


'I got to understand what it means to be a cancer patient': Qualitative evidence from health professional cancer patients and survivors

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Abstract

Objective: The study sought to (1) examine healthcare professionals' (HCPs) lived experiences of cancer and (2) generate evidence to inform policy and clinical practice for cancer care.

Methods: This was a qualitative study conducted between January and December 2020 on HCPs who were ill with, or who had survived cancer in Uganda. Purposive sampling was used. A demographic form and an open-ended topic guide were used to collect data. Face-to-face and telephone interviews were conducted in English; audio-recorded data was collected until saturation was reached. Colaizzi's framework of thematic analysis was used.

Results: Eight HCP cancer patients and survivors from medical, allied health, and nursing backgrounds participated in the study. Their mean age was 56 years (29–85). Five were female. Four broad themes emerged from the interviews: (1) experience of pre-diagnosis and receiving bad news, (2) impact on self and role identity, (3) healthcare system and treatment experiences, and (4) the gaps and what should be done.

Conclusion: Cancer patient-hood introduces vulnerability and remarkable disruptions and suffering in nearly all domains of quality-of-life, that is, in professional identity and work, social, emotional, physical, and economic facets of life. Participants identified how they experienced a healthcare system which was costly and staffed by unmotivated staff with limited access to resources, which resulted in many unmet needs and an overall poor experience. Participants identified how, in their view, the healthcare system in Uganda needed to be better resourced, protected by policy and legislation and how cancer awareness among the population needed to be improved.

Keywords

Qualitative, survived cancer, health professionals, quality of life, palliative care

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Introduction

Being a cancer patient and/or survivor is a unique experience for a healthcare professional (HCP). Cancer survivorship has been defined as a facet of an individual's identity that consists of "the health and life of a person with cancer until the end of life."¹ Cancer remains a major and an increasing public health problem globally, being one of the leading causes of death and morbidity in both high-income countries (HICs) and low- and middle-income countries (LMICs). Cancer is the second leading cause of deaths in the United States² and the third in Australia.³ It is one of the major causes of death and morbidity in Africa, where cancer patients have the

poorest outcomes and the shortest survival rates when compared to other parts of the world.⁴ According to the GLOBOCAN 2018 report of the International Agency for Research on Cancer, Africa registered 811,200 new cancer

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cases (4.5%) and 534,000 cancer deaths (7.3%) of the total world cancer burden.⁵

It has been reported that a diagnosis of cancer brings a myriad of disruptions in the life of a person. For instance, worry about the uncertain future and fear of death creates persistent physical and psychological problems in cancer patients.⁶ Such problems manifest as disrupted social roles, threatened and, or actual loss of independence, self-esteem, depression, anxiety, fear, violence, difficulty in communication, and lack of willingness to participate in self-care programs^{7,8}

When HCPs receive a cancer diagnosis, their cancer experience is even more multidimensional; both subjective and tangible, and different compared to the experience of non-HCP patients,⁹ with this experience varying between different cultures.⁸ According to Kenny et al.,¹⁰ HCP patients' view of cancer patient-hood journey is influenced by their background knowledge of the illness. Prior professional background could lead to professional role ambiguity denoted by difficulty in 'handing-over' the professional identity and accepting the patient identity.^{9,10} The limited research done into gaining a deeper understanding of HCPs illness experiences shows that having a professional background can result in heightened tensions because of one's specific care needs but can also facilitate greater control over one's care.^{11,12} Evidence shows cancer survivors report finding meaning from their illness experiences and gain insights that affect the way they view life.¹³ This finding is corroborated by Fox et al.¹¹ and Wolf et al.,¹⁴ who found that HCPs lived experience of illness can yield rare insights about patient-hood, and this new lived 'twist' of life and newfound empathy can help improve one's future clinical practice and patient care.

Globally, and in Uganda, there's a rising trend in cancer incidence and prevalence. It is thus inevitable that many HCPs will receive a cancer diagnosis.³ However, there is scant evidence about the experiences of HCPs who become ill with cancer. Anecdotal evidence shows the experiences and support needs of HCPs who are recipients of cancer care differ from those of lay patients.^{9,10} What research has been done has concentrated on the experiences of cancer patients from a narrow scope of medical professions; mainly physicians and surgeons.^{3,11} There remains scant understanding of the experiences of other professional cadres such as nurses and the allied HCPs. Yet, differences in professional backgrounds could potentially reveal variations in cancer patient-hood experience, for example, due to factors such as medical hierarchy, and/or level of interaction and relationship with patients. Studying physicians may also over represent individuals with a particular socioeconomic status (SES). Furthermore, the existing research is disproportionately concentrated in high-resourced economies. Again, differences in SES can cause unique limitations in generalizing findings to low-resource contexts.

