

Challenges Encountered by Family Caregivers of Prostate Cancer Patients: A Qualitative Inquiry

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Abstract

Background

In Ghana, prostate cancer is more prevalent than all other cancers with a mortality rate of 75% partly as a result of late presentation to the health care facilities. Limited health services provision across the country and shortages of skilled nurses place a significant demand on family caregivers who are often ill-equipped for the caring role resulting in a lot of challenges. As they are expected to provide complex care at home with little resources, information, and support, yet, the healthcare system rarely addresses the challenging needs of these family caregivers. This study explored the Challenges encountered by family caregivers of people with prostate cancer.

Methods

A qualitative phenomenological descriptive study was adapted using a semi-structured interview guide to conduct in-depth interviews with twelve (12) family caregivers of prostate cancer patients selected through a purposive sampling technique at the Cape Coast Teaching Hospital. All interviews were recorded, transcribed, and analyzed thematically.

Findings

The significant statement extracted from verbatim transcripts (analysis of transcripts) produced three main themes as key challenges relating to; Education and Training needs, Resources and Caregiver-nurse relationship issues with seven (7) sub-themes that collectively hindered the family caregivers ability to effectively perform their caring role. Thus making it difficult for them to meet the care demands. Sub-themes that emerged were; lack of preparedness towards the caring role, lack of knowledge about condition/ treatment, misconception about the condition, lack of accommodation facilities, financial constraints, poor communication and poor staff attitude.

Conclusion

Caregiving is associated with significant challenges that hinder family caregiver's ability to effectively care for the patient; further diminishing caregiver's quality of life and quality of patient care. Healthcare professionals especially nurses should, therefore, consider these challenges faced by family caregivers and put in measures to obviate them through education, preparation, and support.

Background

Prostate cancer is the second most frequently diagnosed cancer in men worldwide, accounting for 1.3 million new cases (1) and causing 358,989 deaths in 2018 (2). In Africa, research has shown that low Prostate-specific antigen (PSA) testing, limited population-based cancer registries in most parts of the continent and late presentation to health facilities made it difficult to control (3). The story is however not different in Ghana, as people living with prostate cancer face the problem of late diagnosis resulting in a high mortality rate of about 75% with only 17.7% survival rate making the condition the leading cause of death among men (4). This rate of prostate cancer in Ghana is a reflection of limited screening for cancers, poor access to healthcare facilities and cultural beliefs (5). Thus, an increasing number of advanced cases of prostate cancer coupled with staff shortage and inadequate space in our health care facilities to accommodate all these patients (6). This has resulted in family members/ friends automatically assuming the role of a caregiver under difficult conditions with little knowledge and support from a health care professional, especially nurses.

Family caregivers play an important role in the overall care of people with prostate cancer. The role of the family caregiver is increasingly being considered as a valuable substitute for formal care; due to the current shift in healthcare delivery (6). However, caring for a patient with cancer is generally viewed as one of the most stress-inducing caregiving challenge faced by family members as it involves complex and sometimes unfamiliar procedures (7). The caregiving experience is associated with several care-related problems as well as barriers making the caregiving role problematic further hindering the caregiver's ability to perform their role effectively. Given the intricate nature of the caregiving role, preparing the family caregiver towards the task ahead is very critical. Caregivers need knowledge and skills to effectively perform the role. Yet available literature suggests that many of these family caregivers receive little or no preparation at all for the task they are expected to assume (8,9). Little research has examined the challenges encountered by family caregivers of patients with prostate cancer despite the high morbidity and mortality rate of prostate cancer and the extensive involvement of family caregivers in caring for these patients. (10) revealed that out of 768 caregivers of cancer patients, most of them (55.1%) had less confidence to manage symptoms, (88.6%) had a lack of awareness about pain assessment and management, and (86.8%) of them could not decide how and when to deliver the care. The majority, (85.1%) of them had financial problems in the family, (97.7%) had a lack of knowledge about the disease, and 667 (86.9%) had a lack of resources to provide care.

Therefore, these family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, as well as receive little guidance from the formal health care providers (8). For these reasons, they may be unfamiliar with the type of care they must provide or the amount of care needed. Hence, provide care by trial and error and feared to make a mistake (8). They may not know resources available to them, how to access and best utilize these available resources (8).

Although, caring for a sick relative with a serious condition such as prostate cancer can be to some extent fulfilling, it may also be costly especially in monetary terms. Cancer in the advanced stages may render the person jobless, Yet, its management involves a lot of money. The responsibility for ensuring that the patient goes through treatment rests on the family, in most cases the family caregiver, thus becoming a burden. Limburg, Shaw and McBride (11) asserted that parents of children under 10 had the highest percentage of lost work, and mothers whose children were diagnosed with leukaemia had the highest percentage of lost work at 92%. An increase in lost work was also noticed during palliative versus curative treatment of the disease including prostate cancer (11). Given and colleagues also reported in their study that, caregivers of cancer patients took loans, sold their homes and used other financial resources to pay for the expensive cost of treatment that was not covered under health insurance (12). Others also complained of even going bankrupt due to the expensive cost of treatment (13).

