Lived experiences of prostate cancer patients below 55 years of age: A phenomenological study of outpatients receiving treatment at the Uganda Cancer Institute

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Abstract

Background: Cancer of the prostate is globally the second commonest cancer among men. Its incidence in Uganda is rising and is currently reported at 5.2%. It is responsible for about 25% of cancer deaths among male Ugandans. The diagnosis and treatment of prostate cancer is associated with massive psychosocial effects on top of the biomedical implications both for the patient and the healthcare system. Understanding these implications from the patients' perspective may help inform service planning and resource allocation. This study aimed to explore the lived experiences of men below 55 years of age with prostate cancer at Uganda Cancer Institute.

Methods: The study design was qualitative with a phenomenological approach based on social constructivism theory. Open ended questions were used to conduct in-depth interviews with purposively selected prostate cancer patients at Uganda Cancer Institute (UCI) until theoretical saturation was reached. Their care givers were also interviewed to aid triangulation. Thematic-content analysis of data was performed using Tesch's eight steps.

Results: Twelve patients and eight care givers were interviewed. The recurrent themes were lack of information and unavailability of health workers, altered lives and/or state of doubt, sense of loneliness and lack of support groups. Two marriages were broken as a direct consequence of the experience with prostate cancer. Inconsistent information or complete lack of it and unacceptably long waiting times led to disillusionment and frustration with the health care system. None of the participants received any counseling.

Conclusions: The unmet needs from these experiences included psychosocial support, clarity of information and psychosexual support for treatment related side effects. Strengthening a holistic multidisciplinary approach and creation of support groups may help improve the experience with prostate cancer in Uganda. **Keywords:** prostate cancer, lived experience, phenomenology, Uganda

Main Text

Introduction

There is arguably a global cancer crisis. It is predicted that the global burden of cancer will reach just over 22.2 million by the year 2030. Three quarters of these will be in lowand middle-income countries (LMICs).[1],[2] This burden puts a financial and psychosocial strain on health systems, families and individuals affected by cancer. Prostate cancer is the second most common cancer in men. The incidence is on the rise in Uganda and is currently reported at 5.2%.[5] In 2014, it was responsible for 25.1% of cancer deaths among male Ugandans. Despite this relatively high percentage, the median survival of new pathologically diagnosed prostate cancer in Uganda ranges between 8 to 12 years.[6] During this time, patients have to face the consequences of treatment that include sexual dysfunction, urinary incontinence, bowel problems, anxiety, depression and a generally reduced health related quality of life.[7] From studies of patients' lived experiences, sexual dysfunction is reported to be the most devastating and is worse following radical surgery.[8] Studies elsewhere have shown that a diagnosis of prostate cancer is associated with a massive psychosocial onslaught on the patient far beyond the physical diagnosis itself and/or side effects associated with treatment.[9] Lack of adequate information and counseling on expected experiences before, during and after treatment commonly leads to disillusionment and non-adherence to conventional medical/surgical treatment. This among other system factors could explain the 55% rate of loss to follow up of prostate cancer patients in Uganda.[6] Improving quality, coverage and acceptability of prostate cancer care in Uganda would among other things require a patient centered approach. This involves an understanding of patients' lived experiences in order to inform policy and resource allocation. Such psychosocial knowledge and support could potentially reduce delay in seeking care and improve adherence to proposed standard treatment.[10],[11] There is no published data regarding experiences of Ugandan men diagnosed with prostate cancer. This study aimed to fill this knowledge gap by exploring the lived experiences of relatively young men with prostate cancer in Uganda.

Methods

Theoretical perspectives and study design

The philosophical framework underlying the study is that of social constructivism. In this view, meaning is created by individuals as a result of their interaction with the world and its objects. Its ontology is therefore relativism/multiple truths while it is epistemologically subjective.[12] The individual's meanings are affected by their prior

knowledge, beliefs and culture. This however should be differentiated from constructionism in which meaning is or has been constructed by society or culture the individual belongs to.[13] By looking at the lived health related experiences of men with prostate cancer, the study set out to find the different meanings these men made out in their individual interaction with the disease (and its treatment modalities) and health care providers. The investigation therefore presents itself as eclectic and exploratory. A qualitative research design utilizing in-depth interviews was chosen to explore this concept. The design was chosen firstly due to the paucity of knowledge surrounding the experiences of men with prostate cancer in Uganda. Secondly, qualitative research would enable investigators to discover, understand and describe meanings people assigned to their lived experiences.[14] To qualitatively study this phenomenon, an interpretive phenomenological approach was chosen. Phenomenology strives to understand meaning of social phenomena from the perspective of those experiencing it.[15] It seeks a description, analysis and understanding of lived experiences.[16] The approach is interpretive because investigators made meaning out of the meaning participants made from their lived experiences.[17]

