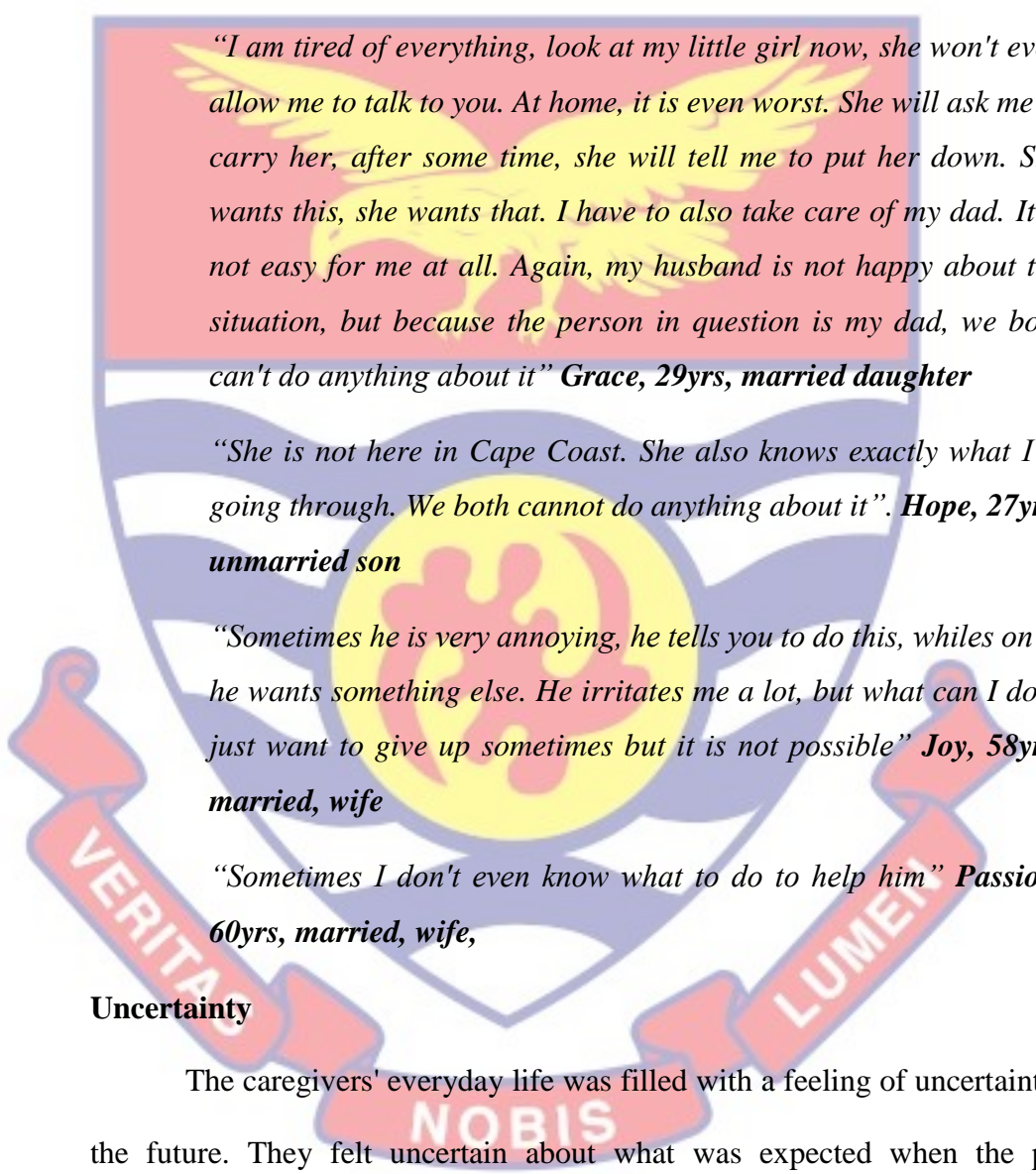
“It was difficult at the beginning because I was preparing to write GRE (Graduate Record Examination) exams to help me further my education abroad but because of the illness, I had to put all my dreams, goals, and plans on hold. So, it was not easy at all to finally come up with the decision of putting everything on hold. Now I have to wait until he recovers” **Hope, 27yrs, unmarried, son**

“My life has come to a standstill. I don't go anywhere. I am trapped at home. I can't even visit my husband. All my thoughts revolve around this house now” **Grace, 29yrs, married, daughter**

“I have tried to speak with my siblings but they are also not ready to help. They don't think for a second that I also have a home and a life

to live as well, or this is their father too. I don't want to talk about them" Love, 38yrs, married, daughter

Participants believe their current situation is unchangeable and thus nothing can be done about it



"I am tired of everything, look at my little girl now, she won't even allow me to talk to you. At home, it is even worst. She will ask me to carry her, after some time, she will tell me to put her down. She wants this, she wants that. I have to also take care of my dad. It is not easy for me at all. Again, my husband is not happy about the situation, but because the person in question is my dad, we both can't do anything about it" Grace, 29yrs, married daughter

"She is not here in Cape Coast. She also knows exactly what I'm going through. We both cannot do anything about it". Hope, 27yrs, unmarried son

"Sometimes he is very annoying, he tells you to do this, whiles on it, he wants something else. He irritates me a lot, but what can I do. I just want to give up sometimes but it is not possible" Joy, 58yrs, married, wife

"Sometimes I don't even know what to do to help him" Passion, 60yrs, married, wife,

Uncertainty

The caregivers' everyday life was filled with a feeling of uncertainty about the future. They felt uncertain about what was expected when the patients' conditions were unpredictable.

One of the caregivers described the experience as

*“Thoughts like, eii is it going to get better? Is he going to get well? These thoughts were coming during the earlier stages when the condition was serious, I mean before the surgery” **Peace, 36yrs, unmarried daughter***

Apart from feeling uncertain about the future, this spouse felt that if she understood the process of treatment and had been prepared before taking up this role, she would be able to provide the physical/mental support patient needed at the time.

She stated** “I’m always worried and afraid because I don’t know what this is leading to anymore. More so, no one educated me on how to go about things at home, and because of that, it is a problem, as I find myself in a fix, not knowing what to do for him especially when he is in pain and all pain medications have been given” **Forgive, 62yrs, married wife

Concealment

Concealment emphasizes family caregivers' behaviour to suppress their real emotions toward their patient's condition or their situation. Participants avoided showing the truth and their real emotions, like tears, sadness, pain and worry in front of the patients. Participants reported that they concealed their feeling to prevent the patients from worrying and feeling sorry for themselves.

*“And even when I’m worried, I make sure I hide my feelings from him because he will also become more worried” **kindness, 64yrs, married, wife***

"I got tired most of the time especially from lifting and transferring from one spot to the other with body and waist pains but I didn't want him to see that this is what I was going through. So, even with the pain, I don't complain" Hope, 27yrs, unmarried, son

Social Impact

Social impact is another category extracted from the main theme "Effects of caregiving" that indicated the effect of the role on their day to day interactions. The participants narrated their experience by stating that they had restricted social life due to their increased burden during the caregiving process. According to their statements, while some of the participants failed to adequately look after their children due to the caregiving-related burden, some of them had to give up on their jobs/ livelihood. Others experienced turmoil in their marriage as a result of the role they play, time for grooming was also a problem. Whereas sexual concerns were a major problem for the younger caregivers, the older ones had something different to say.

Sexual Concerns

Participants were not very open about expressing concerns on sexual matters. Some of the spouses and children both married and unmarried however tried to provide a brief expression of their experiences. For some of the family caregivers (children of the patients), the inability to sexually satisfy their spouses, girlfriend and boyfriend were as a result of having been separated from them to take care of their fathers. And this was a source of worry for most of them. Others (spouses of these patients), however, reported that the men had no strength for sex and also, some did not want to worry them knowing they are sick. More so, it is not

a source of worry as they already have their children. Others also joked with their husbands about their sexual function even their children and nephews. The rest preferred not to talk about it.

“Hmm...we only talk on the phone oo. I told you he is in Kumasi. So, if we only talk on the phone, that should tell you what I am trying to say” **Grace, 29yrs, married daughter**

“And since I took up this role my marriage has been on the rocks because I had left him and the children all alone” **Love, 38yrs, married, daughter**

“My girlfriend is in Kumasi, I can't go there. But she understands. Sometimes she comes around” **Hope, 27yrs, unmarried, son**

“He was a footballer. Now because of this condition, he has become weak all of a sudden. He can't do anything; I mean anything at all. He has become weak in all areas. But the truth is that it is not a problem because we already have children, and we have even passed childbearing age.” **Mercy, 67yrs, married, wife**

“Oh no, our sexual life is not much of a problem. The other time his nieces and nephews were even teasing him with it. He told them that, now the strength is not there but if it was there why not. More so, we have given birth to all our children. The most important thing is for him to recover from this condition. I also don't have any problem in that regards” **Forgive, 62yrs, married, wife**

“It is not a problem, because we have all our children now. As for me, I am there, but now he is the one who does not have the strength anymore to do it” **Passion, 60yrs, married, wife**

Role /Role adjustment

The participants described their various roles and how some of these roles were adjusted due to the care they provided to their patients. The roles played and the adjustments in these roles were influenced by whether the patients were ambulant or bedridden. All the spouses were involved in cooking, washing, cleaning, and bathing. Lifting of the patient was performed by some caregivers alone without assistance. Again, accompanying husband to the hospital, reminding husband of reviews, follow-up visits, buying of medication and ensuring husband takes medication, were reported. Moreover, caregivers (Children of the patient) who had children and were separated from them because they needed to take care of their fathers had their husbands and eldest children take care of the responsibility of taking care of their nuclear home in their absence.

Participants (Children of the patient) had their husbands/eldest children take up the role of parenting entirely

“My children live with their dad in Mankessim. They are three, two boys and a girl. The eldest is 15 years and a boy. He assists his dad in taking care of his other siblings. I visit home once a while to check up on them” Love, 38yrs, married, daughter

“I have 6 children, plus the one I’m carrying now they will be 7. The eldest is 20 yrs. My husband is very supportive and he understands the situation. He mostly takes care of the children when I’m not around so I don’t have any problems in that regards. My eldest child also assists in so many ways. She can take care of her siblings in our absence” Faith, 40yrs, married, daughter

Participants cleaned, bath and cook for their patient

“In the morning I go on to boil water to clean him up and then assist him with the brushing of his teeth. I then go ahead to find out what he wants to have for breakfast, then I prepare it for him. He is not able to do much for himself. He sits in the wheelchair all day, so cleaning him up is a very difficult task...” **Love, 38yrs, married, daughter**

“In the morning he will want to visit the toilet but he can't use the public facility so he will have to go to the toilet in a pot then I make sure I discard it. When it comes to his food, I prepare what he wants to eat. But my major problem is the toilet. Because if he needs to go to the toilet three times, I have to make sure I go for it afterwards to take it to the mains to discard it...” **Forgive, 62yrs, married, wife**

“When we wake up in the morning, I clean him up, then I find out from him what he will prefer for breakfast. The truth is he could not eat much especially when the condition became serious. I do everything from cooking, washing and cleaning for him. if he needs to go to the toilet, I have to assist him.” **Passion, 60yrs, married, wife**

Participant accompany patients for reviews, ensures they have taken their medications

“The care I provide has to do with his eating, washing off his clothing and other personal hygiene needs. You can see that now he is weak, so I need to carry the water with the bucket to the bathroom for him, the main care is with the eating/washing of his clothing and ensuring that he takes his medications. Also, I take him on most of the hospital rounds, especially for the reviews and doing investigations and so on” **Grace, 29yrs, married, daughter**

“I bring him for reviews and also make sure I collect all the medications as well as ensure he takes them. Most often I bring him to see the doctor when the date of review is not even up, because he continuously complains about pain everywhere. Look at my condition, sister it is not easy at all” Faith, 40yrs, married, daughter

Participant had to secure a place in the hospital before the patient shows up

“Today I had to wake up at 4 am and prepare everything then rush down to the hospital to get his card and things ready and also join the queue so that we can see the doctor on time. So, I had to take the lead to secure the place while he joins later” Mercy, 67yrs, married, wife

Participants were involved in lifting and turning patients without assistance

There is no toilet in the house hence, I must lift him unto a chamber pot, and then lift him back again unto the wheelchair with no one to assist. At night he may also call to assist him to change positions or turn in bed” Love, 38yrs, married, daughter

“Initially it was very difficult, especially carrying him here and there because he is in a wheelchair” Hope, 27yrs, unmarried, son

Loss of livelihood

It was found that patients who were previously working had saved up some money, hence caregivers did not have to seek support from elsewhere, whereas caregivers who were previously working had to stop to stay home and care for their spouses and fathers. Those who were not working, therefore, depended on their children, siblings, friends and other family members for financial survival. The participants openly expressed themselves regarding the difficulties they go through as a result of them losing their livelihood. Again, a daughter who is a seamstress

shared her experience on how she has lost customers because she could not take the time to sew for them.

“Yes I was working as a seamstress but since he took ill, most of my clients have come for their clothes. I have even cut some of them, so you can just imagine the heat I’m in. I’m not able to make time to sew for them” **Love, 38yrs, married, daughter**

“I used to travel and bring plantain and other foodstuffs to sell but because of my husband’s illness, I’m not able to go to work anymore. Hmm, madam, look yesterday the only money I had on me was eight cedis. I’m not happy at all, I know what I get any time I go to work and when I was doing my business but now, I can’t do anything because of this illness.” **Joy, 58yrs, married, wife**

“I am a farmer but since the condition started, I haven’t been able to go to work. So, life has been very difficult” **Humble, 62yrs, married, wife**

Grooming

Most of the participants reported that taking care of their appearance was a thing of the past because of the stress associated with the role. Others had difficulties because their patients were on admission hence had to sleep in the hospital. One participant, however, did not have a problem with grooming

“Even myself I’m not able to make time in taking care of my appearance. I have started keeping my hair natural by force” **Grace, 29yrs, married, daughter**

“No, now I no longer think about my appearance especially ever since the condition got serious. Besides I sleep in this hospital, how am I supposed to do that” **Passion, 60yrs, married, wife**

Participant takes care of her appearance

"I'm able to take care of my looks somehow, it is not much of a problem" Love, 38yrs, married, daughter

Turmoil

This is a subcategory that emerged under the social impact, in an attempt to answer the first research question "Experience of caregivers of prostate cancer patients". Turmoil describes the confusion, agony and emotional trauma these caregivers (married daughters of patients with prostate cancer) go through in their marriages as a result of the role they play. They mentioned that,

"And ever since I took up this role my marriage has been on the rocks (Sad). This is a serious issue between the two of us now (Sad). Sometimes when I call, he refuses to answer my calls. If he does then it is all quarrels (Hmmm...). Every trivial issue becomes a misunderstanding between us" Love, 38yrs, married, daughter

"He is not happy about the situation, but because the person in question is my dad, we both can't do anything about it. Because he can't voice out his feelings, the slightest issues he gets offended. Sometimes, even things that do not even warrant that he gets offended becomes a major problem that we end up quarrelling about. Things we used to joke about, now becomes an issue to fight about" Grace, 29yrs, married, daughter

Leisure activities

Leisure activities describe the time caregivers take typically after having taken care of their caring responsibilities for the day to have some pleasure, attend functions, gathering and spend time with friends. Participants stated that they did

not have time for recreational activities. Others tried to manage some time to take care of very important things, and even that, they made sure to make it brief so they can quickly return home. One participant, however, was able to make time for leisure activities anytime any day without worries.

Some participants manage some time to take care of very important things

“Yes, but it depends on the time, and also it has to be brief so that I can quickly come back home to take care of my dad. That is if I have to attend an important function” **Love, 38yrs, married, daughter**

“Yes, but I'm not able to stay out for a long time and I don't go far from home. Even during the initial stages, I was not going to church at all because there was no one to take care of him” **Peace, 36yrs, unmarried, daughter**

Participants did not have time for recreational activities

“Now I don't travel, I don't go anyway. Even if there is a problem in my home town, I must force to return home the same day. I can't sleep over. This illness has affected my life badly” **Mercy, 67yrs, married, wife**

“I am not able to go anywhere since the condition started but my friends and family understand my current situation. So, if I don't show up at gatherings it is not a big problem” **Humble, 62yrs, married, wife**

“No, I'm not able to anymore. Besides we live alone, I don't have anybody staying with us who will take care of him when I am away. So, I have no other choice than to stay home by his side” **Passion, 60yrs, married, wife**

“As for attending programmes and spending time with friends it’s impossible for now because I need to make sure my dad is okay and I also can’t leave him and go anywhere because he is not well” Faith, 40yrs, married, daughter

Participant was able to make time for recreational activities because there was someone to assist the patient in case he needed something.

“Yes, I go anywhere I want to go, especially church. There is this little girl who used to stay with us. So, if I prepare everything down, I can leave. She is only there to go on errands for him in case he needed something” Kindness, 64yrs, married, wife

Participants were able to spend time with friends and engage in some leisure activities at home

“Yes, I’m not able to live my life as I use to. For instance, those days when I go out, I don’t come back home early but now I don’t spend more than 2 hours outside (I mean when I’m far from home) because I know that I will be called. However, when I am home, I play video games and also some of my friends come around for us to play football. When my dad needs me, he calls on my phone.” Hope, 27yrs, unmarried, son

One participant, however, was able to make time for leisure activities

Oh yes, I go anywhere I want to go. There is no one at home to take care of him when I leave. So, I commit him in the hands of the Lord. Joy, 58yrs, married, wife

Challenges Confronting Caregivers of Patients with Prostate Cancer

Family caregivers of prostate cancer patients face multiple challenges which impact their quality of life and well-being. These

caregivers described the caregiving role as a very intense experience. In answering the second research question “**What are the barriers to caring for patients with prostate cancer**”. Findings show that participants encountered several difficulties due to a lack of skills and knowledge to care

for these patients thus making it difficult for them to meet the care demands. *Subthemes that emerged were; lack of preparedness towards caregiving role, lack of knowledge about condition and treatment, misconception about the condition, financial constraints, lack of knowledge about available resources, and communication concerns between caregivers and healthcare professionals*

Lack of Preparedness towards Caregiving Role

Preparedness in this study has to do with a caregiver's perceived readiness for the caregiving role, which encompasses multiple domains, including the provision of physical care, and emotional support. Preparing the family caregiver towards the caring role is an important area that needs to be addressed by health professional especially nurses. Yet too often these family caregivers are poorly prepared for this vital but difficult role that takes a toll on them, by extension, the patient. Participants in the present study reported not asked by healthcare professionals what they needed to care for the patient. They stated

“No one explained to us what was happening. Also, in terms of how to care for him at home, no one thought us how-to, not even the nurses” Love, 38yrs, married, daughter

“The only thing they told us about was in connection with the administration of the medication at home and the date for review.

Even that, he was the one who was told, not us" Peace, 36yrs, unmarried, daughter

"No one educated us on how to take care of him at home" Grace, 29yrs, married, daughter

"During our stay in the hospital, none of the nurses explain to us how to care for him at home upon discharge" Joy, 58yrs, married, daughter

"No one took the time to explain to us, how to care for him at home" Mercy, 67yrs, married, wife

"No one educated me on how to go about things at home, and because of that, it is a problem, as I find myself in a fix, not knowing what to do for him sometimes especially when he is in pain. But we were told how to administer the medications. No one mentioned any side effect that may result from the administration of any of the medications" Forgive, 62yrs, married, wife

"They educated us on how to administer the medications. But nothing else" Humble, 62yrs, married, wife

Lack of Knowledge about Condition and Treatment

Caregivers have become part of the triad of care. Effective caregiving and decision making requires that they understand the course of disease and treatment. Their ability to care for their patients may be hampered by their lack of understanding of the disease and treatment patient receive. Some participants reported a lack of knowledge about the condition and treatment resulting in the patient going through a lot of pain. One participant also reported confusion as a result of a lack of adequate education on the condition and treatment. Another participant, however, reported having received adequate education on the condition and treatment.

Lack of knowledge about the condition and treatment resulted in confusion

“One thing I've always wanted to ask is that people say the man is old so doctors telling us that he needs surgery is all lies. They just want to take our money” **love, 38yrs, married, daughter**

“I suggest that in situations of this sort the patient and relations should be educated on what is going on. For instance, when we came, all we were told was he has prostate cancer. Today too, we have just been told that he will have an orchidectomy...Laughing. No one is explaining things to us. They tell you these big words without breaking them down for you to understand” **Grace, 29yrs, married, wife**

Participant lack of education on condition and treatment resulted in the patient going through a lot of pain

“One more thing is that initially we were not told that the catheter must be changed after some time. No one informed us about that, so he had it on for a long time and this resulted in pain. The catheter stayed in for over a month and two weeks. When it should have been in there for just three weeks and then changed at the hospital” **Peace, 36yrs, unmarried, daughter**

One participant, however, received education on condition and treatment

“The doctor explained everything about the condition before surgery. The things he will need for the surgery were communicated to us. Also, upon discharge, we were told how to administer the medications at home” **Mercy, 67yrs, married, wife**

One participant did not receive any education but read about it on the internet

“No one but what I do is I read around the condition and also on the medications from the internet. Apart from consulting our family doctor friend” Hope, 27yrs, unmarried, son

Misconception about the condition

One of the challenges that family caregivers encounter in the process of caring for their relations with cancer has to do with the beliefs and misconceptions people have about the condition. It has become clear that cancer-related stigma and myths are important problems that must be addressed. Findings from this study show that there is evidence of myths associated with cancer such as the belief that cancer is a fatal and contagious disease. Others also believe that one may contract it as a result of immoral behaviour or a punishment from God or ones' enemies. Family caregivers reported that these misconceptions lead to fear/panic and also a decrease in the support network.

