Exploring Home-based Supportive and Palliative Care for men living with Advanced-stage Prostate Cancer in a resource-limited Sub-Saharan African Country (Ghana)

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1 Abstract

Background

The development of palliative care and research into palliative care are burgeoning fields in global south resource-poor countries. Due to inadequate institutional-based palliative care or health care institutions being stretched for resources, home-based care becomes an indispensable option. Home-based informal family caregiving is an under-explored area in Africa. In Ghana, PWAPC are mostly cared for in the home context. This study explored health care professionals, patients' and caregivers' experience of living with and or caring for PWAPC in a resource-poor setting where the bulk and responsibility for care is predominantly provided within the informal sector.

Objectives:

1. To explore the experiences of PWAPC about home-based care: what support and care they receive, and to identify if/how care could be improved.

2. To examine the experiences and perceptions of family caregivers of PWAPC about providing care (for instance coordinating care, providing the care responsibility with others, provision of medical care, how they learn to care, how the care changes over time as the patient health deteriorates, and how they think about their health).

3. To understand how caregivers manage their role and the challenges this presents in the provision of emotional and practical care.

4. To explore the experiences of healthcare professionals (HCP) on the home-based care of PWAPC and their families and finding out what HCPs think the challenges are for PWAPC and family caregivers.

Methods

This study was multiple perspectives and multi-method qualitative study using individual interviews, joint interviews, and focus group discussion. Repeat interviews were conducted with PWAPC and their family caregivers across a period of up to 6 months usually two months apart. A total of 23 PWAPC, 23

family caregivers, and 12 healthcare professionals yielded 68 interviews to get a holistic understanding of such care. Four patients were lost to follow-up during the second phase of the interview due to death. The healthcare professionals participated in mainly focus group discussion.

The data was recorded and transcribed. An inductive thematic analysis approach was used to identify commonly recurring themes developed from within the data. Links were made between findings and theories and what these mean for practice.

Findings

Living with and or caring for a PWAPC could present challenges and disruption of family lives; this requires continued support and readjustment to cope. The study highlights three main themes from the analysis and synthesis of all the interviews. These include:

- *Managing illness in a resource-limited context.* This consist of the high cost of treatment and day to day care, combining care with paid work, mobilising resource for care in a rural setting, unavailability of formal palliative care services to the home, and the gaps (physical and practical needs, psychosexual needs, and information needs) that exist in care provision.
- *Family caregiving*. Family caregiving involves dealing with practical and emotional issues about home care, how to navigate the care at home usually unassisted by professionals, pain management, and the disruption in the family unit following prostate cancer. It also shows the coping strategies adopted to deal with challenges such as the spirit of reciprocity, compassionate informal networks, having faith in God, and having positive thinking about life.
- *Managing prostate cancer stigma, and dealing with prostate cancer in the context of masculinity*. Prostate cancer stigma is multi-layered: prostate cancer as a stigmatising disease, shame associated with prostate cancer symptoms and stigma of some treatment methods for

prostate cancer such as removal of the testes. Prostate cancer threatens masculinity physically, socially, emotionally and sexually and this has implication for men's health and wellbeing.

Conclusion

This study adds to the understanding of living with advanced prostate cancer within a resource-limited and non-Western setting; providing both nursing and sociological insights. The research indicates some flop in home-based palliative care and the ineffective collaboration between caregivers and healthcare professionals for home-based care due to lack of resources and policy direction. The need for palliative care coordination, resources, and training for patients and their family caregivers is thus evident. Family caregivers in this study demonstrated a strong sense of responsibility and were motivated to provide care underpinned by cultural beliefs that frown upon the desertion of the sick. This finding is unique and different from Western societies where there are more resources to support family caregivers and more recognition of their needs.

The findings highlight the need for the urgent development of policies/resources and health promotion. There is a need to increase awareness of prostate cancer with the aim to reduce the stigma attached to the disease and its symptoms. The health and social care policies and health promotion should take into account the existing informal social networks, culturally appropriate care and the enormous contribution of family caregivers, who provide pivotal support for the care of PWAPC.

2 Scholarly work from this thesis

Published abstracts:

Salifu, Y., Almack, K., & Caswell, G. (2018). The Changes, Challenges, and Coping Strategies of Men Living with Advanced Prostate Cancer in a Resource-poor Country. Journal of Pain and Symptom Management 56(6):e71. DOI: 10.1016/j.jpainsymman.2018.10.181

Salifu, Y., Almack, K., & Caswell, G. (2018) Exploring caregivers' experiences of caring for men with advanced prostate cancer in a resource poor setting: a qualitative serial interview study. BMJ Supportive & Palliative Care, 8 (Supplement 1), p. A13.

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Salifu, Y., Almack, K., & Caswell, G. (2017): Living with Prostate cancer in Ghana. LINK17 Student-led interdisciplinary Research Conference, East Midlands Conference Centre, The University of Nottingham, UK.

Conference posters

Salifu, Y., Almack, K., Caswell, G. (2019). Stigmatised Changed 'Social Identity' in Men: Consequences of Prostate Cancer? First Graduate School Research Celebration Week Event, University of Nottingham, Nottingham, UK.

Salifu, Y., Almack, K., Caswell, G. (2018). Home-based palliative care for advanced prostate cancer patients in a resource-poor setting (Ghana). 10th World Research Congress of the European Association for Palliative Care (EAPC), Bern, Switzerland.

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Awards

- Best abstract for Plenary presentation - 1st International Seminar of EAPC RN and the EAPC Reference Group on Public Health and Palliative Care in Brussels, 25-26 October 2018.
- Prize winner International EAPC RN seminar on public health research in palliative care to attend the conference in Brussels, Belgium.
- Best oral presentation, East Midlands Doctoral Research Network at Bishop Grosseteste University, Lincoln.
- Graduate School Travel Prize, by University of Nottingham to participate in the 10th World Research Congress of the European Association for Palliative Care, Bern, Switzerland.

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[1] I dedicate this thesis to men living with prostate cancer (especially those who died during and after the study) and their families. It is equally dedicated to my mum and dad, Hajia Salamatu and Alhaji Abubakar Salifu.

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7 List of Abbreviations

ADT	Androgen Deprivation Therapy
APC	Advanced Prostate Cancer
FMSH	Faculty of Medicine and Health Science
GoG	Government of Ghana
GSS	Ghana Statistical Service
HCP	Healthcare professionals
HIV/AIDS	Human Immunodeficiency Virus/ Acquired Immunodeficiency Syndrome
HPC	Home-based Palliative Care
KATH	Komfo Anokye Teaching Hospital
KBTH	Korle Bu Teaching Hospital
KNUST	Kwame Nkrumah University of Science and Technology
MoH	Ministry of Health
NCARE	Nottingham Centre for the Advancement of Research into Supportive, Palliative and End-of-life Care
NHIS	National Health Insurance Scheme
NHS	National Health Service
NSAIDs	Nonsteroidal anti-inflammatory drugs
NSCC	National Strategy for Cancer Control
PCa	Prostate Cancer
PCT	Palliative Care Team
PSA	Prostate Specific Antigen
PWAPC	Person with Advanced Prostate Cancer
UoN	University of Nottingham

Treatment for Advanced Prostate Cancer

The main treatment is to suppress androgen production and principally treatment is palliative, no cure. However, managing the side effects of treatment and providing supportive care (pain management, bone health by regular intake of calcium, etc.) are essential (Droz et al., 2014).

Hormone Therapy

Hormone therapy or androgen deprivation therapy (ADT) does not kill the cancer cells but causes *changes* in the body's hormone equilibrium to impede cancer cells from developing. This will then improve the quality of life of the patient and prolong survival of the patient-what is termed palliative care. Hormone treatment is usually used when the cancer is inoperable, or it is used in conjunction with other treatments such as surgery or radiation therapy.

Orchiectomy

This surgical removal of the testes, responsible for the production of about 90% of the testosterone in the body. Although it is a long-lasting and irreversible procedure, it is the most cost-effective and one-time procedure. Although, it is a surgical procedure it is regarded as a method of hormonal therapy.

Luteinizing hormone-releasing hormone (LHRH) Agonists

The LHRH is a principal hormone that aid in the production of testosterone. The LHRH agonist is used to block the release of the LHRH; however, it causes a 'flare' reaction that leads to an increase in testosterone in the first few weeks following the initiation of the treatment. Drugs such as Zoladex, Eligard, and Lupron are the common LHRH agonists used. It is usually given once at least monthly

LHRH Antagonists

These class of drugs prevents the further transitory rise in the prostate-specific antigen (PSA) level usually caused by the LHRH Agonists while at the same time blocking testosterone production by inhibiting LHRH stimulation. Firmagon, usually given monthly, is an example of this group of drug.

Anti-Androgens

Anti-androgens, for example, Casodex, flutamide, and Nilandron are used in conjunction with the LHRH agonist to prevent the sudden increase of testosterone levels that characterise LHRH administration. Although it causes

a less sexual side effect as compared with LHRH agonist, anti-androgens is not very effective as LHRH agonist or orchiectomy in managing advanced prostate cancer. Hence it is usually used with other therapies.

Inhibitors and Blockers

The prostate gland produces about 90% of entire testosterone in the body while the remaining 10% is by the adrenal gland. When the prostate cancer becomes castration-resistant despite administration of hormones and the adrenal glands or prostate cancer cells start to produce androgens that exacerbate the progress of cancer, then a much more aggressive treatment is used. This group of the hormonal drug either prevent the production of androgen (example Zytiga) or block receptor signalling (Xtandi).

The most common side effects associated with the hormone treatment include pain in the breast or breast enlargement, decreased libido, diarrhoea and or constipation, high risk for fracture among others.

Palliative Radiation

Radiotherapy is a procedure that aims the prostate gland or a specific site where a controlled radioactive power is directed to kill cancer cells. It can be used with other treatment option or alone. It can be administered externally or by injection into the blood.

Chemotherapy

This is mostly used to kill rapidly growing cells and cancer cells when other treatment options are not very effective. Examples include Taxotere and Jsevtana combined with prednisone, and it relieves pain. Due to its side effects, when chemotherapies are administered, there is some time lapse for the body to recover from the effects of the drugs before the next treatment. It usually comes in the form of infusion given over a few weeks.

Immunotherapy

This is a form of biological therapy with preparations that are designed to treat prostate cancer by using the body's immune system especially after hormone therapy has failed. The drug identifies and attacks prostate cancer cells using the body's immune cells. Examples of immunotherapy include Provenge and PROSTVAC.

Bone Health

Drugs such as Xgeva and Zometa reduce the natural rate of bone destruction as well as the damage caused by metastatic prostate cancer cells and therefore, reduce pains and fragility that characterises the bones in patients with prostate cancer. Xofigo, given as radiation, also relieves pain and delay the cancer trajectory.

Palliative Surgery

In this case, the surgery aims to relieve symptoms associated with prostate cancer such as urinary symptoms. A procedure known as *transurethral resection of the prostate* (TURP) is performed to relieve urinary obstruction following prostate enlargement from cancer. Other forms of surgery such as freezing the prostate tissue (*Cryosurgery or Cryoablation*) may be performed to freeze prostate tissue to denature the cancer cells. Another type of surgery that usually leads to urinary incontinence and erectile dysfunction, *radical prostatectomy*, involves the total removal of the prostate gland and affected tissues and lymph nodes around the prostate.

CHAPTER 1

1 Introduction

1.1 Background and rationale

Nearly 45 million out of the 58 million annual global cancer deaths occur in developing countries, with an estimated 60% of patients needing palliative care at one point or the another (Stjernswärd et al., 2007). Furthermore, evidence suggests that palliative care in the global south, where there are limited resources, the family plays a significant role and the family has a 'traditional' duty of ensuring that the sick are cared for (Hanrahan, 2018). Prostate cancer is one of the leading causes of cancer death in men in both developed and developing countries, and incidences are disproportionately high among African Americans (Hsing et al., 2014, Diaz, 2006, Wu and Modlin, 2012). Globally, prostate cancer ranks sixth in cancer deaths among men (Adeloye et al., 2016). Whereas one in eight (12.5%) men develop prostate cancer globally, incidence doubles among black people where 25% of men develop cancer (Prostate Cancer UK, 2016); and this is believed to be linked to hereditary and diet (Whittemore et al., 1995). It is projected that with the increasing westernisation lifestyle and improving economies, the incidence rate in African men are expected to increase (Chu et al., 2011).

The World Health Organisation (WHO) guideline for effective cancer control consists of six modules: planning, prevention, early detection, diagnosis and treatment, palliative care, and policy and advocacy (WHO, 2007). The WHO's Public Health model for palliative care indicates that a clear palliative care policy guides implementation for a good outcome (Stjernswärd et al., 2007). Stjernswärd and colleagues (2007) also suggest that home-based palliative care (HPC) improves the quality of life for 100 million patients a year globally; and subsequently, home care is an emerging trend of care for patients in countries such as Australia (Abel et al., 2013) and the UK. Palliative care services are not equitably available for most people especially those in developing countries (Harding and Higginson, 2005b). In this study, home-

based care refers to unpaid care delivered by family caregivers (wives, children, siblings, and parents).

Hospices and nursing care homes are usually not common in most African countries except in South Africa and some Eastern African countries where the patients and their families pay for such services (Swartz, 2015, Powell et al., 2011, Harding et al., 2010). An example in Africa where research has been carried out and suggested that HPC is an affordable option as well as sensitive to the sociocultural context is Uganda (Ddungu, 2011). Hence, the World Health Organisation calls for HPC for patients in resource-limited countries where patients rely heavily on the pivotal role of family caregivers and other available informal services, and because of lack of alternatives such as institutional-based palliative care (WHO, 2002, Morris et al., 2015, Merriman, 2010).

The inadequate resources and or lack of specialised palliative care health facilities have increased the demand on family caregivers for cancer patients in Africa countries who require care at home (Powell et al., 2011, Powell et al., 2014). Even where home-based professional palliative care is delivered, it would have been difficult to provide care for many patients receiving palliative care without the vital role of family caregivers (Harrop et al., 2014, Grande et al., 2009, Hudson et al., 2008). Nonetheless, home caregiving in general and family caregivers, in particular, are faced with challenges (Kristjanson and Aoun, 2004, Hudson et al., 2009). These challenges are mainly due to the magnitude of care needed, the fluidity of the disease trajectory, and the increasing demands of the patients' needs; physical, psychological, economic, and spiritual (Hudson et al., 2010, Hudson et al., 2009, Honea et al., 2008). However, there is no clear policy about supporting informal family care in Ghana nor evidence of how both the caregiver and the patient experience such care. In the absence of a comprehensive national policy guideline in Ghana for home-based care in general and prostate cancer care in particular, research evidence to support the development of local policy is timely, as in most African countries (Harding et al., 2013b).

1.1.1 Definition of palliative care

The World Health Organisation defines Palliative care as ‘‘an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual’’ (World Health Organization, 2002). The World Health Organisation further elaborates that palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients’ illness and in their grief;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance the quality of life, and may also positively influence the course of illness;

- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to understand better and manage distressing clinical complications.

Clarifications to 2002 definition: in 2014

1. Palliative care is needed in chronic, as well as life threatening conditions

2. There is no time limit or prognostic limit on the delivery of palliative care

3. Palliative care involves three levels: the palliative care approach; general palliative care; specialist palliative care

4. Palliative care can be delivered in any setting

Box 1: Palliative care

1.1.2 Palliative care in Africa

It is estimated that there are more than half a million annual deaths from cancer in Africa and that by 2020, 70% of new cancer cases will be in the developing world (Harding and Higginson, 2005a, Harding et al., 2013a). In Africa, the majority of the palliative care facilities came into being in response to the pandemic HIV/AIDs (Sepúlveda et al., 2002). However, there are vast disparities in the service delivery of palliative care across Africa in the areas of capacity, the range of service provision, and accessibility (Clark et al., 2007). Countries in Africa where palliative care is well established include Uganda, South Africa, Ethiopia, Tanzania, and Kenya (Manicom, 2011, Swartz, 2015, Aga et al., 2009, Kipp et al., 2007, Selman et al., 2013, Malloy et al., 2011). South Africa and Uganda, Africa's leaders in palliative care, are ranked 34th and 35th respectively per the 'Quality of Death' index out of 80 countries becoming more established, while Ghana is in 54th position (The Economist Intelligence Unit, 2015). The score evaluates the quality, availability and the cost of end-of-life care as well as the basic end-of-life healthcare situation of

each country. Some of the challenges facing palliative care in Africa include weak or non-existent government policies, lack of education on palliative care, and unavailability of (and or expense of) essential drugs such as opioids (Ddungu, 2011, Stjernswärd et al., 2007, Powell et al., 2011). However, in 2011, Rwanda was the first African country to inaugurate a national policy for palliative care as well as a strategic plan and operational programme that aimed at improving the quality life of cancer and HIV/AIDS patients and their families (Ntizimira, 2018).

Some researchers (Burton et al., 2012) have recommended the need for more in-depth investigations into the kind of support required for home-based palliative informal family care taking into account the cultural understandings of care. For example, Abel and colleagues (2013) uphold that the immediate social network mostly influences the care of the individual. In what they described as the *circle of care* (see figure 1), they indicate that the individual is at the centre of care and he/she is circled by 'porous' layers of care provision that altogether influence the care received.

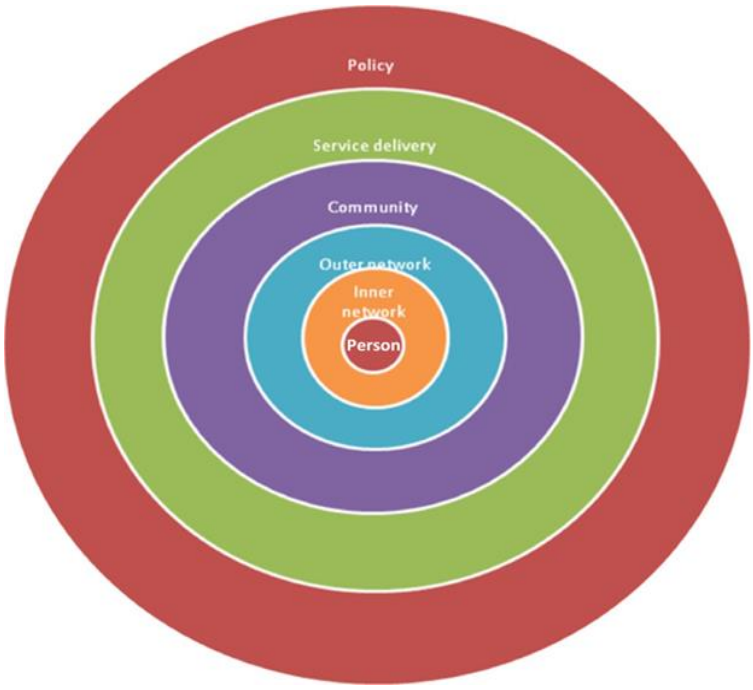


Figure 1: Circles of Care Abel at al. (2014)

Most West African countries do not have any palliative care services, except Gambia, Ghana, Mali, and Nigeria with varying degrees of palliative care provision. Cote d'Ivoire is the only West African country with a generalised palliative care provision, where such services are decentralised and integrated into the health system (Powell et al., 2014). Lack of research on palliative care practices in resource-limited contexts conceals the challenges and means that there is no evidence base upon which to build policy (Clark et al., 2007). Even in resource-rich countries, literature highlights the multidimensional needs of patients and caregivers throughout their care role (Selman et al., 2013, Lawton, 2002, Mehta et al., 2014, Lowther et al., 2015, Hudson et al., 2010, Kirk et al., 2004). This study, therefore, explores the understanding and the experience of the home-based informal family care in a non-westernised context.

1.2 The Ghanaian context

1.2.1 Socio-demographic data

Ghana is an Anglophone country located on West Africa's Gulf of Guinea with an estimated surface area of 238,540 (square kilometres). This comparison implies Ghana's total land surface area is almost equivalent to that of the United Kingdom's 243, 610 square kilometres (UK's population is about two and a half times bigger than Ghana). The World Bank ranks Ghana as a lower middle-income country with an estimated population of approximately 28.21 million comprising of 48.8% males and 51.2% females (World Bank, 2016). The estimated proportion of the people that fall between the ages of 30 and 70 years is 30.9% with an average life expectancy of 61 years (WHO, 2014). Generally, Ghanaian women have a lower socioeconomic status compared to men with a national literacy rate of about 71.5%. The national daily minimum wage is GH₵ 8.80 [£1.36], and approximately 24.5% of the population lives below the poverty mark of $1.25 per day (World Bank, 2012). According to the Ghana Statistical Service [GSS] over 80% Ghanaians work in the private informal sector and this together with the formal private sector constitutes 93.1% of the entire workforce in Ghana (Ghana Statistical Service, 2012). In the

private informal sector, 45.8% are farmers out of which 95.1% are crop farmers usually for subsistence purpose. Ghana's population is denser in the lower half of the country, and the population of each region is shown in Figure 2.

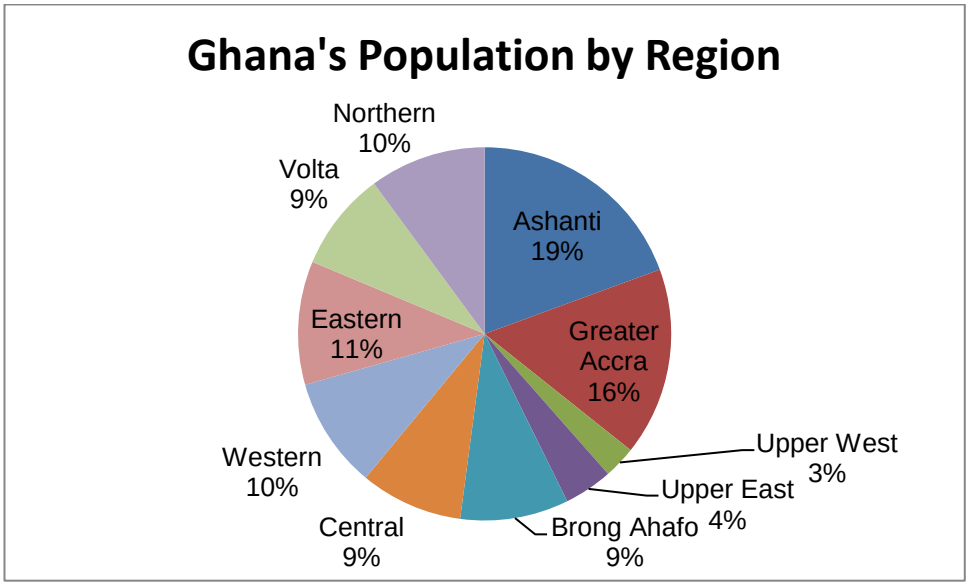


Figure 2: Ghana's Population in percentages

As indicated in figure 1, the Ashanti region (research setting) is the most populous region followed by the Greater Accra region where the capital of Ghana, Accra is located. Statistically, 50.9% of Ghanaians live in urban areas while the remaining 49.1% live in the countryside. The Ashanti region has a land surface of 24,389 km^2 and the second largest region.

Ghana is a multi-faith country. Religious beliefs affect health-seeking behaviour including needs for care provision in Ghana (Binka et al., 2018) as well as the coping with illness (Maliski et al., 2010b, Phelps et al., 2009). The main religious groups in Ghana are illustrated in figure 2.

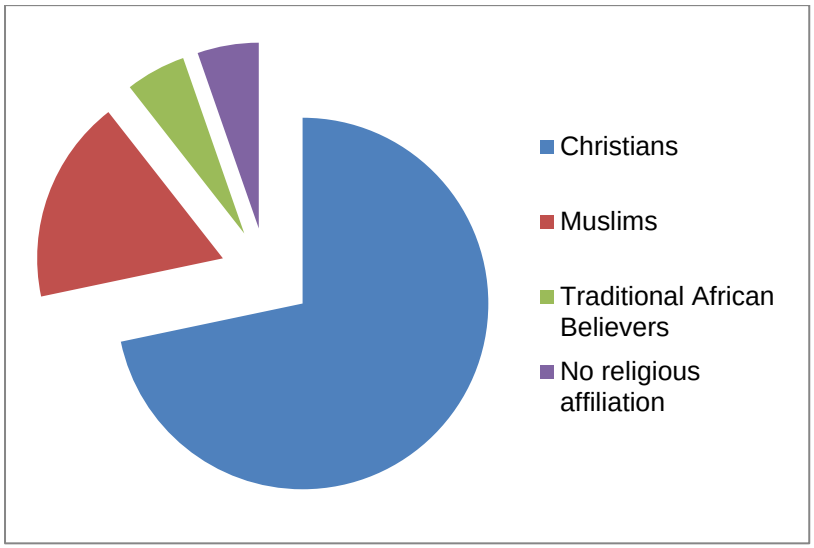


Figure 3: Religious Groups in Ghana

1.2.2 Ghana – Health Care system

The Ministry of Health (MoH) mainly oversees the provision of health care services in Ghana and the Ghana Health Service (GHS), with religious health facilities, private hospitals, and civil societies supplementing the care in underserved communities (MoH, 2011). However, there are vast variations in health care delivery in Ghana because most major hospitals and pharmacy shops are located in urban areas whereas the rural areas usually do not have modern healthcare facilities.

Each of the ten regions in Ghana has a regional hospital that serves as a referral centre in that region, but only four of the regions have teaching hospitals. The four teaching hospitals have the state of the art equipment for health care delivery such as screening various cancers. However, only two of the four teaching hospitals provide palliative care for cancer patients. There is a National Health Insurance Scheme (NHIS) in Ghana which was operationalised in 2005 to provide financial access to health, but this is subject to registration and an annual renewal to be eligible for free health care. In accordance with Ghana's Legislative Instrument (LI) 1809 Schedule II part I & II, the National Health Insurance Authority (NHIA) has a list of services that should be covered in the NHIS (NHIA, 2013), but this does not cover the treatment of cancers, except for cervical and breast cancers which were

included in its most recent policy on benefit package. Consequently, patients with prostate cancer and their families are responsible for the cost of medications such as chemotherapy, Prostate-specific antigen (PSA) test, radiation therapy, hormone replacement, and other in-patient services.

1.2.3 Palliative care in Ghana

Annually 16,600 of cancer cases are recorded in Ghana with estimated 12,700 cancer deaths in 2008 (Ministry of Health, 2011). It is projected that the figure could be higher due to low awareness that results in the late report of cases to the hospital.

Ghana, like many African countries, does not have recognised palliative care services integrated into the healthcare services across the country (Burton et al., 2012, Clark et al., 2007). Ghana is still at a fledgling state of palliative care provision although the need for such services has gained attention due to reports of an increasing number of cancer cases (MoH, 2011). Palliative care in Ghana commenced in 2006 following some lessons learned from other African countries such as Uganda and South Africa through stakeholder meetings. There was very little palliative care activity in Ghana before 2003. In 2006, the Ghana Palliative Care Association (GPCA) was formed. Two major teaching hospitals provide the palliative care services namely; Korle Bu Teaching Hospital (KBTH) and Komfo Anokye Teaching Hospital (KATH) (see Appendix A). They provide hospital-based palliative care services for the entire nation. Palliative care services at KBTH and KATH were established in 2012 and 2015 respectively, and there are Palliative Care Teams (PCTs) responsible for the care of both in-patient and outpatient care. The PCTs are multidisciplinary teams comprising oncologists, nurses, pharmacist, psychologist, social workers, and chaplains. However, the services provided by the PCTs are not a 24-hour service and only operate on selected days in the week. For example, the KBTH PCT clinic runs on Mondays and Thursdays for outpatients and in-patients respectively. The in-patients are usually found across many different wards in the hospital because there is no designated ward for such patients. The PCT members, therefore, attend to those in-

patients upon referral. As a result, family caregivers at home care for men with prostate cancer requiring palliative care and they (PWAPC) report only to the hospital when the condition deteriorates or for example, they are visiting the hospital for chemotherapy or radiotherapy.

KATH PCT clinic is relatively new and operates on Fridays only. The team is still under development, and they do not have a permanent unit for its operations. They also do not have a designated ward for the care of palliative patients. Their primary duties are to attend to the palliative care needs of patients mostly on an outpatient basis and attending to in-patients on admission by managing pain and other symptoms and providing supportive care. The two PCTs rarely do home visits to check on discharged patients receiving home-based continuity of care. There are many resources and operational challenges to the professional delivery of home-based care by healthcare professionals (HCPs) (Gyakobo et al., 2015). These include having no clear policy guidelines for care, insufficient funding, the high cost of medicines including morphine for pain control, inadequate bed space to admit more palliative patients at the hospitals, and late referral of patients to the team for management. Moreover, KATH has identified some operational challenges such as not being able to carry out home visits due to time constraints, limited staffing, and time to travel but also factors such as the unavailability of a vehicle for that purpose; some patients live miles away from the hospital.

Under the circumstances, palliative care is currently only available in a minimal outpatient and inpatient basis, and there are no community-based palliative services or health professionals who are mandated to provide support and care for PWAPC and their caregivers at home. Family caregivers who may best be described as the ‘general practitioners’ of the patients, therefore, care for most patients. They take the most significant responsibility for the care most of the time. As already noted, the family caregivers continue to have a substantial care role to play if the patients are admitted to the hospital for care.

Specialised palliative care services are recommended by the European Association for Palliative Care (EAPC) to offer in-patient services at home or

in a home-like environment (Inbadas et al., 2017); however, Ghana lacks such facilities even at the hospital. Palliative care in Ghana is affected by the organisational capacity to admit in-patients, geographical distribution of the services, and the type of palliative care services available (Gyakobo et al., 2015). There are no community-based palliative services in Ghana where PWAPC and other patients could receive care. Unlike the UK, where specialised palliative care services are provided by the National Health Services (NHS) as well as independent hospices, Ghana has no such facilities. An expert recommendation by the EAPC suggests that for every 100, 000 population there should be one home care team, and for every 200,000 people there should be one in-patient dedicated palliative care services units and one hospital support team (Inbadas et al., 2017). The recommendation of the EAPC means that Ghana with an estimated population of about 25 million, there should be about 250 home care teams, 25 in-patient SPC units, and 25 hospital support teams to provide effective and high-quality care.

1.2.4 Cultural Beliefs and Health-seeking behaviour

In most African countries including Ghana, the belief in supernatural and evil powers causing diseases is still relatively common especially when the condition is a chronic and life-threatening one such as advanced cancer (Van Dyk, 2001, Matthews et al., 2002). As an author notes:

> The cultural association of male superiority, the importance placed on virile masculinity, and the linking of sickness with a supernatural encounter (ancestor, evil spirit, or deity) all contribute negatively to the male attitude with regard to health and foster a reluctance to seek medical care (Hayes and Bornman, 2018).

These beliefs held by patients and their families might influence them to explore alternative cures such as seeking the services of traditional medical practitioners, and faith healers (MoH, 2011). For this reason, patients may be accessing 'treatment' that might be detrimental to their health.

As noted in section 1.2.1, cultural beliefs affect how people react to and cope with illness. In a study to explore the socio-cultural content of decision-making among bereaved relatives who have lost their loved one to cancer, Githaiga, and Swartz (2017) indicate that cultural beliefs affect people's health-seeking behaviour, and care provision. For instance, it has been reported in Ghana that impotence (one of the cardinal symptoms of advanced prostate cancer) is an issue people are reticent to talk about because of stereotype about masculinity and prostate cancer stigma (Amidu et al., 2010, Adinkrah, 2012). In Ghana, there are issues around help-seeking given that prostate cancer is widely rumoured to be a disease of men who are promiscuous (Obu, 2014a). So where masculinities of men are severely challenged, for example, due to loss of economic control, a break in patriarchal custom, and sexual incompetence some men commit suicide to avoid the shame and embarrassment and to maintain their cultural dignity (Andoh-Arthur et al., 2018, Adinkrah, 2012).

In Ghanaian society, there is a strong belief in the reciprocity of care when one needs help because of ill-health or incapacitation especially among blood relations (Brown, 2015). This belief has been demonstrated in the work of Brown (2015), who used a common Ghanaian local expression to emphasise how caring is an expectation from society. Brown (2015) states: *"Sɛ wawofo hwɛ wo ama wo si ɛfifi a wo nso hwɛ no ɛma ne se ntutu"* (If your parents have taken care of you for your teeth to develop, you must also care for them until their teeth fall out).

It is important to note that family caregiving in Ghana, just like other African countries, is primarily a gendered responsibility. Caregiving is mostly believed to be the duty of women; the wives, daughters, sisters, and mothers of the sick patient (Tarimo et al., 2009, Kipp et al., 2007, Sanuade and Boatemaa, 2015). In some cases, the family caregiver has to relocate and adjust their routine to take care of the sick. Consequently, the caregivers (usually women) face challenges as they navigate to provide care to a sick family member. Providing care towards the end of life of a relative is considered as a socio-cultural responsibility of the family, and society believes it to be a sign of love and an obligation. Others also provide care towards the end of one's life for fear of

‘post-mortem retribution’ [the ability of dead relatives to punish (and reward) the living] (Hanrahan, 2018).

1.2.5 The low up-take of prostate cancer screening in Ghana

More than two-thirds of Ghanaian men present prostate cancer at a very late stage where local invasion and metastatic spread has already occurred (Ministry of Health, 2011). The late presentation has been attributed to the lack of awareness of prostate cancer screening. Inadequate facilities for detection and the cost of screening further serve as barriers for seeking health care (Obu, 2014a). As a result, patients are likely to report to the Hospital at an advanced stage of the disease when they have started to experience symptoms such as difficulty in urination, pain, and impotence. Alternatively, doctors may suspect and detect prostate cancer when the patient is seeking care for other health problems. When prostate cancer has become advanced, its management becomes complex, and often, the cost of treatment is high. As noted earlier, the incidence of prostate cancer is high, occurs at a comparatively younger age, and more aggressive in black Africans and African Americans (Chu et al., 2011, Hayes and Bornman, 2018). This might present more financial difficulty because patients are still likely to be of working age (Dassah et al., 2018, Gott et al., 2015). This might lead to emotional problems, for example, as the men gradually lose their ability to maintain family responsibilities, as well as experiencing a decline in their sexual relationship.

The clinical incidence of prostate cancer is increasing in Ghana (Yeboah et al., 2016). Few private health facilities such as Medi-Moses Prostate cancer offer some screening and treatment mainly using PROSTACURE Herbal tea. The cost and affordability of prostate cancer care services in Ghana is a substantial issue based on the average income of the Ghanaian worker, as detailed under socio-demographic data above. Without adequate support from the health professional in delivering home-based care, we do not know how the care is done and that is what this work sought to establish. This study explored how care is done, why the care is done that way and whether or not the care meets the aspirations of the patients and those who matter to them.

1.2.6 My perspective

I am a Registered General Nurse (RGN) in Ghana with ten years of experience consisting of eight years of clinical work and two years of teaching. That experience brought me to encounter Komfo Anokye Teaching Hospital (KATH), one of the two teaching hospitals that have started institution-based palliative care for cancer patients. My role as a clinician drew my attention to cancer patients who attend and receive care at the hospital. Most of the patients are usually treated for their acute medical conditions, and they are then discharged home for their family caregivers to assume care with little or no supervision from health care professionals.

Similarly, during my teaching role, nursing students have shared their experiences about cancer patients who were discharged, but patient and caregivers reported that they had little or no information about how to handle the care at home. Questions that I had in mind then was how are care done at home and why the care is done that way? Whether or not the care meets the care needs of PWAPC and their caregivers.

These questions aroused my interest in finding out how these patients and their caregivers navigate their way through the process of providing care at home. With my professional background, I believed I would be in a position to negotiate access to patients and family caregivers, in seeking to understand their experiences and develop understandings of how we might establish improving support for the informal care provided to patients at home.

1.2.7 The thesis structure

- **Chapter 2** is the literature review and provides an overview of prostate cancer, its stages and the treatment options available for men living with prostate cancer. It goes on to provide context for relevant research work in home-based care for advanced prostate cancer. Then gaps were identified to pave the way for this research alongside justification for this study.

- **Chapter 3** describes the methodology, methods and study design that cohere with the philosophical underpinning of this study. Ethical procedures and ethical issues are explained, reflection and reflexivity are also detailed in this chapter. In addition, particular attention has been paid to all efforts that ensured the trustworthiness of the study.

- **Chapters 4, 5, and 6** form the 'Findings Chapters' each dealing with key analytical themes identified from the findings of the research as follows:

    - Chapter 4 is the first of the findings chapters, and it is themed ***Managing care in a resource-poor Setting*** and the perspectives of healthcare professionals about home care and palliative care. This chapter talks about the financial challenges, mobilising resources for care and the gaps in care provision.
    - Chapter 5 is concerned with ***Family Caregiving.*** The main issues addressed in this chapter are the practical and emotional aspect of care, how caregivers navigate the day-to-day care and the disruption caused by the effects of the illness on the family. It concludes by looking at how the family cope and deals with the challenges identified.
    - Chapter 6 is the last of the findings chapters, and it examines ***Cultural response: Stigma and Masculinity***. This chapter is divided into two: the first section presents findings of prostate cancer stigma, and how men and their caregivers respond to stigma. The second section examines how prostate cancer affects the masculinity of men living with prostate cancer, and how links to stigma.

- **Chapter 7** summarise the key findings and relate this to policy, research, and practice implications. It concludes with recommendations for palliative care in Ghana PWAPC and their families.

CHAPTER 2

2 Literature review

2.1 Introduction

This chapter is divided into two main parts to provide an overview of advanced prostate cancer and a literature review of relevant studies about home care for advanced prostate cancer. Following a wide-ranging review of the experiences of caregivers and patients in receipt of home-based informal care, this section presents the results of a narrower appraisal that focuses specifically on the published research addressing the experiences of home-based palliative care for patients with advanced prostate cancer and their family caregivers. The purpose of the review in this section was to evaluate research on home-based palliative care for advanced prostate cancer patients and to identify gaps in knowledge to pave the way for this current research.

2.2 Section 1: Overview of prostate cancer and its Treatment

2.2.1 Definition

Prostate cancer is a malignancy of the prostate gland, a walnut-sized structure found in males, located behind the urinary bladder and in front of the rectum. The prostate gland secretes prostatic fluid, and the gland together with seminal vesicles and the testicles produce the semen (Brunner et al., 2010). When the prostate is enlarged (Benign Prostate Hypertrophy, BPH) or cancerous, it produces Prostate Surface-Antigen (PSA). In prostate cancer, there is prostatic cell growth (excess enlargement) because of *dihydrotestosterone* derived from *testosterone*. This enlargement causes varying degrees of obstruction to the urinary urethra (see figure 4) and causes symptoms such as urine retention and or frequent scanty urination, and pain when it becomes advanced.

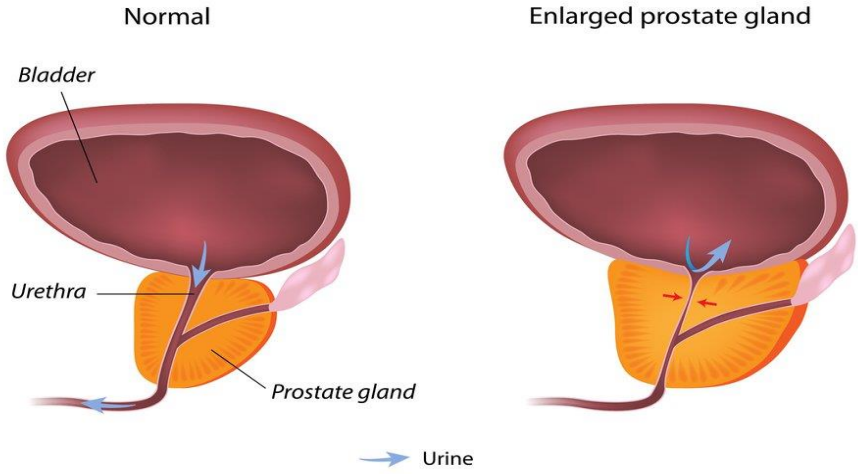


Figure 4: The Normal and Enlarged prostate *Photo* source: NHS

2.2.2 Risk factors

Ageing is a key risk factor (after age 50 and about one-third of cases in men above 65 years). It affects people of the African American ethnic group higher than other ethnic groups. The incidence increases where a person has other close family members who have been diagnosed with prostate cancer (Brunner et al., 2010).

2.2.3 Staging of prostate cancer

One of the standard clinical grading system in clinical practice for prostate cancer is the Gleason Score (Epstein et al., 2016, Heidenreich et al., 2014); however, evidence shows disagreement between the Gleason score[2] (based on needle biopsy) when the prostate is examined as a whole (Sved et al., 2004). Other classifications typically used in Ghana such as the TNM system and the Jewett system classify prostate cancer by the degree of primary cancer/tumour (T), the involvement of lymph node (N) and whether or not there are metastases (M). For this study, prostate cancer is classified as:

[2] Gleason score is a grading system used to determine the aggressiveness of prostate cancer. It ranges from 1-5 and describes how much the cancer from a biopsy looks like a healthy tissue (lower score) or abnormal tissue (higher score).

STAGE I: The cancer cells are confirmed *at a single* small part of the prostate within the prostate gland.

STAGE II: The cancer cells are found in one or both lobes of the prostate gland.

STAGE III: *Localized Advanced Prostate Cancer*. This stage is where the cells of the prostate cancer have spread beyond the shell of the prostate gland to the tissue surrounding the prostate, except the lymph nodes.

STAGE IV: *Metastatic prostate cancer.* In this type of cancer, either the lymph or both the lymph nodes and distant organs and tissue from the prostate for example rectum, bones, liver, brain or lungs are affected through *metastasis* (spreading to other organs away from the point of origin).

2.2.4 Advanced prostate cancer

Prostate cancer is 'advanced' if it overgrows in size and the cancer cells spread to other parts of the body through blood or lymph nodes. Therefore, advanced prostate cancer in this study refers to patients who had been diagnosed as having either Stage III or IV prostate cancers as described above. PWAPC have signs and symptoms such as:

- Erectile dysfunction
- Urinary incontinence
- Pain
- Urethral and bladder outlet obstruction (poor urine stream, the frequency of urination and at night, blood in urine and scanty urination.)
- Anxiety and depression
- Anaemia
- Chronic renal failure
- Loss of sex drive (libido)
- Spontaneous Pathological fracture
- Nausea
- Other symptoms related to tissue metastasis

Further information on the overview concerning the treatment of advanced prostate cancer is presented in the preface (page xiv).

2.3 Section 2: Review of relevant literature

There is an increasing burden of chronic illness and infectious diseases, such as TB/HIV in low and middles income countries, as well as non-communicable diseases (NCD) such as cancers. There have been many studies in Africa on TB/HIV, but not on NCD. Among the cancers, also, there is no study that has explored the care needs of men with prostate cancer and their care caregivers as compared to TB/ and HIV. Although prostate cancer disproportionately affects African men, there is a lack of knowledge about the needs and interventions for this specific group (Adeloye et al., 2016a). With a projected rise in life expectancies and urbanisation in Africa, the burden of prostate is expected to increase compared with other cancers/ illness.

In this chapter, the literature review is very focused on home-based palliative care, especially for men with prostate cancer due to the unique symptoms men with prostate cancer have. However, further discussions of wider literature that relates to specific issues such as stigma and masculinity are also presented later in the chapters.

2.3.1 Review Question

To achieve the purpose of the review, I used the following question to guide the literature search: What evidence exists on the experiences of patients and their caregivers living with and managing advanced prostate cancer at home in resource-limited contexts such as Ghana?

2.3.2 Search Strategy/ Eligibility for reviewed papers

The strategy used for the search was developed by combining keywords such as ‘prostate,’ ‘experience,’ ‘home care,’ ‘palliative’ and ‘caregivers.’ Results were exported to reference manager software (Endnote), and Appendix 0 indicates the keywords used for the search. The eligibility of the papers used is shown in Table 1 below.

Table 1: Eligibility for included papers

Inclusion criteria	Exclusion criteria
Articles published in the English language.	Papers published in other languages.
Papers that used qualitative methods	Quantitative studies, mixed methods with more quantitative emphasise.
Adult patients and caregivers	Children and paid caregivers
Research conducted at home-based or community setting.	Hospital-based or institution based settings.
Papers that included patients or caregivers of prostate cancer patients as participants.	Papers in which patients and or their caregivers are not participants
Papers that emphasised on experiences about care and caregiving.	Papers that do not include care.

The databases used for the search included Cumulative Index of Nursing and Allied Health Literature (CINAHL), MEDLINE, ASSIA, EMBASE, WEB of SCIENCE and the Cochrane Library, and the reference lists of related reviews. CINAHL, for instance, has been known for its greater depth of collating qualitative nursing research and hence its usefulness in this search.

The selection process was in two phases. First, the title or abstract of each identified article was assessed against the inclusion criteria. Then those articles that met the requirement were retrieved together with reports that did not have adequate information in the abstracts to determine eligibility. Finally, the extracted texts were then rigorously vetted to determine a final selection of papers matching the inclusion criteria.

The search was initially limited to an African context but most databases recorded zero with CINHAL recording four papers related to palliative care for prostate cancer. The search was then expanded to include papers from a broader perspective and to look at other conditions needing palliative care in resource poor environments. The search generated 6158 possibly relevant

articles. Papers rejected after reading the title and or abstract, and duplicates were 6059. Further reading of papers led to 79 out of the 99 articles failing to meet the full inclusion criteria, so they were removed at that stage. Reasons for the rejection were as follows: papers that were not about home-based informal family care (n= 46) and papers with participants other than family caregivers or patients (n = 33). Figure 5 shows the flow chart of the search process. Twenty papers were included, and this is presented in Appendix 0.

Out of the twenty included studies, seven were carried out in the United Kingdom (UK), six in the United States of America (USA), three in Canada, and one each in Australia, New Zealand, Norway, and Togo (Africa). There were 14 qualitative studies and six systematic reviews. Out of the 14 qualitative studies, seven recruited family caregivers as participants, six used patients, and one used patients and their caregivers. The specific qualitative approaches used for the 14 studies were as follows: descriptive (n=2), photovoice methodology (n=1), grounded theory (n=1), phenomenology (n=3), narrative (n=1), exploratory (n=1), and cross-sectional (n=1). However, four studies did not specify the qualitative approach they used.

All six systematic reviews did a quality assessment of the papers they included in the study. Three of the systematic reviews looked at the experiences of only family caregivers while the other three explored the experiences of both caregivers and patients.

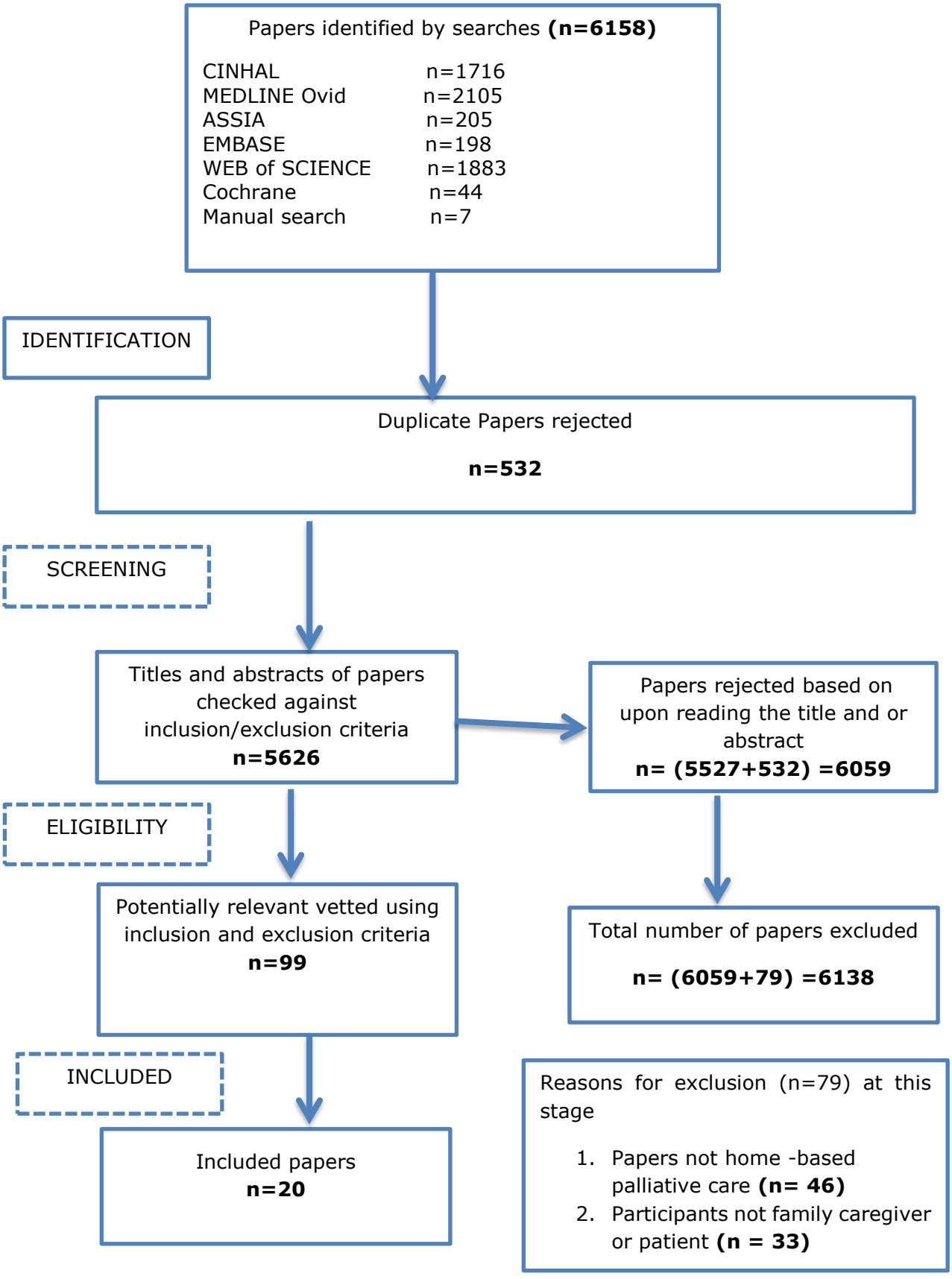


Figure 5: Flow chart of the search process

2.3.3 Synthesis of literature and discussion of common themes

The analysis and integration of the included papers resulted in three major key themes. This discussion looks at each of the significant key themes and the impact of the themes identified in the resource-poor context. The three important themes are care or caregiving, enablers/barriers to care and the cultural importance of providing care. Again, the discussion of the themes is focused mainly on the 20 papers reviewed all of which in one way or the other incorporate caregiving for prostate cancer or experience of it or home care for terminal cancer. I also drew on a more extensive relevant body of literature to contextualise and back up some points.

Theme 1: Care/Caregiving

Out of the 20 studies, 19 identified and examined the key theme: care/ caregiving. The literature suggests that caregivers encountered some level of exhaustion and lacked adequate sleep, the need to be healthy and courageous to provide care, and they experienced difficulties in providing the care required. Caring for patients with terminal cancer also means that caregivers are usually confronted with emotional challenges. The caregiving role is associated with considerable changes in the familial function and presents challenges about making decisions about care and working with other family members. Literature suggests that providing care for a cancer patient for the first time can lead to apprehension and anxieties, as caregivers aimed to ensure they were providing the 'right' care. Some studies suggested that caregivers use a process of *'trial and error'* as they care (Totman et al., 2015, Stajduhar et al., 2013).

Again, some caregivers may in addition to caring for the patient, need to care for children (Seal et al., 2015). Thus, most caregivers are 'sandwiched' between meeting the needs of their children and that of the patient. Lack of support was identified as a significant source of burden for caregiving and overburden caregivers could have fatigue (Totman et al., 2015). According to Sinfield and associates, (2012) exhaustion if not managed well could lead the patient getting into a hospital or a nursing care home. Caregiver fatigue could be a severe issue in the Ghanaian situation where home-based care is the only practical mode of providing care, at least, for the time being.

Studies identified caregiver needs in learning how to carry out care at home such as administering medication and lifting patient (Bessa et al., 2012, Funk et al., 2010, Funk et al., 2015, Paterson et al., 2015, Seal et al., 2015, Stajduhar et al., 2013, Ventura et al., 2014). It was interesting to note that some caregivers are actively seeking support to enable them to care (Ream et al., 2008, Funk et al., 2015, Stajduhar et al., 2010, Grande et al., 2009, Aoun et al., 2015, Paterson et al., 2015, Payne and Grande, 2013, Stajduhar et al., 2013, Ewing et al., 2013). This then raises the question about whether or not caregivers in Ghana also seek support given the limited health care professionals in palliative health care. What specific assistance will they find; how might these support needs be met or unmet and are the support needs similar to those outlined in the review studies, primarily carried out within resource-rich settings?

In a recent study to pilot a supportive navigation role by nurses to patients and their families with chronic disease in rural India, Pesut and colleagues (2017) discovered that weekly or fortnightly visits by nurses helped in early identification and resolution of issues regarding disease and symptom management, emotional and physical support, as well as advanced care planning. The nurse navigator helped address complex, and multi-faceted problems using available social, health, and informal community resources. The 2-year study gave nurses the time to record information about the patients and their caregivers, while also allowing them to provide advocacy and education, as well as mobilising resources for care (Pesut et al., 2017). The study reports high satisfaction of families and the patients and enabled patients who wished to die at home to do so, while also reducing the number of emergency department visits by patients. The study recruited 25 patients and 11 family caregivers, which might raise questions about the generalisability of the findings outside that context. The participation in the study brought palliative care services closer to the patients and their families, enabling them to remain in their familiar environment to receive care. Such person-centred care represents the core value of palliative care specifically and nursing as a whole.

Lack of information appears to add yet another layer of complexity to living with and managing prostate cancer. Lack of explicit information on prostate cancer makes both PWAPC and their caregivers feel anxious and troubled. Ironically, caregivers may not even know the sort of information they need, or where to find information to help them care. For example, Sinfield et al. (2012) used qualitative interviews and focus group on exploring caregivers' experiences of caring for prostate cancer patients in the UK. Their study indicated that a lack of awareness of sources of help and lack of understanding of information was a key barrier to care. Similar findings were reported by other studies (Hamilton and Sandelowski, 2004, Paterson et al., 2015, Stajduhar et al., 2013, Ventura et al., 2014).

Another important issue concerning care was the decisions caregivers make in home-based informal care including decisions about when to give necessary medications and feeling responsible for its consequences (Payne et al., 2014, Totman et al., 2015). A qualitative study by Payne and colleagues (2014) in England to explore how caregivers managed medications of terminally ill patients at home, found that caregivers have some fears about the administration of medicines, its effect and how they deal with any side effect. For example, they cited the regime as complex and had concerns about when to use 'as needed' medications. How caregivers deal with patients' medicines at home will be interesting to explore within the context of Ghana where there are fewer resources to support informal caregivers in such decision-making. At the current time, the members of the Palliative Care Team (PCT) do rarely visit the patients at home. Additionally, the illiteracy rates in Ghana (as noted earlier), lack of internet access across some communities (discussed at 4.3.1) and small cancer support agencies add to the problems faced by caregivers in this regard.