No inquiry has been conducted into the cancer experience of HCPs in neither Uganda nor Africa in general. Hence, the

study is the first to delve into this understudied area. The study aims to share novel insights of HCP patient-hood in a low-resourced context and illuminate common pitfalls in the health care system, and suggestions for improvement of cancer care as they apply to HCPs living with cancer in Uganda.

Methods

Study setting and design

The study was conducted in Uganda and employed descriptive phenomenology using thematic analysis as proposed by Colaizzi¹⁵ and Edward and Welch,¹⁶ to elicit and gain deeper understanding of the phenomenon under study; healthcare professionals' lived experiences of being cancer patients. The duration of the study from conception to completion was one year, that is, between January and December 2020.

Eligibility and sampling criteria

Participants were purposively sampled to include HCPs who; (1) had a current or previous diagnosis of cancer and (2) had completed or were undergoing cancer treatment. An HCP in the context of this study is defined as a professional with a background of medical, clinical or nursing training, that is, doctors, nurses, midwives, clinical officers, and dentists. Participants were recruited in liaison with cancer and palliative care providers. Settings included Mbarara Regional Referral Hospital oncology unit, Mobile Hospice Mbarara, Hospice Africa Kampala Uganda, and the Palliative Care Association of Uganda through Oncology nurses and palliative care providers. The research assistants in each of the study settings were given information about the study by the principal investigator (GN). They then identified individual eligible participants and briefly informed them about the study. For the eligible participants (HCP cancer patients or survivors) who were willing to participate in the study, the research assistants provided their contact details to GN, who then contacted each participant and provided them with detailed study information. Three of the participants were given study information and consented to participate by email, while five consented by hand signature on printed information-consent forms. Recruitment continued until data saturation was achieved.^{17,18}

Data collection

A demographic form and a topic guide written in English with open-ended themes were used to collect data. The topic guide was piloted on two non-health professional cancer patients. The topic guide comprised of themes on: pre-cancer diagnosis history, receiving and effect of bad news of a diagnosis of cancer, healthcare system and treatment experience, effect of cancer on the professionals' identity, and questions and recommendations of the participants. Data was collected

by GN between April and September 2020. Due to restrictions imposed by the Covid-19 pandemic, some interviews (three) were conducted over the phone, while five were face-to-face. Follow-up and probing questions like; *what do you mean by that? How did it make you feel?* (. . .) were added to seek a deeper understanding of the HCPs lived experiences. Each interview was audio-recorded using a mobile smart phone and saved using anonymized codes for later purposes of transcription. Data saturation was reached after eight participants were interviewed. Interviews lasted between 24 and 58 min. All interviews were conducted in English.

Rigor

It is important to report about some salient elements of the research team on this study. First, all the members of the research team were HCPs. While none had an experience of cancer patient-hood, all had history of working with cancer patients in clinical and research practice.

Aiming to establish the suitability of the tools in collecting valid and reliable data, the demographic form and the topic guide were first pre-tested on two non-health professional cancer patients. Data collection was undertaken by one of the authors (GN) who has experience in conducting qualitative interviews to ensure consistency in the data, that is, minimized data variability. Based on the qualitative nature of the study, data analysis was undertaken simultaneously with data collection, and this guided determination of data saturation, a point (8th interview) at which no new themes emerged from the data and data collection was stopped.

Data analysis

Audio-recorded interviews were transcribed verbatim by GN. The transcripts were then sent to five of the interviewees to confirm they were a true reflection of their shared experiences. Colaizzi’s¹⁵ seven-step framework of thematic analysis was used: (1) the initial reading of all transcripts, (2) extraction of significant statements/themes, (3) formulation of meanings, (4) clustering of themes, (5) exhaustive description, (6) fundamental structure formation, and (7) validation of findings.¹⁶ GN read and re-read each verbatim transcript to gain a fuller understanding of the data. Significant themes/statements were then identified through line-by-line highlighting using colored ink pen. These were given a fuller reading, and transcripts that showed thematic similarities were stratified into broad-based clusters of meaningful themes. The full transcripts, initial themes, and the broad theme clusters were then shared and compared with PE, EN, and SWA, and discussions were made (mainly on areas of disagreement) before reasonable level of consensus were reached. Final consensual amendments were then integrated into the results. An exhaustive description of themes to provide a clearer description of participants’ lived narratives was done and guided report writing.