“People say it is a condition that has no cured so I was scared when I first heard he has cancer” Love, 38yrs, married, daughter

“Eeeii... in my place when you hear cancer it means that the person is going to die. You are waiting to die. Others don't even want to hear the word at all. Some also say it is infectious. So, after telling them, you will notice that they begin to isolate themselves from you and the patient” Grace, 29yrs, married, wife

“Because it is a condition that kills” Mercy, 67yrs, married, wife

Participant believes that cancer may result from something bad done in the past/ evil done to others

“Anything may be the cause. Currently, the world is being ruled by the devil, so anything can happen. Someone may contract a condition as a result of something done in the past. Others, from their enemies” **Forgive, 62yrs, married, wife**

“Because I know it is not a good illness, it mostly kills its victims” **Favour, 41yrs, married, daughter**

“Because some people say it is infectious, others also say it kills its victims within a short time” **Kindness, 64yrs, married, wife**

“What I know about cancer is that it is a wound that develops inside the body, so when you are put on medications for some time you get cured and that is all. But when we came here, we were told that he was going to have surgery because of cancer and that got me worried. Meaning, I was wrong about the condition...” **Passion, 60yrs, married, wife**

Financial constraint

All participants admitted having financial difficulties. Some mentioned that it resulted in a delay in treatment causing the patient to go through so much pain. Others had to try herbal preparation which made the condition worse. One participant mentioned that the government must be able to support because most of the patients were retirees.

“We were required to deposit 1000gh, that same day so that the surgery can be done the following day but unfortunately for us, we could not raise the amount so we had to go back and come after we raised the money” **Love, 38yrs, married, daughter**

“In the beginning, I took a loan, because I had spent all my money on medical expenses” **Peace, 36yrs, unmarried, daughter**

*“Earlier on I made mention that, he told the doctor that financing the treatment is now a problem so if there is an alternative, he may want to try that, but the doctor said no, and that he should get the money and return to continue with the treatment. He then decided to start herbal treatment at home, it helped with the pains to some extent but was not very effective because urination was difficult...” **Forgive, 62yrs, married, wife***

Participant complained of financial difficulties and also lack of support from the government

*“Another issue has to do with money, the little money we raise must go into this sickness. Either we are buying medications or paying for hospital bills and lab test. We are both retired. Besides, I believe that as pensioners some of the medications must be free, we have served the country our entire life....” **Mercy, 67yrs, married, wife***

*“I sleep here because of the money involved in going home and returning every day. My home is a bit far, so If I have to always go and return it will be very expensive” **Humble, 62yrs, married, wife***

*“At the moment, we need financial support. We have spent all our monies and savings on this condition. My children are in school and I need to pay fees” **Favour, 41yrs, married, daughter***

Lacked knowledge about available resources

All participants reported not being informed about resources available to them by healthcare personals such as counselling services. They stated that

*“I have never been to a counsellor before, wasn't aware they existed in this hospital” **Favour, 41yrs, married, daughter***

“I have not visited a counsellor. I am not aware of their services. More so I cannot afford their services” **Humble, 62yrs, married, wife**

“I have never sought counselling services anywhere; I didn't even know there is something of that sort in this hospital” **Passion, 60yrs, married, wife**

Communication concerns between caregivers and healthcare professionals

A primary role of cancer family caregivers involves interacting with various providers and professionals on behalf of their loved ones. Lack of effective communication between healthcare personnel and family caregivers is an important issue, particularly because it can lead to errors and poor patient outcomes. Findings from the study show that patients went through avoidable pains as a result of ineffective communication. Also, resulted in an unnecessary waste of resources and the feeling of inadequacy.

Participants reported poor communication

“By the grace of God, we were able to raise money for the surgery. However, the date scheduled for the surgery was cancelled after all preparations made, we were then asked to send my dad home. The reason for the cancellation was not communicated to any of us yet he was discharged to be brought back a week later. We still had to pay for the discharge.” **Love, 38yrs, married, daughter**

“Initially we were not told that the catheter must be changed after some time. No one informed us about that, so he had it on for a long time and this resulted in pain. The catheter stayed in for over a month and two weeks. When it should have been in there for just three weeks” **Peace, 36yrs, unmarried, daughter**

“Sometimes I don't even know what to do to help him because no one told me anything” Passion, 60yrs, married, wife

Difficulties encountered within the healthcare environment affecting the caregiver's role.

The experience of caring for a family member with cancer is associated with several care-related problems and trials for the caregiver. Family caregivers encounter many difficulties within the hospital environment that affected the care they provide to their patients. **This was a major theme that emerged.** Healthcare environment/ professionals especially nurses are insensitive to these unmet needs and thus, are not able to provide them with the necessary support to effectively provide the care expected of them. Participants shared their experience on the challenges they encountered within the hospital environment under *accommodation facilities and staff attitude.*

Lack of accommodation facilities

Some of the participants said that the hospital where their patient received treatment was far from their home, which was tiring for them to commute to and from the hospital when their patients are on admission as it resulted in financial difficulties from the high expenses on transportation to and from the hospital. Besides, the hospital did not provide caregivers with any place to stay, resulting in them sleeping outside the wards, on the floor and being exposed to poor conditions and mosquito bites.

Two of the caregivers stated

“My home is quite far, so if I have to always go and return it will be very expensive. Again, the hospital has not provided a place for us, we sleep outside on the floor and exposed to mosquito bites”

Humble, 62yrs, married, wife

“Even me... I would have stayed in if there was a place I could spend the night. The hospital has no place for caregivers who have their patients on admission, we have to sleep outside on the floor, yet, if there is something to be done for the patient and you are not around it won't be done until you return” ***Love, 38yrs, married, daughter***

Poor Staff Attitude

Providing quality care involves doing the right thing at the right time, and improving the health outcome for both patients, their family caregivers as well as the community at large. It is also important that a welcoming atmosphere within the healthcare environment is ensured. However, this is mostly not the situation. Participants complained of poor staff attitude and unfavourable conditions within the healthcare environment which affected the role they played negatively. Some of the caregivers complained that they had to wait long hours at the Out Patient Department (OPD) before the clinic started, others complained of poor staff attitude making it impossible for them to be approached. One participant also pleaded that conditions be improved in relation to the neglect of care when family caregivers are not around.

A wife of one of the patients' stated

“When we visit the hospital, there is too much waiting time. We come very early but the clinic does not start early at all. They must try and do something about it for us. Because we are already exhausted and some of the patients are also in pain and very sick”

Mercy, 67yrs, married, wife

Another participant also mentioned

“Also, to the hospital staff, especially the nurses and doctors. I know with every work there is time to start. They must report at the right time because patients come to the hospital and wait for a long time before they are seen. They must also watch how they relate to the patients and their relatives especially the nurse. Their attitude makes it difficult for us to even ask them for anything”

Forgive, 62yrs, married, wife

“Another issue has to do with some of the nurses, some are very disrespectful. They must change their attitude towards caregivers and patients. Because sometimes we want to ask them to clarify something but we are not able to, for fear of being embarrassed”

Kindness, 64yrs, married, wife

Participants complained of staff neglecting patients in the absence of family caregivers

“Please I would like to plead with the ward staff that if there is anything that needs to be done for our patients in relation to their treatment, they should do it so that when the relatives come around they can pay for them, rather than neglect the patients when the relatives have been sent out of the unit. It is very frustrating” ***Faith, 40yrs, married, daughter***

Participant complained about lack of support from hospital staff

"Mostly when we come, I have to do all the errands, go here, go there, and also wheel him around all by myself so this time my son was home so we came with him. Formally, some orderlies help relatives with wheeling of patients but now they don't do it anymore...." **Forgive, 62yrs, married, wife**

One participant, however, commended the nurses for their good work

She stated "aww, the nurses did very well, they treated the situation with urgency. Immediately, they called the doctor and put him in bed and started with treatment" **Mercy, 67yrs, married, wife**

Coping strategies used by family caregivers

This section reflects problem-solving strategies that allow caregivers to deal with upcoming issues. **It was another major theme that emerged from the data collected.** The cancer process is a traumatic period for both patients and their family caregivers. Participants used several coping methods. Most family caregivers reported using spiritual coping to ease their problems, including *being more religious* while in their current situation, *proactively seeking information* was also reported by family caregivers by using the internet and also from family friends within the health field. Others also reported that *accepting their situation* helped them to cope with it. More so, *active planning, relaxation/listening to music, and medication abuse* were also some strategies used.

Religiosity

The caregivers' religious beliefs demonstrated their faith in God. When the cancer caregivers felt hopeless and felt that they had nothing to hold on to because

everything was very unpredictable, they prayed, others have their pastors come home to pray for the patients. Praying was one way to strengthen their courage.

Some participant said *“I believe that God will heal him soon”*

Love, 38yrs, married, daughter

“The church comes home to pray for him, I also join them to pray for him because I know God will heal him” ***Peace, 36yrs, unmarried, daughter***

“I only pray for God to heal him” ***Forgive, 62yrs, married, wife***

“The truth is that, we are not very spiritual, He will not even go to church if I opt to take him, but I try to attend service sometimes and I pray for him because I believe God has the power to heal him” ***Grace, 29yrs, married, daughter***

One participant believed that God has brought this upon her husband, so He is the only one who can heal him. She stated

“He is not able to go to church. But I go to church with my children to pray for him. I believe that the lord almighty will heal him. This life has a beginning and an end, so it is all part of the end. I believe that everything that is happening is from God. So, I’m grateful and say thank you to Him for keeping my husband alive for me” ***Mercy, 67yrs, married, wife***

One participant prayed as it helped relieve her worries

“I always pray for God to bless him with good health and long life. We always depend solely on God. Believing and handing everything over to Him help relieve me of my worries” ***Kindness, 64yrs, married, wife***

Active Planning

Family caregivers usually have their health affected due to the complexity of the role they play. However, they improve in their health and adapt much better once they develop the role of caregiving and use effective coping methods such as active planning. Most of the participants mentioned that adopting this strategy was very helpful.

Mercy mentioned that

“I try to plan my activities for the day, it helps a lot. In so doing I'm able to take some time available to rest. And I don't get things piled up on me” **Mercy, 67yrs, married, wife**

Others also stated that

“I plan my day before daybreak, so I may say I plan the day before the next day. So, before I wake up in the morning, I already know what I need to do within the day. This helps a lot, as I can complete most of the things I need to complete for the day” **Humble, 62yrs, married, wife**

“I plan everything. For instance, this morning he has eaten, I have prepared his lunch. So, after talking to you I will set off for work. By the time I return in the evening, he would have had some tea already. So, when I plan it helps me a lot” **Kindness, 64yrs, married, wife**

Denial/Acceptance

The diagnosis was unexpected, particularly in the patients who had no family history of cancer, having no signs, or any risk behaviours that caused cancer. Soon after being shocked by hearing the bad news, the caregiver was in a stage of

disbelief and denial. It was hard for her to accept that this was happening. A daughter narrated

“When I was informed that my dad had cancer, I asked the doctor if he was sure, I just could not believe it. He has gone from one hospital to the other, yet all these hospitals could not detect it. It made me very sad but eventually, I had to accept that this is a reality. My dad truly has prostate cancer” **Grace, 29yrs, married, daughter**

Relaxation/ Listening to music

Relaxation/ listening to music is another sub-theme that emerged from the main theme of coping strategies used by family caregivers of prostate cancer patients. Music as a form of coping strategy provides physical, psychological, emotional and spiritual benefits for both the patient and the caregiver. It relieves fear and anxiety, manage symptoms and promotes relaxation by providing the caregiver with a sense of control over mind and body at a time of paramount uncertainty. Participants explained that listening to music and relaxing in bed helped relieve the stress associated with the role.

Grace mentioned

“I excuse myself, leaving them both to sit somewhere all by myself to listen to music especially when I am done with everything. I like music so anytime I listen to it, it relaxes and calms me down. Other times I go to sleep leaving them by themselves” **Grace, 29yrs, married daughter**

Participant relaxes in bed without listening to music

“I realized that when I am stressed up due to the workload at home combined with my job, I start experiencing headaches. So, I just relax and I am fine. So that is what I did, I try to get some proper sleep or sometimes just lie in bed not asleep but just to relax my mind and body” **Peace, 36yrs, unmarried, daughter**

Support Systems

The caregivers' daily routine was disrupted by travelling to and from the hospital and doing household tasks. Family and friends were described as significant support because they do not only share the caregivers' burden but also helped to support the patients physically and emotionally. In this study, findings showed that support provided by family and friends were in three ways. Emotional, Physical and Financial support. Family members could alternatively be with the patients and assist with household responsibilities. Others also mentioned receiving emotional and financial support from friends, church and family member. Two others went for loans. Support from family and friends had been helpful, the caregivers thought that burden would have been harder without this kind of support.

Participants received emotional support from family and friends

“Sometimes my mum encourages me, people from church also comes around to talk to me especially when they come to offer communion to him and commending me for the good job I’m doing. I also encourage myself sometimes.” **Love, 38yrs, married, daughter**

“I get a lot of encouragement from my colleagues from work”
Peace, 36yrs, unmarried, daughter

“Yes, I have a friend and also my baby's father encourages me a lot. They tell me very soon everything will be over so I should exercise patience and not give up on him. I also encourage myself a lot, because the task is not an easy one” **Grace, 29yrs, married, daughter**

Participants received physical support from friends

“So, as I said earlier, we have a family friend who is a doctor. He has been very helpful as he assists us in case of any difficulty. If I'm not sure about something or don't understand something I call him and he takes his time to take me through” **Hope, 27yrs unmarried, son**

“I have a friend who is a nurse, she used to work outside the country but she is back in Ghana now. She tried for me by helping me out with some of the things I need to do/ need not to do for him. She has been very supportive” **Kindness 64yrs, married, wife**

“We met a family friend who is a doctor at the hospital so, when we needed assistance or clarification, we call on her. She has been very helpful” **Peace, 36yrs, unmarried, daughter**

Family members alternatively stay with patients in the absence of the caregiver

“My mum is mostly around to take care of the cooking at home as well as other things in my absence. Just that I don't have to stay out for too long because she is also not very well” **Hope, 27yrs, unmarried, son**

“Sometimes my uncle is around, so before I leave for work, I prepare everything, including his food and keep it in a food warmer in the kitchen. Anytime he requests for it my uncle will serve him” **Peace, 36yrs, unmarried, daughter**

“I have a little girl at home who assists him when I am not at home. I prepare everything down for him anyway. So, the little girl is just

*there to go on errands in case he needed something" **Kindness, 64yrs, married, wife***

Participants received financial support from friends, family members and the church

*"Yes, especially financial support from one or two friends because the money was just going like that. And I needed money to buy one or two things, sometimes medicine. Initially, I took a loan" **Peace, 36yrs, unmarried, daughter***

*My children help, and also the little saved up by my husband. At church too, support is provided for those who need it. **Forgive, 62yrs married, wife***

*"Hmm, my siblings are the ones who support and sometimes my dad's friends too. My siblings are five, plus myself we are six. The five are all working" **Hope, 27yrs, unmarried, son***

*"He has a cocoa farm, so we harvest some of the cocoa and sell to take care of the bills. Sometimes the children also support" **Passion, 60yrs, married, wife***

*"My dad was working before this sickness, so he is using his savings at the moment. We haven't gone for loans and also haven't received any financial support from anyone so far" **Grace, 29yrs, married, daughter***

Others went for a loan

*"Loan has been our source of financial support since this condition started" **Faith, 40yrs, married, daughter***

*"Apart from the financial support I received from my friends, I also took a loan to help me out with some things since I had spent all I had already" **Peace, 36yrs, unmarried, daughter***

Medication abuse/ self-medication

The role of the caregiver can be very demanding and stressful even though others find it rewarding and fulfilling, but the high-stress lifestyle can put the caregiver at risk for alcohol and substance abuse. This not only hurts your health and well-being, but also the life of the person you are caring for. Participant-reported taking sleeping pills to help with sleep. She stated

"I always find myself very tired and exhausted. At night I find it difficult to sleep, so, to enable me to have some good sleep, for the more difficult task the next day I sometimes take sleeping pills. I usually get them from the pharmacy" Favour, 41yrs, married, daughter

Summary of Findings

The findings of this study revealed the experiences family caregivers go through as they care for their relations with prostate cancer. The findings presented were all from the data generated from the experiences of family caregivers of prostate cancer within the Cape Coast Metropolis. In this study using a phenomenological approach to examine the experience of family caregivers of patients with prostate cancer allowed the researcher to capture the experience from the family caregivers' perspective. As a result, healthcare personnel especially nurses were better able to support family caregivers and deliver interventions that are most meaningful to these individuals. In light of beliefs around patient-centred care, it seems logical that interventions geared toward supporting family caregivers would be free of paternalism. Thus, grounded in knowledge emerging from the caregivers themselves. The findings of this study will add to the gaps in existing

knowledge within the areas of similar studies. The findings will also lead to amendments if not new policies on the care of both prostate cancer patients and their family caregivers rather than only the cancer patient by stakeholders. More so, the knowledge generated from this study offers a foundation for future studies involving family caregivers of these patients. That will enhance the evidence-based knowledge available to clinicians to effectively support these individuals.

Revisiting the conceptual framework used in this study which was adapted from the Quality of life model by Betty Ferrell (2001) and the Transactional model of stress /coping and adaptation by Lazarus and Folkman (1984). The study used only three of the constructs in the framework which were modified to suit the current study: physiological experience, social experience, psychological experience. All the constructs under coping in the transactional model of stress and coping were used in addition to other constructs that may serve as a barrier developed by the researcher through the review of the literature. The authors' developed framework supported all the findings of the study including the new sub-themes that emerged in addition to those within the framework. A major theme; difficulties encountered within the health care environment affecting the caregiver's role, fell outside the framework. From the findings of the study, fatigue, sleeplessness, pain, and altered eating pattern were consistent with the framework, however, sleeplessness, altered eating pattern and fatigue were the major findings under this category. Pre-existing diseases and weight loss emerged as subthemes but fit under the physical experience domain. The social experience domain was also consistent with the following sub-themes of the finding: role/role adjustment,

sexual concerns, leisure activities, appearance/grooming. Turmoil and loss of livelihood were key subthemes that surfaced under the social experience domain. Under this category, role/role adjustment, leisure activities, turmoil and loss of livelihood were major findings. Anxiety and feeling of hopelessness were also consistent with the psychological experience domain. However, four other subthemes which emerged under this domain were empathy, uncertainty, inadequacy and care as obligation/’Giving back’. Major findings under the psychological domain were anxiety, inadequacy, care as obligation and hopelessness. In addition, the lack of knowledge about the condition and treatment, financial challenges, Misconception (culture) and communication concerns were consistent with the framework under the barrier domain. Lack of preparedness towards the role emerged as new subthemes. Major findings identified under this theme were lack of preparedness, misconception, lack of knowledge about the condition/treatment and financial challenges. The interview also provided insight into the coping strategies used by family caregivers of patients with prostate cancer.

The subthemes that emerged were denial/acceptance, active planning, support systems, seeking knowledge and medication abuse which were consistent with that of the framework. However, relaxation/listening surfaced as a new subtheme under the coping strategy domain. Major findings under this section were active planning and support systems, Nevertheless, lack of accommodation facility and poor staff attitude emerged under a major theme, ‘challenges within the healthcare environment affecting the caregiver’s role’ which were not consistent with the conceptual framework.

Discussion of Findings

This qualitative study has shed light on the caregivers' needs, challenges and ways of coping. In this study, although the experience of caregiving is not always negative and while the caregivers' positive assessment of their care role and their adoption of effective coping strategies can lead to positive outcomes (MacKenzie & Greenwood, 2012), the present study was conducted to explore the experiences of family caregivers caring for prostate cancer patients in the Cape Coast Metropolis, which led to the emergence of such major themes as 'effects of caregiving', 'challenges confronting family caregivers' and 'coping strategies used by family caregivers'. The discussion also focuses on the 'difficulties encountered within the healthcare environment affecting the caregiver's role, a new theme that emerged from this current study. The discussion for the study is, however, organized under demographic characteristics followed by effects of caregiving, challenges confronting family caregivers, difficulties encountered within the healthcare environment affecting the caregiver's role and coping strategies used by family caregivers.

It appears, however, that the caregiving role is associated with a lot of challenges. These challenges are caused by an imbalance between the demand for care, skills, knowledge and resources available to meet those demands (Penner & McClement, 2012). Knowledge and skills are one of the crucial roles of inpatient care. However, many caregivers lack the knowledge required for providing adequate and safe care, received no preparation and guidance from healthcare

personnel, and are uninformed about the resources that are available to them (Nemati et al., 2018a). Thus, adapting to the caregiving role is very difficult.

Demographic Characteristics of the Participants of the study

In the present study, all the participants were children and spouses of the patients. Twelve participants were involved in the study. All twelve were Christians and Ghanaians within the Cape Coast Metropolis. This finding is consistent with the findings of a study by Ofori (2017) and the Ghana Statistical Service (2013) report which revealed that Christians form the largest and the most popular religious group in Ghana with approximately 72% of the population identifying with it. This is also supported by findings from several studies that indicated that the majority of Ghanaian caregivers used religiosity/spirituality as a way of dealing with the stress of caregiving (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Aziator, 2016; Ofori, 2017).

Also, findings revealed that six of the caregivers were children of the patients, five females and a male. Four females out of the five were married with children whereas the remaining one was not married but in a serious relationship. The only male was also not married but in a serious relationship. This finding shows that the majority of the participants were females who were married with children. The revelation show similarities with findings from studies conducted by Kyei-Arthur (2013); Van der Geest (2002) and Sackey (2005) who reported that most patients are cared for by females/wives. In contrast, Sanuade and Boatemaa (2015) reported an approximately equal male to female ratio for caregivers in Ghana.

Furthermore, the spouses of these patients had been married to them between (10-30) years with children. Two of them had children before marrying their husbands. Some of the patients also had children before marrying their present spouses. This indicates that the majority of the caregivers (spouses) were married, These findings corroborate findings from the earlier works of La Vecchia et al. (1993) and Newell, Pollack, Spitz, Sider and Fueger (1987), who revealed that marriage was associated with the higher reported occurrence of prostate cancer for the reason being that support provided by spouses lead to greater chances of diagnosis, survival and better outcomes for the condition. This finding, however, contradicts those of several studies that state that married life could lower the risk of developing prostate (Bae, 2015; Dennis & Dawson 2002; Evans et al. 2010; Lian et al. 2016; Tyson et al. 2013).

