

RESEARCH METHODOLOGY: DISCUSSION  
PAPER - METHODOLOGY

# Psychosocial and emotional morbidities after a diagnosis of cancer: Qualitative evidence from healthcare professional cancer patients

Germans Natuhwera<sup>1</sup>   | Peter Ellis<sup>2</sup> | Stanley Wilson Acuda<sup>3</sup> | Elizabeth Namukwaya<sup>4</sup><sup>1</sup>Hospice Africa, Kampala, Uganda<sup>2</sup>CEO Intelligent Care Software, Canterbury Christ Church University, Canterbury, UK<sup>3</sup>Institute of Hospice and Palliative Care in Africa, Hospice Africa Uganda, Kampala, Uganda<sup>4</sup>Makerere University School of Medicine, Kampala, Uganda**Correspondence**Germans Natuhwera, Little Hospice Hoima, Hospice Africa, Kampala, Uganda.  
Email: [gmatuhwera@hospice-africa.org](mailto:gmatuhwera@hospice-africa.org); [ngermans16@gmail.com](mailto:ngermans16@gmail.com)**Abstract****Aim:** This inquiry aimed to; (1) examine the psychosocial and emotional sequelae associated with cancer patient-hood experience in healthcare professionals (HCPs) in Uganda, (2) generate evidence to inform clinical and nursing practice about the needs of HCP patients with cancer.**Design:** This was a qualitative phenomenological study.**Methods:** The study was conducted among HCP cancer patients and survivors recruited from oncology and palliative care settings in Uganda. Data were collected via audio-taped, face-to-face or telephone open-ended interviews. Interviews were transcribed verbatim. Thematic analysis was used.**Results:** Eight HCP cancer patients and survivors participated in the study. Their mean age was 56 years, range 29–85 years. Three major themes emerged: (1) From a healthcare provider to a patient, (2) Socioeconomic challenges, and (3) Coping and support strategies.**KEYWORDS**

cancer patient, cancer survivor, emotional, experience, healthcare professional, morbidities, psychosocial

## 1 | INTRODUCTION

It is well known ‘diseases don't read books’ and healthcare professionals (HCPs), like everyone else, receive cancer diagnoses and become vulnerable to the emotional and psychological morbidity associated with it. However, there is little research evidence on the emotional and psychological experiences and needs of HCPs who become ill with cancer. The little evidence that exists is disproportionately concentrated in high-resourced countries, meaning the situation in low-resourced countries remains unknown.

## 2 | BACKGROUND

Cancer is common worldwide and the cancer burden is disproportionately more concentrated in low-and middle-income countries (LMICs). Globally, in 2012 alone, 65% of all cancer deaths occurred in LMICs (International Agency for Research on Cancer, 2019), and this is projected to increase to 75% by 2030 (The Lancet, 2018). Cancer remains prevalent and is among the prime causes of mortality and morbidity, in high-income countries (HICs) with strong healthcare systems (Agur et al., 2014; Australian Institute of Health and Welfare, 2017). In many LMICs, sub-Saharan Africa included,

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timely and effective cancer care are hampered by the limited availability of, and access to quality cancer care including skilled health personnel, that is, surgeons, oncologists, pathologists and infrastructure (to screen, diagnose and treat cancer), limited or a lack of public health insurance schemes and associated high out-of-pocket spending on health care by each individual, limited and expensive, and/or frequent stock outs of essential cancer therapies, that is, surgery, radiotherapy, chemotherapy, palliative care, etc., and limited research (Dare et al., 2015; Nakisige et al., 2017; World Bank, 2013). For example, in Uganda, there is only one radiotherapy treatment centre, based at Mulago national referral hospital, while chemotherapy is available in three of the 16 regional referral hospitals. Thus, it is unsurprising that cancer incidence, prevalence, mortality and morbidity rates are significantly higher and continue to rise in LMICs, whereas mortality rates in HICs are either decreasing or stable (Torre et al., 2016). The net effect is that cancer treatment outcomes are worse in LMICs than in HICs (Mallath et al., 2014).

Receiving a diagnosis of cancer has been shown to be accompanied by significant psychosocial and emotional disruptions such as shock, anxiety, depression and stigma (Brinkman et al., 2013; Ljungman et al., 2014). In a recent study of cancer professional patients' experiences in Australia, Lagad et al. (2019) found participants experienced unanticipated shock, anxiety, worry, frequent questioning of self and the unfairness and difficulty accepting their diagnosis.