Theme 2: Enablers/barriers to care

Out of the 20 papers reviewed, only five talked about financial resources as a barrier to care (Bessa et al., 2012, Jones et al., 2011, Maliski et al., 2010a, Paterson et al., 2015, Payne et al., 2014). Three out of the five studies recruited African/ black American men as participants (one study was conducted in Togo and two in the USA).

To understand the sources of support and financial problems associated with prostate cancer care, Jones et al. (2011) conducted a study using 11 rural and 12 urban-based African-American men in Virginia and Maryland, USA. The study concluded that the medical health insurance of participants plays a vital role in cancer management. The medical health insurance, according to the study, reduced patients' worry about any financial obligation for the treatment because the health insurance helped absorb the cost of treatment entirely or taking a substantial part of it. Additionally, in a similar study with African American/black men with prostate cancer indicated that participants with a low-income and no insurance relied on their faith in God and support of others for financial help (Maliski et al., 2010b).

Financial cost implications are a serious concern, especially where the patients have no access to free health care or medical insurance. The problem seems complicated in a low-income setting as in the study of Bessa et al., 2012 that was conducted in a West African country, Togo where most people do not have health insurance. Hence, this could be very worthy of further inquiry in the context of Ghana where the treatment of prostate cancer is not covered by health insurance. The challenges of providing palliative care in a resource-poor setting are well documented (Onyeka, 2011, Clark et al., 2007, Harding and Higginson, 2005b), and limited resources for care affects the quality of life (Jansen van Rensburg et al., 2013). As will be discussed in Chapter 5, the family plays a core role in the provision of such care (Aboderin and Hoffman, 2015) and they have unique needs themselves and do require support and (Jack et al., 2015).

The faith of patients with prostate cancer and their caregivers, expressed through religion and spirituality. This was identified by (Angelo and Egan, 2015, Bessa et al., 2012, Jones et al., 2011, Levy and Cartwright, 2015, Maliski et al., 2010a, Paterson et al., 2015, Stajduhar et al., 2013, Totman et al., 2015, Ventura et al., 2014) as a significant source of strength in facing cancer. Faith may help overcome the anxiety and panic associated with cancer diagnosis. For instance, one study identified that belief in God was a resource employed

by some patients and caregivers to cope with the situation (Hamilton and Sandelowski, 2004). Faith or belief in God has been a resource drawn upon by caregivers and patients to cope with their situation.

The indigenous belief that prostate cancer relates to promiscuity stigmatises PWAPC and their caregivers, which stifle help seeking. Prostate cancer stigma links to aspects of masculinity in the Ghanaian context (Andoh-Arthur et al., 2018).

Furthermore, the mutual support between patients and their caregivers was found to be instrumental in facilitating the care experience (Hamilton and Sandelowski, 2004, King et al., 2015, Sinfield et al., 2012a). In situations where patients and caregivers lack support, it could increase the burden of care and loneliness. Some caregivers have expressed the need for respite care to allow them to have some rest (Ventura et al., 2014). Totman (2015) indicates that support offered to caregivers in their caring role reduces the sense of isolation and anxiety and encourages them to approach the caregiving with renewed resilience and hope. Men living with prostate cancer found reassurance by others to be emotionally supportive (Hamilton and Sandelowski, 2004). Jones et al., (2011) noted in their study conducted in the USA the need to signpost patients to available supportive resources. In the Ghanaian context, resources such as leaflets on managing prostate cancer is lacking, and this requires exploration of how families manage without such resources, and whether, there are other resources that they can draw on as alternatives.

Both patients and their caregivers employ various strategies to cope with the situation they find themselves. Most patients complain of deteriorating sexual ability, and side effects are affecting their daily lives, as well as their intimate and social lives (Ervik and Asplund, 2012, Krumwiede and Krumwiede, 2012, Sinfield et al., 2012a, Wu and Harden, 2015). The men are, however, reluctant to talk about it because of the sensitive nature of the topic (Krumwiede and Krumwiede, 2012, Paterson et al., 2015). Partners of prostate cancer patients have also been reported as needing support to adjust to changes in their intimate relationships due to the erectile dysfunction of their spouses (Paterson

et al., 2015). This worry seems to heighten if the partners are not sure where to seek advice. This will be highly relevant in a context (Ghana) where there will be particular issues around help-seeking given that prostate cancer is widely rumoured to be a disease of men who are promiscuous (Obu, 20214) and an issue people are reticent to discuss because of possible stigma (Amidu et al., 2010, Adinkrah, 2012).

Studies found that some men engage in activities such as gardening to have some respite from their emotional stress (Ervik and Asplund, 2012). A few studies found evidence in the belief that expressing these feelings is therapeutic and brings a great sense of emotional relief (Hamilton and Sandelowski, 2004, Levy and Cartwright, 2015). In many societies, however, norms of masculinity may lead to men enduring pain and suffering, and not to show signs of it. For example in Ghana, expressions such as 'barima ɛnsu' (men should not cry) are usually used to depict as a good sign of bravery (Andoh-Arthur et al., 2018). This, therefore, makes it essential to explore how men are expected to behave in the culture of Ghana and how relevant this might be in the care experience, health and help-seeking behaviour.

According to Funk et al. (2010) involving caregivers in care, and empowering them to be able to provide quality care knowledgeably is vital in boosting their coping strategies. Owing to the vast cultural differences among the areas, (where these studies were conducted), and the culture in Ghana, examining and identifying the coping strategy of the caregivers and patients has been be an essential consideration of the study.

Theme 3: The importance of providing care for the sick

Some PWAPC believe that they are dealing with a 'troublesome' body (Krumwiede and Krumwiede, 2012). Patients and caregivers may feel overwhelmed with their situation to the point that they lose the will to live or become withdrawn and depressed (Bee et al., 2009, Levy and Cartwright, 2015, Tanner et al., 2011, Totman et al., 2015, Ventura et al., 2014). Withdrawal from others and depression can lead to self-isolation and impact on quality of life for both patients and caregivers. However, the period of

caregiving or receiving care could serve as an opportunity to form and strengthen relationships as described later in section 0.

Five studies found evidence of positive aspects of the outcomes of care where caregivers identified caring for their loved ones as fulfilling and 'giving back time'. A 10-year review of qualitative research in this field by Funk and colleagues (2010) suggest that some caregivers regard the care experience as fulfilling regardless of the difficulties that characterise it. Although words such as 'burdensome' and 'stressful' are frequently used to describe the experience of care, it is crucial to keep in mind that some caregivers are satisfied with the care and describe it as an opportune time to demonstrate love, appreciate and give back to the patient. The care responsibility, therefore, may bring inner peace for caregivers and helps build an even closer relationship.

This reciprocity of care has been demonstrated in a study by Bessa et al., 2012 that sought to explore the perspectives of caregivers caring for their loved ones with cancer in Togo, Africa. Statements such as ‘it is my job’ (Bessa et al., 2012) and ‘you only have one chance to get it right’ (Totman et al., 2015) confirm the commitment of caregivers to help their loved ones. Reciprocity of care is a fundamental concept across some Western countries such as Sweden (Brobäck and Berterö, 2003) and the UK (Totman et al., 2015). In Ghana, reciprocity of care is highly cherished (Brown, 2015), especially when dealing with frail adults (Van der Geest, 2002). The social duty to support their loved ones in times of need is seen as a call to duty. This ‘duty’ is sometimes regarded as obligation caregivers must fulfil (Bessa et al., 2012). Some caregivers hold the view that neglecting the sick will result in an unpleasant consequences in their lives as already discussed in section 1.2.4. Such findings, therefore, highlight the importance of considerations of the cultural and societal expectations about family members toward caring for the sick, in differing contexts.

2.3.4 Summary and Gaps in the studies

Home-based care for patients with advanced prostate cancer is an understudied area in resource-limited countries, particularly given the infancy of palliative care and other health and social care support available. Among the gaps in literature were:

1) Most studies in the literature review were descriptive and lacked more in-depth analysis,

2) Studies were retrospective, for example, an experience of care after the patient had died, and

3) Generally involved patients or caregivers in non-African high socio-economic class who were usually affluent. Nevertheless, even in resource-rich contexts, patients and caregivers were reported to have complex unmet care needs as well as requirements for signposting them to sources of support. This issue raises the question of care need of patients and their caregivers in the Ghanaian context where such services and sources of support are at best limited and at worst non-existent.

Additionally, the majority of papers reviewed had participants with an average age of 65 years; however, in Ghana, it is known that prostate cancer happens in comparatively younger men of about 50 years. My sample included younger men compared to the studies I reviewed for different experiences.

Additionally, disparities in the health systems, provision of care, access to services and support systems between developed countries (where the majority of the studies were carried out) and Ghana may affect the applicability of these findings to other resource-poor contexts such as the latter. Again, most participants had the privilege of free treatment at the point of access (e.g., via the UK NHS) or were able to access medical insurance for their treatment. Hence, the need for a study in a resource-limited context such as Ghana where such free or insured medical care is not available for prostate cancer patients.

2.3.5 The significance of the study

The literature review suggests unmet needs in caring for cancer patients at home especially in areas such as how to care, information, and resources for care, practical and emotional support. The literature also suggests that differences in the care even in the westernised context where resources such as funds for palliative care are well developed. Overall, there is a lack of research that explored home-based informal family care in a non-westernised context.

This study is based on the opinion that the goal of developing palliative care in Ghana will not be achieved without the unique and critical role of home-based care for cancer patients, as well as family caregivers involved in the provision of the care. This study thus reveals some useful information to provide evidence-based quality care for patients and their families requiring palliative and terminal care within the socio-economic, cultural and political circumstances of Ghana.

The study that was found in the non-westernised context (Bessa et al., 2012), did not take into account the perspective of the patients or healthcare professionals. Another study in Ghana that attempted that endeavour only examined identifying characteristics of caregivers and the causes of the burden of providing care at home (Sanuade and Boatemaa, 2015). My study proposes to fill that gap by investigating what the home care experience looks like for PWAPC, their caregivers and the healthcare professionals and what can be done even to improve the situation.

Men living with prostate cancer do not have medical insurance covering their treatment[3]. Again, men are traditional heads of family units in Ghana and as part of their masculine norm to provide for their families' needs and as such prostate cancer might influence families socio-economically. Therefore, this

[3] The National Health Insurance Scheme (NHIS) do cover some treatments component for cancers such as cervical and breast cancer, unlike prostate cancer.

group (men living with prostate cancer) was thought to elicit a clearer and extensive experience of home-based informal care.

The Ministry of Health of Ghana has outlined a strategic plan for the 'control' of cancers close to a decade ago (Ministry of Health, 2011). No study has reported about the home care of cancer patients in general and prostate cancer specifically. Therefore, a study that examines the care needs of the patients and those of their family caregivers and health care professionals are not only timely but also necessary.

With the increasing incidence of cancers in Ghana (Laryea et al., 2014), and because of lack of hospices and limited institutional palliative care facilities in Ghana, this study may identify some training and support needs for caregivers and health professional involved in home-based care (Girgis et al., 2014). This study will provide an evidence base for healthcare professionals to provide the needed support and or care.

2.3.6 Chapter Summary

This chapter is in two parts: the first part looked at the overview of prostate cancer and the various palliative treatment used to manage prostate cancer. The second part has detailed an overview of the literature relating to advanced prostate cancer by exploring relevant and related studies. These studies were usually conducted in a resource-rich context and literature demonstrate a dearth of studies in resource-poor settings. The review was discussed under three main themes: care/ caregiving, enablers of/barriers to care, and the relevance of providing care to the sick, especially the head of the family unit.

It concludes by emphasising the gaps in the literature and justifying the need for this study especially in a resource-poor context where home-based palliative care in an unexplored topic. It also shows the aims and objectives of the research based on the identified gaps. Therefore, a qualitative study that seeks to understand the experiences of men living with prostate cancer, those of their caregivers, and healthcare professionals, as well as the role of socio-cultural norms in their care, is, therefore, essential. The next chapter discusses the methodological approach adopted.

3 CHAPTER 3

Methodology and Methods

3.1 Introduction

This chapter demonstrates how I have chosen the most appropriate methodological approach to meet the research aims and objectives. Then I will justify the philosophical underpinning and the decision about qualitative methods used to explore the experiences. The chapter also provides a description of, and rationale for, the choice of research design, methods of collecting data, selection of participants, access, data analysis process and management of data. It gives a detailed account of ethical considerations as well as the ethical approvals that were negotiated and offers clarity of the research process to demonstrate rigour.

This research aimed to investigate the experiences of home-based supportive and palliative care of PWAPC, their family caregivers and healthcare professionals in Ghana. Therefore, it was necessary to select a methodological approach, which would permit the elicitation and interpretation of participants' experiences of providing or receiving care. To achieve this, I used a qualitative methodological approach, underpinned by social constructivism to unravel the unique experiences of participants (Creswell, 2013, Mackenzie and Knipe, 2006, Becker et al., 2012).

3.2 The aim of the study

This study explored the experiences of men living with advanced prostate cancer in Ghana and the experiences of their family caregivers and Healthcare professionals. Throughout this thesis, the term home-based supportive and palliative care will generally refer to emotional or practical care for patients. As such, it will include the experience of handling incontinence and management of other symptoms, administration of drugs, management of side effects of medications including vomiting and nausea, pain management, pressure sore prevention and control, and nutrition. It also involve what the provision of such care means to PWAPC and their family caregivers.

Objectives

1. To explore the experiences of PWAPC receiving home-based care; what support and care they receive and to identify if/how care could be improved.
2. To examine the experiences and perceptions of family caregivers of PWAPC providing care at home.
3. To understand how caregivers manage care and the challenges this presents in the provision of emotional and practical care at home as well as coping strategies used.
4. To explore the experiences of healthcare professionals (HCP) regarding home-based care for PWAPC and their families and finding out what HCPs think the challenges are for PWAPC and family caregivers.
5. To explore the practice and policy implication for palliative care with the view to strengthen the palliative health care system and to enhance any existing support networks for PWAPC and their families in Ghana.

3.3 Philosophical underpinning: social constructivism

According to Creswell (2013), research is informed by some beliefs and assumptions, whether those assumptions are expressed or not. However, the declaration of these assumptions will help readers to follow the line of argument and know the extent to which the researcher's influence may represent in the findings. According to Crotty (2009) and Silverman (2011), the theoretical positioning of a researcher underpins the concept, the conduct, and interpretation of the research. They further argue that the academic orientation positions the researcher and the study within a specific point of view (ontology) and links with what is to be known (epistemology).

Many methods can be used to generate qualitative data (Macnee and McCabe, 2008, Creswell, 2012) but the technique should align with the methodology to ensure theoretical congruence (Mayan, 2009). From an ontological point of view, people's description and interpretation of realities are multiple; and interview either individually or in groups is one of the key routes to explore

multiple realities (Silverman, 2013). The researcher creates knowledge and meaning of participants' experiences (Ritchie et al., 2013) as they journey with the participants through their stories (Kvale, 1996).

As people, we create meaning and make sense to a greater extent, through our interaction and relation with others and our subjectivity is as important as our unique experiences (Baxter and Jack, 2008, Scotland, 2012). A constructivist perspective is rooted in multiple realities of which, from a subjectivist epistemological standpoint, the investigator and participant jointly create understanding (Denzin & Lincoln, 2005). Constructivists believe that there are as many constructions as possible (Guba, 1990). With constructivist perspective, the underlying belief is that realities are not 'out there' but instead 'reality' is constructed and shaped by social and cultural influences (Guba and Lincoln, 1989, page12). Guba (1990) further argued that there are many ways of looking at the same body of knowledge and so "*no unequivocal explanation is ever possible"* (page 25). The researcher acknowledges the importance of multiple realities and the need to represent the voices of participants (Creswell, 2013). In this study, therefore, the findings are a *creation* of all the participants and the researcher constructed in a specific social context of caring for men with advanced prostate cancer at home.

It is difficult to study people's experiences objectively especially in an exploration of this nature where complexity and context are essential (Walshe et al., 2004). It also implies that the constructivist researcher aims to understand the meaning of action(s) from the actor's point of view (Lincoln and Guba, 1985), rather than a prediction of cause and effect (Polit and Beck, 2013). Hence the aim of this research to explore the perspectives of PWAPC and their caregivers as well as HCPs about the provision and or receipt of palliative and home-based care. The theories of stigma and masculinity underpin this study. Again, how the social construction of illness impacts on the socio-cultural belief of prostate cancer has been examined.

3.4 Social Construction of Illness

Advanced prostate cancer disease manifest biologically; however, there are socially experienced aspects of it. The socially constructed experiences of PWAPC include managing stigma and the notions of masculinity as detailed at 6.2 and 6.3. The context within which prostate cancer is experienced and managed goes beyond the individual and connects to broader societal issues such as the resources available and the availability of palliative care especially in the home setting. PWAPC may all have urinary incontinence, for example, but the experience of that will vary depending on the social context and country where men live. The experience of prostate cancer and the attitude towards it is also socially constructed practice in Ghana.

Social constructivism roots from the interpretive paradigm and the central underpinning of social constructivism are the belief that realities are jointly constructed (Conrad and Barker, 2010). Illness and disease, according to this theory, will have different meanings and experiences for patients, and in part underpinned by differing socio-cultural contexts within which they live. As a nurse, I am drawing on such a sociological theory to help me understand the patients' grounded experience and not just the medical condition. Such understanding will ensure holistic care, which is a core aim of palliative care and a core aim of this thesis, to understand not only the patients' disease and symptoms but also the entire picture about how patients and their family members experience the illness trajectory.

Taking its root from medical sociology, the social construction of illness has been a valuable theoretical underpinning for research about health and illness in the last half-century and has led to unique broader understandings about the social dimensions of diseases (Conrad and Barker, 2010). Contrary to the medical model, which assumes that diseases are universal and invariant to time or place, social constructivism emphasises how the meaning and experience of illness is shaped by the cultural and social system (Conrad & Barker, 2010). Therefore, some diseases such as prostate cancer although biomedical disease may also have some socio-cultural undertone that needs to be considered in the management (Sulmasy, 2002, Kunkel et al., 2000).

One critique of the social constructivism perspective is that it overemphasises the social aspect of the disease. While it is usually difficult to draw a line between illness (socially constructed) and disease (biomedical condition), there seem to be the need to look at the experience of prostate cancer from the social as well as biomedical viewpoints that shape such experiences (Sulmasy, 2002). Scholars have investigated patients experiences of chronic diseases such as prostate cancer (Wood et al., 2017), Epilepsy (Szaflarski, 2014, Conrad and Joseph, 1983), HIV/AIDs (Herek et al., 2013, Tsai, 2015), leprosy (Rocha-Leite et al., 2014) and others and its effect on quality of life. Prostate cancer as a biopsychosocial disease (Sulmasy, 2002, Kunkel et al., 2000) therefore, needs to be understood in a holistic rather than a fragmented viewpoints. In the next section that follows, I argue how my philosophical underpinning fits well with the methodology and methods I used for this study.

3.5 Study Methodology and theoretical congruence

Mayan (2009) indicates that adherence to a method's procedures ensures methodological coherence. Generally, researchers in the health and social sciences use two primary research paradigms: qualitative and quantitative research methodologies. Whereas the quantitative research paradigm seeks to establish a *cause and effect* relationships between variables using quantifiable procedures (Polit and Beck, 2013), qualitative approaches, on the other hand, are concerned about the interpretations that people make about a particular experience (Carter and Little, 2007). This approach helps to understand the 'why?' behind the 'what? (Fossey et al., 2002a), aiming at 'identifying the variety of constructions that exist' (Guba, 1990). It is argued that personal experiences may be difficult to judge using a quantitative research approach since it does not take into accounts the individuality of human experiences (Macnee and McCabe, 2008). The qualitative method for this study helped to provide interactive discussion and relationship between the researcher and participants. According to Creswell (2013), the choice of qualitative research is appropriate if the study is required in a naturalistic setting, and multiple methods are used together to understand the phenomenon fully (Chamberlain et al., 2011). Creswell (2013) further states

that the use of qualitative study is suitable if the researcher seeks to unravel meanings that participants make, and when the voices of participants are to be taken into consideration such that their ideas form the building blocks of the themes rather than the researcher's ideas.

Additionally, qualitative research allows for a holistic explanation of the phenomenon, and the researcher acts as an instrument for the generation of data. It enables the researcher to do the necessary modification and changes as and when needed during the field work rather than following a rigidly designed questionnaire that may not be appropriate in the circumstances of the current study (Creswell, 2013, Fossey et al., 2002a, Macnee and McCabe, 2008). More importantly, a qualitative approach to research enables the researcher to collect data about emotions, significances, and values (Seymour et al., 2005).

Several qualitative research methodologies could have equally been adopted for this research. For example, a case study approach was explored as a possibility but deemed not appropriate because it will be difficult to attach healthcare professionals to the patient and caregivers' clusters. Undertaking an ethnographic study was also considered but potentially could be too challenging at a pragmatic level because the patients are geographically dispersed. It might be difficult to do adequate observations of several participants to understand their experiences in their domestic environment entirely. Hence the use of a general qualitative approach. The section that follows looks at the study design.

3.6 Design of the study

A single interview with participants whose condition is potentially sensitive limits storytelling; therefore, this study adopted a repeat interview technique. This study adopted an exploratory qualitative repeat study design using semi-structured face-to-face interviews to understand participants' experience of the cancer trajectory. Moreover, such study design is appropriate when the research seeks to explore complex experiences (Cordon and Millar, 2007). People construct and make meaning, often these changes over time, in the context of a particular social and economic constraint. A repeat in-depth

interview resonates with the clinical aim to provide continuity of contact with patients and their families, and usually, there is a dearth of such studies (Stajduhar et al., 2010). More importantly, the use of repeated in-depth interviews has been advocated for research that is potentially emotionally sensitive to participants or the researcher or both (Rowling, 1999) and has been employed in caregivers research (Payne and Grande, 2013).

Since patients with advanced disease can have sudden changes in their condition, the use of a repeat interview technique (Murray et al., 2009) helped in getting critical understandings into patients' changing experiences of advanced prostate cancer. As part of the flexibility of qualitative research, this study was prepared to interview patients and their caregiver(s) together if they so wish (Morris, 2001).

The repeat interviews were used for only PWAPC and their caregivers either as in-depth individual interview or dyad (Murray et al., 2009, Morgan et al., 2013). Twenty-three interviews in total were done during the first phase and 19 interviews during the second phase of the interviews with the period between 8 and 12 weeks apart. Four patients died during the study, hence the 19 interviews during the second phase.

The average of two months between the first and subsequent interviews was in line with the total time available for the data collection phase of this research. Moreover, the time gap between interviews was sufficient to allow better rapport with participants. The second round of interviews aimed to facilitate discussion of sensitive issues around living with and/or caring for advanced prostate cancer, that participants might be reticent to discuss initially due to unfamiliarity. The further interview with the patients and their caregivers also offered an opportunity to follow-up on issues in the previous interviews that were not clear. Murray and colleagues (2009) claim that repeat interview technique, when planned carefully, can resolve the theoretical and methodological concerns that most of us encounter. Furthermore, the repeat interview study was appropriate to the main aim of the research of exploring the experiences of home-based supportive and palliative care of PWAPC in Ghana.

Nonetheless, just like any other method of inquiry, repeat interview method is not without pitfalls (Murray et al., 2009). Firstly, there is the issue of ethical difficulties around seeking repeated consent and when the patient's condition changes, and could not participate in the study, or the patient dies. In this current study, four participants died. Secondly, the repeat interview could be distressing to a researcher having to engage repeatedly with emotional issues that patients and their caregiver go through. In this study, I had frequent debriefing sessions with my supervisors, and that was useful in dealing with most of the emotional issues that were encountered in the field. Thirdly, participants' attrition is a challenge in most repeat (serial) interview studies. Only four out of the 23 patient/caregiver participants (17.40%) did not take part in the subsequent interview due to the death of the patient (see Table 2 for a reason). The fourth problem with the repeat interview technique is the issue of volumes of data that could be overwhelming (Holland et al., 2006). To address this issue of data overload, I collated and analysed the interviews for the first and second phases in light of the research aim and objectives.

3.7 Study context and location

Participants were recruited through Komfo Anokye Teaching Hospital (KATH), in Ghana. KATH is located in the most populous region in Ghana, the Ashanti region with Kumasi as the capital town. The hospital is accessible through several road networks in Kumasi and almost surrounded by police quarters and a military garrison.

According to the Ghana Statistical Service (GSS), the Ashanti region has a total projected population of 4,780,380 during the 2010 population and housing census (GSS, 2012). Due to its strategic location in Ghana, the 1200-bed capacity Teaching Hospital serves the surrounding communities and receives referrals from about six out of the ten regions in Ghana. Therefore, KATH provides health care for a larger and more varied proportion of people in Ghana, and hence could be described as having ethnically diverse patients. In the context of Ghana, ethnic diversity means different indigenous tribes within the country because a specific tribal group dominates each region in Ghana. The Oncology unit of KATH is responsible for attending to most cancer cases. In this study, the Oncology Directorate and the Urology units of the Department

of Surgery were used as a point of contact to recruit participants (patients) registered as receiving home palliative care. Before ethical approval in Ghana, permissions to conduct the study at both the Surgery department (see Appendix D) and Oncology Directorate with reference number: KATH/ONC/11/16/001/RS (see Appendix E) were sought.

3.8 Ethical consideration

3.8.1 Ethical approval procedure

Beginning the fieldwork, I sought separate permission from the other directorates of the Hospital where some patient participants were to be recruited. However, the process was smooth, so it did not adversely affect the schedule of the work. An appropriate ethics approval from the Faculty of Medicine and Health Sciences (FM&HS), University of Nottingham (Ethics Reference number: F12092016) was secured, as attached at Appendix F. Additionally, a Certificate of Registration (Registration number: RD/CR16/247, [Appendix G]) from the Research Development Unit (RDU) of KATH was obtained. Then the copies of the certificate and the research proposal was then used, as a prerequisite, to apply for ethics from the Committee on Human Research, Publications and Ethics (CHRPE) at Kwame Nkrumah University of Science and Technology (KNUST), the affiliate of KATH, for another ethics approval (Ethics Reference number: CHRPE/AP/496/16) as per Appendix H

3.8.2 Ethical issues

I encountered and handled some ethical dilemmas during the data collection process. I was confronted with the ethical issues of the sensitivity of the topic, prostate cancer in men and torching on sad events in the lives of PWAPC and their families (This has been discussed further in section 3.13.5). There are significant ethical challenges when dealing with research of this nature because *of 'perceived cultural sensitivities associated with palliative care'* (Seymour et al., 2005 page 170). These issues were addressed as the study evolved as discussed below.

1. First, talking to family caregivers and patients about advanced prostate cancer, got some of them emotionally upset during the interview (DeMarrais and Tisdale, 2002) as well as caregivers (Robson, 2001). Participants were reminded that if they do not wish to discuss very sensitive experiences, they have the right to decline and can stop the interview whenever they feel uncomfortable. Conversely, the use of interviews in exploring opinions of patients and their caregivers has been noted to sometimes be therapeutic in itself as they share their difficulties (Gysels et al., 2008) but that was not my aim for using this approach. Being a nurse and a previous counsellor for tuberculosis patients, I have some expertise to debrief following an interview of a distressed participant. I then followed them up through a phone call to find out how they were faring later on. No participant needed the services of a professional counsellor, but if they did, there were plans in place to refer them to a nearby hospital or the counselling unit of KATH.

2. Second, the issue of having to interview participants at their home. There is no law on this in Ghana, however, I ensured my safety during home interviewing by keeping a log and informing someone each time I went to the field (participant's home) and when I was expected back. Again, a similar procedure was used for the interviews that took place at the Oncology Unit at the Hospital. That study setting was familiar to me, and subsequently, it did not raise the much personal safety issue. I had always carried my identification cards on my (Students' ID and Voters' ID) and showed it to participants if required.

3. There were several instances where I was caught in a professional and researcher role conflict. I noted some participants were carrying out procedures of care that I believed was not an appropriate practice based on my nursing background. For instance, during one of the filed work, I was told about the caregiver using face flannel in place of sterile gauze to clean a supra pubic wound.

4. Some patients or caregivers tried to seek some professional assistance from me knowing my background as a health worker. Dealing with such a situation with my 'researcher hat' was challenging. It is sometimes difficult operating at

the boundaries, being both a clinician and a researcher (although I was apparently in the setting as a researcher). In some instances, patients and/or their caregivers asked clinical based questions in the course of the interview, wanting me to inform them about clinical issues on their minds or that they did not understand. Usually, when clinical issue came out, I told them that I would come back to that and in some cases, and I try to talk to them after the interview. Primarily, however, I signposted them to the hospital for assistance.

3.8.3 Consent

I gave each participant an information sheet (a copy at Appendix I) that contained details of the research been undertaken. Again, before each interview, I explained the purpose of the study to all participants.

Enough time was given for participants to decide whether to participate in the study after they were given the information sheet. Participants were informed that the interview could be emotionally challenging and that they should think about it if they want to partake in the study. Where required I further explained the study and answered any arising issues.

The aim of the research was explained, thoroughly, to each participant in the language that the participant understands, and any potential benefits and risks explained before commencing the data collection. Consents were also sought to record the interview (see Appendix J for consent form).

I told the participants that the recording is to enable an accurate record of their account for the experiences each participant was informed about their right to opt out at any point in the course of the study without suffering any discrimination or consequences because of such decision. Before participation, each participant was required to consent as an indication of agreeing to participate willingly. Additional verbal permissions were requested to record the conversation.

3.8.4 Confidentiality

On confidentiality, I told participants that the data would be kept strictly confidential and some anonymised extracts from their interviews will be used in the report writing. However, in a few instances where care procedures were not being carried out properly and endanger life, the hospital was notified with the permission of the patient/family. Each participant was made aware that their personal data would be kept during the data collection period (averagely six months) so that they can be contacted for the repeat interview. I also informed participants that the data would be kept for seven years following the completion of the study and the data will be destroyed afterward.

The data were anonymised using fictitious names. All the 23 patients and their caregivers who participated in this study have their names replaced with pseudonyms, and none of the 12 health care professionals has any traceable identity in this report. To ensure this, I used composite stories so readers cannot readily identify the identity of participants. All recorded data was stored and password protected on a University on Nottingham server. In addition, all documents concerning participants are stored in a locked cabinet at the University postgraduate office. All potentially identifiable information was stored separately from the other data.

The participants were informed that a regulatory authority or the supervisors of the project might review their data. This information has been treated with the confidentiality policy of KATH, and the Data Protection Act 843 (Ghana Parliament, 2012) as well as the data policy of the University of Nottingham.

3.9 Access to study participants

As indicated earlier, three participants groups were recruited for this study; PWAPC, family caregivers, and HCPs, who were members of the palliative care team (PCT) at the hospital.

3.9.1 Sampling and Recruitment

A purposive sampling was used based on a set of criteria (as detailed in Table 2) and participants capacity to shed light on the research question at hand (Holloway and Wheeler, 2010). Where possible, I made efforts to ensure some

variation within the patient group (PWAPC) to get a broader perspective by considering age, educational background, and ethnicity of participants (Creswell, 2012). The Palliative Care Teams (PCTs) or staff working at the oncology or urology units were informed of the study's aims and objectives and they were the first point for identifying and making contact with potential patient participants. This was so because all the PWAPC have their health records at the directorates of Oncology and Surgery and therefore staff there best served as gatekeepers to contact prospective participants. After getting potential patient participants, they also became the second gatekeepers to reach out to their family member whom they believed was their primary caregiver.

Passing through the hands of "gatekeepers" has pros and cons but can avoid time wasting and difficulty in accessing participants (Giulianotti, 1995). The gatekeepers also can negotiate for participants' inclusion. However, they could as well erect barriers due to their time commitment and roles (Namageyo-Funa et al., 2014). They can also sway the kinds of participants recruited, by nominating those whom they see as ideal research participants who may not necessarily be so. The Komfo Anokye Teaching Hospital (KATH) has the records of patients, and by passing through the members of PCT (gatekeepers) at KATH, I was also complying with the confidentiality code as prescribed by KATH and the Data Protection Act, 2012 (Act, 843) in Ghana. The inclusion criteria for participants are shown in Table 2:

Table 2: Inclusion Criteria[4] for participants

	Participant	Inclusion criteria	Exclusion criteria
Eligibility	*PWAPC*	• Diagnosed with advanced prostate cancer. • Receiving care at home and willing to be interviewed. • Capacity to consent. • Speaks English or the local Ghanaian language I speak. • Willing to consent for his family caregiver to be approached.	• A patient participant who is seriously ill and unable to communicate or interviewed, as determined by HCPs • PWAPC who does not want to take part. • Patient with no family member willing to take part in the study. • A patient who cannot speak English or the local Ghanaian language.
	Family caregiver[5]	• Nominated by the patient. • Family member providing informal care to the patient. • At least 18 years old, with at least three months care experience •Willing to participate and capable of giving informed consent • Able to speak English or the local Ghanaian language. • Not providing paid service.	• Paid caregiver (family member or otherwise) • Caregiver less than 18 years. • Family caregiver not nominated by the patient. • Unable to give informed consent.
	Health Care professional (Palliative Care Team)	•At least six months of working experience. •Unit heads of Oncology or Urology units	

[4] Criteria for participants who qualify for the second phase of the interview was only patients and family caregivers. However, where a patient dies or withdraws from the study, the family caregiver will not be interviewed.

[5] Family caregiver a person related by marriage or by blood (parents, siblings or children) and having main responsibility for care.

3.9.2 Patient participants

The HCPs who served as gatekeepers spoke to potential PWAPC participants. Eligible patients who were willing to participate in the research were invited, after describing the purpose and data gathering method for the study to them. Due to the poor addressing system in the location for postal services, most patients were contacted phone call[6] (if he agrees so) through the members of staff at the oncology unit. A member of the palliative care team subsequently gave potential participants an information sheet, and the content explained clearly to them. Each participant was then allowed some time (for up to a week) to think about it or perhaps consult other people for their views about taking part in the study or not. Participants were then followed up by a phone call to confirm their participation. Those who confirmed were asked to choose time and place convenient to them to be interviewed.

3.9.3 Family caregivers

Family caregivers who are responsible for most of the day-to-day care of the patients were recruited after the patients had given consent for their primary caregiver to be approached. In this study, a family caregiver is an unpaid family member of the prostate cancer patient (wife, children, mother, and siblings) whom the patient considers as his primary caregiver providing hands-on care. The family caregivers were contacted with the permission of and through the patient (PWAPC). Family caregivers who agreed to participate were recruited after I provided them with additional information about the research To obtain rich and extensive information about the experience of practical care at home for palliative patients, caregivers who have done that role for at least three (3) months were included in the study.

[6] It is common for at least a member of a households to have a mobile phone in Ghana

DANQUAH, M. & IDDRISU, A. M. 2018. Access to mobile phones and the wellbeing of non-farm enterprise households: Evidence from Ghana. *Technology in Society,* 54**,** 1-9..

3.9.4 Healthcare professionals (Palliative Care Team)

Staff members were identified through the coordinator for the palliative care unit at the hospital (members of the Palliative Care Team). These care professionals were engaged in a focus group discussion. Though they did not provide direct home care for prostate cancer patients, PCTs' perspectives were useful. It provided an understanding of the different realities on home-based palliative care based on their experiences of talking with the patients and the family caregivers as demonstrated in similar studies (Giesbrecht et al., 2015, Worth et al., 2006, Almack et al., 2012, Johnston et al., 2009, Gysels et al., 2011). They were recruited through the nurse in charge of the Oncology unit after, I wrote to the team about this research. Members who agreed to participate were further provided with an information sheet and each member gave written consent.

It is important to note that the different group of participants in this study was recruited to explore as much as possible the multiple realities available (Creswell, 2013, Creswell, 2012), but not to triangulate the findings. Therefore, the information healthcare professionals gave provides a fresh perspective on the experiences of the patients and family caregivers.

Duration of study

The study lasted for at nine months, and this commenced following ethical approvals from September 2016 to May 2017. This duration was used to recruit participants, conduct and transcribe interviews and some initial analysis of the data. The recruitment process is outlined in Figure 4 below:

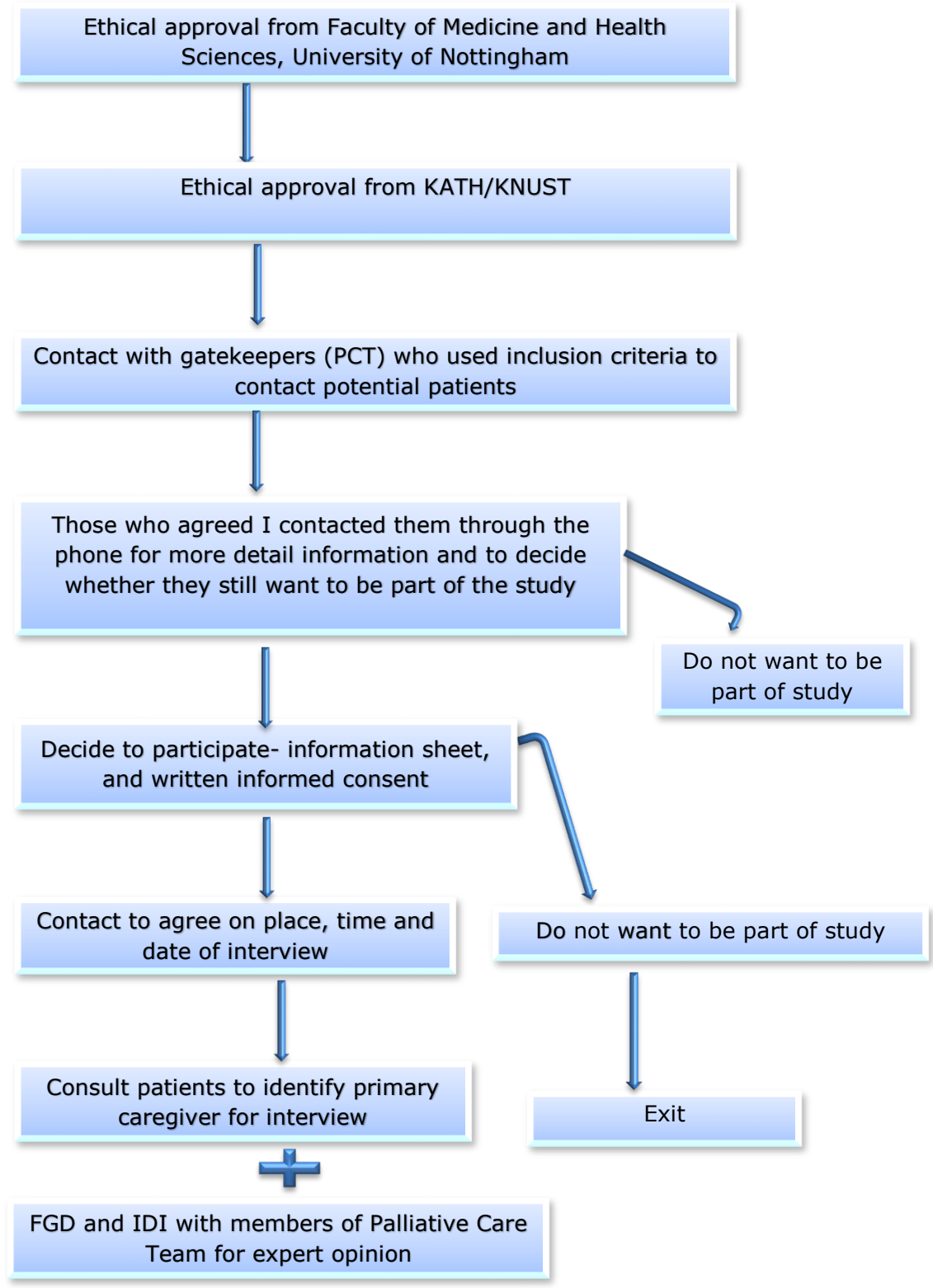


Figure 5: Recruitment procedure

3.10 Sample size

Fifty-eight participants took part in the study's first phase, and 38 participants were followed-up during the second round of the interviews. This was a high number out of the estimated 60 participants. The breakdown of all participants is as follows: men living with prostate cancer (n=23), family caregivers (n = 23), healthcare professional (n=12).

During the first phase of the study, 12 patient participants and family caregivers each were recruited for individual interviews (n=24) while 11 patient/caregiver pair were recruited for dyad interviews (n=22). The joint/dyadic conversations have some merits and demerits that need to be acknowledged (see section 3.11.2). Two focus groups were conducted with nine healthcare professionals who were members of the palliative care team (n=6, n=3). Due to practically unfavourable work schedules, three out of the 12 health care professionals who initially planned to take part in the focus group were interviewed individually.

For the second phase of the interviews (repeat), patients and family caregivers were followed up. Overall, 38 participants took part and this was due to the death of four patient participants (refer to inclusion criteria for the second interview as detailed in section 3.9). Nine each of patient participant and family caregivers were recruited for individual interviews (n=18), and ten patient/caregiver pairs were recruited for dyad interviews (n=20). The aim of the second interview was to follow up information that was not clarified during the initial interview.

The deaths account for the eight participants who did not take part in the follow-up interview. This sample size was sufficient to explore the experiences of home-based care in depth and quality (Thorne, 2008). In a qualitative study, the sample size is determined not based on a statistical estimate but by the number of participants that can provide information-rich data capable of fully exploring the depth and breadth of the research problem (Holloway and Wheeler, 2010, Creswell, 2013, Macnee and McCabe, 2008). Moreover, this was the determining factor for each of the participant's size selected. For

further details about the patient participants, see case narratives in Chapter four.

3.11 Strategies for data generation

Individual interviews, dyad/joint interviews, and focus group discussion were the techniques for collecting data. All the three methods allow for the development of richer data set for analysis as well as the enabling the participants and me to co-construct knowledge.

A semi-structured interview guide was developed based on the literature review and my interest in how care is done or received, in a resource-poor setting, and what that means to PWAPC and their caregivers. There were different interview schedules for patients only, caregivers, and health care professionals. Where the dyad interview was done, the components of the patients and caregivers interview schedule was used concurrently. In addition, patients and caregivers were given a preference for separate or dyad interviews. However, each interview schedule covered key areas such as setting the scene, the experience of receiving or providing care, and detailed questions around prostate cancer. Topics covered in a form of an interview guide are detailed in Appendix K. The three main techniques through which the data was generated are discussed below.

3.11.1 In-depth Interviews (IDI)

I conducted individual interviews with participants described in section 3.10. The use of the in-depth interview was most appropriate method for individual views (Silverman, 2013) that are detailed (Creswell, 2013) and for participants to talk about intimate issues they feel uncomfortable to discuss in the presence of others (Grondhuis Palacios et al., 2018).

The interviews were semi-structured, and this allowed for some fluidity of the process while at the same time ensuring that I was able to ask about issues raised in the literature. That is, the guide applied flexibly to allow the

participants to say the things that they wish to say and for me, as a researcher, to be able to follow their lead.

The open-ended nature of the interviews was ideal for exploring sensitive topics, and the face to face approach established a sense of rapport between participants and me to deliberate (Louise Barriball and While, 1994, DeMarrais and Tisdale, 2002). I was able to infer through the interviews what participants think about dealing with prostate cancer symptoms in the home context and why they think/feel so (Ritchie et al., 2013, Cupchik, 2001, Mack, 2010, Tuli, 2011).

Using a repeat interview, I followed up, approximately two months after the initial interview, nine patients and caregivers each to understand participants' experience of the cancer trajectory. The follow-up interview was necessary since it helps to uncover and understand PWAPC and caregivers experiences (Corden and Millar, 2007, Neale and Flowerdew, 2003) and an opportunity for participants to share an experience that might be missed in the previous interview. Again, such follow-up interviews allow participants to feel more comfortable to talk.

3.11.2 Dyad (Joint) Interviews

The initial aim of the design was to interview patients and caregivers separately, but this was not possible in some situations because the patients and their caregiver preferred to be interviewed together. The inherent fluidity of the qualitative research methodology (Creswell, 2013, Polit and Beck, 2013) ensured that these participants were able to share their experiences through a combined interview approach. The dyadic interview offers opportunities for providing detailed information as in the individual interviews and as well as the complementary discussion in a focus group (Morgan et al., 2013). They (patients and family caregivers) both have a shared experience (living with and or caring for Prostate cancer) as well as a pre-existing relationship (family members). So dyadic interviews are said to be very important "when the researcher wants both social interaction and depth when the narrative is valued, and when interaction in larger groups might be problematic" (Morgan

et al., 2013, page 1283). On the other hand, a participant in a dyadic interview might withhold information because of the presence of the other or one person may control the discussion.

Furthermore, the main aim of the research is the generation of rich data to answer the research aims and objectives. It is recommended by Morris (2001), who conducted a study on the needs of patients living with cancer and their caregivers, that where investigators are interested in exploring a social connection or situation, joint interviews are appropriate (Morris, 2001). The dyad context in this study was culturally suitable as well as time and cost saving. However, where there seem to be a sour relationship or disagreement between the caregiver and the cared for, the joint interview may not unveil sensitive issues the parties have (Morris, 2001, Morgan et al., 2013). For example, after a dyad interview with a couple, the wife told me while escorting me out that her husband, 56 years, cannot have an erection at all despite using some drugs but she did not want to discuss that during the dyad interview for her husband to 'feel bad' in my presence. The use of dyad interview created opportunities for discussion of issues that might not have come out in individual interviews because participants feel more in control in dyad interviews (Braybrook et al., 2016). However, the use of dyads interviews could pose some confidentiality challenges, and participants may be reticent talking about some very personal issues (Braybrook et al., 2016, Morgan et al., 2013).

Interviews with patients and family caregivers were conducted at each participant's convenient place either at or near their homes or a private room at the oncology unit at KATH or any other preferred venue for the interview. The interview progressed starting with a rapport such as finding out how they want to be addressed and how their day was like. Due to their acquaintance with each other, this encouraged participants to share their stories in a relaxed manner (Chirban, 1996). The progression of the conversation was kept in check with the interview guide (Appendix K) to guarantee that all the relevant issues were explored while allowing for unexpected information that I have not envisaged. The loosely- structured nature of the questions and the face-to-face manner of the interview encouraged participants to share their experiences and simultaneously to allow probes for clarification, and more

profound understanding and to get rich information from participants (Boyce and Neale, 2006, Kvale, 1996).

Each of the interviews whether individual or joint lasted on average between 60 and 90 minutes. With permissions sought, all interviews except two were audiotaped and later transcribed to allow for qualitative analysis of the content of the discussion. Two of the transcripts were based on a written record of an entire interview because the participants (one patient, and one caregiver) declined to be interviewed on tape. The recorded data ensured that participants' intonations were taken into consideration during data analysis, to give context and stress the importance of the issue been discussed. Literature indicates that interviews requires participants with good recall ability and communication skills and involves unique art in interviewing (Boyce and Neale, 2006, Stake, 1995). However, I have experience of carrying out sensitive research interviews with patients living with Tuberculosis (Salifu et al., 2017, Salifu et al., 2016, Salifu and Eliason, 2017).

3.11.3 Focus Group Discussion (FGD)

The healthcare professionals most of whom were the Palliative Care Team (PCT) of KATH were involved in two sessions of focus group discussion for their views on home-based care and I only moderated the discussions and probed for clarifications (Krueger and Casey, 2014). The focus group discussions took place at the conference room at the Oncology department of the Komfo Anokye Teaching Hospital (KATH). A volunteer from the oncology department assisted with the arrangement of the meeting place, and organisation of the meeting for the focus group discussion. I occasionally wrote down a few keynotes and did not need anyone records since an audio recorder was used to record all proceedings.

The views of the staff were primarily going to augment the issues discussed with the patients and the caregivers and for their expert opinion about home-based palliative care. For active discussion, two sessions of interviews consisting of a group of 9 participants (n=6, n=3) participated in the discussion (Silverman, 2013). As discussed earlier, three (3) other staffs (Pharmacist,

Social worker, and Oncology Physician) who, by their work engagement, could not participate in the second focus group discussion were interviewed individually.

The use of a focus group interview is essential for consensus or debate on participants' experiences and perspectives on home-based care for advanced prostate cancer patients. Focus group discussion promote synergy and snowballing of ideas thereby bringing additional insights that would have been missed if the individual participants were interviewed separately (Ho, 2006, Hennink, 2007, Krueger and Casey, 2014). The focus group comprised of nurses, doctors, and counsellors whom all work at the same hospital and on patients with palliative care needs and this served as common ground for discussion (Creswell, 2013, Hennink, 2007). However, as characteristic of focus group discussion, participants at a point lost focus and complained about the challenges they face as workers some of the time instead (Hydén and Bülow, 2003). I therefore, had the duty of moderating the discussion in order not to lose focus of the aims.

Furthermore, I wrote field notes in a few cases where the interview was not recorded, and this was taken into accounts during data analysis. The fieldwork notes also included incidence that happened during the interview or things that could not be captured on the audio such as gesture, to aid the description and interpretation of the data. Again, I made notes about my impression and participants' interpretation as I read the transcripts while highlighting classic excerpts from the data (in colours) that was to be used to support my claims.

3.12 Data Analysis

The focus of the analysis was to describe and interpret the experiences of the participants, and why such experiences were relevant to them. Therefore, a thematic analysis approach was used because it applies to a variety of philosophies and methodological analysis. Furthermore, thematic analysis is appropriate for analysing all kinds of interviews about people's conceptuality about a particular experience, and to look for *patterns of meanings* across the data sets (Braun and Clarke, 2006).

There are several ways of analysing qualitative data. However, the techniques used should be inductive and iterative with the sole aim of interpreting the meaning as expressed by participants (Guest et al., 2011, Thorne, 2000). Both content and thematic analyses are widely used qualitative data analysis for nursing research (Vaismoradi et al., 2013, Mayan, 2009). Qualitative content analysis analyse the theme of the data based on the frequency of its occurrence using the iterative process (Miles and Huberman, 1994). A thematic analysis identifies, describes and interprets concepts within the data implicitly and explicitly (Silverman, 2013).

In this study, I used the thematic analysis approach to describe and interpret the experience of living with, or caring for prostate cancer, in line with the research aim and objectives (Mayan, 2009, Vaismoradi et al., 2013) and to record patterns across the three data set (Braun and Clarke, 2006). I analysed all the data (from PWAPC, family caregivers, and HCPs) as a whole rather than analysing them individually and then comparing, contrasting and integrating because I was interested in the complementary insights of the various perspectives. Braun and Clarke (2006) further argue that thematic analysis is appropriate for generally all qualitative research and, unlike other analytical frameworks that are tied to a particular theoretical perspective.

I investigated managing the data with a software package (Nvivo). However, I was deeply familiar with the data via an ongoing iterative process of analysis; undertaking all the interviews myself. As a result, I had sufficient in-depth knowledge of my data sets to be able to organise it in a way that facilitated analysis without recourse to a qualitative software package. All the 68 interviews were analysed together as a whole. My field notes gave additional context to set out case study narratives for each patient and caregiver set of interviews as detailed in Appendix L. The description of how the research was carried out and the practicalities of the research process has been detailed below using Braun and Clarke (2006) thematic analysis process as a guide.

The practical details of the data analysis fashioned according to Braun and Clarke (2006) six-phase approach are as follows:

1. *Familiarisation.* I engaged actively with the data by undertaking all interviews myself. Secondly, the transcription of interviews afforded me another opportunity to get a greater sense of the storyline. I read all the transcripts repeatedly to get a broader sense of it, and I made notes along about the general impression. I also used the field notes to help me understand the interviews and help contextualise all the interviews. This together with the Case reports (See Appendix L) helped me to be familiar with the data.

2. *Generating Initial Codes*: The next stage after familiarising with the data, was to note clear and salient *patterns* in the data both internally consistent and externally divergent (Marshall and Rossman, 2006). The analysis here involves highlighting aspects of the information that represents the essence or essential characteristics of the transcripts.

   I did this by working through each of the hard copies of the transcripts with highlighters. My supervisors also looked at the transcripts, the codes generated, and we discussed this in meetings. The analysis also includes descriptions of the codes at this stage and with illustrative quotes that were later used to support the narrative and the interpretations. Here, my main aim was to look at how best the emerging categories and themes answer my research objectives. The analysis procedure progressed throughout the fieldwork using a repeated approach of analysing, verifying, and drawing conclusions about generated codes. At this stage also, I listened back to the audio for clarification when in doubt.

   This approach allowed me continuously to move back and forth from emerging data to check whether there are similarities or differences and pick up some interesting findings in the subsequent interviews.

3. *Searching for Themes:* This is a stage where I identified the themes, the structure highlights significant or fascinating information from the data and useful in answering the research question. The identification of themes was across all the data sets from PWAPC,

family caregivers, and the HCPs. I used different colours to highlight categories that belonged to a particular theme. For example, different colours were used for stigma, masculinity, and caregiving. I wrote my initial ideas about the codes were on the right-hand side of each of the transcript to aid in reviewing the themes later. Each of the three overarching themes from this study was developed from the data. The entire data sets were analysed based on the data rather than coding with a pre-conceived idea as this might truncate any opportunity to identify interesting findings (Polit and Beck, 2013).

4. *Reviewing Potential Themes*: The next stage in the analysis was to revise the uniqueness and diversity of the emergent themes so that the categories and the themes are 'internally coherent, consistent, and distinctive' (Braun and Clarke, 2006). I revised severally all the themes and categories that have been written and creating a mind map that captures the entire data sets into one. This revision of the numerous themes led to 3 major overall themes, 10 sub-themes, and 32 categories. I then looked at the data in context and in relation to relevant literature on family care, stigma, and masculinities as explained in Chapters 4, 5 and 6. Each of these themes is presented at the beginning of each finding/discussion chapter to signpost readers (see pages 72, 110, 142). These themes and categories informed and directed the writing of my final report.

5. *Defining and Naming Themes:* After coming up with three thematic maps, I examined themes closely and moving some sub-themes. Each theme was colour-coded. Here again, I read the data linked to each theme and made a final decision whether the data cohere under the theme and how the theme is linked to the entire data set. Themes from all the interviews from patients, caregivers, and healthcare professionals were brought together to address the research questions.

This phase comprises refining the ideas and ensuring that collectively, it captures the experiences expressed in the data and comprehensively covers the contours of the entire data body.