Ethical statement

The study was approved on February 26, 2020, by Hospice Africa Uganda Research Ethical Committee (HAUREC) protocol number HAUREC-079-20. Written informed consent was obtained from all subjects before the study. Cancer care providers (oncology and palliative care) were contacted and informed about the study. These then contacted the eligible participants, who permitted them to share their contact details with the research team. GN then contacted each potential participant. Study information and consent forms written in English were then emailed to individual participants to aid informed and voluntary consent making. Data collection was undertaken by GN. Two eligible HCPs declined participation in the study. Participants who were interviewed via telephone calls consented by mail/text, while face-to-face interviewees consented by way of signature.

Results

The findings generated four broad themes, that is, (1) experience of pre-diagnosis and receiving bad news, (2) impact on self and role identity, (3) healthcare system and treatment experiences, and (4) the gaps and what should be done.

Participants’ sociodemographic profile (Field data: March-September 2020), See Table 1

Table 1. Participants’ sociodemographic profile.

Variable	Number
Gender	
M	3
F	5
Profession	
Medical doctor	2
Registered nurse/midwife	5
Clinical officer (Physician’s assistant)	1
Age group	
20–29	1
30–39	0
40–49	1
50–59	3
60–69	2
≥70	1
Type of cancer	
Lymphoma	2
Cancer of cervix	1
Leukemia	1
Skin cancer	1
Endometrial cancer	1
Colorectal cancer	1
Urethral neoplasm	1
Year diagnosed with cancer	
2010–2015	1
2015–2020	7

(Continued)

Table 1. (Continued)

Variable	Number
Cancer treatment received	
Chemotherapy only	3
Chemotherapy and palliative care	2
Surgery and radiotherapy	1
Surgery and palliative care	1
Palliative care only	1
On/receiving active treatment	
Yes	2
No	6
Had health insurance at diagnosis and during cancer treatment	
Yes	4
No	4
Worked in cancer or palliative care before	
Yes	5
No	3

Narrative summary of sociodemographic data

Eight HCPs participated in the study and data saturation was reached. Their age range was 29–85 and mean age 56 years. The majority (five) were female. Five had a nursing background, two were medical doctors, and one an allied HCP. The majority (seven) had received active cancer treatment (chemotherapy, or surgery or radiotherapy or combination), two had received active cancer treatment and palliative care, while one had received only palliative care. Only two of the participants were still receiving active cancer treatment at the time of the study.

Qualitative findings

Four broad themes emerged from interviews with the participants namely: (1) the experience pre-diagnosis and receiving bad news, (2) impact on self and role identity, (3) healthcare system and treatment experiences, and (4) the gaps and what should be done.

Theme 1: experience of pre-cancer diagnosis period and receiving bad news

The HCPs shared their symptom experience before the cancer diagnosis was made. While two of the participants had expected the diagnosis of cancer and were not shocked by the news, mainly because of their background medical knowledge, and history of working with cancer patients, six of the participants did not expect a cancer diagnosis:

I slept when I was ok. In the morning, I went to the bathroom to bathe. When I passed my hand around my neck, I felt a swelling; it was a big swollen lymph node. I got scared! As a health worker, I suspected cancer because I had knowledge about it from school. (HCP3, Clinical officer)

I think I was not surprised because I knew the diagnosis would be cancer. So, it didn't surprise me at all. (HCP1, Medical doctor)

I had not anticipated it would be cancer, and I started getting worried after receiving the results when I knew it's cancer. You know, cancer treatment is not normally easily accessible. You know that you are going to die, everything loses sense. Even before you die, cancer drugs are very expensive. So, these things were getting me worried. (HCP4, Nurse)

Theme 2: impact on self and professional role identity

Pain and symptoms experience. All the interviewees reported an experience of pain and distressing symptoms in their illness trajectory, caused either by cancer, and/or toxicities of cancer treatment, in particular radiotherapy, chemotherapy, and surgery. The most common and disturbing toxicities reported were fatigue, nausea and anorexia, nail and skin color changes, alopecia, easy bruising, amnesia, and erectile dysfunction. Four of them experienced excruciating pain:

The pain was so bad in the mornings, and I was always afraid to go to bed at night. I was terrified to get pain in the morning. At one point I was crying in pain; there was a crucifix (she wears a wide smile) in my room on the wall and I would look up to it and shout Jesus, Jesus [. . .]. (HCP6, Medical doctor)

Chemotherapy cracked my lips and gums. I couldn't eat anything, the hair started falling off. My lips became so dry, all the mucous membranes cracked. Going to the toilet, going to pee was very painful, eeeh! . . . (HCP2, Nurse)

A skin cancer survivor described how she suffered excruciating toxicities of phototherapy arising from negligence by her primary attending doctor. She recounted,