Anecdotal evidence shows the transition from a professional to patient role identity is a huge challenge for cancer patients with a healthcare professional (HCP) background. In her book 'the other side', a story of her lived experience with metastatic sarcoma, Granger (2012), a medical doctor, wrote that handing over her professional identity and assuming the patient role was not only difficult but also undesirable. This similar lived experience is corroborated by Dr. Henry Marsh a neurosurgeon, who, in his latest book, 'And finally: matters of life and death', narrates the story of how he struggled with identity challenges when he became a prostate cancer patient, in particular wearing two identities; the doctor and an anxious patient. During his first consultation with his oncologist, Marsh recalls how he told his oncologist 'Please talk to me as a doctor', and the oncologist replied him 'That's not how we do things here'. He further shares his reflection of the thoughts that flooded his mind as he left the hospital after the consultation,

I have crossed to the other side. I have become just another patient, another old man with prostate cancer, and I knew I had no right to claim that I deserved otherwise. (Marsh, 2022)

Furthermore, in their study, Lagad et al. (2019) reported HCP cancer patients expressed the desire to be treated as professionals, while others wanted to be treated both as a professional and as patient. In his book 'when doctors become patients', Klitzman (2007) wrote that HCPs have an 'Illness happens to them (patients) over there, not us' attitude, and are used to being in charge in the clinical setting, this notion

### What does this paper contribute to the wider global clinical community?

1. The first study in Uganda and possibly Africa, to study the psychological and emotional impacts of cancer in HCP patients
2. The paper identifies novel findings and corroborates anecdotal literature from individual HCPs about their cancer patient-hood experiences
3. The paper outlines evidence-based practical recommendations crucial to the improvement of cancer care for HCPs cancer patients

is reflected in a The Lancet Editorial (2016) which reported that doctors have the mentality to view themselves as people who treat the sick and do not get sick themselves. However, when they become patients, this perceived control is surrendered and the resultant feelings of erosion and disempowerment of their role identity lead to heightened vulnerability (Lagad et al., 2019; Tuffrey-Wijne, 2015). In this patient role, they find it hard to apply their knowledge to themselves and need support from their professional colleagues (Campbell, 2012).

It can be argued the support needs of HCPs who become patients are different from those of lay patients. According to Tuffrey-Wijne (2015), an associate professor of nursing who was diagnosed with grade-2 breast cancer, HCPs who are patients experience immersion in the healthcare system from a myriad of perspectives-; (1) a patient, (2) a critical analyst; studying themselves being a patient, (3) an observant HCP; assessing how other HCPs do their work and (4) a researcher, processing and analysing healthcare structures and procedures.

Other psychosocial challenges reported among HCPs who become patients include subjective limitations in accessing health care such as reluctance to consult colleagues on emotional and treatment-related concerns due to self-disclosure issues, fear of ramifications upon return to work, stigma of being identified as a cancer patient, and a heightened feeling of intrusion (Lagad et al., 2019; Tuffrey-Wijne, 2015). In their lived experiences of cancer, Campbell (2012) and Granger (2012), found many HCPs patients shun routine healthcare settings such as waiting areas for patients and opt to be seen in separate rooms, or out-of-hours, while for some, the daily reminder of cancer makes it hard for them to cope.

Paucity of research evidence means that, perhaps, the nature and quality of care given to, and received by HCP cancer patients in health settings is based on assumptions that their experience of cancer, and so needs are similar to those of non-HCP cancer patients. The study sought to add empirical evidence in this understudied area, in particular to (1) examine the psychosocial and emotional sequelae of a cancer diagnosis on HCPs in Uganda, (2) generate evidence to inform clinical practice with regard to the needs of HCPs with cancer.

### 3 | METHODS

#### 3.1 | Study design and setting

A cross-sectional qualitative design employing descriptive phenomenology was used to gain in-depth accounts of the psychosocial and emotional morbidities following the diagnosis (Ellis, 2019a; Sydney et al., 2017). The study was conducted in Uganda among HCPs with lived experience of a cancer diagnosis, and recruited from both private and public settings. Private, not-for-profit settings were mainly hospice and palliative care providers; Hospice Africa Kampala (HAKLA), Mobile Hospice Mbarara (MHM), the Palliative Care Association of Uganda (PCAU), mainly through members who knew some of the eligible participants at an individual level. Public setting included only Mbarara regional referral Hospital (HRRH) oncology unit. All the study settings were urban.