6. *Producing the Report*: This stage I wrote down the final analysis and making links between relevant stigma and masculinity theories and especially care in resource-poor context. As indicated, the themes and categories were used as a road map in writing the findings of the data analysis that resulted in three main chapters. This write-up also includes a reflexive account on analysis for readers to follow how I arrived at those decisions. The report also shows samples of distinctive extracts from the transcripts to support claims I have made in view of the literature and overall research aims and objectives. This whole process was inductive, iterative and 'back and forth' similar to *figure 7.*

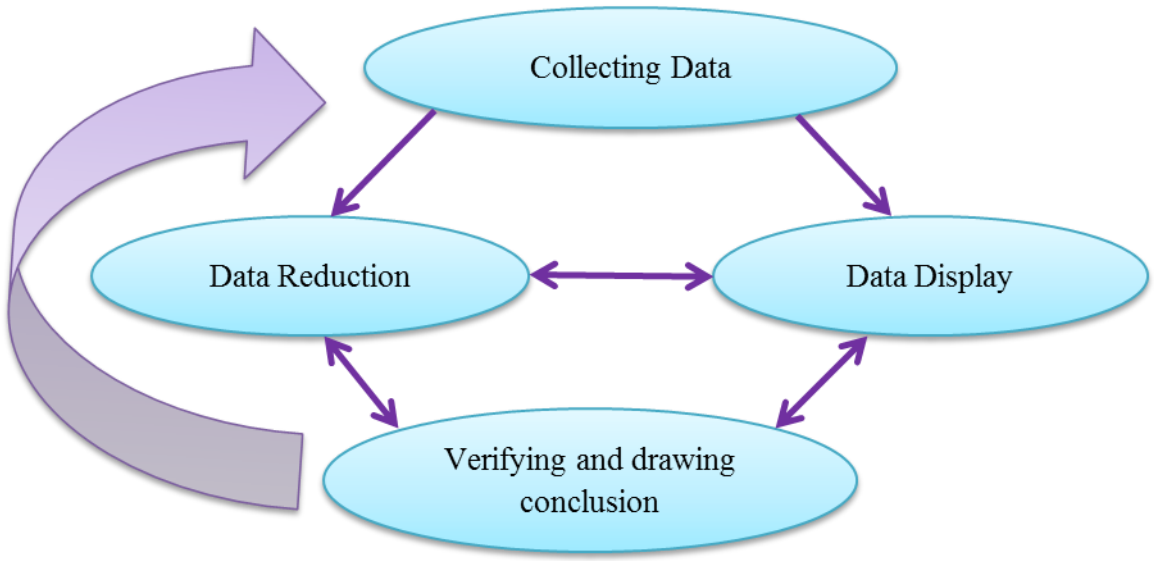


Figure 6: Iterative model of Analysis, Miles & Huberman (1994)

To sum up, I familiarised with each interview and field notes through repeated reading. Subthemes and themes were developed from the entire data sets and the findings contextualised to reflect the accounts of the meanings and interpretations of the participants.

3.12.1 Data management

Interviews were collected on an encrypted digital audio recorder and transferred immediately to a password secure server at the University of Nottingham. All transcripts, files, and identifiable details were stored separately in a secured password-protected computer.

To ensure proper data management, each dyad interview transcript was prefixed with D0, and for Health care professionals (HCP) followed by a unique serial number for easy identification. For example, D05 represents dyad interview number 5 and HCP 03 represent interview for the health care professional number 3.

I used pseudonyms for family caregivers and PWAPC to anonymise them. Moreover, the pseudonyms used in the report will allow readers to follow the unfolding storyline.

3.13 Trustworthiness of Data/ Study's rigour

Rigour in qualitative studies helps to ensure that the conclusions arrived by the investigator accurately represent the participants' experiences and to demonstrate that those conclusions are credible and authentic (Guba and Lincoln, 1989, Polit and Beck, 2013, Creswell, 2013). With the constructivist approach, the findings were produced through the investigative lens and the imaginative mind of the investigator (Mayan, 2009). Lincoln & Guba (1985) maintain that instead of trying to establish reliability and validity as in the positivist paradigm, it is more appropriate to deliberate on a trustworthiness in qualitative research in the areas of credibility, transferability, dependability, and confirmability (Lincoln & Guba, 1985) as discussed below.

3.13.1 Credibility

The diversity of information sources (patients, family caregivers, and health professionals) allowed different perspectives on experiences of home-based care to be studied enhancing credibility (Polit and Beck, 2013, Creswell, 2012). This in effect strengthens the emerging contextual data and increases

assurance of the soundness of the findings (Creswell and Miller, 2000). The credibility of this work is enhanced in some ways:

Throughout fieldwork, I maintained a fieldwork diary to chronicle the events during the interviews and the data collection that could not be captured on the tape such as gesture, and to reflect on the evidence emerging from the work. During each interview, I probed further to clarify whether what I think about the participants' account was correct.

Again, the themes emerged from within the data, and these were discussed during frequent meetings. Therefore, debriefing and discussion meetings between my supervisors and me also added to the credibility of the findings.

3.13.2 Transferability

The sample in this study was not in any way and did not intend to be a representative of all prostate cancer patients and their family caregivers in Ghana, and therefore, there are no claims to generalise findings. Nonetheless, adequate context about the location has been provided (see chapter one). Again, this study has provided detailed information about the recruitment process for patients, caregivers, and HCPs. I have also presented the composition of the participants, where interviews took place to guide readers to make transferability judgement. To help readers do to this, information about me and my assumptions (detailed at 1.2.6), and the philosophical foundations of the study are provided. Readers will have to determine whether or not the findings are transferable to their contexts (Polit and Beck, 2013).

3.13.3 Confirmability

Since every research has its philosophical underpinnings, I have made my beliefs and assumptions (social constructivism) explicit so that readers can make a judgement with the stated ideological beliefs in mind.

Appropriate signposting has been provided throughout the work to establish the evidential trail. Again, enough evidence is presented to support the claim of knowledge and this increase the traceability of the analysis process and to

signpost readers through the work. More importantly, the limitations of this work have duly been acknowledged (Shenton, 2004).

3.13.4 Dependability

I have made explicit all decisions taken to arrive at the findings and conclusions for others to think through how these were reached. I have further given a comprehensive procedural account about data analysis, and this ensures the dependability of this work based on the information provided.

3.13.5 Reflexivity/Reflection

In qualitative studies, the inquirer plays a significant role in data collection and analysis or data generation (Shenton, 2004, Creswell, 2012) because the we are part of the social world and could be influenced or be influenced by the study environment. Therefore, a greater sense of reflexivity on the part of myself as an investigator could be helpful. As recorded earlier in this thesis, I have been mindful of his professional background as a nurse as well as a teacher at a university. Reflexivity strengthens the quality and ensures the transparency of qualitative research (Marshall, Fraser, and Baker, 2010). Marshall and colleagues (2010) describe reflexivity as critical self-reflection throughout the research as it develops.

Mayan (2009) indicates that there are tendencies for academics to approach data analysis deductively. However, using an inductive approach of analysis emerging themes in the study were developed from the data rather than from my personal, professional beliefs, assumptions, and experiences (Charmaz, 2006, Miles et al., 2013, Carter and Little, 2007, Miles and Huberman, 1994). I, therefore, approached the data with an idea of capturing unexpected information as well (Charmaz, 2006). Frequent discussions with my supervisors assisted in this endeavour.

It is reported that our experiences adds credibility to the research; I have the exposure to the use of qualitative research during my masters having had some training in Qualitative research methodologies from the University of

Alberta, Edmonton, Canada as well as practical experience interviewing people in a clinical setting. My two supervisors have extensive experience in conducting qualitative research primarily in the field of palliative care.

During the interview, I kept a diary of his experiences and thought which was useful to be reflexive. The writing of diary and field notes also served as means to cope with some of the emotionally challenging aspects of dealing with sensitive and emotional issues of participants (Rowling, 1999, Dickson-Swift et al., 2007). The reflexive accounts relating to the period before, during and after the data collection and analysis captures personal thoughts and experiences that might have influenced the research directly or indirectly. The notes also included an impression of the participants' area of residence, where interviews were done at home, to give a general sense of the context in which the care was provided. Reflexivity according to Marshall and colleagues (2010) could have several variations including *introspection, inter-subjective reflection, honest reflection, social critique, inter-subjective reflection, and collaborative reflection (*Davis & Klaes, 2003; Lipp, 2007; Munhall, 2007). However, for this thesis, the first two is discussed within the context of my personal experience of interviewing men living with prostate cancers and their significant others in a resource-limited setting.

I encountered and learned many interesting issues during the data collection processes, which I have reflected on as follows:

The first critical issue I experienced was my own emotional responses to dealing with a sensitive aspect of the study (Rowling, 1999). Some participants were nervous as they chronicled their challenges in dealing with the care as well as how generally unhappy they were because they did not expect such kind of disease in their lives. As human as we are, I was sometimes saddened by the plight of the patients and their caregivers as they narrated their experiences. When talking about issues of end of life care, a feeling of emotion and distress may be inevitable, and this research was not an exception (Ashton, 2014). The pain and the sentiments of the patients and their caregivers were powerful, and this required strong self-control (Valentine, 2007). The issue of some patient participants dying during the data collection period (n=4) was

emotional for me as well. Customarily I commiserated with the families by calling them to express my condolence. In one of the instances, the family member gave an invitation card to me, inviting me to the funeral rite of their deceased. In line with Ghanaian culture, I honoured this invitation.

Another issue that I found worth reflecting upon was the interaction I had with the members of the palliative care team who recommended to me to speak to the hospital's social welfare officer. During the focus group with the staff, they highlighted that some of the support the PWAPC receive or could get is through the social welfare department. This prompted me to arrange an interview with the social welfare officer. The interview of the social welfare officer was very insightful and added a lot of rich information to my data. It also gave me the opportunity to appreciate the willingness of HCPs to provide care despite their challenges. One HCP narrated how she used her own car and money to fuel, buy some items and visit some PWAPC (and other patients with other palliative care needs) at their homes. Others shared their experiences of having to support some patients at the hospital in order for the patients to access treatment- such as chemotherapy, radiotherapy, surgery.

Furthermore, this research work made me appreciate the researcher/ professional boundary that I had only read of in textbooks. During the fieldwork, I observed some practices of care by PWAPC and their family caregivers, which required my swift intervention as those practices threatened the quality of life of PWAPC. At the home of Boat, I observed that his supra wound where his pubic catheter was inserted into the abdomen was being infected. I enquired from them how they do wound care. I was informed that they use a flannel cloth to clean the wound and after the wound cleaning, they wash and dry the flannel cloth on a window for reuse. This was because their supply of gauze has finished and they have not been able to get more. I had to intervene by explaining to them the dangers of using an unsterile cloth to dress the wound and this could lead to infection of the wound, the peritoneum and eventually sepsis. When I was told they have run out of their supply of gauze, I sought their permission to inform the Hospital about it and to urgently request for a new supply of sterile gauze for Boat's wound dressing. After this explanation, the family gave me permission to inform the hospital about their

situation. I further reassured them that, my decision to inform the hospital about this would not, in any way, affect their care they will seek at the hospital.

Another scenario was the case of Gyasi who was using a wheelchair and had sores at the sacral area. This happened during the second interview at his residence. Gyasi had become lean and had developed bedsores because of infrequent change of position or turning in bed. He had also lost appetite. I was again, caught between the professional /researcher dilemma. Since this development had a severe impact on Gyasi's quality of life, I educated the caregivers on the need to change Gyasi's position in the wheelchair and support it with soft pillows. I told them to turn him about four hourly during the night to minimise further development of bedsores. I also educated them on the need to clean Gyasi properly after personal care since leaving the skin moist can also lead to skin breakdown.

Some participants who described the visit to their homes as a 'show of love and concern' appreciated my presence in the field (participant's home). Others also indicated that it allowed them to be relaxed in their homes and for me to see some of the things at first hand. For example, during both interviews, Stella, Ofori's wife and caregiver, was also glad that her husband's situation had necessitated a visit by a health care professional. She saw my visit as special since no health personnel has visited them either for an interview or to offer support. She further indicated that she has been relieved by the opportunity to speak to me.

Furthermore, I have learned, while doing this study, the need for us to be very flexible in collecting qualitative data. Some participants were more comfortable with individual interviews where they could tell me about some sensitive and confidential issues that they did not want the other party to know. Most participants who had sensitive and confidential information usually opted for individual interviews instead of dyad interviews. This revelation points to the power of individual interviews providing an opportunity to share some 'sensitive' information that might not be revealed in other types of interviews.

Again, where dyad interviews were used, caregivers were careful using some words such as 'death' in order not to upset or demoralise PWAPC since

discussing death in the presence of a seriously ill person in Ghana is regarded as approving his death. The use of dyad interviews in this study offered a significant methodological insight about how PWAPC and their family caregivers relate. Interviewing PWAPC and their caregivers together provided very insightful data about the impact of prostate cancer on the family, and their shared experience of how they transverse their journey and the meaning and interpretation of such experiences.

Additionally, I equally became aware of how vulnerable we as researchers (especially me as an early career researcher in the field of palliative care) could be dealing with sensitive and end of life issues. I steadily became self-aware of the fact that exploring topics such as advanced prostate cancer elicited emotional distress. Moreover, the frequent debriefing sessions I had with my supervisors in the form of supervision meetings and other correspondence were helpful support in dealing with most of the difficulties. Speaking to my supervisors was helpful because they are experienced in this field and were able to offer both emotional and academic support. One other way that helped me to get rid of strong feelings was writing about the emotional challenges in field notes and my engagement with others about these issues.

My fieldwork experience also brought me closer to the family unit as a whole than it would have been in a clinical setting. Some participants occasionally called to tell me about their progress and of course some deterioration in their condition. In one instance, when the patient died, the family invited me to the funeral and told me it was the wish of the patient too. This happened about six weeks after I had interviewed Mike and his lovely caregivers. Upon the invitation of the family, and as customs demands, I honoured the funeral invitation and attended his funeral ceremony.

3.14 Chapter Summary

Chapter 3 provides a detailed debate of the methodological and ethical perspective of this research. I have provided a justification for the use of a qualitative repeat interview study design, as well as the participants groups that took part in the study. Also, explanations are offered to the effect that the analytic approach used was theoretically and methodologically coherent. In-depth interviews were conducted with 23 families. All transcripts were analysed using an inductive thematic analytic approach. This technique is used to interpret identified logical pattern (themes) from within the data rather than using a predetermined coding system. The data analysis was in keeping with Braun and Clarke's (2006) approach. This was achieved by reading the transcript thoroughly and noted codes that were potentially important. Then the codes were organised and this allowed me to distil some key themes to attain a deeper understanding of home-care with the help of some supporting quotes from the data to evidence the claim. All the themes emerging from the data were reassessed with, and links were made between theories and the findings. I have also provided reflection about some of the insightful experiences I had while undertaking a sensitive research in a resource-limited context such as researcher/professional dilemma. The next section introduces the three interpretive chapters.

Introduction to the Findings chapters

This chapter provides an introductory overview of the three interpretive sections by giving case narratives of the 23 men interviewed. The importance of case descriptions is enormous as it offers the opportunity to examine the complexities and contextual issues that are central in palliative care (Walshe et al., 2004).

For every advanced prostate cancer participant, the type of palliative treatment(s), fundamental care needs, family caregiver(s), and number/type of interviews are provided. All these aim to provide rich contextual information about each participant and the study as a whole (Miller and Dingwall, 1997). I used pseudonyms for all the 23 men (PWAPC) and their caregiver(s). The table below gives information about the vital information about the 23 PWAPC who participated in this study. See Appendix L for the cases narratives for PWAPC who participated in this study.

Table 3: Characteristics of men with prostate cancer

Age (years)	Number of participants
49-58	6
59-68	10
69-78	4
79-88	3
Total	23
Religious Affiliation	
Christian	17
Moslem	5
Traditional African religion	1
Marital status	
Married	17
Single	1
Divorce	1
Widowed	4
Type of palliative treatment[7]	

[7] some of the men received more than one treatment

Hormone treatment	15
Surgical Castration (2)/ Radical prostatectomy (4)	6
Radiation	4
No longer being actively treated	4
Key caregiver	
Wife/spouse	10
Child/Children	9
Mother	2
Sibling	2
Level of education	
Nil	8
Primary	5
Secondary	2
Tertiary	8
Number of children	
0-3	4
4-6	14
7-10	5
Occupation	
Nil	3
Teacher	1
Farmers	3
Retired (both mandatory & voluntary)	8
Traders	4
Priest	1
Artisans	3

The age range of men with prostate cancer was 53 to 81 with a mean age of 65.

This study sought mainly to explore, using a qualitative approach, patients, caregivers, and healthcare professionals' experiences of home-based supportive and palliative care of PWAPC in Ghana. The study captured the

perspectives of PWAPC, their family caregivers and health care professionals who were members of the palliative care team.

Palliative care in most resource-limited African countries can be challenging for caregivers who mostly manage patients in informal settings (Busolo and Woodgate, 2015). Moreover, even if the experience of providing that care is overwhelming, there is no outside support available (Bessa et al., 2012). As a clinical nurse myself, I came to appreciate what the day-to-day life of these patients was when I was still in practice. Some of these patients were interviewed in their homes and I came to appreciate some literature that indicates the myriad of problems advanced cancer patients and their family caregivers encounter (Grbich et al., 2001, Farquhar et al., 2016, Meeker et al., 2014, Angelo and Egan, 2015, Seal et al., 2015, Stajduhar et al., 2013).

In the subsequent interpretive chapters, it is clear that numerous challenges affect not only PWAPC but also their caregivers at home and the healthcare professionals who attend to their health needs at the hospital. The problems range from the provision of care amidst technical and logistical issues, the effects of prostate cancer on the lives of the patients' and caregivers' daily lives, and the disruptive nature of advanced for of prostate cancer on the physical, psychological and the physiological wellbeing of the men and by large extent their caregivers. Again, the health and social care systems presently do not provide adequate support for these men and their caregivers worsening this situation. Despite these challenges, there seem to be some informal social network systems and that paternalistic framework that ensures the small resources are put to the best use for patients' comfort.

My duty as a researcher, and in line with the social constructivist underpinning, is, therefore, to do 'storytelling' through the eyes of the participants by interpreting their opinion on the receipt and/or giving of care at home. Most participants found it beneficial to talk about their experiences. For example:

> …*when his condition became worse, besides he couldn't walk and do most of the things for himself, I sent him to the hospital again. They (health staff) just told me to go home and manage him. I*

mean I have no idea about some of this care. It is good that I am telling you this because you are also a health worker *(Jeremy, Babaamu's son, individual interview 1).*

You know how our health system works. Everywhere you go there are challenges. The managers are usually not interested in that, but they want fat allowances and positions. It is so provoking to be given such tedious work without the needed adequate logistics. It is sad (P06, focus group 1).

As soon as the nurse told me that someone (referring to me) who is also a nurse wants to have a chat with me about my disease, I was happy. I said to myself, what has changed? I had not had that opportunity outside the clinic (Oncology) to discuss issues that concern only me. At least, I have vent some of my challenges out a listening ear (Ofori, individual interview 1).

The opportunity to speak openly about the things that frustrated them appeared to give participants across the three different groups a sense of relief. The following three chapters, therefore, present a synthesis of the experiences of the 23 men living with prostate cancer and their family caregivers as well as the interpretations from the healthcare professionals (12) who participated in the study.

I must confess that the data that was generated was voluminous. Perhaps this was partly due to the repeat interview approach. Consequently, a presentation of the full accounts of all the interviews might exceed the limit permitted by this thesis. In line with the philosophical underpinning of this study, interpretive social constructivism, interpretation of participants' accounts is provided.

The overarching themes developed inductively from across the datasets are presented in the next chapters (4, 5 and 6) as follows:

- Providing care in a resource-poor setting
- Family caregiving: The stoicism and chaos
- Cultural response: Stigma and Masculinity

The themes are supported by direct quotations from participants to evidence claims. The presentation of the findings mirrors the significant themes and their link with the respective categories as diagrammatically represented in figure 7.

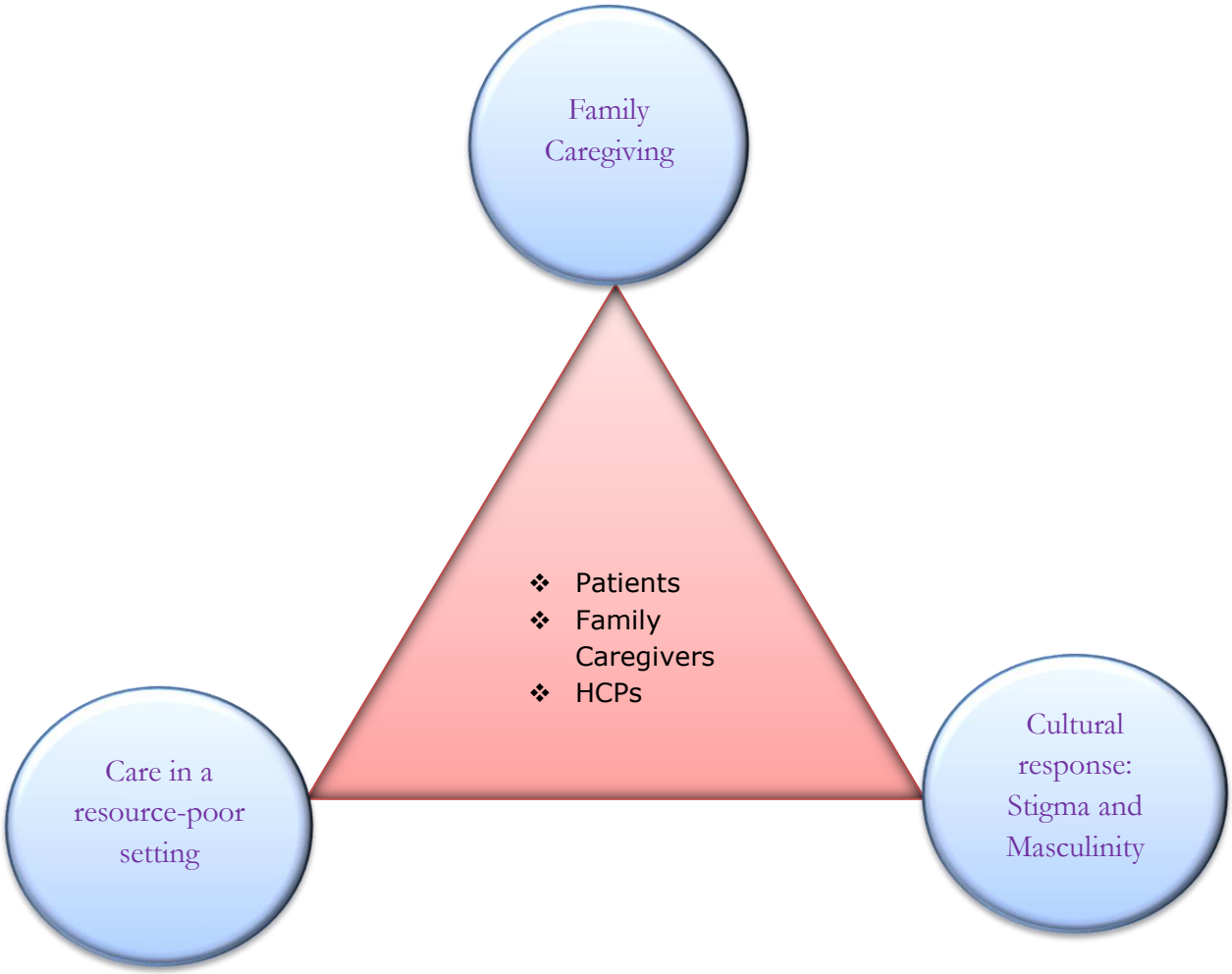


Figure 7: Three Overarching Emergent Themes

4 CHAPTER 4

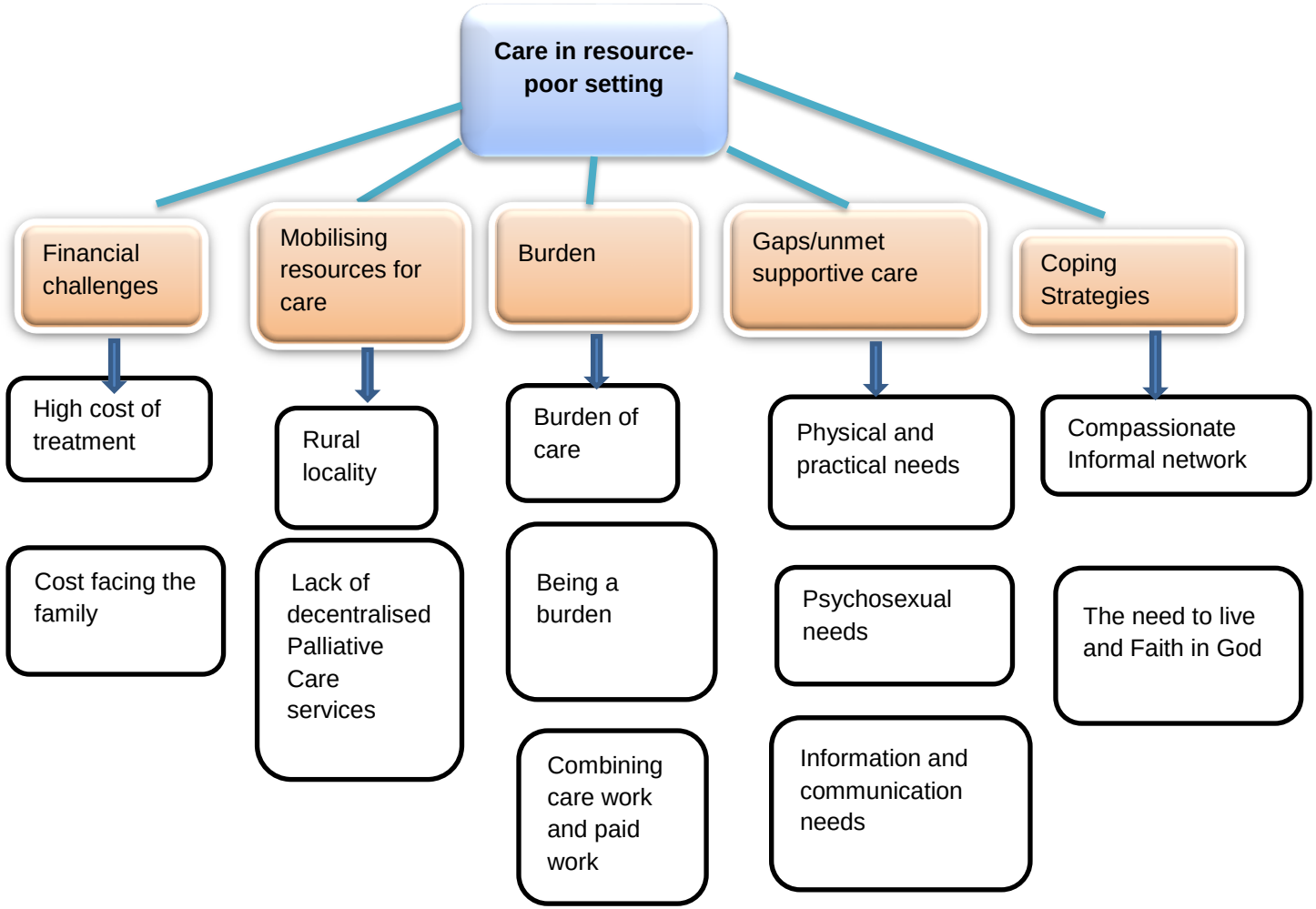


Figure 8: Theme 1-Care in a resource-poor setting

Managing Serious Illness in a resource-poor Setting

4.1 Introduction

Palliative care provision in Ghana is at a fledgling state (as discussed earlier in section 1.2.3). Caring for PWAPC in a resource-limited setting conflates some different financial, human resource, and infrastructural concerns. There is limited access to good quality palliative care in Ghana and a heavy reliance on home-based family caregiving (Yennu et al., 2018). PWAPC rely on family care at home; as there are no in-patient palliative care services, or community palliative care centres where patients can receive supportive and palliative care.

Additionally, healthcare professionals rarely undertake home visits for support and care. Due to the sparse health care services which are usually poorly resourced in most African countries, family home-based care remains fundamentally significant, with the end of life care taking place within the family setting (Harding and Higginson, 2005b). Healthcare professionals (members of the Palliative Care Team) report significant difficulties in carrying out their home visit duties mainly due to logistical challenges and inadequate numbers of staff (see section 1.2.3). In Ghana, where the entire health care cost of patients with prostate cancer is the responsibility of the patients and the caregivers, this increases the burden of care. However, the informal social network and sense of familial responsibility are key factors that ensure the patients receive the necessary support within the means of the family.

This chapter captures the experiences of PWAPC and their family caregivers in resource-poor settings. It also incorporates the views of healthcare professionals interviewed, who have had some contact with or are involved in the management of such patients. The chapter explores the social, physical, emotional and economic ramifications of living with cancer or supporting cancer care. Additionally, the chapter describes the coping strategies used to navigate through the care process. Consequently, this chapter aims to address the shortage of evidence about caring for PWAPC in a resource-poor setting and suggests that the informal social networks are crucial in the care at home, so efforts to improve present social support systems are essential. In the section that follows, I discuss the financial implication of managing

care in a resource-poor context. The chapter then concludes with the various coping strategies that are adopted in the face of these challenges.

4.2 Financial challenges

A common finding from all interviews was the economic impact of caring for someone in a home context where government support is virtually absent. Patients and their families reported turbulent financial situations. The need for financial support increases due to high treatment cost facing the family. Again, in some of the cases, the patients are retired or are not strong enough to engage in paid work. Where caregivers or the family are unable to get enough money for treatment, this causes financial difficulties (Binka et al., 2018). In this study, participants highlighted the cost of treatment and other auxiliary expenses that led high expenditure for the care. These costs coupled with other financial commitments such as the cost of childcare, for example, causes financial crises. The economic challenges are mostly brought about by the cost of prostate cancer treatment including the cost of drugs and laboratory tests, and the cost the family face for the day-to-day care including buying of supplies for care among others.

4.2.1 The high cost of treatment

One significant financial challenge that runs through most of the 68 interviews (from both patients, caregivers and healthcare professionals) was the high cost of treatment. PWAPC are usually managed with at least one of the following treatment plans:

1. Hormone therapy to prevent the cancer cells from further growth;
2. Surgery to relieve distressing symptoms associated with cancer;
3. Chemotherapy to destroy fast-growing cancer cells, and
4. Radiotherapy to kill the cancer cells.

According to healthcare professionals, the choice of the methods depends on factors such as the extent of cancer, the patient's preference and crucially the

patient's ability to pay. This excerpt from one of the health professionals during an individual interview emphasise this:

> *There are about four treatment options that we can provide for now. Hormonal therapy is costly for most patients. Radiotherapy too same with the additional problem of over-reliance on the equipment's good state (HCP 03, individual interview).*

The above was further re-echoed by other health professionals in one of the focus group interviews.

> *The relatives do contribute and pay for the drugs because the drugs are costly. For example, the Zoladex is GH1, 700.00 (£340) per each session and most patients can't afford (P01, focus group 2).*

On the part of the men living with prostate cancer, the cost of treating prostate cancer could mean selling all that one has acquired in life to be able to afford treatment as articulated below;

> *I had to sell my plots of land at (withheld), another in my hometown, my car and emptied my life savings to buy chemotherapy drugs, do the labs and the others. Had it not been that (selling of property) I would have been dead long ago (Ofori, individual interview 1).*

As the quotes illustrate, the cancer treatment options (such as chemotherapy and radiotherapy), are expensive, and the cost is entirely borne by the patients and the families without any insurance coverage. Additionally, the patient has to pay in full all the cost for diagnostic investigations such as prostate-specific antigen (PSA), a biopsy (removal of body tissue for investigations) as well as consultation fees. What is worrying to some patients and their families is the fact that even though they have subscribed to the National Health Insurance Scheme (NHIS), they are still required to pay in full for any treatment at the hospital because prostate cancer service is not covered under the insurance scheme.

Men with prostate cancer have to make ‘out of pocket payment’ at the hospital to receive care regardless of their NHIS status. That is, patients and their families have to pay for the cost of tests and treatment before services are delivered to them and they find this a difficult problem. One patient participant expressed his views that he has been treated unjustly:

> *This insurance thing (NHIS) came about 10-15 years ago, and I have been contributing my tax towards that. Most time when I renew I don’t use it (service) throughout the year. Now that I am in dire need of it, I have been denied. This is very unfair. Is that how to treat the weak and vulnerable? I can’t afford GHC2, 000 (£400) each time I go for chemo [chemotherapy] (Daama, individual interview 2).*

Gyasi also spoke about how difficult it is for his family to get money for his treatment:

> *It is tough times to get money, and I am on a pension now and, my wife is not working. My children are helping me. We pay for everything when we go to the hospital, from A to Z; everything is all about money (Gyasi, individual interview 2).*

The participant in the above extract, just like many others, was unhappy about the discriminatory nature of the NHIS that has excluded men with prostate cancer, who are mostly around the age of 60 years and they either are retired from active work or may not be in the position to work to pay for their medical expenses.

Also, patients are required to pay for all the pain medications needed for the control of pain at home. The financial challenges of patients are well known to and are a concern for, healthcare professionals as well.

> *It is not easy for them (patients). I think those who are unable to pay do not even come back for treatment after they have been diagnosed. There was a patient who came in yesterday with his drug, he told me that he wants to go and eat before the treatment and decided to leave his drugs there. So I asked him to send the drugs along since someone could take it. And the drug is so expensive, you know. Then the patient exclaimed ‘hmm madam; I have to go hungry for some days just to be able to buy this drug’ (P06, focus group 1).*

The comment above demonstrates how some patients go without food to be able to afford to pay for their drugs at the hospital. These findings support the literature that suggests that the high cost of treatment decreases access to health care in a resource-limited context (Bessa et al., 2012). The study of Jones et al. (2011) also reaffirms how African-American men in the USA could not have afforded treatment for prostate cancer if the medical insurance did not cover the cost of treatment. Other studies conducted in the UK also highlighted the financial burden that men living with prostate cancer and the families experience while managing care (King et al., 2015, Payne et al., 2014, Paterson et al., 2015). In this study, the cost of cancer treatment such as radiotherapy and chemotherapy was a crucial barrier in the management of prostate cancer. The high cost of treatment and health services together with other costs the family faces (discussed in the next section) contributes to psychological distress for both PWAPC and the families.

4.2.2 Other cost facing the family

The caregivers face an enormous financial cost in caring for their loved ones at home. Some families reported that they kept detailed accounts of the items that they have bought and those yet to be purchased. Additional costs paid for by caregivers include bed sheets, detergents, perfumes, barrier cream, powders, incontinent pads, mattresses or mats, extra pillows, etcetera. One caregiver, Stella, who cares for her husband, Ofori, said:

> *This is the third mattress that I have bought. When the mattress continuously gets soaked with urine, it gets to a time that it needs to be disposed of. I buy [diapers] alone almost GHC 300.00 (~£55) every month. We have to (buy) Dettol (detergent), plastic bag to cover on the bed, and so on. All these cost much money. The amount we spend on these is nearly the same as the chemos [chemotherapy] and the labs. Hmm 'ɛyɛ asem ooo' [it is a big issue at hand] (individual interview 2).*

The above quote indicates the challenges of getting money for the daily expenses at home in addition to the money needed to pay hospital bills. Due to the incontinence

of Mr. Ofori, his family has to buy incontinent pads among other things to manage the situation, which according to them was costing much money. In another case, Teiko who was caring for his father, Norbert, indicated that he had spent all the savings in his accounts and now things are challenging.

> *You know, I am taking care of the finances as well with little support from others (family members). Sometimes, after struggling to pay for his hospital bills, it becomes difficult to get money for our expenses at home. It is hard, getting enough money for bills and 'chop' money [cash for daily expenses] (Teiko, Norbert's son, individual interview 2).*

Nii, who has had the surgical operation done and now receiving hormonal therapy said:

> *Prostate cancer should've been a disease of the rich. Yes, because it is costly to be treating prostate cancer. I pay for every medication, and it's (appointment) monthly. I think this (prostate cancer) is not a disease that poor people can battle with for long. The cost is too much (Dyad interview 1).*

The difficulties described by men and some primary family caregivers appear to be made worse because of other cost associated with the care at home. In consonance with this study, availabilities of supplies of incontinence pads (Sinfield et al., 2012b), and other resources for dealing with urinary incontinence such as detergents were a big problem for most families (Carter et al., 2011). My study highlights the financial burden of the men and their caregivers because of the cost of treatment that medical insurances do not cover, expensive anti-cancer drugs and investigative procedures, and unemployment or low earning work that does not match the expenses for such treatment. Research conducted in New Zealand notes that the costs of caregiving could be both direct (such as the cost of drugs and transport) and indirect (such as job loss) and these could result in significant debt for family caregivers (Gott et al., 2015).

Other studies in Ghana indicate that financial burden, lack of support networks also affect the care of people with mental disorders (Ae-Ngibise et al., 2015), cervical and breast cancers (Binka et al., 2018, Bonsu et al., 2014), and the elderly (Sanuade and

Boatemaa, 2015, Brown, 2015). The next section describes ways PWAPC and their families mobilise the needed resources for care.

4.3 Mobilising resources for care

One key aspect of the care at home is the ability to assemble the needed logistics for care. Unlike some Western countries, there is no community palliative care service where patients could get professional care for wound dressing, and so forth. There is also difficulty in affording material resources such as bed sheets, toiletries, incontinent pads (for those who are incontinent and not using catheters), gauze, and barrier cream among others. The implication of locality and proximity to health facilities and lack of available palliative care support services were found to make caring for a person in such context challenging. Again, difficulty in obtaining palliative care services in remote parts of the country was reported (described at 4.3.2).

The following extract illustrates some of the issues that came up with two of the caregivers.

> *I was terrified upon hearing that devastating news. Eii, [Exclamation] bad cancer? Everyone is afraid of cancer so when the doctor told us that my dad's cancer was terrible, I knew we were finished. I was thinking where was I going to get the money and other things for his care since we know insurance [Health insurance] doesn't cover his illness (Joobu, Asamoah' son, dyad interview 1).*

Joobu raises what appears to be a potentially a significant issue. Being a caregiver also, means one is responsible for mobilising resources for care. When the help is not forthcoming from other family members, the caregivers are compelled to deal with the situation alone. As indicated by Joobu, he uses the phrase "I knew we were finished" to emphasise the high cost to treat cancer, the unpreparedness to assume a caring role, and where to look for help. Literature reports the complexity of the caregiving role (Angelo and Egan, 2015), signposting family caregivers to sources of support (Funk et al., 2010) while dealing with the difficulties that will make home caregiving unattractive (Johnson et al., 2016). Another caregiver also shared her opinion on providing care in the resource-limited context.

Hmm. It has not been easy at all. I have to get enough money to be used for his treatment, and the lab test and all that. At home too, I have to take care of him together with the children. I mean it is tough to do all these at the same time (Tilaata, Sharms' wife, individual interview 1).

Tilaata and Joobu, who are both caregivers, stress the fact that to care for a PWAPC involves much money and other resources and mobilising such funds could be challenging to handle. The issue is both a major concern for caregivers and the patients themselves.

As I indicated the other time, the radiation cost GHC 2,000.00[8]*, and the medication (injection) cost GHC180.00. I know you are in this country as well and you know the difficulties in getting such an amount especially when you don't work (Ofori, individual interview 2).*

Ofori, whose excerpt is above, is a retired schoolteacher who was very concerned that even if he were to be in active service and all his salary put together, the amount would not be enough for the cost of treatment let alone other ancillary costs associated with the care.

It was difficult for some patients and families to mobilise the needed funds for treatment at the hospital, and in some cases, it takes a couple of months to do that. The following quote from Kwaku, who was on palliative radiation and chemotherapy, typifies the above narration:

I am late buying the prescribed drugs now. This (prescription) was given to me about four months ago. I should have even gone for the next session of treatment by now, but I am still struggling to get the money. I have a child as young as 12 years, and I need to take care of them as well. It is a pity (Kwaku, individual interview 2).

Kwaku was worried about his inability to raise money for the treatment at the hospital, other expenses as well as money for the upkeep of his younger children. Organising

[8] At the time of the interview this was equivalent to £350 (£ 1 = approximately GHC 6).

money for treatment is quite an issue for men on intermittent treatment such as chemotherapy that needs to be taken at least every 2-3 months. Participants who had had surgery (removal of the testes) and did not require further chemotherapy and radiotherapy, did not usually emphasise much on the cost of treatment because this is a one-off treatment. However, healthcare professionals indicate that many men do not want their testes to be removed. The healthcare professionals also added that one treatment option rarely works correctly when the cancer is advanced, so even those men who agree to have their testes removed might need other complementary treatment such as radiotherapy or chemotherapy later on.

Another important source, although not reliable, for some of the patients interviewed (only three of them), is the social welfare department of the hospital. Some participant told me of getting little sporadic financial support, and the staff from that department also echoed this.

> We *sometimes get some small support for the patients, but it is not reliable at all. These are monies donated by others to support. Inother cases, we write letters to the management (of the hospital) to write off the debt of these cancer patients when we establish that genuinely, they have no means to pay that money (HCP 03, individual interview).*

The above is an indication of no adequate support facilities in place and on a fair basis from which PWAPC can rely on. This is in contrast to other developed countries where adequate formal financial support systems are in place such as *Prostate cancer UK*. Other families can gather the courage to talk to the media and the public (with anonymity) for financial help. However, this must require courage given the stigma around prostate cancer (as detailed in section 6.2) and the stigma around 'begging' or asking for charity. For example, Okonore whose husband (Kwaku) was on both radiation and chemotherapy decided to seek help from the public through a radio station. She narrated:

> *A friend led me to the radio station for some support. However, my husband was against that idea and told me he better die than to be begging for money for treatment. I had to stop from seeking that kind of help though we*

have no regular source of funds for the cost of treatment (Okonore, Kwaku's wife, individual interview 2).

Kwaku agreed to the support from the public, and although the appeal was helpful, he was not happy to 'beg' from people to survive virtually.

Yes, I had to stop her from going to the radio to seek help from others. As I told you, I have eight children with my wife, and I have the drugs to buy, so I need money. Nevertheless, I am not comfortable that the begging is becoming a routine for people to start calling me a beggar. I can't stand that shame (Kwaku, individual interview 2).

Although Okonore and her husband admit having challenging financial difficulties, the stigma around begging compelled them to stop seeking such kind of help. This corroborates with earlier research in Ghana that indicates that begging is regarded as *stigmatising and devaluing* to a person's integrity (Kassah, 2008).

Family members and children of patients sending money to PWAPC are some of the ways that patients get financial support for their treatment. However, those who may not have relatives abroad to help and other sources of financial support resort to borrowing for their treatment. The following quote is illustrative of the above.

Hmmm, we have borrowed monies all the time. From friends and neighbours and anytime I hear a knock on my door, I'm frightened because I think it might be one of our debtors. Last two weeks one of them (debtors) was here, in fact, no explanation is given to her (debt collector) could calm her temper. I wept and blamed it all on this disease (Ivy, Nii's daughter, dyad interview 1).

The participants in the above quotes indicate the anxiety they go through, as they fear, debt collectors will come after them. The anxiety further complicates the difficulties already faced by cancer per se. In the case of Opanin, he had borrowed money from his employers, and when he retired, the company wrote off his debt on humanitarian grounds.

4.3.1 The Implication of rural locality and access to palliative services

Three main issues of access to palliative care services, transportation, and access to pain medications are common. It was clear that those PWAPC who lived in remote parts of the country or far away from the Oncology unit had an additional disadvantage in accessing care at the hospital. The few home visits that the members of the palliative care team were able to do in the past fell within the metropolis or few kilometres outside the metropolis. Again, some patients and their caregivers need to set off from their home days before their scheduled appointment to reach the Oncology clinic appointment. Customarily, most of the patients have to do their Prostate Surface Antigen (PSA) test a day prior to the appointment and because these facilities are not available at the periphery of the country, they have to spend about 2 to 3 days any time they have to go to the oncology unit for chemotherapy or hormone treatment. In that case and if they have no relatives around who are willing to accommodate them, they have to find a rented accommodation or perhaps sleep on the corridors of the hospital overnight.

The centralisation of big hospitals and pharmacy shops in the cities have some implication on caring for patients at home. Sometimes searching for pain medications could be difficult. Also due to distance from the hospital, transportation cost becomes an issue. One caregiver, Teiko indicated:

> *Anytime we need to send him to the hospital for labs; we have to hire a taxi from where we live to [name withheld] and take another one from there to [name withheld]. Then we take 'trotro' (commercial vans) and another taxi to the hospital. After the test, we have to come home or sleep somewhere to see the doctor the following day (Teiko, Norbert's son, individual interview 1).*

Teiko told me that he had sought a transfer from work to a neighbouring town close to his father to take care of him. Due to the distance from the Hospital, Teiko has to request about two days off work to take his father to the Hospital. Moreover, other caregivers have similar situations to those faced by Teiko.

Access to pain control drugs could pose a challenge due to the rural locality of some patients. One participant who lived in a small town several kilometres from the Teaching hospital narrated what went through getting his prescribed oral morphine:

> *The problems appear to be unending. After struggling to get some money to buy the drugs (chemotherapy and analgesics), I combed all the pharmacies around I didn't get the drug. Even our own (district hospital) I didn't get the drug. Why do they ask us to buy drugs that are not available*? (Kwakwa, dyad interview 1).

District level hospitals may not have the capacity to do some laboratory investigations for men with cancer. Therefore, patients in rural areas have an additional challenge when it comes to seeking for these supportive services. In the same vein, other men interviewed who live at deprived places usually far from the Oncology department; they have to spend 2 or 3 days any time they have an appointment for treatment. Issifu, who is the primary caregiver for Omar had this to say:

> *Spending a whole of two or more days for an appointment at Gee (the Teaching Hospital) something else. When I am not around, no one else wants to do this kind of job and staying a day or two without even getting a proper bath. If I want to stay in a hotel or guesthouse, it is all a matter of additional cost, you know…After all the struggle I sometimes have to go and search for the prescribed drugs to buy if it is out of stock at the oncology pharmacy (Issifu, individual interview 1).*

Issifu's account shows quite starkly the difficulty in accessing tests locally and difficulties involved in obtaining medicines. He describes how, as a caregiver, he arranges to send his brother to the Hospital and sometimes to have to spend the night in the corridors of the hospital with his brother because he neither has no relatives in the city to stay with nor has money to rent a place to stay. It is therefore, difficult for people who are ill and feel terrible to experience this.

It took a long time for me to travel to visit some research participants, for example, in one municipality, which is 196 kilometres away (four and a half hours' drive). Again,

one participant who was residing at another town close the northern border of the country, about 620 kilometres away from KATH, had to schedule with me so that each time he came to the Hospital for chemotherapy, we had the interview there instead of me traveling almost 11 hours to his residence.

It shows an evident disparity with other countries where specialised palliative care is provided even in a home setting (Inbadas et al., 2017). And this finding supports a similar study in other resource-limited African countries where palliative care has not been incorporated into the national policies except in Rwanda and Swaziland which have a separate national policy and execution plan, with Kenya, Uganda, Tanzania, and South-Africa which have palliative care integrated into public health services (Ntizimira et al., 2014).

4.3.2 Unavailability of decentralised palliative health services

It was noted that palliative care provided by healthcare professionals rarely delivered beyond the boundaries of the hospital. During the discussion with the healthcare professionals, although there is a palliative care team who are tasked with coordinating the care of patients and ensure continuity of care, in reality, these plans are difficult to be implemented due to some of the issues raised previously. No comprehensive health and social policy framework are identifying, equipping, and coordinating care for patients at home in a holistic and multi-professional way.

> *I blame this on the inconsistent health policies; some government will introduce some health policies, and others will abolish it. The government has not been very helpful as far as the cost of cancer care is a concern (P05, focus group 1).*

As a result of the lack of other satellites palliative care outlets to provide the needed services to patients and also help with practical support and information services, patients regardless of their condition have to report in person to the Oncology Directorate for some procedures to be done. One particular patient, Gyasi, has to be transported via ambulance each time he needs to go to the hospital. He is a wheelchair user, and has lost weight and has pressure sores that make using public transport

difficult. The family was worried about the fact that they have to hire an ambulance for a journey of about 6 hours due to unavailability of palliative care points or similarly health professionals doing some of the services closer to them. Gyasi narrated:

> *I had some interruption in my treatment (chemotherapy) due to my inability to pay for drugs (Casodex). It has not been easy paying for an ambulance, drugs, etc. I am* grateful to the children for the care and love they have shown (Gyasi, dyad interview 2).

Gyasi who depends on his children for financial help following his retirement from active service was worried about the fact that he has to be transported all the way from one region of the country to the hospital.

Additionally, patient and caregiver participants were concerned about getting hold of healthcare professionals when new or unexpected symptoms occur while they are at home. Irene, the caregiver of Kwakwa, spoke about an instance where her husband who is on hormonal therapy had a fever and blocked catheter.

> *It was a nightmare for me when my husband had a fever, and his catheter blocked. I called the hospital, and I couldn't get through. In addition, my husband was in severe pains; I became restless because if I had to take him to the hospital that time, I would get there about 7 pm and the clinic (oncology) closes around 5 pm (Irene, Kwakwa's wife, dyad interview 1).*

The patients and caregivers who reside far from the Hospital, and have difficulty reaching out to healthcare professionals were worried about that since palliative care facilities are not provided at district levels and even most of the regional level hospital. This finding resonates with the results that adequate access to healthcare professionals, especially specialist nurses throughout, is beneficial in the provision of home-based care (King et al., 2015).

In resource-rich environments, for example, Scotland where palliative care services are brought to the doorstep of patients (Inbadas et al., 2017), caregivers are likely to have much easier access to emergency treatment at the hospital. The occurrence of additional symptoms is likely to be very hard on the patient and very stressful for

caregivers when expert support is not on hand. Lack of professional help (Bamidele et al., 2018) has been a key barrier to the adequate provision of care at home. It is important to note, the caregivers' sense of reciprocity of care (see section 5.3) is vital in the provision of home care, and this has been reported in a previous study (Imm et al., 2017). The cost of treatment, care, and the challenges of mobilising resources for care raises the issues about burden care and how some PWAPC feel they are a source of burden for their families.

4.4 The burden of care and 'Being a burden.'

Home caregiving by relatives can have numerous challenges. Caregivers expressed the complexity of the care and how they are overwhelmed with the increasing amount of care they need they provide. In as much as most family caregivers, describe the care as a familial responsibility and a common (traditional) obligation to fulfil, others talked about the burden of care they endure as discussed next.

4.4.1 Burden of care

Family caregivers have been described as 'being the linchpin of care' (Totman et al., 2015), ensuring that they get things right all the time. Family caregivers are virtually the '*general practitioners'* of PWAPC at home since they practically do everything for the patients. They spend more hours with PWAPC than anyone else and sometimes proving care that they are 'physically unable to accomplish' (Angelo and Egan, 2015). They usually decide with the patients or in some cases take the decisions themselves about what and how the care is to be done. Caregiving for patients was viewed from different standpoints by the family caregivers. As discussed previously, most of the caregivers were happy with their role because they found the care as a means to reciprocate and show of love for their relatives in times of need. Again, others were satisfied with being in a position to help and the fact that the care increase bond that exists among family members. However, the care was also reported to be challenging due to some factors including an increased workload; morbidity especially the spouses

who were older; isolation and deprivation of personal life; emotional distress; depression and fragmentation of the family unit and relationships.

Caregivers who were interviewed alone usually discussed the burden of care. Where dyad interviews were used, the caregivers usually masked their statement in order not to let the patient feel bad or seen as a 'burden.' The complementary response is one of the main methodological strengths of dyad interviews over separate interviews as discussed at 3.11.2. It is possible that some caregivers did not want to discuss something in front of the patient to upset them. For example, Atta's caregiver and son, Karikari, exemplified the burdened nature of the care after the interview when he was escorting me out. He narrates:

> *Getting the money for treatment, transport, buying 'pampers' mostly rest on me. Very little support is coming from my family because they do not have it. I also do take the central role in the care because of the physical effort required to carry him and all that. I have become 'one man thousand.' "Nipa baakofoɔ, mebɔ asore dɔn esaa susɔ nkanea"* [*He is responsible for a work that requires many people] (Karikari, Atta's son, dyad interview 1).*

The above quote and particular metaphor (*been accountable for a task that needs many people)* indicate inner turmoil arising from overburden that the necessary care can present. Caring for someone can be burdensome especially when one does not receive the support of others. Karikari articulated his emotional difficulties in doing most of the care for his dad and arranging to get some resources to help with the care. The care involves mobilising money for treatment and diagnostic investigations.

Additionally, there is a practical task, which may involve lifting, bathing, cleaning, feeding, and some decision-making about medication. In situations where only one person is responsible for carrying out a range of tasks, this can lead to caregiver fatigue as expressed in the quote by Karikari. This overburden of care has been reported as one of the barriers in the provision of home palliative care by informal caregivers (Angelo and Egan, 2015). Although lacking in Ghana, family caregivers may need tailored support, respite and regular assessment of their own needs (Jack et al., 2015)

so that they can be well to look after their relatives. The next section looks at how some PWAPC think they have become a liability for their caregivers and families.

4.4.2 Being a burden on the family

In some cases, patients were also concerned about their situation and the fact that they have become a burden on their families and caregivers. Some patient participants believe that instead of them looking after their families, as their traditional duty as men, they are instead been cared for by their wives, children, and siblings. This is discussed in detail under the subheading '*Masculinity'* (Chapter 6). The men see this as being a burden on others. Gyasi, who used a wheelchair and almost entirely dependent on the family for everything had this to share:

> *I think I am distressing my family. I have become a burden for them. It is not easy getting money nowadays, so if I see the cost they are incurring to take care of me and also lifting him and all that, I feel bad about it honestly (Gyasi, dyad interview 2).*

As noted earlier, Opoku was quite worried that his wife is overburdened with physical care due to his weight. Some participants reported that aside from the challenges of paying medical bills, transport, and other resources for cancer management, caring for someone especially as a new role can be emotionally and physically demanding. Palliative care for patients living with advanced prostate cancer appears not to address the psychosocial care for the patient's family. Psycho-social care has become part of the ethos of palliative care in Western countries but not integrated into the palliative care systems in Ghana where there are limited resources for palliative care, and palliative care is still developing. One caregiver narrated:

> *My husband told me he knows he is a burden on us. We are doing our best to help him but we need support from the hospital as well* (*Ataa, Asamoah's wife, dyad interview 1).*

The lack of practical resources for care and inadequate support for caregivers are challenging emotionally and physically as indicated by Ataa who was caring for her 65-

year-old husband, Asamoah. She was thinking about his husband's swollen legs, pains, and distended abdomen, which they described as 'duabo' (curse).

Some of the tasks seem inconsequential but with time could culminate into severe symptoms such as back pain and general weakness. Caregivers lift patients, push a wheelchair, and carry patients. When care management is overwhelming, exhaustion and burnout set in and this might explain why most caregivers complain of musculoskeletal pains because of the daily hands-on care they provide. A typical example is the situation of Irene who was the primary caregiver for her husband, Kwakwa. Irene wept as she talked about her pain.

> *Sometimes we cry together, we both are in pain. I don't want him to feel the pain alone. I have visited the hospital several times with back pain. I can't bend down well. The care at home involves personal cleaning and all that. I help clean his catheter and all that. One day, I fell and … (crying). [I offered her a tissue]. That is the situation here (Irene, Kwakwa's wife, dyad interview 1).*

The challenges of caring for someone could be overwhelming, and some caregivers still hold on to the caring role as a sign of showing appreciation to their sick loved ones (as discussed in chapter 5), but not because the care was undemanding. It is challenging, and some caregivers have been doing this for several months or a few years with no respite.