The first time I came out of the phototherapy machine I was derailed, weak. The second week, I started feeling burning sensations. I told the doctor and he said, "you're still on a low dose, continue it will go." These were student doctors. Third day, I couldn't continue any more. The whole body became red. It was painful as if I was standing in electricity. I went to show the doctor. and he said, "why did you continue?" The senior doctor was not always there. He would say "[HCP2] has come, you open the room (phototherapy room) for her" . . . (HCP2, Nurse)

She further narrated another incident where she was given treatment for her comorbid illness (hypertension) that interacted with phototherapy for the cancer:

He [the doctor] said, "are you on any medications?" I told him yes, Doctor I told you I was on anti-hypertensive Losartan-H. He said what? Losartan-H? That was our mistake; Losartan-H is sensitive to phototherapy. By this time, all the legs were red, face was red, and everything was red. I couldn't put on a skirt. When anything touched, it was so sensitive. Oh! That was the agony.

Effect of cancer on professional role identity. The participants then voiced how cancer impacted them, as individuals and as HCPs. Cancer robbing and disempowering them of their professional role identity was a common emergent theme. For some, getting a cancer diagnosis was a shock, and they questioned self and God as to how the cancer diagnosis came about. There was an emerging recognition that being a HCP did not, as some may have previously assumed, protect against getting cancer. This translated into a reframing of self as a patient, rather than self as a HCP, which came as a shock:

I'm not the only one [in a faint tone]. Doctors die, professors die, they get sick and die. So, I knew that I'm also like them. We health workers are human beings like others. That one is obvious. I can get sick like anybody. (HCP4, Nurse)

I was really anxious. I asked myself, a health worker? Where did it (skin cancer) come from? How did it come? I'm always careful with the soaps I use on my skin . . . ! (HCP2, Nurse)

They further discussed how by being patients, their abilities to offer patient care and do daily work were impacted, mainly due to disruptions caused by cancer itself, and toxicities of treatment mainly pain and fatigue:

After the first two chemo doses, I became too weak and dizzy. I could enter the office (clinical room) and sit. I could ignore like; taking temperature, blood pressure . . . until I finished the second cycle . . . (HCP3, Clinical officer)

Increased awareness of cancer patient-hood. HCP cancer patients then narrated the 'positive' side they found in cancer patient-hood, and how this has increased their awareness of what it means to be a cancer patient. Their lived experience brought to them an understanding of the suffering cancer patients navigate and this amplified their compassion for empathic patient care:

I got to understand what it means to have a cancer diagnosis. It impacted me positively, it gave me the opportunity to see how the healthcare workers treat patients, because I went through that myself, and then it gave me more zeal to talk about palliative care, the need for palliative care for everybody who needs it. Because I now understand what pain means, what it means to go through chemo, what it means to be a patient in our healthcare system. I used to talk about it, I used to teach about it, but I had not definitely gotten the experience. (HCP8, Nurse)

After becoming a patient, whenever I receive a patient, I normally put all my knowledge to give him or her proper service. These days I'm even very suspicious of a cancer. Whenever I see any sign, even if it's one, I do advise the patient to rush to Mbarara (regional referral hospital). It gave me a lesson; to find this cancer in stage one, I came early and I got chance. The ministry of health, non-governmental organisations, and all stakeholders need to reach people and health workers in the villages. Health workers in the villages are about money [. . .]. (HCP3, Clinical officer)

Theme 3: healthcare system and treatment experiences

Cost of cancer care. Seven participants received their cancer care in Uganda, while one accessed care from overseas (in the UK). Four had health insurance cover but an equal number did not. Financial suffering and burdens were more commonly reported by those who lacked insurance:

I had to receive the results and go back home to look for money for treatment. After one week, I came back with around Uganda shillings 500,000 (\$139). I'm getting a salary of Ugx 550,000 per month. Of course, before you start treatment, you have to undergo various tests. The whole 500,000/= got finished on investigations before even going for a CT scan. I had to go back home. (. . .). The treatment at the cancer institute is not affordable. Since I started chemo (in March 2020), I buy Dacarbazine every two weeks, and it's around 180,000/= per coming, plus the expenses of hiring a motorcycle (Ugx 30,000-40,000), and then putting in fuel. So it's been tough on my side. (HCP3, Clinical officer)

However, even those that had insurance cover, narrated the huge costs and the unaffordability of cancer treatment and investigations, while some participants, especially those that had no insurance cover discussed their painful experiences of how cancer and the associated huge out-of-pocket expenditures on treatment jeopardized their financial standing:

Cancer treatment is not an easy thing. It's quite costly and exhausting. If I wasn't on insurance, I wouldn't have managed. The surgery itself costed like Ugx 4million, then the numerous investigations, I had MRI twice, that's over a million . . . You're going for this investigation its Ugx 1.2million, how many people can easily afford those costs? It's not easy for a common person from [. . .] (mentions a few rural areas of low socioeconomic status). (HCP8, Nurse)

Challenges and barriers to cancer care. This was the most common and challenging segment in their narrations. HCP cancer patients and survivors narrated the challenges, pitfalls, and barriers that existed in the healthcare system, and how it was not an easy system especially for the poor, common persons to navigate.