#### 3.2 | Sampling and eligibility selection

Healthcare professionals with lived experiences of cancer were recruited using purposive sampling. Inclusion criteria were (1) a current or previous diagnosis of cancer confirmed histologically or by imaging, (2) completion, and/or active cancer treatment, and/or hospice and palliative care (PC), (3) an HCP background and (4) ability to speak English. Participants were recruited from cancer and palliative/hospice care settings. Data saturation, a point where no new data emerge despite further interviews was used as a basis for the determination of an appropriate point at which data collection was suspended (Ellis, 2019b).

#### 3.3 | Data collection

Data were collected by GN who has experience in conducting qualitative interviews with cancer, palliative care patients and used a structured demographic datasheet and an open-ended topic guide based on the aims of the research. The topic guide was first piloted on two non-HCP cancer patients. The themes in the topic guide covered participants' experiences in the following areas: *pre-diagnosis, during diagnosis and after diagnosis including impact on one's professional identity, social interactions and cancer treatment experiences*. Interviews were conducted on the day, time and in a place preferred by each participant. Five of the interviews were conducted face-to-face and three by telephone. Open-ended and probing questions like *would you please share with me how you received the news of your cancer diagnosis. How did it affect you? How has undergoing cancer treatment been for you? (...)* were used to gain a fuller understanding of the psychosocial and emotional impact of cancer on the HCPs. Interviews were audio-recorded (using a reliable mobile smartphone) and saved using anonymized codes. The interviews lasted between 24 and 58 min. Data saturation was reached at the 8th interview. A trend was observed from the 6th

to the 8th interview when emergent themes became repetitive, hence interviews were suspended at the 8th interviews. GN kept a diary for reflexive purposes.

#### 3.4 | Data analysis and reporting

Pseudonymization, that is, use of identity-concealing codes was used in reporting findings to ensure participants' anonymity. The audio records of the interviews were transcribed verbatim. Colaizzi's (1978) seven-step framework of qualitative data analysis was then applied to the transcripts; (1) 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 (Edward & Welch, 2011). Initial analysis was done by GN, who read and re-read the verbatim transcripts to gain fuller familiarization with the data. Significant themes were then recorded in the margins of each interview. These initial themes were then sorted based on their thematic similarities and abstracted into broad-based clusters of meaningful themes. The transcripts, initial themes and broad-based theme clusters were then cross-checked and discussed with PE, EN and WSA, who have experiences in qualitative data analysis, and agreement was reached on the themes and thematic clusters. An exhaustive description of theme clusters to provide clearer descriptions of participants' lived narratives was done. Validation of findings through member-checking; transcripts were returned to five of the interviewees who confirmed the information was a true reflection of what they had shared.

The reporting of study findings was guided by the consolidated criteria for reporting qualitative studies (COREQ) 32-item checklist (Tong et al., 2007). The checklist has three broad domains -: Research team and reflexivity (8 items), study design (15 items) and analysis and findings (9 items) that are used to appraise research findings to ensure credibility.

#### 3.5 | Ethical statement

Ethical approval was obtained from Hospice Africa Uganda Research Ethics Committee, approved protocol number HAUREC-079-20. Institutional approval was obtained from managers of oncology clinics and the hospice settings where the patients were enrolled. The clinic leads contacted potential participants and, on agreement of the patients, shared their contact details with GN who contacted them, and provided study information for informed consenting. The information included -: voluntariness of participation and a guarantee of anonymity and confidentiality during the conduct of the study and reporting of findings. Participants were informed beforehand about the possibility of experiencing emotional breakdown, discomfort during or after interviews, and were asked to approach GN, or the research team, for emotional support. Two HCPs declined participation in the study.

Study information and consent forms, written in English, were then emailed to individual participants. Participants who were interviewed by telephone calls consented virtually (by email/text), while those interviewed face-to-face consented by signature. Two HCP participants experienced emotional breakdown during interviews; one during face-to-face and telephone interviews each, and were given emotional support. An additional follow-up phone call to each was made a day after the interviews and found the participants were doing well, with no emotional distress.