Moreover, family caregivers have become part of a triad of care, and effective caregiving requires that caregivers understand the course of the disease and the changing treatment goals. Knowledge about the condition and its management is one crucial area that has been neglected by healthcare providers especially nurses (14). Information on areas such as the cause, signs and symptoms, prevention, administration of medication at home to avoid medication errors and identifying adverse effects are very vital details that need to be provided by healthcare professionals to improve quality of care (12). In a study conducted by Sajjadi and associates, on the assessment of the common problems faced by Iranian family caregivers of patients with breast cancer, they reported that failure of health care professionals in giving the required information and knowledge about the patients' disease and the caregivers' health was a major problem faced by these family caregivers (15). Although, most of the caregivers in Iran wanted to achieve more care-related information, however, due to the absence of certain educative and supportive centre for them, this need remained unmet (15).

Also, providing care to a sick family member is a tradition embedded in African culture. It is regarded as an age-old act of kindness, love and loyalty which binds family members together (16). Cultural norms and values have a substantial effect on how caregivers perceive their own caregiving experiences and their roles as caregivers (17). However, culture in its way may also serve as a barrier that hinders the effective role of the family caregiver. In Ghana, several studies have been conducted in relation to the improving management of prostate cancer in respect to patient care (18–22) with less emphasis given to the challenges faced by the family caregiver. Although (23) addressed the experience of spouses of patients with prostate cancer, her study was limited in scope as other members of the family are involved in care delivery aside spouses. Thus, trying to identify some of these challenges confronting the family caregiver and how it hinders the care they provide can be a step towards resolving the problems faced by the family caregivers of these patients. Thus, this study explored the barriers encountered by the family caregiver of people with prostate cancer.

Methods

Study design and setting

This is a qualitative study based on descriptive phenomenology, involving a purposive sampling of family members considered as family caregivers by the patient. This approach was adopted because, it allowed the researchers to obtain an in-depth understanding of the challenges that hinder their role as caregivers, leading to a detailed account based on their experience. Our study was reported according to the consolidated criteria for reporting qualitative studies (Appendix 1).

Participants recruitment

The present study participants included family caregivers of patients with prostate cancer who provided care to prostate cancer patients. These were family caregivers who provided the most assistance to the prostate cancer patients and were involved in the care of the patient for at least eight (8) hours, provided care for at least 6 months and above, and are aged ≥ 18 years (the age considered as maturity stage according to the 1992 constitution of Ghana) and were willing to participate. The study, however, excluded bereaved family caregivers who no longer cared for patients living with prostate cancer. The selection was done using purposive sampling from the Genito-urinary clinic and the male surgical unit of the Cape Coast Teaching Hospital (CCTH). Patients who met the criteria for the study were recruited by the doctors and directed to the researcher in the consulting room. The patients were asked to identify who they considered their family caregiver and contact information of these family caregivers were retrieved. The researcher contacted the family caregivers on telephone and explanation on the importance of the study was provided. Once they agree to participate in the study, the interview was scheduled and conducted at their convenient venues, date and time. Twelve (12) participants were selected based on (24) recommendation of 5-25 participants, with the emphasize of saturation in mind as proposed by (25). Data saturation was observed at the point where no new information was obtained from the new participants (26).

Study Setting

The study was conducted at the Genito-urinary unit of the Cape Coast Teaching Hospital. The hospital was established on the 12 August 1998. It receives many referral cases from Cape Coast and beyond and serves as a facility for medical students from the University of Cape Coast and a Centre of learning for several health professionals. The hospital has several units which include a Genito-urinary unit for management of cancer cases. It, however, does not have accommodation facilities for patient relatives who bring their patients from far and near as

referral cases from other facilities. This study area was selected because the Central region and for that matter, Cape Coast has no other hospital that sees to prostate cancer patient apart from the Cape Coast Teaching Hospital. Also, per the researcher's knowledge of existing literature, no study on prostate cancer has been undertaken in the Central region.

The outcome of Pilot Testing

In this study, a pilot test was conducted with two participants at the Cape Coast Teaching Hospital. After the pilot, two questions under section B of the guide was merged. The question that was merged into the other was "Do you know the name of cancer your relative is suffering from?" And the question into which it was merged was "Please kindly tell me about your relation's condition". It came to the researcher's notice that upon asking the second question the first question was answered. Also, two questions under section C were omitted. These questions were "What are the resources you have used so far to help you get through this situation?" Would you like to share a saying that describes this experience?" The two questions were omitted because, again, the first question was embedded in a previous question asked and the second question was not well understood by the participants hence the participants found it difficult to provide an answer to it (see Appendix 2).

Data collection

Data collection was done using an in-depth interview guide to conduct face to face interviews (one on one) of 12 participants. This approach promoted confidentiality while allowing the participants to freely express/elaborate on their feelings, thoughts and experience (24). BO was also able to gain direct knowledge about participants experience through broad and open-ended questions. The interviews lasted between 40-50 minutes and it took place in the homes of participants, and within the hospital premises at the hospital snack bar/eatery and outside some of the wards since their relatives were on admission until data saturation was reached. The data collection lasted between March and May 2019. The nonverbal communications of the participants, participants' mannerisms and anything vital to the study such as participant crying, laughing, feeling of sadness, anger, and moodiness during the interview were recorded in a field diary and dated. This helped the BO understand the data generated during transcription All interviews were audio-recorded and transcribed verbatim concurrently.