Unmotivated and insensitive healthcare workers. They described a slow system, in particular the public healthcare system with healthcare workers that were sometimes non-caring, unmotivated, and insensitive to the needs of vulnerable, suffering patients, including cheating, and habitually seeking bribes from patients:

. . . healthcare workers don't follow protocols. If you go to UCI [Uganda Cancer Institute], there are so many pharmaceutical companies selling their medicines. The doctor does not prescribe what's available, he prescribes what the company has brought to him and tells him you prescribe I will give you a commission.

They prescribe very expensive formulations, yet equally cheap and effective drugs are there [for free] in the public pharmacy. (HCP1)

You go to hospital; no one wants to know that you're a cancer patient. We would get lost when going for radiotherapy, when they understand that you're a cancer patient, they want to first deceive you to cheat you, and you're there crying in pain . . . (HCP7)

Burn out versus negligence of duty. They further narrated the healthcare delivery setting and how on one hand there were overworked healthcare workers close to burnout and on the other negligent health workers. Habitual absenteeism, seniors, and consultants leaving junior doctors in charge of patients and without supervision, and scarcity of cancer care specialists were commonly mentioned by the participants. A skin cancer survivor narrated how she was always left to operate a phototherapy machine herself and how she got severe toxicities from a wrong, overdose:

The doctor told me; you press one button and then press another one and then put start. That was on the first day. Second day, he told me better learn how to do it because other patients do it (phototherapy machine) themselves. He would say (#2) has come; you open the room (phototherapy treatment room) for her. One day I did it wrongly and was on a higher dose. It's the intern doctor who came and corrected it. Then, on weekends they were never there at the referral. So, there's no one to run the machine. (HCP2, Nurse)

It is not an easy system. First of all, you have got to be very patient. Secondly, the healthcare workers seem to be tired, and not motivated. If me a colleague who was working with them I could see and read that, then I wonder what the other person gets! Then, things are slow; when you expect sympathy you don't get the sympathy. When you expect people to direct you don't get directed. It's like you've to manoeuvre your way through. I'm just imagining for a local person, just a local Ugandan, it's hard, really hard and frustrating. You go in the morning, and you will see the doctor in the afternoon. And you don't have energy, you see patients sleeping on the floor. You can't sit on that chair, even the benches are not there, they are inadequate. (HCP8)

Poor communication. Poor communication including during the breaking of bad news, giving medical instructions, and on being referred to other care providers was commonly reported. Some reported challenges in accessing the right information, but few who were in leadership positions or working in cancer and palliative care settings were able to receive important information from their colleagues. A participant narrated the terrible experience of how her biopsy report was disposed of at the regional referral hospital:

They took off a biopsy from two places and it was so painful, without anaesthesia. I can't forget that thing [. . .] at the referral. They said come after 2 weeks. After 2 weeks, I go back no

results; no one even knew my name! Then one of them asked; did you pay? I said no, no one told me to pay. He said that's why it (biopsy) was thrown away . . . They (at the regional hospital) referred me to Kampala, but they did not tell me which doctor, or hospital. Even the doctor in Kampala, he did not explain to me, he just said go to Nairobi . . . (HCP2, Nurse)

Unmet care preferences. The participants described their knowledge of the kind of care they needed, but in some instances, their preferences were not respected, or were overridden, by the attending clinicians:

When I consulted the person in charge of the CT scan (at the regional referral hospital), he told me he would give me the film without the report; that the people to write the report were not there. I had to go to a private hospital. (HCP3, clinical officer)

I asked whether I could see the palliative care people because I was in so much pain, and you know what the nurse said. "I was too early for that care," I knew what I needed for that pain; I needed morphine. . . then the doctor said to me; they had to admit me to give me morphine. They would not give me morphine. Imagine, and this is UK where Palliative care started. (HCP6)

Ability to reflect on the challenges faced by their providers. Participants acknowledged that despite the challenges and deficiencies in the healthcare system, cancer healthcare workers were disproportionately few compared to the numbers of patients. They appeared overworked and tired. They commended health workers at Mbarara Regional Referral Hospital cancer unit:

I normally travel to health centres and find health workers ignoring patients. But at the cancer institute in Mbarara, it's different. Yes, sometimes they delay us, but those people know the kind of patients they are working on. They normally control the emotions, there's a way how they handle us. I think those people were trained. (HCP3, Clinical officer)

Health workers are also human beings. They are few in hospitals and cancer patients are very many. They work for longer hours, and they get tired, they shun patients . . . (HCP7, midwife)

Positive experiences. They then narrated scenarios and moments in the continuum of their cancer illness where their suffering was relieved. A participant with chronic excruciating urethral pain that was not responding to pethidine and tramadol injections happily recounted how palliative care received from a hospice controlled her pain and renewed her quality of life:

The pain was too much and ever increasing. I was being given tramadol and pethidine injections for the pain the whole of 2017. 2018, I came to know about hospice, and they started me on morphine. Since then, the pain got controlled. I thank hospice, they have managed my pain. They counselled me and I'm now better. I don't think I would still be alive if it's not because of hospice. (HCP5, Nurse)

Theme 4: gaps and what needs to be done

Finally, participants discussed the gaps in the healthcare system that needed to be addressed to improve cancer care for patients, including:

Commitment from policy makers. Participants discussed deficiencies in cancer care that exist in the healthcare system. They attributed these mainly to slow, and or a lack of proper, legislation and commitment from policy makers in passing laws and policies that prioritize cancer and palliative care:

It normally comes through experience. When these policy makers get the experience of cancer, they will go and lobby for money to allocate to cancer and palliative care. The money is there; the government doesn't lack money. We have enough money for doing those things, except going to the moon. (HCP1, Medical doctor)

Collaborative capacity and improved resources for cancer care. They cited a number of desired remedies including the need for more awareness campaigns about cancer, by policy and survivors with lived experiences of cancer, need to make cancer treatment free, increasing training and the number of cancer care professionals, remunerating health workers well, and scaling up cancer services to regional centers:

Cancer is real, and cancer can attack anybody. We need to work together to ensure that cancer services in our country are efficient so that the local, common person does not suffer, but also the government should really fund the cancer treatment, or else many will continue to die helplessly. It's quite expensive when you get cancer, and it drains all the resources. If they could make the system easy, the flow . . . They should train more healthcare workers, and the healthcare workers who need to be trained are there but I'm not so sure whether the system is training them, and also make sure they retain and remunerate them appropriately. (HCP8, RN)

We need a parliamentary forum on cancer; such a thing, parliamentarians get education; people talk to them related developments in cancer, policy formulation . . . so, they are always updated. And then, you know parliamentarians are ever changing, the one who has the interest today, tomorrow he is out. You need to start all the time, yet policy formulation needs continuous efforts. (HCP1)

They should put up cancer treatment centers in every region. You travel all that distance (over 90KM), you reach Mulago [Uganda's national comprehensive cancer treatment center], it rains on you, and you sleep on polythene paper on the veranda . . . Getting care is too expensive. Patients can't afford it. Government should make cancer treatment free. (HCP7)

Discussion

The main aim of this inquiry was to examine the lived experiences of HCP cancer patients and survivors in Uganda.

Four major themes emerged, (1) the experience of pre-diagnosis and receiving bad news, (2) impact on self and role identity, (3) healthcare system and treatment experiences, and (4) the gaps and what should be done.

The themes highlighted in our interviews with HCPs are important to contextualize based on the differing socioeconomic and demographic characteristics of the participants. For example, financial difficulties were more common and higher in those that lacked insurance to finance their medical expenses. Participants who had a history of training and working in cancer and palliative care settings reported better social and moral support and easier coping, as opposed to their colleagues who had not. It appears likely the training and experiences of prior working with cancer patients prepare an individual to accept the reality of cancer. The majority were immersed in shock and questioning self and God following the news of cancer diagnosis. Older participants, physicians/medical doctors, and those with a history of working with cancer patients experienced less emotional and psychological suffering than their nursing and allied health colleagues after a cancer diagnosis. These findings corroborate those of Kenny et al.,¹⁰ who reported that the experience of HCP cancer patients is shaped by their background knowledge of the disease.