## 4 | RESULTS

Three major themes emerged from the interviews (Figure 1): (1) from a health provider to a patient, (2) socioeconomic challenges and (3) coping and support strategies (Table 1).

### 4.1 | Theme 1: From a healthcare provider to a patient

#### 4.1.1 | Psychological and emotional disruptions

Receiving the news of cancer diagnosis was described as a unique and disturbing moment. Six of the participants were immersed in great psychological and emotional suffering comprising either: shock, anxiety, hopelessness, worries about the cost of treatment and fear of the unknown, cancer recurrence, disability, job loss and disempowerment of professional and gender role identity, and/or death:

I felt my life was coming to an end. I was upset. Actually, the handover that I had, I didn't wait for any other formalities... my mind was saying I think I'm dying

(#2, RN)

...I decided to go for a skin biopsy, and it confirmed chronic lymphoblastic leukaemia (CLL). I felt sorry, I was stressed

(#4, RN)

Findings showed other HCPs do not know how to handle their colleagues who become cancer patients. Being insensitive while giving the unwelcome news was a common emergent theme, for example, some were told the news of a cancer diagnosis over the phone when they were not prepared, and the results were not explained which was overwhelming for them:

... I felt so scared, sad, when they told me its cancer. You know cancer is incurable. They sent the results on my phone.

(#7, Midwife)

They think that any patient can take it as mycosis fungoides, it's a normal thing...! A nurse is a human being, a nurse can feel, and a nurse can react. But they say mycosis fungoides! I had to go and look on internet [google] and I found it was cancer! I was shocked...

(#2, RN)

Being given inadequate information on being given a referral to higher centres for further specialist attention, and during investigations prior to arriving at a cancer diagnosis was reported and resulted in emotional suffering. One participant with skin cancer broke down as she recounted how, at a regional referral hospital, lab personnel told her biopsy ('taken off without anaesthesia') was thrown away just because she did not pay money for processing it, yet no one told her about the payment.

Participants who were insensitively given unwelcome news reported more psychological and emotional morbidities than their counterparts. One, a young newly graduated and married clinical officer, narrated how insensitively he was given the news of his cancer diagnosis by a consultant surgeon:

He held the envelope and told me; you've to wait for Doctor... to give you the results. Of course, it came into my mind! If it was good news, he would have just given the results to me. So, telling me to wait for the Doctor., as a health worker, I suspected cancer. I started seeing myself as someone who's not having more than 10 years to live; losing hope, seeing what I have been planning (...). I became speechless... After the Doctor coming, he called me, and he was in a hurry. He gave me the results when he was hurrying, and he told me "I have to give you the results how they are. You have a cancer..."

(#3, Clinical Officer)

Receiving contradictory information about their state of health and stage of the cancer was also reported. Occasions of conspiracy of silence, where the attending health provider 'blanketed' the news of a cancer diagnosis from the HCP cancer patients was also reported. A noteworthy observation is that emotional suffering heightens as cancer advances to incurable stages, e.g. one participant, a widow bedbound with metastatic cancer of the cervix and two colostomies, exhibited more severe emotional suffering than colleagues with early stage, curable disease:

He (the doctor) told me "your cancer is still in early stages and the uterus we already removed it; you'll be okay". What hurt me most is the doctor to tell me he forgot to remove the lymph node (inguinal). Even in Kampala, people told me if they had removed the lymph node, I'd have cured. Then to tell me that the uterus got cured, that now the cancer is