> *Bra [brother], I am tired. I'm tired (emphasis). Ever since he became like this [immobile], I am the only person lifting him morning and evening. Moreover, anytime he wants to [visit the toilet]. I cannot go anywhere, and I cannot work. Even if I decide to go out for a while, my mind is always at home. I try not to let him see that he is a burden on us (Solo, Opoku's son, individual interview 1).*

The above quote demonstrates that some caregivers have to be around the patient most of the time and could affect their own life as well. Since all the caregivers interviewed were adults, they had other care commitments for their children or grandchildren and thus are sandwiched between care role and taking care of their children or grandchildren. The concept of 'sandwich' generation is where caregivers

have to, for example, in this study, care for their ill father/spouse and their children or grandchildren (Jack et al., 2015).

Some patients do not want to be a burden to their families (Lockie et al., 2010, Sinfield et al., 2012b). The issue of overburden care has been reported in other studies and this impacts on negatively on the patients' quality of life (Totman et al., 2015, O'Hara et al., 2010, Omoyeni et al., 2014). It is important to note that such overburdened care might result in the health problems of the caregivers as well (Ewing et al., 2013). Due to the crucial role of the family caregivers in the provision of care in a resource-poor context, identifying and understanding these unique challenges is important for them to be adequately supported. The section next talks about combining the caring role and paid work.

4.4.3 Combining care work with paid work

One major issue of caregivers who were between the ages of 18 years and 50 years and usually government workers was the challenge of combing the care responsibilities and their paid work. It was quite challenging because they needed to give equal attention to both their paid work as well as the care at home. In other times, they have to deal with a conflicting schedule in respect of caregiving such as doctor's appointment, laboratory investigation or having to travel to buy prescribed drugs. This, in some, cases caused caregivers to be absent from work.

> *I work with the government agency at [name withheld], and whenever he is due for review, I have to take about three days off from work to accompany him to the laboratory for the test a day before his review and all that. One day my boss told me that my excuses are becoming too much and he doesn't like it. It is hard to care for someone and work at the same time; I can't even concentrate at work (Ivy, Nii's daughter, dyad interview 1).*

The situation was similar for Teiko who, as referred to previously, had requested a transfer from the city to a district closer to his father to assist with the day-to-day care of his father.

I was always anxious when I receive a call from home. I decided to request a transfer to [name withheld] be closer to him and provide all the needed care. It was tough for my younger brother who was lifting him alone, cleaning and bathing him. It is hard, but if we don't do that, who else will? (Teiko, Norbert's son, individual interview 2)

The extracts from Ivy and Teiko, both caregivers, indicates how difficult it can be to combine caring for someone at home and doing paid work at the same time especially if the paid work is miles away from home. Ivy talked about how difficult it was to care for her father and combine the caring role and her paid job. Additionally, she spoke about the anxiety that is becoming increasingly difficult to take time off work because her employer is not supportive and the potential risk of losing her job. These findings have been reported in a study in the UK that confirms the difficulty of combining informal care work and employment (Carmichael et al., 2008). There is no legal policy presently in Ghana aimed at supporting caregivers who might need to combine care and paid work. Some of the issues grounded in participants' account about how they feel, especially unsupported by the healthcare professional and the wider healthcare system are discussed in the next section.

4.5 Gaps/unmet supportive care needs in care provision

The perspectives of all the participant groups (patients, caregivers, and healthcare professionals) did indicate some unmet needs in the provision of palliative care that impact on the overall health status of men with prostate cancer (Watson et al., 2016). These gaps or *unmet supportive care needs* are varied, and the discussion covers all the perspectives. For healthcare professionals, three key issues were identified as gaps that serve as barriers to effective home-care and palliative care in general. These are *inadequate staff*, *lack of needed facilities* (for example to admit and carry on home visits), and *lack of commitment* by authorities in health (already empathised in section 1.2).

4.5.1 Back and forth; no progress

The healthcare professionals expressed concerns about limited resources to care for the patients when they come to the hospital. For example, HCPs spoke about having no beds or facilities for admission (for hands-on caring) for patients at the Oncology department. The beds available are specifically for patients who need to receive some treatment (chemotherapy). One nurse in a focus group discussion indicated:

> *They (patients) are provided a short stay here. We don't admit the patients here. We don't have the beds here. Even if we were to admit them here, we don't have the qualified palliative care nurses to care for them (P03, focus group 1).*

The above was an indication of some of the infrastructural challenges that the nurses and other health workers have to handle. They also shared their thought about how the everyday life of the patient and their caregivers look like when they are coming to the hospital for treatment, which is usually preceded by diagnostic investigations the day before. Again, some of the patients are turned away due to, for example, malfunctioning equipment.

> *We don't have a place of abode for the patient, no place for recreation or respite. We have patients coming in for the RT (radiation therapy) only to be told that the machine has broken down (P03, focus group 2).*

> *Someone has travelled all the way from [name withheld]. Some come and the first day or the second day the machine is out of service, so the patients run out of funds because they have to eat and hire a place to sleep. Some have to go back and return a few days later. They start day 1, 2, and 3 then the machine is spoilt again. I mean what are we doing? (P04, focus group 2).*

The health care professionals expressed concern about the logistical challenge for their work at the hospital and the impact on their patients and on their ability to do their best. This includes lack of beds for admission of patients, inadequate specially trained oncology/palliative nurses, the frequent machine breaks down (radiotherapy), and lack of money to home visit patients. At the time of the interview, the unit had only three

nurses out of the about 15 nurses who have had post-graduate training in either oncology or palliative care.

Another significant gap in the management of patients at home is the lack of resources to facilitate staff being able to do home visits or lack of assisted care by health care professionals at the home of patients when necessary. There are no community-based palliative care centres or health professionals mandated to follow up with the patients at home. Additionally, those patients who for some reason do not report to the hospital for their routine treatment, for example, chemotherapy are not followed up.

During both focus group discussions, the issue of the gaps in the coordination and management of palliative care was highlighted. This adds to the feeling of isolation for the families as described by one caregiver who explained their situation as ‘feeling of being alone in the middle of a deep sea.’

> *We have a logistics challenge in this facility, and it affects how we can supervise and care for the patients in their homes. Caring for a patient at home comes with resource needs. They need clothes, pampers (incontinence pad), Dettol (antiseptic) and others to care for the patients. The whole thing is cyclical. We are just moving back and forth — no progress (P02, focus group 2).*

One nurse with a background in palliative care during one of the focus group discussion said:

> *For home visits, we have done very few. Besides, those few ones it was our monies we spent to visit and see how they were faring. I cannot blame the staff for not [going for the visits] because I cannot tell them to use their monies for visiting patients continuously. Even we do struggle with staff members sometimes for the shift at the wards. Again, the few times I went to visit patients I felt sad seeing their situation that require some technical help (P01, focus group 2).*

The above quote from one HCP during the second focus group (FG2) points to several issues. I got the impression that some staff self-fund visits to patients at home. This suggests that the gaps in the coordination and management of the palliative care

service make it likely that some of the patients 'fall through the gaps'. This means that there is a likelihood that most patients might be lost by default since little is done to follow them up due to this apparent disconnect in service provision between the hospital and the home. The HCPs were emphatic about the 'loss of control' after the patients leave the premises of the hospital because they are not in the position to supervise their care at home or have community healthcare workers who take on the care from them. The HCPs also indicate that due to the pressure of the work, they are unable to provide comprehensive individualised education all the time to patients and their caregivers at the hospital. This lack of professional support has been reported by another study (Gysels et al., 2011). Addressing this lack of professional help is essential because when HCPs provide adequate support to patients and families, it reduces anxiety, decreases their isolation and ensures less difficult caregiving (Totman et al., 2015). The PWAPC and their caregivers described unmet care needs in the area of practical care, psychological care, and information/communication needs described next.

4.5.2 Physical and practical needs

One gap in the provision of home-based care is the unmet practical needs. Advanced prostate cancer is associated with various levels of functional limitations, and family caregivers need to help patients live a decent life. Some caregivers describe the care in the home as demanding enough physical strength especially when the patient has reduced mobility or cannot do many physical activities for himself. As described early on, such practical care could lead to caregiver fatigue and burden. Most of the caregivers require some respite after looking after their loved ones for some time. In some cases, others help with the care and run some 'shift' while in a few of the cases one person mainly does the care. The excerpts from Opoku and his wife exemplified the above need for physical assistance.

> *My wife finds it difficult to carry me from the bed. The other time we all fell together on the floor. I am wondering what will happen if she becomes sick because of all the physical stress (Opoku, individual interview 1).*

This couple seems to be doing quite well financially due to their children abroad who send funds for their upkeep. They could afford to hire someone to assist in care because all their children are working in different towns. However, Opoku does not feel comfortable with other people attending to his care needs, and this puts much practical work on his wife. The above points to the need for practical support from HCPs at home. The role of HCPs providing competent care for patients at home and being present has been reported in the literature (Sarmento et al., 2017). Sarmento and colleagues (2017) argue that HCPs should be empowered with resources that will help provide care to meet the home palliative care needs of patients and their family caregivers.

4.5.3 Psychosexual needs

One important needs expressed by men was psychosexual needs. The psychosexual results from the treatment-related side effects. The loss of sexual potency is discussed in more detail in Chapter 6 (section 6.3.3). In this section, the focus is on unmet psychosexual needs. Most PWAPC interviewed (16 out of the 23) said they felt unhappy because their sexual needs were not prioritised or talked about by health care professionals. Therefore, this may lead to decreased quality of life due to the psychological discomfort men and their couple experience. Some men resort to the use of herbal medicine whose dosages, sterile preparation, and safety cannot be guaranteed. Opoku narrated how sexual relations did not receive attention and Kwaku talks about how his search for treatment proved futile:

> *At the hospital, that is not discussed. There is no time, and everyone is around. So I heard from the radio about some drug that people were attesting to, and I bought it. One family friend recommended some 'abibiduro' (herbal drugs) for my problem (erectile dysfunction). I had to stop this particular one (herbal drugs) when my anus became sores (*Opoku, *individual interview 2*).

> *I take 'lawyer' (sex enhancing drugs). Because if you don't take those things,it is a sad story. However, even after using it for some time, I think I am 'back to square one' (no improvement) (Kwaku, individual interview 2).*

Opoku talks about little or no effort to discuss and address the psychosexual problem and that he did not have privacy to do so by using the phrase '*everyone is around'* while been attended to at the hospital. He used some herbal drugs that lead to sores in the anus compounding his care needs. Kwaku who has used unprescribed herbal medicine that he bought himself also reports that after a time, he came back to *'square one'* having been disappointed. This finding corroborates the ideas of Grondhuis Palacios et al., (2018), who suggested that psychosexual needs affects men psychological wellbeing and leads to loss of quality of life (Grondhuis Palacios et al., 2018). The authors concluded that the changes in the sexual relationship equally affect their couples and this is a critical unmet need among the majority of men living with prostate cancer. Grondhuis Palacios et al. (2018) indicate:

> "There are limited opportunities for men and partners to address the impact of the treatment-related side effects on their sexual health during follow-up consultations since priority is given to disease control" (page 4170).

It was quite revealing that the unpredictable disease trajectory of prostate cancer, the financial implication of its management among others cause some anxiety and psychological imbalance for both the cared for and the caregiver. The problems associated with symptom control also increase the risk of depression and anxiety as well as affecting the quality of life (Wu and Harden, 2015). The unprecedented levels of responsibility that needs to be fulfilled can result in an emotional upset, and that could affect the care been given. The following excerpts from a patient and two caregivers are manifestations of some of the psychological issues that are associated with receipt of or providing care at home.

> *Now, look at me in this (wheelchair). Sometimes I wish that I were dead. Because I have many issues on my head to deal with at the moment…..and you know it is not that easy. Firstly, I am sick and weak. Secondly, I have to think*

about where to get money for treatment. And I have a family to look after (Gyasi, dyad interview 2).

I think my dad is depressed because of what people say about prostate cancer and his status in the church (Karikari, Atta's son, dyad interview 1).

He has been thinking a lot. The disease has already happened, and I think he has to get over it and forget about what others say (Adwoa, Atta's wife, dyad interview 2).

The above quotes point to emotional upsets that patients and their caregivers go through. These are attributed to difficulties in seeking funds for the management, the stigmatising of prostate cancer, and other challenges that are associated with home care.

On the part of some of the HCPs, they agree with the PWAPC that there is limited time to discuss how to address each symptom. As a result, some PWAPC buys some drugs (usually unprescribed or herbal medicine) to improve their sexual health. In an interview with one HCP, he explains how sexual performance medications are advertised to attract customers including PWAPC who mostly have erectile dysfunction.

*There is no enforcement of the law regulating their use (*sexual performance medications)*. Therefore, people keep selling it. Patients do take herbal drugs and other unauthorised drugs at home. We are aware of that, and some (patients) do tell us. It is just the question of the authorities insisting on the law because the law is clear cut on that issue/advises that are related to health care that should not be disseminated on the radio. Moreover, I think the patients are made to believe in whatever is promised them on the radio (HCP 01, individual interview).*

The above quotes give a different perspective about the psychosexual needs of PWAPC. Although the HCP agrees that, they might not be meeting the psychosexual needs of the men and their spouse, other 'external' forces, for example, the activities of commercial drug sellers adds another layer of complexity. The retail drug sellers

who usually sell these drugs at public places entice the men who are most desperately looking for a cure to their sexual problem. This finding resonates with previous studies that report that HCPs are reluctant to discuss sexuality with cancer patients and their spouses (Gilbert et al., 2016, Hinchliff and Gott, 2011, Grondhuis Palacios et al., 2018), and this contributes to psychological distress of men with prostate cancer (Costa et al., 2019). Again agreeing with Gilbert et al., (2016), unmet support needs and sexual information for PWAPC and their spouses has to be looked at especially since participants in my study reports the using of unprescribed sex-enhancing drugs (especially since the activities of commercial drug sellers are not strictly regulated). The next section explores what kind of information PWAPC and their caregivers need for their care.

4.5.4 Informational and communication needs

Access to information about prostate cancer and its management, and how healthcare professionals communicate the message, is vital for patients and their caregivers. Information about care is particularly crucial as the needs of patient and family vary as illness advances (Kirk et al., 2004). Therefore, an information/communication unmet need is one of the main problems in home-based palliative care (Ventura et al., 2014) and there exist learning gaps that need to be addressed (Funk et al., 2015).

In this study, the need for further information for care was evident in many transcripts of the patient participants and that of their caregivers.

> *Well, I was told I had prostate cancer, and it was a 'serious one' so I needed some drugs to control it. So with how to deal with the day-to-day management at home, we were not told anything precisely (Ofori, individual interview 1).*

Not only the patients were concerned about some information to clarify their thought, but some still hold the belief that the disease is not 'curable' by doctors. Some were curious to seek further information about other possible cause (usually superstitious) and or cure for their disease.

The doctors told me plainly that my disease is not treatable, but they (doctors) can help me manage it. My understanding was that the condition was beyond them. When I told my friend that I think my disease is beyond the doctors, he (his friend) introduced me to someone (herbalist), but I later found that my condition was not improving after using the herbs (Ali, individual interview 1).

Benewaa who is caring for her son, Nelson, expressed a similar sentiment.

Right now, I have to care and do everything for him. When I need something, I don't know how to get the doctors and ask. If someone does come to help or check on us regularly, that will be good and reassuring. But with the look of things, I am tempted to believe my son's case is a 'hopeless' one (tears flowing) (Benewaa, Nelson's mother, dyad interview 1).

Some patient and family participants indicated that it is reassuring to speaking to health care workers about the problems they encounter with the care at home. Therefore, they pleaded for an opportunity to be in touch with some staff or for staff to visit patients at home to assess progress and assist with practical care or service when needed. Eno who was the primary caregiver of her husband, Mike, articulated this during an interview:

It is good to speak to you (as a health worker) because it is reassuring. Most time something crops up, and we have no idea about it, you know. However, when I call or report it to the staff, they can explain things and reassure my husband and me. We need more of these and they (staff) visiting the patients at home to provide the needed help as well (Eno, Mike's wife, dyad interview 1).

Eno was a trained teacher herself, and she knew some of the healthcare professionals that enabled her to call to seek direction and counsel. Another caregiver, Dzifa (Efo's wife), had this to say.

Ever since he (husband) had this condition up to now, I haven't seen anyone (health worker) calling to check on me let alone coming around to see me (to visit). We are on our own after leaving the hospital premises until we go there again.

The expression 'we *are on our own'* send a powerful message to me about how some of the caregivers felt 'disconnected' with the healthcare professional as discussed in detail earlier in this chapter (see section 4.3.2). PWAPC and their caregivers highlighted that regular visits by a HCP would be appreciated and this was interpreted as a sign of showing more concern and emotional support to them. Previous studies called for the need such care needs for people with other diseases such as mental health (Ae-Ngibise et al., 2015) and adolescent and young adult cancer patients (Bibby et al., 2016).

Healthcare professionals also agree with the patients and the caregivers that there are some informational lapses. During the second focus group with the healthcare professionals, one participant indicated:

> *I must be frank that despite the effort to inform and educate patients, there are still more to be done. More especially with our competitors out there (herbal practitioners) polluting their [patients] minds about cancer and its treatment. We are not practically able to do one on one education all the time, as you know. That would have been the ideal situation because each patient has a peculiar problem (P01, focus group 2).*

The above quote suggests how inadequate information/communication poses challenges to the effectiveness of home-based care. Good communication is essential for all palliative care activities and coordination (Barclay et al., 2007). A similar study that explored communication between caregivers and healthcare professionals found that care was improved and distress reduced when there was a concordant relationship between caregivers and healthcare professionals (Caswell et al., 2015).

A primary concern of palliative care is the support that the patients and their caregivers require in the cancer trajectory. The issue of palliative care has received considerable critical attention in the westernised countries, and the World Health organisation indicates that palliative care should meet all aspects of the patient and their caregivers' needs (physical, psychological and spiritual). However, a recent systematic review of the needs of men living with prostate cancer shows inadequate emotional, informational, and physical support (Paterson et al., 2015). Patients with other chronic

diseases such as HIV AIDS faces similar need in resource-poor settings (Selman et al., 2013). Even in developed countries, for example, the UK where palliative care has gained enough prominence, psychological problems, sexuality-related issues and dealing with persistent urinary tract infections remain areas where support needs are required (Ream et al., 2008). Specifically in an African context, where there are deficient and dispersed palliative care resources and services the unmet needs in the practical, social, psychological, spiritual, emotional, informational, and physical domains could be quite a worrying issue (Busolo and Woodgate, 2015) and this has been recommended for further research (Brearley et al., 2011).

My study therefore, contributes to the understanding of these needs in a resource-constrained setting by looking at the views PWAPC, their family caregivers, and HCPs. The identification of these care needs is vital for the planning of future care as reported in literature (Harrison et al., 2009). To close the gaps, it is significant to, first, appreciate these gaps, make these known to all stakeholders in palliative care management so that patients and their caregivers who require some support do not 'fall through the gaps'. The next section discusses coping strategies.

4.6 Coping Strategies/Supportive care

It is clear that the challenges associated with the care of advanced prostate cancer in the context resource-poor settings are enormous. However, patients and their family caregivers rely on some structures to help with the care. Research using 12 African American men with prostate cancer to explore their experiences of quality of life post-prostatectomy[9], concluded that reinforcing the social support systems could improve men's quality of life (Imm et al., 2017). As a nurse, I found social support systems in this thesis very useful for several reasons.

Firstly, everyone may at some period in the lifetime, become a caregiver for a patient with a chronic disease such as advanced prostate cancer or at the end of his life.

[9] Surgical removal of the prostate gland

Specifically, in Ghana where there are limited institutional-based palliative care facilities and no hospices, the majority of such patients will spend most of their time in their home with their families. The vital role of the family caregiver in end of life and palliative care and the supports the family relies on for care cannot be overestimated.

Secondly, men with advanced prostate cancer will spend more of their time each year with their family at home than with the healthcare professional or at the hospital. I believe that when healthcare providers are aware of what helps the patients, caregivers, and the family as a whole to cope or 'manage their affairs' at home, it is likely to improve the quality of life of the men and those significant to them (Denyes et al., 2001).

4.6.1 Compassionate Family and Informal social network

Notwithstanding the unmet needs and the challenges experienced, the informal social network is supportive of home-based care where each family member plays a significant role, directly or indirectly, for the care of the patients. The patients and their families rely on the support of the social network of the extended family to mitigate some of the challenges (Shields et al., 2006). Sources of support for the care of patients were many and could be financial support, practical help, emotional support, informational and spiritual guidance. Patients and their caregivers appreciated each of these supports.

The informal network and the communal living were cited in many instances. In one case, Zaliatu, Ali's wife told me that someone whom his husband helped financially some years ago paid her husband's hospital bills. She narrated this during a repeat interview that took place in a private room at the oncology unit.

> *There is a family friend of ours. When he heard about my husband's condition, he came here himself. I narrated all the problems to him; he promised to help us. So indeed, he has done his best to help. He said that my husband had ever helped him some years back when he (family friend)*

*needed help and because of that, he has decided to help us too (*Zaliatu, Ali's wife, *dyad interview 2*).

This support was very timely for the couple as all hope seem to be lost. As soon as they received the money from the benevolent friend, they were able to report to the hospital for the next treatment appointment. Opoku recounted:

My children are abroad; two of them, so they do send me money to pay my bills and for maintenance. That has been helping the situation; if not, I would have been dead by now. The other time, the doctors wrote some drugs for me to buy, I didn't get some here so I told them (children) and they bought and sent it down (Opoku, individual interview 2).

Opoku made a stark statement about how essential additional sources of financial support are in the care at home. This finding is supported by earlier studies about the role of financial support in-home care (Jones et al., 2011, King et al., 2015, Payne and Grande, 2013, Payne et al., 2014, Seymour et al., 2007). Moreover, this is particularly important in the Ghanaian context where no government subsidy or medical insurance support such care.

In Ghana, most people still live and are connected with the extended family. In times of need, and more so during illness, other members of the family offer emotional support as well as practical support. In most of the situations, more than one family member cared for patients, and the care is done in turns and usually cooperatively.

The relevance of informal social networks in home care has been reported in a study (Imm et al., 2017). Support of the family and others were very compassionate as evidenced by the quote below:

….my family has been so good to me and caring for me. Despite the general belief that getting prostate cancer is a punishment for men who cheat on their partners [having lived a promiscuous life], every family member has been very supportive ever since I became bedridden. My wife is a God-sent gift to me… she is such a supportive wife (Sharms, individual interview 1).

I think my wife is the glue that holds me together. I was shattered and completely lost touch with reality. I nearly gave up, but she stood and continued to stand by me. She coordinates with my other family members to ensure that my care is done well. I don't know how I am going to pay her back (Kwakwa, dyad interview 1).

I cannot thank my family and friends enough. They are such fantastic people. The family network has been helpful (Gyasi, dyad interview 1).

These quotes evidence the vital role of family and informal social network. In their study to find out some of the care family provide for their relatives, Evans and colleagues (2016) indicated the central role that the family plays in the care of patients at home and some patient participants in the study suggests that '*without the family, we're* nothing' (Evans et al., 2016 page 67). A systematic qualitative review that explored the support men with prostate cancer need, indicated the crucial role of family caregivers especially spouses in providing compassion (King et al., 2015).

Another important source, although not reliable, is the social welfare department of the hospital. Few families dared to seek support through the media to the public (with anonymity) for financial help. The quote that follows illustrates the above assertion:

I admit that we are not at good financial position to support all these cancer patients. I mean not only prostate cancer alone but also all the others [cancers]. Sometimes there is some external support from religious groups, corporate organisations, and the media (radio stations and Television). We do that through an appeal for a fund. It is not a reliable and regular source of funds. It is always inadequate (HCP 03, individual interview).

As indicated by the HCP, the social welfare faces financial challenges, and they are not in a position all the time to help the patients without voluntary donation because the government does not usually allocate fund for such activities. He also reported that for prostate cancer patients, in particular, they may face a little more difficulty appealing to others for assistance due to the cultural aspersions attributed to prostate cancer (prostate cancer stigma is discussed in detail in section 6.2).

4.6.2 The 'need' to live and Faith in God

One key resource that patients living with prostate cancer rely on is the sense of personal worth and achievement in their lives, and what (Binka et al., 2018) describes as 'positive attitude' (page 3). Some argue that they have achieved something good in life and should not be devastated by the experience of prostate cancer and more especially what people think about them.

In one of the dyad interviews, Samson and his wife articulated their views as follows.

> *I thank God for everything [pause]. I have achieved a lot in life. Others are far older and cannot account for what I have. This should rather be a source of strength than worry. As for what people out there say about prostate cancer as 'adwamanfoɔ yadeɛ' (promiscuous disease), I don't care much about that (Samson, individual interview 1).*

> *….as my husband said, we experience much gossip about prostate (cancer). Initially, I was so worried about it, to be honest. After some time we decided to look at the positive aspect of life and move on (Eno, Mike's wife, dyad interview 1).*

Hope and the need to stay alive inspired most PWAPC and their caregivers to get on with the challenges as they transverse the prostate cancer journey. Some decided to talk to close friends and family members about their problems. Other men and their families focused on their capabilities and not their challenges.

> *I don't keep things to myself any longer. It makes matters worse. I talk to my family about my problem. That plan works for me. I get inspired and encouraged by their soothing words (Sule, dyad interview 2).*

> *I stay happy by looking at my strength rather than my weaknesses (Samson).*

The inspiration and motivation also help the caregivers to give their best. They rely on the love and emotional support from other family members. Key community people including the religious heads also played important role for some PWAPC and their caregivers.

I usually get encouragement from my pastor after he shares a word of God with us. Most often, I feel completely down and think all is over. However, when he (man of God) comes around to talk to us, I feel revitalised (Eno, Mike's wife, dyad interview 1).

I've planned to visit one pastor in Accra (capital of Ghana) who has been giving instant healing to the sick. I have been watching that programme on television. I believe that as soon as I get there, I will be healed (Kwaku, individual interview 1).

Faith in God is an essential assistance for patients and their families in Ghana as detailed in 1.2.1. When the religious and social needs of patients and their caregivers are met, they cope well with their emotional challenges (Laranjeira et al., 2013). Patients and their family caregivers relied on some strength such as the presence of a Supreme Being, the worth of their lives (positive aspect of their lives), and the support from other members. Relying on one's faith in dealing with difficult times especially in sickness is reported in a study in Ghana (Aziato and Adejumo, 2014). Most patients and their families saw their situation as a time to reconnect with the Supreme Being than never before. They asked God to forgive them for any offense they might have committed, knowingly or otherwise. Some patients become more spiritually active to deal with their problem.

In all things, I shall give thanks to God. I believe things might change. You see, when I go there (hospital) and see others in wheelchairs and all sort of things, I thank God for my situation (Boat, individual interview 1).

Ofori and his wife, Stella, indicate that they are keeping the faith and believe God will handle the situation.

We are Christians, and we rely on the teachings of the church to live in difficult times. This is the very time we must show a renewed faith. This is 'ɛnsohwɛ' (difficult times in life) and we are ready to overcome (Ofori, individual interview 2).

As discussed previously, religious beliefs affect health-seeking behaviour including needs for care provision in Ghana (Binka et al., 2018) as well as the coping with illness (Phelps et al., 2009, Maliski et al., 2010a). Also, the spirit of solidarity or support is very key for families when dealing with a sick loved one (Evans et al., 2016). The use of resilience, traditional remedies, support from family and friends, religious support has been reported in a systematic review study that explored experiences of Black African and Black Caribbean men living with prostate cancer (Bamidele et al., 2018) as well as their spouses (Bamidele et al., 2019).

The above points to the fact that patients' needs should be looked at from the family's perspective and that even where family supports exist, there are challenges discussed such as pain management and stigma (see next section) and the social context in which such care occur. This finding observed in this study, therefore, address some of the socio-cultural issues as part of dealing with the end of life issues in Africa as pointed out by Gysels et al. (2011).

4.7 Chapter Summary

The main aim of this chapter was to look at the care of PWAPC in a resource-poor setting, and it synthesised the perspectives of patients, family caregivers, and healthcare professional. One major issue in managing patients with advanced prostate cancer in Ghana was the enormous financial implication due to that fact the health insurance does not cover treatment including investigation and consultation relating to prostate cancer. Again, some other expenses catered for by the family include buying incontinence pads, barrier creams, and other items for care at home.

It also looked at how patients and families have to mobilise resources for their care due to poor social care services in place to support them. The challenges seem to worsen for PWAPC who lived very far away from the oncology unit or live at the rural areas where transport cost and poor communication services could further stifle access to support from healthcare professionals who only operate from the hospital and hardly do home visits to these patients. Family caregivers are the indispensable bridge between patients and the health providers providing invaluable support and care

for men living with prostate cancer. The chapter further highlighted the ‘disconnects’ and ‘gaps’ in the provision of holistic palliative care services that is mainly due to a lack of coordination among the health care workers and family caregivers. There are also inadequate items for operational activities to provide satellite services to patients needing some practical and technical support from the health workers. PWAPC and their family caregivers indicate that visits by health care professional is a sign of great concern for them, and give them the feeling that they matter and someone cares about them. Additionally, visits by HCPs could be an opportunity to address patients’ unmet needs at home. The chapter concludes by looking at the role of compassionate informal social networks, positive attitude towards life, and faith in Supreme Being that help PWAPC and their caregivers to cope even in the midst of the myriad of challenges.

5 CHAPTER 5

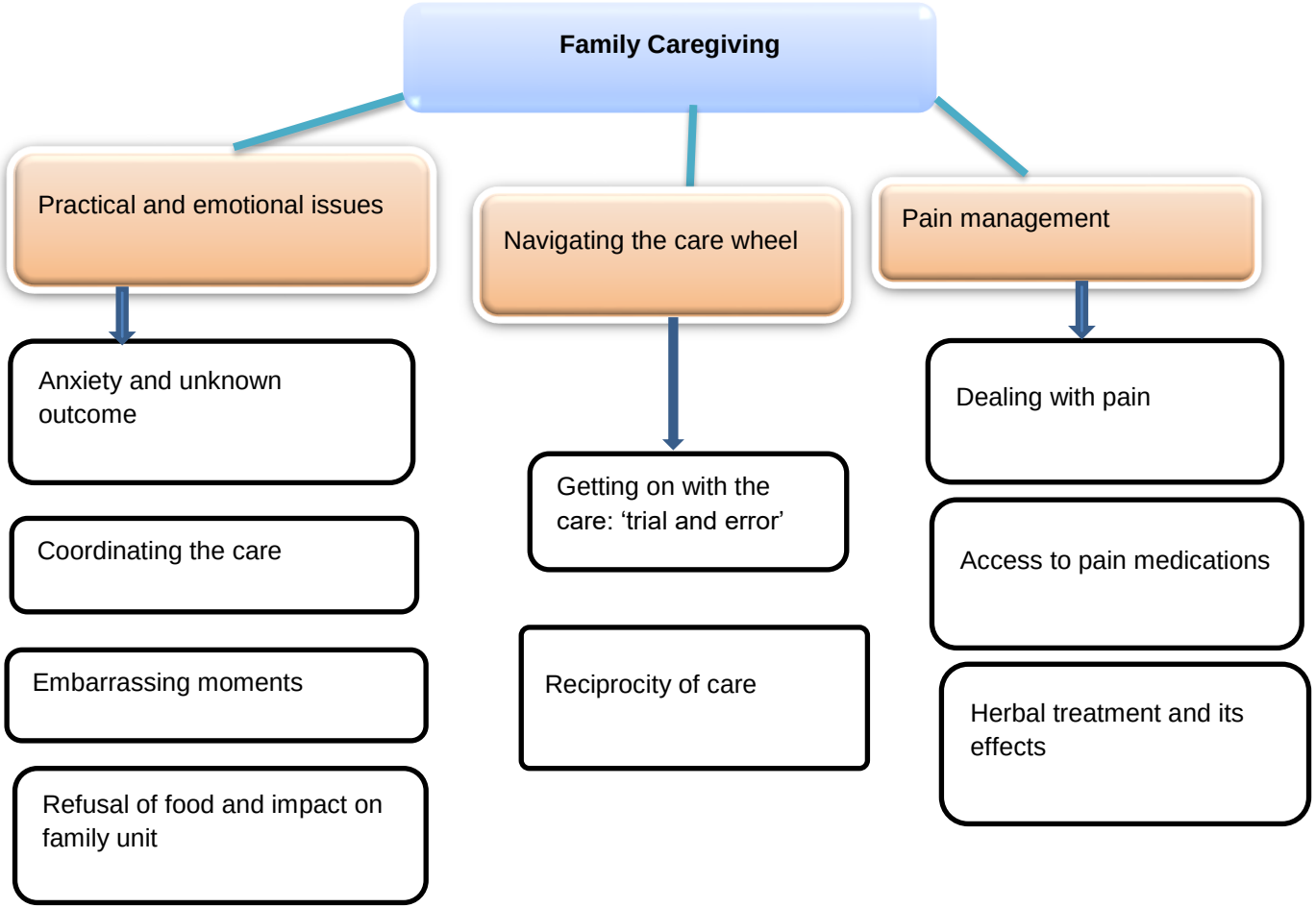


Figure 9: Theme 2-Family care giving

Family Caregiving - The stoicism and chaos

5.1 Introduction

This chapter outlines the role of the family in the care of men living with advanced prostate cancer and how challenging the care could be on the patients, the caregivers, and the family unit as a whole drawing from the perspectives from the patients and the family caregivers. The family provides a pivotal role and comfort cushion on which people fall on in times of need such as a debilitating illness (Morgan, 1996) and the care is considered as the obligation of the family (Evans, 2010). The support of family members in providing care for PWAPC at settings where there are no long-term institutional care facilities cannot be overemphasised (Woodman et al., 2016).

The issue of familial obligation has received considerable critical attention. Finch and Mason (1990) explored the kind of care responsibility that children are enjoined to provide for their aging parents in England. They, however, conclude that this sense of obligation has a limit. Devine and Heath (1999), drawing upon the seminal research by Finch and Mason discuss a myriad of ways in which the family serves as significant sources of useful and financial support for their relatives. It has also been the foundation for many social intervention policies (Devine and Heath, 1999). However, in reality, and agreeing with Devine and Heath (1999), there are dilemmas and complex issues about whether the family's support will be readily available and whether the family is obligated to provide care.

Devine and Heath (1999) further argue that in most cases families feel obliged to assist their relatives because they feel those relatives deserve help especially if such support is within the families' means. Another important issue is the concept of reciprocity where there is an expectation to give back to a family member in respect of a previous help or favour/care received. However, they also indicate that some family members avoid responsibility by making appropriate justifications and therefore, there are 'normative and negotiated aspects of family responsibilities' (page 45).

Collectively, there is a body of research that outlines the critical role of the family in caring especially at home, both within sociological and palliative care as reported in

literature (Morris et al., 2015, Broom et al., 2016, Sarmento et al., 2017, Woodman et al., 2016). Although in Ghana, there is no explicit policy rhetoric about the central role that the family play in palliative and end of life care, studies from neighbouring West African countries and Ghana have indicated the critical functions of families in end of life care (Evans et al., 2016, Bessa et al., 2012, Hanrahan, 2018).

Advanced prostate cancer affects the home space and not just the individual with the disease. The critical roles of unpaid caregivers in ensuring the comfort, care and well-being of patients at their end of life, and the burdens the caregivers endure are explicitly evident in the literature (Grande et al., 2009, Morris et al., 2015). Grande and colleagues uphold that through their unpaid work, family caregivers contribute substantially to the economy of their respective countries and in some cases to the detriment of their health. The family caregiver provides emotional support, intimate care, and direct hands-on care. They are the closest companion and what Abel and colleagues (2013) will call the 'inner network' of the patients. Sometimes the family feel exhausted with care and are also responsible for the care of their children (Seal et al., 2015), feel distressed (Moore et al., 2017), and they need the necessary support to carry out the needed care at home (Grbich et al., 2001). Broom et al. (2016) described informal caregiving as challenging and creating 'moral ambivalence' (page 998). There is, therefore, the need to explore and identify the concerns of patients and their families in home palliative care to ensure how best to support them (Sarmento et al., 2017).

Additionally, it is argued that home care reduces cost and it is likely to ensure that people die at or close to home as some wish; although this belief has been contested (Pollock, 2015). Generally, Ghanaians are reticent in discussing death perhaps due to traditional beliefs, and consequently, both patients and caregivers (Seymour et al., 2007, Seymour et al., 2010) usually avoid discussions around advanced care planning. Unlike the UK, where most people are likely to die at the hospital (Pollock, 2015) based on the current arrangement of palliative care services, home deaths are more likely (Morris et al., 2015). This chapter explores the practical and emotional issues that arise in caring for PWAPC at home and how the family caregivers navigate through the care. It then analyses how caregivers manage pain at home, and the disruption the home care brings to the family.

5.2 Practical and emotional issues

Caring for a loved one with terminal diseases can be emotion-laden and practically challenging (Moore et al., 2017, Morris et al., 2015) and some studies even recommend support for such caregivers themselves (Aoun et al., 2005). Family caregivers especially spouses report the difficulties coping with prostate cancer and its associated emotional problems, and the resultant changes in their lives in the areas of socialisation, travels, and sexual relationship (Tanner et al., 2011).

The care of the men in some cases also means watching over their treasured property or assets (children and so on). Care at home is a multi-faceted activity and require coordination. The interviews with PWAPC and their caregivers highlight several difficult encounters, and this has been sub-categorised in the sections below.

5.2.1 Challenges to deal with- anxiety and unknown outcome

Most of the problematic situations that participants talked about was focused on the stresses they experienced, both patients and their caregivers. Due to the unclear and fluctuating trajectory nature of the symptoms of advanced prostate cancer, almost all the patient and caregiver(s) participants explicitly or implicitly referred to feelings of anxiety and fear relating to the unknown outcome of care. One of the causes of anxiety was because of the significant financial challenges for the care at home and the cost of treatment at the hospital (as discussed in section 4.2).

Living with or caring for cancer brings a significant disruption in the family life; role changes, the difficulty for young children to further their education, and having to live a life with uncertainty. These issues are some of the challenges to deal with alongside practical care. The data points to the detrimental effect this might have on the general wellbeing and life of the patient and family caregivers.

Still, caregivers are responsible for assessing and relieving prostate cancer symptoms. In one of the dyad interviews with Mike and his wife, Eno, the anxiety that they find difficult to deal with is evident:

……..his condition became worse. I didn't know what was going on. I have been managing him at home, but what happened about two weeks ago, I was frightened to death. That was a weekend, they [staff at Oncology], don't work on weekends. And at this stage, if he is admitted, that will be another source of worry moving up and down the hospital and going to school (to teach) because my son had travelled then (Eno, Mike's wife, dyad interview 1).

It is terrifying. I feel like dying. I am……. I don't know how my condition is going to end (Mike, dyad interview 1).

Eno's expression 'frightened to death' described how she felt when Mike's condition deteriorated and his catheter was removed leading to urine retention.[10] They were confused about what to do and demonstrated uncertainty regarding not knowing what is happening and importantly not knowing how it might progress/end. The situation was even more complicated because of the distance from the hospital and lack of readily available support from HCPs in managing care at home. They later that day, went to the District hospital where the issue was resolved and reported back to the Oncology department on the next working day (Monday).

Some couples such as Eno and Mike were able to share their concerns and fears openly in front of each other, but this was not the case for all of the participants. In some cases, this led to conflict between them (discussed in the next section). For instance, during one interview the patient found it difficult to talk to his caregiver about his problems as expressed below:

He seems not to know what was wrong with him when asked, despite him not sleeping at night. That makes me worry, and sometimes I pick up a few quarrels with him (Sabi, Boat's brother, individual interview 1).

What I picked from the above was that Boat, 78, does not communicate his needs with his caregiver (Sabi). Sabi indicated that it was frustrating and worrying for him, and has

[10] Urine retention is the inability to urinate, usually due to blocked urethra, leading to severe pain and discomfort.

led to some arguments. However, Boat told me a slightly different thing about his uncommunicativeness about his needs:

> *The main problem is that I have waist and leg pains. I can't walk, and my legs feel numb. When I complain, they (family members) say it is old age. However, I don't think ageing means pain. So I decided not to complain lately to them (Boat, individual interview 1).*

In the above quote, Boat was reluctant to burden his brother with constant demands or complaints, however, in one instance the non-communication of the need could be due to a memory problem.

> *Now, he easily forgets things. I suppose that is why he finds it difficult. I mean he finds it difficult to say what he needs. I observe him and predict what the problem might be (Boadiwaa, Opoku's wife, individual interview 1).*

It seems, therefore, that both family caregivers and patients have challenges that they need to deal with, and this can lead to conflict between them. Conflict can stem from feeling the patient is withholding information or not discussing their needs. While the patient may be trying to protect their family members from burdens of care, it can put more pressure and worry on family caregivers regarding not knowing what to do or, as Boadiwaa observes, she has to watch and guess what to do, which she finds difficult.

Talking about fear and issues of communication between family members also surfaced during the interview. Communication coupled with fear and uncertainty could serve as an obstacle to good quality care at home. In such cases, most caregivers became increasingly aware that their loved one is getting near their end of life; however, they do not easily discuss that with the patient. The following excerpts buttresses the above assertion.

> *I know he is not going to be very well again (dying), but I am keeping the faith and don't want to worsen his emotional state by telling him the reality. His feet are swollen, and his abdomen boated. It is indeeda challenging task (Ataa, Asamoah's wife, dyad interview 1).*

He 'dies' and 'resurrects' most of the times. His condition has thrown us [the family] into a state of confusion. We don't know what to do (Sophia, Samson's daughter, individual interview 1).

The metaphors "not going to get very well again," "dies" and "resurrects" are indicative of the level of fear having to care for someone at home. Discussing death about a seriously ill person is seen as a taboo especially in the presence of the sick (Evans et al., 2016, Leclerc et al., 2014). Sophia's used of the word 'dies' though metaphorical; I believed she did so because she was interviewed separately in the absence of her father, Samson. It might also explain why Ataa who was interviewed jointly with her husband, Asamoah, used the phrase that her husband was 'not going to get very well again' instead of using 'dying.' As noted by Evans et al. (2016), talking about death is a taboo so Ataa did not speak openly about her feeling that her husband was nearing his end of life, although it was implied.

Sebastian, the son, and Eno, the wife of Mike (81 years) indicated that they knew their father/husband had some bad episodes but were emphatic that his current stage was one in which they were fearful for what future holds for them. As a result, they indicated how they (caregivers) were always close to him.

I can't go far from him even to the market to get some foodstuff due to his unstable condition. We are always close and have our eyes on him. He is kind of 'on' and 'off' (Eno, Mike's wife, dyad interview 1).

I am his only son. And the eldest as well. I have to be with him in a situation like this. You will never know what is going to happen (Sebastian, Mike's son).

Here again, the metaphorical use of use of "off and on" denotes unstable condition. A patient close to the end of life curtails the activities of family members – all lives on hold. Indecision heightens fear (Costa et al., 2019) and causes distress especially when one leaves the house without knowing what the situation is as reported in a study (King et al., 2015). Mike died before the next scheduled interview.

As discussed above, the fear of living with loved ones who are going through pain and distress was both explicit and implicit in the narratives of the patients and the

caregivers. In some cases, this was so hard to bear. PWAPC and caregivers have spoken about the complexity and seriousness of their loved one's conditions due to the frequent exacerbations of symptoms and progressive deterioration that characterises such stage as demonstrated.

> *It is very severe pain, and I scream like a woman in labour (Boat, individual interview 1).*

> *It was one sunny afternoon, and no one was home except me. His condition changed for the worse. His eyes were gazing at the ceiling. I was terrified to death. I shouted and cried, and then people rushed in here. They had to rush him to the hospital. It was a terrifying one, and I remember, as vividly as if it were yesterday (Dzifa, Efo's wife, dyad interview 1).*

While the first quote reports severe unbearable pain Boat experienced, the second quote chronicles Dzifa's fear of loss following sudden change, and not knowing what to do. Participants expressed the frustration about cases where the condition of their loved ones suddenly changes. In most cases, some appear helpless and do not know what to do. Others start to pray to God to intervene while others cannot control but to shout for help.

Therefore, PWAPC and their caregivers use different strategies (detailed in section 4.6) to 'cope' with terrifying situations. This finding also highlights how families have to cope with such situations in the absence of professional care being available/accessible – which has been discussed further in the previous chapter on resource-poor contexts. It is therefore important to assess for and manage anxiety (Costa et al., 2019). Dealing with sudden unsuspected changes in patient's condition brings about the problems of how care is managed and more so when there are divergent views from caregivers as argued in the next section.

5.2.2 Coordinating the care/Handling Conflicting opinions

Caregiving is a shared responsibility for the family (Githaiga and Swartz, 2017). Providing care at home can involve multi-tasking, which requires some level of

coordination and cooperation between the patient, family caregivers, and healthcare professionals. Such coordination mainly involves but are not limited to arranging for transport, arranging for follow up, taking hard decisions and organising the caring role such that it fits into some of their tight schedules. Additionally, it involves getting prescriptions, arranging the family's finances and acting as a proxy for patients, accompanying patients for treatment or appointments.

Most caregivers are responsible for mobilising resources from the wider family. Such resources are mainly money for upkeep and treatment, supplies such as incontinence pads, among other things. It takes some considerable effort to liaise with other members especially those who might not be staying nearby, as Samuel, explained:

> *…it is not comfortable doing that and that all alone. I need to ensure that I direct the affairs relating to care to avoid confusion and all that. But it is not as simple as that (Samuel, Tawiah's* son, individual interview 1).

Tawiah has nine children and, Samuel, the 6th born, has to take on the caregiving role. Three of Samuel's sibling live in neighbouring West African country and three others (females, are married and moved to their husbands' house far away from home), and two siblings in school. Samuel, therefore, feel obliged to do so many not a specific task as a caregiver. Samuel gets a respite when any of his siblings visit for a few weeks or when the other two students are on holidays.

There were several cases where patients and caregiver(s) had conflicting views regarding some decision to care, preferences, and approaches regarding care. In some cases, a patient's opinion is different from the caregivers and vice versa. In a more complicated situation, the patient and one or more of the family member hold different ideas from the primary caregiver. Such instances bring tension in the care at home.

In one scenario, there was a conflict in care approach whether to use the orthodox or alternative traditional medicine. Kwaku's wife, Okonore, described the situation

> *Other family members were pushing him to undergo chemotherapy while others vehemently opposed to it. It has to take some intervention from a terrific family*

friend who came to settle the misunderstanding. Even after that talk, some were not very happy deep down within so I think it has also affected how those who were against are contributing financially to the care.

On one side of the family was a group who think that prostate cancer is a biomedical disease and that doctors should be able to 'handle' the situation. On the other side were a group that believed that the patient had been cursed because of the swollen feet and abdomen, difficulty in breathing, and persistent weight loss. They, therefore, believed that the doctors could not 'handle' such cases since the situation is 'beyond' them.

5.2.3 Embarrassing moments: 'We keep wetting ourselves.'

Leaking of urine or free urine flow (urinary incontinence) is a significant problem of men with prostate cancer. PWAPC further indicate that urinary incontinence causes disgust to sight, and the smell of urine are some of the main reasons for reduced social engagement. Furthermore, incontinence causes considerable social and psychological impact on the lives of the people. As a result, there was a need to make some special adjustment in life to accommodate the incontinence (Forbat, 2004). Some of the men were using an indwelling catheter, but there were occasional leakages due to improper fixing and prolonged use. Participants talked about the embarrassment they felt when others became aware of their incontinence:

The main problem is the urine (incontinence. It causes embarresmment to me (Boat, individual interview 2).

He cannot sleep well, due to the frequent urination and wetting. It worries me a lot, to be frank with you and sometimes I am impatient with him. Due to this, he is always indoors, and I realised that others do not usually want to sit very close to him because of the strong odour of urine. I wash and keep him clean, but he wets himself sooner than we can imagine (Fuseina, Sule's mother, dyad interview 2).

The urine problem (difficulty in urination) affects my daily life and my sleep as well. 'I urinate in pieces,' 'it doesn't flow,' 'the stream is very thin' and I get some stains in my pant (Opoku, individual interview 2).

As demonstrated in the extract above, Boat articulated the challenge that he experiences day by day due to the smell of urine. The smell of urine is usually a result of the dribbling of urine due to weak urinary sphincters or complete incontinence resulting from non-functioning sphincters (Brunner et al., 2010). The smell of urine due to leaking catheters or inability to control one's bladder is stigmatising (this is discussed in chapter 6).

Eno articulated how agitated she becomes when her husband removes the cork of the catheter and on one occasion when he deliberately cut it off with blade causing a mess in their living room.

I feel so bad when that happens. Sometimes I become impatient with him (Mike), to be honest. The other day he cut off the catheter [looking tearful], and the whole room was stinking with urine. Now I feel shy to allow people to enter our hall and that is why I decided to speak with you here [close to a detached kitchen] and not near there [room] (Eno, Mike's wife, dyad interview 1*).*

The smell of urine was difficult for them both to handle. Mike[11] cuts off the cork because he does not want it there. A situation that creates extra work and distress for Eno, and has a further impact on her being embarrassed to have people into her home. The odour makes her fearful and avoids potential stigma. Such avoidance leads to self-isolation.

As a result, some PWAPC decide to, or are advised, by their caregivers to stay in solitude or to remain home as much as possible as reported by Boat (a PWAPC), Fuseina and Eno (family caregivers) in the above quotes. It is argued that incontinence and its management are complex issues to deal with and can be emotionally upsetting for both PWAPC and the close relations particularly the caregivers (Cassells and Watt,

[11] Mike has been getting confused lately and he pulls the catheter out or cuts it when no one is around.

2003). Again, managing incontinence means dealing with dirty work or handling sensitive or private parts of a person (Twigg, 2000, Lawler, 2006, Brittain and Shaw, 2007).

There are varied ways in which the incontinence is managed depending on the needs and circumstances. The use of plastic sheets on chairs or beds/mat, use of urine bottles/pot (known in the local language as 'Kuruwaba'), incontinence pad and urinary catheter with or without a bag. The advent of incontinence pad (usually called pampers) has reduced the incidence of some men wetting their clothes with urine. However, due to reasons such as frequent changing of the incontinence pad, the cost of buying the 'pampers' and lack of availability in some rural localities, some do not use them. The financial cost of dealing with incontinence can have a negative consequence on the patient and the caregivers, especially where there is inadequate government support. In managing incontinence, some participants indicated the need for items such as incontinence pads, financial support, and practical help from health staff. One of the graphic descriptions of the call for support was captured in the following narrative when Ofori's wife, Stella, was interviewed:

> *The government should support us. These men have contributed all their life to develop this nation. They (government) should care for men with cancer, who are now retired, as they would've done for their own (politicians)[12], so please tell those people (authorities) for us (families) (*Stella, Ofori's wife, individual interview 1).

This comment perhaps is linked to the political atmosphere at the time. This interview took place about two weeks prior to Ghana's 2016 Parliamentary and Presidential elections.

Some men feel uncomfortable wearing the diapers all day and in some cases all nights as well. Others reported feeling not only painful but felt that wearing the 'pampers' is so demeaning and they have been treated infantilised. However, other men and their

[12] Stella indicated politicians such as Member of Parliaments some of whom her husband taught takes huge salaries, receive ex-gratia (emoluments and benefits) at the end of every full term of the legislature, and get medical treatments abroad so they care less about their plight.

caregivers indicate that the 'pampers' and the catheters usually made a significant difference in their social life.

Some family members talked about the presence of incontinence with its resultant odour about being worried that others might feel that his family members do not care for the patient properly. As Teiku explained:

> *Others may think we are not taking care of him or perhaps we have neglected him. But you see, odour knows no boundary. Unlike the leakage that could be trapped by the 'pampers' (incontinence pad), you can do little about the odour even with the strongest perfumes (*Teiku, Nobert's son, individual interview 1)*.*

> *I must be frank; it is because he is my dad and my love for him; that is why I am still doing this. I think it will be difficult for any other person to deal with his mess. But such is life, good or bad we must deal with it (Jenny, Baabamu's daughter, individual interview 2).*

The above narrative deliberates on the smell, the leakage of urine, staining of clothes, and the embarrassment that patients and their caregivers' encounter daily. In extreme cases such embarrassment and the odour contributes to the social isolation or what is described as social death[13] before the natural death (Borgstrom and Walter, 2015); however, none of the participants reported having experienced that situation.

Another important but rare finding was the discomfort a caregiver felt when dealing with 'private parts' due to gender difference between the patient and the caregiver, although they are close family (father and daughter).

> *I feel uncomfortable doing all the cleaning 'under' (perineum) and all that. Dealing with an older adult's [private part] is quite difficult for me[14] (Ivy, Nii's daughter' dyad interview 2).*

Ivy's quote presents another issue- that of providing intimate care. Providing intimate care might be uncomfortable for some. However, this was said to be 'uncomfortable'

[13] In this context refers to extreme form of isolation or exclusion from social activities.
[14] As caregiver providing intimate care of cleaning and washing the body of her own dad.

but not particularly difficult. Potentially this induces discomfort and dislikes where they have to expose and or touch body parts considered as 'private.' It can be difficult for a patient regarding privacy and dignity as well, and this was the case of Opoku, who was uncomfortable when others, except his wife, to do his intimate care (see narrative in Appendix L). Although this contradicts with the systematic review finding where they did indicate that all personal care needs of home care patients are met (Ventura et al., 2014), it supports the views of previous investigators (Papastavrou et al., 2012, Lawler, 2006). Lawler's (2006) seminal work about the care of the body points to the embarrassment that both nurses and patients feel when their private body parts are touched, as part of the nursing care or accidentally by a patient during the provision of intimate body care or where a person is naked.

Personal care can also be stressful for caregivers because they usually lack formal training. The problem of gender and intimate caregiving among the elderly has been raised in the literature (Wong, 2005). Wong (2005) explains that where children are providing personal care for their elderly relatives such as parents and in-laws, they feel embarrassed touching or exposing others private body parts. The problem of caring for people of the opposite sex has also been reported in a formal care setting with trained health care personnel (Inoue et al., 2006). However, this could lead to poor quality care as it could serve as a formidable barrier in the provision of personal care that will ensure that the patient appears good, looks refresh and dignify. Such restrictions may also worsen the issue of dealing with urinary incontinence and odour. Wong (2005) went to indicate the conflicts and stress that this cause for both cared for and the caregiver, particularly women who are by default expected to be "natural" caregivers in most societies.

I acknowledge that this finding is more surprising that it has not been well documented. Therefore, this must be an area worthy of exploration since caregiving is culturally considered as the role of women in Ghana (Hanrahan, 2018) and to find out whether or not male caregivers caring for female relatives do have a similar experience.

5.2.4 Refusal of food and impact on family life

Some of the side effects of chemotherapy used in treating cancers include nausea, vomiting, and loss of appetite (see 0 for details). The loss of appetite or vomiting after meals led a few men refusing to eat or eating small amounts of food. Because most families in Ghana practice communal eating (sometimes from the same bowl or in smaller groups), this can become a challenging issue for families if a member of the family is refusing to eat. In some cases, preferred food was prepared for the sick only to be rejected by the patient. Eleven out of the 23 men had loss of appetite and were eating little or refused food sometimes while 12 men did not have a significant problem with eating.