Also, the ages of these spouses were between 58-67 years whereas the adult children were between the ages of 27-41 years. All of the participants provided care to a relative; commonly a parent or a spouse. In the present study, findings revealed that all participants (both young and old) reported been negatively affected by the role they played. However, these findings contradict findings reported by Apkanidiok and Anarado, (2014) and Anthoni et al. (2001) who revealed that the family caregivers within their active/productive years were negatively affected whereas the family caregivers in the younger age experienced greater benefits/less stress with the caregiving role. The present study further revealed that eleven of the participants lived in the same house with the patient, only one lived elsewhere. However, the participant spends the entire day with the patient with the majority

reporting being the sole caregivers of these patients and having taken up the role between the periods of 6 months to 2 years. Most of the participants engaged in petty trading and farming. This revelation substantiates a report by Nyamky and Hormeku (as cited in the Ghana Statistical Service, 2013) who reported that 80% of the Ghanaian populace works within the informal sector. These caregivers were also out of jobs because their jobs did not allow the flexibility needed to work and provide care, which is also validated findings from the study by Ofori (2017), who reported that most of the participants had to stop work and businesses to take care of their partners.

Effects of Caregiving

This is a major theme that emerged from the recent study, with three sub-categories which are the physical, psychological and social impact. These sub-categories are discussed as follows

The Physical Impact of the Caregiving Role

The physical impact of caregiving is closely associated with the physical tasks that caregivers are expected to perform. As the condition advances for the person with prostate cancer, so does the caregiver experience an increase in physical demands. The caregivers assume additional roles once performed by the prostate cancer patient/change in roles as their disease progresses. In the area of physical impact, family caregivers encountered major problems such as sleeplessness, fatigue, altered eating pattern. Others also reported having experienced pain (headache, waist pain, body pain) and weight loss.

Lack of sleep was a frequent complaint of most of the family caregivers. Sleeplessness results from persistent worry from the outcome of the condition, financial burden and also staying awake to constantly check on the patient. Others reported having to take a sedative to induce sleep. This finding is consistent with that of Ofori (2017) who reported that participants had sleepless nights and, others had to take sedatives to sleep. The findings of the present study are further echoed in the works of Aziato and Adejumo (2014), Carter (2006) and Glajchen, (2012). It is therefore well established in the literature that sleep deprivation is a major issue experienced by family caregivers of cancer patients which are viewed as problematic as it causes daytime fatigue and depression for a long time, thus affecting not only the family caregiver but also the quality of care provided to the patient (Aziato & Adejumo, 2014; Byun, Lerdal, Gay, & Lee, 2016; Fletcher et al., 2009; Glajchen, 2012). Nevertheless, findings also revealed that family caregivers experiencing insomnia because they lived with / cared for the patient is not always the case. In adding to existing knowledge the present study revealed that others did not have problems with sleep. This may probably be because the patient kept his suffering away from the caregiver in order not to be a source of worry to her at night (Wittenberg, Borneman, Koczywas, Del Ferraro, & Ferrell, 2017).

Given the increasing demands for caregiving for prostate cancer patients, fatigue among family caregivers is a growing health concern. Higher levels of family caregiver fatigue are associated with poorer quality of care for the patient. The results of the current study demonstrated that fatigue is a rather common symptom among family caregivers of patients with prostate cancer due to

caregiving difficulty, burden, and strain from physical activities. This corroborates findings from a study conducted by Ofori (2017), who confirms the assertion that the daily assistance provided to patients with prostate cancer resulted in spouse fatigue. Fletcher et al. (2009); Yao et al. (2017) mirrored the findings of this study by asserting that family caregivers of patients with prostate cancer experience fatigue due to the difficulties involved in taking care of these patients daily. More so, to add to existing knowledge, the findings of this present study established an association between fatigue, caregiving and employment status, however, in contrast, a study by Campbell et al. (2004) showed no association between these three. Furthermore, the present study revealed no association between the age of participants and level of fatigue, this is therefore not consistent with the findings of Ofori (2017) who identified that the older the participant, the highly likely they complained of fatigued with the task of care.

Altered eating pattern was another major worry among family caregivers. Most of the caregivers reported eating once a day or not eating at all, and rather taking in drinks due to loss of appetite. This was attributed to the increased workload making it impossible for them to make time for food. Similar findings were reported by Ofori (2017), however, in her study, participants had to engage in fasting and that prevented them from eating. The case is different in this current study as there was no relationship between fasting and change in eating habits. Report from the current study also revealed that some participant ate well, this suggests that there are situations where the caregiver's eating pattern is not affected despite the stress involved in caregiving. This revelation is, therefore, adding to

existing knowledge. However, other studies have confirmed that family caregivers experience loss of appetite/ decreased appetite as a result of the role they play (Beesley et al., 2011; Stenberg et al., 2010). Weight loss was also reported by some participants, attributing it to their inability to make time for food and also persistent worrying about the patient's condition. This finding is consistent with a study by Secrekus et al. (2014) who reported that participants experienced a loss of appetite and weight loss as a result of the stress of caregiving. Similarly, the findings of the present study identified an association between anxiety over the condition and weight loss.

Some participants also reported pain as a concern in the present study. The experience of pain was in three different ways namely body pains, waist pain and headache. The experience of pain according to participants was a result of the physical support provided including helping patients with daily activities (such as lifting, changing position, turning patient in bed etc), managing patient's disease and medical appointments. This finding validates that of Given et al. (2011), who reported that caregivers experience headaches and severe body aches as a result of the caregiving role, this assertion is further concurred by Ofori (2017). Several other kinds of literature have it documented that family caregiver of patients with cancer experience problems such as headaches and muscles pain (Beach, Schulz, Yee, & Jackson, 2000; Ferrell, Dow, & Grant, 1995; Tsigaropoulos et al., 2009). It is therefore imperative that, as nurses, these family caregivers are provided with the skills and training needed for them to carry out the role without it having a detrimental effect on their health such as educating on body mechanics and also on

pain management at home. However, to achieve this, health care professionals (nurses) may require training in pain management as suggested by Aziato and Adejumo (2014) to be able to transfer this knowledge to these family caregivers.

Likewise, the findings of the present study reported worsening of a pre-existing waist problem during the laborious task of caregiving. This finding is supported by Ofori (2017) where participants presented an increase in their blood pressure with associated pre-existing conditions such as diabetes and asthma. A study by Northouse, Katapodi, Song, Zhang and Mood (2010) further concurs by stating that participants had difficulties in managing their chronic diseases due to the stress of caregiving. Nevertheless, none of the participants in the present study reported having a pre-existing chronic condition such as diabetes or hypertension. This may be because the majority of the caregivers were petty traders and farmers making them active since one of the causes of hypertension/ diabetes is living a sedentary lifestyle (Hu, 2003). The caregiving role does not only affect the caregiver physically but also psychologically.

The Psychological Impact of Caregiving

Psychological impact is also one of the effects of caregiving. Sub-themes such as anxiety, a feeling of inadequacy, hopelessness, and care as obligation/ 'Giving back' were major concerns. However, some participants reported uncertainty and concealment as concerns they face.

The present study reported that the prevalence of anxiety in prostate cancer patient caregivers is much high. Whereas the presence of cancer itself is a dominant source of anxiety in caregivers, several other factors may exaggerate the symptoms

such as financial burden and fear of losing a loved one. Most of the participants demonstrated lots of worry due to the financial burden, change in patient's physic and news of cancer/treatment. This finding coincides with findings by Sercekus et al. (2014) who reported that participants experienced such feelings as distress, sadness, shock, anxiety, weakness, depression and even fear of losing a loved one in the process of caregiving. This is further mirrored in the work of Ofori (2017) who asserted that participants were anxious about losing their husbands to prostate cancer. A persistently high level of anxiety in family caregivers if not managed may lead to depression which can negatively impact the caregiver's immune system and overall psychological health (Geng et al., 2018; Walsh et al., 2018). Therefore, it is important that the family caregivers are assessed and the appropriate assistance provided as there is a more quickly disruption in psychological health than physical health (Schulz & Sherwood, 2008).

Equally, the findings of the present study revealed that participants were uncertain about the future. Uncertainty about the condition / its consequences was a major concern reported among some of the participants. The feeling of uncertainty made some of the participants worried especially when they do not know what to do to help the patient since the condition is unpredictable. Sajjadi et al. (2016) defined uncertainty as, the primary feeling of confusion, stress and indefiniteness associated with the disease. In addition, it is said to be a major component of the experience of the disease that is common among participants in many different studies which causes a restriction in the caregiver's life, disrupting her mental system and affect her adaptation to the existing situation. This finding is in line with

findings reported by Nemati et al. (2018a), where participants reported a feeling of uncertainty about the consequences of the disease and a constant mental preoccupation with the patient's problems as a major concern. Doumit, Huijer, Kelley, and Nassar (2008) identified a similar finding among the Lebanese cancer population.

A feeling of hopelessness was also unravelled in the study findings, as participant reported how they can not do anything about their current situation, setting aside personal development with their entire focus on how to care for the patient (Trudeau-Hern & Daneshpour, 2012), how their life and plans revolved around the patient/home. Their life has come to a halt, knowing that they are trapped and can not do anything about the situation until the patient recovers. A daughter explained how she can not be with the husband because of the role she is currently playing, and how both she and her husband can not do anything about it till her dad recovers. From the findings of the study, the feeling of hopelessness increases when prostate cancer begins to progress and the treatments start. This brought the caregivers' normal living to a standstill. This finding corroborates with the work of Ellis, Lloyd Williams, Wagland, Bailey and Molassiotis (2013) in a study that explored the experiences of patients with lung cancer in cancer patients and their primary carers. It was reported that assuming the caring role brought the normal life of caregivers to a halt. Senden et al. (2015) further validate this claim by adding that family caregivers' hopes, plans and goals for the immediate future must be put on hold/ changed to meet the needs of these patients.

Also, findings in this present study showed that family caregivers identified the role they played as honouring their fathers and spouses, therefore caring for them is a way of 'Giving back'/ as an obligation. Rossi and Rossi (2018) support this assertion by stating that Individuals feel the strongest obligation to help their parent, spouse, and children especially in times of need. Most of the participants considered this very rewarding and were ready to do it over and over again without complaining. Comparable findings came to light in earlier studies concerned with the experiences of stroke, cancer, and dementia patients. The family caregivers of these patients often do so of their own volition and a genuine love for the patients. In such caring relationships based on love and integrity, the caregiver derives great satisfaction from being able to relieve, bring solace and care for the patient (Pitceathly & Maguire, 2003).

The findings of the study also revealed a feeling of inadequacy among family caregivers of prostate cancer patients. Participants stated that their inability to provide proper care and satisfy the unreasonable concerns of the patient created a feeling of inadequacy. Others also reported that not being able to please the patient and settle medical expenses on time for treatment to commence was very worrying and frustrating. This inadequacy may be partly due to their inexperience, lack of money and lack of a previous encounter with care-related problems. Fergus and Gray (2009), validates this by stating in a study among breast cancer patients and their partners, that the partners felt that they have not been able to do enough for the patients, and thus continuously question their ability/ capacity to provide sufficient care for the patient. Again, the lack of adequate information and support

from health care professional may also have contributed to a feeling of inadequacy. A participant mentions how unbearable it was to watch her old man in so much pain and discomfort and yet not know what to do. Esbensen and Thomé (2010) confirm this assertion. It is therefore important that these family caregivers are empowered with the information and skills needed to adequately care for these patients at home.

Still, the findings revealed that family caregivers had to hide their feelings in the presence of the patients for fear of making them sad and having them feel sorry for themselves. Therefore, in their state of pain and strong emotion, they try to look strong. This finding is consistent with a study conducted by Lee and colleague which revealed that both patients and family caregivers hide their feelings from each other to look strong (Lee & Bell, 2011). This assertion was further supported in other studies (Hilton, Crawford, & Tarko, 2000; Lethborg, Kissane, & Burns, 2003). Furthermore, Liu, Mok, and Wong (2005) indicated in their work that cancer patients received the greatest emotional support from their close family members and that their optimistic attitudes and a positive atmosphere had a positive impact on the patients. From the present study, hiding emotions from patients met the family caregiver expectation of ensuring a positive atmosphere filled with love. However, the effect of having concealed strong emotions may be detrimental to the health of the family caregiver (Sercekus et al., 2014). It is, therefore, necessary that this area is addressed by a healthcare professional through the creation of support groups where family caregivers can come together and share their experiences; thus, providing an avenue to vent out these negative feelings.

The feeling of empathy for the patient was another subtheme that emerged under this subcategory. This describes the family caregiver's capacity to understand or feel what the patient is experiencing from within. Gleitman, Fridlund and Reisberg (2000) also defined empathy as a feeling of sympathy and concern for the suffering of another with the desire to relieve this suffering. In this present study, caregivers empathized with patient especially when they find them go through so much pain in an attempt to pass urine. Others mentioned that they felt the patient's pain. The empathetic theory proposed by Davis (1994) supports this assertion by stating that empathy-related processes are influenced by motivating factors (eg, the degree of suffering or deficits experienced by the affected person) and that inhibiting factors can detract from the caregiver's motivation to expend mental energy to engage in empathy toward the patient.

It is however established that empathy and helping behaviours are hallmarks of quality care, but when family caregivers are challenged, caregiver confidence can be diminished, resulting in unsafe, poorly timed, and suboptimal care of the patient (Davis 1994). For instance, a study in a non-prostate cancer context found in their sample of 302 pairs of caregivers and care, recipients, that when caregivers experienced more anger, they engaged in fewer empathy-related behaviours toward the person with lung cancer (Lobchuk, McClement, McPherson, & Cheang, 2012). It is therefore important that healthcare providers become aware of the potential impact of caregiving on caregivers and assess caregiver needs thus improving the emotional status of caregivers through education, treatment of mood problems and other interventions. Family caregivers should also be encouraged to voice the

emotional or psychological impact or challenges that they are experiencing in the caregiving role to promote patient quality care.

Social Impact of Caregiving on the Family Caregiver

The study also revealed several impacts of the care on the social life of the family caregiver. The study identified subthemes as sexual concerns, role/role adjustment, leisure activities, turmoil. Grooming was the least amongst the complaints made.

Sexual concerns were a major problem for the married children of these patients who have taken up the role of caregiving. Most of the caregivers especially the married children of these patients who had to leave their nuclear home to stay with their sick fathers to care for them had concerns with their sexual life. They were also worried that their separation from their husbands and children may lead to divorce. This assertion is concurred by Kim, Baker, Spillers and Wellisch (2006), who stated that family caregiver may experience conflict among their changing family roles and responsibilities, strain in marital and family relationships. Also, the study by Bookwala (2009) on the impact of parent care on marital quality and wellbeing in adult daughters and sons revealed that these group of family caregivers were unhappy in their marriages due to the demands of the caring role. The findings of the current study, on the other hand, revealed that the spouses of these patients were not worried at all, they mentioned that all they pray for is for their spouses to recover from the condition. More so, they have passed childbearing age and as a matter of fact, they already have their children. Hence there is no cause to worry about sexuality and intimacy. If the strength of the man is there fine. Otherwise,

they would not want to burden their sick spouses with the issue of sex. Others also explain how they continue to encourage them and assure them that sex is not an issue. This is consistent with the work of Roth and colleagues who revealed that participants, in an attempt to ensure that their partners do not worry about issues of sexuality/affection, give up on sexual intercourse (Roth, Weinberger, & Nelson, 2008). In contrast, a study by Ervik et al. (2013) revealed that avoidance/ inability to engage in sexual intercourse was a source of worry to them. Another study reported that caregivers (spouse), as a result of the role they played perceived their partners as patients and not sexual partners (Hawkins et al., 2009). This finding, however, is not consistent with the present study.

Role/role adjustment is another major finding under the social impact domain of this study. The majority of the participant reported having to adjust their current role to enable them to provide the care necessary. Participants (children of the patient) who had children and were separated from them because they needed to take care of their fathers had their husbands and eldest children take up of the responsibility of taking care of their nuclear home in their absence. This was evident in a study that revealed that family caregivers failed to adequately take care of their children because most of the attention and effort was directed towards taking care of the patient (Sercekus et al., 2014). Likhoyaaali et al. (2017) further agreed by reporting negligence of spouses, children and responsibility towards the small family by family caregivers as a result of the caregiving role. Nevertheless, it was reported that having to take up roles formally assume by the patients resulted in role overload, this was described as a major problem by Otis-Green and Juarez

(2014) which was further affirmed by Chambers et al. (2011). It is necessary that children of these patients who have taken up the role of caregiving be counselled together with their spouses by health care personnel.

Loss of livelihood was another major concern of these family caregivers. Most of them had to give up on their jobs to stay home and care for the patient as the majority of these participant were farmers and petty traders. This resulted in financial difficulties as the patients were too sick to work, and as the caregiver, the burden of expensive medical treatments depended on them. This finding is consistent with a similar work by Limburg et al. (2008). Several other studies also confirm this (FCA, 2016; Miedema et al., 2008; Penner & McClement, 2012; Sercekus et al., 2014). This implies that economic cost is much more remarkable among these family caregivers since patients have little/ no health coverage with most of these caregivers out of a job/retired.

In addition, study findings showed that the caregivers devoted themselves completely to the task of caregiving thus had no time for leisure activities. Most of the participant because they feared that the worse may happen in their absence, others also tried to make some little time to attend to very pressing and important issues. Brazil et al., 2010; Penner and McClement (2012), supports this finding by arguing that caregivers are faced with restrictions in their life as a result of the role they play leading to isolation. Mosher, et al. (2013) further buttresses this statement by pointing out that isolation may lead to distress. Several other studies confirm that social isolation may have a detrimental effect on the family caregiver (Shih,

Hsiao, Chen, & Lin, 2013; Stajduhar, 2013; Terakye, 2011), thus the need for this to be addressed.

Turmoil describes the confusion, agony and emotional trauma these caregivers (married daughters of patients with prostate cancer) go through in their marriages as a result of the role they play. This participant described how the relationship between them and their spouses had grown worse since they took up the role. This made them very worried and sad; also with a fear of separation/divorce from their spouses. Consistent with the present study, findings from the work of Bookwala, Pasternak, Pruchno and Newsom (2007) reported that adult children who do not even live with their care-recipient parent may have their marriage affected. Another study also revealed that parents moving into the marital homes of their children to be cared for may have a detrimental effect on their marriage (Bethea, 2002). In the same vein, a study by Voydanoff and Donnelly (1999) that tested the interaction between caregiving and marital quality with depressive symptoms using a cross-sectional data from a U.S. national probability sample of 2,414 men and women reported that the number of hours spent on providing care for parents was associated with more depressive symptoms for adult daughter caregivers who reported a higher level of marital disagreement. However, in the present study, no evidence of depression was identified yet.

Challenges Confronting Caregivers of Patients with Prostate Cancer

Family caregivers are faced with diverse challenges as they take up the role of caregiving. The findings of the present study revealed major challenges such as lack of preparedness towards caregiving role, lack of knowledge about condition

and treatment, misconception about the condition, financial constraints. Lack of knowledge about available resources and communication concerns between caregivers and healthcare professionals were also reported. However, all other findings under this theme are discussed below.

Lack of preparedness towards caregiving role was a major concern among all the participants. The family caregivers reported receiving no preparation towards the role of caregiving hence lacked the knowledge and skills to effectively play the role. According to Schumacher et al. (1998), preparedness describes the family caregiver's perceived readiness for the caregiving role, which encompasses multiple domains, including the provision of physical care, emotional support, and instrumental support. Considering the difficulty involved in providing care to a patient, these caregivers must be empowered with the skills and knowledge needed to embark on this journey. However, the case is not so. Like the findings reported in this study, Mazanec et al. (2018) stated that family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, as well as receive little guidance from the formal health care providers. Besides, the report from the participants of the current study showed that they were more than willing to take on the responsibility of patient care, despite preordained financial and psychological burdens as most of these caregivers considered the assistance they provided as "Giving back". Yet, they lacked the skills and knowledge required to take up the role. In contrast, a study by Scherbring (2002) found no association between caregiver lack of preparedness and caregiver burden/ barrier to care, a finding also supported by Fujinami et al. (2015). A single salient reason

that can be drawn from this finding is that preparing the family caregiver for the task ahead is very important if health personnel have the wellbeing of both the patient and caregiver at heart.

Findings from the study revealed that knowledge about the condition and its management was one area that healthcare providers both nurses and physicians have neglected (Nemati, Rassouli, Ilkhani, & Baghestani, 2018b). Most of the participant reported having received little to no knowledge at all on the condition and its management. It was reported that the number of times to administer the medication was communicated to them, however, no education was given on the side/ adverse effects of the medications, how to identify these side effects and even the measures to take at home before bringing the patient back to the health facility if necessary. Etemadifar et al. (2014); Sajjadi et al. (2016) affirm this assertion by stating that caregivers reported the failure of specialists in giving the required personal information and specialist knowledge about the patients' disease and the caregivers' health as a major problem that remained unmet. Travis et al. (2000), further reported that the lack of knowledge on the condition and its management resulted in medication errors. It is therefore imperative that as health practitioners the required information be provided to reduce the uncertainty and stress among these family caregivers thus, promoting patients quality care.

Financial constraint was another problem that came up. The majority of the participants complained of financial difficulties. Some had to depend on their children, friends and other family relatives, others went for loans. Some participants had to use up their savings, and retirement benefits. Some of the

patients /participants had to try herbal preparation due to the high cost of treatment. And others went bankrupt due to the expenses involved in managing this condition. This finding is echoed by Given and colleagues who reported in their study that, caregivers of cancer patients took loans, sold their homes and used other financial resources to pay for the expensive cost of treatment that was not covered under health insurance and even went bankrupt (Bradley et al., 2007; Given et al., 2011). The finding also revealed that most of these caregivers had lost their livelihood due to the increased physical and financial burden associated with the role (Brazil et al., 2010; Family Caregiver Alliance, 2016). This financial challenge appears to reflect the economic status of the study setting as Cape Coast is one of the poorest regions in Ghana. However, in contrast with the findings of the present study, Mosher et al. (2015) revealed that complementary and alternative medicine was viewed to be more favourable/ effective. Participant in the present study rather worsens their condition making the caregivers' role more difficult when they opted for the use of herbal preparation. To add to existing knowledge report from the current study revealed that the use of herbal preparation for the management of prostate cancer rather worsened the patient condition further causing more distress/stress to the caregiver.