Ethical issues

The study was approved by the Institutional Review Board (IRB) of the University of Cape Coast (UCC) (UCCIRB/CHAS/2018/24) and the ethical committee of the CCTH research unit (CCTH/RDS/2019/41). Letters of authorization were provided by the committee to be sent to the heads of the urology clinic and surgical unit. Each participant was given a consent form to read and sign/thumbprint, those who did not have the literacy ability were assisted, and all misunderstandings clarified about days/week before the interview. In instances where participants could not read English, the researcher herself translated in Twi to ensure that the participants understood everything written on the consent form. All participants signed/ thumbprint informed consent form after detailed explanation provided. They were also informed of their right to opt-out at any time.

Data Analysis

In this study, data analysis was conducted concurrently with data collection using (27). Following closely the data analysis approach proposed by Colaizzi (27), the lead researcher (BO) familiarised herself with the verbatim transcribed data by reading and re-reading through them numerous time in an attempt to get an understanding of what the participants were trying to say. Step two involved extracting significant statements deemed relevant to the

study. At this point, the researcher identified all statements in the accounts that were of direct relevance to the study under investigation (such as “we were not given reasons for cancellation of surgery”, “we could not raise the money for surgery”, “prostate cancer is incurable”, “no one explained how to care for him at home”). Step three followed by formulating meanings from the relevant statements extracted earlier. The researcher again, at this stage identified meanings relevant to the study that resulted from a careful consideration of the significant statements while ensuring that their presuppositions and presumptions about the phenomenon are set aside through bracketing (28). The researcher then grouped the identified meanings into themes that were common across all accounts in step four. At this point, three major themes “Education and Training”, “Resources” and “Caregiver- nurse relationship” emerged with seven (7) sub-themes. In step five, the researcher wrote a full and inclusive description of the phenomenon, incorporating all the themes produced at step four. Step six typically involved a return to research participants for member-checking of created profiles of their experiences and verification. Participants' views on the study results were obtained directly via phone calls. Eventually, all participants were satisfied with the results which entirely reflected their feelings and experiences. Finally, step seven incorporated any new or pertinent data obtained into the final study. However, no new information emerged.

Ensuring Trustworthiness of the data

To guarantee the trustworthiness of the study the four main criteria proposed by Lincoln and Guba (29) namely credibility, transferability, dependability and confirmability were followed. Credibility was achieved by ensuring that contact was maintained with participants to verify if the findings of the study were true to their experiences. By using member checking, “which was achieved by getting agreement from the participants on the emerged results through phone calls (24). Transferability was also achieved by recruiting nominated sample, Dependability by keeping an audit trail. Confirmability was established, through the verification of results with participants, and using their own words in generating the description of their experiences. Bracketing was also ensured, by documenting researcher’s preconceptions before the onset of the study through the use of a reflective diary, thus, eradicating any biases inherent in the researcher believes and attitudes (24). BO again promoted bracketing by participants because she realized that the knowledge of her being a nurse (which she had disclosed to the participants before the commencement of data collection) made it difficult for some of the participants to frankly express their feelings/opinion; believing that their responses may affect the care that was rendered to their patients (30).

Findings

Description of Participants Demographic Characteristics

The study participants were twelve (12) in number and aged between 27 – 67 years. The family caregivers included six (6) spouses and six (6) children of the patients. The number of years of marriage by spouses were between 10-30 years with children. Two of the participants had children before marrying their husbands. And some of the patients also had children before marrying their present spouses. These spouses had between one to five children with their present spouses. The six children who took up the caring role were five females and a male. Four females out of those five were married with children whereas one was not married but in a serious relationship. The male was also not married but in a relationship. All participants were Ghanaians and Christians. Two participants were government workers on retirement. One participant was a seamstress, four were petty traders, two were farmers and three were professionals of which one is a mental health nurse awaiting posting, a teacher and a secretary. The duration of care was between 6 months - 2 years. Most participants preferred to speak Fante which was their native language. However, other participants also spoke several other languages such as English, Ga and Twi. Four of the interviews were completed in participants home. Eight took place within the hospital premises. Five of the patients of

these caregivers were on admission and the rest were at home. Nine of the participants were sole caregivers whereas three had assistance occasionally from others/family members. The residential location for these family caregivers within the Cape Coast Metropolis varied between urban and rural settlements (see Table 1).