> *He keeps on refusing food. We all can't eat either. Yesterday I prepared fufu[15] and soup, and he said he wanted "bayere ampesi" (boiled yam). So I had to go to the market and get him some that late evening. After I prepared him the food, he refused. Moreover, that has been the trend recently (Okonore, Kwaku's wife).*

> *Our main problem is that he doesn't eat enough. He needs to eat to get strong and for us too to get the appetite to eat. If he refuses food for days, everyone is bothered too. He eats little porridge in the morning, and that is all for the day. Last week all the dinner was discarded because we were sad when he refused everything (Eno, Mike's wife, dyad interview 1).*

The above excerpts from Eno and Okonore express worry that PWAPC cause for the families. When men have little appetite, efforts and resources are put into enticing men to eat (e.g., buying ingredients to prepare special meals) so there are multiple consequences of men losing their appetites – impact on family routines of eating together, additional resources to source and cook special meals, and the worry of patients refusing these meals as well. This finding about the worries caregivers as well as the family experience when a dying relative refuses food corroborates with other studies (Ellis, 2018, Hughes and Neal, 2000).

[15] A local Ghanaian delicacy made from pounded cassava usually with plantain or cocoyam and it is eaten with soup

Caregivers expressed apprehension about the effects of their loved ones eating just a little or not eating as well as the sense of guilt that they (caregivers) might have done something wrong that is why their food is refused as expressed in the quotes below.

> *He wanted 'aprapransa'[16] I didn't have the money, so it was Tuesday that my son sent money to us. I made the food, and it tasted so nice, but he (Sule) ate very little. Money is hard to come by so when he does that, it is worrying (Fuseina, Sule's mother, dyad interview 2).*

> *I don't have an appetite for food. I took some vitamins I bought from the drug store, but it didn't improve much. It is not that I don't want to eat but just that the appetite is not there. As for the drink, I drink small so that I don't have to be getting up to urine frequently (Boat, individual interview 2).*

> *I am unsure if I have pissed him off or something. I don't figure out why he refuses his best food. I can't tell. He might be annoyed, or he is doing that intentionally to end his life (Sabi, Boat's brother, individual interview 2).*

Refusing food or eating just a little was a difficult everyday family experience for life in families who are managing a loved one with a severe disease like advanced prostate cancer. Eating food means a lot for a family, and in Ghana, when a husband refuses to eat food prepared for him by his wife it is interpreted as the husband has dispute with the wife. The repeated refusal of food made some of the families worried and made them think if they have offended the men in any way. This resonates with the findings that food has a 'social and symbolic importance' (Abbots and Coles, 2013). Again, it is a sign of waste when food is not eaten as captured in Fuseina's quotes and they were worried that without adequate consumption of food, their relative was not going to get better or PWAPC are starving themselves to death. The narration by Boat about not wanting to get up to urinate often underscores his decision not to drink more despite his inability to eat food. The practice of patients not eating worsens distress as described by family caregivers such as Fuseina, Sabi and Eno; this has been reported

[16] Food made from roasted corn flour, palm oil, tomatoes, fish (sometimes with crabs) and spices

in the literature (Lavis, 2018). The next section describes how the family navigates the care at home and what caring for the sick mean to them.

5.3 Navigating care at home

The primary family care providers were mostly spouses, sons, daughters, bothers, and mothers. I have the impression that each of these categories of caregivers has diverse experience and circumstances, and in most cases how they go about the care and the support that PWAPC needed was quite different. However, some key issues run through the interviews and this is described in the subsections below.

Going about the daily care role involves decision making caregivers make (Funk et al., 2015) based, usually, on their knowledge and intuition (De Graaff and Francke, 2009). It was apparent that the family caregivers get some level of support from other members of the family and benevolent individuals or organisations such as the church, and the public.

5.3.1 Getting on with the care

One important thing is that many family caregivers might not have any prior experience of caring for someone who is seriously ill. The caring role can be overpowering as caregivers navigate their way through to find information and resources to aid day-to-day care.

Undoubtedly, provision of care is a mix of skills and special knowledge that is gained by training, previous experience or by observing how others do the care(Sinfield et al., 2012a, Funk et al., 2010, Sarmento et al., 2017, Caswell et al., 2017). However, for most of the caregivers, except three who were health workers, all the others had no formal training. Others especially the spouses or the elderly caregivers might have observed or participate in some level of care for previous family members. Therefore, for the majority of the caregivers, it was the first time performing the caring role or better still of learning to care.

Some were explicit that they lack the requisite nursing or medical skills and as such reported some 'trial and error' method in their delivery of care. In some situations, as in the case one caregiver, Mawuli, there was some indication to suggest that the care provided is deficient and this led to his relative developing bedsores. Most caregivers indicate that they use their intuition for the care they provide. In some of the cases, however, aside from the trial and error, caregivers actively asked from others especially trusted family and friends or relied on what nurses and physicians told them.

Provision of care was a complex and tedious task. The level of care given depends on the needs of the patient and their physical ability. Overall, some men were able to care for themselves regarding personal care, others needing some assistance and yet others require greater support for their activities of daily living. This involves the provision of physical, passionate care, and emotional care.

The men who had difficulties with mobility had additional risk developing skin breakdown/wounds. Where incontinence was improperly managed, cases of urinary infection were reported. This connects with an earlier section about the provision of intimate care, privacy, and dignity discussed in section 5.2.3 above. One patient and caregiver shared their experience on this:

> *I can't walk, and at times, I urinate on myself unconsciously. When I went to see the doctor, I was told I had infections in my penis and my sacrum. We don't know how to prevent this (Babaamu, individual interview 1).*

> *He has been in bed for quite some time now. About one year……he is very heavy for only one person to handle. Therefore, he has a big sore in the lower back. …..It's difficult for us (caregivers) to avoid this if we can't anticipate and know what to do (Mawuli, Efo's grandson, dyad interview 2).*

The 'how to care' dilemma consist of practical care, how to minimise pain and increase comfort, how to prevent complications among others. For instance, Norbert's caregiver reported:

> *For the care at home, it is mostly trying one thing or the other and see, which one works best…we most times, do 'trial and error' honestly. We are on our own*

when we are at home. Healthcare is not my field of training; mine is an accounting and I don't know how to nurse big wounds etc (Teiko, Norbert's son, individual interview 1).

Teiko points to the fact that there is some technical part of the care, such as caring for the urinary catheter and wound care, which was beyond his expertise. He also talked about using 'trial and error' most time, especially when managing his father's pain. Stajduhar et al's (2013) study indicates that most family caregivers learn by 'trial and error', the use of previous experience and directions given by others. This supports this current study where caregivers did mention that they took up the caring role with no training or idea about what to do but do things 'as they go.' This was what Stajduhar at al's (2013) referred to as "learning from your mistakes" or "learning the hard way" (page 659). However, unlike Stajduhar and collegues' (2013) study, most participants and their families did not use active information seeking as a way of learning how to care, and this is perhaps due to the stigma around prostate cancer (as discussed in section 6.2.2 in the next chapter). It might also be due to the limited access to the internet (as discussed previously in section 4.3.1), lack of available information guide for prostate care and absence of home care health professionals. Participants, therefore, used reactive rather than proactive means to seek for ways to care.

Caring for someone at home also involves a 'new' role that members may not have performed before or are not very comfortable with. This was the case for children caregivers especially the females. Seeing the nakedness of their dad was something that was quite 'unpleasant.' However, spouses usually did not seem to have much difficulty with such a role. One daughter, for example, said:

It is sometimes difficult dealing with his nakedness and all that. One day I was very sick, and my sister-law who visited wanted to assist. When she realised that she has to deal with my dad's 'private' part she refused. My dad didn't like it either (Ivy, Nii's daughter, dyad interview 2).

However, a spouse did indicate that providing intimate care was not a problem and the husband felt relaxed.

I have been doing the care and sometimes supported by Solo (their son). I think he (husband) doesn't like it when others or the female children to bath and change his pampers (incontinence pad) (Boadiwaa, Opoku's wife).

Ivy points to the challenges of her sister-in-law; Betty, wanting to assist with the care but Betty did not feel comfortable dealing with the nakedness of her-father-in-law, Nii, Ivy's father. This finding is quite interesting because, in most African countries, women and young people are responsible for most of the home-based practical care (Robson, 2000).

Furthermore, Sophia (Samson's daughter) and Jenny (Baabamu's daughter) also provided care without their fathers resisting the care of their intimate area. As discussed in section 5.2.3, Ivy has not been that close to her dad for about 20 years. Since this was beyond the scope of this research, a further exploration of this care and gender issues will be fascinating. That study might also consider caregivers who might not be related, by blood, to the patient just like is the case of Ivy's sister-in-law.

Contrast to the discomfort of providing intimate care, there are different positive impacts of caregiving on family relationships. The day-to-day care, to some families, had made their intimacy somewhat stronger. For example, Ivy, who had not stayed with her dad for a long while shared her experience.

I can say that we are much closer, as a family and me especially to my dad. That is not to say we are happy with his current situation but we are more intimate than before for a while now and the bonding is real (Ivy, Nii's daughter, dyad interview 2).

In the absence of HCPs managing and coordinating the care at home, family caregivers plan and execute the care at home. The family caregivers as part of the day-to-day care assess patient's condition to administer drugs, make most judgements and decide what care might be appropriate usually using their intuition with little or no support from the healthcare professionals. They care and refer cases 'above' them to the hospital or in some cases traditional herbalist for further management. They are virtually in charge of the care direction of PWAPC. They spend most hours with them

than anyone else. They usually decide with the patients or in some cases take the decisions about what and how the care is to be done. Maegyida's wife shared her experience:

> *My son and I do all the care here at home. Anytime my husband is discharged from the hospital we take charge at home doing everything because no health staff has ever come home to assist or something. If my husband's condition becomes worse, we then send him [back] to the hospital for a few days for management (Abiba,* Maegyida's wife, indidivual interview 1*).*

Some of the men also expressed explicitly or otherwise that the family is their medics taking care of them in the home context.

> *I must be thankful to the doctors for their excellent work at the hospital and for helping us to live. I can't thank my wife enough. She is my 'doctor' at home ensuring that I get all the care I need….. My children too are very helpful for the up and down movements (Baabamu).*

Baabamu's comment demonstrates the great responsibility that the family caregiver take. The family members are becoming 'experts' in their care at home. However, family caregivers who become the frontline of care can also be quite complex to manage as reported in similar work earlier (Payne et al., 2015). Although most caregivers see the care as *'giving something back' (Totman et al., 2015)*, this indicates how family caregivers are expected to decide care at home unsupported (Laryionava et al., 2018). This is what has been described as *'professionalization'* of family caregivers (Neergaard et al., 2008). The reasons for providing care was seen by many as a duty to fulfil or in few instances as not wanting to incur the wrath of 'ancestors' on them as described in the next section.

5.3.2 Reciprocity: A duty to fulfil

One important thing that was explicit but sometimes implicit was the sense of moral 'duty to care'. As outlined early on in the methodology chapter (Table 2), the family caregivers were unpaid relatives (brothers, mothers, children, spouses, and

grandchildren). Throughout, there was frequent mention of the fact that family caregivers have to care for their loved relative as their customary duty. The reciprocity was understood from several points of views. First, there was the general belief that the father is the spiritual head of the family and that there is an obligation to ensure that he is cared for. Second, other caregivers saw caring as a time to give back to the men they love and the sacrifices the men (PWAPC) have made and continue to make in their lives. Third, there was also the belief that the caregivers are providing the care to these men so that in case they fall sick in their old age or have a similar problem in the future, their children or family members will not leave them to their faith. The fourth reason for reciprocity was the fact that society frowns on the neglect of the sick, so they have to provide care. Finally, the belief in post mortem punishment if they neglected the sick. The following are excerpts to support the typologies of reciprocity enumerated.

> *We want to show him love and support by giving back what he did for us when we were young and fragile (Agyei, Gyasi's son, individual interview 1).*
>
> *We are also men; a similar thing might happen to us. You can't tell what will happen. Can you? (Otoo, Gyasi's son, individual interview 2).*

The central issue has to do with 'protecting the sick.' This supports a previous study in the northern part of Ghana where married daughters and daughters-in-law of the seriously sick man are expected (traditional norm) to relocate from their husbands homes to assume care responsibilities (Hanrahan, 2018).

This together with concerns as noted of what others might think were issues raised. This is interesting sociologically because we do get caught up in concerns about being seen to be a good son or a good daughter. This demonstrates domestic and emotional labour where people likely want to not only explain what they do but importantly are aware of how others view them - and present themselves, not just as caregivers, but also as good caring caregivers – doing the right thing. This outcome of the study resonates Totman et al.'s (2015) 'you only have one chance to get it right' and 'being held in mind' when they conducted a study on the emotional challenges that family caregivers encounter.

Additionally, other participants demonstrated the other forms of reciprocity enumerated above. In Asamoah's case, his son, Joobu, felt he is helping his father for fear of God. Joobu left to the city to look for a job after his secondary school when his father decided not to further his (Joobu) education. Joobu believes the father is suffering from the wickedness and neglect that he (father) made him go through some time past. However, Joobu has resolved not to pay his father back in his coins but to 'teach' him how it feels like to receive help when it is most needed. Joobu narrated:

> *He is my birth father. He refused to send me to school even though he had the means to do so. I have decided to teach him how it feels like when someone rescues you timely….If I think about those past events, I wouldn't have been here to care for him (Joobu, Asamoah's son, dyad interview 1).*

Opanin's wife and caregiver, Achiaa, narrated why she is motivated to care:

> *I must be with him especially this time he needs me the most, for better or worse, and in sickness and life. Anything different, I know I have offended the God I serve (Achiaa, Opanin's wife, dyad interview 2).*

Joobu's narrative is exciting because instead of repaying his father for not looking after his (Joobu) education, Joobu decides to teach his father the correct moral way of being responsible. In the second quote above, Achiaa saw the care as a duty she has to do for her husband, Opanin. However, Sophia articulated additional reasons for providing care for her father:

> *I must care for him. No two ways about that. God will not forgive me if we abandon him because he (dad) has done a lot for the family and me. I can't even stand the criticisms from others. Everyone knows what my dad has done for us growing up (Sophia, Samson's daughter, individual interview 1).*

Karikari also elaborated further another reason to care for his father.

> *We are doing our best to help him live. If one is not careful and something happens, (he dies), that guilt is going to stay with you, and you will not be forgiven (Karikari, Atta's son, dyad interview 1).*

The above quotes highlight that family caregivers felt they have the moral obligation to care and in some cases make a decision for the patients as reported in earlier studies (Quinn and Evans, 2010, Bessa et al., 2012, Hanrahan, 2018). One researcher talks about belief in ancestral vengeance and the metaphor '*if one is not careful'* used by Karikai is indicative of a fear of retaliation by the dead. This belief confirms an earlier work by Hanrahan (2018) that post-mortem retribution can be a reason why some relatives will feel obligated to provide care.

Caregivers in this study demonstrated a strong sense of responsibility and were motivated to provide care by cultural beliefs that frown upon the desertion the sick. This corroborates with other studies where the notion of 'giving something back' to others was noted to be held in esteem in society (Totman et al., 2015) and the spirit of reciprocity of care especially for the for the elderly (Van der Geest, 2002). Different participants responded to these discourses in differing ways. There is much talk about 'duty', and reciprocating past good gesture (love) shown to them (not in Asamoah's case with his son, Joobu). Family obligation continues to play an important role due to the moral codes and relevant expectations, and attitudes expected of family members towards one another in Ghanaian society especially concerning the sick person. Being seen to be a good son/daughter, wife, etc. is important, and some caregivers such as Agyei (son), Kwakwa (son), and Achiaa (wife) demonstrated this.

As part of their duties, caregivers are to make sure that the plans of the cared for is fulfilled even after death. As discussed, talking openly about death to the seriously ill person is seen as a taboo in the Ghanaian society. This might suggest that the person initiating such a conversation wants the patient dead (Githaiga and Swartz, 2017). Therefore, a culture that does not encourage the contemplation or discussion of death, people are reticence about broaching dying and any issues concerning advance care planning (Ekore and Lanre-Abass, 2016).

Although most PWAPC prefer not to mention the word 'death,' they aimed to have a peaceful 'exit' from the world by using terms such as 'when my time is up', 'when God calls me', 'when I am no more', among other statements. Most of the men saw their

caregivers as people whom they could trust to take care of their cherished property (known in the local Akan language as agyapadeɛ) including children when they die.

> *I am sure that God will heal me. I know I will be better and well before my exit from this world. When God calls me, I am sure he will continue to take good care of the others too (Nii, dyad interview 2).*

> *It is sad; now I want someone to look after my children. I pray their children (his grandchildren) will do the same for them also. When I am no more, I will want my children to be looked after and not to suffer. Wherever I am (after death), I will bless the person fulfilling this wish for me because my children have looked after me (Gyasi, dyad interview 2).*

Moreover, none of the caregivers talked about death and dying or used the word death perhaps of the reasons stated above or because of the difficulties discussing issues of advance care planning (Almack et al., 2012). The belief of not discussing death about the sick makes me curious about how families might deal with advance care planning. This was out of the scope of this study, and future investigators might consider this.

5.4 Pain management

Pain management is a dominant feature of palliative care. For effective pain management, there is a need to identify when pain exists, how pain is managed, and how to monitor the effectiveness of pain therapy. Pain management in chronic diseases is usually a complex and challenging one. One has to have the knowledge of determining the level of pain accurately or communicate it, good knowledge of how pain is managed, and the resources for pain management. In pain management, the issue of subjectivity in assessing pain, access to drugs especially oral morphine, and how drugs are managed are critical to the effective pain control (Merriman and Harding, 2010).

5.4.1 Assessing and dealing with pain

Assessing pain was a joint decision by patients and their caregivers. For most patients, the pain was sometimes unbearable and relatively constant. The pain location and

intensity seem to be different for most men. Men living with prostate cancer used words such as a ‘bit,’ ‘tormenting’ and ‘unbearable.’ That notwithstanding, most of them reported waist pains, back pains, and general body pains, Specifically, pains in the anus and penis usually followed some intrusive diagnostic procedures, but this usually lasts for a few days to weeks. One PWAPC narrated his experience of pain:

> *Hmm, the pain is very unbearable sometimes. The last time I cried. That made my wife and children also followed suit as if we were all mourning (Nobert, individual interview 1).*

One caregiver expressed her frustration of having to deal with pain control as follows:

> *You know, it is hard. After giving all the medicines to him, and he still complains of pain… when it happens like that... I am entirely at lost (Ivy, Nii’s daughter, dyad interview 2).*

Pain, as described by some men, was a problematic issue to bear. It causes not only the physical discomfort to the patient but the emotional distress to the family. Norbert’s quote “as if we were all mourning” is powerful reflection about the family’s reaction to pain. That, in a sense, may also depict anticipatory grief (Paiva et al., 2015). Ivy, a caregiver, also shares her experience of how incredibly difficult it was to see her father in pain and she was helpless to be able to do more, after giving all the pain medications. The expression of anticipatory grief resonates with the findings of Mehta et al., (2014) study that explored sources of family caregivers’ distress in managing pain in the home context that revealed that “it hurts to watch somebody you love suffer” (page 98).

In some instances, participants seem to suggest that some complaints about pain are ignored or it is treated as one of the ‘usual’ things.

> *After I went for the procedure, that night I couldn’t sleep at all. I was awake all night. I slept a while in the morning, and the pain came again. I complained… I asked for stronger pain relief, but it was ignored…. It was. They (caregivers) think I might be demanding unduly (Nelson, dyad interview 1).*

Nelson talked about caregivers ignoring his call for a stronger pain relief drug. As illustrated by Ivy above, caregivers have a limit of what they could do to control pain without the support of health professionals. This feeling of being unassisted by health professional managing pain at home has been reported by a current study that highlights the challenges caregivers have in the areas of drug administration and feeling unsupported by professional staff (Wilson et al., 2018). My finding also corroborates with others on pain management becomes more problematic in resource-poor settings where there is lack of access to and affordability of potent pain drugs as reported in previous studies (Powell et al., 2011, Ntizimira et al., 2014, Downing et al., 2015, Clark et al., 2007).

5.4.2 Pain medications: Accessibility and Managing side effects

The main pain medications used for treating moderate to severe pain in Ghana are morphine and pethidine-classified under controlled drugs-one cannot buy it over the counter even with a prescription. Usually, pethidine is administered under the supervision of a trained practitioner at the hospitals in case of severe pain especially following surgery. As indicated early in Chapter 4, in Ghana PWAPC have to pay for all the services including drugs. In cases where they do not have enough money to buy the drugs at the hospital, they may have to either travel back (could be several kilometres for some) or to buy the prescription at private pharmacies. Participants, however, complain of the difficulty of getting oral morphine and other pain medications at nearby pharmacies. And this seems to affect the effective management of pain at home.

Quite a few are lucky to have the drugs from the children or relations abroad who send them the drugs whenever it is prescribed.

> *As for buying drugs, I have no problem. Any time the doctors write it for me; I ring my sons abroad to inform them. They buy and send them to me. Sometimes I have a stock that could last for about over six months (Samson, individual interview 2).*

In some cases, patients and their caregivers doubted the potency of some of the drugs they bought. They supported their claim with the information they hear on the radio about the influx of fake drugs in the market.

> *Now, most of the drugs out there seem not to be effective. I prefer to get the drugs at the hospital where I go for review (study site). But sometimes, they too, they run out of stock (Ali, individual interview 1).*

> *I suspect the drug we bought is fake. The one I bought for my son seems not to work. Usually, with the same dose he is ok but… with the one we got recently I think it is not original. It even looks different (Fuseina, Sule's mother, dyad interview 1).*

Adding to the issue of fake drugs, one of the healthcare professionals has hinted the problems that they have realised about fake drugs in the local drug market.

> *Since we are unable to stock enough drugs here for them (patients because of apparent reasons [financial challenges] the patients are likely to buy inferior or fake drugs from the market when we prescribe the drugs but do not have some to dispense. It is a worry (HCP 03, individual interview).*

The above quote further explains the difficulty in managing pain in Ghana due to lack of supplies, and the tendency of patients to buy less potent drugs. Although access to drugs at the point of service is different in developed countries such as the UK, pain control continues to be a critical issue in prostate cancer management (Kunkel et al., 2000). Other studies also report that there are challenges for caregivers in deciding what dosage is enough in order not either over medicate or under medicate patients at home (Payne et al., 2014, Wilson et al., 2018). Several measures were put in place to manage the pain associated with prostate cancer including the local application of heat, use of drugs such as nonsteroidal anti-inflammatory drugs (NSAIDs). The challenge that families have managing medication at home and serving as a source of stress has been reported in studies (Angelo and Egan, 2015, Wilson et al., 2018). In my study, one caregiver narrated how challenging it was for her managing pain at home. One family caregiver articulated her experience of managing pain at home.

It has been a vigil night for us for the past few days, and we all were panicking. When we send him to the hospital, they give the same drugs. I didn't know what to do after he complains even after giving him all his pain drugs (Safia, Boat's caregiver, individual interview 2).

It is evident that patients and their caregivers are concerned about pain control in the home context where there is very little involvement of other qualified health professional. They described managing the symptom as 'big issue,' 'fearful' and 'panicking,' especially where access to pain control drugs are limited (Harding and Higginson, 2005b). This finding suggests that there is a further need for symptom control. One scholar described family caregivers experience of distress managing pain as feeling "overwhelmingly responsible," unsupported," and "flying blind" (unprepared) (Mehta et al., 2014). The next section looks at the use of other remedies such as traditional or herbal medicine for pain management.

5.4.3 Use of herbal drugs

The use of some locally manufactured drugs that are heavily advertised on the local market on the radio stations and television was quite common for some of the men. These drugs are usually announced on buses, marketplaces, church premises, mosques, etc. and the sellers claim the drugs can cure enhanced sexual performance, cure erectile dysfunction, treat pain, or treat cancer 'completely' (Kyei et al., 2017). The following quotes from a caregiver and PWPAC give insights about the use of herbal drugs.

We got some herbal drugs from a woman who is known to be good in that field. After some time we realised the drug wouldn't be helpful. After about three days of using the boiled herbs, it started to go bad, and it smelled so bad (Eno, Mike's wife, dyad interview 1).

I went to (name withheld), and I got those drugs because they said when I use them I wouldn't need to have the catheter in place. I paid a lot. After some time, my problem became worse (had sores at the anus). I went there again, and still,

my problem wasn't solved. I had to stop and report to the Hospital (Ofori, individual interview 1).

Almost all the men, in one way or the other, had used some of these herbs and or traditional Chinese medicines at one point or the other. Although one study report no potential risk in the use of herbal drugs among cancer patients (Alsanad et al., 2016), potential health risks have been reported in Ghana (Asoogo and Duma, 2015, Binka et al., 2018, Kyei et al., 2017). Other risks have been reported in Africa (Downing et al., 2015), USA (Galbraith et al., 2012, Tanner et al., 2011), Malaysia (Khan and Jacob, 2017), and Palestine (Ali-Shtayeh et al., 2016). The impetus behind using such herbs are mainly due to sociocultural beliefs, patients' lack of knowledge, and lack of consultation with healthcare professionals (Khan and Jacob, 2017). Some of them were careful in talking about these, as they were aware that health workers discredit the use of such drugs and their awareness that I am also a HCP, most of them did not want to talk about that explicitly.

The belief that some diseases are 'unnatural' and 'not treatable by doctors' had an impact on care at home (Onyeka, 2011) and HCPs should encourage honest discussion about some of these treatment choices (Patterson et al., 2002).

In this study, some of these patients use the drugs from the hospital in additions to some local remedies. The traditional medicines were used to cure prostate cancer, manage pain or to treat erectile dysfunction. For example, Opoku used herbal drugs and developed sores in his anus

I took some herbal drugs (forgotten the name) to treat the cancer. I stopped when I have sores in my anus (Opoku, individual interview 1).

Maegyida had used some herbal drugs alongside his conventional treatment from the hospital to treat his sexual weaknesses.

*I used some herbal drugs to treat my erectile problem. It was ok at first but now the problem is worse (*Maegyida, *individual interview 2)*

The above quotes Opoku has been reported in other studies where herbal drugs were used as anti-cancer agent (Nie et al., 2016, Safarzadeh et al., 2014). The use of complementary traditional medicine for the treatment of prostate cancers has been recommended (Obu, 2014b). Due to the increasing use if traditional medicine among cancer patients (Kuo et al., 2017), HCPs must caution patients and look at for adverse drug interaction between conventional and traditional medicine (Patterson et al., 2002). The increase use of traditional medicines are due to the professed benefits and satisfaction (Bahall, 2017).

It is equally important to note that some PWAPC resort to the use of herbal or traditional medicine when they believe that the disease has a spiritual cause. For example, when a person gets swollen feet and abdomen it is generally believed to be caused by a curse (spiritual cause). Therefore, in such circumstances patients seek traditional medical practitioner's treatment. It is therefore, important for further work to be done to explore the kinds of traditional medicines they use, what informed that decision, the perceived benefits, and some of the side effects they experience.

5.5 Chapter summary

The chapter describes the importance of the family, extended family and other informal support structures in caring for men with cancer at home. The family creates a place where men feel safe and supported, albeit some varying degrees of challenges about care, pain management, and 'disruption' in the family due to cancer. The family assists with resources and show love and compassion. They liaise to get support from friends and other organisations and coordinate care within the family and between the home and the health facility.

However, family caregivers experience significant challenges, burden in taking on a caring role, and usually neglected their health in the process. Knowing what, how and when something needs to be done could be challenging for the caregivers and sometimes causes some conflict. In some cases, a solution to one problem creates the other and thus moving from the frying pan to fire. For example, dealing with bedsore and infected wounds without sterile dressing poses risk to patient's life.

Reciprocity or cultural duty to care for the sick is a key strength in home-caregiving. This is underpinned by the fact that men are the heads of family units, and society do not only frown on deserting them but also incurring the wrath of the dead. Most caregivers also saw the need of life caregiving as an opportunity to give back, reconnect, and to say a proper good bye to a dying relative.

Managing pain and drug side effects at home could cause distress to caregivers and patients who usually feel unsupported by healthcare professionals.

This research noted that most participants have ever used an alternative health treatment such us the use of herbal drugs or traditional medicine to manage their condition or it is been used alongside orthodox medicine.

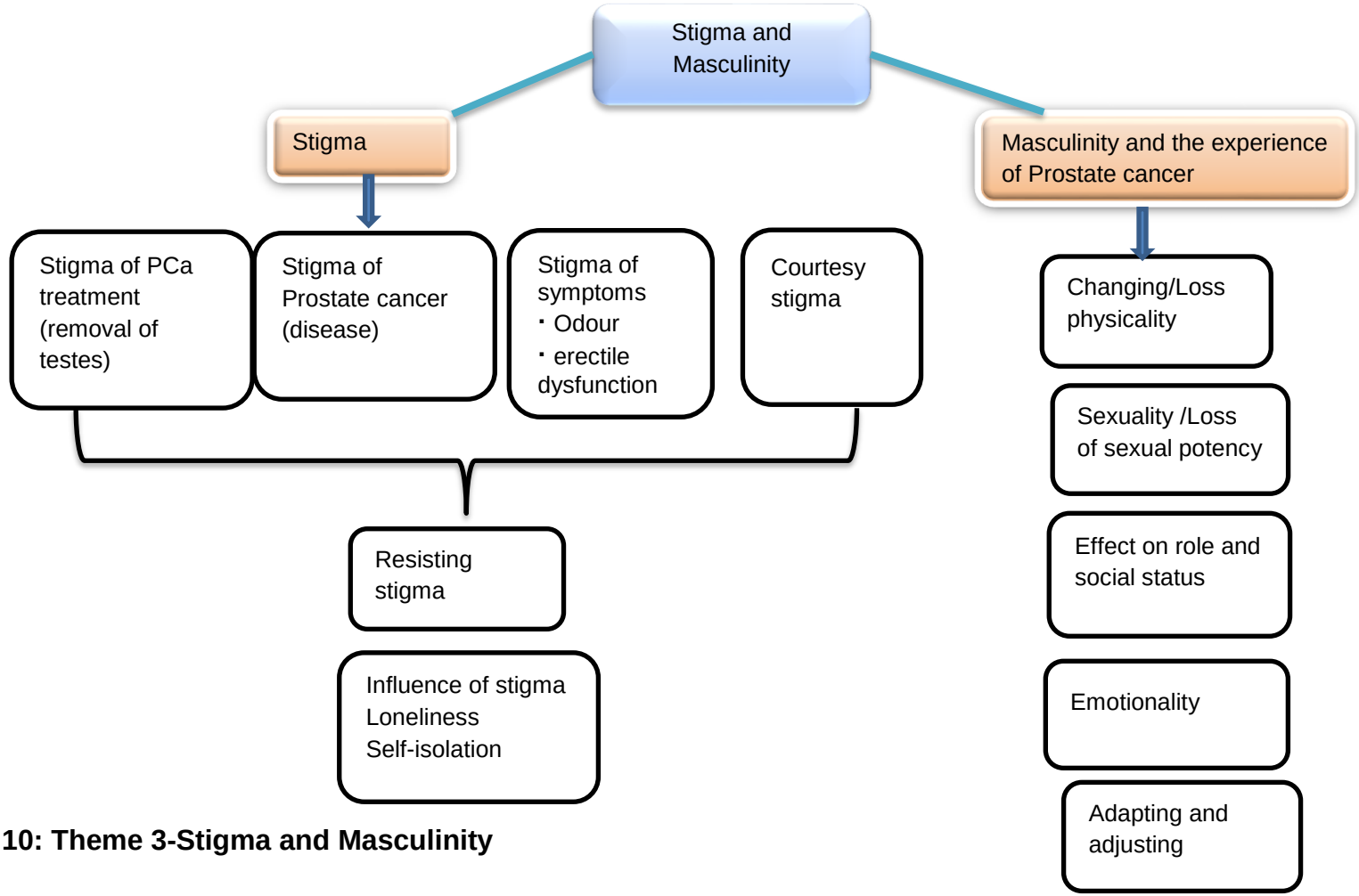


Figure 10: Theme 3-Stigma and Masculinity

Cultural Responses: Stigma and Masculinity

6.1 Introduction

In the two previous chapters, I looked at the issues surrounding family caregiving and caring for men with prostate cancer in a resource-limited setting. This chapter presents the findings on responses to prostate cancer as a stigmatising disease and how it impacts on men's masculine identities. The historical and cultural beliefs that surround cancer in general and reproductive cancers such as prostate cancer, in particular, affects PWAPC and their significant others (Paiva et al., 2015). Culture and beliefs influence prostate cancer experience in Africa (Blocker et al., 2006). For example, some of the socio-cultural responses include beliefs that link prostate cancer to sexual immorality and a perception that prostate cancer is an evil disease (Hayes and Bornman, 2018). These cultural definitions of masculinity affects men's post-treatment experiences and coping (Bamidele et al., 2018). These strong cultural responses to prostate cancer may mean that some men with prostate cancer hide their diagnosis for fear of stigmatising reactions from others — additionally, prostate cancer influences masculine identities. I take as my starting point that masculinity is a culturally embedded and socially constructed phenomenon and prostate cancer on which have profound impacts.

This chapter is divided into two sections; in the first section of this chapter, stigma theory is reviewed with respect to the findings and the various ways participants reacted to the stigma. The second section looks at theories of masculinity and discusses how prostate cancer can influence men's sense of their masculinity.

6.2 Cultural Responses-Stigma

The experience of stigma among men living with prostate cancer can be as devastating as prostate cancer itself (Arrington, 2008). Stigma (perceived and actual) was a key feature running through participants' accounts of living with prostate cancer, and this has consequences for their psychological well-being (Levy and Cartwright, 2015). Evidence show that some societies stigmatise people with cancer including prostate cancer (Arrington, 2008, Binka et al., 2018, Ju and Zhang, 2014, Omoyeni et al., 2014).

The symptoms of advanced prostate cancer such as impotence and incontinence (Fergus et al., 2002)) may also be stigmatised especially in resource-poor settings. For example, in the UK, issues such as urinary incontinence may not be stigmatised because there are resources to mask it (full access to washing machines, showers, incontinence pads) and there are nurses who visit patients to help with the care. This is less likely in resource-poor settings and seems not to be the case for most men who participated in this study.

First, I outline the work of the leading stigma theorists, and then I examine the stigma that patients and caregivers encountered, how they responded to this and the consequences for their quality of life, dignity, and reputation.

6.2.1 Stigma Theories

The term stigma originated from the Greek word ‘stigmata’ to mean a visible designed bodily sign that identifies and exposes the bearer who is usually ritually polluted, blemished or has questionable moral status or bearing ‘the mark of the outcast’ (Graham, 2009). Stigma is defined as socially unwanted, divergent, or disgusting features that shame or spoil an individual's ‘social identity’ as perceived by others and this may not only affect the stigmatised person but also others close to him, for example, the family (Goffman, 1963). The gap between ‘virtual social identity’ (stereotyped assumptions) and ‘actual social identity’ (attributes an individual truly possess) is what Goffman (1963) defines as a stigma. In the ground-breaking work of Goffman (1963), that aimed to understand society’s values, ideas, and beliefs, he explained that stigma is persistent and causes a devaluation of a person’s acceptance. Goffman's theory of stigma was concerned with various forms of nonconformity that delineate an individual who is socially ascribed as ‘‘different’’. Goffman described stigma as a trait which ‘is deeply discrediting’ (Goffman, 1963) and classified stigma into three. These are:

1. Physical stigma. This refers to the various physical deformities (Physical attribute) of the body
2. The stigma of character traits (Blemishes of certain characters).

3. The stigma of group identity (tribal stigma)

For this research, the stigma of physical attribute and the stigma of groups are most relevant. While noting that a stigmatised individual may have experienced one or different types of stigma, the focus of this research is to consider how defamed individuals react to such responses and the consequences it has on their social interactions and their daily lives.

Goffman, from a symbolic interaction perspective, makes two further distinctions of stigma: the 'discreditable' person and the 'discredited' person to mean people whose stigma is not recognisable and those who have a known or visible stigma respectively. While it is worth noting that prostate cancer, especially in the earlier stages, may not be immediately obvious for others to know (discreditable); its symptoms such as urinary incontinence, and extreme weight loss are noticeable. Again other side effects of treatment, for example, hair loss and breast enlargement, might be pronounced for other people to know that something is ‘wrong’ or ‘different’ with the person (discredited).

Another important type of stigma that is relevant to this work is what Goffman (1963) referred to as a courtesy stigma. Courtesy stigma denotes the stigmatisation of others because of their association with a person with a stigmatising attribute. In this case, some family caregivers reported their experiences with others that they believed constituted defamation — for example, a mother of a child with epilepsy or family caregivers of men living with prostate cancer. Scambler and Hopkins (1986) refer to this as the ‘affiliation’ stigma. For example, dealing with toileting and incontinence is a significant source of shame for not only the care recipient but the caregiver as well. Regardless of the form, the stigma associated with prostate cancer experience is described by participants as emotionally upsetting and causes anger and embarrassment.

Goffman (1963) further indicates that the stigmatised person uses an adaptive technique which he termed as ‘passing’ and ‘covering’ to deal with stigma. That is the discreditable person (invisible stigma) has to manage information by keeping his stigma as a secret while the discredited person (visible stigma) has to handle the

tension arising from his known stigmatising identity. Goffman explained the terms ‘passing’ and ‘covering.’ He described ‘passing’ as refusing to disclose a stigmatising condition that is unknown to anyone as a way of concealing the stigma. He further talked about situations where a person’s stigma is immediately apparent to others. In both cases, according to Goffman, the individual has little to do except in the latter where the individual could decide to regulate his contacts with people in society. In this study, however, patients and caregivers were aware of the potential of the stigma attached to prostate cancer but at least in the early stages could conceal and/or others did not necessarily know that the patient had prostate cancer. Moreover, Goffman noted this in his work:

> It is apparent, however, that these two extremes, where no one knows about the stigma and where everyone knows, fail to cover a great range of cases (Goffman 1963, page 92).

Goffman used the term ‘covering’ to mean employing an adaptive technique to reduce the consequence of stigma on the person. Here the individual’s main aim is to reduce tension associated with the stigma and live a more comfortable life as practicable by managing the stigma. It is clear that the techniques employed by the stigmatised in ‘passing’ could be the same in ‘covering’ or the two can go together. Goffman emphasised the above with an illustration as:

> Dark glasses sometimes worn to give voluntary evidence of blindness may at the same time be worn to cover evidence of defacement – a case of revealing unsightedness while concealing unsightliness (page 125).

Moving on to other descriptions and theorisation of stigma, I present the work of scholars such as Ragins (2008) who have developed Goffman’s work further by examining how invisible stigmatised identity is disclosed. Ragins examined the perception of stigma by looking at how people disclose ‘invisible stigmatized identity’ both at work and in non-work areas. She coined the term ‘disclosure disconnect’ to refer to different levels of disclosure in different settings (Ragins, 2008). She identified three states of identities about disclosing stigmatising identity: identity denial, identity disconnect, and identity integration.

She indicates that identity denial denotes a situation where a person conceals a stigmatised identity because of the associated shame. Identity denial is believed to have some adverse psychological effect such as stress on the person. Some work before Ragin's (2008) study described the impact of concealed stigma as a mental preoccupation or what they termed as "private hell" (Smart and Wegner, 2000). The second element of Ragin's model, identity disconnect, represent a range of complete disclosure in one domain and hiding of the stigma in the other. She went on to give an example of a person who hides his sexual identity from his co-workers but who discloses this information to people he lives. She observed that one of the challenges of this is where others (for example family members) unconsciously let out information to other people (co-workers). Lastly, Ragin defines identity integration as full disclosure of stigma at all domain of the person such as at home and work.

The above description of types of disclosing invisible stigma is important for this chapter as it examined the reasons for and the consequences of one disclosing stigma across different aspects; workplace and out of work environment. Ragins' work is relevant for this study such that it sets out how disclosing information and withholding it can influence the quality of life. Moving on, other concepts about stigma such as felt and enacted stigma (Scambler and Hopkins, 1986) will be drawn upon in this thesis.

Now I turn to my findings to illustrate the kind of stigma where some men perceive that they are socially marginalised. The findings are discussed based on four different layers of the stigma that PWAPC and by extension their caregivers experience. First layer – the disease itself (prostate cancer) which includes how the media and institutional responses contribute to stigmatisation. Second layer – the stigma of symptoms of the prostate cancer that includes impotence, urinary incontinence and odour. The third layer of stigma encapsulates stigmatisation of some of the treatment of prostate cancer such as removal of the testes, and hormonal therapy. The last layer of stigma is the stigma affecting the family especially the caregivers- courtesy stigma. The chapter concludes with a discussion on how stigma is resisted, and if such approaches fail, the impact of being stigmatised.

6.2.2 Stigma of having Prostate Cancer

Prostate cancer stigma is one of the three layers of stigma identified in this work. This type refers to the stigma associated with the prostate cancer itself. I will draw on some literature from Scambler and Hopkins, and later on, outline how their work resonates with data from my study. Scambler and Hopkins (1986) conducted a study on the stigma associated with epilepsy. They extended Goffman's work and made a useful distinction between 'felt' and 'enacted' stigma. They suggest that this distinction has further explanatory power than Goffman's conventional viewpoint on stigma. They defined enacted stigma as the experience of encountering discrimination from others associated with their socially unacceptable (stigmatised) identity while felt stigma is the fear of encountering stigma. Scambler and Hopkins' framework of 'felt' and 'enacted' stigma distinction was further elaborated by Jacoby (1994) who conducted a study using people with epilepsy in remission to examine the nature and degree of stigma in such a population. His conclusions are supported by the difference observed by Scambler and Hopkins between 'felt' and 'enacted' stigma. Jacoby, however, indicates that further work was needed to explore other contributing factors of the feeling of stigma and the tag of 'undesired differentness' (page 273). An enacted stigma is the real experience of being stigmatised and marginalisation in most of their social encounters, wherever they occurred (Jacoby, 1994). Scambler and Hopkins (1986) state that:

> Felt stigma is more complex. It refers principally to the fear of enacted stigma, but also encompasses a feeling of shame associated with being epileptic (page 33)…. felt stigma normally preceded rather than resulted from episodes of enacted stigma (page 37).

The experiences of the stigma associated with prostate cancer were evident in my study and expressed by both men with prostate cancer and their family caregivers. Key among them is stigmatised concealable identity. People will usually conceal their identity for good reasons such as avoiding shame, and emotional effects associated with stigma and discrimination.

The majority of men and their caregivers expressed the fear of being stigmatised (felt stigma) more than reports of actual stigmatising responses by people (enacted stigma). Consequently, some of the patients living with prostate cancer were ashamed to talk about their disease to others or they do not exactly tell what their disease was all about-except in cases where such disclosure was for support. Patients and their caregivers may decide who, when, where and what to 'tell others' or 'hide from people.'

Prostate cancer is stigmatising on different levels; the cultural associations of what having prostate cancer means (as a promiscuous disease) and the media responses as discussed next.

Prostate Cancer's association with licentious behaviour

One useful reference which participants including men, caregivers, and healthcare professionals made were the fact that prostate cancer is perceived to be associated with men's immoral sexual behaviour. Participants reported that prostate cancer is regarded as a 'sexually promiscuous' disease and therefore shameful.

For example, Sharms indicates that he felt he had to hide his prostate cancer diagnosis from his wife for some time before telling her due to the stigma around the disease and for fear of the disruption that the news would bring into his marriage, which could lead to a divorce. He said:

> *As soon as it was confirmed that it was prostate cancer, I knew I was heading for trouble. Because we all, including my wife, know that, having multiple sexual affairs caused prostate cancer. Consequently, it was difficult for me to break the news to her because it was a big shame and I didn't know if that would make her pack her belongings and move out of my life (Sharms, individual interview 1).*

Kwakwa, on the other hand, told his wife but together they agreed to keep his secret from others to preserve his self-image.

We [he and his wife] decided to keep it as a secret because you cannot trust everyone when it comes to such things, you know. When the information is out there, that is it; you can't prevent it from spreading. Can you? As soon as the information is out there, people will start looking at you with some suspicious look when you walk past them, and I wouldn't like that (Kwakwa).

The data suggest there is some conventional belief that prostate cancer is associated with sexual promiscuity. As noted in the above quotes, one of the ways of dealing with felt stigma is to conceal it as done by Kwakwa. Hiding health problems might have consequences for the help-seeking behaviour of men and its potential effect on the quality of life and dignity. For example, one patient participant said he 'pretends to be normal' when discussing issues on sex to avoid shame.

…….So I pretend to be normal when we have such conversations because I can't bear that shame (Ofori, individual interview 1).

Some participants (patients mostly and occasionally caregivers) expressed other stigmatising consequences of prostate cancer being associated with immoral sexual behaviour. Ali narrated how his co-workers made a mockery of his diagnosis:

You know with this disease (prostate cancer), others will tell you in your face that you have had several sexual encounters (usually with multiple partners). I worked at (name withheld), besides the other co-workers do make some jokes about me after they heard I've prostate cancer. I try hard not to be worried, but it is not easy to ignore such silly jokes (Ali, dyad interview 2).

Additionally, Sule who had been diagnosed with prostatic adenocarcinoma and had lost his wife a year earlier expressed worry about things that some of the people say about him including some of his extended family members. He narrated:

My uncle who used to visit me stopped visiting me. That happened when I told him my disease was prostate [Prostate cancer] and he told me oh so you have been a 'bad man' and sleeping around with women all along. I took it as a joke, but it has been something I have observed over some time now. Lately, the

other family members are not calling to check on me as they use to do. Though, I am getting on; I have my mum and the kids…...(Sule, dyad interview 2).

Sule is a widower, and his mother is caring for him. He complained of rectal bleeding, weakness in the limbs, low backache, painful and frequency of urination. Sule's account of neglect by some family members because of the stigmatised nature of his cancer is a classic example of an enacted stigma (of both of the disease and the symptoms). Sometimes stigma seems to override moral obligations. For example, Sule's mother, Fuseina, who is the primary caregiver, indicated that they are finding it difficult to buy the prescribed drugs because they have run out of money and some of her family members have neglected him at this point – an illustration of real practical (financial) consequences to being stigmatised.

The responses of PWAPC and their families were varied taking care not to accidentally reveal information about their 'hidden' identity by either concealing it or using discretion such as in Ofori's case. Others evade stigma through a refusal to acknowledge it or deliberate avoidance of confrontations that will reveal their identity as identified in previous work (Riessman, 2000) as discussed later in this chapter.

Media and institutional responses

The media was seen to contribute to the stigmatisation of prostate cancer as captured in the participants' narratives. From the data, for example, the media reaction and some individual's responses to prostate cancer are usually negative due to the widely held belief that prostate cancer affects men who have been sexually immoral. One respondent from my study illustrated this argument well: Ofori was open about some of the news about prostate cancer as a licentious disease. He narrates:

The way the media talk about prostate cancer as an abominable disease, I don't want people to know I have this disease. I can't stand that shame and embarrassment. I thought the hospital would be a place where others will get to know about us (prostate cancer patients). So initially I was thinking about this a lot, but later I realised that at that place (Hospital) no other patient could easily

know about the diagnosis of the other…….so I was happy that they (staff members) were confidential and I hope they continue with that (Ofori, individual interview 1).

Another participant also expressed similar sentiments:

I hear people talk about prostate cancer and its symptoms negatively on the radio every day. For instance, there is news out there saying people with prostate cancer are not men enough and therefore anyone with the disease should go to 'A' clinic for help. Such adverts on the radio shame us. Other radio stations say prostate cancer is a disease of men who flirt so I am careful telling people about it (Maegyida, individual interview 1).

The above is an illustration of both an enacted and felt stigma and the role the media plays in stigmatising men with prostate cancer. Although the press stigmatise them, patients do appreciate how health staff members at the Hospital keep their prostate cancer status secret.

This might affect seeking the needed resources and support. One PWAPC and a caregiver shared their experiences:

When the diagnosis was made, I was very shy to tell people and even some close friends for some help (for money). Prostate cancer? How was I going to start that story? (Ofori, individual interview 1).

My husband and the family decided to keep the secret in the family. There was no need to sell the information out there. Isn't it? So how then do you ask for help? Unless you lie to them by saying, he is suffering from a different disease, for example, stroke (Zaliatu, Ali's wife, dyad interview 1).

The above quotes show some elements of stigma (felt) which has been discussed extensively in section 6.2. My interest here is about the potential effect of the lack of disclosure to get support (especially money) from other family members for the treatment. Zaliatu told me during the second interview how relieved they were when a

family member came to their aid to support them when they (she and the husband) gather the courage to open up to other family members for support.

Some men living with prostate cancer also believe they are socially marginalised by the healthcare institution and the government for 'excluding' them from medical insurance and even more so at the time that they are ageing and unable to do a paid work. Tawiah who described himself as being in 'financial crisis' had this to say:

> *….. Do they (HCPs) want to tell us it is a crime to have this disease? I don't just understand why I have contributed my tax towards insurance that excludes me now that I am in financial crisis. This law is cheating and…. I mean I don't work any longer and how do I pay for all those bills and medical expenses? This is discrimination, and I am not happy about it. Why is it that people with Malaria, Diabetes, Hypertension are treated free and not we the vulnerable ones? (Tawiah, individual interview 1).*

Tawiah's quote suggests elements of institutional stigmatisation because he believed that the exclusion of men with prostate cancer from all medical insurance points to the fact that they have an 'abominable' disease. Regarding the identity stigma associated with prostate cancer, some men had the opinion that because prostate cancer is socially stigmatised, that was why their treatment costs were excluded from the health insurances. Tawiah's expression of worry that despite the taxes and the contribution he has made and even having registered with the NHIS, he does not benefit from the insurance scheme and he sees this as a form of discrimination against people with prostate cancer. He thinks it is probably due to the belief that people have about the cause of prostate cancer. Media stigma is an important finding that has not received attention since media stigma or what I call institutional stigma is an unexplored area in the literature.

During the focus group discussion and the interview with healthcare professionals, it was revealed that HCP are aware that men with prostate cancer are stigmatised in this way. However, some men reported feeling stigmatised by healthcare professionals themselves. For example, Tawiah, a father of nine, reported he been upset about a stigmatising statement a doctor once made when he went to the hospital for an

appointment (see case narrative, Appendix L). Tawiah reports, he was hurt by the doctor's comment and indicated that he is not likely to let that doctor attend to him again if he has the choice. Interestingly, however, out of the 23 men interviewed; only Tawiah talked about an experience he encountered with a healthcare professional concerning his prostate cancer status, which he considered as defaming.

6.2.3 Symptoms of Prostate Cancer and how this is stigmatised

An interesting form of a stigma associated with men with prostate cancer, and not fully recognised in existing literature, was noted from the data. This kind of stigma is not directed at prostate cancer as a disease as such but the symptoms. In addition to the stigmatisation associated with prostate cancer, this further layer of stigma was also identified to be solely associated with the symptoms. Stigma can, therefore, aggravate psychological distress in PWAPC and together with other symptoms such as unmet sexual needs and urinary problems lead to reduced quality of life (Ream et al., 2008).

Three main symptoms of prostate cancer reported by participants as stigmatising were *impotence, urinary incontinence and odour, and extreme weight loss and change in body image*. The first two will be discussed in this section while the change in body image will be discussed in the masculinity section. The stigma exhibited by the participants was either felt stigma, for example, fear of impotence being stigmatised, or enacted stigma such as experiencing shame due to urinary incontinence.

Impotence/ erectile dysfunction and Stigma

Sexual impotence was found to be not only stigmatising but also led to questions about one's masculinity. The role of impotence and its effects on men is discussed in the section under masculinity. Men in this study expressed their concern about what others may think of them if people get to know that they (PWAPC) were 'not men enough' and cannot have sex with their wives. The following excerpts support the above claim.

> *I feel shy talking about this, but I have to. Hmm, I 'can't stand on my feet' (meaning he is unable to have sex). I feel guilty about it, and we (he and his wife) are both young, so I am worried what my wife is going through right now. I am also worried if she has discussed this with any of her friends* (Kwaku, *individual interview 2*).

Kwaku has discussed the guilt that he has with his wife while hiding the information from others due to the fear of stigma. This links to 'identity disconnects' discussed earlier. Kwaku is hiding information from most friends, but he was still worried because some family member may let out the information to other people. Another participant also re-echoed similar concern:

> *My ability to have sex is minimal. Additionally, I strongly suspect the drug as the cause. I know, as a man you need to be complete if not you are ashamed even to talk about this with your friends (Ofori, individual interview 2).*

Conventionally men are believed to possess their sexual dexterity regardless of ill health and to be able to have phallocentric[17] sex. Both Kwaku and Ofori expressed the shame of having reduced sexual ability that makes them not 'men enough' regarding sexual intimacy. Such situations are usually kept secret for fear of being stigmatised unless the disclosure of such information is to seek a remedy for the impotence as reported in a related study in Australia (Chambers et al., 2018). For example, Maegyida kept his sexual weakness as a secret until such a time that he needed to come out before things got out of hand. He narrates:

> *So I kept it (reduced sexual drive) to myself, and I started to buy some herbal drugs so that I can 'stand on my feet' (he laughs). However, later on, I realised that I needed to be bold and come out before the worse happens. I told the doctor that though he advised I will get sexual weakness, but I think this has gotten too far.*

[17] Penetrative sex where the penis is the primary focus. So in cases of impotence, this activity is affected.

From the above quote, it can be inferred sexual weakness or impotence is something shameful and therefore, tarnish their image as men in the eyes of others. This kind of shame is what Goffman (1963) described as ‘deviance and labelling’ attached to stigmatised people. The other cardinal symptom of advanced prostate cancer that causes stigma is urinary incontinence.

Urinary Incontinence and Odour

The second prostate cancer symptom that was identified to be stigmatising is urinary incontinence. Urinary incontinence is usually a consequence of advanced prostate cancer or its treatment. Urinary incontinence is another problem that undermines a person’s dignity as an adult and also problematic in the care of men with advanced prostate cancer (Ostaszkiewicz, 2017). It contributes to the loss of social status and dignity of men and therefore, impacts adversely on the quality of their social and sexual life (Nilsson et al., 2011). According to Brittain and Shaw (2007) who explored the consequences of living-and-dealing with incontinence among informal caregivers indicate that urinary incontinence is stigmatising and constitute a loss of ‘self-control’ for the patients and to the caregivers as dirty low-status work. For example, urine stains on clothes and the odour of urine have an impact on self-image and self-esteem particularly when resources to manage the incontinence are limited (Brittain and Shaw, 2007).

Urinary incontinence is a social problem for most men with advanced prostate cancer, and it serves as a considerable social barrier due to the potential embarrassment it causes. Atta’s quote typifies a felt stigma not of prostate cancer itself but its symptom-urinary incontinence.

> *I have been having this urine problem [incontinence], and I cannot control the urine flow. Because of that, I need to be cleaning myself regularly, and sometimes I can smell bad odour and see stains of urine on my dress. How can I be in public with this embarrassment? What will people say of me? That makes me anxious a lot (Atta, individual interview 1).*

The quote from Atta suggests concerns about incontinence and having a 'urine problem.' Furthermore, incontinence, which usually occurs in advanced prostate cancer, has further potential for being stigmatised due to its associated strong smell that ward off people.