Again the findings of this study disclosed that the majority of the participants expressed a lot of misconception about the condition. This indicates that culture plays a major role in how caregivers perceive and go about the caregiving role. Some participants reported that cancer may be contracted as a result of immoral behaviour or punishment from God which is consistent with the

finding of a study by Kuan Lee Wai (2016). Others also believe it is a punishment from one's enemies for mistreating them, this mirrors findings from Lui and Ip (2009). Another finding reported by participants was that cancer is contagious and fatal, an assertion confirmed by Lee and Bell (2011). These beliefs resulted in fear/panic and further decreased the support network (Cheng et al., 2013). A single relevant perspective that can be drawn from this finding is that the people within the context of the study needs to be well educated about prostate cancer/cancer in general. However, in contrast to the work of (Lee, 2007), no association was reported between caregiver tension and the diagnosis of cancer.

Difficulties encountered within the healthcare environment affecting the caregiver's role.

This is a new theme that emerged from the findings of the present study. Finding has revealed that not only do these unpaid caregivers encounter problems at home as they play the role of caregiving, but the healthcare environment is also another place that may contribute negatively to the caregiving role resulting in more stress and distress among these family caregivers. There are two subthemes under this main theme; lack of accommodation facility and poor staff attitude

The majority of the participants narrated how they slept on floors outside of the ward in the open, exposed to harsh weather conditions and mosquito bites all because the hospital has not provided a place for caregivers who have their patients on admission to rest or spend the night. Others also mentioned that they had to stay because their home is quite a distance from the hospital, and as such commuting to and from the facility was financially draining coupled with their loss of livelihood

and expensive medical cost making life very difficult. This finding is consistent with the work of Sadigh, Nawagi and Sadigh (2016) who studied the Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda revealing that Ninety per cent of informal caregivers stayed at the hospital for 11 days on average, with a range of 1-60 days. While staying at the hospital, 89% slept on the hospital floor. Three per cent returned home each evening to sleep, two per cent slept in the prison barracks where members of the police force stayed, one per cent slept in Bwaise, an urban slum and other one per cent shared the hospital bed with the patient. This finding indicates that it is very important that hospitals provide a place of resting for these family caregivers especially considering a referral point hospital like the Cape Coast Teaching Hospital to relieve some of the stress and burden associated with the role.

Similarly, under the major theme “challenges confronting family caregiver within the health care environment” emerged staff attitude as a sub-theme. Some of the participants reported waiting long hours at the Out Patient Department (OPD) before the clinic starts. Others also complained of poor staff attitude making it difficult for them to be approached, and neglect of patient care when a family caregiver is not around. Of concern in these findings were caregiver reports of a poor attitude. According to Delicado Useros, Espín, Parra and Martínez (2012) nurses’ attitudes and activities with caregivers are influenced by lack of time, hospital workload and organization. Although these reports were few and most caregivers tolerated such behaviour, it made coping/ information seeking difficult. It is therefore, necessary that healthcare providers ensure better behaviour to

improve upon customer service and patient/caregiver satisfaction through the organization of workshops for its staff. Effort must also be made to increase the staffing numbers.

Coping strategies used by Family Caregivers

Caregivers not only have to tackle the challenges they face but have to maintain their caregiving role as well (Silveira, Given, Given, Rosland, & Piette, 2010). It is known that family caregivers use different coping strategies in dealing with the difficult situations associated with the role of caring, adjust to the changing life events and managing the illness of the patient under their care (Karabulutlu, 2014; Kelly et al., 2008). In this present study, the most frequent coping strategies used by caregivers were religiosity/active planning/support systems. Others reported relaxation/ listening to music. Some also mentioned that accepting the situation helped them cope. Some participants engaged in information seeking and medication abuse.

Religion plays a significant role in the lives of the Christian population. Traumatic experiences such as diseases are believed as the way through which God tests us. Anger at God is an unacceptable emotion, and people try to make sense of this experience. Religiosity is an important psychological resource that improves coping, adaptation and quality of life (Harandy et al., 2009). This study revealed that religiosity was an effective coping resource for the caregivers of these patients. It is deemed necessary to mention that religiosity as a coping strategy used by most family caregivers has been well documented in African literature (Ae-Ngibise, Doku, Asante, & Owusu-Agyei, 2015; Aziator, Odai & Omenya, 2016; Bussing et

al. 2014; Ofori, 2017). This was, however, not surprising and coincidentally all caregivers recruited for the study were Christians as reflected in the demographic information provided.

In this present study, it was also determined that the support family caregivers received from their family, friends, and healthcare professionals were very helpful in coping with the difficulties they encountered, but some of them did not receive adequate support. Likewise, Lethborg et al. (2003) determined that the support received from friends or family members was very important for caregivers. Some of the participants reported not receiving adequate support from healthcare personnel, this is consistent with Eriksson and Lauri (2000) who pointed out that caregivers needed to get information and emotional support from healthcare professionals, but they received less support than they needed. In the same study, it was also determined that the caregivers considered the staff devoting enough time to them as the most importantly emotional support. Similarly, Hilton et al. (2000) determined that the patients' caregivers did not know what to do and thus needed support from healthcare professionals. Also, previous research has emphasized that support from the healthcare system and its providers can influence caregivers' coping abilities (Stajduhar, 2003; Stajduhar & Davies, 1998). Therefore, it is important that healthcare professionals allocate time to caregivers to listen to their problems and to identify their needs, and should provide them with necessary training, skills and information needed to effectively play the role of caregiving with less stress as well as also make them aware of resources available.

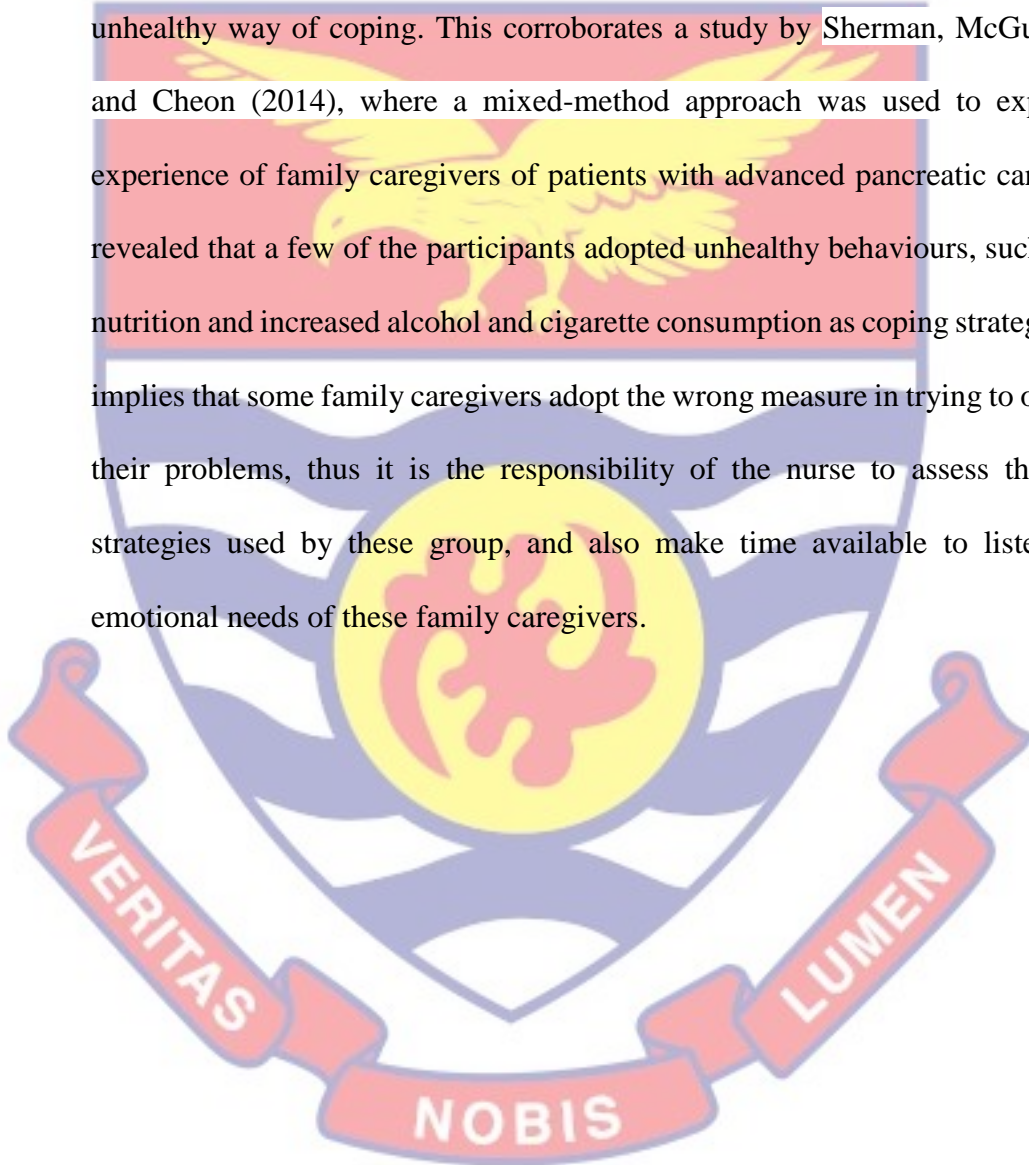
Like the findings reported here, studies have shown that some caregivers use denial/acceptance as an effective approach to coping with the stress of caregiving (Coyne, 2013; Coyne, Wollin, & Creedy, 2012). In line with the present study, Eaton et al. (2011) revealed findings that pointed to the fact that family members used more emotion-focused coping strategies than problem-focused coping strategies. However, contrary to the findings of this present study family caregivers were better able to cope with the strains of caregiving. Kelly et al. (2008), reported that family caregivers who used emotional focus coping strategies such as denial and avoidance lead to greater strain in coping. It is therefore important that health care professionals consider the family caregiver's response to the cancer diagnosis, as the reaction of the family caregiver to a patient's illness can influence the adjustment of the patient to the illness (Northouse, 1995) and impact upon the family caregivers involvement in care provision (Raveis, Karus, & Pretter, 2000). The information obtained from these interviews may aid health care personnel especially nurses in counselling or supporting family caregivers dealing with the cancer diagnosis of a loved one.

Again, the finding of the present study has established that the majority of the participants used active planning as the coping strategy to deal with the pressure associated with caregiving. Active planning is a problem-focused coping strategy, which is focused on the resolution of the problem experienced. This strategy enables the caregiver to be more active, establish an action plan and cognitively accept the problem to find ways/means to adapt or come up with a solution to deal with it (Pérez-Cruz, Parra-Anguila, López-Martínez, Moreno-Cámara, & del-Pino-

Casado, 2019; Şahin & Özbay, 1999). Consistent with the present study, Ko et al. (2005) reported that spouses of prostate cancer patients experienced less stress when they adopted constructive problem-solving skills such as active planning. Marguerite et al. (2017) confirm this assertion. Thus, as healthcare providers it is therefore important that family caregivers are provided adequate information on the right coping strategies to adapt to the developing status as recommended by Lazarus and Folkman (1984).

The least strategy that emerged from the findings of this present study as coping styles used by these caregivers were relaxation/ listening to music, seeking knowledge on the condition and medication abuse. Music therapy as a form of coping strategy used by family caregivers have gain recognition in research; which suggest that the caregiver well being is promoted through the use of music therapy (Cuttillo, Reynolds, & Madan-swain, 2015). The participant reported that listening to music helped promote relaxation and relieve the stress associated with the role; also promoting a feeling of calmness. This corresponds with one study that found positive effects on reducing anxiety, depression, and blood pressure among caregivers of adult patients with cancer following either a nurse-led or recorded music intervention that involved 30 minutes of listening to live or prerecorded relaxing music (Lai, Li, & Lee, 2012). Other studies have also supported this finding (Magill, 2009; O'Kelly, 2014). The findings of this study thus provide information on the efficacy of music therapy for caregivers of a prostate cancer patient that can be used by healthcare personnel especially nurses to educate this group.

Medication abuse was reported as a way to cope with the task of caregiving according to the findings. The finding revealed that, due to the strain and stress that accompanies the role, pain-relieving medications are constantly taken to relieve pain, promote relaxation and sleep. However, this strategy is considered an unhealthy way of coping. This corroborates a study by Sherman, McGuire, Free and Cheon (2014), where a mixed-method approach was used to explore the experience of family caregivers of patients with advanced pancreatic cancer, that revealed that a few of the participants adopted unhealthy behaviours, such as poor nutrition and increased alcohol and cigarette consumption as coping strategies. This implies that some family caregivers adopt the wrong measure in trying to overcome their problems, thus it is the responsibility of the nurse to assess the coping strategies used by these group, and also make time available to listen to the emotional needs of these family caregivers.



CHAPTER FIVE

SUMMARY, IMPLICATION, LIMITATION, CONCLUSION AND RECOMMENDATION

This chapter presents the summary of the study, the implications of the study to nursing practice, education and, research. It also includes the limitations, conclusion and recommendations of the study.

Summary

As a society with an increasing concern with the incidence of prostate cancer, it has become necessary that family caregivers take on greater responsibility with regards to managing patients' condition at home. Crucial to this task is the caregiver's ability to effectively play the role of the caregiver while ensuring that they are in optimum health. However, the case is often not what is expected. A qualitative descriptive method was employed to explore the experiences of family caregivers of patients with prostate cancer in the Accra metropolis with participants recruited from the urology clinic and the surgical ward of the Cape Coast Teaching hospital. A semi-structured interview guide was purposefully used to recruit twelve (12) participants for this study. Ethical approval was given by the Institutional Review Board of both the University of Cape Coast and the Cape Coast Teaching Hospital. Participants who consented were interviewed and the data were transcribed verbatim. Participants were identified with codes and the data gathered were analyzed using the technique of Colaizzi (1978) data analysis. The study revealed findings based on the author's developed framework adapted from the

quality of life model applied to family caregivers (Ferrell, 2001) and the transactional model of stress, coping and adaptation by Lazarus and Folkman (1984). Participants age ranged from 27 to 67 years (both spouses and children of the patient). Four major themes emerged with their subthemes. Caregivers of patients with prostate cancer were fatigued; participants experienced sleeplessness and altered eating pattern as major concerns. Others presented sexual concerns, role adjustment, turmoil and loss of livelihood/income as major social concerns. Participants were anxious about the patient's condition, how to take care of medical expenses and change in patient's physic, felt inadequate, uncertain and hopeless (Life halted) about the situation. Some also observed the role as fulfilling as they considered the care rendered an obligation/ "Giving back". This led to several challenges that resulted in financial constraints because they have to leave their jobs to take up the responsibility of caring for the patient. Other participants challenge had to do with the lack of preparation for the caregiver role and the lack of knowledge on the condition and its management making their work very difficult. As if these challenges were not enough, the hospital environment also was a challenge to most of the participant who had their patients on admission. Most of them had problems with where to spend the night/ rest whiles on the hospital premises. Others had a lot to say about staff attitude making it difficult to seek information. In trying to cope with these challenges the participants employed several measures such as believing that God will bring their suffering and that of the patient to an end by healing him, planning their day to take some time to rest since the task is arduous. Others used denial/acceptance, relaxation/listening to

music, while most of them made use of the available support systems (Emotional/Physical/ Financial).

Implications of Findings

The findings of the study have several implications that needed to be addressed. These implications are in relation to nursing education, practice and research.

Nursing Practice

For ages, health care providers and most importantly nurses have concentrated on providing care for patients while neglecting the needs and concerns of the family member/loved ones who cared for these patients at home. The findings of this study have brought to light that these family caregivers are hidden patients themselves, hence as nurses, they must be seen as such so that care can be extended to them.

In addition, nurses need to consider the positive perspective of caregiving to enable the caregiver to also perceive the positive aspect of the situation. Positive perception helps the caregivers overcome the negative aspects of the situation. Thus, enhancing the development of these perceptions promotes better coping and the higher the chance that they will accomplish the ultimate goal expected of them.

Similarly, nurses must endeavour to assess the family caregivers needs to help provide the care/assistance required. To achieve this, the nurse must develop a professional relationship with the patients and their family caregivers, especially those that build trust and emotional support to help caregivers to feel more comfortable and willing to express their feelings.

Furthermore, family caregivers need preparation to meet the demands of their new responsibilities. Nurses must, therefore, focus on adequately preparing the caregivers (with the knowledge, information, skills and resources) to assume the caregiver role as this promotes the development of successful coping which is enhanced through the sense of accomplishment especially when they see that they can help the patients become more comfortable and able to handle the situation.

Likewise, there is the need to provide both patients and family caregivers/community, information on the causes, sign/symptoms, management of cancers as this will help a long way to clear the misconceptions these family caregivers have about the condition.

More so when patients are discharged from the hospital there is a need for nurses to ensure that these clients and their family caregivers are handed over to the community health care worker for continuity of care.

Nursing/public education

Advanced practice nurses should be trained in the area of cancer with emphasis made on how to care for, support and educate family caregivers. Colleges of School of Nursing should review content to include if not a course on oncology nursing (where the caregivers' role can be emphasized) to help equip the trainees with the basic knowledge on how to provide care for this group. In addition, organizing in-service and regulator training for nurses and public health nurses will promote increase knowledge in the area of prostate cancer.

Nursing Research

The findings of the present study brought to bear that culture played a major role in how family caregivers perceived their role and even how the care is rendered to these patients. Therefore, there is a need for further studies on the role of culture in the experiences of prostate cancer family caregivers among a multicultural group to help establish findings per other culture.

Also, further research is required in the area of preparedness of family caregivers of prostate cancer patients towards the caregiving role. Furthermore, future research may be considered in the area of nurses involvement of caregivers from the nurses' perspective. Similarly, an in-depth understating of the caregivers' experiences cannot be achieved only from a qualitative study. The mixed research design of qualitative and quantitative methods may be valuable for further studies of the family caregivers' experience with caring for patients with prostate cancer.

Conclusion

Currently, in Ghana, family caregivers have an important place in the health care system. They take on the majority of the care responsibility at home, therefore, it is important that they are prepared for this role through the provision of knowledge, skills, resources and supports both from the other family members, government and health professionals. The coping strategies of these family caregivers must be explored to inform practice in order to improve the quality of life of the family caregivers. Similarly, nurses and other healthcare personnel are encouraged to increase the education regarding cancer symptoms and management to the family caregiver, patient as well as the community at large. Nurses must therefore take the responsibility of ensuring that patients are getting the needed

treatment and care and family caregivers receiving the needed support in line with clinical guidelines.

Limitations

The findings of this study focused only on the experiences of caregivers of prostate cancer patients. This might likely have influenced the findings since this may not be the case in other conditions. The findings also revealed that all of the participants were Christians (not purposeful), there could be a limitation with application to the non-Christian population. Culture played a major role in this study context, however, other groups within the country may present a different picture.

Recommendation

With reference to the findings of this study, the following recommendations have been made to the Ministry of Health, Ghana Health Service, Nursing and Midwifery Council of Ghana, Counselling Experts, Caregiver Support Groups and the Cape Coast Teaching Hospital.

Ministry of Health (MOH)

The MOH has been set up and mandated to ensure good health and vitality for all people living in Ghana. Thus, promoting the quality of life of these family caregivers and their patients forms part of the ministry's mandate. The Ministry of Health therefore should:

Make the total cost involved in the diagnosis/treatment of prostate cancer-free under the Health Insurance Scheme considering the age group most affected and the cost involved in the management of the condition.

To collaborate with other stakeholders to promote programs on the early screening and management of prostate cancer among men in the country.

Provide accommodation facilities in referral point regional hospitals for family caregivers of prostate cancer patient/patient who have travelled a long distance to the facility because they have been referred there for further management especially because Cape Coast Teaching Hospital is under the MOH.

Ghana Health Service (GHS)

The GHS should:

Implement approved policies that support the wellbeing of family caregivers of prostate cancer patients

Develop a charter on the rights and responsibilities of family caregivers just as it has on patients (The Patient Charter) considering the current shift in the health care system today with family caregivers taking up the caring role at home.

Implement approved policies on the development of educational programs that will increase the awareness, screening and management of prostate cancer

District health care facilities should have cancer units where family caregivers and their patients can go for medical treatment.

Nursing and Midwifery Council of Ghana

To liaise with the Ghana College of Nurses and Midwives to train advanced practice nurses (specialized oncology nurses) who are knowledgeable in the care, support and education of these patients and their family caregivers.

Also, at the nurses training institution levels, the nursing and midwifery council should ensure that the course content is reviewed to include a course on oncology nursing if not, with more emphasis made on the family caregiver.

Counselling experts

The hospitals should liaise with counselling experts within churches and other organizations to make their services available to these family caregivers.

Caregiver Support Group

Up until now, there is no caregiver support group for patients with prostate cancer identified per the researchers' knowledge, it is therefore important that a local caregiver support group is established in which the members have increased responsibility for sustaining the network. This may offer a more sustainable mechanism to address some of the needs/concerns of these caregivers.

Cape Coast Teaching Hospital

The Cape Coast Teaching Hospital's Genitourinary and Surgical Units should:

Ensure that family caregivers of prostate cancer are educated on the condition and its management options as well as involved in the care process

Adequately prepare the family caregivers for the responsibility of caring through the provision of needed skills/ knowledge/ resources to effectively perform the caring role.

Check the waiting time at the OPD before the clinic starts since it has been reported as a contributing factor to patient and caregiver stress and suffering

Establish support groups for these family caregivers to serve as a venue to discuss and manage some of their challenges as far as the role is concerns

Provide accommodation facilities in their small way for the family caregivers who have their patients on admission. Considering this can in the long term generate revenue for the facility.

Incorporate the use of complementary and alternative medicine in the treatment options for these patients and their family caregivers if possible.