Transcripts

Coded sub-themes

Main

themes

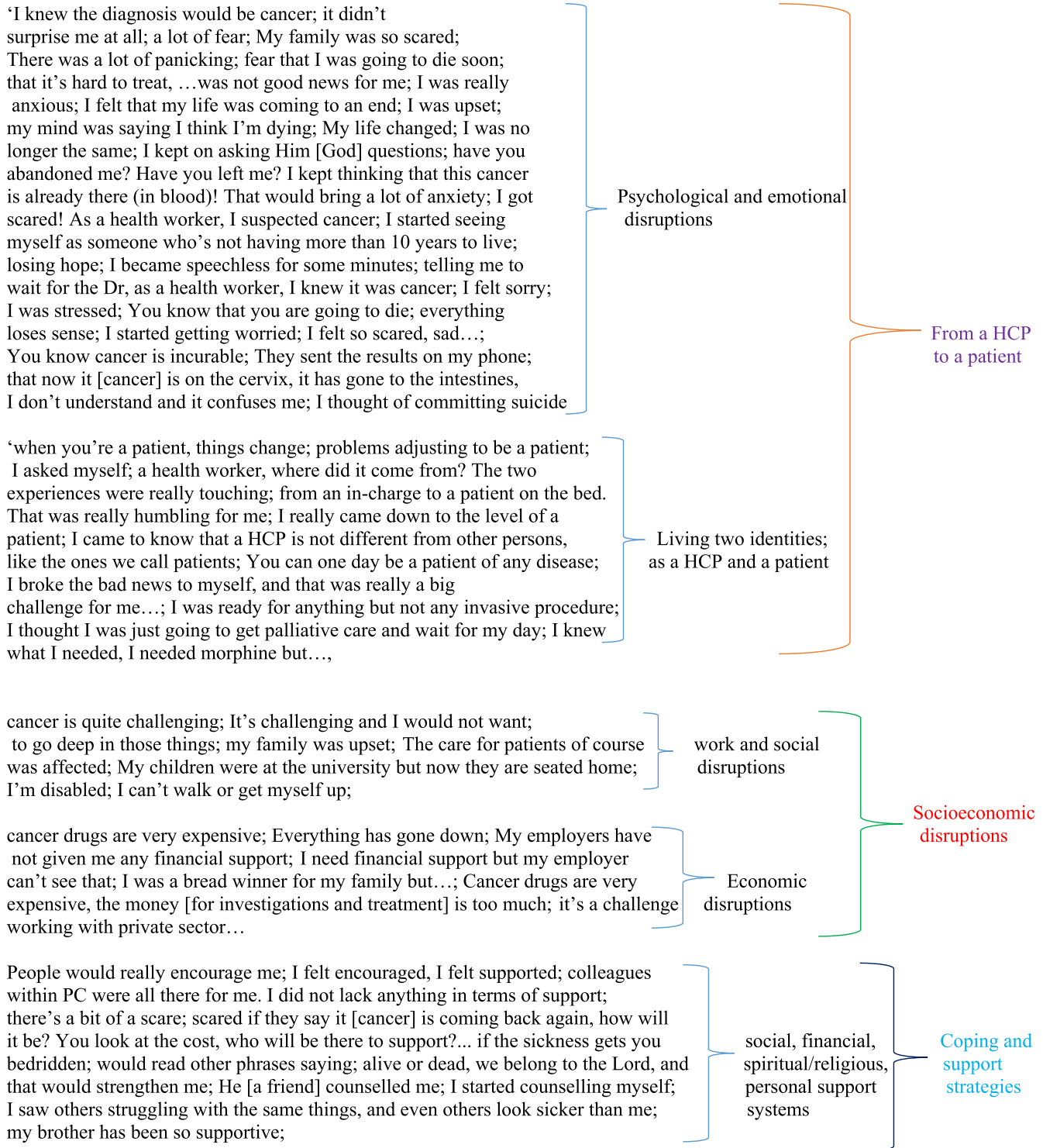


FIGURE 1 Tree diagram showing themes development during thematic analysis

on the cervix, it has gone to the intestines, I do not understand, and it confuses me (#7, Midife)

Healthcare professionals were not spared the challenges of the health system including inadequate supplies of medications and healthcare workers to review them, insensitive and uncaring health

TABLE 1 Sociodemographic characteristics of participants (N = 8)

Variable	Number
Gender	
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
Leukaemia	1
Skin cancer	1
Endometrial cancer	1
Colorectal cancer	1
Urethral neoplasm	1
Year diagnosed	
2010–2015	1
2016–2020	7
Cancer treatment received	
Chemotherapy only	3
Chemotherapy and palliative care	2
Surgery and radiotherapy	1
Surgery and palliative care	1
Palliative care only	1
Health insurance	
Yes	4
Worked in cancer or palliative care before	
Yes	5

Note: Participants ages ranged from 29 to 85, mean age 56 years. One was retired, two employed in the private sector, two in public service, and one was unemployed, while the remaining two had retired but were working as volunteers as shown in Table 1 above.

workers, and expensive and oftentimes unaffordable cancer treatment and investigations. These exacerbated their psychological symptoms to the extent that one abandoned treatment and developed suicidal ideation:

When I reached oncology clinic, because of delaying us, it came almost to noon when health workers had not seen any patient and remember I'd come the

day before, I slept there, that stress exacerbated the other stress (suicidal thought he had had the previous night). I decided to leave the chemo. I rode my motorcycle... I wanted to commit suicide...