Atta, like other participants, expressed worry about how others perceived him. He thus concealed the information from others in order not to suffer 'disclosure disconnect.' Besides, since incontinence is associated with prostate cancer, it is likely that it will give a cue to others that the patient might have prostate cancer.

The following are examples of both felt and enacted stigma associated with urinary incontinence following prostate cancer.

> *The main problem is that I can't control my urine. I am not aware when the urine is coming out. Experiencing this kind of thing is embarrassing. In order to avoid this, I have decided to remain indoors. I hardly go out to avoid such embarrassment (Opanin, dyad interview 1).*

> *What even embarrassed me most was wetting myself in the presence of visitors. We had a traditional marriage ceremony here (in his house). Because I am the head of our clan in this area and I had difficulty walking, they did the ceremony here so I can perform my customary function. I used some tissue to protect my underwear anyway but my wife detected that my cloth was wet behind me. As a result, she intentionally said to me that it seems your glass of water poured on your dress. I was very ashamed of that because others saw it too. It was a big shame (Efo, dyad interview 1).*

The above quotations from Opanin and Efo are clear examples of 'felt' and 'enacted' stigma respectively that is associated with urinary incontinence as a symptom of prostate cancer. Stigma causes significant emotional distress to men. For example, Opanin further expressed his disgust about his inability to control his urine:

> *How can a senior man like me be soiling myself this way? What kind of embarrassing life is this? I am ashamed of it. And I think other people in such a situation will get the feeling of what I have (Opanin, dyad interview 1).*

Opanin decided to stay at home most of the times so that if he gets wet, he can change himself. When it is necessary for him to go out, he has to wear incontinence pads, which he described as ‘not comfortable’ wearing them. Moreover, caregivers also shared their view on dealing with urine incontinence.

Additionally, some caregivers see handling incontinence as well as other bodily secretions as a dirty activity. For example, Sabi one of the caregivers of Boat did say he is sometimes tired of doing the ‘dirty’ work.

> *It is hard dealing with all the dirty work. I mean cleaning Boat’s urine, the wound and all that is a difficult thing but I have to help. Sometimes I have to hold my breath while providing care. His wound is infected, it is offensive, and I know you realised that yourself. The smell has taken over (the house), and people do not usually want to walk in here (Sabi, individual interview 2).*

Sabi did indicate the scent of urine, and from his brother’s suprapubic wound (wound at the lower abdomen) was something that was very offensive and difficult to deal with (see Chapter 4). He explains that they did not have strong detergents to sanitise his brother’s room and this has led to the odour ‘taking over’ the entire house. Again, this leads to the patient feeling ashamed of causing discomfort to others and the caregiver may be ashamed inviting visitors to their home. However, the findings here is inconsistent with one study that explored the viewpoints of caregivers about the social effects of handling incontinence or living with incontinence in the UK. That study indicate that the use of incontinence pads and the urinary catheters made ‘a world of difference’ as it prevented the inconvenience and shame of leaking urine in the midst of others (Brittain and Shaw, 2007).

The stigma may account for why some men do not want to discuss the problem with others or perhaps seek help. On a few occasions, two men, Asamoah, and Nii (see Appendix L; number 18 and 23) blamed themselves that they (might have) been cursed when they experienced swollen feet and tummy. The media propagate such concerns, and in addition to the stigma of prostate cancer may stifle health seeking. Again, because of what men described as the ‘embarrassing symptoms’ associated with prostate cancer such as incontinence and erectile dysfunction (discussed in the next

section 7.4.3), men feel reluctant to explore avenues for help especially from unfamiliar people. Stigma in some cases was a reason for late presentation of symptoms to the hospital just like the use of alternative traditional therapy (see section 5.4.3). Caregivers dealing with the incontinence regarded it as dealing with 'dirt' and this together with their ties with men living with prostate cancer form part of the stigma of association they experience as discussed in the next section.

6.2.4 Courtesy stigma

It has been reported in the literature that stigma and other cultural licentious meanings attached to some diseases impact negatively on family caregivers providing palliative care (Williams et al., 2015). These issues also expose the families and the caregivers to shame as well (courtesy stigma). For instance, one of the three caregivers of Baabamu also did indicate how bad he feels when he has to cope with the incontinence.

> *This situation is unpleasant to cope with now. It is worrying to get urine and faeces all over the place. He can't control his urine, so he sometimes smells so what happens when a visitor appears all of a sudden? (Jenny, Baabamu's daughter, dyad interview 2).*

The data in this current study indicate the PWAPC does not only experience that stigma but their caregivers as well (courtesy stigma). This was mainly based on the belief that a man with prostate cancer is a man having sex with numerous women. The spouse of Mr. Ali reported the embarrassment she felt when she requested support from her close friend.

> *…. and I had to speak to some of my friends to help us. I had the shock of my life when my childhood friend was bold to tell me that my husband was a cheat that was why he has 'flirting men's disease'. I wept. I did. I realised that some people gave me some funny look afterward and decided never to tell any other [person] about my husband's illness (Zaliatu, Ali's wife, dyad interview 1).*

Two more caregivers share their encounters of shame because of their caring relationship with the men.

aniwudeɛ (stigma) is real for them (PWAPC) including we (caregivers) who care for them. I was surprised when my niece decided not to have dinner with me because I finished cleaning my granddad's catheter. That day we had Banku [moulded corn dough] and okra stew for dinner (usually eaten with the bare hands). We usually eat supper together at home. I didn't know it was because I started caring for the catheter. So later, she kept on giving me excuses (Mawuli, Efo's grandson, dyad interview 1).

my dad's situation became worse, and his rubber [catheter] was leaking so everywhere was smelling of urine. I could smell the urine on me. I wasn't surprised when a shop attendant teasingly said to me at a shop where I went to buy some things for my dad 'why have you wet yourself in bed?' That made me shy…….. but you know, it is part of the whole life, there is little you can do really (Teiko, Norbert's son, individual interview 1).

The above accounts report degrading comments, which caregivers of men with prostate cancer experienced. In the case of Teiko, he finished cleaning his dad and wanted to buy some washing power from a shop to do some washing. He said he was 'embarrassed' but claimed that he was not bothered. To caregivers, comments of this kind constituted disrespect. For example, in the case of Zaliatu, she reports that the way people looked at her strangely and gossiped about them impacted on her free movement in her neighbourhood. She states:

Because of that strange look, when I am walking to the market I don't use the short route via where my friend stays, I prefer to go all the way around and back through the same route. I don't feel comfortable because in this neighbourhood they gossip a lot (Zaliatu, dyad interview 1).

The various examples of stigma experienced by the men and their caregivers, as well as the circumstances of care or the patients' condition, contributes to loneliness and isolation in some circumstances (Brittain and Shaw, 2007).

Prostate cancer and its treatment effects such as incontinence was found to be stigmatising, discrediting and had adverse social effects for both the patients and the

caregivers. Reiterating this, stigma among caregivers of HIV/AIDs patients has also been reported in Ghana (Mwinituo and Mill, 2006). Consequently, courtesy stigma has practice implication for PWAPC and their family caregivers. The stigma of this kind does not only contributes to isolation but also their unwilling to disclose prostate cancer diagnosis among the extend family but may limit access sources of support as reported (Bamidele et al., 2019).

6.2.5 The stigma associated with Prostate cancer treatment

The broader socio-cultural context in which prostate cancer treatment can be stigmatised is explored in this section. During one of the focus group discussions, the healthcare professionals expressed their concern about the challenges reported by the PWAPC due to the perceived fear of social ridicule. Participants (mostly men and healthcare professionals) reported three main prostate cancer treatment/management approaches as contributing to the prostate cancer stigma tag. There are surgical removal of the testes or surgical castration (which is commonly known in the Twi Ghanaian language as *'sa'*), the use of hormone therapy, and digital rectal examination.

Surgical removal of testes

One of the treatment options for prostate cancer is the surgical removal of both testicles to repress testosterone -male hormone- that is responsible for masculine attributes that form part of masculine identity (Brunner et al., 2010). Since the possession of testes is a key attribute of a man, its removal is perceived as making the person less of a man. Therefore, most men with prostate cancer refused surgical treatment that involves the removal of the testes on the ground of fear of stigma. They claimed that the absence of the testes in a sense meant that they were no longer 'men.' Again, other men refused the removal of the testes for fear of losing their sexual function-another stigmatised issue discussed above. One participant exemplified the above:

> *I was deeply worried when the doctor told me about the castration. I exclaimed whaaat! I don't want people to refer to me as 'barima a yasa no' (a castrated man). I didn't want to do that because the testicles make me who I am (a man).*

Also, how was I going to explain this to my wife? (Damaa, individual interview 2).

Surgery, I mean the Orchiectomy (removal of the testes) is available, but most men refuse based on some superstitious beliefs such as not able to have sex or the tag of being castrated (HCP 03, individual interview).

This de-masculinisation can lead to stigma- either as enacted or felt. De-masculinised men feel stigmatised because they think they have been rendered impotent by removing the 'thing which makes them men' (the testes) as reported in a study (Broom, 2004). The mere fact that the treatment option is to 'castrate' make some men feel they are 'different' from other men because such acts are regarded as punishment since the testicles are considered to be the prerequisite of a man's social existence (Klaus, 2004).

Hormonal therapy

The hormonal drugs especially Androgen Deprivation Therapy (ADT) for the treatment of prostate cancer (PCa) medically castrate men and make significant changes in their body image that can lead to stigma. For instance, Cushman and colleagues (2010) explored how the use of language such as the terms 'castrate' influences men living with prostate cancer, their preparedness to accept treatment, and how it affects their psychosocial health and quality of life. They emphasised that:

> Many PCa patients treated with ADT perceive themselves as "unmanly" due to their loss of traditional gender signifiers, including the decline of sexual function, and because of the development of feminine physical traits that often accompanies this hormone therapy (Cushman et al., 2010).

My data suggest that men described changes in their body resulting from hormone therapy as embarrassing and shameful. Where such changes were extreme, these men will usually prefer others not to see them for fear of feeling demeaned in front of others. One member of staff narrated:

The surgery (surgical castration) and hormonal therapy do the same work so to speak. That is to shut down the androgen. In cases where the patient does not

agree to the surgery due to certain beliefs about removing the testes, we offer hormonal therapy, which still has similar effects on the body such as breast development, weight loss, hair loss, and others. We receive complaints about these changes, and how they are unhappy about it. Others come in here wearing several layers of clothes to mask the weight loss (HCP 03, individual interview).

A patient participant also shared his experience:

People might think I lived 'unholy' life. Looking at how I have grown very lean and become ugly those people may also think I have AIDs (Damaa, individual interview 1).

The above quote suggests that men undergoing such treatment need adequate information about what to expect and that they require practical support to demystify the stigma of prostate cancer such as extreme weight loss and changes in physical appearance (examined in detailed in section 6.3.2). Cushman and colleagues (2010) concluded that castration (medical or surgical) suggests 'powerlessness—socially, politically, and sexually' and this adds to the embarrassment and "othering" felt by a castrated cancer patient (page 3). Cushman and colleagues' (2010) conclusion is pivotal in the exploration of men and their family caregivers' stigma regarding how they transverse prostate cancer experience.

During an interview with one health care professional, he indicated that some men refused the surgical removal of the testes for fear that their sexual power, will be adversely affected although the other treatment options have a similar mechanism.

The Casodex[18] (hormone-based chemotherapy) causes medical castration, but because their (patients) testicles are not removed, most of them prefer that to the surgery. Most refuse the surgery. Oh yes, the surgery is a no-go area for them because they feel the absence of the testes will prevent them from having

[18] See fore page 0 for the common treatment options used for advanced prostate cancer in Ghana.

sex and it also bothers on some beliefs and perhaps stigma (HCP 03, individual interview).

Perhaps for perceiving that surgical removal of the testes will affect their sexual drives and alter their self-image and identity (as discussed previously), some men refused the option of having surgery to remove their testes. Other men were also concerned about what people will say about them, and how bad they will feel if others got to know that they no longer have testes. Out of the 23 men with prostate cancer whom I interviewed 16 said they were offered the option of surgery (which was cheaper and a kind of one-off management approach), all refused, except three. One of those three men, later on, agreed when his symptoms were becoming worse, and he had no means of buying the increasing dosage of drugs being prescribed for him.

6.2.6 Resisting Stigma

In her work 'Stigma and Everyday Resistance Practices: Childless Women in South India' Riessman (2000) reviews and extends the work of Goffman. She concluded that there is a need to reconsider the Western assumptions embedded in Goffman's concept of stigma because participants in her study used some techniques to destigmatise themselves. Riessman (2000) examined women's infertility and wrote that it was nigh on impossible to conceal stigma because having children was the role of women, and they were continually questioned about why/why not/when they are giving birth. Riessman (2000) critiqued Goffman's assumption that stigmatised persons hold the same view about his or her stigma as those who do not experience the stigma, and she claims that 'in the empirical world, there are countless instances in which individuals disavow the dominant perspectives' (page 114). She further argues that the individual 'react' to rather than reject or resist the judgement placed on them by others while agreeing with other scholars who believe that the 'self' is more active than the one in Goffman's framework.

Consequently, Riessman outlines three kinds of strategies that individuals may ordinarily employ in resisting and avoiding the possibility of being stigmatised by others. These strategies are 1) determinedly avoiding confrontations (strategic avoidance), 2) rejecting the stigmatised tag (resistant thinking), and 3) taking a bold

and firm stand when interacting with others (speaking up and acting out) (Almack, 2007). A study conducted in Ghana among patients with leprosy indicates that faith is another means of dealing with stigma (Dako-Gyeke, 2018).

Some of the men might believe that promiscuity does cause prostate cancer; some might know that it does not. For example, Sampson said he was not ashamed or was not bothered to tell people about his diagnosis because he believed that telling people about it was something useful to do; he narrates:

> *….. Cancer, in general, is assumed 'incurable' and deadly. When they get to know it (cancer) affects the prostate then it becomes more shameful. I am not bothered, and I keep asking questions about it from my daughter who is a nurse and her colleague workers, and most people because it is said that 'when one advertises his disease; that is when he gets the appropriate remedy for it' (Samson, individual interview 1).*

Samson seemed to adopt Riessman's 'resistant thinking' (2000) strategy in which he refuses to accept that prostate cancer is a stigmatised disease. This study also brings a new kind of resistance to stigma where men tried to compare their past sexual behaviours with others usually family members they described as worse than them regarding sexual immorality. This was captured in the narrative below.

> *I don't believe multiple and frequent sexual intercourses with women causes it (prostate cancer)… Moreover, I have proof of that. My elder brother who is three years older than me and my cousin who is of the same age as me have both had several love affairs with women. I mean a lot, and my father used to advise them both on that. I have had only two women in my entire life: one girlfriend whom we broke up and my wife. Why do I have prostate cancer, and they don't? If indeed that allegation is true, I suspect their prostate cancer might have reached its highest peak (Nelson)*.

Nelson is resisting the claim that prostate cancer is caused by immoral sexual behaviour. He does so by comparing and quantifying the numbers of ladies he has had a sexual encounter vis-a-vis his elder brother and his cousin whom he described as

people who have ‘chased ladies.’ Thus, they tried to quantify the number of women they (men with prostate cancer) have had sex with and compare with others (men without prostate cancer) whom they considered as womanisers. Therefore, some men compared their sexual lifestyle with others in an attempt to resist the notion of prostate cancer as a licentious disease. However, in this study other forms of reacting to stigma such as ‘condemning the condemner’ (speaking up and acting out) and ‘medicalisation’ of the prostate cancer stigma (Scrambler 1986) was not very evident. This might mean that PWAPC will need support and awareness to help them resist any attempt to stigmatise them as recommended in the conclusion chapter (Chapter 7).

6.2.7 Impact of Being Stigmatised-Loneliness and self-isolation

The overall consequence of the stigma- resulting from the prostate cancer as a disease, its symptoms such as urinary incontinence, and perhaps for being associated with the person with stigmatising identity (courtesy stigma) is the tendency for one to become isolated.

Social isolation was found to be high among Africa American men living with prostate cancer in the United States (Bowen Jr, 2016). In this current study, the stigma of prostate cancer affected lives of PWAPC and their caregivers within the wider social network. Some patients might have had extreme weight loss either due to the trajectory of advanced prostate cancer or because of the adverse effects of the treatment or both. Understandably, such changes led to some men being reluctant to be seen in public, and this affects their communication with others (Ventura et al., 2014).

A key aspect of social isolation relates to the loss of social networks, usually external that the patients used to enjoy. Some men and their caregivers revealed their inability to perform roles associated with their social statuses. Specific reasons mentioned included incontinence and extreme weakness; both of which had severe impacts on their daily lives. For some of the caregivers, looking after men who were bed bound or wheel-chair user implied that they needed to be at home most of the time, thereby also isolating them from the wider society.

For those men who were still working, there were disruptions to their employment because of weakness arising from the cancer trajectory and the treatment regime. The following excerpts illustrate how men feel and become more isolated:

> *I hate being lonely, but now I have no choice. It is really difficult been lonely (Atta, dyad interview 2).*
>
> *Errm my social life is gradually declining. It is worse now. I must say honestly. I am always around (home) and don't go that far, so I don't see what goes on and all that. When I visit friends, I have to be going to the toilet frequently, say every few minutes, so I don't want that situation to happen (Kwakwa, dyad interview 2).*
>
> *I am restricted in this (wheelchair), I can't go anywhere. I wish I could go round as I use to do before, but my condition is getting worse. Being in one place is something I am not used to, but now I don't have that choice (Gyasi, dyad interview 1).*

The quotes above show evidence of the limited social interactions of Atta, Kwakwa, and Gyasi, which contribute to their loneliness and sadness. The experiences they describe are illustrative of the experiences of most of the men interviewed. It is also noted that some key side effects of prostate cancer such as frequency in urination affected their daily lives and relationships such that they have to be 'around' their homes and in their familiar environment where they can address issues such as frequently visiting the toilet. Kwakwa went on to further state that the potential stigma of his situation might have contributed to a few of his friends not visiting. He narrates:

> *About two years ago when I didn't have this problem (urinary incontinence), my friends (two of them) use to visit regularly anytime I am unable to go to them. However, when I started having that problem, things have changed a bit. You know, I know I smell of urine although my wife helps to clean here all the time. I think the smell of my urine might be the reason, though they (friends) have not told me so (Kwakwa, dyad interview 2).*

As explained earlier, some PWAPC had issues with urinary incontinence. The above quote indicates how urinary incontinence and possible consequences such as staining and smell of urine contributes to self-isolation. The caregivers who were caring for less mobile PWAPC also shared a similar experience of having been cut from others because they must at all the time be closer to the patients, or they could only go out from the house if other family members give them some respite. The following quote from Otoo is typical of the above explanation:

> *My father is unable to walk or even get up on his own. We have to help clean him and put him in the wheelchair when he wants to urinate or go to the toilet; he needs help. We are usually around all the time just in case (Otoo, Gyasi's son, dyad interview 2).*

This quote indicates that the self-isolation is not only the problem of the men with prostate cancer but the caregiver(s) as well. Otoo explained why he and his brothers have to be around to care for his father on a 24-hour basis, and this contributes to a sense of isolation especially, when he has to care for his father for several weeks before his brothers come in to help him.

The next section explores how the issue of stigma, incontinence, and changes in masculinity influences the lives of men and their caregivers. Having discussed how stigma affects PWAPC and their families, the final section of this chapter addresses ways in which prostate cancer affects the masculine identity of men and its consequence on help/health seeking.

6.3 Masculinity and experience of prostate cancer

Stigma and the threat to masculinity (de-masculinisation) jointly affect men's experience of prostate cancer and that of their family members. It is reported that men's sense of masculinity is diminished following prostate cancer and its treatment (Alexis and Worsley, 2018b). The changes in masculine identity following cancer treatment in men are challenging for them in their social settings, and that calls for a reconstruction of their identity (Mesquita et al., 2011). The prostate is described as a 'symbol of man's

masculinity' (Santos Araujo et al., 2013 page 3889) contributing greatly to the attributes of manhood. This, according to Santos Araujo and colleagues (2013), is because the prostate plays a key role during sex, enhancing a feeling of satisfaction and contributing to the physical appearance of men.

Additionally, there are social expectations related to masculinity that men have to be 'fearless, tough, and stoic' (Mahalik et al., 2003). According to Arrington (2008), prostate cancer disease exemplifies, more than any other disease, the 'social construction of masculine identity' (page 299). Elements identified in previous studies to be socially constructed and associated with masculine identities include resilience (Edley and Wetherell, 1997), well-being and strength (Oliffe et al., 2018), muscular body (Yvonne, 1998), body image (Weber and Sherwill-Navarro, 2005), sports (Burgess et al., 2003), and sexual potency (Arrington, 2008). Arrington (2008) reported findings on how men's masculine sexual identity is affected by prostate cancer, in particular, due to the impact on their sexual lives and their bodies as a whole. He (Arrington, 2008 page 229) indicates that:

> Perhaps no other disease illustrates the social construction of masculine identity more vividly than prostate cancer, an illness whose common symptoms and treatment effects (for example, erectile dysfunction and incontinence) leave men with a diminished sense of agency over their bodies.

This section looks at relevant theories of masculinity, how internalised male roles influences men's physical, sexual, social as well as the emotional lives and the strategies PWAPC adopt to cope with these changes.

6.3.1 Theories of masculinity

In this section, I draw upon relevant theories of masculinity to explore the social construction of participants' experiences of prostate cancer and its impact on their general health and wellbeing. Postmodern theories propose masculinity as a gendered social construct; as such it is a crucial socio-cultural factor that affects men and their health-related behaviours (Evans et al., 2011). Consequently, as Cecil and colleagues

(2010) has observed, 'it has been suggested that men's health behaviour is linked to societal beliefs about masculinity' (Cecil et al., 2010). An in-depth understanding of these practices and men's health needs can inform health promotion intervention that will not only impact the health outcomes of men but (also) their significant others such as the caregivers.

An influential work in the sociology of masculinity is the social theory of gender by Connell (1995). Connell defines masculinity as a social construction that is driven by culture, locality and particular historical periods (Connell, 1995). He indicates that we should understand masculinities as "*configuration of practice*"[19] that is relatively fluid rather than a basic understanding of one's personality or character. He further claims that these configurations of practice are hierarchical and varies in different societies. Therefore, the hierarchical nature of the configuration of practice either facilitate or restrain men's behaviour in different contexts. He also indicates that the configuration of practice become embedded in social institutions and structures (Connell and Messerschmidt, 2005, Connell, 1995). I support this idea drawing from the Ghanaian context (as discussed in Chapter 1) where men are placed higher on the social ladder based on gender, and changes in masculinity threaten their social statuses. While Connell and colleagues accept the theory of masculinity has generated debates mainly about masculinity seen as "men's studies" and "critical studies on men" (Connell et al., 2004), others have gone on to look at masculinity in the plural – a recognition that not all men are positioned the same.

One of such key contributors to the field of masculinity is Robertson (2007) whose work "*Understanding Men and Health"* has become seminal writing. Robertson suggests that masculinities and 'health practices' are influenced by social contexts and challenged the notion that men are 'unconcerned' about their health and he further suggests that men are concerned about maintaining their 'male identity' following diseases (Robertson, 2007). Further extending the work on masculinity, Robertson, and colleagues (2016) asserts that 'masculinities can be recognised as both the producer and product of both structure and agency' (page 64). Robertson and

[19] Categorised as Hegemonic, Subordinated, Marginalised, and Complicit. However, further expansion of these patterns of masculinity is beyond the scope of this thesis.

associates (2016) responded to critiques of masculinities frameworks in three parts: critiquing the ‘call for’ not using the term masculinity; how masculinity should be understood using empirical data to buttress this; and the implications of understanding masculinity for research, practice and broader social context (Robertson et al., 2016).

Due to the increasing literature on masculinity in health and wellbeing, and the complexities and the poorly defined concept of masculinity, some scholars held the view that the term ‘masculinity’ should be abolished. Robertson et al., (2016) responded to that debate by raising three important points that I think is relevant to my study. The first part of Robertson and colleagues (2016) work looked at critiques of the concepts of masculinity-three diverse viewpoints that all suggested that the term masculinity should be abolished entirely. The first perspective maintains that masculinity is primarily used to denote personality traits or character types. The second critique of the term masculinity is based on Petersen’s (2003) postmodernism social theory that believes that masculinity and femininity create false gender division in society despite the fluidity nature of gender. Peterson concluded by saying that masculinities need to be looked at in a much broader scope because of the ‘power relations and the social constructions of masculine identity and the male body’ (Petersen, 2003). The third critique on masculinity was spearheaded by an Australian author (Macdonald, 2011, Macdonald, 2006) that are specifically related to health where men are blamed for their health outcomes. For example, masculinity is used for men’s for misbehaviour, and Macdonald (2011) suggested that instead, we should look at the broader social determinants of health.

The second part of Robertson et al., (2016) study focused on the need to retain the concept of masculinity, returning to Connells (1995) work discussed above. They, like myself, agreed with Connell’s assertion about the configuration of practice (arranged in hierarchical order) that varies both between and within men. Connell (1995) further asserts that these configurations of practice are rooted in the structure of the society that influences their behaviour in different environments. However, the *patriarchal*

dividends[20] (a term first used by Connell, 1995) and dominance by men are continually being challenged and reshaped (Connell, 2016).

The last part of Robertson and colleagues (2016) work focuses on the implications of understanding masculinity for men's health. They indicated that an understanding of masculinity is essential in research to address the existing inconsistencies in men's health practices, for example, exercising and heavy smoking at the same time. Such knowledge is beneficial practically for intervention for men and those significant to them such as the caregivers. Again, such contradictions will allow clinicians to develop ways to address the unique needs of men's health and their families. Another recommendation that I believe is also important for my study is an in-depth understanding of masculinity should form part of public health agendas to create awareness and educate society on men's health issues. Such interventions should look in broader context issues such as stigma and masculinity as well as social determinants such as education that influences (both positively and negatively) men's health practice that leads to different health outcomes.

Chronic illness such as prostate cancer might lead to 'biographical disruption' where masculinities are profoundly disturbed (Bury, 1982). The uncertainty that characterised such chronic disease means that masculinity has to be negotiated and re-negotiated by men due to 'the loss of work identity, social roles, and the sense of isolation' (O'Brien et al., 2007). For instance, an important influencing factor for men living with prostate cancer is the endorsement of 'gender scripts', that is,

> 'ways of thinking, feeling, and acting based on socially prescribed norms of masculinity- being independent, being unemotional, and defining one's worth in terms of sexual potency' (Burns and Mahalik, 2007).

Not only are men supposed not to demonstrate any sign of emotional weakness such as crying which may be interpreted as 'behaving like a woman' (O'Brien et al., 2005), they are expected to demonstrate masculine ideals such as bravery, independence,

[20] The various ways of benefiting from patriarchy without fully being an active advocate of it. BROWN, D. 2006. Pierre Bourdieu's "Masculine Domination" thesis and the gendered body in sport and physical culture. *Sociology of Sport Journal,* 23**,** 162-188.

power, and leadership (Gough and Robertson, 2017). A recent study by Flurey et al. (2017), which draws on previous work by Gershick and Miller (1995), investigated the impact of chronic disease (Rheumatoid arthritis) on the masculine identities of men, a subject they described as not having been given much attention. It was concluded that these men might have to adjust and adapt their activities and their view of themselves due to their chronic illness and in effect 're-write their masculine script' (Flurey et al et al; page 115).

Three masculinities strategies have been identified as possible responses where men are unconcerned to present themselves in a hegemonic masculine manner (Gerschick and Miller, 1995). The first two strategies apply to this current work. Although Flurey et al.'s study involved men with a chronic illness, there are similarities with my findings in the ways in which men navigate between conflicts and difficulties in order to maintain multiple masculinities at different times. This is what has been described as 'the chameleonisation of masculinity' (Ward, 2015 page 233).

The first typology of strategies indicates that some men still try to maintain 'masculine' activities (e.g., sporting activities or being a 'breadwinner') as well as a masculine image (e.g., not crying in public). Second, some men renegotiate some of the masculine roles that they were unable to perform due to the illness. Flurey et al. (2017) report that the effect of chronic illness may affect, for example, their identities as working men. Therefore, men who are breadwinners of their family experience a lack of work and not earning income as guilt inducing. Having a life-limiting condition may also mean a loss of social contact and network for some men.

Turning now to my findings, PWAPC interviewed were concerned about the masculine attributes that they reported were declining or at worst lost. Such characteristics include having a deep voice, being muscular, sexually active, having self-esteem, and asserting power at least in the family (Navon and Morag, 2003). It is postulated that living with a chronic disease is a matter of 'enduring and suffering' as well as a period of reconstruction of the self (Öhman et al., 2003). Maintaining a sense of personal identity (to be one's self) is very important to patients' experience of illness (Seymour et al., 2007).

Masculinity and the experience of prostate cancer remain largely under-described. This section addresses this and explores how masculinity mediates men's experience of having prostate cancer and how their gendered identities as men are affected. Furthermore, the experiences are interwoven, as far as possible, by drawing upon the data from family members who provided care at home for men with prostate cancer. The section also considers the resources adopted by the men and their caregivers to deal with the situation.

In this study, a recurrent theme in the interviews with men living with prostate cancer was how they define their masculinity about (hetero) sexuality and the physical attributes of the male body. There are also further aspects of what it means to be masculine (related to their role in the family), and their statuses in society. The patriarchal society in Ghana is an important aspect of men's lives not only in the family as the head but also in the dominant patrilineal society. Ghana is generally a patrilineal society. Also, this places men as high social figures. It is important to note that few tribes in Ghana such as the Akan clan practice matrilineal inheritance where they inherit from their mother's side, the inheritance is actually from the mother's brother (one's uncle). Again, in that same society, the King is the traditional head of the tribe and has the highest traditional authority, just like in communities who inherit from their father's lineage (patrilineal inheritance). This societal hierarchy supports and highlights prominent traditional and social roles that Ghanaian men play in their respective traditional societies. Men, therefore, are shaped by gendered role expectations and physical appearance. The men in this study reacted differently; albeit with some general concerns about how such changes affect their social roles and statuses.

6.3.2 Masculinity in Africa

Several viewpoints such as positivist (looking at male anatomy), constructivist (looking at male gender), and postmodernism (floating identities) are all perspectives about masculinity and how HCPs perceive this influence health care (Moynihan, 1998). Despite been very central in the African context, masculinity received some attention in literature a few decades ago. Over the last twenty years, gender has become a major

research focus in Africa studies, resulting in a surge of rich material. Yet our understanding of and how masculinity affects and affected by health practices remain largely unexplored in Africa. For example, despite the vast disparity even between men in southern Africa, some belief of male superiority still persist (Morrell et al., 2012). Some pioneering authors have first analysed the concepts of and the constructions of masculinity among African men (Lindsay and Miescher, 2003). The authors identified some key aspect of what the concept of masculinity encompasses. They indicate that masculinity is gendered, socially constructed, relational and hegemonic (Lindsay and Miescher, 2003).

Again, the work of Morrell and Ouzgane (2005) on African masculinities cannot be overlooked. They addressed the issue of masculinities in the African context and went on to further link these to other critical men's studies in relation to Africa. They, like Connell (2016), also argue that even among men there are power variation and that of opportunities that subsequently leads to different life trajectories. Masculinities vary in the African continent across time and space. In as much as there are commonalities, there is diversity among African men based on factors such as religion, colour (white and black Africans), language, and influence of colonialism (Morell, 2007)

Morell (2007) hypothesised the social inequality between black and white South African men. For example, he queried why most black South African men are still poor despite the abolishing of the apartheid over two decades ago? For example, the belief that men have to prove their virility, because of construction of masculinity in Zambia, led to some having multiple partners and engaging unprotected sex that escalated the risk of contracting HIV/AIDS (Simpson, 2007). Sampson (2007) also highlight that some men, in order to prove their masculine supremacy and to their sexual potency, engaged in risky and usually forceful sexual with women. He further indicated that boys, as they grow to become men, observed that men must exercise power over women and this had an implication on their identities and some risky behaviour such as indulging risky sexual relations that result in the high incidence of HIV/AIDS.

In most African cultures, masculinity or manhood is highly a social construction (Barker and Ricardo, 2005). The body is considered gendered, upbringing and roles are all gendered where men as considered as heads of households (Dover, 2005). Dover's ethnographic study in Zambia revealed a social construction of and a distinction between 'hard' men and that of a 'soft' woman. Men and boys are taught to be different and superior to women and the possession of the penis is regarded as a moral authority and a symbol of potency (Dover, 2005).

From the ongoing argument, I agree with other authors that indeed masculinity varies across societies, developed and developing, and even within the African context, there are still significant variations in different counties and communities. It is important, therefore, for the healthcare professional to recognise these variations and act accordingly when intervening for men with health problems. In my study, I explored how prostate cancer affects the masculine construction of Ghanaian men, and how they, and their family, react to that and the stigma that comes with it. Consequently, It is important to take into context what are the masculine ideal men aspire to achieve and maintain and what the society, also, looks for in men and how these expectations from society and PWAPC affects their men's experience of living with prostate cancer. The next section looks at the aspects of masculinity prostate cancer affects mostly in Ghanaian men.

6.3.3 How Prostate cancer affects masculinity

In this section, I explore participants' experiences of prostate cancer as a disease, and the impact of changes, such as incontinence and erectile dysfunction on men's sense of masculinity. These challenges create gaps between who these men are and what society expects them to be; and this constitutes stigma, according to Goffman (1963). Reporting on my findings, the changes that affect men's masculine identity are varied, and they are discussed under the following four components:

1. *Physicality*: This includes changes in appearances (muscle, gait, dress, and so on), incontinence, body not functioning well and fatigue/weakness that affects men's masculinity.

2. *Sexuality:* consisting of issues such as impotence, reduced sexual drive, and the presence of indwelling catheter preventing penetrative sex.

3. *Social status and role:* dignity, role changes, being dependent on others and the inability to engage in meaningful employment. These challenges breach men's masculine ideals

4. *Emotionality:* men are required to be emotionally stable. Consequently, depression, anxiety, sorrow may be additionally hard to express

Physicality-Changing (Loss) of physical appearance

Although constructions of masculinity may differ across different cultures and historical periods, there are some physical features such as being muscled and tough that are universally regarded as the qualities that men should possess (Gray et al., 2002, Wall and Kristjanson, 2005, Adinkrah, 2012, Oliffe, 2006, Chambers et al., 2017). As discussed in subsection 6.4.3, some side effects of prostate cancer treatment, for example, erectile dysfunction affects the identity of men. One key issue that arises post prostate cancer treatment is the changes in the physicality of men and how it affects masculine identity as well as their quality of lives (Chambers et al., 2017). As reported in one of the main seminal articles used for this study, men with an advanced form of prostate cancer are said to be 'struggling with the unreliability of body' (Krumwiede and Krumwiede, 2012).

The physical changes following prostate cancer treatment include exhibiting typical characteristics of a woman such as high-pitched voice and enlargement of the breast. These are attributes associated with (for many) effeminate masculinity. In addition, the changing physical appearance was quite a concern for the Ghanaian men who tend to be fastidious about their appearance and in recognition that people may judge them by the way they look. The following are some of the quotes that typify men's concerns:

No, I wasn't like this at all. The first day I went to the oncology, I walked there myself, and I was strong. I was not like 'skeleton' at that time. Now see me, there have been vast changes. I have worn out. I look like someone with HIV/AIDs……hmm, so it is part of the reason why I don't go out for people to see how bad I look. I have lost so much weight that some of my friends can't recognise me easily. I feel shy about my appearance (Daama, dyad interview 2).

I used to be the General Manager of (name of company withheld), and I must say God blessed me and I achieved a lot in life. I have been exposed to many prominent people, and our friendship continues even after I had retired. The treatment has affected my physique. When I complained, the doctors told me it is the drugs I've been put on. Indeed, I use to be a very handsome man and well-built, but now my voice even sounds like a that of a lady, look (showing his hair) it's sparse, and I look like a child with kwashiorkor [a malnourished child] (Opoku, individual interview 1).

Hmm, this disease has changed me into a woman more or less. I don't know what to do. After starting the chemo for some time, my breast has begun increasing just like that of ladies….. Look, it is serious. If this (developing breast) should continue, it means, I might need to wear brassiere [he laughs] (Nii, dyad interview 2).

Some men I interviewed, for example, Damaa, Opoku, and Nii reported their loss of strength and power. To them, physical strength is a key characteristic of being a man. The use of physical appearance as a measure of one's masculinity resonates with the findings that Brazilian men are receiving chemotherapy as a cancer treatment. The men expressed resentments about the changes in their masculine physical identity, reduced physical strength and ''Becoming Different'' (Mesquita et al., 2011). The findings further support the previous studies conducted in Australia (Chambers et al., 2018) and the UK (Kelly, 2009).

The caregiver of Daama added to the conversation about how her husband is worried about his ailing body and appearance. She narrates:

> *My husband is very particular about his physical appearance, and the clothes he wears. Therefore, my sisters used to tease me that it was one of the reasons I accepted his proposal without giving a second thought when he did propose. When I was a teenager, I was selective in choosing a friend; and the way they looked and dressed nicely counted. One day my husband said something that made me sad, he said 'do you suspect I have AIDS as well? But I reassured him it is not only AIDS, which cause severe weight loss (Seiwaa, Daama's wife, dyad interview 2).*

Seiwaa seems to be concerned about the physical appearance of her husband. Consequently, negotiation of masculinities appears not only to be a worry for the men but also for their spouses or caregivers as well due to the potential distress and stigma it has, as well as touching on the men's dignity (Gilbert et al., 2014). Again, one caregiver Karikari reported that his father was troubled about how his church members might think about his lean body following his ill health.

> *I know my dad is thinking a lot about his weight loss, and what people might say because of his status in the church (as a pastor). He asked me one day if I've ever heard people talking about his new look (Karikari,* Atta*'s son, dyad interview 2).*

Men's construction of self was of particular concern because of the new identity resulting from the significant changes in their physical appearance and status. In both cases, Damaa and Atta were concerned about the drastic changes in their physical appearance and probably wanted to find out how others might think about them. In their study, Maliski and colleagues (2008) identified that lack of physical strength made men feel vulnerable, and loss of strength contributes to a sense of incapability. The changes in physical identity resulting from prostate cancer have an effect on their roles and social status as men. The physical changes contributed to the stigma as discussed in the previous section in this chapter but is relevant here in that physical identity forms a core component of a Ghanaian man's masculine identity. Previous research has confirmed that changes to the body and self- images of patients living with prostate cancer are of major concern to men (Cecil et al., 2010) and this can have repercussions

on their self-image (Weber and Sherwill-Navarro, 2005). For instance, men perceive that having ‘no balls’ (testicles) means they are powerless and have no confidence (Cushman et al., 2010). A study by Broom (2004) explored how masculinity is socially constructed among Australian men with prostate cancer and noted the problems with men’s gender identities and the effect of ‘cultural codes of masculinity’ in shaping their experiences of the disease (Broom, 2004 page 73).

It was noted from both healthcare professionals and the men with prostate cancer that castration meant tampering with a critical masculine trait of men. One HCPs indicated:

> *The treatment of prostate cancer brings some physical changes such as hair loss, weight loss, and changes in the skin colour (especially with the radiotherapy). All these lead to some changes in body image which most of the men complain to us (HCP 01, individual interview).*

Adding to this, one PWAPC said during the interview that the surgical removal of the testes is not a treatment option for him regardless of the consequences of not choosing that. He recounted:

> *I haven’t reported sick to the hospital in years. I have been strong until this time… As for that operation, I ruled it out. It was out of the options for me from day one. Eii [exclamation] taking my testes out will mean I am no longer a man. The balls make us men, you know (Maegyida, individual interview).*

As indicated in Maegyida’s account, the testes symbolise manhood and are believed to play a role in sexual intimacy. Therefore, the absence of the testes means that his masculinity is threatened in addition to the potentially stigmatising effect of testes removal, and this leads to psychological distress for men. The surgical removal of the testes is one procedure that is done to reduce the production of testosterone and androgen that nourishes the growing cancer cells. However, there is some superstitious belief that such men are rendered ‘women’ (to be discussed in detail later) and therefore, the few men who agree to do that surgical intervention will not usually want to disclose it to others because of discriminatory remarks, derogation or disrespect that they go through.

I was hurt when my friend referred to me as the castrated man after my operation. Yes, he looked into my face and told me that if my testes are removed just like it's done for some animals such as goat, then I'm not a man any longer, and he giggled. He was like, so you have become a woman now? This pissed me off, how could he? (Nii, dyad interview 1).

Nii appeared worried that his friend, whom he had shared secrets with, made a mockery about his situation by linking him to a castrated male goat. This kind of ridicule was not only pertained to the general population but including some HCPs as well as discussed.

In Ghana, masculinity is socially constructed in such a way that critical components of it are the man having an appropriate physical appearance plus his social/familial status. Therefore, masculine identity is compromised by failing or deteriorating bodies. It must be noted that not only are there the physical changes because of prostate cancer disease, but there are additional complexities (as outlined above) that are interwoven with the sexuality, psychological and social issues.

It is important to note that the change in physical appearance affects the sense of identity felt by the men. For example, adorning dressing as in the case of Sampson who usually prefers to put on his traditional wear (ntoma).

I cannot put on my beautiful ntoma (traditional Ghanaian wear) because of the catheter etc. I have become so lean than I ever imagined I could have been. I need to wear something that can conceal it (catheter) and cover my entire body (Samson, individual interview 1).

I was put on one drug, but that makes my breast to be enlarged. I didn't know what to do (Kwaku, individual interview 2).

The loss of physical appearance was partly due to the feminising side effects of chemotherapy and hormone replacement drugs that lead to breast enlargement, loss of hair and changes that contribute to the disfiguring of the masculine feature. This was also reported in another study involving men with prostate cancer who reported

that some changes such as breast developing following treatment is an affront to their masculinities (O'Brien et al., 2007).

The changes in physical appearances of men also impact on their roles as Ghanaian men and affected their sense of dignity both in their households and in the communities in which they lived. As noted already, men's embodiment should be seen as both material and presentational. The changes in body appearance that prostate cancer brings, described by Robertson (2007) as 'changing bodies', affects men's embodiment and their image (Kelly, 2009). For example, Samson explained how the use of an indwelling catheter affected his adornment of a traditional dress (ntoma) to attend important occasions such as funerals and festivals. The adornment of traditional costumes, according to a study in Ghana, adds meaning to who we are as people and our wellbeing (Kangmennaang and Elliott, 2019). The section that follows looks at yet another important issue that affects men's sense of masculinity because of prostate cancer.

Sexuality-Reduced/loss of erectile function

Another consequence of prostate cancer that affects masculinity, as well as stigma, is impotence. Men's cultural sense of themselves as being a man- having a masculine identity- affects their response to prostate cancer in general and erectile dysfunction specifically. A survey of 253 men living with prostate cancer showed that 80.5% experienced various degrees of erectile dysfunction (Grondhuis Palacios et al., 2018). Oliffe (2005) conducted a study on 15 Anglo-Australian men using in-depth interviews. He explored the impact of impotence on men's sexuality and intimate relationship as well as how these affect their masculinity. He also argues that phallocentric sexual activity that primarily involves the use of the penis is reduced as libido and emotions negatively affect intimacy. He further indicates 'If an erection, as the starting point, could not be achieved then penetrative sex was no longer an option' (2005, page 2259).

Erectile dysfunction among older men and their inability to erect and sustain erection leads to the use of prescribed drugs or otherwise, orthodox or alternative- for sexual

enhancement (Gledhill and Schweitzer, 2014). It is reported that prostate cancer more than any other disease disrupts the socially constructed masculine identity of men due to some symptoms such as erectile dysfunction and incontinence that characterises the disease and or its management (Arrington, 2008) and the psychosocial impact it has on men (Wittmann et al., 2009). Loss of sexual capacity affects men's masculinity (Fergus et al., 2002) because they interpret the absence of their sexual power as 'not men' enough (Adinkrah, 2012).

A recent review of the literature conducted by Chambers and colleagues (2017) to look at the issues of erectile dysfunction, masculinity and the psychological effects following prostate cancer treatment found that 'masculinity underpinned how men interpreted and adjusted to their experience' (2017 page 60). They further argued that men with prostate cancer who experienced erectile dysfunction had a poor quality of life and psychological outcome. However, they also noted that men used conventional coping reactions such as acceptance, emotional control, stoicism, or rationalised that for example, erectile dysfunction is inevitable due to their increasing age. Others include redefining sex to include but not limited to erection and penetration and using previous evidence of their sexual prowess such as having children to comfort themselves (Chambers et al., 2017).

Before that, an earlier study has reported that wives of men with erectile dysfunction were troubled about the changes in their sexual intimacy because of their husbands having prostate cancer (Galbraith et al., 2012). Women's perspectives on prostate cancer's impact on intimate relationships are not usually addressed (Tanner et al., 2011) and therefore including their views in this study has offered some greater understanding. The issue of sexual dysfunction has been recognised as one of the main problems of cancer survivors (Brearley et al., 2011) and some men refused the use of alternative means to drive sexual satisfaction because they do not want to be labelled as 'artificial' men (Arrington, 2003). Some of the PWAPC in this study resorted to the use of drugs, mostly herbal preparations, with the aim of enhancing their sexual power. For men who have a urethral catheter in place, it caused significant impediment to the sexual relationship. Treatments for prostate cancer, especially those involving hormonal and neoplastic agents, extinguish libido significantly in most men as well. It

is, therefore, common for men who had surgery or receiving those agents or undergoing radiation to report a declining zeal for sex (Oliffe, 2009). Kwakwa, Maegyida, and Ofori shared their thoughts:

> *One of the main problems I'm worried about is my inability to have sex. When I reported to the hospital, there was nothing much they [doctors] did about it. Then they said this is usual with prostate cancer. I have been thinking about this, and for some time, I thought I was going mad. Yes, I did (Kwakwa, dyad interview 2).*
>
> *Here I am. My dignity as a man is no more. I can't pride myself as a complete man. No, I can't. I am losing my manhood to this bad disease despite all the drugs I have used, but all have ended up in vain (Maegyida, individual interview 2*).
>
> *I have never in my life seen a 'bad' disease like prostate cancer before. Oh yes, it is a bad disease. After depriving me of my money and all that (through buying drugs etc.), it had deprived me of having sex as well. That is a very deadly disease, killing me before my real death. The government should do something about it before all the men in the country become useless (Ofori, individual interview 1).*

The above quotes from Kwakwa, Maagyida, and Ofori represent the concerns of men about their declining sexual strength and the stigma there have (enacted and felt). Maagyida's statement 'my dignity as a man is no more' shows how difficult men have to handle issues of sexual impotence. Also, this confirms the finding that majority (50.6%) of men found it difficult to deal with changes in their sexual life due to erectile dysfunction caused by prostate cancer (Grondhuis Palacios et al., 2018).

Still, others such as Opoku and Baabamu were emphatic about what they described as penis 'not working'. They narrate:

> *As a man, I am supposed to satisfy my wife sexually. But hey! That's not usually the case. I am overly concerned about my inability to have sex because I can't*

have an erection for long. Some days my thing doesn't wake up at all (Opoku, individual interview 2).

My manhood is not functioning. It is not working. I mean it is dead. I don't have any feeling at all, I am not happy about it at all, and I keep thinking about it. I hope that the treatment they are giving me will help me regain my manhood back so that I can become a man again (Baabamu, individual interview 2).

The above quotes, from the PWAPC perspectives, indicate a 'breach of masculinity' due to their reduced or inability to have sex as part of their patriarchal duties. The metaphors '*manhood is not functioning'* and *'losing my manhood'* show a lack of power to fulfil a duty that is expected of men. This finding is yet another perspective of how men want to express their masculinity but perhaps not like a risky sexual behaviour that was found in Zambian men (Simpson, 2005, Morell, 2007). Although generally, people are reticent when it comes to issues relating to sexuality and sexual activity, most PWAPC I interviewed, especially Maegyida were open in talking about their decline or absent drive for sex. They were concerned about the effects of impotence on their sexual lives, their pride as men, and their self-image as 'real' men. In some situations, they direct their anger at their spouses. Additionally, in the case of Maegyida for example, he was concerned about how his wife coped with his impotence despite her assurance that she is ok. He narrates:

I suspect she might not be pleased about my current situation…. she tells me she's fine, but then I doubt it. You know, I am older than she is, and I think I am depriving her something important in life. With this, if you are not careful your wife can even divorce you and go for another man [he giggles]. The whole thing is a complex issue, isn't it?(Maegyida, *individual interview 2*).

Maegyida expressed the fear his wife abandoning him due to his declining sexual function and this corroborates with the previous study where African men with prostate cancer have expressed the same (Anderson et al., 2013). This finding supports Chambers and colleague's study (2017) where some Australian men with prostate cancer were concerned about changes in sexuality that affected their dignity as men

and feared how the partners might be coping. Other men also shared their experience about the changes in their sexual ability that they described they are unable to perform.

> *My manhood is not functioning properly. It (penis) plays hide and seek with me. Occasionally I feel like having sex, but no effort to get it erect will work. Sometimes, it (penis) erects at the wrong time or when my wife has gone out for something or gone to work. It is a sad story, and it's something that is bad to experience (Kwaku, individual interview 1).*

> *My thinking intensifies anytime when it is getting to bedtime. Yea, I am useless in bed nowadays. Any time we are going to bed, I feel guilty for not being able to do my 'job on the bed' because I am a half-man (Sharms, individual interview 2).*

Nineteen out of the twenty-three men whom I interviewed touched on the various aspect of their sexuality. The men described themselves in the context of sexual performance using terms such as 'not man enough,' 'from the frying pan to fire,' 'journey of no return, 'pitiful in bed,' 'absence of their manhood,' better to be dead than living a half-life.' The sexual potency of men is a revered masculine trait in Ghana, and therefore impotence is highly stigmatised (Andoh-Arthur et al., 2018). This view has also been expressed in other works in different countries, such as Canada (Evans et al., 2011), the UK (Alexis and Worsley, 2018a, Arrington, 2008), and Australia (Chambers et al., 2017).

Erectile dysfunction (impotence) is a perpetual tormentor for men living with advanced prostate cancer. The men saw erectile dysfunction and urinary incontinence as a double slap on their face and a dent in their self-image as men. In combination- incontinence and impotence- lead to loss of control over their body and an inability to satisfy their sexual drives. It is reported that most of the sexual dysfunction is due to medical treatment (Arrington, 2008) and surgical treatment usually leads to urinary incontinence as well. So in effect erectile dysfunction is a common side effect of most prostate cancer treatment, whether medical, surgical, radiation or hormonal therapies. For fear of losing their sexual drive, almost all the men interviewed except two refused

to undergo surgery that involved the removal of the testes. One of them shared his views:

> *I didn't want to do that operation at all. But it became necessary. More so, I was already weak in bed (reduced sexual drive), so I said there was no point refusing the operation. It was hard to believe that prostate cancer could do this to me. Hmmm so now being with my wife is like living with a best friend, nothing more sexual intimate. Yes, I mean having sex (Baabamu, individual interview 2).*

The caregivers who were the wives of the men interviewed also highlighted their experiences in the context of sexual activity. While it was identified as an issue, women were more concerned about their husband's health state rather than their ability to have sex:

> *Hmmm, sex is not my main worry now but rather how he will be healthy so that we have a happy life together. I am a bit worried sometimes, but I am not bothered at all if I don't have sex (Okonore, Kwaku's wife, individual interview 2).*

> *There was a time I asked myself whether he will ever be able to regain his erectile function. It's a pity though to me, and I know he (husband) worries more about it (Stella, individual interview 1).*

The above quotes indicate that not only is sexual health a problem of PWAPC but their spouses as well. Spouses had divergent views about their men's erectile inefficiencies. The views from both PWAPC and the spouses add to the methodological strengths of this study by the inclusion of caregivers (most of whom were spouses). This finding agrees with one study that explored the sexual health of couples treating prostate cancer (Grondhuis Palacios et al., 2018). The authors reveal that some spouses of PWAPC may not demand or initiate sexual conversation in order '*not to pressure the partner to perform'* (page 4174), or perhaps to sympathise with them as in the case of Stella. However, some wives, for example, Seiwaa, disagreed with most of the others and she narrated:

Sex is good and fundamental. That is why the Bible says that do not deny your partner of sex. But I know it is not his fault; he is not refusing me sex; if that is the situation then I have a cause to complain, but this has to do with his 'car engine' not turning on. I wish he could recover from that because it is a worry to both of us (Damaa's wife, Seiwaa, individual interview 1).

These different perspectives from the spouses are interesting and highlight the needs for HCPs to assist couples about how to cope with changes in sexual relations and to do so based on the individual needs. This supports a study that says spouses of men living with prostate cancer need help to adjust to changes in their intimate relationships (Paterson et al., 2015). However, the majority of HCPs have neither the skills nor the knowledge to help couples with problems in their sex lives. A study by Grondhuis Palacios and colleagues (2018) indicate that little attention is paid to how prostate cancer impact on couple's sexual lives. In my research, for instance, Seiwaa's husband, Daama, equally shared his concern about the erectile dysfunction that he described as 'worse thing' that has ever happened to him.

I must tell you that the worse disease in the world is this (prostate cancer)…… oh yes! Now I am useless. I have a beautiful wife, but I can't do anything. I lie by her side like a piece of wood until daybreak. We aren't siblings, so I have to do something even if it is occasionally. I feel guilty about this, and I feel shy to discuss this, but I know you people [health staff] look after us when we are sick, that's why I feel free to tell you about it (Daama, individual interview 1).

During my interview with the health care professionals, some did indicate that many men reported the issue of erectile dysfunction at the hospital any time they get the opportunity. The medical oncologist explained:

those who are on the 'hormonals' (hormone therapy), like the Zoladex, (in particular) shuts down the testes-by not producing androgen. They need to be educated on the side effect such as dizziness and occasional headaches. Also, these are something that when we tell them, they can manage on their own. The most important and the prominent one is the erectile dysfunction and loss of libido. Those people need some counselling, and we do advise them and

assure them that once they are off the hormonal treatment, they will regain the power a bit (HCP 02, individual interview).

It is important to note that health professionals also indicated that the psychological state of the patient could lead to decreased interest in sex. He went on to state:

When the cancer is advanced, it usually has some significant effect on a patient's sexual life. This may be due to the patient's lack of interest in sex or inadequate energy for sexual activity. Loss of interest in sex (libido) affects a person's ability to have an erection. Tiredness, anxiety, and depression can affect the desire for sex negatively. All the symptoms I have mentioned are usually present in cases of advanced prostate cancer (HCP 02, individual interview).

It is more evident now that reduced /inability to have sex is a common problem that most men with prostate cancer discussed. They described a failure to have sex as worrying, as they firmly believed sex is an essential part of married life and an essential indicator of manhood. Not being able to have sex was perceived as a 'humiliating threat to identity' (Cushman et al., 2010). Some men were reluctant to talk about it because others will get to know that they are 'not men enough.' Sexual weakness was a key issue not only for men but also for caregivers. The findings of this study support those of Alexis and Worsley (2017) who indicates that sexual weakness is the most distressing experience men with prostate cancer encounter. This is further supported by another study where men with prostate cancer indicated that reduced libido impacted negatively on masculinity as they are seen as 'less a man' or 'not man enough' in the eyes of others (O'Brien et al., 2007, Santos Araujo et al., 2013) and remain the most unmet needs (Watson et al., 2016).