Study setting

The investigators recruited men below 55 years with prostate cancer at Uganda Cancer Institute between 17th/July/2017 and 14th /august/2017. The choice of age group was arbitrary and influenced by the authors' experience, growing cancer burden among young people and the greater reproductive health implications this poses on them. Data collection took place at Uganda Cancer Institute –Mulago, which is the country's national cancer center. On a typical day at the Cancer Institute, patients are sent to the general outpatients following triage where they are either admitted to the wards or scheduled for review by a specialist depending on the type of cancer. Private and general prostate cancer patients are seen on Fridays and Wednesdays respectively on an outpatient basis by a physician who runs the clinic. Patients requiring admission are accorded all the care they need and are admitted either on the general or private ward. Study subjects were recruited from general outpatients, Wednesday and Friday clinic and from the wards. Face-to-face interviews were conducted at Uganda Cancer Institute (UCI), in a room that was provided by the Nurse in-charge. This allowed for a comfortable naturalistic setting so that the phenomenon of interest is not manipulated.[18] Only the participant, interviewer and in a few instances the carer were present to encourage comfort and openness of the participant.

Sampling and sample size

This research used purposive sampling in order to obtain participants who have direct experience of the phenomenon being studied. After interviewing 12 men with prostate cancer and 8 care givers, new participants did not generate any new findings and the sample size was considered to have been achieved.[19] Some participants were interviewed more than once for purposes of ensuring clarity. We included men with a diagnosis of prostate cancer, enrolled in care at UCI and currently undergoing or have completed treatment such as prostatectomy, chemotherapy, radiotherapy and/or hormonal therapy with ability to understand and speak English and/or Luganda. Critically ill patients were excluded. Family and/or caregivers were asked to participate if they were above 18 years of age.

Ethical considerations

The study received ethical clearance from the faculty of health sciences of Uganda Martyrs University Nkozi and UCI Research and Ethics Committee. All participants were availed adequate information and a consent form before participation in the study. Data was anonymized and stored in hardcopies, audiotapes and locked away in a secure cabin accessible to only the investigators.

Data collection

We used in depth interviews for data collection. The following five open ended questions were used: Tell me about what it was like for you on that day you were told you had prostate cancer.

- How was your encounter with the healthcare professionals?
- How has prostate cancer affected your life?
- How have your relatives and friends been affected?
- How has your outlook on life been affected?

To ensure an in-depth understanding as well as aid triangulation of data, care givers were also interviewed. The questions below were used as a guide.

- Tell me how (name's) life has changed from the time he was diagnosed with prostate cancer
- How has (name's) illness affected your family?

The interviews were recorded and at the end of the interview, both the researcher and the participant listened to the audiotape to ensure audibility and completeness.

Establishing rigor

The following strategies were taken to ensure credibility, transferability, dependability/reliability and conformability: The investigators created rapport and spent time with patients as they attended their clinic appointments. This allowed for prolonged engagement. Thick rich descriptions of patients' experiences ensured transferability.

A decision trail and self-reflection was kept throughout the research process to ensure reliability. These reflections together with bracketing and use of longer quotes promoted conformability. Use of field notes, member checking and triangulation ensured credibility. For member checking, we presented the main themes of the findings through a follow up interview with the participants to find out whether their views were well presented, and this was carried out on their next visits to avoid change of opinions. Interviewing care givers provided for triangulation of data.

Data analysis

Data analysis was an iterative process.[14] Thematic content analysis was used. This is an inductive approach of analyzing qualitative data.[20] The data was organized categorically and chronologically, reviewed repeatedly and continually hand coded using color code schemes. Participants' taped interviews and diaries were transcribed verbatim. Open coding was carried out where the investigators read each transcript and made notes in the margins of words, theories or short phrases that summed up what was being said in the text. The process followed Tesch's eight steps of the coding process.[21]

Results

The characteristics of the study participants are summarized in the Table.

Lived experiences

Data from each participant was processed and organized separately, later it was grouped together to form the experiences. To develop central and meaningful structures of the experience, we used the four existential: lived time, body, space, relations (Figure).

Lived time (temporality)

This is subjective time as opposed to objective time or clock time.[22] Lived time is time that appears to speed up when we are enjoying ourselves or slow down when we are experiencing a disinteresting situation.