Table 1: Participants Demographic Characteristics

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

Family caregivers of prostate cancer patients face multiple barriers which impact their quality of life and well-being. These caregivers described the caregiving role as a very intense experience. Findings from the study show that participants encountered several difficulties due to lack of skills and knowledge to care for these patients thus making it difficult for them to meet the care demands. Sub-themes that emerged were; lack of preparedness towards the caring role, lack of knowledge about condition/treatment, misconception about the condition, financial constraints, poor communication, lack of accommodation facilities and poor staff attitude (see Table 2)

Table 2: Showing Themes and Sub-themes

Main Themes	Sub-themes
Theme 1: Education and Training	Lack of preparedness towards the caring role Lack of knowledge about condition/ treatment Misconceptions about condition
Theme 2: Resources	Financial constraints Lack of accommodation facilities
Theme 3: Caregiver-Nurse Relationship	Poor communication Poor staff attitude

Theme 1: Education and Training Needs

This theme describes caregivers education and training needs impacts on their caring roles. Emerging subthemes include lack of preparedness, lack of knowledge of the condition and misconceptions about the condition,

Lack of Preparedness towards Caring Role

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

"No one explained to us what was happening. Also, in terms of how to care for him at home, no one thought us how-to, not even the nurses" **Love**

"The only thing they told us about was in connection with the administration of the medication at home and the date for review. Even that, he was the one who was told, not us" **Peace**

"No one educated us on how to take care of him at home" **Grace**

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

"No one took the time to explain to us, how to care for him at home"

Mercy

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

Forgive

"They educated us on how to administer the medications. But nothing else" **Humble**

Lack of Knowledge about Condition/Treatment

Caregivers have become part of the triad of care. Effective caregiving and decision making requires that they understand the course of disease/ treatment and resources available to them. Their ability to care for their patients may be hampered by their lack of understanding of the disease and treatment patient receive as well as resources. Some participants reported a lack of knowledge about the condition and treatment resulting in the patient going through a lot of pain. Others also reported confusion as a result of a lack of adequate education on the condition and treatment. Whereas, others reported having received adequate education on the condition and treatment. All participants again reported not being informed about resources available.

Lack of knowledge about the condition and treatment resulted in confusion

"One thing I've always wanted to ask is that people say the man is old so doctors telling us that he needs surgery is all lies. They just want to take our money" love

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

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

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

Participant, however, received education on condition and treatment

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

Participant did not receive any education but read about it from the internet

*"No one but what I do is I read around the condition and also on the medications from the internet. Apart from consulting our family doctor friend" **Hope***

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

*"I have never been to a counsellor before, wasn't aware they existed in this hospital" **Favour***

*"I have not visited a counsellor. I am not aware of their services. More so I cannot afford their services" **Humble***

"I have never sought counselling services anywhere; I didn't even

*know there is something of that sort in this hospital" **Passion***

Misconception about the condition

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

*"People say it is a condition that has no cure so I was scared when I first heard he has cancer" **Love***

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

*"Because it is a condition that kills" **Mercy***

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

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

*"Because I know it is not a good illness, it mostly kills its victims" **Favour***

*"Because some people say it is infectious, others also say it kills its victims within a short time" **Kindness***

*"What I know about cancer is that it is a wound that develops inside the body, so when you are put on medications for some time you get cured and that is all. But when we came here, we were told that he was going to have the surgery because of cancer and that got me worried. Meaning, I was wrong about the condition. I also heard that it can kill and the fact that my husband is going through so much pain because of this cancer is also something that tells me that cancer is much more serious than I thought" **Passion***

Theme 2: Resources

Limited resources were reported as barriers to caregivers roles. Relevant themes that emerged include; financial constraints and lack of accommodation,

Financial constraint

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

*"We were required to deposit Ghc1000, that same day so that the surgery can be done the following day but unfortunately for us, we could not raise the amount so we had to go back and come after we raised the money" **Love***

*"In the beginning, I took a loan, because I had spent all my money on medical expenses" **Peace***

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

*condition. He tried about four different herbal facilities” **Forgive.***

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

*“Another issue has to do with money, the little money we raise must go into this sickness. Either we are buying medications or paying for hospital bills and lab test. We are both retired. Besides, I believe that as pensioners some of the medications must be free, we have served the country our entire life. The national health does not cover most of the investigations. At our age, we don't have money, the government must do something about it” **Mercy.***

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

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

Lack of accommodation facilities

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

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

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

Theme 3: Caregiver-Nurse Relationship

A good nurse-caregiver relationship has therapeutic benefits however, participants reported concerns in this regards. Sub-themes that emerged include poor communication between caregiver and nurses and poor nurse attitude towards caregivers.

Poor communication

A primary role of cancer family caregivers involves interacting with various providers and professionals on behalf of their loved one. Lack of effective communication between healthcare personnel and family caregivers is an

important issue, particularly because it can lead to errors and poor patient outcomes. Findings from the study show that patients went through avoidable pains as a result of ineffective communication. Also, resulted in an unnecessary waste of resources and the feeling of inadequacy.

Participants reported poor communication as follows:

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

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

*"Sometimes I don't even know what to do to help him because no one told me anything" **Passion***

As if the challenges encountered by these family caregivers are not enough; even within the health care environment are faced with even more difficulties which further impact on their role. Family caregivers encounter many difficulties within the hospital environment that affect the care they provide to their patients. Healthcare environment/ professionals especially nurses are insensitive to these unmet needs and thus, are not able to provide them with the necessary support to effectively provide the care expected of them. Participants shared their experience on the challenges they encountered within the hospital environment

Poor Staff Attitude

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

A wife of one of the patients' stated:

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

Another participant also mentioned

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

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

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

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

Participant complained about lack of support from hospital staff

*"Mostly when we come, I have to do all the errands, go here, go there, and also wheel him around all by myself so this time my son was home so we came with him. Formally, some orderlies help relatives with wheeling of patients but now they don't do it anymore. You can just imagine that if I had not come along with my son what I was going to do because I couldn't have wheeled him around in this state" **Forgive***

Participant, however, commended the nurses for their good work

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

Discussion

Summary of key findings

This study sought to explore the barriers encountered by the family caregiver of people with prostate cancer. Family caregivers are faced with diverse challenges as they take up the role of caregiving. The findings of the present study revealed major challenges such as lack of preparedness towards the caring role, lack of knowledge about condition and treatment, misconception about the condition, financial constraints. Poor staff attitude and poor communication concerns between caregivers and healthcare professionals were also reported. However, all other findings under these themes are discussed below.