Prostate cancer and its treatments typify a fascinating context for the understanding of masculinity, and how, masculinity affects health and men's social roles. The next section looks at the cultural expectation of men as against men's real ability to meet those expectations.

Socio-economic role status change

Another important issue that runs through the data were changes reported in men's roles in society and the home, due to their physical weakness that results in a feeling of been infantilised. Men are beneficiaries of the way society is structured around masculinity, and this is what (Connel, 1995) called 'patriarchal dividend.' Prostate cancer affects the performance of men's roles in the society (as men), and one study suggests a psychoeducational training for men with prostate cancer to cope with the loss of their patriarchal dividend following the effect of prostate cancer (Burns and Mahalik, 2007). Generally, Ghanaian societal norms consider masculinity, being a man, to include being in charge of one's affairs, and withstanding difficulties without showing signs of it. Highlighting the role of men in society, John Oliffe (2006) indicates:

> Fatigued bodies were unable to deliver regarding both physical prowess and social presence. The inability to provide physical labour threatened long-standing relationships with the traditional gender roles of breadwinner, provider, and protector. Being unable to keep up, let alone compete with other men (and women) also forced participants to reformulate and re-locate many previously held practices of 'doing' gender (page 420).

Prostate cancer contributes to de-masculinising men because it affects their ability to fulfil what is cultural desirable of being a man. Such social practice, for example, and the belief that men must always provide for their family may contribute to poor wellbeing. As one participant puts it, his situation was like moving from the 'head' to the 'tail.'

> *…now the whole thing is like moving straight from the head of the family to the tail. Because when one is unable to do things for himself (care), he becomes like a child, needing the care. That is not to say my caregivers disrespect me, but it is something that exists… (Boat, individual interview 2).*

Mr. Boat just as all other Ghanaian men are expected to be responsible for the welfare of his immediate family and their kin (extended family). Changes in roles and status have implications on the dignity of the men who are culturally regarded as the head of family units and communities.

I think this disease has made me like a child. I sometimes wet myself with urine when my rubber (catheter) is off. I need someone to help me do the entire cleaning (Mike, dyad interview 1).

All that I can say is that I don't feel to have that control over myself as before. It is a bit of a challenge seeing yourself moving from that level (high) at both work and home to a wheelchair life. I was in charge of giving instructions at our command (military), but now I have to follow instructions from others… (Gyasi, dyad interview 2).

As other men described, Gyasi and Mike recounted how they have moved down the social ladder due to the debilitating effects of prostate cancer. Mike was a former head teacher and an elder[21] of his church. Therefore, he was quite concerned that, for example, he needs someone to help with his care thereby felling infantilised.

Gyasi also recounted how he gave 'command' at his workplace as a military man, and at home, in his role as the head of the family. The reported that his family relied on him for money and welfare, a role he enjoyed. However, things have changed, and he is now at the 'other side', needing to be given care and helped in and out of his wheelchair. He added there was a time that he told his family that he would have preferred being dead. The above quotes evidence that men with prostate cancer experience deep concern due to loss of dignity and status in the family and society, and therefore they become reliant on others for their survival. Narratives from most PWAPC showed that their provider and protector roles as head of the family were affected. This cherished provider and protector role of men support previous studies (Chambers, 2017; Oliffe, 2006).

This finding is consistent with the work of Andoh-Arthur and colleagues (2018) who suggested that a man's social identity is closely associated with the accumulation of wealth and being able to provide for the family's economic needs. Therefore, having

[21] The work of elders is unique among church leaders. As overseers, they are responsible for everything that is related to the work of the church. (Seventh-day Adventist Elder's Handbook - Alaska Conference)

economic control relates closely to a man's ability to fulfil his masculine aspirations (Andoh-Arthur et al., 2018). As discussed in the previous chapters, PWAPC have challenges with employment and difficulties getting funds to support their bills, and these affect their daily life in the context of being a man. Some authors have observed that when men are struggling to fulfil their breadwinner role to provide for their families (Nixon, 2009, Robertson et al., 2017), and in times of difficult economic recession and joblessness, it can result in mental illness and suicide (Robertson et al., 2017, Andoh-Arthur et al., 2018, Antonakakis and Collins, 2014). In Ghana, family systems exist largely around patriarchal lines, and so a role reversal, for example, from a breadwinner to dependency could be socially difficult for men to cope.

In most traditional homes in Ghana, men are the head of the family units and are usually responsible for taking care of the family financially (Lambrecht, 2016). Prostate cancer management puts an extra financial difficulty on the income of the family (as elaborated in section 4.2.) while at the same time PWAPC become less able to shoulder their financial responsibilities (to children, relatives/extended family). Men are mostly the main source of income, and they take care of their nuclear family and sometimes some members of the extended family. Participants reported the following quotes.

…when my husband had this [disease], I knew the family was in trouble. That took the staple out of the family. My husband plays a central role in our family lives by providing for us (Abiba, Maegyida's wife, individual interview 1).

This condition has indeed affected every aspect of my life; that is my work, marriage, and parental responsibilities. I cannot even pay my children's school fees because of the bill [hospital bills]. So, now I have become unmanly in a way (Kwaku, individual interview 2).

The quotes 'I knew the family was in trouble,' and 'unmanly' are powerful and expression of incredibly difficult times for the family. The onset of prostate cancer disrupts this status of men who are 'heads' of family units and providers to become those that the families are rather looking after and this resonates with a previous study

(Chambers et al., 2018). This is reported a similar study where the authors described such happenings as ‘fragmentation of the family unit’ (Bessa et al., 2012).

Men are breadwinners and when they are not able to work due to severe disease affects the entire family; this finding has been reported in literature from both Western and non-Western contexts (Andoh-Arthur et al., 2018, Bamidele et al., 2018, Alexis and Worsley, 2017, Flurey et al., 2017, Stapleton and Pattison, 2015). Bamidele et al., (2018) study, for example, that explored the experiences of Black African and Black Caribbean men further suggest that when men’s role as breadwinner is affected, it can impact on their quality of life as well as their psychosocial wellbeing. When men are unable, as heads of the family units, to discharge core duties such as decision-making, initiating sexual conversation and breadwinner, they feel that they have failed to deliver their cultural expectations.

Different families react to this development differently. Some do seek help from others (detailed at section 4.6) while some think that they do not have to ‘wash their dirty linen’ in public or seek external support probably due to the potentially stigmatised nature of prostate cancer (discussed in section 6.2). The belief of not wanting to ‘wash dirty linen in public’ seems to affect the sources of support families call upon until the situation was unbearable. Issues of erectile dysfunction, loss of social status, stigma, and embarrassment resulting from incontinence may affect the emotional wellbeing of PWAPC.

Emotionality of living with advanced prostate cancer

As pointed in the previous sections, the weakness PWAPC experience from prostate cancer and its treatment impacts on person’s emotions and activities of daily living as well as the desire for sex. Also, issues about the stigma around prostate cancer, and the disruption of the family cohesion, as described previously, all collectively influence men’s psychological state and this affects their general well-being. The changing physical appearance and image in men, feelings of loneliness, stress, and anxieties about treatment side effects can affect a person’s psychological state of mind. However, because men are assumed to be emotionally strong (Medina-Perucha et al.,

2017), some men and indeed HCPs may underestimate the kinds of emotional support that PWAPC need. For example in the Ghanaian society, men are expected to endure pain and not to show signs of weakness or cry in the presence of others (barima ɛnsu). Consequently, PWAPC may find it difficult to express signs of depression and anxiety openly and this affects their coping with prostate cancer as reported in previous work (Evans et al., 2011).

Additionally, prostate cancer may significantly alter a person's lifestyle, for example, being indoors because of immobility or poor physical health. For some, the financial challenges and the feeling of being a burden on others (described in chapter 4 and 5) contribute to this worry. In effect, the physical effects of prostate cancer influence men's psychological health and vice versa. For instance, anxiety affects a person's sleep and appetite. This can also lead to poor or worsening physical health. These emotional problems, if unchecked, may lead to depression and suicidal tendencies as reported by Kwaku.

> *I had ever thought of ending my life when things were very tough. I've suffered. I have. For a man like me to have no cedi[22] (money) on me, it is a sad story. I thought there was no point in wasting all the resource on me while the children still have no secure future. I prefer my children getting money to be in school. [Tears dropping] …..(Kwaku, individual interview 2).*

The above quote illustrates the deep emotional turmoil Kwaku experienced because of the loss of his economic independence following prostate cancer. The metaphor a "*man like me to have no cedi"* indicates a dint to his patriarchal status as a man, and also a reversal of role from a 'provider to the provided for' in the family. This confirms two studies conducted in Ghana that found that men's shame of not been able to perform their economic responsibilities and losing their patriarchal control have psychological effects and if this is not properly identified and curbed, can lead to suicidal ideation and suicide (Adinkrah, 2012, Andoh-Arthur et al., 2018).

[22] Cedi (plural cedis) is the Ghanaian currency.

Adinkra's study (2012) concluded that some men who recognise that they are unable to fulfil their culturally implied masculine roles might ultimately choose to commit suicide rather than face the shame associated with the failure. Adinkra's study (2012) on masculinity and male suicidal behaviour points to three findings that are relevant to my study; 1) how men battled the shame not been able to undertake their economic responsibilities, 2) men losing patriarchal control, and 3) impotence.

Firstly, Adinkra's study (2012) showed that some men did commit suicide due to the shame of being unable to fulfil their socially- prescribed economic roles as providers for their families. Secondly, the study noted thirteen of the cases men killed themselves because of sexual impotence. As noted, male sexual identity is highly invested in sexual performance. Thus, sexual impotence is equated with sexual inadequacy and, by extension, a threat to masculine identity. Thirdly, the study explored how the loss of (actual or potential) patriarchal control could lead to shame and suicidal ideation. Adinkrah (2012) reported in his work:

> The night before the murder, his wife had mocked him about his sexual impotence, saying he was 'not a man'. In another incident, a 63-year-old man killed himself in response to the shame of his sexual impotence and his wife's consequent extramarital affairs (page 479).

One cannot underestimate the impact of prostate cancer on men's emotional well-being. This is exacerbated by norms of masculinity where men feel unable to express their emotions. In one circumstance, Atta described how he has to hide his feelings from his wife and children. He narrates:

> *Occasionally I'm sad, but as a man, I have to hide some of those feelings from the children and their mother (his wife). But you can't hide it all the time, they get to know and ask you about it. Sometimes I regret still living (Atta, dyad interview 1).*

Atta's quote is a typical case of some of the difficult emotional times and how some men try to hide emotions. This finding supports Chamber and colleague's study (2017) that indicated that some men did not talk about their emotional problems to their family

to avoid worrying them or to protect them from emotional stress. These emotional difficulties affect caregivers such as in the case of the caregivers of Baabamu (Jenny) and Ali (Zaliatu) who were tearful and expressed the emotional difficulties they face. This supports an earlier work that suggests that caregivers (especially spouses) of men with prostate cancer equally report distress (Couper et al., 2006) and similar distress was reported in managing HIV/AIDs (Selman et al., 2013).

My findings indicate that the social expectation and definition of masculinity could be health damaging, and in Ghana, emotional distress and stigma have also been reported at as problems associated with caregiving (Ae-Ngibise et al., 2015). It is further supported by another study that concluded that the psychosocial problems of men with prostate cancer are not given equal attention as compared to physical problems (Watson et al., 2016). Since culture shapes human motivation and behaviour, the understanding about how men feel and react is important for the planning of health intervention for men and those significant to them such as the caregivers as recommended by previous studies (Robertson, 2007, Gough and Robertson, 2017). These findings enhance our understanding of how prostate cancer affects the masculine roles of Ghanaian men and implication of this is the possibility that men's health in general and prostate cancer care in particular, need to factor in all these issues that influence masculinity and health. The final section provides a summary on how stigma and masculinity influence care, and its implication for health seeking and health policy.

6.4 Chapter Summary

This chapter has two parts; and explored how prostate cancer affects men's masculine role and their place in the family and society as a whole, and the stigma that is associated with living with prostate cancer in a culturally conscious setting.

The first section of the chapter looked at the stigma of prostate cancer, which was found to be multi-layered: the stigma of the prostate cancer itself, the stigma associated with its symptoms, and stigma of some treatment options for prostate cancer such as the removal of the testes. There is little literature that sheds light on this kind of stigma

especially regarding the stigma of symptoms and treatment. There is a socio-cultural belief that prostate cancer is associated with sexually immoral behaviour. The media and institutions such as – healthcare and government through the health insurance scheme also play a role in the forging and propagation of rumours about prostate cancer as caused by immoral sexual behaviour as perceived by PWAPC.

Symptoms of prostate cancer are found to be stigmatised. Urinary incontinence affects a person's sense of self thereby bringing a sense of shame and humiliation. Two key concerns were the leakage of urine that causes embarrassment and pungent odour that usually leads to self-isolation. These emotional and psychological effects also affect the caregivers who additionally suffer courtesy stigma. PWAPC and their caregivers experience at least one form of stigma or the other, and they respond to these using passing, covering and resistance in some cases. Some treatment methods such as the removal of the testes and hormone replacement therapy are stigmatised due to its ability to cause feminine feature in men.

This chapter has argued that prostate cancer is a stigmatising illness in Ghanaian society and participants respond to the prostate cancer stigma in various ways. Therefore, the findings contribute to the understanding of stigma in a male-specific cancer (prostate cancer).

The second section of this chapter explored how masculinity and social statuses are affected and its impact on changing physical identity, sexuality (function and strength), social status and role, and emotional wellbeing. This section relied heavily on the writings of Connell (2016) and Robertson's (2007) theories of masculinity that indicate that masculinity is relatively fluid and different for different people in different settings (or within the same person in the same environment). It is worth noting that while men may enjoy some privileges for been 'men,' some socio-economic and cultural factors contribute to men's health and this aspect has not received considerable attention by policymakers, researchers and health professional.

My study also challenges those traditional beliefs that 'men are always strong,' 'men are meant to endure hardship'. The chapter further looked at managing illness in the context of masculinity - how socio-cultural norms of masculinity shape participants'

responses. To this end, health professionals should not homogenise all men and HCPs must realise the unique needs of PWAPC and provide care accordingly. The next chapter provides an overview of the overall findings and their significance, concludes, and recommend ways of providing improving support for men living with prostate cancer and their caregivers.

7 CHAPTER 7

7.1 Summary, Conclusion, and Recommendation

7.2 Introduction

This chapter recaps the key findings and new insights from my study. Firstly, an overview of the main findings is presented, highlighting what my research adds to existing knowledge. Secondly, it develops the links between the findings, relevant theories, and previous research studies. Thirdly, the implications of this study to the field of prostate cancer, palliative care, and home-based family caregiving are presented, and what these findings mean for future research, policy and practice are set out.

This study has examined how prostate cancer affects Ghanaian men's masculinity in the areas of social status, physical, emotional and sexual ability, and how these collectively influence their health and quality of life. The spirit of reciprocity of care solidarity that the family and the community show to patients with cancer is an excellent source of support including faith in God. Caregivers also demonstrated a strong sense of obligation and were inspired to provide care by cultural beliefs that frown upon the abandoning of the sick. However, there is a 'disconnect' between the coordination and caregiving at home by the family caregivers and the care provided by health care professionals at the clinical setting.

This research has also demonstrated the unmet needs of the caregivers who sometimes find it extremely difficult to mobilise resources for the care and face an extra challenge if they stay very far away from the hospital. The chapter then gives a reflection on the strengths and limitations and makes concluding remarks.

7.3 Overview of the main findings

This study aimed to explore the experiences of home-based supportive and palliative care (emotional and practical) of PWAPC in Ghana and with specific objectives outlined in section 3.1. This research was partly necessitated by the growing number of prostate cancer cases, which is usually diagnosed at advanced stage, in Ghana and its heightened prevalence in black Africans (Hayes and Bornman, 2018, Bamidele et

al., 2018, Imm et al., 2017, Oladimeji et al., 2009, Ministry of Health, 2011, Chu et al., 2011). My study was also appropriate and timely due to a dearth of information about home-based family care in non-westernised context for PWAPC. It helped to explore issues such as challenges of proving care in a resource-poor settings adding to our understanding about what we know about other diseases (Bessa et al., 2012, Lambert et al., 2013, Salifu et al., 2018, Omoyeni et al., 2014, Sheehy-Skeffington et al., 2014, Aoun et al., 2015, Stajduhar et al., 2013, Mehta et al., 2014).

As discussed earlier in section 3.12, the analysis was done by amalgamating the perspectives of all the participants and maintaining the focus on the care for PWAPC at the centre of the analysis. The study produced three main and related themes that emerged from the data. These themes are managing illness in a resource-limited context (*Chapter 4*), Family caregiving (*Chapter 5*), and the cultural response to prostate cancer -as a stigmatising illness and in the context of masculinity (*Chapter 6).*

Chapter 4 provides an in-depth understanding of how the day-to-day care for PWAPC is primarily achieved within the confines of the home, where there is a rare involvement of professional palliative care staff. Due to lack of medical insurance, families incur substantial financial costs both direct (such as the cost of drugs and transport) and indirect (such as job loss), and some caregivers may have to give up paid employment to undertake such care. In the absence of statutory financial and social support, some caregivers expressed concerns about being overburdened with this high cost of care. Funding the cost of care must be factored into future support from statutory bodies to address the financial burdens placed on families.

Chapter 5 further describes how the family provides care. It talks about the practical and emotional issues of caregiving within the family context, how they undertake the care at home. It also highlights managing pain and medication, and the disruption that prostate cancer brings into the family. It touches on the overburdened nature of care that caregivers experience because they get little or no technical support from the HCPs. Families have to cope and in effect become medically proficient in the absence of professional input. Chapter 5 also goes on to talk about the social network of family that supports the care. Even if the care becomes very burdensome and difficult, part

of the motivation for the care is underpinned by the socio-cultural belief in the reciprocity or ‘giving back,’ and the fear of retribution after death (see section 1.2.4).

Of unique importance for most men living with prostate cancer, is the effects of prostate cancer on masculinity. Chapter 6, describes (in one section) how prostate cancer is stigmatised and the effects of this stigma on both help and health seeking for men. For example, the stigma around ‘begging’ or asking for charity made some men reject soliciting for donations or articulating their financial needs to others and rather prefer to die in ‘dignity’.

The other section looks at, in detail, how prostate cancer breaches pertinent patriarchal norms, threatens men’s sexual potency, and adversely affects their body image and socio-economic statuses. It also looked at how prostate cancer is causing once independent men are now becoming increasingly dependent on family caregivers for physical care and support.

This thesis highlights what palliative care looks like in a resource-poor context for a stigmatised cancer not covered by medical insurance. Family usually spouse and children, primarily meet the care needs of PWAPC, and the study’s findings provide rich insights into the challenges for families traversing the prostate cancer journey, and coping strategies used. In addition to the challenges this presents, families are also dealing with a stigmatised illness. Further adjustments are also evident about men’s perceptions of their masculine identity, and the impact of prostate cancer on their identities. These issues are discussed using relevant theories and the implications of this regarding the delivery of informal and professional care.

7.4 Findings and its relevance to theories and previous research

There are multiple theoretical perspectives, explicit or otherwise, that can be used to make sense of data (Guba, 1990). I have relied on relevant theories to explain and contextualise the findings. However, I acknowledge that despite conscious effort to use

a wide range of theories to help make sense of these findings, other theories, when used, may contribute to the understanding of these findings.

7.4.1 Care in a resource-limited context

This section reiterates the key points when caring for PWAPC in a resource-poor setting. My study highlights the financial burden of treating prostate cancer, the challenges of managing care due to rural locations, and problems of having a centralised formal palliative care services. The study also identifies the gaps in providing physical care such as preventing bedsores, unresolved psychosexual needs, and inadequate information for PWAPC and their family caregivers. Other studies support my findings. For example, in Weber and Sherwill-Navarro's (2005) study, the cost burden for the treatment of prostate cancer causes much psychological distress especially among people who do not have adequate support services. Weber and Sherwill-Navarro (2005) further argue that men with prostate cancer might require more information and emotional support especially those with low educational background and or with limited access to the internet (for being more marginalised than the average population). This finding about increased impact of prostate cancer on marginalised men contributes to earlier works on masculinity where the authors indicate that masculinity has to be looked at from a broader context such as education and housing that could influence men's lives differently (Connell, 2016, Robertson et al., 2016, Macdonald, 2006, Connell, 1995).

Home family caregiving in Ghana is challenging where there are no government funding or professionals to assist in the care at home. As detailed in chapters 4 and 5, there is no government funding that supports the care of PWAPC. Funding for palliative care is different in resource-rich countries, for example, in The Netherlands where professional home care is provided for and funded by the government (De Graaff and Francke, 2003). For instance, Haltia and colleagues (2017) undertook a study to examine the resource and amount spent on home-based care for patients with advanced breast, prostate, and colorectal cancers. They found out that almost the

same amount spent on health care was also spent on ancillary care at home, bringing more financial pressure on caregivers.

Furthermore, my study draws on the recommendations of other reviews as a way of improving support for patients and caregivers in Ghana. One such study used nurse-led mobile palliative care services in the UK to assist families to reduce cost and to help them in undertaking some specialist care at home (Mitchell, 2013). The nurse-led interventions have the potential of reducing cost, resources and hospital admission and/or its duration (Salamanca-Balen et al., 2017). A similar study (Casey et al., 2017) supports this; where the contacts the nurses made with patients during visits helped patients and their families in dealing with emotional issues. My findings are further supported by another study that has recommended educational packs for caregivers that are developed based on their unique need are useful (Funk et al., 2015).

The use of Community capacity-building approach also has proved successful in some rural localities in Canada, and one example of this approach has been detailed in work by (Pesut et al., 2015). Literature indicates factors such as poverty, and poor access to health care impacts on men's health especially in sub-Saharan African and global south countries (Gough and Robertson, 2017). The Community capacity-building interventions led by nurses had provided relief and met the palliative care needs of rural older adults with an advanced disease living in rural communities (Pesut et al., 2017).

My study makes a vital contribution to the understanding of living with advanced cancer in a resource-poor context, and we cannot assume that western models of the delivery of palliative care can often be transferred in a different context. The findings of my study indicate the urgent need for nurses to provide support for caregivers at home, the establishment of specific programs and services to meet the unmet informational and psychological needs of caregivers of PWAPC. Additionally, frequent reassessment of caregiver needs seems to be indicated as some are overburden with care, and lack resources for the care. This study also points out how caring in a resource-limited context with no government funding places enormous care responsibilities on primary caregivers, usually families.

7.4.2 Family Caregiving

This study indicates the pivotal role of family caregivers in managing patients at home and providing incredible devoted care. The burden of care responsibility is well documented in the literature, but the majority of this research is from western perspectives. What my work adds again is a richer understanding of family care in a different context where palliative care patients are almost entirely dependent on family members to care for them and in effect do the job of a palliative care nurse. The family needs to be taken into account when assessing the care needs of men living with prostate cancer. This is because participants recounted the contribution of other family members who were not mainly doing practical care for the patients but were instrumental in providing emotional care and giving financial support for the care.

As discussed in sections 4.3 and 4.5, there is no well-coordinated relation of care between the hospital and the family caregivers. The situation now could be described as at best, fragmented and at worse, non-existent. Family caregiving experiences are both positive and negative, and this depends on several factors discussed in section 4.6. For example, patients benefit from having social networks in place to support their care, and this must be strengthened. Perhaps this is an indication of how isolated the families feel as indicated by their appreciation of me (though in a research capacity) wanting to know more about their situations – and the fact that I was a health staff visiting them at home was a bonus. A family told me '*Thank you. What you are interested in finding out are things other people will not bother to find out'.*

My background as a nurse informs my analysis and recommendations. As such, one suggestion is the need to develop further home-based palliative care services. This will ensure that PWAPC and their caregivers could get access to the needed care at home as discussed in Chapter 5. Since the financial burdens placed on families and patients for such services are enormous, a further recommendation is that these services are resourced at a national level. However, this is not going to be a straightforward task looking at how dispersed some participants are relative to the palliative care centres. This will be in the form of community care supervised by district nursing services. It will be, therefore, relevant to liaise formally with other lower level hospitals and clinics to support families caring for someone with palliative care needs. This will ensure that

patients who default treatment are traced and supported. Hence, there is a need for comprehensive health and social policy on palliative care at home for PWAPC.

This study extends our knowledge of reciprocity either as a way of giving back to others or in anticipation of what they will get in the future. In what was described as reciprocal practices of '*solidarite'* [solidarity or support], was found to be a key element in family caregiving in Senegal (Evans et al. 2016). My study, just like Evans et al.'s (2016) study, indicates care is mostly gendered. A total of 17 females and six males in my study provided care. In addition, these women caregivers were mostly spouse, mother, and daughter who do most of the practical care while the male caregivers are usually responsible for the financial obligations. However, the men did some care that involves lifting or required enough physical activity.

In resource-rich contexts, pain is managed with adequate support, and there are systems of anticipatory prescribing so making it much easier to control complex pain. However, in resource-poor settings, and especially at home where there is no professional staff providing care, the process is trial and error, and management of pain and other symptoms may involve the use of herbal drugs, where most of the accuracy of doses are not guaranteed. This finding supports and contributes to previous research into how family caregivers learn to provide care in Canada which indicated that family caregivers provide care by experimenting (Stajduhar et al., 2013). My study highlights both issues that arise in resource-poor contexts such as access to pain medication, affordability of drugs, assessment, and monitoring of pain and the stress this can place on families who have to manage the patients' pain, pay for drugs or witness loved ones suffering.

7.4.3 Cultural responses to Prostate cancer stigma and Masculinity

This study explored the stigma that is associated with living with prostate cancer in a culturally conscious setting and how prostate cancer affects men's role within the family, which raises awareness of the need to understand culturally specific contexts. The stigma of prostate cancer is multi-layered: the stigma of the been diagnosed with prostate, the stigma associated with its symptoms, courtesy stigma, and the stigma of

some treatment choices for prostate cancer. This requires multiple layers of managing stigma, and this is of particular importance since many writings about stigma have not addressed this. Prostate cancer stigma may have an impact on health and help-seeking behaviour because some men and their families do not want to 'wash their dirty linen in public'. As noted earlier in the first section of Chapter 6, PWAPC and their families are not utilising some ways of resisting stigma such as speaking up and challenging stigma openly through political action and medicalising their situation to evoke sympathy (Scrambler 1986). As a result, stigma may hinder the option to fundraise for treatment if the patient and family are unable to fund for treatment.

The data also support other seminal work that highlights how chronic illness such as prostate cancer can affect men's masculine identities. As explained in chapter 6, the traditional belief that men must be resilient, strong, fearless, and protector/provider for their families as well as being able to conceal vulnerability and emotions and may not need much care and receipt of social support systems are unsubstantiated. This finding is consistent with those of other studies that suggest that men are not keen to seek help or to live a healthy lifestyle (Robertson et al., 2016, Connell, 2016, Connell and Messerschmidt, 2005). However, the debate about help-seeking seems diverse in the literature because it is reported elsewhere that men, unlike women, are reluctant to find support from healthcare professionals (Addis and Mahalik, 2003).

The understanding of these 'cultural codes of masculinity' (Broom, 2004) is vital for providing quality and culturally-sensitive public health education to men with prostate cancer (Ali et al., 2017) as well as in reinforcing existing social support systems (Imm et al., 2017). The implication of this is that healthcare professionals should actively look out for and present themselves in a manner that men will share whatever problems they might have.

My study further indicates the relevance of independence and self-control as important masculinised standards, as reported in a previous study (Gough and Conner, 2010) and as discussed in section 6.3. It is, therefore, imperative for clinicians to organise the care for men around the principles of independence and self-control as far as practicable. Again, my study like other studies such as (Robertson, 2007) and (Oliffe

and Mróz, 2005) challenge the impression that men do not care about their health and are reserved in seeking health. So far, this section has focused on the discussion of the three main themes in this thesis: care in a resource-poor setting, family caregiving, and the cultural response to prostate cancer. The following section will discuss the contributions this thesis makes to theory, nursing care, policy and the impact of this study in providing prostate cancer awareness.

7.5 Significant contribution made by this thesis

The experiences of receiving and or giving care to patients with advanced prostate cancer in resource-limited countries is an understudied area despite the increasing number of cancer cases in recent times and those who require home-based care. This study is one of the very few that has explored home-based informal palliative caregiving and from the perspective of men, their families, and health care professionals. As far as I know, this is the first palliative care research solely on prostate and home-based palliative care with the additional advantage of blending the perspectives of men, their families, and health care professionals. Consequently, this study contributes theoretically and methodologically to the field of prostate cancer and home-based care. It also contributes to my understanding as a nurse and a researcher, and both experiences will enhance my teaching as an academic. These contributions have been elaborated under the headings below.

7.5.1 Theoretical contribution

This study makes theoretical contributions in the area of family caregiving, stigma, and masculinity. The study demonstrates the relevance of patriarchal norms to the social wellbeing of men. In addition, it throws more light on how breaches to masculinity are affected by male-specific chronic disease such as prostate cancer. Four main areas of masculinity are affected by prostate cancer. These include the physical changes resulting from treatment that lead to altered body image and self-identity, the loss or reduced sexual potency that is seen by men as ‘not been man enough’ or not a

complete man. Additionally, PWAPC reported the loss of social status and patriarchal norms, and emotional problems resulting from the anxiety of dealing with the complex issues and loss of economic power.

This study contributes to the ongoing debates on masculinity (masculinities) by earlier authors (Robertson et al., 2016, Carmichael et al., 2008, Connell, 1995, Connell et al., 2004, Wedgwood, 2009, Demetriou, 2001 , Robertson, 2007, Robertson et al., 2010). Robertson et al.'s (2010) work regarding health and ill-health notes and challenges the notion that men are 'disconnected from their bodies' emotionally. In his previous work that contributes to understanding about Watson's (2000) 'male body schema,' he indicates that the male body is 'material and representational' (Robertson, 2006). The material and representational elements, he explains, are inseparable and influences men's health behaviours and their health. My study further adds to knowledge by concluding that male-specific cancer has profound implications for men's masculine identities. Apart from the changes in the body image and self-identity resulting from treatment side effects, it also simultaneously devalue the socio-cultural statuses of men. This results in continuous emotional distress that is further compounded by simultaneously dealing with shifts in a masculine identity, e.g., diminished sexual potency — cumulative levels that impact on the quality of their lives – and those of their family members too. This shifts in a masculine identity support the work of Connell (2016) who indicates that the masculinity symbolises a configuration of practice that men move within and between in a particular context.

The perspectives from the caregivers also suggest that 'masculine' act as indicated in the above studies might also contribute to the late presentation of symptoms, unhealthy practices such as using unprescribed drugs or unapproved herbal drugs to enhance sexual potency. This contributes to the literature about how men are reticence about their health issues because of the general notion that men must be strong and stoical (Hinchliff and Gott, 2011, Medina-Perucha et al., 2017, E. et al., 2003, Addis and Mahalik, 2003).

Again, such practices have indirect negative health implication for others such as family caregivers, and policy must take this into account (Evans et al., 2011). This call

is significant because men are usually seen to be strong and thus, help/health-seeking are regarded as 'feminine.' Again, health seeking may be affected because men are in a state of stress to 'live up to conventional masculine ideals' (Gough and Robertson, 2017). As explained earlier, Goffman (1963) draws our attention to stigma as the distinctive gap that exists between a person's real identity and societal expectation/ conventional masculine ideals. No evidence in the literature has attempted to link masculinity and stigma in prostate cancer patients, and my study has tried to do just that.

This study also identifies different layers of stigma for men with prostate cancer. The key point here is that stigma of prostate cancer is relevant – the cultural context is relevant (more stigma experienced in Ghana more than would be the case in, for example, the UK). My study has uncovered layers of stigma related not only to this culturally specific context of having prostate cancer but further shame due to managing the symptoms – some of which are harder to manage in a resource-poor setting, e.g., due to lack of supplies to manage incontinence and offensive smell. A unique kind of stigma, the stigma of prostate cancer symptoms, is theorised and this stigma is independent of people's knowledge of one's disease. This, therefore, extends and add to the awareness about stigma previously described in the literature (Graham, 2009, Scambler and Hopkins, 1986, Jacoby, 1994, Goffman, 1963). While earlier study (Riessman, 2000) indicates that participants do not always accept stigma tag but resist it, this study notes that prostate cancer stigma is opposed overtly by a few of the participants.

Furthermore, this study also adds to the knowledge about stigma by indicating that one person could experience both enacted and felt stigma (detailed at 6.2). So it is paramount for healthcare professionals to explore men's view about prostate cancer and address any enacted stigma as well as addressing the felt stigma perpetuated by others and those on family caregivers (courtesy stigma); to reduce suicide and suicidal tendencies (Andoh-Arthur et al., 2018, Mitchell and Praetorius, 2015).

This study contributes to the discussed body of knowledge and this ensure that the provision of palliative care is underpinned by evidence. To the best of my knowledge this is a pioneering repeat interview qualitative study in Ghana and sub-Saharan Africa that has utilised multiple perspectives (patients, caregivers, HCP) and various data collection methods (individual interviews, joint interviews, and focus group) to gain a holistic view about living with and or caring for advanced prostate cancer.

The study highlights the input from family caregivers. For example, the perspectives of wives on their husbands' loss of sexual function. It is unusual to have such a perspective alongside the views of the men. The finding here contributes to Grondhuis Palacios et al.'s (2018) study by addressing the little attention of literature on the impact of prostate cancer on wives sexual lives. Also, I have discussed the inadequacy of pain management, and it is worthwhile to highlight that, too, given that patients and caregivers make decisions about pain relief. This research extends our knowledge of pain management especially and medicines in general at home as done by earlier researchers (Wilson et al., 2018, Merriman and Harding, 2010). Having discussed how this study contributes to a body of knowledge, the next section will consider how this knowledge could impact on practice.

7.5.2 The implication for nursing practice/Social care

Nursing practice is influenced by quality research and teaching. My aim of undertaking this research was to provide useful insights to clinicians and experiential teaching about the field of palliative care and nursing care (Polit and Beck, 2010). The findings from this study about family-caregiving care in resource-poor context and the effects of masculinity and stigma on the lives of families were not only emotive but also challenging. The investigation also revealed some coping strategies and supportive, informal networks that help with the care at home despite the complexities of the challenges thereof. As a result, these understanding and providing improving supports for such groups are essential (Pesut et al., 2015, Casey et al., 2017, Gott et al., 2015, Grande et al., 2009, Wilson et al., 2018, Sinfield et al., 2012c, Stajduhar et al., 2013, Pollock, 2015, Angelo and Egan, 2015).

Due to the pivotal role that caregivers and the family in general play in the home care of their loved ones, it might be laudable to have these caregivers given some basic training about best care practices including managing pain, and they should be supported with the necessary logistics to enhance the care they provide. The government of Ghana could take the lead role, and other charitable organisations could play essential roles in supporting the government.

Highlighted in this study is the peculiarity of advanced prostate cancer due to the complex and the dynamic nature it been ingrained with socio-cultural beliefs. Healthcare professionals can meet the needs of men living with prostate cancer and their caregivers by considering these findings. For example, the families' appreciation of having an individual visit them, i.e., me talking to them about their experiences and the additional benefit for them knowing me as a nurse could mean their willingness for professional support.

This allowed families to share very pertinent issues and secrets (for example sexually related issues) and to allow me to see at first-hand how the families go about the care at home.

We must ensure and be sensitive when talking about prostate cancer on radios, televisions, and online in order not to fuel the perceptions of participants who believed some comments on these media are stigmatising. Also, some proactive educational awareness raising to dispel myths, which stigmatise PWAPC, is recommended.

These experiences may influence and challenge both current and future care for patients receiving care at home.

To achieve this nursing/ social care, this study recommends the need to provide support for people who may require practical assistance in caring for a relative at home while involving the family as reported elsewhere (Allen et al., 2007). There is the need to provide satellite palliative care services to make such services accessible and readily available close to the patients and their caregivers.

Another means to provide supportive care measures is through the use of telecare initiatives (Scotté, 2012) especially in resource-poor settings. Numerous studies highlight the benefits and cost-effectiveness of telecare, especially where geographical access is an issue. This might be very useful in Ghana where there are significant geographical access and limited resources for care at the Hospital.

Telecare combines a variety of technological devices, including mobile phones, laptop computers, cameras, and remote monitors for the monitoring, assessment and evaluating patient's care away from the clinical settings (Johnston, 2014). Telecare has proved to be useful in home palliative care (Tieman et al., 2016) and can be used in a range of settings including homes (Kidd et al., 2010) as a means of follow-up (Cox and Wilson, 2003).

Telecare is useful for out-of-hours supports and discussions through telephone or video calls between family caregivers and HCPs. For example, Eno expressed her frustration of not knowing what to do out-of-hours when her husband's condition deteriorated. Some authors indicate that telecare is useful in supporting the management of palliative patients in symptom management at home (Kidd et al., 2010, Roberts et al., 2007, Celler et al., 1999).

The use of telephone or mobile device could be helpful in proving information on managing symptoms at home as done in other countries (Richards et al., 2018, Schildmeijer et al., 2019). For example, the use of mobile apps in managing prostate cancer symptom has been reported in Sweden (Langius-Eklöf et al., 2017). Although Telecare in palliative care has proved to reduce caregiver burden and anxiety (Zheng et al., 2016), in resource-poor contexts, where there are network coverage problems, such telecare could benefit from non-synchronous online communication (van Gurp et al., 2015). This should be taken into consideration in Ghana especially in parts of the country where internet connectivity is unstable.

7.5.3 Policy implication

Health promotion and interventions contribute to men's health outcome and wellbeing but need a conscious political well to ensure that the inequality and inequitable distribution of services do not disadvantage the less social and economic groups, such as in global south countries (Robertson and Baker, 2016). According to William, Robertson, and Hewison (2009), the role of political commitment in the implementation of policies that influence men's social and economic lives cannot be overlooked. Currently, in Ghana, there is no healthcare policy that supports family caregivers who provide home care and its accompanying high cost. The issue of burden of care and the high cost of care is well documented in the literature (Gott et al., 2015). In westernised countries where policies of mandated funding exist to support home caregiving, there are reported remarkable relief to families and the health outcomes of the patients (Knaul et al., 2017), and a specific mention could be made of the UK (Harrop et al., 2014) and the Netherlands (De Graaff and Francke, 2003). WHO Model for Palliative care recommends that there should be a policy on palliative care in countries, services incorporate palliative care and such services including drugs are accessible (Stjernswärd et al., 2007). For instance, in Sweden, there is a prostate cancer pathway for managing care as a way to improve patients experience (Schildmeijer et al., 2019).

In light of this study, it is important that the health and social care of these men and their families who face challenges are captured in legal policy. Such policy will cover the practical or technical support for the government to cater for the health and social care needs of PWAPC. To give the political commitment (Robertson and Hewison, 2009), the Ghana Ministry of Health (MoH), the Ministry of Gender and Social Protection, the Social welfare Department could collaborate and involve the activities of Non-governmental organisations (NGOs) interested in cancer prevention and management.

World Health Assembly resolution WHA 67.19 (WHO, 2014) endorsed member countries to incorporate palliative care into the mainstream health system with an emphasis on the community/home-based care through primary healthcare.

The specific areas that might be prioritised, based on the findings of this study, include:

- Addressing socio-economic issues that hinder the management of prostate cancer such as the cost of treatment, access to care and information.
- Creating opportunities for and encouraging men to divulge their emotions to improve help-seeking and health-seeking behaviour
- Identifying sources of difficulties for patients and their caregivers then plan ways of ensuring that their quality of life is enhanced.
- To develop information resources to assist patients and family in home care for PWAPC.
- Efforts to ensure the provision of satellites palliative services to patients requiring practical support for PWAPC.

More importantly, given the current trend of the number of people living with prostate cancer in particular and other cancers in general, the Nursing and Midwifery Council of Ghana could include palliative care as part of the basic requirement training for all nurses, just as it is done in the UK.

7.5.4 Future research

The need to support people living with advanced prostate cancer in resource-limited setting or with a little resource for care are documented (Abel et al., 2013). Considering the complex and multifaceted nature of palliative care for advanced prostate cancer, views about other disciplines that were not captured (such as faith leaders, the views of traditional healers, and NGOs) could be explored in other studies. Further research about a palliative care model within the context of Ghana that takes into consideration the socio-cultural norms, the unique needs, and the collective strengths of PWAPC and their significant others would be worth exploring. Just in line with the healthcare system in Ghana (see section 1.2.2), this proposed palliative care might be organised into primary (family and community), secondary (healthcare professionals), and tertiary (palliative care experts) palliative care services. The experts are to support and provide

technical help to the healthcare professionals (HCP), who will do the same for the community support services and family caregivers. This model will also help to bridge the gap (as discussed at 4.5) between informal family caregiving and the professional palliative care.

Again, research into advanced care planning that takes into accounts of the needs of men living with advanced prostate cancer (Seymour et al., 2010) appears relevant. Prostate cancer has an overall effect on the family particularly dependent children and the sensitivities around its discussion is fuelled by some socio-cultural beliefs and stigma. Further research that explores the views of dependent children of men living with prostate cancer will be worthy. Additional research may explore in detail other sources of support, for example, faith-based organisations, the media, and NGOs-available to men living with advanced prostate cancer.

Bering in mind the general belief in and acceptability of alternative health treatment, there is a need for further study on why men with prostate cancer use alternative medicines. Furthermore, a deeper exploration of how men with prostate cancer and the families draw on faith in dealing with prostate cancer trajectory appears necessary.

7.5.5 Impact of this study / Dissemination of Research Findings

Based on the findings of this study and my immense interest developed for this field of inquiry, I established a Non-Governmental Organisation called Prostate Cancer Support Heritage (ProCaSH)[23] that seeks to identify and support the needs of men with prostate cancer and their families to live a comfortable life. Pictures of some activities are shown below.

[23] ProCaSH is in Ghana and it is mainly concerned with the health and social welfare of patients with prostate cancer as well as their family caregivers. It also disseminate information to health workers.





To aid the dissemination of findings of this study, some works from this research have been presented during seminars and conferences in Ghana, UK and, internationally. Again, a couple of abstracts publications has been done (*see page iv*), and in due course, full articles will be published in peer-reviewed journals both professionals and academic.

Increasing awareness of prostate cancer is critical, and this should involve and incorporate the activities that men prefer. The outreach should target areas where men work or where men are likely to assemble. Again, social media websites such as Facebook, and LinkedIn, has been created to disseminate information and make links with others to promote the course of prostate cancer management. Likewise, while raising awareness, we could solicit for funds to support the care of PWAPC.

7.6 The study's strengths

This study involved men with advanced cancer, and some were near the end of life,[24] this was sometimes emotionally challenging times both for them and me, as they shared their experiences (Seymour et al., 2005). Been the first study in Ghana in this particular area and due to limited information, the study recruited a wide range of participants- PWAPC, family caregivers (children, spouses, mothers, and siblings) and

[24] Patients who are in their last 12 months of life (of course known retrospectively). In this study, 4 patients died before their next scheduled interview appointment. May their souls rest in peace

palliative care professionals. The aim was to give a more in-depth and holistic understanding of the experience of home-based care. The information from diverse perspectives was useful in contextualising the findings of the study. Again, using men from diverse geographical backgrounds and men of various social classes adds to the study's strength. This might ensure transferability in other location with similar socio-cultural characteristics as the study participants or resource-poor settings.

Furthermore, the introspective accounts of the participants ensured that the experiences captured were vivid and fresh in memory (Polit and Beck, 2013). The study also employed variations of the interviewing method- individual interviews, joint/dyad interviews (men and their caregivers), and focus groups (for the HCP) depending on its appropriateness. The use of individual interview approach allowed flexibility where it was practically impossible to have the patient and the caregivers to be interviewed together whereas the purpose of focus group discussion and dyad interviews proved to be highly efficient in triggering discussions and acted as prompts for others to expand on (Morgan et al., 2013, Hennink, 2007, Ho, 2006). This flexibility of study design adopted is a key benefit in qualitative research studies (Fossey et al., 2002b, Ritchie et al., 2013, Miles et al., 2013).

Moreover, the repeat nature of the study (4–12 weeks intervals) offered the researcher an opportunity to follow-up emerging trends in the data, and explore further on issues that were unclear during the previous interview (Walshe et al., 2017).

7.7 Limitations

It must also be noted that while dyad and focus group are useful in providing complementary information, those approaches could limit the discussion of participants (Murray et al., 2009).

Access to some participants was problematic due to far distances they lived. For example, some participants lived about 10 hours' drive away from the recruitment centre. Consequently, I had to travel long miles to interview some participants and in

some cases, participants were excluded from the study (from recruitment) due to practical challenges in reaching out to them[25]. It was fantastic, however, to have the members of the palliative care team help recruit them when patients came for review or appointment. It means that patients who for some reasons were not reporting to the hospital during the time of the study were more likely not to be recruited.

Another perceived limitation of this study is the recruitment of patients from only one of the Palliative care centre. As a result, conclusions made may not be an accurate representation of PWAPC. However, the main aim of this study was not meant to generalise but instead provide a context-specific and rich understanding of the experiences of giving and receiving care in the home setting. Efforts have been made to ensure the trustworthiness of the findings (Polit and Beck, 2013, Guba and Lincoln, 2005). Notwithstanding these limitations, I do not think these affect the conclusions made.

7.8 Conclusion

The literature demonstrates a dearth of information about informal caregiving at home for men with prostate cancer in a non-westernised context. The findings of this study reveal untold stories about home caregiving that is complex, challenging and at the same time supportive due to existing family social support systems and informal networks. The challenges are mainly due to undertaking care role with little or no prior knowledge about how to care, the disruption of the families due to, for example, reduced income from a breadwinner, stigma of being associated with someone with prostate cancer and the breaches in masculinity resulting in changes in body image and sexual potency.

Being a qualitative study, with mixed data sources, one of its greatest strengths is the range of issues uncovered that impact on the experiences of these men and their caregivers and the contextual nature of these. These issues range from the

[25] Those who for some reasons could not also come to the hospital within the study period to be interviewed.

interpersonal dynamics between these men and their caregivers and to structural concerns relating to caregiving in a resource-limited context.

The development of health and social policy that takes into account the unique challenges of these families appears not only timely but also very relevant. Such a legal policy is key to families because as their resources deplete and they become 'tired' of helping, patients will have no other option that will ensure their continued existence and good quality life. There is a strong advocate for the inclusion of Prostate Cancer in the National Health Insurance Scheme and other support for patients and their family caregivers. Again, developing a training programme of care for this group by health regulatory bodies such as the Nursing and Midwifery Council of Ghana is recommended. Such training must emphasise mainly on how to assist men and their families address their physical, social, sexual, and psychological needs. There is an urgent need for other systems that support patients in rural communities, for example, the use of telecare or phone line where PWAPC and their family caregivers could speak to nurses and other HCPs for advice and support as used elsewhere (Cox and Wilson, 2003, Stern et al., 2012, Kidd et al., 2010).

Additionally, there are evident needs for support in the areas of practical and emotional care. Regardless of these problems, the informal social network offers an enormous amount of support for the patients and their caregivers that need to be strengthened. With the supports to reduce stigmas, this could potentially open up other resources for care such as neighbours. The findings of this study are significant because home-based care has the potential to reduce the number of visits that patients will make to the hospitals, reduce the cost for families, and lead to improved fulfilled life even in the midst of some difficult challenges.

This study confirms earlier works that challenge the notion that men are reticence about their health issues. We must, therefore, avoid the basic notion that homogenise all men as the same and begin to look at how issues of men's health changes within the same person and among men. The need for culturally appropriate, family-centered

care by knowledgeable, culturally sensitive and skilled healthcare professionals are important.

Prostate cancer causes disruption in the lives of men and their families as they transverse the prostate cancer journey, this study is pioneering in looking at masculinity and stigma together in men with prostate cancer. There is a need for social and health policies to support palliative care of PWAPC at home. Increasing awareness about prostate cancer is critical and provision of ‘how to do’ health education packs to support families. Ghanaians have the professional, legal and moral duty to ensure that men with prostate cancer and their caregivers live even improved and more dignified life.

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9 Appendices

Appendix A: Palliative Care Centres in Ghana



Appendix B: Keywords used in the systematic search

No	Searches
1	exp Prostatic Neoplasms/
2	(Prostate adj2 (cancer* or neoplasm*)).mp.
3	1 or 2
4	exp Home Care Services/
5	exp Home Nursing/
6	exp Caregivers/
7	((home adj2 (care or caring or nurs* or based or support*)) or (home* or domicil* or non-professional*) adj3 (care* or caring* or nurs* or support*) or (family adj2 (care or caring or nurs* or based or support*)) or (community adj2 (care or caring or nurs* or based or support*)) or (homecare or caregiv* or care giv*)).mp.
8	4 or 5 or 6 or 7
9	3 and 8
10	experienc* or understand* or view* or perspect* or attitude* or percept* or perceiv* or feel* or opinion* or idea* or thought* or think* or valu* or evalu* or approach* or personal* or respon* or belie* or emotion*).mp.
11	(palliativ* or "end of life" or eol or advanced*).mp.
12	10 or 11
13	9 and 12

Appendix C: Main Themes from Thematic Analysis of literature

KEY THEMES			Care/Caregiving					Enablers/ Barriers to care				Outcomes of care	
No.	**Author**	**Country**	**Overburden/stress**	**How to care**	**Information needs**	**Medication/ side effects**	**Uncertainty**	**Financial/logistic needs**	**Faith and Hope**	**Support from others**	**Coping and adapting**	**Giving up/ Isolation**	**Fulfilling**
1	Angelo et al. (2015)	NEW ZEALAND	X		X	X			X	X			X
2	Bee et al (2009)	UK	X	X	X					X			
3	Bessa, et al (2012)	TOGO	X					X	X	X	X	X	X
4	Ervik & Kenneth (2012)	NORWAY	X		X		X				X		
5	Funk, et al. (2015)	CANADA		X	X		X						
6	Funk, et al (2010)	CANADA	X	X			X						X
7	Hamilto & Sandelowski (2004)	USA	X	X	X	X							
8	Jones et al. (2011)	USA						X	X	X			
9	Krumwiede & Krumwiede (2012)	USA	X		X		X			X	X		
10	Levy & Cartwright (2015)	UK					X		X	X	X	X	
11	Maliski et (2010)	USA							X	X			
12	Paterson, et al (2015)	UK	X	X	X	X		X	X	X			
13	Payne et al. (2014)	UK	X					X		X			X
14	Seal, K., et al. (2015)	UK	X	X						X			
15	Sinfield, et al (2012)	UK	X	X	X		X			X			
16	Stajduhar et al. (2013)	CANADA		X	X		X		X	X	X		
17	Tanner et al. (2011)	USA	X								X	X	
18	Totman, et al. (2015)	UK	X				X		X		X	X	X
19	Ventura et al (2014)	AUSTRALIA	X	X	X				X			X	
20	Wu et al. (2015)	USA	X			X				X	X		

Appendix D: Permission Department of Surgery, KATH

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY, KUMASI
COLLEGE OF HEALTH SCIENCES
School of Medical Sciences
DEPARTMENT OF SURGERY

5th May, 2016

NCARE (Nottingham Centre for Advancement of Studies into Supportive, Palliative and End of Care)
School of Health Sciences
Queens Medical Centre
Nottingham, UK
NG7 2HA

Dear Sir,

RE: REQUEST FOR PERMISSION TO CONDUCT A STUDY

In response to your letter dated 25th April 2016, requesting for permission to conduct a study on "Exploring home-based supportive and palliative care for patients with advanced-stage prostate cancer in a resource-limited Sub-Saharan African country" in the Directorate of Surgery, I am by this letter communicating to you the acceptance and subsequent grating you the permission to conduct the said study in the Directorate of Surgery.

You are required to strictly adhere to the conditions governing clinical investigations as per the Committee on Human Research, Publication and Ethics (CHRPE) of the Kwame Nkrumah University of Science and Technology, Kumasi.

Prior to the commencement of the study, you are again required to submit a copy of your approval letter from the CHRPE, and any other Institutional Review Board (IRB) to the Department of Surgery, KATH.

Wishing you a successful in your clinical investigation.

Yours faithfully,

DR. CHRISTIAN KOFI GYASI-SARPONG
HEAD, DEPARTMENT OF SURGERY

Private Mail Bag, University Post Office, Kumasi, Ghana. Phone: 233-03220-22307. Fax 233-3220-22307.
E-Mail: surgerysmskath@gmail.com Website: www.knust.edu.gh

Appendix E: Permission Oncology Department, KATH

KOMFO ANOKYE
TEACHING HOSPITAL

P. O. Box 1934
KUMASI - GHANA
Tel: +233 - 3220 - 22301- 4
Fax: +233 - 3220 - 24654/24621
Website: www.kathhsp.org

Our Ref. No:.....

Your Ref. No:.....

KATH/ONC/11/16/001/RS

HEAD OF DIRECTORATE
ONCOLOGY DIRECTORATE
KATH/ KUMASI

24TH NOVEMBER, 2016

MR. YAKUBU SALIFU
UNIVERSITY OF NOTTINGHAM
DEPARTMENT OF HEALTH AND LIFE SCIENCES
NOTTINGHAM.

Dear Yakubu,

PERMISSION TO CONDUCT RESEARCH ON"EXPOLRING HOME –BASED SUPPORTIVE AND PALLIATIVE CARE FOR PATIENTS WITH ADVANCED – STAGE PROSTATE CANCER IN A RESOURSE LIMITED SUB-SAHARAN AFRICAN COUNTRY This is to confirm that the Oncology Directorate has given approval for you to conduct a clinical research on "**Exploring home –based supportive and palliative care patients with advanced – stage prostate cancer in a resource limited sub-Saharan African Country**" at Oncology Directorate, having first gone through the Study Design.

Sincerely,

DR. EMMANUEL AMANKWA – FREMPONG PhD
CLINICAL ONCOLOGIST

1

A Centre of Excellence

Appendix F: Ethics Approval from FMSH, UoN.