REFERENCE

- Abdollah, F., Sun, M., Thuret, R., Abdo, A., Morgan, M., Jeldres, C., ... Karakiewicz, P. I. (2011). The effect of marital status on stage and survival of prostate cancer patients treated with radical prostatectomy: a population-based study. *Cancer Causes & Control*, 22(8), 1085–1095. <https://doi.org/10.1007/S10552-011-1007/S10552-01>
- Aboderin, I. (2004). A decline in Material Family Support for Older People in Urban Ghana, Africa: Understanding Processes and Causes of Change. *Journal of Gerontology Series B: Psychological Sciences and Social Sciences*, 59(3), S128–S137.
- Adeloye, D., David, R. A., & Aderemi, A. V. (2016). An Estimate of the Incidence of Prostate Cancer in Africa : A Systematic Review and Meta-analysis. *PLoS One*, 11(4), e0153496. <https://doi.org/10.1371/journal.pone.0153496>
- Ae-Ngibise, K. A., Doku, V. C. K., Asante, K. P., & Owusu-Agyei, S. (2015). The experience of caregivers of people living with serious mental disorders: a study from rural Ghana. *Global Health Action*, 8(1), 26957. <https://doi.org/10.3402/gha.v8.2695>
- Ahern, K. (1999). Ten tips for reflexive bracketing. *Qualitative Health Research*, 9(3), 407–411.
- Akpan-Idiok, P.A., & Anarado, A. (2014). Caregivers' perceptions of burden and benefits of caregiving to cancer patients attending the University of Calabar Teaching Hospital, Calabar, Nigeria. *The Pan African Medical Journal*, 18.

Akpan-idiok, P.A, & Anarado, A. (2014). Caregivers' perception of Benefits of Caregiving to Advanced Cancer Patients Attending the University of Calabar Teaching Hospital, Calabar, Nigeria. *International Journal of Cancer*, 10(2), 54–64.

American Cancer Society. (2018). Prostate Cancer Risk Factors. Retrieved September 19, 2018, from <https://www.cancer.org/cancer/prostate-cancer/causes-risks-prevention/risk-factors.html>

American Institute for Cancer Research. (2019). About the Report | American Institute for Cancer Research (AICR). Retrieved July 10, 2019, from <https://www.aicr.org/cancer-research/dietandcancerreport/about.html>

Amoah, G., Acheampong, D. O., Kofi Christian, G. S., Acheampong, E., Azorliade, R., Addai Arhin, K. A., ... Amankwaa, B. (2018). Knowledge, Attitude and Perception of Prostate Cancer among Male Adults in the Kumasi Metropolis: A Descriptive Cross-Sectional Study. *Journal of Urology and Research*, 5(2), 1–9. Retrieved from <https://www.jscimedcentral.com/Urology/urology-5-1099.pdf>

Antoni, M. H., Lehman, J. M., Kilbourn, K. M., Boyers, A. E., Culver, J. L., Alferi, S. M., ... & Price, A. A. (2010). Cognitive-behavioural stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. *Health Psychology*, 20(1), 20–32. <https://doi.org/10.1037/0278-6133.20.1.20>.

Arthur, F., Yeboah, F., Adu-Frimpong, M., Sedudzi, E., & Boateng, K. (2006).

Prostate cancer screening in Ghana - a clinical benefit? *Journal of Science and Technology (Ghana)*, 26(1), 1–7. <https://doi.org/10.4314/just.v26i1.32955>

Asamoah, F. A., Yarney, J., Awasthi, S., Vanderpuye, V., Venkat, P. S., Fink, A.

K., ... Tagoe, S. N. A. (2018). Contemporary Radiation Treatment of Prostate Cancer in Africa: A Ghanaian Experience. *Journal of Global Oncology*, 4, 1–13. <https://doi.org/10.1200/jgo.17.00234>

Asuquo, E. F., Etowa, J. B., & Adejumo, P. (2013). Assessing the Relationship

between Caregivers Burden and Availability of Support for Family Caregivers' of HIV/AIDS Patients in Calabar, South-East Nigeria. *World Journal of AIDS*, 3(4), 335–344. <https://doi.org/10.4236/wja.2013.34043>

Aziato, L., & Adejumo, O. (2014). Psychosocial Factors Influencing Ghanaian

Family Caregivers in the Post-Operative. *Africa Journal of Nursing and Midwifery*, 16(2), 112–124.

Aziato, L., Odai, P. N., & Omenyo, C. N. (2016). Religious beliefs and practices in

pregnancy and labour: an inductive qualitative study among post-partum women in Ghana. *BMC pregnancy and childbirth*, 16(1), 138.

Badger, T., Segrin, C., Dorros, S. M., Meek, P., & Lopez, A. M. (2007). Depression

and Anxiety in Women With Breast Cancer and Their Partners. *Journal of Nursing Research*, 56(1), 44–53.

Bae, J.M. (2015). Human papillomavirus 16 infections as a potential risk factor for

prostate cancer: an adaptive meta-analysis. *Epidemiology and Health*, 37, e2015005. <https://doi.org/10.4178/epih/e2015005>

Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. *Psychology and Aging, 15*(2), 259–271. <https://doi.org/10.1037/0882-7974.15.2.259>

Becker, M. H., & Maiman, L. A. (1975). Sociobehavioral Determinants of Compliance with Health and Medical Care Recommendations. *Medical Care, 13*(1), 10–24.

Beesley, V. L., Price, M. A., & Webb, P. M. (2011). Loss of lifestyle: Health behaviour and weight changes after becoming a caregiver of a family member diagnosed with ovarian cancer. *Supportive Care in Cancer, 19*(12), 1949–1956. <https://doi.org/10.1007/s00520-010-1035-2>

Bello, J. O. (2017). Predictors of survival outcomes in native sub-Saharan black men newly diagnosed with metastatic prostate cancer. *BMC Urology, 17*(1), 39. <https://doi.org/10.1186/s12894-017-0228-0>

Bernard, H. (2002). *Research methods in anthropology: Qualitative and quantitative approaches*. (3rd ed.). Walnut Creek, CA: Alta Mira Press.

Berry, L. L., Dalwadi, S. M., & Jacobson, J. O. (2018). Supporting the Supporters : What Family Caregivers Need to Care for a Loved One With Cancer. *American Society of Clinical Oncology, 13*(1), 35–42. <https://doi.org/10.1200/JOP.2016.017913>.

Bethea, L. S. (2002). The impact of an older adult parent on communicative satisfaction and dyadic adjustment in the long-term marital relationship: Adult-children and spouses' retrospective accounts. *Journal of Applied Communication Research*, 30(2), 107–125. <https://doi.org/10.1080/00909880216582>.

Bliese, P. D., Edwards, J. R., & Sonnentag, S. (2017). Stress and well-being at work: A century of empirical trends reflecting theoretical and societal influences. *Journal of Applied Psychology*, 102(3), 389–402. <https://doi.org/10.1037/apl0000109>

Blum, K., & Sherman, D. W. (2010). Understanding the Experience of Caregivers: A Focus on Transitions. *Seminars in Oncology Nursing*, 26(4), 243–258. <https://doi.org/10.1016/j.soncn.2010.08.005>

Blumberg, S. J., Vahratian, A., & Blumberg, J. H. (2014). Marriage, Cohabitation, and Men's Use of Preventive Health Care Services.

Bookwala, J, Pasternak, C., Pruchno, R., & Newsom, J. T. (2007). *Effects of parent-care transitions on adult sons' and daughters' marital relationships*. *Generation of Relationships and Relationships Across Generations: Conference Proceedings of the Combined 7th Annual APS PORIG Conference/IARR Mini-Conference*. Retrieved from http://www.sdrs.info/documents/PDF/7th_Annual_PRIG_Proceedings-published.pdf#page=19

Bookwala, Jamila. (2009). The impact of parent care on marital quality and well-being in adult daughters and sons. *Journals of Gerontology - Series B Psychological Sciences and Social Sciences*, 64(3), 339–347. <https://doi.org/10.1093/geronb/gbp018>.

Bradley, S., Sherwood, P. R., Donovan, H. S., Hamilton, R., Rosenzweig, M., Hricik, A., ... Bender, C. (2007). I could lose everything : Understanding the cost of a brain tumour. *Journal of Neuro-Oncology*, 85(3), 329–338. <https://doi.org/10.1007/s11060-007-9425-0>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Bray, F., Jemal, A., Grey, N., Ferlay, J., & Forman, D. (2012). Global cancer transitions according to the Human Development Index (2008–2030): a population-based study. *The Lancet Oncology*, 13(8), 790-801.

Brazil, K., Bainbridge, D., & Rodriguez, C. (2010). The Stress Process in Palliative Cancer Care : A Qualitative Study on Informal Caregiving and its Implication for the Delivery of Care. *American Journal of Hospice & Palliative Medicine*®, 27(2), 111–116. <https://doi.org/10.1177/1049909109350176>

Brown, C. R., Hambleton, I., Hercules, S. M., Unwin, N., Murphy, M. M., Nigel Harris, E., ... Younger-Coleman, N. (2018). Social determinants of prostate cancer in the Caribbean: A systematic review and meta-analysis. *BMC Public Health*, 18(1), 1–14. <https://doi.org/10.1186/s12889-018-5696-y>

Brown, R. M., & Brown, S. L. (2014). Informal caregiving: A reappraisal of effects on caregivers. *Social Issues and Policy Review*, 8(1), 74–102. <https://doi.org/10.1111/sipr.12002>

Buchbinder, M., Longhofer, J., & McCue, K. (2009). Family Routines and Rituals When a Parent Has Cancer. *Families, Systems and Health*, 27(3), 213–227. <https://doi.org/10.1037/a0017005>

Burns, N., & Grove, S. (2011). *Understanding Research: Building an Evidenced Based Practice* (5th ed). Maryland Heights, Missouri: Elsevier Saunders.

Büssing, A., Wirth, A. G., Reiser, F., Zahn, A., Humbroich, K., Gerbershagen, K., ... & Baumann, K. (2014). Experience of gratitude, awe and beauty in life among patients with multiple sclerosis and psychiatric disorders. *Health and Quality of Life Outcomes*, 12(1), 63.

Byun, E., Lerdal, A., Gay, C. L., & Lee, K. A. (2016). How Adult Caregiving Impacts Sleep: a Systematic Review. *Current Sleep Medicine Reports*, 2(4), 191–205. <https://doi.org/10.1007/s40675-016-0058-8>

Caelli, K. (2001). Engaging With Phenomenology : Is It More of a Challenge Than It Needs to Be ? *Qualitative Health Research*, 11(2), 273–281.

Calys-tagoe, B. N. L., Yarney, J., Kenu, E., Adwoa, N., Amanhyia, K. O., & Enhill, E. (2014). Profile of cancer patients ' seen at Korle Bu teaching hospital in Ghana (A cancer registry review). *BMC Research Notes*, 7(1), 577. <https://doi.org/10.1186/1756-0500-7-577>.

Campbell, L. C., Keefe, F. J., McKee, D. C., Edwards, C. L., Herman, S. H., Johnson, L. E., ... Donattuci, C. F. (2004). Prostate cancer in African Americans: Relationship of a patient and partner self-efficacy to quality of life. *Journal of Pain and Symptom Management*, 28(5), 433–444.

<https://doi.org/10.1016/j.jpainsymman.2004.02.020>

Cancer.Net. (n.d.). Coping With Cancer. Retrieved July 22, 2019, from <https://www.cancer.net/coping-with-cancer>

Cappiello, M., Cunningham, R. S., Knobf, M. T., & Erdos, D. (2007). Breast Cancer Survivors Information and Support After Treatment. *Clinical Nursing Research*, 16(4), 278–293.

Carpenter, D. (2007). Phenomenology as a method. In H. J. Streubert & D. R. Carpenter (Eds.), *Qualitative research in nursing: Advancing the humanistic imperative* (pp. 75–99). Philadelphia, PA: Lippincott.

Carson, J. (2005). The strengths and weaknesses of research designs involving quantitative measures. *Journal of Research in Nursing*, 10(5), 571–582. <https://doi.org/10.1177/136140960501000506>

Carter, N., Bryant-Lukosius, D., DiCenso, A., Blythe, J., & Neville, A. J. (2010). The supportive care needs of family members of men with advanced prostate cancer. *Canadian Oncology Nursing Journal*, 20(4), 166–170. <https://doi.org/10.5737/1181912x204166170>

Carter, P. A. (2006). A Brief Behavioral Sleep Intervention for Family Caregivers of Persons With Cancer. *Cancer Nursing*, 29(2), 95–103.

Carter, P. A., & Chang, B. L. (2000). Sleep and Depression. *Cancer Nursing*, 23(6), 2–6.

Carver, C. S., & Connor-Smith, J. (2010). Personality and Coping. *Annual Review of Psychology*, 61(1), 679–704. <https://doi.org/10.1146/annurev.psych.0930>

08.100352

Cassidy, T., & McLaughlin, M. (2015). Psychological distress of female caregivers of significant others with cancer. *Cogent Psychology*, 2(1), 1–12. <https://doi.org/10.1080/23311908.2014.999405>

Chambers, S. K., Pinnock, C., Lepore, S. J., Hughes, S., & Connell, D. L. O. (2011). Patient Education and Counseling A systematic review of psychosocial interventions for men with prostate cancer and their partners. *Patient Education and Counseling*, 85(2), e75–e88. <https://doi.org/10.1016/j.pec.2011.01.027>.

Cheng, H., Sit, J. W. H., Chan, C. W. H., So, W. K. W., Choi, K. C., & Cheng, K. K. F. (2013). Social support and quality of life among Chinese breast cancer survivors: Findings from a mixed-methods study. *European Journal of Oncology Nursing*, 17(6), 788–796. <https://doi.org/10.1016/j.ejon.2013.03.007>

Chindaprasirt, J., Limpawattana, P., Pakkaratho, P., Wirasorn, K., Sookprasert, A., & Kongbunkiat, K. (2014). Burdens among Caregivers of Older Adults with Advanced Cancer and Risk Factors. *Asian Pac J Cancer Prev*, 15(4), 1643–1648.

Chu, L. W., Ritchey, J., Devesa, S. S., Quraishi, S. M., Zhang, H., & Hsing, A. W. (2011). Prostate Cancer Incidence Rates in Africa. *Prostate Cancer*, 2011, 1–6. <https://doi.org/10.1155/2011/947870>

Cochrane, B. B., & Lewis, F. M. (2005). Partner's Adjustment to Breast Cancer : A Critical Analysis of Intervention Studies. *Journal of Health Psychology*, 24(3), 327–332. <https://doi.org/10.1037/0278-6133.24.3.327>

Cohn, R. J., Goodenough, B., Foreman, T., & Suneson, J. (2003). Hidden Financial Costs in Treatment for Childhood Cancer : An Australian study of Lifestyle Implications for Families. *Journal of Paediatric Hematology/ Oncology*, 25(11), 854–863.

Colaizzi, P. F. (1978). *Psychological research as the phenomenologist views it* Sage.

Cook, M. B., Wang, Z., Yeboah, E. D., Tettey, Y., Richard, B., Chokkalingam, A. P., ... Hutchinson, A. (2014). A genome-wide association study of prostate cancer in West African men. *Human Genetics*, 133(5), 509–521. <https://doi.org/10.1007/s00439-013-1387-z>

Couper, J., Bloch, S., Love, A., Macvean, M., Duchesne, G. M., & Kissane, D. (2006). Psychosocial Adjustment of Female Partners of Men with Prostate Cancer. *Psycho-Oncology*, 15(11), 937–953. <https://doi.org/10.1002/pon.1031>

Coyne, E. (2013). The strengths and resources used by families of young women with breast cancer. *Australian Journal of Cancer Nursing*, 14(2), 10–16.

Coyne, E., Wollin, J., & Creedy, D. K. (2012). Exploration of the family's role and strengths after a young woman are diagnosed with breast cancer: Views of women and their families. *European Journal of Oncology Nursing*, 16(2), 124–130. <https://doi.org/10.1016/j.ejon.2011.04.013>

Creswell, J. W. (2014). *Research design: International student edition*. Sage.

Creswell, J. W., & Creswell, J. D. (2017). *Research design: Qualitative, quantitative, and mixed methods approach*. Sage publications.

Creswell, J. W., & Plano Clark, V. L. (2017). *Designing and conducting mixed methods research*. Sage publications.

Cutillo, A., Reynolds, N., & Madan-swain, A. (2015). Music Therapy and Coping in Caregivers of Children with Cancer. *Annals of Pediatrics & Child Health*, 3(5), 25–27.

Davidson, K. (2002). Gender differences in new partnership choices and constraints for older widows and widowers. *Ageing International*, 27(4), 43–60.

Davis, M. H. (1994). *Empathy: A social psychological perspective*. Madison, WI: Brown and Benchmark.

Delicado Useros, M. V., Espín, A. A., Parra, E. C., & Martínez, A. B. (2012). Family Caregivers : Nurses ' Perceptions and Attitudes. *Social Medicine*, 6(3), 151–161. Retrieved from <http://www.socialmedicine.info/index.php/socialmedicine/article/view/609/1206>

Denberg, T. D., Beaty, B. L., Kim, F. J., & Steiner, J. F. (2005). Marriage and ethnicity predict treatment in localized prostate carcinoma. *Cancer*, 103(9), 1819–1825. <https://doi.org/10.1002/cncr.20982>

Dennis, L. K., & Dawson, D. V. (2002). A meta-analysis of measures of sexual activity and prostate cancer. *Epidemiology*, *13*(1), 72–79. <https://doi.org/10.1097/00001648-200201000-00012>

Denzin, N. K. (2013). *Interpretive autoethnography*. (Vol. 17). Sage publications.

Doumit, M. A., Huijer, H. A., Kelley, J. H., & Nassar, N. (2008). The Lived Experience of Lebanese Family Caregivers of Cancer Patients. *Journal of Cancer Nursing*, *31*(4), E36–E42.

Driessnack, M., Sousa, V. D., & Mendes, I. A. C. (2007). An overview of research designs relevant to nursing: part 2: qualitative research designs. *Revista Latino-Americana de Enfermagem*, *15*(4), 684–688. <https://doi.org/10.1590/S0104-11692007000400025>.

Eaton, P. M., Davis, B. L., Hammond, P. V., Condon, E. H., & McGee, Z. T. (2011). Coping Strategies of Family Members of Hospitalized Psychiatric Patients. *Nursing Research and Practice*, *2011*, 1–12. <https://doi.org/10.1155/2011/392705>.

Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology*, *13*(8), 562–576. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed6&NEWS=N&AN=2004371138>.

Egote, A., Ossei, P., Quarshie, E., & Taylor, J. (2018). Age as a risk factor for prostate diseases : A 6-year selective prospective study among males in the Brong Ahafo region of Ghana. *Journal of Medical Research*, *4*(3), 154–157.

Ellis, J., Lloyd Williams, M., Wagland, R., Bailey, C., & Molassiotis, A. (2013). Coping with and factors impacting upon the experience of lung cancer in patients and primary carers. *European Journal of Cancer Care*, 22(1), 97–106. <https://doi.org/10.1111/ecc.12003>

Englander, M. (2012). The interview: Data collection in descriptive phenomenological human scientific research. *Journal of Phenomenological Psychology*, 43(1), 13–35. <https://doi.org/10.1163/156916212X632943>

Eriksson, E., & Lauri, S. (2000). Informational and emotional support for cancer patients' relatives. *European Journal of Cancer Care*, 9(1), 8–15. <https://doi.org/10.1046/j.1365-2354.2000.00183.x>

Ervik, B., Nordøy, T., & Asplund, K. (2013). In the Middle and on the Sideline The Experience of Spouses of Men With Prostate Cancer. *Cancer Nursing*, 36(3), E7–E14. <https://doi.org/10.1097/NCC.0b013e31824fe1ef>

Esbensen, B. A., & Thomé, B. (2010). Being next of kin to an elderly person with cancer. *Scandinavian Journal of Caring Sciences*, 24(4), 648–654. <https://doi.org/10.1111/j.1471-6712.2009.00756.x>

Etemadifar, S., Bahrami, M., Shahriari, M., & Farsani, A. K. (2014). The effectiveness of a supportive educative group intervention on family caregiver burden of patients with heart failure. *Iranian Journal of Nursing and Midwifery Research*, 19(3), 217.

Evans, S., Metcalfe, C., Patel, B., Ibrahim, F., Anson, K., Chinegwundoh, F., ... Ben-Shlomo, Y. (2010). Clinical presentation and initial management of Black men and White men with prostate cancer in the United Kingdom: The

PROCESS cohort study. *British Journal of Cancer*, 102(2), 249–254.
<https://doi.org/10.1038/sj.bjc.6605461>

Fagnäs, S., & Odame, J. (2013). Birth registration and access to health care: An assessment of Ghana's campaign success. *Bulletin of the World Health Organization*, 91(6), 459–464. <https://doi.org/10.2471/BLT.12.111351>

Family Caregiver Alliance. (2016). Caregiver Statistics: Work and Caregiving | Family Caregiver Alliance. Retrieved July 4, 2019, from <https://www.caregiver.org/caregiver-statistics-work-and-caregiving>.

Farmer, P., Frenk, J., Knaul, F. M., Shulman, L. N., Alleyne, G., Armstrong, L., ... Seffrin, J. R. (2010). Expansion of cancer care and control in countries of low and middle income: A call to action. *The Lancet*, 376(9747), 1186–1193. [https://doi.org/10.1016/S0140-6736\(10\)61152-X](https://doi.org/10.1016/S0140-6736(10)61152-X)

Faulkner, L., & Trotter, P. S. (2017). Data Saturation. In *The International Encyclopedia of Communication Research Methods* (pp. 1–2). John Wiley & Sons, Inc. <https://doi.org/10.1177/1468794107085301>

Fergus, K. D., & Gray, R. E. (2009). Relationship vulnerabilities during breast cancer: Patient and partner perspectives. *Psycho-Oncology*, 18(12), 1311–1322. <https://doi.org/10.1002/pon.1555>

Ferrans, C. E. (1996). Development of a conceptual model of quality of life. *Scholarly Inquiry for Nursing Practice*, 10(3), 293–304. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9009823>

Ferrell, B. (2017). A Review of Family Caregiving Intervention Trials in Oncology. *Journal for Clinicians*, 67, 318–325. <https://doi.org/10.3322/caac.21396>.