Synthesis of study findings with previous evidence

Lack of preparedness towards caregiving role was a major concern among all the participants. The family caregivers reported receiving no preparation towards the role of caregiving hence lacked the knowledge and skills to effectively play the role. According to Schumacher, Stewart and Archbold (31) preparedness describes the family caregiver's perceived readiness for the caregiving role, which encompasses multiple domains, including the provision of physical care, emotional support, and instrumental support. Considering the difficulty involved in providing care to a patient, these caregivers must be empowered with the skills and knowledge needed to embark on this journey. However, the case is not so. Like the findings reported in this study, Mazanec, Reichlin, Gittleman and Daly (8) stated that family caregivers often feel unprepared to provide care, have inadequate knowledge to deliver proper care, as well as receive little guidance from the formal health care providers. Besides, the report from the participants of the current study showed that they were more than willing to take on the responsibility of patient care, despite preordained financial and psychological burdens as most of these caregivers considered the assistance they provided as "Giving back". Yet, they lacked the skills and knowledge required to take up the role. In contrast, a study

by Scherbring (32) found no association between caregiver lack of preparedness and caregiver burden/ barrier to care, a finding also supported by Fujinami et al. (9). A single salient reason that can be drawn from this finding is that preparing the family caregiver for the task ahead is very important if health personnel have the wellbeing of both the patient and carer at heart.

Findings from the study revealed that knowledge about the condition and its management was one area that healthcare providers both nurses and physicians have neglected (33). Most of the participant reported having received little to no knowledge at all on the condition and its management. It was reported that the number of times to administer the medication was communicated to them, however, no education was given on the side/ adverse effects of the medications, how to identify these side effects and even the measures to take at home before bringing the patient back to the health facility if necessary. Sajjadi et al [15] and Etemadifar et al. [34] affirm this assertion by stating that caregivers reported the failure of specialists in giving the required personal information and specialist knowledge about the patients' disease and the caregivers' health as a major problem that remained unmet. Travis, Bethea and Winn (35), further reported that the lack of knowledge on the condition and its management resulted in medication errors. It is therefore imperative that as health practitioners the required information is provided to reduce the uncertainty and stress among these family caregivers thus, promoting patients quality care.

Again the findings of this study disclosed that the majority of the participants expressed a lot of misconception about the condition. This indicates that culture plays a major role in how caregivers perceive and go about the caregiving role. Some participants reported that cancer may be contracted as a result of immoral behaviour or punishment from God which is consistent with the finding of a study by Kuan (36). Others also believe it is a punishment from one's enemies for mistreating them, this mirrors findings from Lui and Ip (37). Another finding reported by participants was that cancer is contagious and fatal, an asserted confirmed by Lee and Bell (38). These beliefs resulted in fear/ panic and further decreased the support network (39). A single relevant perspective that can be drawn from this finding is that the people within the context of the study needs to be well educated about prostate cancer/cancer in general. However, in contrast to the work of (40), no association was reported between caregiver tension and the diagnosis of cancer.

Financial constraint was another problem that came up. Majority of the participants complained of financial difficulties. Some had to depend on their children, friends and other family relatives, others went for loans. Some participants had to use up their savings, and retirement benefits. Some of the patients /participants had to try herbal preparation due to the high cost of treatment. And others went bankrupt due to the expenses involved in managing this condition. This finding is echoed by Given and colleagues who reported in their study that, caregivers of cancer patients took loans, sold their homes and used other financial resources to pay for the expensive cost of treatment that was not covered under health insurance and even went bankrupt (12,13). The finding also revealed that most of these caregivers had lost their livelihood due to the increased physical and financial burden associated with the role (41,42). This financial challenge appears to reflect the economic status of the study setting as Cape Coast is one of the poorest regions in Ghana. However, in contrast with the findings of the present study, Mosher et al. (43) revealed that complementary and alternative medicine was viewed to be more favourable/ effective. Participant in the present study rather worsens their condition making the caregivers' role more difficult when they opted for the use of herbal preparation. To add to existing knowledge report from the current study revealed that the use of herbal preparation for the management of prostate cancer rather worsened the patient condition further causing more distress/stress to the caregiver.