The University of Nottingham

Direct line/e-mail
+44 (0) 115 8232561
Louise.Sabir@nottingham.ac.uk

28th September 2016

Faculty of Medicine and Health Sciences

Research Ethics Committee
C/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

Yakubu Salifu
PhD Student, Nursing Studies
c/o Dr Kathyrn Almack
Principal Research Fellow
Room 58a, B Floor
Nottingham Centre for the Advancement of Research into Supportive Palliative & End of Life Care (NCARE).
School of Health Sciences
QMC Campus
Nottingham University Hospitals
NG7 2UH

Dear Yakubu

Ethics Reference No: F12092016 – please always quote
Study Title: Exploring home-based supportive and palliative care for patients with advanced-stage prostate cancer in a resource-limited sub-saharan African country (Ghana)
Chief Investigator/Supervisors: Dr Kathyrn Almack, Principal Research Fellow, Dr Glenys Caswell Senior Research Fellow, Nottingham Centre for the Advancement of Research into Supportive Palliative and End of Life Care (NCARE).
Lead Investigators/student: Yakubu Salifu, PhD Student, NCARE (Nurse/Lecturer in Ghana)
Type of Study: PhD, Interviews/focus group, qualitative, overseas: Ghana
Proposed Start Date: 1/10/2016 **Proposed End Date:** 30/09/2017 12 mths
No of Subjects: 50 **Age:** 18+ years
School: Health Sciences

Thank you for submitting the above application which was considered by the Committee at its meeting on 12th September 2016 and the following documents were received:

Home-based palliative care for advanced prostate cancer patients Final Version 1.0, 29/08/2016:

- FMHS REC Application Form
- Protocol
- Favourable response from Head of Study Site, Department of Surgery Kwame Nkrumah University of Science and Technology (KATH), Kumasi, Ghana ref no: SMS/DS.KATH/76 dated 4th May 2016
- Participant Information Sheet: Patients
- Participant Information Sheet: Family Caregivers
- Participant Information Sheet: Health Care Professionals
- Interview Guide: In-depth Interview- patients with prostate cancer
- Interview Guide: In-depth Interview- Family Caregivers
- Focus Group Discussion- members of Palliative Care Team
- Consent Form for Patients
- Consent Form for Family Caregivers
- Consent Form for Healthcare Professionals

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

The University of Nottingham

A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.

A favourable opinion is given on the understanding that the conditions set out below are followed:

1. You must follow the protocol agreed and inform the Committee of any changes using a notification of amendment form (please request a form).
2. You must notify the Chair of any serious or unexpected event.
3. This study is approved for the period of active recruitment requested. The Committee also provides a further 5 year approval for any necessary work to be performed on the study which may arise in the process of publication and peer review.
4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp Lamagdni

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix G: Certificate of registration

KOMFO ANOKYE TEACHING HOSPITAL

RESEARCH AND DEVELOPMENT UNIT (R & D)

CERTIFICATE OF REGISTRATION

REG. NO RD/CR16/247

This is to certify that

Prof/Dr/Mrs/Mr/Ms. *Salifu Yakubu*

has registered his/her proposed study titled. *Exploring home-based Supportive and Palliative Care for advanced-stage Prostate Cancer Patients from Patients' and Caregivers Perspective: A Patient-Centered Case Study in Ghana*

.....with the Research and Development Unit.

Date. *9th September, 2016*

Name of issuing officer *Ms. Juliet Ampomah Frimpong*

Signature .....

K/16/0072625

Receipt No

***This certificate does not constitute ethical clearance for the conduct of the study but proof of registration of study with KATH. Ethical clearance from the Committee of Human Research Publications and Ethics (CHRPE) is required to conduct the study*

Appendix H: Ethics Approval from KNUST, Ghana

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY
COLLEGE OF HEALTH SCIENCES
SCHOOL OF MEDICAL SCIENCES / KOMFO ANOKYE TEACHING HOSPITAL
COMMITTEE ON HUMAN RESEARCH, PUBLICATION AND ETHICS

Our Ref: CHRPE/AP/496/16

25th November, 2016.

Mr. Yakubu Salifu
C/o Abubakar Salifu
Post Office Box 1
Sekyere South District Assembly
AGONA-ASHANTI

Dear Sir,

LETTER OF APPROVAL

Protocol Title:	*"Exploring Home-Based Supportive and Palliative Care for Patients with Advanced-Stage Prostate Cancer in a Resource-Limited Sub-Saharan African Country (Ghana)."*
Proposed site:	*Oncology and Urology Units, Komfo Anokye Teaching Hospital.*
Sponsor:	**Principal Investigator.**

Your submission to the Committee on Human Research, Publications and Ethics on the above named protocol refers.

The Committee reviewed the following documents:

- A notification letter of 9th September, 2016 from the Komfo Anokye Teaching Hospital. (study site) indicating approval for the conduct of the study in the Hospital.
- A Completd CHRPE Application Form.
- Participant Information Leaflet and Consent Form.
- Research Protocol.
- Interview Guide.

The Committee has considered the ethical merit of your submission and approved the protocol. The approval is for a fixed period of one year, beginning 25th November, 2016 to 24th November, 2017 renewable thereafter. The Committee may however, suspend or withdraw ethical approval at any time if your study is found to contravene the approved protocol.

Data gathered for the study should be used for the approved purposes only. Permission should be sought from the Committee if any amendment to the protocol or use, other than submitted, is made of your research data.

The Committee should be notified of the actual start date of the project and would expect a report on your study, annually or at the close of the project, whichever one comes first. It should also be informed of any publication arising from the study.

Thank you Sir, for your application.

Room 7 Block J, School of Medical Sciences, KNUST, University Post Office, Kumasi, Ghana
Phone: +233 3220 63248 Mobile: +233 20 5453785 Email: chrpe.knust.kath@gmail.com / chrpe@knust.edu.gh

Yours faithfully,



Osomfuor Prof. Sir J. W. Acheampong MD, FWACP
Chairman

Appendix I: Participant information sheet



Home-based care for patients with advanced prostate cancer

Participant Information Sheet

This study aims at exploring experiences of care for patients with prostate cancer in Ghana. You are invited to participate in this study. To help you make a decision whether or not to participate, this sheet explains why the research is being done, and what it would involve for you. You may as well talk to others about it before deciding to take part of the study. Please take the time to read the sheet and contact me if you need further information.

What is the purpose of the study?

I am conducting a study to find out from patients with advanced prostate cancer and their caregivers what their experience is and how they navigate through the care experience at home. This is important to find out what challenges might exist and how patients and caregivers have been coping so that effective measures could be adopted to improve the quality of care and life.

Why have I been invited?

You have been invited because you are a patient diagnosed with advanced prostate cancer and receiving care at home/ caregiver of such patient. The staffs from the palliative care team have identified you as being a suitable participant for the study.

Do I have to take part?

It is up to you to decide whether to take part in the study. If you do wish to take part in the study, you will be given this information sheet to keep and asked to sign or thumbprint a consent form. If you do decide to take part, you are still free to withdraw at any time, and without giving a reason. This will not affect you in any way.

What will happen to me if I take part?

You will be expected to share your personal experience of living with/caring for prostate cancer at home, challenges encountered, coping strategies used, and what you think could be done differently for improved care. The discussion will be like an everyday conversation that will last for 60-90 minutes. You may also be contacted later for about 15 minutes for some clarification of the issues discussed.

I would also like to obtain background information such as your age, to help to understand your story better but this will be anonymised.

If you are invited and agree to take part, the interview would be conducted face-to-face at your own home, a private room at Komfo Anokye Teaching or a preferred location of your choice. If you would like, a family member who is involved in your care may attend.

What are the possible disadvantages and risks of participating?

There are no particular risks associated with this study. We appreciate that taking part will require your time, and sharing such experience could be quite emotional. In case you get emotional, you will be counselled afterward or referred to a counsellor at the hospital.

What are the potential benefits of taking part?

There may be no direct benefit to you. However, the experience you share during the study may help organise and provide better service provided by the Ministry of Health and related agencies and could improve the quality of life of other patients and their families who have a similar condition in the future.

Will it cost me anything to take part?

It will not cost you anything to take part in the study. The researcher will bear the cost of posting letters using pre-paid envelopes. The interview will be conducted during your normal scheduled hospital visits or at your home.

Will my taking part in the study be kept confidential?

Yes. We will follow established ethical and legal practices, and all information about you will be handled confidentially. All information collected about you during the study will be kept strictly confidential. Any information about you will have your name and address removed, and a unique code will be used, so you cannot be identified. Only members of the research team and the authorised representatives of the study sponsor will have access to your personal data. Your personal details will not be provided to anyone else or used for any purpose other than our research. Only the research team will know this information.

Nevertheless, if any of the information you discussed bothers on public safety or public interest, or upon request for public order by the National Security by Data Protection Act, 2012 (Act, 843), we will then inform you of such development before divulging such information.

Will the research team have access to my medical details and social care records?

No. The researcher will only act through the staff at the hospital or Kumasi cancer registry that shall provide details such as date of birth, date of diagnosis, health insurance status, treatment type you are on such as chemotherapy or radiotherapy. This information will be treated with the confidentiality policy of KATH, and the Data Protection Act, 2012 (Act, 843).

What will happen if I do not want to carry on with the study?

Your participation is voluntary, and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw from the study, then the information collected cannot be erased, and this information may still be used in the project analysis. You will continue to receive treatment as normal from KATH or any other Preferred Primary-care Provider (PPP).

What if there is a problem?

If you have any concerns about the study, you are encouraged to speak to a member of the research team, and they will do their best to answer your questions. You can

contact any one of the researchers. Their contact details are given at the end of this document. If you remain unhappy and wish to complain as follows formally:
Komfo Anokye Teaching Hospital:
Email: info@kathhsp.org
Telephone: 03220 22301 – 3
Address: P.O. Box 1934, Kumasi, Ghana.

What will happen to the results of the research?

The results of the research will be published in scientific journals and patient newsletters. You will not be identified in any report or publication. Results will be made available at the researcher's website and will be communicated to stakeholders through both national and international conferences.

Who is organising and funding the research?

asThe research is being conducted as part of a doctoral research project at The University of Nottingham, and funded by Government of the Republic of Ghana through Ghana Education Trust Fund (GET Fund). Experienced researchers at Nottingham Centre for the Advancement of Research into Supportive, Palliative, and End of Life Care (NCARE), United Kingdom (UK) supervise the research.

Who has permitted the study to be carried out?

Independent Research Ethics Committee, to protect your safety, rights, wellbeing, and dignity, examines this research in the UK. This study has been reviewed and given a favourable opinion by Research Ethics Committee, UK and the Committee on Human Research, Publications, and Ethics (CHRPE), Kwame Nkrumah University of Science and Technology (KNUST), Ghana.

Further information and contact details for the study:

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Thank you for taking the time to read this information pack

Appendix J: Consent Form



Faculty of Medicine and Health Sciences

School of Nursing

Participant Identification Number…

CONSENT FORM

Title of Project: Exploring home-based supportive and palliative care for patients with Advanced-stage Prostate Cancer in a resource-limited sub-Saharan African country (Ghana)

Research Team:

Mr. Yakubu Salifu, Ph.D. student University of Nottingham, UK

Prof Kathryn Almack, University of Hertfordshire

Dr. Glenys Caswell, Senior Research Fellow, NCARE, UoN

Please write your initials in the boxes provided

1. I confirm that I have read the information sheet dated..... ……..for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that authorised individuals may look at relevant sections of my data collected during the study from the University of Nottingham, from regulatory authorities or from the Ministry of Health (Ghana) or its accredited representative, ☐

where it is relevant to my taking part in this research. I permit these individuals to have access to my records.

4. I understand that upon request as per Act 843 of the Data Protection Act 2012, this information may be made accessible to the appropriate authority under the Laws of Ghana. ☐

5. I agree to my family caregiver being informed of my participation in the study and agree with him/her to be interviewed. ☐

6. I understand that the information held and maintained by the Komfo Anokye Teaching Hospital (KATH) and the cancer registry may be used to help contact me or provide information about my health status. ☐

7. I consent to use of audio-taping, with possible use of verbatim quotation or use of disguise photographs ☐

8. I agree to take part in the above study. ☐

Name:……

Address: ……

Telephone number: … Signature: …….

Date: …….

I confirm that I have fully explained the purpose of the study and what it involved too. I have given the above named a copy of this form together with the information sheet.

Investigator's Signature:…… ……..

Date: ……

Investigators Name:……Study Volunteer Number: …….

Appendix K: Interview Guide

Introduction

I am pleased to have you talk to me about this research. My name is Yakubu Salifu, a Ph.D. Nursing student at the University of Nottingham. I want to seek your permission again to record the discussion to get details of what we are discussing. I may write down a few points during the discussion.

This discussion is confidential, and the recorded information will be kept securely. I wish to remind you again that you can discontinue the discussion process at any point if you wish not to continue. You may also press the stop button of the recorder if you do not like some part of the discussion to be recorded. You are entitled to hold the information you may not want to share without suffering any penalty.

Prof. Kathryn Almack and Dr. Glenys Caswell of the University of Nottingham supervise this research. Let me know if you have any burning question before we start the interview

Topics

a) In-depth Interview-patients with prostate cancer

Can you please walk me through your experience after the cancer diagnosis and living with this condition?

How do you manage the condition at home and whom are those involved in most of the care?

Could you please tell me how the care is done? What role do you play personally?

How do you get information about your condition and how it is managed?

How satisfied are you with the care at home?

Please tell me more about the resources and support that are available for the care. (Probe: Emotional, practical, financial, etc.)

Can you please share common challenges or barriers that are affecting the care at home?

How can care be improved in your own opinion?

b) In-depth Interview-Family caregivers of patients

Please tell me about yourself as the caregiver and how you became a caregiver

Can you walk me through how your day is like regarding the care you provide? Probe

How do you provide the care and how will you describe such experience?

(Probe: logistics for care, how and where they get it, etc.)

How do you navigate your way through the care and your personal life? Tell me more

Tell me a little more about some experience that helps with the care

How do others contribute to the care (family members, HCP, religious bodies, government, NGO, etc.) and what exactly do they do?

In every activity, there might be challenges one way or the other. How have you confronted some challenges regarding care?

Probe: How is the conflict, if any, arising from the care managed (between caregiver, patients, HCP and other family members?)

Are there any challenges (Probe: how to care, informational need, support, financial, professional, emotional, etc.)

Are there some approaches you think could be done to improve care (who? And what is expected)

c) Focus Group Discussion-members of Palliative Care Team

Can you please tell me how patients are treated here and the plans for their continuity of care at home?

Please tell me more about some of the experience of home care (from your point of view as care providers, and from what you might have gathered from patients and their caregivers

How can these problems be dealt with/ handled?

What are the strengths that can be relied on to improve care?

9.1 Appendix L: Case Narratives for the 23 PWAPC

9.1.1 Boat

Age	78
Key Caregivers	Brother (Sabi) and Brother's wife (Safia)
Main concerns	He quickly forgets things (according to caregivers), difficulty in walking, a suprapubic catheter[26] in place, pain at the lower abdomen and legs, numbness of the legs, frequent urination.
Interview type: IDI[27]	Interview 1: At home with Boat and Safia Interview 2: Home with Boat and Sabi, 8-weeks later
Palliative treatment	None
Work/Source of income	Unemployed/His support comes from his brother and nephews
Religion	Moslem

Mr. Boat has been disabled since his 30s and has never been married. Mr. Boat is entirely dependent on the family for food and shelter and medical care. He needs assistance for his care. He has a suprapubic catheter in place, and the site is infected with some pus. Some urine leaks through the catheter and sometimes through the accidental opening of the cork of the catheter. His room has a strong scent of urine, and his room is occasionally mobbed with an antiseptic/disinfectant lotion (Dettol).

The patient is worried that due to his incontinence and his weakness he cannot perform the five daily prayers as a Muslim. They are unable to afford the cost to perform a surgery to remove his testes (orchiectomy) and fee for chemotherapy that is approximately £1,000.00.

During the second interview, Boat was worried about his inability to walk and do personal care himself, he complained of sleeplessness and loneliness. The patient says he is not happy about this at all.

> *I keep wetting myself, and I cannot control it (urine). It makes my room smell, and that is why others don't come close most times. This saddens me because*

[26] A small incision into the lower abdomen where a catheter is inserted to drain urine. It is usually done when the urethra is blocked completely by, for example, growing cancer tissue.
[27] In-depth Interview (one on one)

I am becoming weaker and weaker as the day goes by. I am most of the time indoors and feel lonely. I feel sad, and I do not know how this will end.

During the second interview, Boat indicates his pain seem worse. Moreover, the caregivers seem overwhelmed with the care at home. Sabi narrated:

We did not receive any training in managing his problems. We were told to send him home and bring him when there are serious problems we can't handle. We are his doctor virtually here at home.

However, Sabi indicates that Boat can eat a bit more than before.

9.1.2 Kwaku

Age	57
Key Caregivers	Wife (Okonore)
Main concerns	Difficulty in urination, reduced sexual ability, swollen feet and abdomen, difficulty in breathing, losing weight
Interview type: IDI	Interview 1: At Hospital with his wife, Okonore Interview 2: At home with Kwaku and Okonore, 8-weeks later
Palliative treatment	Radiation and Chemotherapy
Work/Source of income	Auto-Mechanic
Religion	Christian

Kwaku has eight children; his eldest child is 37 years and youngest 12 years. He is concerned about the children's welfare, as he cannot work as previously. He lives about 60 kilometres from the hospital and has to go there daily for radiation therapy. For fear of becoming impotent, he refused a surgical operation to have his testes removed. He believes his disease is a big blow to his life.

This condition has indeed affected every aspect of my life; my work, marriage, and my parental responsibilities (Kwaku).

He believes he might have been cursed. As a result, he sometimes uses herbal drugs prepared by a native doctor, visits 'men of God' for healing miracles.

I don't think it's usual. I think this is 'duabo' (curse) so I sometimes seek prayers from men of God to fight the devil on my behalf.

Okonore, the wife, on both occasion highlights the emotional pain that the husband expresses despite all reassurance she gives him. Kwaku, according to the wife, appears to be worried about his physical appearance (hair loss, weight loss, and enlargement of his breast). The weight loss according to the wife has made the husband wear thick clothing to conceal the enlarge breast, and he (husband) feels uncomfortable on sunny days.

> *It is emotionally upsetting to see him this way, the urine problem, and all that. We have to let him wear more clothing so that he looks big to disguise the weight loss (Okonore).*

It was clear from Kwaku and his wife the problems that they face daily dealing with the cost of treatment and living. Therefore, the patient and the care caregiver expressed how their lives have changed for worse following the diagnosis of advanced prostate cancer.

9.1.3 Omar

Age	55
Key Caregivers	Brother (Issifu)
Main concerns	Difficulty in breathing, Dizziness, had a catheter in place. Inability to pay for his drugs
Interview type: IDI	Interview 1: At home, with Omar and Issifu Interview 2: At home Omar and Issifu, 9-weeks later
Palliative treatment	Chemotherapy
Work/Source of income	Trading/Farming
Religion	Moslem

Omar has been admitted twice within a month and has been admitted three times since the diagnosis. He is on chemotherapy. Omar has recently received three units of blood to treat anaemia. He was looking tired, and his speech was a bit slow. Omar had a urinary catheter that has been in place for more than two months. He complained of pains in the penis and foul-smelling discharge from the penis. He said he had no money to go to the hospital and he was feeling weak as well. He looked very weak and pale and was breathing fast. He told me he is usually sad and does not have the means to

pay for care at the hospital. He showed me prescriptions that he is yet to buy because the family has no money to buy drugs. He sleeps a lot due to his feeling of tiredness.

When Issifu, his brother, was interviewed, he told me that he helps with his care. However, Issifu told me that he thinks turning his brother in bed may make Omar feel discomfort.

> *'I am afraid of turning him and disturbing him might worsen his case. It is complicated how to handle him at home (Issifu).*

Issifu indicated that they sought for the services of a traditional herbal practitioner[28] and the condition seems not to improve. Therefore, they are looking up to God since all their hopes are running out. They are still wondering what might have caused the disease. On the second interview, Omar has managed to buy some of the drug (Haematinics and some painkillers) through the help of another family member. However, because the amount was not enough, he is yet to buy the chemotherapy drugs.

9.1.4 Daama

Age	54
Key Caregivers	Mother (Kyerewaa) and wife (Seiwaa)
Main concerns	Losing weight, emaciated, difficulty in breathing, dizziness had a catheter in place because of the difficulty in urination. Inability to pay for his drugs
Interview type: IDI	Interview 1: At home with Damaa and his mother, Kyerewaa The patient died five weeks later, and no follow-up interview conducted.
Palliative treatment	Chemotherapy and Hormone replacement
Work/Source of income	(Early retirement)/ Family support
Religion	Christian

Damaa has three children (22, 18 and 15 years) whom he described as 'very young.' He has been laid off from work, and he received compensation before his illness. The

[28] Such services are very cheap in comparison to standard medical treatment and they could seek such services on credit and pay later on.

cost of his treatment has affected his ability to support his children financially. His wife, Seiwaa, is a junior officer in civil service who works in a different town. She, therefore, takes care of her husband during the weekend while Damaa's mother, Kyerewaa, is responsible for the care during the weekdays. Daama knew he was terminally ill and was sad about this.

> *I am getting weak day in and day out, and that makes me wonder if that is the end of my life. It is tough having to lose all my independence in doing intimate and personal things. So when I cry, she (mother) also cries with me. We cry together most of the time.*

Aside from the emotional state during this interview, Damaa was particularly worried about his 'body'. He was worried about what people will think about his 'new look,' and he avoids people seeing him in that state.

> *People might think I lived 'unholy' life. Furthermore, looking at how I have grown very lean and become ugly, some people may think I have AIDs.*

While interviewing Damaa' mother, Kyerewaa, it was a rather an emotional one. Kyerewaa spoke about the burden of care she has to undertake and due to her old age (75 years) she gets tired easily. She noted that when her son is sad; it makes her cry.

> *I cry most of the time, and I can't stand it when he cries. I am afraid that he will die and leave me. I instead want him to bury me and not the other way round.*

9.1.5 Opoku

Age	77
Key Caregivers	Wife (Boadiwaa) and Son (Solo)
Main concerns	Backaches, difficulty in urination, pain, weakness, and dizziness. Others include reduced sexual ability, sores at the anus, and easily forgets things.
Interview type: IDI	Interview 1: At Home with his wife, Boadiwaa Interview 2: At home, seven weeks six days later
Palliative treatment	Chemotherapy and Hormone replacement
Work/Source of income	Retired
Religion	Christian

Opoku is a retired sale's manager of a respectable Company in Ghana. He is still able to do most of his personal care, and he is unhappy for others doing that for him. If he is unwell, his wife or the male children do that with some hesitation though. He has refused surgical castration as an option for palliative management. Three of his six children are abroad, and according to him, the children are supportive regarding his finances.

> *They (children abroad) have been supportive of the payment of my hospital bills and everything. I am very sure (if it) hadn't been their immense financial support I would have been dead long ago.*

Opoku was concerned about a load of physical work his wife (Boadiwaa) is performing and how this might affect her health.

> *I am heavy (weigh 87kg), my wife finds it difficult to do most of my care alone if I am unable to do that because of pains. I know that she is stressed at times, but she is managing.*

Opoku asked many questions about his illness. For example, he wondered whether prostate cancer was caused by promiscuity and whether the sexual weakness is reversible. Boadiwaa, Opoku's wife, recounts some of the problematic situations about dealing with the care at home especially about his body care. Opoku does not like others to see his nakedness, and this means the wife does the care most time alone.

He doesn't like others seeing his nakedness even his female children. As a result, I am usually stressed doing personal care alone because he's very heavy (Boadiwaa).

9.1.6 Ofori

Age	67
Key Caregivers	Wife (Stella) and Son (Boansi)
Main concerns	Reduced sexual ability, challenges paying hospital bills, had use of other herbal drugs initially.
Interview type: IDI	Interview 1: At Hospital; and with Stella at home Interview 2: At home with Stella, seven weeks four days later
Palliative treatment	Radiotherapy, chemotherapy, and hormonal therapy
Work/Source of income	Retired/Pension pay
Religion	Christian

Ofori married Stella about 14 years ago after his first wife died. Ofori, just like other men, has problems raising money for his treatment. He has been advised to have a surgical operation to have his testes removed (orchiectomy) to bring down his testosterone level. Comparatively, the surgical intervention (removal of the testes) is cheaper, but Ofori fears to become impotent after the procedure despite all assurance by the medical team. He narrates:

Radiotherapy and hormones are costly. I chosed this option instead of the surgical procedure because the doctors told me that they have to remove my testes. I didn't like the idea of the removal of the testes at all.

My ability to have sex is minimal. Moreover, I strongly suspect the drug as the root cause.

As a devoted Christian, Mr. and Mrs. Ofori rely on the faith in God to deal with the difficulties.

You know the disease cancer is dangerous, I thought it is even transmittable. I was afraid it could affect my wife through sex.

During the follow-up interview, Ofori was very appreciative of the fact that someone (researcher) has had time to come to his house to discuss issues about himself because that was an opportunity to address 'personal' and 'pressing' issues.

During both interviews, Stella was also glad that her husband's situation had necessitated a visit by a health care professional. She said:

If you people are leaving your work at the hospital to come home and find out from us how we are coping, then this is undoubtedly a good sign in our health care. I had not seen this before ever since he had this disease.

9.1.7 Samson

Age	70
Key Caregivers	Daughter (Sophia)
Main concerns	Waist Pains
Interview type: IDI	Interview 1: At home with Samson and Sophia separately Interview 2: At Hospital with Samson and Sophia separately, eight weeks two days later
Palliative treatment	Surgery and chemotherapy
Work/Source of income	Retired/ sales from their Fuel Station
Religion	Christian

Samson is a retired educationist. He has a brother who is a doctor, and his daughter (Sophia) is a nurse. Sampson has his own business that his son helps him to run. Samson indicates that he loves his children so much and does not want his children to be denied the opportunities he did not have. At some point in time, Samson said he was fed up with the condition and wish he was dead. He also queried why prostate cancer is stigmatised by some section of the community and this affect help/health seeking due to shyness.

This disease is rumoured to be the disease of people who 'like sleeping with women,' because of witchcraft, etc. This is worrying to me because even cancer, in general, is believed to be 'incurable' and 'infectious' so when they get to know it affects the prostate, then it becomes more shameful…..but it is said that 'when one sells his disease then he gets the appropriate remedy.'

Samson strongly believes that the support and the care he is receiving from his family is because of how he has cared for them in a kind and lovely manner. He noted that he was taking good care of his children and their spouses and they, in turn, are doing their best to care for him now that he needs some care.

If not because of my children, things will have been worse. One is currently looking after my business for me. Caring for me is essential but looking after my business too is important because the treatment requires money.

The other children are also supportive. Moreover, I think this is retaliation of the care I gave them.

Sophia talks about the disagreements she gets with his dad due to her father's habit of buying un-prescribed drugs. She also narrated the difficulty they had as a family convincing him (Samson) to have a surgical operation. Sampson opposes to the option of having a surgical procedure as suggested by the doctor because he will be castrated, and that will make him 'less of a man.'

9.1.8 Baabamu

Age	73
Key Caregivers	Children (Jenny, Jeremy, Tim)
Main concerns	Pains, the high cost of treatment, disturbed sleeping, frequent urination, and reduced sexual potency
Interview type: IDI	Interview 1: At Oncology Unit Baabamu and Jenny Interview 2: At home Baabamu and Jenny, almost eight weeks later
Palliative treatment	Surgery
Work/Source of income	Retired/Proceeds from Farming
Religion	Christian

Baabamu lives with his ailing wife, Ann, and their last born, Jenny, in his farming village after retiring from active work. He has been experiencing frequency in urination that affects his sleep and comfort.

> *I have been having problems with sleep because I wake up about eight times in the night to urinate and this affect my rest a lot.*

He is increasingly worried about his inability to have sex, a situation he describes as very 'worrying and degrading' as a man.

> *My manhood is not functioning. It is not working (2x). I don't have any feeling at all, and I am not happy about it. I hope that the treatment they are giving me will help me regain the lost function because this is worrying and degrading.*

He narrates that the doctors do not tell enough information about his progress and what to expect and concluded that his condition was getting worse.

> *I was scared then, and I kept asking myself how bad is my condition that has led to doctors passing me round like a baton?*

Another vital issue he talked about was that society frowns on some behaviour such as men reporting sick all the time and disrespect for men who have lost sexual potency.

Sometimes, men are made to believe that we are strong and hence if you are seen all the time complaining or visiting the hospital then they tag you as 'not man enough.'

A key point raised by the primary caregiver (Jenny) is that Baabamu's health is deteriorating. According to her, Baabamu no longer goes out to his friends as previously because of his condition now. Jenny thinks her father is despondent lately.

He is a bit reserved now. Moreover, this is uncharacteristic of him (Jenny)

9.1.9 Tawiah

Age	63
Key Caregivers	Son (Samuel)
Main concerns	Pains despite taking all pain medications, urinary incontinence, financial challenges.
Interview type: IDI	Interview 1: At Hospital with Tawiah and Samuel Died
Palliative treatment	Surgery
Work/Source of income	Trader
Religion	Christian

Tawiah, a father of nine, has been a successful entrepreneur, and he used to trade in many of the regions in Ghana. He is, however, unable to do this due to his ailing health.

Ever since my condition became severe, I have not been able to work again but rather fighting for my life back. It, however, seems that I am fighting a lost battle. This battle is beyond me, far beyond my capability.

He was concerned about the effect of his ill health on his social relations and his work.

I can't visit my friends, and I have to be indoors most of the time because I cannot walk beyond a few metres without getting tired. I am most times bored in one place.

Tawiah refused to be audiotaped despite all assurance of confidentiality. To him, the stigma toward prostate cancer patients exists and even added that some health care providers do use words that stigmatises prostate cancer. He recounted,

> *During one visit, the doctor asked me how many children I have, and I replied 'nine.' He told me that because I have plenty of children that is why I have this disease. To me, he was linking prostate cancer with sex, and that was a shame to me*.

Samuel, his sixth child, and caregiver informed me that they are in financial crisis and cannot afford the cost of treatment because the breadwinner of the family is now unable to provide enough for them. They, therefore, find it hard to get money for his test, drugs, and to pay light bills. This situation sometimes causes some friction in the family.

Tawiah pleaded that the government and the health authorities to include the treatment of prostate cancer under the national health insurance.

> *the problem is that when one of them helps me with money, he/she expects the others to do same the next time I need money, and sometimes I end up not receiving anything from them*
>
> Tawiah died before the next scheduled interview.

9.1.10 Sharms

Age	65
Key Caregivers	Tilaata (Wife)
Main concerns	Pains during sex, anxiety
Interview type: IDI	Interview 1: At home with Sharms and his wife,Tilaata Interview 2: At home with Sharms and his wife Tilaata, seven weeks five days later
Palliative treatment	Chemotherapy
Work/Source of income	Retired/Pension pay
Religion	Christian

Sharms like other participants refused the option of palliative surgery (castration-removal of testes) due to fear of losing his sexual potency. He complained of pains when having sex and he experiences terrible side effects after taking the hormone therapy.

> *Whenever I take the drug, my throat becomes dry, and the dryness affects my voice as well. I feel pains when I have sex, so I don't enjoy sex. This started after my diagnosis.*

Due to the widespread socio-cultural belief about a contributing cause of prostate cancer (being promiscuous), he does not want to discuss his condition to his friends for fear of stigmatisation and use of vulgar words.

Sharms appeared worried, and he accepts that he thinks a lot about his condition. He claims that he is 'psychologically unstable' because he thought a lot about his situation and was afraid one day it could lead to an accident because he drives. However, the fear appears to be reduced when he met a renowned doctor who also had prostate cancer and shared his experience with him. Sharms recounted:

> *I have been a bit relieved when I went to [a Teaching Hospital] for a bone scan. I met one doctor who also had prostate cancer, and he described how prostate cancer is, its treatment and possible prognosis. That explanation gave me some sense of relief and reduced my anxiety.*

Tilaata, Shams' wife, explains that Shams can do many activities himself including driving. She was concerned about how Sharms usually wake up occasionally at midnight and sit on the bed quietly. That according to her saddens her as well.

> *I know he thinks a lot about his condition. I encourage him and cuddle him. He smiles briefly and tells me 'I am ok' but I know he is not, he's anxious (Tilaata).*

Sharms and wife recount some support from extended family members.

9.1.11 Maegyida

Age	57
Key Caregivers	First wife (Muda) Second Wife (Abiba)
Main concerns	Erectile dysfunction, bodily weakness, difficulty in urination
Interview type: IDI	Interview 1: At Hospital with Maegyida and Abiba Interview 2: At home, eight weeks four days later
Palliative treatment	Surgery and chemotherapy
Work/Source of income	Trader
Religion	Moslem

Maegyida has two wives, and currently stays with the second wife and has nine children in all. He claims that prostate cancer is what God 'has given' to him or it is the work of someone (through curse) who is jealous about his business. He refused the doctor's advice to have a urethral catheter inserted because he thinks that will fuel the belief that he had lived a promiscuous life. He claims he has had several sexual encounters with women in the past though.

He appears able to afford the medical cost for his condition. Another issue of concern was a general bodily weakness that affects his business, and also what he termed as 'weakness in bed' (inability to have sex). This led him to buy some locally prepared herbal drugs that are believed to enhance sexual performance.

> *…. I am weak in bed too. Yes, double weakness. This is very worrying that at my relatively young age I have developed this. I find it difficult having erection and ejaculation during sex. I have to rely on drugs to keep me going.*

Maegyida says his second wife shows a lot of love and concern and she understands and copes with his sexual weakness.

> *My wife (the one I stay with) usually encourages me and reassures me to have faith in God. I think that it has been very helpful to me to keep me going. I am using the herbal drugs so that I can 'stand on my feet.' You know, if I don't remedy the situation my wife might be fed up and leave… hahaha.*

However, Maegyida made a comical but emphatic statement that if the sexual weakness persists, it might result in a sour relationship or divorce.

Abiba, his wife, indicates that though the husband's sexual weakness is a problem she is not happy about, but her main concern is the wellbeing of the husband.

> I *am indeed worried about this in our sexual life but hey! His life is supreme to me. I keep on praying he gets better.*

9.1.12 Nobert

Age	72
Key Caregivers	Son (Teiko)
Main concerns	Incomplete emptying of the bladder and lower abdominal pains
Interview type: IDI	Interview 1: At home with his son Interview 2: Died 3 days before the scheduled follow up the interview date
Palliative treatment	Surgery
Work/Source of income	Nil/ Income from his family
Religion	Christian

Norbert is a widower with four children. His son, Teiko, has requested for transfer so that he can be closer to his dad to help provide all the needed care. This disease has given him a new perspective in life. He was particularly worried about his physical appearance. He asserts that though he is getting old, prostate cancer is making him very weak. He indicates that he looks completely different (physical appearance) having lost much weight.

He thinks that because of the nervousness associated with having cancer, he has kept his condition as a secret and only told his children.

> *This is something that must be kept a secret so that when you walk around people will not be pointing fingers at you. Therefore, I don't have the psychological stress of feeling uncomfortable in the community (Nobert).*

According to Teiko, his decision to arrange a transfer to come closer and take care of his father is because it will be more costly and inconvenient to send his father to where he (Teiko) was staying.

> *I was always anxious when I receive a call from home. I decided to request for a transfer to [name withheld] be closer to him and provide all the needed care. It was challenging for my younger brother who was lifting him alone, cleaning and bathing him. It is hard, but if we don't do who else will?*

Teiko describes the emotional and physical challenges of having to combine his paid work and his father's care. He also informed me that due to complications his father has developed, Nobert is usually admitted to the hospital for the treatment of urinary tract infections.

9.1.13 Mike

Age	81
Key Caregivers	Eno (Wife) Sebastian(son)
Main concerns	Pain, sleeplessness, and forgetfulness
Interview type: Dyad	Interview 1: At home with his wife, Eno Interview 2: Died before the scheduled interview date
Palliative treatment	Surgery
Work/Source of income	Retired/Pension pay and family
Religion	Christian

Mike is homebound and has a urethral catheter in place for some months now. He recently developed an infection with discharge from his penis, and he wets himself day and night anytime there is no catheter (he occasionally pulls it out). Eno, Mike's wife, indicates that the state of her husband makes the care difficult because Mike easily forgets things.

> *Life after the diagnosis of prostate cancer has not been easy for us as a family. This is because aside from prostate cancer, my husband now easily forgets things. That makes the management of the condition at home very difficult*.

Due to Mike's deteriorating health, there seem to be care demands that they find it challenging to meet. Eno indicates that Mike is likely to fall, but he refuses to use walking aid claiming it is a 'sign of weaknesses.'

The couple who, were jointly interviewed, indicated that for the past five years they had not had any satisfactory sexual intercourse because Mike developed sexual weakness. This was compounded later on by the catheterisation.

> *With this in place (pointing to the catheter and smiling), I can't even initiate any sexual conversation. The pain is bad. I scream like a woman in labour. My thing [penis] is now useless* (Mike).

Though Mike still receives his monthly pension allowances, that amount is insignificant for his treatment. Eno, a government worker herself and Sebastian, their son, also contribute from their monthly salaries to cover the cost of treatment. Mike has been managed with herbal drugs from a herbalist, but the family stopped this treatment when there was no improvement. Eno coordinates and does most of the care. The care is usually assisted by Sebastian (their son) and in their absence, Solomon, (their grandson).

> *We understand each other; we support each other's view. We seek information from others as well. That helps help us to care (Eno).*

Mike died six weeks after the interview. Upon the invitation of the family, and as customs demands, I honoured the funeral invitation and attended his funeral ceremony (May his soul rest in peace).

9.1.14 Opanin

Age	60
Key Caregivers	Achiaa (Wife)
Main concerns	Losing weight, incontinence, and worries.
Interviews: Dyad	Interview 1: At home with his wife, Achiaa Interview 2: At home with his wife Achiaa, nine weeks later
Palliative treatment	Surgery
Work/Source of income	Teacher
Religion	Christian

On both occasions for the interview, Opanin and his wife Achiaa, were at home waiting for my arrival. Achiaa is the sole her husband, Opanin. Achiaa expressed concern about some overburden care, so her son promised to come in during the vacation to help. She reported about her bodily pains because of lifting and assisting her husband for bathing etc. Besides, there are some grandchildren that she is caring for (their mother died), and that makes her busy.

Opanin spoke about shame and feeling of guilt because he urinates on himself anytime. Additionally, this causes embarrassment in public because of the smell of urine. He reports that increasing care cost has brought untold hardship in the family as they continuously look for money to pay hospital bills, transportation, and buying incontinence pad ('pampers'). During the second interview, Opanin was somewhat more open to talking about sensitive issues about incontinence and sexual weakness. He narrates:

> *I didn't tell you something the other time (during the first interview). It's about urine, and weakness 'down there.' How can an old man like me be soiling myself this way? What kind of stressful life is this? I am ashamed of this honestly, and that is why you meet me home always.*

Achiaa says that after the death of her only daughter, she has assumed full responsibility of caring for her five grandchildren (eldest 21 and youngest 7). Opanin's illness has further brought additional care responsibility. According to Achiaa, she is stressed, and that makes her very sad. She says she has little knowledge about caring

for the sick and that she is ‘doing her best’ for her husband. She requested support from the health staff.

> *With all this plenty of duty, I am doing them all. Please tell the government to come to our aid. I am caring for him as well as my grandchildren who lost their mum. I am suffering [tears running down her cheeks] (Achiaa).*

I offered Achiaa a tissue to wipe her tears, and I reassured her after the interview. She was glad for the opportunity at least to voice her feelings.

9.1.15 Ali

Age	53
Key Caregivers	Zaliatu (Wife)
Main concerns	Pain, difficulty in walking, poor appetite, and sleeplessness.
Interviews: Dyad	Interview 1: At home with Zaliatu Interview 2: At the hospital with Zaliatu 5 weeks later
Palliative treatment	Surgery and chemotherapy
Work/Source of income	Trader/ Support from family members
Religion	Moslem

Ali uses a wheelchair at home and other stand aid to assist in the care at home. Ali was very jovial and wanted to know more about what brought me from England to interact with them (patients with advanced prostate cancer). Ali was fond of going off the tangent, but I had the purpose of the discussion in mind, and I try to bring him back at the appropriate time. As the interview went on, Ali and his wife appeared troubled, and were quite emotional, as they described the challenges they go through to get money for chemotherapy treatment. Ali became emotional as he went on with his narration of the pain he goes through each day.

> *I am suffering. A day without pain is a ‘holiday’ for me. I am in pain every day (Ali).*

> *Yes, he is in severe pain. We have bought all the drugs we could. Moreover, I reassure him all the time, but none seems to work (Zaliatu).*

I debriefed them about some support such as reporting to the hospital for specialist advice. That also gave them an opportunity to ask me questions to which I answered. Ali and his wife, Zaliatu were much more relaxed and cheerful before I left their house. Zaliatu however, expressed worry that there are no support services such as funds available for patients from the government.

Five weeks later, Zaliatu called me that they have had some money and had scheduled an appointment for review at the hospital. We, therefore, on their preference, moved the venue of the next interview to the hospital. Ali looked cheerful and was happy he had received some support from family members to 'fight' his cancer.

> *Luckily, some family members have helped me with some good amount of money for the next three visits (3 months per visit). This is great news because I have money to cover for the next nine months. This will help me fight the disease (Ali).*
>
> *Now that we have had some drugs I think, his pain will reduce (Zaliatu).*

They both looked cheerful as their main hurdle; money to pay for drugs is now sorted, at least for the next nine months.

9.1.16 Nelson

Age	62
Key Caregivers	Benewaa (mother)
Main concerns	Losing weight, urinary incontinence/urgency/ frequency
Interviews: Dyad	Interview 1: At home with Benewaa Interview 2: At home with Benewaa, eight weeks later
Palliative treatment	Surgery
Work/Source of income	Nil /family support
Religion	Traditionalist

Nelson lives with his mother and other family members. To access his room, Nelson needs to climb the staircases, so he is usually indoors. However, Nelson has to come

down the poorly designed stairs when he wants to go to the toilet. He has frequency in urination, and he is compelled to visit the bathroom more often. As a result, he refuses to drink more water because he has to use the bathroom. Nelson has been treated with herbal drugs because the family has no money to continue to buy chemotherapy at the hospital. Currently, some old friends are contributing to taking care of his medical care. Nelson has urinary urgency/ frequency (he urinated twice during the interview that lasted about an hour).

> *There is no money to send him to the Oncology for cancer drugs. He complains about pain. Moreover, the pain medications that he had the last time we went to the hospital got finished. We can't get the same to buy in the pharmacy shops. He cries when he is in severepain, and that makes me cry too (Benewaa).*

The moment was quite emotional when Nelson told me about his awful pain that makes him wish he was dead.

> *You (referring to me) are lucky you met me alive today. My pain is unbearable sometimes, and I scream like a woman in labour [tears]. Is this suffering ever going to end? If it were going to be like this all the time, I would better not be alive (Nelson).*

According to Nelson, he is sad about his condition and does not know what the future holds for him. He has lost his job and friends at the workplace, and he lives in a new unpleasant world of pain and sorrow. He has lost weight drastically, and this has affected his body image. Benewaa, Nelson's mother and caregiver, narrated how difficult it was to get money to support Nelson living with her. Benewaa spoke about people in her neighbourhood and friends who contribute money to help her buy drugs for Nelson.

9.1.17 Asamoah

Age	65
Key Caregivers	Joobu (Son), Ataa (Wife)
Main concerns	Pain, swollen legs,
Interviews: Dyad	Interview 1: At the Hospital with his son Joobu Interview 2: At home with his wife (Ataa), seven weeks three days later
Palliative treatment	Surgery
Work/Source of income	Farming
Religion	Christian

Asamoah has a cash crop farm in one of the regions in Ghana. His cash crop is the primary source of income for him and his family. In his illness, he still depends on his cash crop for paying his drugs, laboratory investigations, and transport. Asamoah complains of pain:

> *My experience is nothing but pain.*

When the patient's condition was not improving even after seeing a doctor, they decided to seek the services of an herbalist and native doctor because they suspected that someone might have cursed him. He and the family alleges it is 'Duabo' (curse) because of the swollen legs and abdomen.

> *When things were getting bad, we thought it was not a 'hospital disease' so we resorted to 'abibiduro' (herbal medicine/black medicine). Some of the medicines are used to smear over my legs, and then several incisions were made on my legs while I drink other drugs*

Asamoah, however, left the place of the traditional herbal practitioner because of the poor environmental conditions after he has spent several months there.

> *While in severe pain, I have the regular duty of driving away the houseflies that settle on my wound while at the same time exchanging pleasantries with people*

passing by. When I am eating, then my battle with the houseflies becomes fiercer; preventing others from settling on my wound and others from landing on the food.

Asamoah gets word of encouragement from his pastor, and the family has been supportive. During the second interview with Asamoah and his wife, Ataa, they appeared relaxed and talked less about their challenges.

Our pastor has been visiting him and giving us words of encouragement. He (pastor) told me that God is the leader and I should have faith in Him and believe I will be well. That has been helpful.

9.1.18 Atta

Age	67
Key Caregivers	Karikari (Son) Adwoa(Wife)
Main concerns	Psychological distress
Interviews: Joint	Interview 1: At the hospital with Atta and his son, Karikari Interview 2: At home with Atta, his wife Adwoa and son about seven weeks later
Palliative treatment	Surgery
Work/Source of income	Priest/Supportive children and the church
Religion	Christian

I had two sessions of interviews with Atta; first with Atta and his son at the Hospital during the first phase. The follow-up interview took place at his house with his wife and later joined by the son during the interview. Though the conversation at the hospital was conducted at a private place, because consultation was ongoing at the clinic there was some background noise, amidst ambulance siren. Atta is a priest and has four children. His son is his primary caregiver, and his wife supports him.

Atta was devastated with the diagnosis at the onset, and for fear of been tagged as 'womaniser,' he was worried about this a lot. He was particularly concerned because of his social status as pastor of a church.

Atta said his illness had brought disruption between him and the wife after the wife was told about the diagnosis of prostate cancer. According to Atta, it nearly ended in divorce

> *One day, my wife asked me to be truthful to her if I have had girlfriends from the church. I was shocked. It brought some misunderstanding between us. However, as the head of the family, I have to swallow some of these things (Atta).*

During the second interview, Atta's son, Karikari, talked about the support they get. They indicate that the church is supportive regarding the treatment etc. The son (caregiver with his siblings) brings in enough money for the care of their dad.

> *I think my dad is unhappy because of what people say about prostate cancer (stigma), and his status in the church [as a pastor] (Atta's son, Karikari).*
>
> *He has been thinking a lot. The disease has already happened, and I think he has to get over it and forget about what others say (Atta's wife, Adwoa).*

Atta seemed to worry more about what others say about the cause of his prostate cancer. He is, nevertheless, optimistic that with time society will appreciate that prostate cancer is no respecter of anyone: promiscuous or otherwise.

9.1.19 Gyasi

Age	64
Key Caregivers	Children (Otoo, Kwame, Agyei)
Main concerns	He is a wheelchair user, lost weight, pressure sores,
Interviews: Dyad	Interview 1: At a private room at the hospital with his first son, Otoo Interview 2: At home, seven weeks five days later with Gyasi and his second son, Kwame
Palliative treatment	Surgery and on chemotherapy
Work/Source of income	Retired/Pension and family income
Religion	Christian

Gyasi is retired and lives with the family. He cannot walk, and he is a wheelchair user. Due to his special needs and significant mobility difficulty, he is always transported to the oncology unit by a private Ambulance service for his monthly appointment. He has had surgery done to remove his testes, and he is currently on chemotherapy. He wears an incontinent pad all the time and always requires the assistance of others for his care and movement. He is thankful to his children for the care they provide him on a rotation basis.

The interview took place in a private room in the oncology unit. Of key concern to Gyasi was the cost of treatment and paying for the service of a private ambulance each time he goes for review at the hospital.

> *He had some interrupted treatment (chemotherapy) due to our inability to pay for drugs (Casodex). It has not been easy paying for ambulance, drugs, and so forth (Otoo).*

Approximately eight weeks later, I had the second interview with Gyasi and Kwame at his hometown about 6 hours away. He appears worried, and he has lost weight. He wants the government to come to his aid because the family spends much money on

his care. Due to reducing physical mobility, he has developed pressure sore that also increase the cost of care because he has hired the service of a nurse to treat the wound. The family is worried about this condition as they described it as 'emotionally challenging.'

> *Hmm, look me at now. I look strange. I am lying down very weak like 'nkokontomire' (cocoyam leaves used as a vegetable). They have spent a lot on me but no improvement (Gyasi).*
>
> *Yeah, as he said, we buy pampers, barrier cream, cotton wool, and others to manage the care at home. It is not an easy responsibility. Not at all (Kwame).*

Gyasi was, however, grateful to the children for the care and the love they have shown him throughout the difficult times.

9.1.20 Sule

Age	54
Key Caregivers	Fuseina (Mother)
Main concerns	Weakness in the limbs, low backache, painful urination, and frequency in urination.
Interviews: Dyad	Interview 1: At home with Sule and his mother, Fuseina Interview 2: At home, seven weeks later with Sule and his mother Fuseina
Palliative treatment	Chemotherapy
Work/Source of income	Nil/ family support
Religion	Moslem

Sule lost his wife about a year ago. His mother, Fuseina, cares for him since his children are still minors. He complains of rectal bleeding, weakness in the limbs, low backache, painful urination and frequency in urination. He is unable to buy his

prescribed Zoladex and Casodex because of the high cost. He is also concerned about the future of his five children (eldest 24 and the youngest 14) in the event he dies.

> *I have pains all over my body. Nonetheless, at this current stage, my main concern now is not even my disease but whom to take care of my children in case I die. My mum is old (74 years) and getting weak. I am a worried man.*

The caregiver complained of the high cost of treatment, which they cannot afford without the help of the other extended family members. Fuseina, his mother and primary caregiver, asked if they (caregivers) could be given some orientation on what to expect and how to deal with situations like that.

> *There are several instances when we have no idea at all, about what we are doing about providing care. We do what we think is right but in reality, it may not. We will also need some logistics for the care of the patients (Fuseina).*

During the second interview, Sule and his mum were quite happy because a friend decided to pay for three months of his treatment cost. Sule described this as a sign of relief at least for the next three months.

> *I am glad that my old time friend heard about my situation and visited me. He paid for my three months' treatment. It was excellent news.*

Sule and his mother, Fuseina, however, indicated that they still think a lot about the situation they find themselves.

9.1.21 Efo

Age	79
Key Caregivers	Dzifa(Wife), Mawuli (Grandson)
Main concerns	Waist pains, erectile problem.
Interviews: Dyad	Interview 1: At the Hospital with Efo and Mawuli Interview 2: At home, seven weeks later with Efo and Dzifa
Palliative treatment	Surgery and chemotherapy
Work/Source of income	Retired/Pension and sales from trading (from his wife)
Religion	Christian

Efo is a 79-year old retired soldier. He believes he has prostate cancer because he was dating many women. He initially refused catheter because he thought that could weaken his sexual drive.

> *I don't want the use of a rubber (catheter). Having the catheter means, the disease is very serious and life-threatening, and besides, that means it has blocked my chances of having sex…he laughs. And I must be honest with you, I have dated many women, and I am not surprised I have this disease (Efo).*

Efo claims that he has not received any health education on what condition he has and how to go about the care. Efo did not remember some test that was carried on him, but he says the procedure causes excruciating pain. The grandson, Mawuli, a third-year student nurse, helped explain some of the issues about the laboratory test his grandfather underwent. The complementary information Mawuli gave is the strength of the dyad interview because this vital information could have been missed in the case of an individual interview.

> *I have realised that anytime he undergoes a PSA test and rectal examination he can't sleep for some days. He, therefore, refuses the tests lately (Mawuli).*

Seven weeks later, Mawuli had returned to school, and I had the interview with Efo and his wife, Dzifa. She was glad that for the first time someone has come over to have a chat with them about their problems. She indicates that her husband is concerned about his inability to have sex as previously.

> *He thinks and worries about his impotence. I am not bothered, but he does. I am concerned about his health (Dzifa).*

9.1.22 Nii

Age	63
Key Caregivers	Ivy (Daughter)
Main concerns	Pain, incontinence, financial difficulty, and shame.
Interviews: Dyad	Interview 1: At home with Nii and his daughter Ivy Interview 2: At home, eight weeks later with Nii and his daughter Ivy
Palliative treatment	Surgery and Hormonal drugs
Work/Source of income	Electrician
Religion	Christian

Nii had undergone bilateral orchiectomy (surgical removal of the testes). His last visit to the hospital for his drugs was six months ago, that is, defaulting three months ago. According to Nii and his daughter, they have not had enough money needed for the laboratory test and drugs.

Nii reported about leaking urine. He, however, gets allergic reactions when he wears incontinence pad (pampers) and has, therefore, stopped wearing some. Nii feels that people might be uncomfortable been with him because of the smell of urine on him.

I feel very bad when people are around because I feel they smell the urine on me. I do my best to contain the situation but when I wear the pampers I get rashes, so I have stopped using that. The urine leaks and stains my clothes most time. Coping with this is hard.

He is overly concerned about how the 'prostate cancer' has affected his social life because he can longer go to church anymore (due to weakness and the for fear of embarrassing himself with the stain and smell of urine). He is also troubled to have changed suddenly from the role of a worker to non-worker and from a 'giver' to that of a 'receiver' and being stigmatised.

He doesn't want to be seen by others. My dad is also concerned about his swollen foot and tummy, something that is widely associated with 'Duabo' [curse]. He says others might say he has been cursed (Ivy, Nii's daughter).

I was hurt when my friend referred to me as a castrated man during a chat. That is devaluing and insulting (Nii).

Nii also reported that one of his family members inquired from his if indeed he (Nii) has engaged in any wrongdoing that might have offended 'someone' so that they (family) can appease the gods to avert the situation.

What I inferred from the interaction with Nii and his daughter was that they believed supernatural causes of disease such as prostate cancer. Therefore, the approach to managing the condition implied the possibility of seeking for the 'cause' of cancer from a spiritualist.

9.1.23 Kwakwa

Age	67
Key Caregivers	Irene(Wife)
Main concerns	Bodily pains and weakness
Interviews: Dyad	Interview 1: At home with Kwakwa and wife, Irene Interview 2: At home, six weeks four days with Kwakwa and wife, Irene.
Palliative treatment	Hormonal therapy
Work/Source of income	Painter
Religion	Christian

I had two interviews with Kwakwa and his wife Irene on two occasions at home. Kwakwa expressed fear of impending death and loss of hope in the treatment. Kwakwa blames himself because he thinks his prostate cancer is because of his past promiscuous life.

> *I don't know whether my body is shutting down (dying). It is something I am always shy to discuss with others. I used to like women at my youthful age; I was nice looking then, and you know women like nice men. I used to drink alcohol too (Kwakwa).*

Kwakwa describes his situation as an 'uncomfortable life' because of the discomfort caused by the urinary catheter, general bodily pains, and weakness. He further reports that the catheter in place is interrupting his chances of having sex.

> *I still take consolation in the fact that my penis can erect just that I can't have sex because of the catheter. Therefore, it has been a great source of worry for me.*

He also recounted the pains he goes through most times.

> *It is indeed a painful disease. The pain during urination is something terrible. The frequent urination worries me as I need to get up on regular times to urinate.*

Irene is concerned about the challenges of caring for her husband amidst other problems such as hospital bills. She was overly worried about the frequent admission of her husband at the hospital.

> *My husband usually reports to the hospital with infections, and I suspect it is because of the catheter (Irene).*

Irene also indicates that the care at home is tedious and sometimes she does not know what to do if her husband still complains after she has given him some drugs.

Appendix M: Certificate of Incorporation-ProCaSH



CG062152017 C0008233462

REPUBLIC OF GHANA

Certificate of Incorporation

I hereby certify that

PROSTATE CANCER SUPPORT HERITAGE

is this day incorporated under the Companies Act, 1963 (Act 179) and that the liability of its members is limited by guarantee.

Given under my hand and official seal at Accra, this 20th day of April 2017

For: Registrar of Companies