Ferrell, B., Dow, K. H., & Grant, M. (1995). Measurement of Quality of Life in Cancer survivors. *Quality of Life Research*, 4(6), 523–531.

Ferrell, B. R., Wisdom, C., & Wenzl, C. (1989). Quality of life as an outcome variable in the management of cancer pain. *Cancer*, 63(11), 2312–2327.

Figley, C. R., & McCubbin, H. I. (2016). *Stress and the family: Coping with catastrophe*. Routledge.

Fitzell, A., & Pakenham, K. I. (2010). Application of a stress and coping model to caregiving in multiple sclerosis. *Psychology, Health and Medicine*, 6(1), 13–27. <https://doi.org/10.1080/13548500125141>

Fitzmaurice, C., Akinyemiju, T. F., Al Lami, F. H., Alam, T., Alizadeh-Navaei, R., Allen, C., ... Naghavi, M. (2018). Global, Regional, and National Cancer Incidence, Mortality, Years of Life Lost, Years Lived With Disability, and Disability-Adjusted Life-Years for 29 Cancer Groups, 1990 to 2016: a systematic analysis for the global burden of disease study. *JAMA Oncology*, 4(11), 1553–1568. <https://doi.org/10.1001/jamaoncol.2018.2706>.

Fletcher, B. A. S., Schumacher, K. L., Dodd, M., Paul, S. M., Cooper, B. A., Lee, K., ... Miaskowski, C. (2009). Trajectories of fatigue in family caregivers of patients undergoing radiation therapy for prostate cancer. *Research in Nursing and Health*, 32(2), 125–139. <https://doi.org/10.1002/nur.20312>

Folkman, S., Lazarus, R. S., Dunkel-schetter, C., DeLongis, A., & Gruen, R. J. (1986). Dynamics of a Stressful Encounter : Cognitive Appraisal, Coping, and Encounter Outcomes. *Journal of Personality and Social Psychology*, 50(5), 992–1003.

Freeman, M. (2011). Validity in Dialogic Encounters With Hermeneutic Truths. *Qualitative Inquiry*, 17(6), 543–551. <https://doi.org/10.1177/1077800411409887>.

Fujinami, R., Sun, V., Zachariah, F., Uman, G., Grant, M., & Ferrell, B. (2015).

Family caregivers' distress levels related to the quality of life, burden, and preparedness. *Psycho-Oncology*, 24(1). <https://doi.org/10.1002/pon.3562>

Geng, H., Chuang, D., Yang, F., Yang, Y., Liu, W., Liu, L., & Tian, H. (2018).

Prevalence and determinants of depression in caregivers of cancer patients. *Medicine*, 97(39), e11863. <https://doi.org/10.1097/md.00000000000011863>

Ghana Statistical Service. (2013). *2010 POPULATION & HOUSING CENSUS: National Analytical Report*. Ghana Statistic Service.

Gilligan, T. (2005). Social Disparities and Prostate Cancer : Mapping the Gaps in Our Knowledge. *Cancer Causes & Control*, 16(1), 45–53.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Duquesne University Press.

Giorgi, A. (2011). IPA and science: A response to Jonathan Smith. *Journal of Phenomenological Psychology*, 42(2), 195–216. <https://doi.org/10.1163/156916211X599762>

Given, B. A., Sherwood, P., & Given, C. W. (2011). Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiology Biomarkers and Prevention*, 20(10), 2015–2021. <https://doi.org/10.1158/1055-9965.EPI-11-0611>.

Glajchen, M. (2012). Physical Well-Being of Oncology Caregivers: An Important Quality-of-Life Domain. *Seminars in Oncology Nursing*, 28(4), 226–235. <https://doi.org/10.1016/j.soncn.2012.09.005>.

Glanz, K., Rimer, B., & Lewis, F. (2002). The theory of reasoned action and the theory of planned behaviour. *Health Behaviour and Health Edification: Theory Research and Practices*, 67–98.

Glaser, B., & Strauss, A. L. (2017). *Discovery of grounded theory: Strategies for qualitative research*. Routledge.

Glaser, R., & Kiecolt-glaser, J. K. (2005). Stress-induced immune dysfunction: health implications. *Nature Reviews Immunology*, 5(3), 243.

Gleitman, H., Fridlund, A. J., & Reisberg, D. (2000). *Basic Psychology*. (5th ed.). New York, NY: W. W. Norton & Company, Inc.

Goldsmith, J., Wittenberg, E., Platt, C. S., Iannarino, N. T., & Reno, J. (2016). Family caregiver communication in oncology: Advancing a typology. *Psycho-Oncology*, 25(4), 463–470. <https://doi.org/10.1002/pon.3862>.

Hagedoorn, M., Sanderman, R., Bolks, H. N., Tuinstra, J., & Coyne, J. C. (2008). Distress in couples coping with cancer: a meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134(1), 1–30. <https://doi.org/10.1037/0033-2909.134.1.1>

Hamilton, W., & Sharp, D. (2004). Symptomatic diagnosis of prostate cancer in primary care: a structured review. *British Journal of General Practice*, 54(505), 617–621.

Harandy, T. F., Ghofranipour, F., Montazeri, A., Anoosheh, M., Bazargan, M., Mohammadi, E., ... Niknami, S. (2009). Muslim breast cancer survivor spirituality: Coping strategy or health-seeking behaviour hindrance? *Health Care for Women International*, 31(1), 88–98. <https://doi.org/10.1080/07399330903104516>

Hassan, Z. A., Schattner, P., & Mazza, D. (2006). Research Notes Doing A Pilot Study: Why Is It Essential? *Malaysian Family Physician*, 1(1&2), 70–73.

Hawkins, Y., Ussher, J., Gilbert, E., Perz, J., Sandoval, M., & Sundquist, K. (2009). Changes in Sexuality and Intimacy After the Diagnosis and Treatment of Cancer. *Cancer Nursing*, 32(4), 271–280.

Hilton, B. A., Crawford, J. A., & Tarko, M. A. (2000). Men's perspectives on individual and family coping with their wives' breast cancer and chemotherapy. *Western Journal of Nursing Research*, 22(4), 438–459. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed5&NEWS=N&AN=10826253>.

Ho, S. M. Y., Saltel, P., Machavoine, J., Rapoport-hubschman, N., & Spiegel, D. (2004). Cross-Cultural Aspects of Cancer Care. In *Cancer, culture, and communication* (pp. 157–158). Boston, MA.: Springer.

Hodges, L. J., Humphris, G. M., & Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social Science and Medicine*, 60(1), 1–12. <https://doi.org/10.1016/j.socscimed.2004.04.018>.

Hodgkinson, K., Butow, P., Fuchs, A., Hunt, G. E., Stenlake, A., Hobbs, K. M., ...

Wain, G. (2007). Long-term survival from gynecologic cancer: Psychosocial outcomes, supportive care needs and positive outcomes. *Gynecologic Oncology*, *104*(2), 381–389. <https://doi.org/10.1016/j.ygyno.2006.08.036>

Hu, F. B. (2003). 'Sedentary lifestyle and risk of obesity and type 2 diabetes', *Lipids*, *38*(2), pp. 103–108. d type 2 diabetes. *Lipids*, *38*(2), 103–108.

Institute of Medicine. (2010). The Future of Nursing Focus on Education. *The Institute of Medicine of National Academy of Sciences*, (October), 1–8. Retrieved from [http://www.iom.edu/~media/Files/Report Files/2010/The-Future-of-Nursing/Nursing Education 2010 Brief.pdf](http://www.iom.edu/~media/Files/Report%20Files/2010/The-Future-of-Nursing/Nursing%20Education%202010%20Brief.pdf)

Jacob, S. A., & Furgerson, S. P. (2012). Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report*, *17*(42), 1–10.

Karabulutlu, E. Y. (2014). Coping with the stress of family caregivers of cancer patients in Turkey. *Journal of Oncology Nursing*, *1*(1), 55–60. <https://doi.org/10.4103/2347-5625.135822>

Katbamna, S., Ahmad, W., Bhakta, P., Baker, R., & Parker, G. (2004). Do they look after their own? Informal support for South Asian carers. *Health and Social Care in the Community*, *12*(5), 398–406. <https://doi.org/10.1111/j.1365-2524.2004.00509.x>

Kelly, M. M., Tyrka, A. R., Price, L. H., & Carpenter, L. L. (2008). Sex differences in the use of coping strategies: Predictors of anxiety and depressive symptoms.

Depression and Anxiety, 25(10), 839–846. <https://doi.org/10.1002/da.20341>

Khan, J. A. (2012). *Research Methodology*. New Delhi: A P H Publishing.

Kim, Y., Baker, F., & Spillers, R. L. (2007). Cancer Caregivers' Quality of Life: Effects of Gender, Relationship, and Appraisal. *Journal of Pain and Symptom Management*, 34(3), 294–304. <https://doi.org/10.1016/j.jpainsymman.2006.11.012>

Kim, Y., Baker, F., Spillers, R. L., & Wellisch, D. K. (2006). Psychological adjustment of cancer caregivers with multiple roles. *Psycho-Oncology*, 15(9), 795–804. <https://doi.org/10.1002/pon.1013>

Kim, Y., & Given, B. A. (2008). Quality of life of family caregivers of cancer survivors. *Cancer*, 112(S11), 2556–2568. <https://doi.org/10.1002/cncr.23449>

Kimberlin, C., Brushwood, D., Allen, W., Radson, E., & Wilson, D. (2004). Cancer Patient and Caregiver Experiences : Communication and Pain Management Issues. *Journal of Pain and Symptom Management*, 28(6), 566–578. <https://doi.org/10.1016/j.jpainsymman.2004.03.005>

Kimura, T., & Egawa, S. (2018). Epidemiology of prostate cancer in Asian countries. *International Journal of Urology*, 25(6), 524–531. <https://doi.org/10.1111/iju.13593>

Kimura, T., & Egawa, S. (2018). Epidemiology of prostate cancer in Asian countries. *International Journal of Urology*, 25(6), 524–531. <https://doi.org/10.1111/iju.13593>

Kimura, T., & Egawa, S. (2018). Epidemiology of prostate cancer in Asian countries. *International Journal of Urology*, 25(6), 524–531. <https://doi.org/10.1111/iju.13593>

Kimura, T., & Egawa, S. (2018). Epidemiology of prostate cancer in Asian countries. *International Journal of Urology*, 25(6), 524–531. <https://doi.org/10.1111/iju.13593>

Klaassen, Z., Jen, R. P., Dibianco, J. M., Reinstatler, L., Li, Q., Madi, R., ... Terris, M. K. (2015). Factors associated with suicide in patients with genitourinary malignancies. *Cancer*, *121*(11), 1864–1872. <https://doi.org/10.1002/cncr.29274>.

Ko, C. M., Malcarne, V. L., Varni, J. W., Roesch, S. C., Banthia, R., Greenbergs, H. L., & Sadler, G. R. (2005). Problem-solving and distress in prostate cancer patients and their spousal caregivers. *Supportive Care in Cancer*, *13*(6), 367–374. <https://doi.org/10.1007/s00520-004-0748-5>

Korb, A. K. (2012). Conducting educational research. Retrieved April 11, 2019, from <http://korbedpsych.com/R05Population.html>

Krohne, H. W. (2002). Stress and coping theories. *International Encyclopedia of the Social Behavioural Sciences*, *22*, 15163-15170.

Kuan Lee Wai, J. (2016). *Cancer and the Family: Distress and Quality of Life among Chinese speaking patients and family caregivers*. The University of British Columbia. Retrieved from <https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0319081>

Kumado, K., & Gockel, A. F. (2003). *A Study on Social Security in Ghana*. Legon: University of Ghana.

Kusi, H. (2012). *Doing Qualitative research- A guide for researchers*. Accra-New Town: Emmpong Press.

Kyei-Arthur, F. (2013). *Physical And Mental Health Outcomes Of Caregiving In Accra*. *Annals Of Tropical Paediatrics*. The University Of Ghana. <https://doi.org/10.1080/02724936.1987.11748497>

Kyei, M. Y., Klufio, G. O., Ayamba, A., & Mohammed, S. (2017). Traditional medicines and alternative practice in the management of prostate diseases in southern Ghana. *Ghana Medical Journal*, *51*(3), 128–137.

La Vecchia, C., Franceschi, S., Talamini, R., Negri, E., Boyle, P., & Irois, C. O. N. (1993). Marital status, indicators of sexual activity and prostatic cancer. *Journal of Epidemiology and Community Health*, *47*, 450–453.

Lai, H. L., Li, Y. M., & Lee, L. H. (2012). Effects of music intervention with nursing presence and recorded music on psycho-physiological indices of cancer patient caregivers. *Journal of Clinical Nursing*, *21*(5–6), 745–756. <https://doi.org/10.1111/j.1365-2702.2011.03916.x>

Lambert, S. D., Bowe, S. J., Livingston, P. M., Heckel, L., Cook, S., Kowal, P., & Orellana, L. (2017). Impact of informal caregiving on older adults' physical and mental health in low-income and middle-income countries: A cross-sectional, secondary analysis based on the WHO's Study on global AGEing and adult health (SAGE). *BMJ Open*, *7*(11), 1–14. <https://doi.org/10.1136/bmjopen-2017-017236>.

Lau, D. T., Berman, R., Halpern, L., Pickard, A. S., Schrauf, R., & Witt, W. (2010). Exploring Factors that Influence Informal Caregiving in Medication Management for Home Hospice Patients. *Journal of Palliative Medicine*, *13*(9), 1085–1090. <https://doi.org/10.1089/jpm.2010.0082>

Lazarus, R., & Folkman, S. (1984). *Stress Management - Part 1 - Stress and Health. Appraisal, and coping*. Retrieved from [https://ccme.osu.edu/ WebCasts Files/562The Management of Stress - 2.pdf](https://ccme.osu.edu/WebCasts/Files/562The%20Management%20of%20Stress%20-%202.pdf)

Lazarus, R. S. (1993). Coping theory and research: Past, present, and future. *Psychosomatic Medicine*, 55(3), 234–247. <https://doi.org/10.1097/00006842-199305000-00002>

Lee, M. Der. (2007). Correlates of consequences of intergenerational caregiving in Taiwan. *Journal of Advanced Nursing*, 59(1), 47–56. <https://doi.org/10.1111/j.1365-2648.2007.04274.x>

Lee, J., & Bell, K. (2011). The Impact of Cancer on Family Relationships Among Chinese Patients. *Journal of Transcultural Nursing*, 22(3), 225–234. <https://doi.org/10.1177/1043659611405531>

LeSeure, P., & Chongkham-Ang, S. (2015). The experience of caregivers living with cancer patients: A systematic review and meta-synthesis. *Journal of Personalized Medicine*, 5(4), 406–439. <https://doi.org/10.3390/jpm5040406>

Lessick, M., & Katz, A. (2006). A genetics perspective on prostate cancer. *Journal of Urologic Nursing*, 26(6), 454-460.

Lethborg, C. E., Kissane, D., & Burns, W. I. (2003). Social Work in Health Care The Impact of Organizational Change on Social Work Staffing in a Hospital Setting The Impact of Organizational Change on Social Work Staffing in a Hospital Setting : A National, Longitudinal Study of Social Work in Hospitals. *Social Work in Health Care*, 37(1), 63–85. <https://doi.org/10.1300/J010v37n01>

Li, H. (2004). Barriers to and Unmet Needs for Supportive Services: Experiences of Asian-American Caregivers. *Journal of Cross-Cultural Gerontology*, 19(3), 241–260.

Li, Q., & Loke, A. Y. (2014). A literature review on the mutual impact of the spousal caregiver-cancer patients dyads: “Communication”, “reciprocal influence”, and “caregiver-patient congruence.” *European Journal of Oncology Nursing*, 18(1), 58–65. <https://doi.org/10.1016/j.ejon.2013.09.003>.

Li, Q. P., Mak, Y. W., & Loke, A. Y. (2013). Spouses’ experience of caregiving for cancer patients: A literature review. *International Nursing Review*, 60(2), 178–187. <https://doi.org/10.1111/inr.12000>

Lian, H., Zhuang, J., Yang, R., Qu, F., Wang, W., Lin, T., & Guo, H. (2016). Focal cryoablation for unilateral low-intermediate-risk prostate cancer: 63-month mean follow-up results of 41 patients. *International Urology and Nephrology*, 48(1), 85–90. <https://doi.org/10.1007/s11255-015-1140-8>

Limburg, H., Shaw, A. K., & McBride, M. L. (2008). Impact of Childhood Cancer on Parental Employment and Sources of Income : A Canadian Pilot Study. *Pediatric Blood Cancer*, 51(1), 93–98. <https://doi.org/10.1002/pbc>

Lincoln, Y. S., & Guba, E. G. (1985). Establishing trustworthiness. *Naturalistic Inquiry*, 289, 331.

Lindlof, T. R., & Taylor, B. C. (2002). Asking, listening, and telling; and Qualitative analysis and interpretation. *Qualitative Communication Research Methods*, 170–246.

Liu, J.E., Mok, E., & Wong, T. (2005). Perceptions of supportive communication in Chinese patients with cancer: Experiences and expectations. *Journal of Advanced Nursing*, 52(3), 262–270. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed7&NEWS=N&AN=161941>

79

Liu, Y., Xia, Q., Xia, J., Zhu, H., Jiang, H., Chen, X., ... Li, S. (2018). The impact of marriage on the overall survival of prostate cancer patients: A Surveillance, Epidemiology, and End Results (SEER) analysis. *Canadian Urological Association Journal*, 13(5), 135–139. <https://doi.org/10.5489/cuaj.5413>

Lobchuk, M. M., McClement, S. E., McPherson, C. J., & Cheang, M. (2012). Impact of Patient Smoking Behavior on Empathic Helping by Family Caregivers in Lung Cancer. *Oncology Nursing Forum*, 39(2), E112–E121. <https://doi.org/10.1188/12.onf.e112-e121>

LoBiondo-Wood, G., & Haber, J. (2010). *Nursing Research: Methods and Critical Appraisal for Evidence-Based Practice*. Mosby.

Lopez, V., Copp, G., & Molassiotis, A. (2012). Male Caregivers of Patients With Breast and Gynaecologic cancer. *Cancer Nursing*, 35(6), 402–410. <https://doi.org/10.1097/NCC.0b013e318231daf0>

Lovell, B., & Wetherell, M. A. (2011). Neuroscience and Biobehavioral Reviews The cost of caregiving: Endocrine and immune implications in elderly and non-elderly caregivers. *Neuroscience and Biobehavioral Reviews*, 35(6), 1342–1352. <https://doi.org/10.1016/j.neubiorev.2011.02.007>.

Lui, C., & Ip, D. (2009). Ethnic Experience of Cancer : A Qualitative Study of Chinese – Australians in Brisbane, Queensland. *Social Work in Health Care*, 48(1), 14–37.

MacKenzie, A., & Greenwood, N. (2012). Positive experiences of caregiving in stroke: A systematic review. *Disability and Rehabilitation*, 34(17), 1413–1422. <https://doi.org/10.3109/09638288.2011.650307>

Magill, L. (2009). Caregiver empowerment and music therapy: Through the eyes of bereaved caregivers of advanced cancer patients. *Journal of Palliative Care*, 25(1), 68–75. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed9&NEWS=N&AN=19445344>

Marfo-Amankwah, J. (2016). *Trends In Cancer Cases And Morphine Prescription At The Korle-Bu Teaching Hospital*. The University Of Ghana. <https://doi.org/10.1038/253004b0>

Marguerite, S., Laurent, B., Marine, A., Tanguy, L., Karine, B., Pascal, A., & Xavier, Z. (2017). Actor-partner interdependence analysis in depressed patient-caregiver dyads: Influence of emotional intelligence and coping strategies on anxiety and depression. *Psychiatry Research*, 258(August), 396–401. <https://doi.org/10.1016/j.psychres.2017.08.082>

Maxwell, J. (2013). Applied social research methods series: Vol. 4. *Qualitative Research Design: An Interactive Approach*, 3.

Mazaheri, M., Eriksson, L. E., Heikkilä, K., Nasrabadi, A. N., Ekman, S. L., & Sunvisson, H. (2013). Experiences of living with dementia: Qualitative content analysis of semi-structured interviews. *Journal of Clinical Nursing*, 22(21–22), 3032–3041. <https://doi.org/10.1111/jocn.12275>

Mazanec, S., Reichlin, D., Gittleman, H., & Daly, B. (2018). Perceived Needs, Preparedness, and Emotional Distress of Male Caregivers of Postsurgical Women With Gynecologic Cancer. *Oncology Nursing Forum*, 45(2), 197–205. <https://doi.org/10.1188/18.onf.197-205>

McConnell, D., Clarke, S., Butow, P., Smith, C., & Sharpe, L. (2004). The relationship between available support, unmet needs and caregiver burden in patients with advanced cancer and their carers. *Psycho-Oncology*, 14(2), 102–114. <https://doi.org/10.1002/pon.825>

McCubbin, L. D., & McCubbin, H. I. (2013). *Resilience in Ethnic Family Systems: A Relational Theory for Research and Practice*. *Handbook of Family Resilience*. New York, NY: Springer. <https://doi.org/10.1007/978-1-4614-3917-2>

McWilliam, C. L., Brown, J. B., & Stewart, M. (2000). Breast cancer patients' experiences of patient-doctor communication: A working relationship. *Patient Education and Counseling*, 39(2–3), 191–204. [https://doi.org/10.1016/S0738-3991\(99\)00040-3](https://doi.org/10.1016/S0738-3991(99)00040-3)

Mellon, S., & Northouse, L. L. (2006). A Population-Based Study of the Quality of Life of Cancer Survivors and Their Family Caregivers. *Cancer Nursing*, 29(2), 2–12.

Mendez-luck, C. A., Kennedy, D. P., & Wallace, S. P. (2009). Social Science & Medicine Guardians of health : The dimensions of elder caregiving among women in a Mexico City neighbourhood. *Social Science & Medicine*, 68(2), 228–234. <https://doi.org/10.1016/j.socscimed.2008.10.026>

Miedema, B., Easley, J., Fortin, P., Hamilton, R., & Mathews, M. (2008). The economic impact on families when a child is diagnosed with cancer. *Current Oncology*, 15(4), 173–178.