Finding has revealed that not only do these unpaid caregivers encounter problems at home as they play the role of caregiving, but the healthcare environment is also another place that may contribute negatively to the caregiving role

resulting in more stress and distress among these family caregivers. Lack of accommodation facility was a problem within the healthcare environment. Majority of the participants narrated how they slept on floors outside of the ward in the open, exposed to harsh weather conditions and mosquito bites all because the hospital has not provided a place for caregivers who have their patients on admission to rest or spend the night. Others also mentioned that they had to stay because their home is quite a distance from the hospital, and as such commuting to and from the facility was financially draining coupled with their loss of livelihood and expensive medical cost making life very difficult. This finding is consistent with the work of Sadigh, Nawagi and Sadigh (44) who studied the Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda revealing that Ninety per cent of informal caregivers stayed at the hospital for 11 days on average, with a range of 1-60 days. While staying at the hospital, 89% slept on the hospital floor. Three per cent returned home each evening to sleep, two per cent slept in the prison barracks where members of the police force stayed, one per cent slept in Bwaise, an urban slum and other one per cent shared the hospital bed with the patient. This finding indicates that it is very important that hospitals provide a place of resting for these family caregivers especially considering a referral point hospital like the regional hospital to relieve some of the stress and burden associated with the role.

Similarly, poor staff attitude/communication was also reported as a challenge encountered within the health care environment. Some of the participants reported waiting long hours at the Out Patient Department (OPD) before the clinic starts. Other also complained of poor staff attitude making it difficult for them to be approached, and neglect of patient care when a family caregiver is not around. Of concern in these findings were caregiver reports of a poor attitude. According to Delicado et al. (45) nurses' attitudes and activities with caregivers are influenced by lack of time, hospital workload and organization. Although these reports were few and most caregivers tolerated such behaviour, it made coping/ information seeking difficult. It is, therefore, necessary that healthcare providers ensure better behaviour to improve upon customer service and patient/caregiver satisfaction through the organization of workshops for its staff. Effort must also be made to increase the staffing numbers.

Conclusion

Caregiving is associated with significant barriers that hinder family caregiver ability to effectively care for these patients. This study has brought to light some of the barriers encountered by this group. Therefore, as healthcare professional especially nurses it is important that these family caregivers are equipped with the knowledge, skills, resources and supports to provide care, as well as prepared adequately towards the new role while maintaining their health and well-being, and providing cancer care for their patients.

Implications of the study findings for nurses.

The findings of the study have several implications for nurses in relation to nursing practice and research.

Nursing Practice

For ages, health care providers and most importantly nurses have concentrated on providing care for patients while neglecting the needs and concerns of the family member/loved ones who cared for these patients at home. The findings of this study have brought to light that these family caregivers are hidden patients themselves, hence as nurses, we must perceive them as such so that care can be extended to them. Similarly, nurses must endeavour to assess the family caregivers needs to help provide the care/assistance required. To achieve this, the nurse must develop a professional relationship with the patients and their family caregivers, especially those that build trust and

emotional support to help caregivers to feel more comfortable and willing to express their feelings. Furthermore, family caregivers need preparation to meet the demands of their new responsibilities. Nurses must, therefore, focus on adequately preparing the caregivers (with the knowledge, information, skills and resources) to assume the caregiver role. Likewise, there is the need to provide both patients and family caregivers/community, information on the causes, sign/symptoms, management of cancer (prostate cancer) as this will help a long way to clear the misconceptions these family caregivers have about the condition.

Nursing Research

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

Limitations of the study

The focus of the study was on family caregivers of prostate cancer patients. However, it is important to acknowledge challenges at all levels especially with the healthcare personnel and the patients themselves. Thus, the findings may not necessarily be representative of caregivers of patients with other health conditions. Nevertheless, the researcher was not interested in the generalization of finding, rather making meaning into experiences shared by participants. The findings also revealed that all of the participants were Christians (not purposeful), there could be a limitation with application to the non-Christian population. Also, culture played a major role in the caring role of these family caregivers in the current study context, however, other groups within the country may present a different picture.

Declarations

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Availability of Data and Materials

The datasets used and/or analysed during the current study are available from the corresponding authors on reasonable request.

Authors Contributions

BO and JPN conceived and designed the study. BO was responsible for the acquisition of data. BO, JPN and EAA were responsible for coding of data. All authors contributed to interpretation of data. BO wrote the first draft of the paper. All authors were involved in the subsequent revision and approved the final manuscript.

Competing Interest

The authors declare that they have no competing interests

Consent for Publication

Not applicable

Ethical Approval and Consent to participate

Ethical approval was sought from the Institutional Review Board (IRB) of the University of Cape Coast (UCC) (UCC1RB/CHAS/2018/24) and the Cape Coast Teaching Hospital (CCTH/RDS/2019/41). Written informed consents were signed/thumbprint by all participants.