Altered lives

Following diagnosis, planned time was disrupted in terms of the things/achievements they looked forward to in the future.

[.....] I do not know how our children are going to stay in school because he is now sick therefore I have to work harder (KG's wife).

State of doubt

Following treatment, time was perceived as being more unpredictable as men had to find their own way of living in the moment.

[.....] Each time I was going for the follow up blood tests I was scared of what the doctor would say, what will happen to me. After the diagnosis, I did not care about sexual desires what mattered was that I am alive, and I have hope that I will live long. (PQ) PQ's example shows that as time passed by he came to terms with his condition and time took on more regularity than it had for many months and he became accustomed to living in the moment. Therefore, plans and life change according to the will of the ill body and what seemed to be important in the past loses its meaning when life is at stake.

Lived body (corporeality)

This describes how participants perceived their bodies through their cancer journey and the limitations or demands that the cancer brought on them.

Becoming a changed man

Men described their bodily experiences from the symptoms they had prior to diagnosis to the changes they encountered while on treatment. Prostate cancer came as a stumbling block in men's path. Participants presented with "bloody urine, urine retention, straining while urinating, back pain" These symptoms disrupted the normal flow of life. Upon diagnosis participants were 'shocked" "surprised" others were filled with "fear" with limited time for adjustment. The example of KJ illustrates how prostate cancer affected men's bodily experience of the world.

[....] I went to see a doctor because I had back pain which he attributed to my work and gave me medicine, however later I developed paralysis of the lower limbs and also the pain worsened that I could no longer help myself and that is when I realized that my health was at stake (KJ).

For other men the illness became evident through the troublesome treatment side effects of "reduced libido, urine incontinence, muscle weakness. BA's example explains how he struggled with the unnoticeable changes in his life.

[.....] When I started treatment, I realized my sex function was going down, so I used some herbal medicine, but it did not work, so I decided to stop going for treatment because I thought I would be better (BA).

The examples illustrate a direct impact of the cancer on the physical body.

Lived space (spatiality)

The space in which we find ourselves affects the way we feel, and we become the space we are in.[22] In this study, prostate cancer had a profound impact on men's

lives and created much grief in response to the loss encountered. Prostate cancer caused interruptions and required adjustments to the unexpected changes in personal, professional and social life. Two themes arose:

Seeking information

Visiting doctors for follow up blood tests are part of the spectrum of living with prostate cancer which requires a supporting health care system and if not, well oriented life becomes overwhelming as MJ reports:

[....] Whenever we go to the hospital we always wait for long before we see the doctor and they are usually few and, in a hurry, so we don't get time to ask questions or even explain how we are feeling. We leave when we are tired and frustrated. The government should help us (MJ).

This shows that besides men with prostate cancer living with the impact of being chronically ill, they also have barriers to overcome in accessing health services.

Sense of loneliness

The other difficult aspect of the disease that was portrayed was those times when men felt isolated and lonely as a result of living with this chronic illness. This was illustrated in SK and MJ's story

[.....] When I was diagnosed with the cancer I became weak and could not support my family, so my wife does most of the work. Due to her work commitments I come for hospital appointments alone, I feel I am a burden (SK)

[....] Due to her work commitments I sometimes stay home alone, and I find myself worrying a lot (MJ)

Lived relations

Being relational means living in relation to others, in recognition of interconnectedness with others.[23] As human beings we are part of the social network that is impossible to ignore. External actions have an effect on our lives especially. In this study, lived relations were expressed in two themes: consistent support and insufficient information from health workers.

Consistent support

Majority of the men were grateful for the support they received from family. BA felt that, "spending time with family is time well spent because they offer the greatest support" during challenging experiences. LG stated, "My wife was very supportive. She helped me accept my sexual changes and I stopped missing my appointments." All of the married men indicated that the most significant emotional and physical support was received from their spouse. This provided a sense of belonging. Two men

reported that their relationships deteriorated after the diagnosis and this frustrated them the more.

Insufficient information from health care workers

All men reported not to have received enough information from health care providers about their illness (duration, treatment options, and expected outcomes). This strained the doctor-patient relationship. More than one participant commented on how the physicians' shortage impacted on the waiting hours and delayed management and in so doing they lost trust in the healthcare system.

Discussion

Interaction with health care providers.