The fear of death, loss of professional identity, stress, worry about their lives, families and the unaffordability of cancer treatment, feelings of hopelessness and worthlessness, that is, life ceasing to have meaning were common. Similar psychological and emotional sequelae were reported among HCP cancer patients in high-resourced countries^{3,9} and in studies done with non-professional cancer patients in HICs and LMICs.^{19–22} Furthermore, the participants discussed how they constantly questioned self and God as to how and why they received a cancer diagnosis. The findings underline the vulnerabilities HCPs navigate when they become sick with life-limiting illnesses such as cancer, an issue commonly reported by other non-HCP cancer patients.^{23,24}

Participants discussed their pain and symptoms experience before their cancer diagnosis, and how the news of cancer diagnosis came. Many narrated how, because of their background knowledge and the symptoms they suffered, they had already suspected the diagnosis would be cancer. Pain and other signs and symptoms, for example, swollen lymph nodes prompted a suspicion of cancer among all the participants who had a prior history of working with cancer and palliative care patients. This observation is reported elsewhere in studies and lived experiences (stories) of HCPs who became cancer patients.^{9–12} However, majority had not anticipated their symptoms were related to cancer. In fact, some had to be advised by their healthcare colleagues to seek specialist attention, while others were prompted by their symptoms to seek further care. Lagad et al.³ similarly found HCPs who became ill with cancer received professional advice from colleagues.

The HCPs then discussed how cancer impacted them, as individuals and as professionals; mainly humbling them and increasing their empathy and compassion for their patients after they went through the cancer patient-hood experience, when they themselves experienced distressing symptoms and pain. Some further narrated how the pre-diagnosis and cancer symptoms experience made them become more aware and suspicious of cancer than ever before, including the need to not to delay onward referral of patients who they receive with cancer-related symptoms. They also came to learn and accept that, just like any other person, HCPs can get sick and become patients and this acceptance humbled them. Findings of this study corroborate previous research which reports HCP survivors of cancer finding new insights that shaped their life, understanding, and future career.^{14,25} Other authors agree that HCPs develop true empathy and become better professionals when they experience a life-threatening illness, or by being patients.^{13,14,26–29}

Participants identified the post-diagnosis trajectory with cancer, including issues like living with and navigating pain and distressing symptoms caused by the cancer itself, and toxicities of its invasive treatments mainly chemotherapy, surgery, and radiotherapy. Common symptoms included pain, fatigue, nausea and anorexia, nail and skin color changes, alopecia, easy bruising, amnesia, and erectile dysfunctions. All the participants experienced pain, including excruciating pain (for some). This is unsurprising as these symptoms commonly occur in nearly all cancer patients.^{20,30} Of the seven HCPs who received active treatment for their cancer, only one did not experience pain as a toxicity of treatment (this being the individual who was treated in the UK). It is not surprising as the health system in the UK, including for cancer care, is well developed with highly specialized cancer care specialists and state-of-the-art equipment compared to LMICs where there is limited human expertise and access to advanced systems and equipment to manage cancer because they were able to afford the costs.

The HCPs discussed another unique experience in their cancer patient-hood trajectory, that of facing the healthcare system and treatment in Uganda as patients. They described inefficiencies, flaws, barriers, and challenges within the healthcare system, how it is difficult to navigate, with inadequate, unmotivated, overworked, and fatigued cancer care personnel, out of stock medicines, and being given inadequate, if any, health information. They explained how the system was slow and very frustrating for them and other cancer patients, particularly the poor. Findings showed healthcare inefficiencies and challenges reported were more prevalent in the public health system. Delays and unclear patient pathways, uncaring staff, and habitual absenteeism, or absconding duty; reporting late to work and leaving work early were common observations reported by HCPs in this study. Unsurprisingly, the participant who was treated in the UK reported fewer health system-related challenges

compared to colleagues who received their cancer treatment in Uganda. However, delays to receive pain relief, caused by clinicians' reluctance to prescribe opioids (in particular morphine) for severe pain was a universal finding.

Delayed and missed treatments due to the unaffordability of accessing care (including transport, accommodation, medicines, and food), inadequate infrastructure for cancer care, inefficiencies in the healthcare system (e.g. out of stock cancer medicines, delays and long waiting times, lack of clear patient pathways) have all been reported in other recent studies in Uganda.^{19,31,32} It was surprising how even HCPs with medical insurance also mentioned financial problems resulting from high out-of-pocket expenditure on investigations and treatment for cancer. They sympathized with those who lacked insurance and the vulnerable, especially the poor cancer patients.

The huge out-of-pocket expenditure on healthcare is not a surprising finding since Uganda has no public health insurance scheme, hence healthcare expenses are largely incurred by individuals. This finding corroborates findings of the Global Burden of Disease Health Financing Collaborator Network³³ which predicted out-of-pocket spending on health care will remain high up to around the year 2040 in low and poor resourced countries. Furthermore, participants who lacked insurance reported longer delays in accessing care, undergoing investigations, and starting treatment as they needed more time to borrow money from lending institutions, colleagues, or to raise funds by selling their assets including land and houses to finance their care.