References

1. Bray F, Ferlay J, Soerjomataram I, Siegel R, Torre LA, Jemal A. Global cancer statistics 2018: GLOBOCAN estimates of incidence and mortality worldwide for 36 cancers in 185 countries. *CA Cancer J Clin* [Internet]. 2018 [cited 2020 Mar 11];68(6):394–424. Available from: <https://www.wcrf.org/dietandcancer/cancer-trends/prostate-cancer-statistics>.
2. Ferlay J, Colombet M, Soerjomataram I, Mathers C, Parkin DM, Piñeros M, et al. Estimating the global cancer incidence and mortality in 2018: GLOBOCAN sources and methods. Vol. 144, *International Journal of Cancer*. Wiley-Liss Inc.; 2019. p. 1941–53.
3. Adeloje D, David RA, Aderemi AV. An Estimate of the Incidence of Prostate Cancer in Africa: A Systematic Review and Meta-analysis. *PLoS One*. 2016;11(4):e0153496.
4. Obu R. The impact of alternative medicine in Ghanaian men of African descent diagnosed with prostate cancer. Kolkata: Indian Board of Alternative Medicine; 2015.
5. Arthur F, Yeboah F, Adu-Frimpong M, Sedudzi E, Boateng K. Prostate cancer screening in Ghana - a clinical benefit? *J Sci Technol*. 2006;26(1):1–7.
6. Agbenyefia G. The Interface Between The Health Professionals and Lay Caregiver at Koforidua Central Hospital In The Eastern Region of Ghana. University of Ghana; 2017.
7. Berry LL, Dalwadi SM, Jacobson JO. Supporting the Supporters: What Family Caregivers Need to Care for a Loved One With Cancer. *Am Soc Clin Oncol*. 2018;13(1):35–42.
8. Mazanec S, Reichlin D, Gittleman H, Daly B. Perceived Needs, Preparedness, and Emotional Distress of Male Caregivers of Postsurgical Women With Gynecologic Cancer. *Oncol Nurs Forum*. 2018;45(2):197–205.
9. Fujinami R, Sun V, Zachariah F, Uman G, Grant M, Ferrell B. Family caregivers' distress levels related to the quality of life, burden, and preparedness. *Psychooncology*. 2015;24(1).
10. Nayak MG, George A, Vidyasagar MS. Perceived Barriers to Symptoms Management among Family Caregivers of Cancer Patients. *Indian J Palliat Care* [Internet]. 2018 [cited 2018 Nov 12];24(2):202–6. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/29736126>.
11. Limburg H, Shaw AK, McBride ML. Impact of Childhood Cancer on Parental Employment and Sources of Income: A Canadian Pilot Study. *Pediatr Blood Cancer*. 2008;51(1):93–8.
12. Given BA, Sherwood P, Given CW. Support for caregivers of cancer patients: Transition after active treatment. *Cancer Epidemiol Biomarkers Prev*. 2011;20(10):2015–21.

13. Bradley S, Sherwood PR, Donovan HS, Hamilton R, Rosenzweig M, Hricik A, et al. I could lose everything: Understanding the cost of a brain tumour. *J Neurooncol.* 2007;85(3):329–38.
14. Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scand J Caring Sci.* 2018;32(1):309–16.
15. Sajjadi M, Rassouli M, Abbaszadeh A, Brant J, Majd HA. Lived Experiences of “illness Uncertainty” of Iranian Cancer Patients: A Phenomenological Hermeneutic Study. *Cancer Nurs.* 2016;39(4):E1–8.
16. Asuquo EF, Etowa JB, Adejumo P. Assessing the Relationship between Caregivers Burden and Availability of Support for Family Caregivers’ of HIV/AIDS Patients in Calabar, South-East Nigeria. *World J AIDS.* 2013;3(4):335–44.
17. Otis-Green S, Juarez G. Enhancing the Social Well-Being of Family Caregivers. In: *Seminars in Oncology Nursing.* WB Saunders; 2012. p. 246–55.
18. Amoah G, Acheampong DO, Kofi Christian GS, Acheampong E, Azorliade R, Addai Arhin KA, et al. Knowledge, Attitude and Perception of Prostate Cancer among Male Adults in the Kumasi Metropolis: A Descriptive Cross-Sectional Study. *J Urology Res [Internet].* 2018;5(2):1–9. Available from: <https://www.jscimedcentral.com/Urology/urology-5-1099.pdf>.
19. Yeboah-asiamah B Perception and Attitude About Prostate Cancer Among Male Teachers In The Sunyani Municipality (A Doctoral dissertation at the University of Ghana) [Internet]. University of Ghana, Legon; 2015. Available from: <http://ugspace.ug.edu.gh/handle/123456789/8195>.
20. 10.1016/j.afju.2016.12.003
Yeboah-Asiamah B, Yirenya-Tawiah D, Baafi D, Ackumey MM. Perceptions and knowledge about prostate cancer and attitudes towards prostate cancer screening among male teachers in the Sunyani Municipality, Ghana. *African J Urol [Internet].* 2017;23(3):184–91. Available from: <http://dx.doi.org/10.1016/j.afju.2016.12.003>.
21. Calys-tagoe BNL, Yarney J, Kenu E, Adwoa N, Amanhyia KO, Enchill E. Profile of cancer patients’ seen at Korle Bu teaching hospital in Ghana (A cancer registry review). *BMC Res Notes.* 2014;7(1):577.
22. Otoo V. Awareness of Prostate Cancer Among Male Soldiers In Ghana Armed Forces [Internet]. University of Ghana, Legon; 2010. Available from: [http://ugspace.ug.edu.gh/bitstream/handle/123456789/21711/Awareness of Prostate Cancer among Male Soldiers in the Ghana Armed Forces_2010.pdf?sequence = 1](http://ugspace.ug.edu.gh/bitstream/handle/123456789/21711/Awareness%20of%20Prostate%20Cancer%20among%20Male%20Soldiers%20in%20the%20Ghana%20Armed%20Forces_2010.pdf?sequence=1).
23. Ofori M. Experiences of Spouses of Men with Advanced Prostate Cancer in the Accra Metropolis (Doctoral dissertation, University of Ghana). [Internet]. University of Ghana, Legon; 2017. Available from: [http://ugspace.ug.edu.gh/bitstream/handle/123456789/23491/Experiences of Spouses of Men with Advanced Prostate Cancer in the Accra Metropolis.pdf?sequence = 1&isAllowed = y](http://ugspace.ug.edu.gh/bitstream/handle/123456789/23491/Experiences%20of%20Spouses%20of%20Men%20with%20Advanced%20Prostate%20Cancer%20in%20the%20Accra%20Metropolis.pdf?sequence=1&isAllowed=y).
24. Creswell JW. *Research design: International student edition.* Sage; 2014.
25. Glaser B, Strauss AL. *Discovery of grounded theory: Strategies for qualitative research.* Routledge.; 2017.
26. 10.1371/journal.pone.0232076
Guest G, Namey E, Chen M. A simple method to assess and report thematic saturation in qualitative research. *PLoS One [Internet].* 2020;15(5):1–17. Available from: <http://dx.doi.org/10.1371/journal.pone.0232076>.
27. Colaizzi PF. *Psychological research as the phenomenologist views it.* 1978.
28. Giorgi A. *The descriptive phenomenological method in psychology: A modified Husserlian approach.* Duquesne University Press.; 2009.
29. Lincoln YS, Guba EG. Establishing trustworthiness. *Nat Inq.* 1985;289:331.