The findings suggest that upon hearing the cancer diagnosis, the men in this study experienced a defining moment. Participants described it as a shock that left them with uncertainty about the future. They reported a mental block and needed time to absorb the news about the diagnosis of cancer. The findings are supported by evidence that the diagnosis of a chronic illness like cancer involves a progression through the five stages of grief.[24] The first stage being denial; it involves an unconscious refusal to accept the facts and in this study it is the confirmation of prostate cancer. It is usually associated with shock and lasts a few days though some people may be locked in it. The second stage is anger followed by bargaining where participants where asking 'why me'. The fourth stage is depression; it involves sadness, fear and uncertainty. The last stage is acceptance which lasts several months. Scaling up psychosocial and spiritual support for prostate cancer patients could help make this experience more bearable.[10] From the study, no man had ever received voluntary screening. In an earlier study, 85.7% of Ugandan men had never been counseled by any physician to undergo screening for prostate cancer.[25] In an attempt to increase awareness, relevant information sources such as media, internet and friends should be used. However, these sources are inadequate without input from health workers.[26] The unavailability of accurate and consistent information caused desperation and loss of trust in health workers and the health care system. In studies done elsewhere, men expressed inconsistent care from the nurses and lack of understanding of the support received from health care workers in dealing with treatment side effects such as urinary incontinence and erectile dysfunction.[27],[28] This has been attributed to limited training of counselors in men's health issues. [29]. Such a situation impedes patient centered decision making and has a negative effect on adherence to treatment.

Experience with the treatment of prostate cancer: understanding the

treatment given and its impact

All the twelve participants interviewed were on treatment and had received hormonal therapy. Only two participants had received surgery. This could be due to the fact that more than 60% of the men in Uganda present with advanced prostate cancer and hormonal therapy is commonly the main stay of management in such cases.[6] The late presentation is attributed to the low levels of awareness about the cancer.[25] At a point when men had accepted their status, new waves appeared namely; treatment side effects, problems with sexuality, a new awareness of the physical body, a feeling of being left alone and distress in the marital relationship. All the participants reported sexual dysfunction and a few reported urine incontinence. These were the main concerns confirmed to have had a serious impact on their lifestyles. The less visible bodily changes especially sexual dysfunction was brought into focus when men tried to fulfill their sexual desires and realized that they were unable to maintain an erection. These men were at risk of rejection, loss of intimate relationships and social withdrawal/depression. In an attempt to preserve sexual function some men defaulted on treatment. Other least frequently mentioned changes were loss of muscle, body weakness and breast enlargement. Evidence elsewhere confirms our findings of incontinence and impotence being the most feared complications of prostate cancer treatment. These side effects led men to opt for inferior forms of treatment to preserve potency. They also tend to avoid public places due to urine leakage and bad odor.[7]-[9],[27] The regular use of diapers and catheter is always a constant reminder of the cancer. Inaccurate communication about treatment side effects is therefore bound to result in disillusionment, distrust towards the medical profession and poor adherence and/or high rate of loss to follow-up.[6],[9]

Support systems

The only reliable support system for participants was their family. Most of the men experienced consistent care and support from their partners as opposed to health workers who were rarely available when needed. From the literature, men's partners are looked at as anchors because they offer a sense of stability during difficult times.[30],[31]

For some of the participants however, the experience of prostate cancer led to a collapse of this support system. Key reasons for this were sexual dysfunction, financial challenges, impaired communication and role reversal.[32] Therefore in order to maintain their masculinity and society's expectations, some men either defaulted on their treatment with the hope of regaining sexual potency or chose social isolation and non-disclosure.[33]

It is known that the most valued support system for men with prostate cancer are direct peer support and their partners. [28] Addition of a healthcare worker helps with the provision of accurate evidence-based information to aid decision making and life choices for these men. Participants had no established support group that could help them in their silent struggles with the disease and its related consequences. None of the participants mentioned receiving care from counselors and psychologists who are vital in any cancer journey. This meant that many of their challenges like impotence, incontinence and other social issues were not addressed. [27], [29] Therefore, for health workers to respond adequately to the biological, psychological and social aspects of this cancer there is need for a holistic approach putting into context the importance of all the four-life world existential.

Conclusions

Participants felt frustrated by the healthcare system and the inconsistency of the healthcare workers. Their unmet needs included psychosocial support, clarity of information and psychosexual support for treatment related side effects. Most of the study participants had advanced disease. The study findings should therefore be interpreted against this backdrop. The lived experiences of these men suggest that prostate cancer care is rather narrowly skewed towards biochemical management rather than a holistic multidisciplinary approach. We recommend structured counseling and setting up prostate cancer support groups. We think that this would make the prostate cancer journey more bearable as well as provide both the nuclear and extended families of these men with coping strategies.

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