Reports of corruption, where healthcare workers seek bribes from patients, and oncologists prescribing expensive formulations when equally effective and free medicines were available, were commonly reported as is the case in elsewhere in sub-Saharan Africa.³⁴ Senior doctors not being easily available and accessible, or leaving juniors in charge when they are not competent to manage patients was another important finding in this study.

In some cases, patients were left to administer treatment to themselves. A participant painfully recounted how at a regional referral hospital, she was told and was always left to administer phototherapy to herself, resulting in severe toxicities of the treatment due to lack of monitoring and supervision from the attending doctors. These findings differ from those of a study by Lagad et al.,³ who found, in Australia, HCPs cancer patients found it easy to navigate the healthcare system including receiving immediate free or subsidized, high-quality care delivered by experts. Similar disparities in accessing cancer care including palliative care, surgery, radiotherapy, and chemotherapy are reported in other large, global studies.^{35–37}

However, increased awareness of healthcare inefficiencies among HCP patients has been reported in other studies. Lagad et al.³ found having a professional background led to an increased awareness of inefficiencies in the healthcare system, as do Tuffrey-Wijne and Williams⁹ who reported

HCPs who are patients experience the healthcare system in unique ways: (1) as an observer- HCP-assessing how other HCPs do their work, and (2) as a researcher-processing and analyzing the healthcare system structures and procedures affecting them as patients, (3) a patient, and (4) a critical analyst-studying themselves being a patient.

Finally, the participants discussed scenarios where, despite knowing what they needed; their preferences were not respected, for example, being denied analgesics (especially morphine) for their pain (sometimes severe), a finding supported by Tuffrey-Wijne and Williams⁹ who found HCPs had unique needs when they became patients.

Strengths and limitations

To the best of the researchers' knowledge, this was the first enquiry to attempt to understand the lived experiences of cancer from the lens of HCPs cancer patients in Africa. The study provides crucial insights in this under-researched area. A rigorous approach to analysis, where the analysis and discussion were primarily based on themes emerging from participants' lived accounts of cancer patient-hood reported verbatim add to the credibility and confirmability of the findings. In addition, the history and experience of working with cancer patients and conducting qualitative interviews with cancer patients by GN, a Ugandan national, add to the richness of the findings.³⁸

The COVID-19 global pandemic with its lockdowns created transport difficulties meaning some interviews were conducted via telephone. This could potentially have limited the capture of vital non-verbal cues and limited the richness of data. Similarly, some responses in socio-economic domain could have been confounded by financial and transport difficulties exacerbated by the COVID-19 pandemic especially for the participants who had to access care during the lockdown. It should be noted that one participant received their cancer treatment in a HIC, versus the remainder seven who received their treatment in Uganda, a low-income country. Differing socioeconomic conditions, including health system-related and healthcare differences could have affected participants' experience of cancer treatment, and the information they shared.

Conclusion

Cancer patient-hood introduces vulnerability and remarkable disruptions and suffering in nearly all domains of quality-of-life of a HCP, that is, in professional identity and work, social, emotional, physical, and economic facets of life. Participants identified how they experienced a healthcare system which was costly and staffed by unmotivated staff with limited access to resources, which resulted in many unmet needs and an overall poor experience. Participants identified how, in their view, the healthcare system in Uganda needed to be better resourced, protected by appropriate

policy and legislation and how cancer awareness among the population needed to be improved.

They emphasized an urgent need to decentralize cancer services to regional centers to avoid delays in cancer care access, make cancer services free of charge, increase staffing of HCPs (especially in public facilities) to manage the increasing cancer patient population, form a parliamentary forum on cancer so policy makers are always informed of developments in cancer and its management, and a cancer survivors' forum where cancer patients can share their lived experiences and needs, an avenue that also has potential to create and strengthen awareness about cancer.

In addition, the authors consider that further research using alternative methodological designs, for example, grounded theory is undertaken to generate deeper understanding of the topic.

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Author contributions

G.N. contributed to conceptualization of the study, study design, reviewing the literature, collecting data, transcription, analysis, and manuscript writing; P.E. contributed to reviewing the literature, analysis, manuscript writing, and reviewing final manuscript for journal submission; S.W.A. contributed to analysis, manuscript writing, and reviewing final manuscript; E.N. contributed to analysis, manuscript writing, and reviewing final manuscript. All authors prepared and approved the final manuscript for publication.

Data management and sharing

To discuss access to elements of the data, please contact peteralanellis@aol.com

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Informed consent

Written informed consent was obtained from all subjects before the study.

Trial registration

Since this study was not a clinical trial, no trial registration was done.

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Supplemental material

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