Monin, J. K., Levy, B., Doyle, M., Schulz, R., & Kershaw, T. (2017). The impact of both spousal caregivers ' and care recipients ' health on relationship satisfaction in the Caregiver Health Effects Study. *Journal of Health Psychology*, 1359105317699682.

Montano, D., & Kasprzyk, D. (2015). Theory of reasoned action, theory of planned behaviour, and the integrated behavioural model. *Health Behavior: Theory, Research and Practice*, 70(4), 231.

Morris, M. E., Grant, M., & Lynch, J. C. (2007). Patient-reported Family Distress Among Long-term Cancer Survivors. *Cancer Nursing*, 30(1), 1–8.

Morse, J., & Richards, L. (2002). The integrity of qualitative research. In *Read me first for a user's guide to a qualitative method*. (pp. 23–41). California: Sage.

Mosher, C. E., Bakas, T., & Champion, V. L. (2013). Physical Health, Mental Health, and Life Changes Among Family Caregivers of Patients With Lung Cancer. *Oncology Nursing Forum*, 40(1), 53–61. <https://doi.org/10.1188/13.onf.53-61>.

Mosher, C. E., Champion, V. L., Azzoli, C. G., Hanna, N., Jalal, S. I., Fakiris, A. J., ... Ostroff, J. S. (2013). Economic and social changes among distressed family caregivers of lung cancer patients. *Support Care Cancer*, 21(3), 819–826. <https://doi.org/10.1007/s00520-012-1585-6>

Mosher, C. E., Ott, M. A., Hanna, N., Jalal, S. I., & Champion, V. L. (2015). Coping with physical and psychological symptoms: a qualitative study of advanced lung cancer patients and their family caregivers. *Supportive Care in Cancer*, 23(7), 2053–2060. <https://doi.org/10.1007/s00520-014-2566-8>

Mselle, L., Evjen-Olsen, B., Moland, K., Mvungi, A., & Wankuru Kohi, T. (2012). “Hoping for a Normal Life Again”: Reintegration After Fistula Repair in Rural Tanzania. *Journal of Obstetrics and Gynaecology Canada*, 34(10), 927–938. [https://doi.org/10.1016/S1701-2163\(16\)35406-8](https://doi.org/10.1016/S1701-2163(16)35406-8)

Munro, S., Lewin, S., Swart, T., & Volmink, J. (2007). A review of health behaviour theories: How useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*, 7(1), 104. <https://doi.org/10.1186/1471-2458-7-104>

Murphy, N. A., Christian, B., Caplin, D. A., & Young, P. C. (2007). The health of caregivers for children with disabilities: caregiver perspectives. *Journal of Child Care, Health and Development*, 33(2), 180–187. <https://doi.org/10.1111/j.1365-2214.2006.00644.x>

Nayak, M. G., George, A., & Vidyasagar, M. S. (2018). Perceived Barriers to Symptoms Management among Family Caregivers of Cancer Patients. *Indian Journal of Palliative Care*, 24(2), 202–206. https://doi.org/10.4103/IJPC.IJPC_27_18.

Nemati, S., Rassouli, M., Ilkhani, M., & Baghestani, A. R. (2018a). Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scandinavian Journal of Caring Sciences*, 32(1), 309–316. <https://doi.org/10.1111/scs.12463>

Nemati, S., Rassouli, M., Ilkhani, M., & Baghestani, A. R. (2018b). Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scandinavian Journal of Caring Sciences*, 32(1), 309–316. <https://doi.org/10.1111/scs.12463>

Newell, G. R., Pollack, E. S., Spitz, M. R., Sider, J. G., & Fueger, J. J. (1987). Incidence of Prostate Cancer and Marital Status. *Journal of the National Cancer Institute*, 79(2), 259–262. <https://doi.org/10.1093/jnci/79.2.259>

Nicholson, N. R. (2009). Social isolation in older adults : an evolutionary concept analysis. *Journal of Advanced Nursing*, 65(6), 1342–1352. <https://doi.org/10.1111/j.1365-2648.2008.04959.x>

Northouse, L. L. (1995). The impact of cancer in women on the family. *Cancer Practice*, 3(3), 134–142.

Northouse, L., Templin, T., & Mood, D. (2001). Couples' Adjustment to Breast Disease during the First Year Following Diagnosis. *Journal of Behavioral Medicine*, 24(2), 115–136. <https://doi.org/10.1023/A:1010772913717>

Northouse, Laurel L., Katapodi, M. C., Song, L., Zhang, L., & Mood, D. W. (2010).

Interventions with Family Caregivers of Cancer Patients: Meta-Analysis of Randomized Trials. *Cancer Journal for Clinicians*, 60(5), 317–339. <https://doi.org/10.3322/caac.20081>

O'Brien, M., Mwangi-Powell, F., Adewole, I. F., Soyannwo, O., Amandua, J., Ogaja, E., ... Merriman, A. (2013). Improving access to analgesic drugs for patients with cancer in sub-Saharan Africa. *The Lancet Oncology*, 14(4), e176–e182. [https://doi.org/10.1016/S1470-2045\(12\)70343-1](https://doi.org/10.1016/S1470-2045(12)70343-1)

O'Kelly, J. (2014). Saying it in song: music therapy as a carer support intervention. *International Journal of Palliative Nursing*, 14(6), 281–286. <https://doi.org/10.12968/ijpn.2008.14.6.30023>

Obiri Yeboah, K. Y. (2018). Prostate cancer, a frightening disease - Today Newspaper. Retrieved September 18, 2018, from <https://www.todaygh.com/prostate-cancer-frightening-disease/>

Obu, R. (2014a). Investigating The Impact Of A Healthy Relationship On Ghanaian Men Diagnosed With Prostate Cancer And Cultural Issues In Ghana-A Discussion Paper On The Physical And Psychosocial Effects Of The Disease And Its Treatment. *Global Journal of Environmental Sciences and Technology*, 1(1), 001–007.

Obu, R. (2014b). Prostate Cancer Incidence Rates In Ghana: The Way Forward! Retrieved September 26, 2018, from <https://www.modernghana.com/lifestyle/5288/prostate-cancer-incidence-rates-in-ghana-the-way-forward.html>

Obu, R. (2015). *The impact of alternative medicine in Ghanaian men of African descent diagnosed with prostate cancer*. Indian Board of Alternative Medicine, Kolkata, India.

Ofori, M. (2017). *Experiences of Spouses of Men with Advanced Prostate Cancer in the Accra Metropolis (Doctoral dissertation, University of Ghana)*. University of Ghana, Legon. Retrieved from [http://ugspace.ug.edu.gh/bitstream/handle/123456789/23491/Experiences of Spouses of Men with Advanced Prostate Cancer in the Accra Metropolis.pdf?sequence=1&isAllowed=y](http://ugspace.ug.edu.gh/bitstream/handle/123456789/23491/Experiences%20of%20Spouses%20of%20Men%20with%20Advanced%20Prostate%20Cancer%20in%20the%20Accra%20Metropolis.pdf?sequence=1&isAllowed=y)

Ogunsanya, M. E., Brown, C. M., Odedina, F. T., Barner, J. C., Adedipe, T. B., & Corbell, B. (2017). Knowledge of Prostate Cancer and Screening Among Young Multiethnic Black Men. *American Journal of Men's Health*, 11(4), 1008–1018. <https://doi.org/10.1177/1557988316689497>.

Oluwole, O. P., Rafindadi, A. H., Shehu, M. S., & Samaila, M. O. A. (2015). A ten-year study of prostate cancer specimens at Ahmadu Bello University Teaching Hospital (A.B.U.T.H), Zaria, Nigeria. *African Journal of Urology*, 21(1), 15–18. <https://doi.org/10.1016/j.afju.2014.09.004>

OncoLink. (2016). Caregiving: Roles and Tasks. Retrieved January 22, 2019, from <https://www.oncolink.org/support/caregivers/caregiving-roles-and-tasks>

Otis-Green, S., & Juarez, G. (2012). Enhancing the Social Well-Being of Family Caregivers. In *Seminars in Oncology Nursing* (Vol. 28, pp. 246–255). WB Saunders. <https://doi.org/10.1158/0008-5472.CAN-10-4002.BONE>.

Otoo, V. (2010). *Awareness of Prostate Cancer Among Male Soldiers In Ghana Armed Forces*. University of Ghana, Legon. Retrieved from [http://ugspace.ug.edu.gh/bitstream/handle/123456789/21711/Awareness of Prostate Cancer among Male Soldiers in the Ghana Armed Forces_2010.pdf?sequence=1](http://ugspace.ug.edu.gh/bitstream/handle/123456789/21711/Awareness_of_Prostate_Cancer_among_Male_Soldiers_in_the_Ghana_Armed_Forces_2010.pdf?sequence=1)

Padilla, G. V., & Grant, M. M. (1985). Quality of life as a cancer nursing outcome variable. *ANS. Advances in Nursing Science*, 8(1), 45–60. <https://doi.org/10.1097/00012272-198510000-00007>

Patterson, J. M. (2002). Integrating Family Resilience and Family Stress Theory. *Source: Journal of Marriage and Family*, 64(2), 349–360.

Patton, M. Q. (2002). *Qualitative research and evaluation methods. Thousand Oaks.*

Penner, J. L., & McClement, S. (2012). Family Members' Experiences Caring for Patients With Advanced Head and Neck Cancer Receiving Tube Feeding: A Descriptive Phenomenological Study. *Journal of Pain and Symptom Management*, 44(4), 563–571. <https://doi.org/10.1016/j.jpainsymman.2011.10.016>

Pérez-Cruz, M., Parra-Anguita, L., López-Martínez, C., Moreno-Cámara, S., & del-Pino-Casado, R. (2019). Coping and Anxiety in Caregivers of Dependent Older Adult Relatives. *International Journal of Environmental Research and Public Health*, 16(9), 1651. <https://doi.org/10.3390/ijerph16091651>

Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: A review. *European Journal of Cancer*, 39(11), 1517–1524. [https://doi.org/10.1016/S0959-8049\(03\)00309-5](https://doi.org/10.1016/S0959-8049(03)00309-5)

Polit, D., & Beck, T. (2006). *Essentials of Nursing Research: Methods, Appraisal, and Utilization* (6th ed.). New York, NY: Lippincott Williams & Wilkins.

Rahman, S. (2017). The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language “ Testing and Assessment ” Research : A Literature Review. *Journal of Education and Learning*, 6(1), 2–12. <https://doi.org/10.5539/jel.v6n1p102>

Raveis, V. H., Karus, D., & Pretter, S. (2000). Correlates of Anxiety Among Adult Daughter Caregivers to a Parent with Correlates of Anxiety Among Adult Daughter Caregivers to a Parent with Cancer. *Journal of Psychosocial Oncology*, 17(3–4), 1–26. <https://doi.org/10.1300/J077v17n03>

Ray, M. (1994). *The richness of phenomenology: Philosophic, theoretic, and methodologic concerns. Critical issues in qualitative research methods.*

Redinbaugh, E. M., Baum, A., Tarbell, S., & Arnold, R. (2003). End-of-Life Caregiving : What Helps. *Journal Of Palliative Medicine*, 6(6), 2–9.

Reinhard, S. C., Given, B., Petlick, N. H., & Bemis, A. (2008). Supporting Family Caregivers in Providing Care. In. In Hughes RG, editor. *Patient Safety and Quality: An Evidence-Based Handbook for Nurses*. (pp. 341–404). Agency for Healthcare Research and Quality (US). Retrieved from <https://www.ncbi.nlm.nih.gov/books/NBK2665/>

Rha, S., Park, Y., Song, S., Lee, C., & Lee, J. (2015). Caregiving burden and the quality of life of family caregivers of cancer patients : the relationship and correlates. *European Journal of Oncology Nursing*, 19(4), 376–382. <https://doi.org/10.1016/j.ejon.2015.01.004>

- Ritchie, J., Lewis, J., Nicholls, C. M., & Ormston, R. (2014). *Qualitative research practice: A guide for social science students and researchers*. London.: Sage publications.
- Roberts, A. (2010). *Barriers preventing early detection of prostate cancer in Black African / Caribbean men living in Westminster. Westminster City Partner.*
- Rolland, J. S. (2005). Cancer and the Family: An Integrative Model. *Cancer* 2005;104(11), 104(11), 2584–2595. <https://doi.org/10.1002/cncr.21489>
- Rolland, J. S., & Walsh, F. (2006). Facilitating family resilience with childhood illness and disability. *Current Opinion in Pediatrics*, 18(5), 527–538. <https://doi.org/10.1097/01.mop.0000245354.83454.68>
- Rosenstock, I. M. (1974). Historical origins of the health belief model. *Health Education Monographs. Health Education Monographs*, 2(4), 328–335.
- Ross, A., & Sundaramurthi, Thiruppavai Bevens, M. (2014). A Labor of Love: The Influence of Cancer Caregiving on Health Behaviors. *Cancer Nursing*, 36(6), 474–483. <https://doi.org/10.1097/NCC.0b013e3182747b75.A>
- Ross, R. K., McCurtis, J. A., Henderson, B. E., MencK, H. R., Maack, T., & Martini, S. (1979). Descriptive Epidemiology Of Testicular And Prostatic. *British Journal of Cancer*, 39, 284–292.
- Rossi, A. S., & Rossi, P. H. (2018). *Of Human Bonding: Parent-Child Relations Across the Life Course*. (1st Edition). New York: Routledge.
- Roth, A. J., Weinberger, M. I., & Nelson, C. J. (2008). Prostate cancer: Psychosocial implications and management. *Future Oncology*, 4(4), 561–568. <https://doi.org/10.2217/14796694.4.4.561>

Roth, D. L., Wadley, V. G., Temple, E. M., & Haley, W. E. (2009). Family caregiving and emotional strain : associations with quality of life in a large national sample of middle-aged and older adults. *Quality of Life Research*, 18(6), 679–688. <https://doi.org/10.1007/s11136-009-9482-2>

Rudestam, K., & Newton, R. (2015). *Literature Review and Statement of the Problem. Surviving your Dissertation: A comprehensive guide to Content and Process*. Sage publications.

Sackey, H. A. (2005). Female labour force participation in Ghana: The effects of education.

Sadigh, M., Nawagi, F., & Sadigh, M. (2016). The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Annals of Global Health*, 82(5), 866–874. <https://doi.org/10.1016/j.aogh.2016.06.005>

Şahin, M., & Özbay, Y. (1999). University students' perceptions of empathic classroom atmosphere. *Hacettepe University Faculty of Education Journal*, 15(15), 74–83.

Sajadian, A., RajiLahiji, M., Motaharinasab, A., Kazemnejad Eklily, A., & Haghghat, S. (2017). Breast Cancer Coping Strategies after Diagnosis: A Six-month Follow-up. *Multidisciplinary Cancer Investigation*, 1(4), 12–16. <https://doi.org/10.21859/mci-01042>.

Sajjadi, M., Rassouli, M., Abbaszadeh, A., Brant, J., & Majd, H. A. (2016). Lived Experiences of “illness Uncertainty” of Iranian Cancer Patients: A Phenomenological Hermeneutic Study. *Cancer Nursing*, 39(4), E1–E8. <https://doi.org/10.1097/NCC.0000000000000282>

Sanuade, O. A., & Boatemaa, S. (2015). Caregiver profiles and determinants of caregiving burden in Ghana. *Public Health*, 129(7), 941–947. <https://doi.org/10.1016/j.puhe.2015.05.016>

Savenye, W. C., & Robinson, R. S. (2005). Using qualitative research methods in higher education. *Journal of Computing in Higher Education*, 16(2), 65–66.

Scharlach, A., Santo, T. D., Greenlee, J., Whittier, S., Coon, D., Kietzman, K., ... Aaker, J. (2001). *Family caregivers in California: Needs, interventions and model programs*. Center for the Advanced Study of Aging Services, University of California: Berkeley.

Scherbring, M. (2002). Effect of caregiver perception of preparedness on the burden in an oncology population. *In Oncology Nursing Forum*, 29(6), 70–76.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *Journal of Social Work Education*, 44(3), 105–113. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (1998). Conceptualization and Measurement of Doing Family Caregiving Well. *The Journal of Nursing Scholarship*, 30(1), 63–70.

Schumacher, K. L., Stewart, B. J., & Archbold, P. G. (2007). Mutuality and Preparedness Moderate the Effects of Caregiving Demand on Cancer Family Caregiver Outcomes. *Nursing Research*, 56(6), 425–433.

Senden, C., Vandecasteele, T., Vandenberghe, E., Versluys, K., Piers, R., Grypdonck, M., & Van Den Noortgate, N. (2015). The interaction between the lived experiences of older patients and their family caregivers confronted with a cancer diagnosis and treatment: A qualitative study. *International Journal of Nursing Studies*, 52(1), 197–206. <https://doi.org/10.1016/j.ijnurstu.2014.07.012>.

Sercekus, P., Besen, D. B., Gunusen, N. P., & Edeer, A. D. (2014). Experiences of Family Caregivers of Cancer Patients Receiving Chemotherapy. *Asian Pacific Journal of Cancer Prevention*, 15(12), 5063–5069. <https://doi.org/10.7314/apjcp.2014.15.12.5063>.

Sherman, D. W., McGuire, D. B., Free, D., & Cheon, J. Y. (2014). A pilot study of the experience of family caregivers of patients with advanced pancreatic cancer using a mixed-methods approach. *Journal of Pain and Symptom Management*, 48(3), 385 <https://doi.org/10.1016/j.jpainsymman.2013.09.006>

Shih, W., Hsiao, P., Chen, M., & Lin, M. (2013). Experiences of Family of Patient with Newly Diagnosed Advanced Terminal Stage Hepatocellular Cancer. *Asian Pacific Journal of Cancer Prevention*, 14(8), 4655–4660. <https://doi.org/10.7314/apjcp.2013.14.8.4655>.

Siguenza, A. M. (2016). *Outcomes Assessment within Prostate Cancer Interventions for Couples : A Narrative Review*. University of Central Florida Orlando, Florida.

Silveira, M. J., Given, C. W., Given, B., Rosland, A. M., & Piette, J. D. (2010). Patient-caregiver concordance in symptom assessment and improvement in outcomes for patients undergoing cancer chemotherapy. *Chronic Illness*, 6(1), 46–56. <https://doi.org/10.1177/1742395309359208>

Songsore, J., & McGranahan, G. (2003). Women's household environmental caring roles in the Greater Accra Metropolitan Area: a qualitative appraisal. *Institute of African Studies Research Review*, 19(2), 67-83. <https://doi.org/10.1037/11224-016>

Spinelli, E. (2005). *The interpreted world: An introduction to phenomenological psychology*. Sage.

Stajduhar, K. (2003). Examining the perspectives of family members involved in the delivery of palliative care at home. *Journal of Palliative Care*, 19(1), 27–35. Retrieved from <http://search.ebscohost.com/login.aspx?direct=true &db=cin20&AN=106885745&lang=es&site=ehost-live>

Stajduhar, K., & Davies, B. (1998). Family Caregiving Experiences. *Journal of Palliative Care*, 14(2), 14–22.

Stajduhar, K. I. (2013). Burdens of Family Caregiving at the End of Life. *Clinical and Investigative Medicine*, 36(3), 121–126.

Stambor, Z. (2006). Caring for caregivers. *Monitor on Psychology*, 37(10), 46–47.

Stefan, D. C. (2015). Cancer Care in Africa: An Overview of Resources. *Journal of Global Oncology*, 1(1), 30–36. <https://doi.org/10.1200/JGO.2015.000406>

Stenberg, U., Ruland, C. M., & Miaskowski, C. (2010). Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19(10), 1013–1025.

Steptoe, A., Shankar, A., Demakakos, P., & Wardle, J. (2013). Social isolation, loneliness, and all-cause mortality in older men and women. *Proceedings of the National Academy of Sciences*, 110(15), 5797–5801. <https://doi.org/10.1073/pnas.1219686110>

Strang, V. R., & Koop, P. M. (2003). Factors which influence coping: home-based family caregiving. *Journal of Palliative Care*, 19(2), 107–114.

Strauss, A. C., & Corbin, J. M. (2008). Basics of qualifying research: Techniques and procedures for developing ground theory.

Subhashini, N. (2014). Assessment of coping strategies among breast cancer patients on chemotherapy. *Narayana Nursing Journal*, 3(1), 43–45.

Sun, V., Grant, M., Koczywas, M., Freeman, B., Zachariah, F., Fujinami, R., ... Ferrell, B. (2015). Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer*, 121(20), 3737–3745.

Terakye, G. (2011). Interaction with the Patients and His Relatives. *Dokuz Eylul University School of Nursing E-Journal*, 4(2), 78–82.

Torre, L. A., Siegel, R. L., Ward, E. M., & Jemal, A. (2016). Global cancer incidence and mortality rates and trends - An update. *Cancer Epidemiology and Prevention Biomarkers*, 25(1), 16-27. <https://doi.org/10.1158/1055-9965.EPI-15-0578>

Travis, S. S., Bethea, L. S., & Winn, P. (2000). Medication administration hassles reported by family caregivers of dependent elderly persons. *Journals of Gerontology - Series A Biological Sciences and Medical Sciences*, 55(7), 412–417. <https://doi.org/10.1093/gerona/55.7.M412>

Trudeau-Hern, S., & Daneshpour, M. (2012). Cancer's Impact on Spousal Caregiver Health: A Qualitative Analysis in Grounded Theory. *Contemporary Family Therapy*, 34(4), 534–554. <https://doi.org/10.1007/s10591-012-9211-9>

Tsigaropoulos, T., Mazaris, E., Chatzidarellis, E., Skolarikos, A., Varkarakis, I., & Deliveliotis, C. (2009). Problems faced by relatives caring for cancer patients at home. *International Journal of Nursing Practice*, 15(1), 1–6. <https://doi.org/10.1111/j.1440-172X.2008.01725.x>

Tyson, M. D., Andrews, P. E., Etzioni, D. A., Ferrigni, R. G., Humphreys, M. R., Swanson, S. K., & Castle, E. P. (2013). Marital status and prostate cancer outcomes. *Canadian Journal of Urology*, 20(2), 6702–6706. <https://doi.org/10.1016/j.juro.2012.02.222>

Ugur, O., Elcigil, A., Arslan, D., & Sonmez, A. (2014). Responsibilities and Difficulties of Caregivers of Cancer Patients in Home Care. *Asian Pacific Journal of Cancer Prevention*, 15(2), 725–729. <https://doi.org/10.7314/apjcp.2014.15.2.725>

Ullrich, A., Ascherfeld, L., Marx, G., Bokemeyer, C., Bergelt, C., & Oechsle, K. (2017). Quality of life, psychological burden, needs, and satisfaction during specialized inpatient palliative care in family caregivers of advanced cancer patients. *BMC Palliative Care*, 16(1), 1–10. <https://doi.org/10.1186/s12904-017-0206-z>.