30. Caelli K. Engaging With Phenomenology: Is It More of a Challenge Than It Needs to Be ? *Qual Health Res.* 2001;11(2):273–81.
31. Schumacher KL, Stewart BJ, Archbold PG. Conceptualization and Measurement of Doing Family Caregiving Well. *J Nurs Scholarsh.* 1998;30(1):63–70.
32. Scherbring M. Effect of caregiver perception of preparedness on the burden in an oncology population. *Oncol Nurs Forum.* 2002;29(6):70–6.
33. Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: a qualitative study. *Scand J Caring Sci.* 2018;32(1):309–16.
34. Etemadifar S, Bahrami M, Shahriari M, Farsani AK. The effectiveness of a supportive educative group intervention on family caregiver burden of patients with heart failure. *Iran J Nurs Midwifery Res.* 2014;19(3):217.
35. Travis SS, Bethea LS, Winn P. Medication administration hassles reported by family caregivers of dependent elderly persons. *Journals Gerontol - Ser A Biol Sci Med Sci.* 2000;55(7):412–7.
36. Kuan Lee Wai J. *Cancer and the Family: Distress and Quality of Life among Chinese speaking patients and family caregivers* [Internet]. University of British Columbia; 2016. Available from: <https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0319081>.
37. Lui C, Ip D. Ethnic Experience of Cancer: A Qualitative Study of Chinese – Australians in Brisbane, Queensland. *Soc Work Health Care.* 2009;48(1):14–37.
38. Lee J, Bell K. The Impact of Cancer on Family Relationships Among Chinese Patients. *J Transcult Nurs.* 2011;22(3):225–34.
39. 10.1016/j.ejon.2013.03.007
Cheng H, Sit JWH, Chan CWH, So WKW, Choi KC, Cheng KKF. Social support and quality of life among Chinese breast cancer survivors: Findings from a mixed-methods study. *Eur J Oncol Nurs* [Internet]. 2013;17(6):788–96. Available from: <http://dx.doi.org/10.1016/j.ejon.2013.03.007>.
40. Lee MD. Correlates of consequences of intergenerational caregiving in Taiwan. *J Adv Nurs.* 2007;59(1):47–56.
41. Brazil K, Bainbridge D, Rodriguez C. The Stress Process in Palliative Cancer Care: A Qualitative Study on Informal Caregiving and its Implication for the Delivery of Care. *Am J Hosp Palliat Med.* 2010;27(2):111–6.
42. Family Caregiver Alliance. *Caregiver Statistics: Work and Caregiving* | Family Caregiver Alliance [Internet]. Family Caregiver Alliance. 2016 [cited 2019 Jul 4]. Available from: <https://www.caregiver.org/caregiver-statistics-work-and-caregiving>.
43. Mosher CE, Ott MA, Hanna N, Jalal SI, Champion VL. Coping with physical and psychological symptoms: a qualitative study of advanced lung cancer patients and their family caregivers. *Support Care Cancer.* 2015;23(7):2053–60.
44. 10.1016/j.aogh.2016.06.005
Sadigh M, Nawagi F, Sadigh M. The Economic and Social Impact of Informal Caregivers at Mulago National Referral Hospital, Kampala, Uganda. *Ann Glob Heal* [Internet]. 2016;82(5):866–74. Available from: <http://dx.doi.org/10.1016/j.aogh.2016.06.005>.
45. Delicado Useros MV, Espín AA, Parra EC, Martínez AB. Family Caregivers: Nurses' Perceptions and Attitudes. *Soc Med* [Internet]. 2012;6(3):151–61. Available from: <http://www.socialmedicine.info/index.php/socialmedicine/article/view/609/1206>.
46. Declaration.

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