Van der Geest, S. (2002). Respect and reciprocity: Care of elderly people in rural Ghana. *Journal of Cross-Cultural Gerontology*, 17(1), 3–31. Retrieved from <http://link.springer.com/article/10.1023/A:1014843004627>

Van Manen, M. (2016). *Researching lived experience: Human science for an action sensitive pedagogy*. Routledge.

Van Ryn, M., Sanders, S., Kahn, K., Van Houtven, C., Griffin, J., Martin, M., ... Rowland, J. (2011). Objective burden, resources, and other stressors among informal cancer caregivers: A hidden quality issue? *Psycho-Oncology*, 20(1), 44–52. Retrieved from <http://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed10&NEWS=N&AN=2011000529>

Vedhara, K., & Irwin, M. R. (2005). *Human psychoneuroimmunology*. (Eds). Oxford University Press on Demand. Retrieved from <https://philpapers.org/rec/VEDHP>

Verhage, B. A. J., & Kiemeny, L. A. L. M. (2003). Genetic susceptibility to prostate cancer. *Familial Cancer Journal*, 96(9), 1380–1385. <https://doi.org/10.1111/j.1464-410X.2005.05836.x>

Vitaliano, P. P., & Katon, W. J. (2006). Effects of stress on family caregivers: recognition and management. *Psychiatric Times*, 23(7), 24–24.

Voydanoff, P., & Donnelly, B. W. (1999). Multiple Roles and Psychological Distress: The Intersection of the Paid Worker, Spouse, and Parent Roles with the Role of the Adult Child. *Journal of Marriage and the Family*, 61(3), 725–738. <https://doi.org/10.2307/353573>

Waldrop, D. P., Kramer, B. J., Skretny, J. A., Milch, R. A., & Finn, W. (2005). Final Transitions: Family Caregiving at the End of Life. *Journal of Palliative Medicine*, 8(3), 623–638.

Wall, C., Glenn, S., Mitchinson, S., & Poole, H. (2004). Using a reflective diary to develop bracketing skills during a phenomenological investigation. *Nursing Researcher*, 11(4), 20–29.

Waller, A., Girgis, A., Currow, D., Lambert, S., & Johnson, C. (2013). Physical, Psychosocial, Relationship, and Economic Burden of Caring for People With Cancer: A Review. *Journal of Oncology Practice*, 9(4), 197–202. <https://doi.org/10.1200/jop.2012.000690>.

Walsh, C., Ewing, L., Cleary, J., Vaisleib, A., Farrell, C., Wright, A., ... Marsland, A. (2018). Development of glucocorticoid resistance over one year among mothers of children newly diagnosed with cancer. *Brain, Behavior, and Immunity*, 69, 364–373. <https://doi.org/10.1016/j.bbi.2017.12.011>

Walsh, F. (2003). Family Resilience: A Framework for Clinical Practice. *Family Process*, 42(I), 1–18. <https://doi.org/10.1111/famp.2003.42.issue-1>

WHO. (2018). Latest global cancer data. *International Agency for Research on Cancer*, pp. 13–15. Retrieved from <https://www.who.int/cancer/PRGloboCanFinal.pdf>

Wiggins, A., Bonney, R., Graham, E., Henderson, S., Kelling, S., LeBuhn, G., ...

Newman, G. (2013). Data management guide for public participation in scientific research. *DataOne Working Group*, 1–41.

Willette-Murphy, K., Lee, K. A., Dodd, M., West, C., Aouizerat, B. E., Paul, S., ...

Miaskowski, C. (2009). Relationship between sleep and physical activity in female family caregivers at the initiation of patients' radiation therapy. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, 38(3), 367–374.

Williams, C. (2007). Research methods. *Journal of Business & Economic Research*, 5(3), 65–72.

Wittenberg, E., Borneman, T., Koczywas, M., Del Ferraro, C., & Ferrell, B. (2017).

Cancer Communication and Family Caregiver Quality of Life. *Behavioral Sciences*, 7(4), 12.

Wood, S. E., Wood, E. ., & Boyd, D. (2007). *The World of Psychology*. Boston: Allyn & Bacon.

Wu, H. S., & Harden, J. K. (2015). Symptom Burden and quality of life in survivorship: A review of the literature. *Cancer Nursing*, 38(1), E29–E54. <https://doi.org/10.1097/NCC.0000000000000135>

Yamoah, K., Beecham, K., Hegarty, S., Hyslop, T., Showalter, T. N., & Yarney, J.

(2012). *Early results of prostate cancer radiation therapy at Korle Bu Teaching Hospital: An analysis with emphasis on research strategies to improve treatment delivery and outcomes among patients in Ghana*. Retrieved from http://meeting.ascopubs.org/cgi/content/abstract/30/15_suppl/e15163.

Yao, D., Guo, Y., Yuan, S., & Zhang, Q. (2017). Fatigue Influence Factors and Coping Strategies among Cancer Patients ' Spouses : A Quantitative Study in China. *Journal of Medicine and Science*, 10(2), 45–52. <https://doi.org/10.7156/najms.2017.1002045>

Yeboah-Asiamah, B. (2015). *Perception and Attitude About Prostate Cancer Among Male Teachers In The Sunyani Municipality (A Doctoral dissertation University of Ghana)*. University of Ghana, Legon. Retrieved from <http://ugspace.ug.edu.gh/handle/123456789/8195>

Yeboah-Asiamah, B., Yirenya-Tawiah, D., Baafi, D., & Ackumey, M. M. (2017). Perceptions and knowledge about prostate cancer and attitudes towards prostate cancer screening among male teachers in the Sunyani Municipality, Ghana. *African Journal of Urology*, 23(3), 184–191. <https://doi.org/10.1016/j.afju.2016.12.003>.

Yeboah, E. D., Hsing, A. W., Mante, S., Mensah, J. E., Kyei, M. Y., Yarney, J., ... Cook, M. B. (2016). Management of Prostate Cancer in Accra, Ghana. *Journal of the West African College of Surgeons*, 6(4), 31–65. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/29181364><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5667721><http://www.ncbi.nlm.nih.gov/pubmed/29181364><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC5667721>

Zanchetta, M. S., Cognet, M., Lam-Kin-Teng, M. R., Dumitriu, M. E., Haag, C., Kadio, B., ... Rénaud, L. (2018). Insights for public education provided by French media on ideas about prostate cancer - A media analysis study. *Health Promotion Perspectives*, 8(2), 92–101. <https://doi.org/10.15171/hpp.2018.12>



APPENDIX A
INFORMED CONSENT FORM

Title: Lived Experiences of Family Caregivers of Patients' with Prostate Cancer in the Cape Coast Metropolis

Principal Investigator: Benedicta Owoo

Address: School of Nursing and Midwifery, University of Cape Coast

General Information about Research

The study involves research on the experiences of family caregivers of patients with prostate cancer in the Cape Coast metropolis. I will seek information from you concerning the experiences and barrier you encounter as you go about the caring role as well as the coping strategies employed. The conversation will be audio tape-recorded with your permission. The information provided will enable nurses, other health care workers and the public understand what exactly family caregivers go through as a result of the role they play. It will also help in the development of strategies, policies and protocols that will be used to address these challenges. The interview will only last between 45-60 minutes.

Procedures

I will be initially introduced to you by the unit staff. Later, an appointment will be booked with those who meet the inclusion criteria. The venue, date and time will be decided at your convenience. You will be given a consent form to read, those who do not have the literacy ability will be assisted. All misunderstandings will be clarified about a week before the interview. You will be allowed to sign or thumbprint the consent form before the interview. In the process of the interview all information elicited will be recorded with an audio-tape with your consent, and then later transcribed. Records on experiences will be written down in a field diary as well as your nonverbal communications, mannerisms and anything vital to the study. The interview will take 45-60 minutes. During the interview, you will be asked to share your experience in relation to the role you play as the caregiver. You will also be required to share with the researcher the barriers you have encountered so far if any, and also the coping strategies you adopted.

Possible Risks and Discomforts

There is an anticipated risk. This is because you will be asked to describe your emotional, physical and social experiences associated with the caring role. In case of any problem the interview will be discontinued, you will be reassured and made calm. An expert from the Cape Coast Teaching hospital will then be invited to provide a free counselling session.

Possible Benefits

You may not have a direct benefit at this time. However, your participation in this study will enable nurses, other health workers and the public to understand exactly what family caregivers go through in the care of patients with prostate cancer. Also, policies, protocol and strategies will be developed by major stakeholders to help curb the issues and concerns you face as a result of caring for your loved ones.

Confidentiality

During the interview process, the information will be recorded with your permission. Under no circumstance will your personal information be mentioned in any part of the research. However, you will be given a code that will be attached to all information concerning you in the interview. I and my two other supervisors are the only people who can have access to your information. You are assured that all information provided will be protected to the best of our ability. The audiotapes will be strictly put under lock and kept for five years in my custody after which it will be discarded. Transcribed data and data used for analysis will be destroyed after the study.

Compensation

There will be no compensation for this study. However, participants will be served snacks and water.

Voluntary Participation and Right to Leave the Research

Your participation in the study is voluntary and you have the right to withdraw at any point in time in the course of the study.

Contacts for Additional Information

Please contact the following people in case you need additional information.

Benedicta Owoo

Phone number: 0243813442

dictaowoo@gmail.com

Dr Jerry PK Ninnoni

Phone number: 0554025222

jerry.ninnoni@ucc.edu.gh

Dr Samuel Victor Nuvor

Phone number: 0205853850

snuvor@ucc.edu.gh

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of the University of Cape Coast (UCCIRB). If you have any questions about your rights as a research participant you can contact the Administrator at the IRB Office between the hours of 8:00 am and 4:30 p.m. through the phone lines 0558093143/0508878309/0244207814 or email address: irb@ucc.edu.gh.

VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title (*Lived Experiences Family caregivers of patients with prostate cancer in the Cape Coast Metropolis*) 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 B

DATA COLLECTION INSTRUMENT

Interview Guide

SECTION A

1. Demographic Information

Identification (ID) Code
Age
Sex
Nationality
Highest educational level
Occupation
Religion
What is your relationship with the patient?

SECTION B

2. What are the experiences of caregivers caring for people with prostate cancer?

How long has your relation been living with the condition?
How long have you been providing care for the patient?
Please kindly tell me about your relation's condition
What exactly do you normally do for him on a daily basis?
How do you think your caring role has affected you physically?

Probes:

Does your caring role affect your eating pattern?

How does your role affect your sleeping pattern?

Do you normally get tired?

- a. Please tell me how you think you have been affected psychologically as a result of your caring role?

Probe: in term of

Do you sometimes feel anxious?

Do you get depressed?

Do you feel distressed sometimes?

Can you discuss some of your fears with me?

Do you sometimes feel helpless?

Do you sometimes lose concentration?

Do you sometimes feel as if you are not in control of the situation?

Please, how has the caring role affected your social life?

Probes:

Do you make time to groom yourself?

Do you feel Isolated?

Are you able to socialization with friends?

Are you able to make time for leisure activities?

Has your current role affected your primary role?

Has your current role affected your sex life?

b. What ways has your caring role affected your work?

SECTION C

3. What are the barriers to caring for patients with prostate cancer?

- a. Please, can you tell me what comes into your mind when you hear that someone has cancer?
- b. What does cancer mean to you and your family?
- c. How do people interpret cancer here in Cape Coast?
- d. What was your reaction when you first learnt that your relation has been diagnosed with cancer?
- e. How would you describe the preparation given to you by the nurses/healthcare team before assuming the caring role?

Probe:

Did you receive any education on the condition?

Did you receive any education on how to manage pain?

Did you receive any education on how to administer medications?

Did you receive any coaching on identification and management of adverse effects of medications?

- f. Please in terms of finances, how would you describe your funding when it comes to providing care.

Probe:

How do you support yourself financially e.g.
Loans, support, donation

SECTION D

4. What coping strategies do family caregivers of patient with prostate cancer use?

Please, how do you cope with caring for your relation?

Probe:

Do you seek external aid such as counselling?

Do you seek religious support?

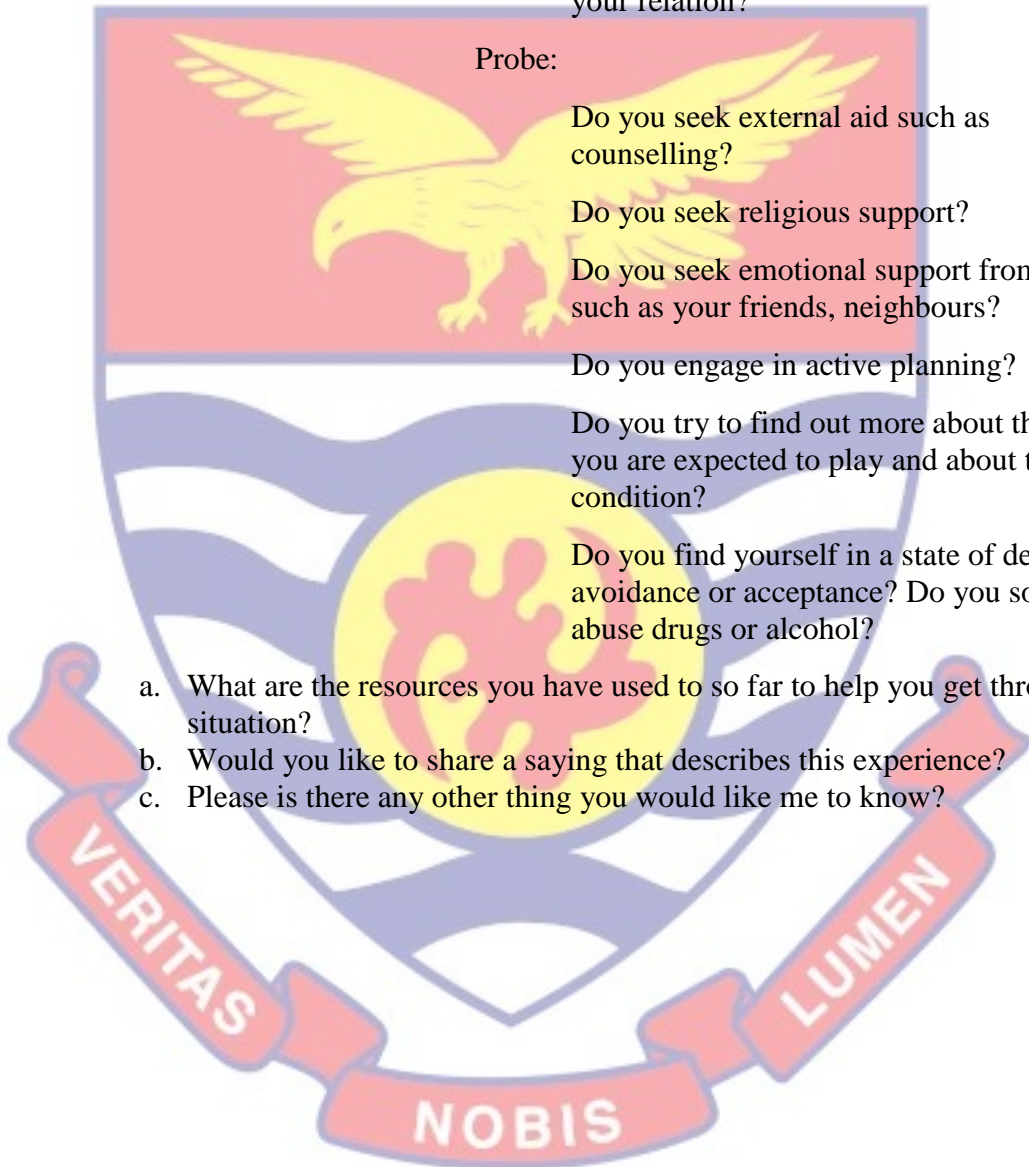
Do you seek emotional support from people such as your friends, neighbours?

Do you engage in active planning?

Do you try to find out more about the role you are expected to play and about the condition?

Do you find yourself in a state of denial, avoidance or acceptance? Do you sometimes abuse drugs or alcohol?

- a. What are the resources you have used to so far to help you get through this situation?
- b. Would you like to share a saying that describes this experience?
- c. Please is there any other thing you would like me to know?



APPENDIX C

ETHICAL CLEARANCE

	UNIVERSITY OF CAPE COAST COLLEGE OF HEALTH AND ALLIED SCIENCES SCHOOL OF NURSING AND MIDWIFERY DEAN'S OFFICE	
Telephone: 233-3321-33342/33372 Telegrams & Cables: University, Cape Coast Email: nursing@ucc.edu.gh		UNIVERSITY POST OFFICE CAPE COAST, GHANA.
Our Ref: SNM/I/4/Vol.1/56 Your Ref:		30 th November, 2018
<p>The Director Directorate of Finance UCC</p> <p>Dear Sir,</p> <p>RE: APPLICATION FOR ETHICAL CLEARANCE TO CONDUCT A STUDY: MS. BENEDICTA OWOO</p> <p>We forward herewith the attached application for ethical clearance from the above named level 850 Master of Nursing students with registration number SN/MNS/17/0008 of the School of Nursing and Midwifery for your consideration, please.</p> <p>Thank you.</p> <p>Yours faithfully,</p> <p> Dr. Dorcas Obiri-Yeboah DEAN</p> <p><small>Kom</small></p>		

APPENDIX D

IRB ETHICAL CLEARANCE

UNIVERSITY OF CAPE COAST

INSTITUTIONAL REVIEW BOARD SECRETARIAT

TEL: 0558093143 / 0508878309/ 0244207814

C/O Directorate of Research, Innovation and Consultancy

E-MAIL: irb@ucc.edu.gh

OUR REF: UCC/IRB/A/2016/296

YOUR REF:

OMB NO: 0990-0279

IORG #: IORG0009096

20TH FEBRUARY, 2019



Ms Benedicta Owoo

Department of Nursing and Midwifery
University of Cape Coast

Dear Ms Owoo,

ETHICAL CLEARANCE – ID: (UCCIRB/CHAS/2018/24)

The University of Cape Coast Institutional Review Board (UCCIRB) has granted **Provisional Approval** for the implementation of your research protocol titled **Experiences of family caregivers of patients with prostate cancer in the Cape Coast Metropolis**. This approval requires that you submit periodic review of the protocol to the Board and a final full review to the UCCIRB on completion of the research. The UCCIRB may observe or cause to be observed procedures and records of the research during and after implementation.

Please note that any modification of the project must be submitted to the UCCIRB for review and approval before its implementation.

You are also required to report all serious adverse events related to this study to the UCCIRB within seven days verbally and fourteen days in writing.

Always quote the protocol identification number in all future correspondence with us in relation to this protocol.

Yours faithfully,

for: Samuel Asiedu Owusu, PhD

UCCIRB Administrator

ADMINISTRATOR
INSTITUTIONAL REVIEW BOARD
UNIVERSITY OF CAPE COAST
Date: 21/02/19

APPENDIX E


CCTH ETHICAL CLEARANCE

CAPE COAST TEACHING HOSPITAL
RESEARCH AND DEVELOPMENT SECRETARIAT

In case of reply the reference number
and the date of this
Letter should be quoted

Our Ref.: CCTH/RDS/2019/41
Your Ref. SNM/R/2/Vol.4/

Benedicta Owoo
School of Nursing and Midwifery
College of Health and Allied Sciences
University of Cape Coast
Cape Coast



P. O. Box CT.1363
Cape Coast
Tel: 03321-34010-14
Fax: 03321-34016
Website: www.ccthghana.org
email: info@ccthghana.com
Digital Address: CC-071-9967
4th March 2019

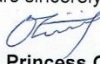
Dear Ms. Owoo,

R&D SECRETARIAT'S INSTITUTIONAL APPROVAL

The Cape Coast Teaching Hospital Research and Development Secretariat (CCTHRDS) have assessed your research topic, "*Lived Experience of Family Caregivers of Patients' Living with Prostate Cancer in the Cape Coast Metropolis.*" which was submitted for institutional approval. The secretariat writes to inform you of the decision to grant you CCTH institutional approval to undertake the study at CCTH.

You are however required to **submit an electronic copy of your findings from the research in the form of an abstract to the CCTHR&D Secretariat email address: ccthresearch@gmail.com**

Always quote our ref. identification number above in all future correspondence with us in relation to this research study.

Yours sincerely,

Ms. Princess G. Ofori
Head, Research, Monitoring & Evaluation

CC. Head, Surgical Sub-BMC
Head, Urology Department/Clinic

APPENDIX F
INTRODUCTORY LETTER



UNIVERSITY OF CAPE COAST, INSTITUTIONAL REVIEW BOARD (UCC-IRB)

University of Cape Coast
College of Health and Allied Health Science
School of Nursing and Midwifery
30th November, 2018.

Thro;
The Dean
School of Nursing and Midwifery
University of Cape Coast.

The Chairman
Institutional Review Board
University of Cape Coast
Cape Coast.

Dear Sir/Madam,

APPLICATION FOR INSTITUTIONAL REVIEW BOARD CLEARANCE

I am a Master of Nursing student and would be grateful if you would review my research proposal on the topic; Lived Experience of Family caregivers of Patients' with Prostate Cancer in the Cape Coast Metropolis.

Find attached are the necessary documents for ethical clearance.

Yours faithfully,

A handwritten signature in blue ink, appearing to read "Benedicta Owoo", written over a dotted line.

Benedicta Owoo
(SN/MNS/17/0008)

UCCIRB
UCCIRB
2017