(#3, Clinical Officer)

Psychological morbidities were fewer and less severe for those who expected a cancer diagnosis, especially if they were older:

I knew it would be cancer. I was not shocked at all. As you get older, you get used to the fact that you can die. Death is part of life.

(#6, MD)

...I think I was not surprised because I knew the diagnosis would be cancer.

(#1, MD)

For some HCPs, their psychological and emotional morbidities were influenced by their professional knowledge of cancer to the extent that even when they were declared cancer free, they continued to worry about the possibility of cancer recurrence with associated or eventual deterioration in health status, for example, disability and becoming dependent, as well as the financial strain of expensive investigations and treatment. The reminders of the 'ugly and painful' cancer experience they went through were enough to cause them constant worry and fear:

You get scared and you're like if they say it [cancer] is coming back, how will it be? You look at the cost, who will be there to support you? Then also if the sickness gets you bedridden, it also brings those memories and it's a scare

(#8, RN)

#### 4.1.2 | Living two identities; as a patient and a health professional

Participants described the professional-to-patient transition and how it impacted them, both positively and negatively. First, they grieved the loss of their professional identity. Second, they discussed the gains realized from the patient identity and how by being patients, they developed more compassion for patients than before:

The two experiences were really touching: from an in-charge to a patient on the bed. That was really humbling for me. (...) when I got the experience, it moved my heart so much. It moved my ego, self-esteem, and pride. I really came down to the level of a patient. I realized that nurse, doctor, anyone can come down to the level of a patient. You sleep on that bed, the stretcher on which you have been



wheeling other people. It humbled me, and it made me so close to patients than anything else. That I will never neglect any single patient! It totally increased my compassion

(#2, RN)

I now don't want to see any patient, especially in pain and I leave them, because I know how pain feels.

(#5, RN)

The cancer patient-hood experience further increased their awareness of the gaps existing in the healthcare system. They discussed challenges in cancer diagnosis, the expenses of treatment and investigations, delays and made recommendations for improvement:

The first contact with the patient, that's where the problem is; the healthcare system is full of so many delays... To have good outcome on cancer, emphasis should be on early detection, including primary prevention, screening programs, early diagnosis and treatment. We should also try to share information about the cancers that we have; most things are about ignorance.

(#1, MD)

For me its experience, experience is the best teacher. Once policy makers see they are healthy, it's okay. But once they have the experience, then they come to learn. So that wherever there are appeals for palliative care, cancer patients, or appeals for healthcare system, they should respond seriously. When they put a policy, let it be there. When they put a machine in the hospital, let someone take care of it. Let them follow up to see; are the machines working? Are they benefiting people? If they're student doctors, let there be someone; a senior with them, not to throw them in the hands of patients when they are not yet competent

(#2, RN)

## 4.2 | Theme: 2: Socioeconomic challenges

### 4.2.1 | Work and family-social disruptions

All eight participants discussed the various disruptions caused by cancer and toxicities of cancer treatment; six of the participants experienced excruciating pain:

Feeling pain everywhere... When you are taking those drugs (chemotherapy), you don't need to do anything. Sometimes I feel terrible pain here (epigastrium), even though you're taking omeprazole

(#4, RN)

...loss of libido and erectile dysfunction started immediately after starting chemo. Then reduced appetite and losing my beautiful hair, it's disturbing me. My fingernails have changed; the palms have become too dark. It's now easy to get mouth ulcers whenever I feed on hard foods...Even people are saying I could be taking ARVs

(#3, Clinical Officer)

A participant, a widow completely disabled by metastatic cervical cancer, recounted how she suffered while receiving radiotherapy at the Uganda Cancer Institute:

I had to foot every morning from Kawempe to get radiotherapy (about 10km) and after treatment walk back to my rented room. The stomach is very empty, you're surviving on watermelon, you reach in the room you've no energy to prepare a meal. Even the neighbours no one cares about you. That life was not good at all

(#7, Midwife)

All of them had significant disruptions to their bodily abilities and this affected their daily activities of living. Some had to retire early, while others had to navigate working with distressing symptoms:

I work from Monday up to Friday from 8 am to 5 pm. I normally come on Wednesday to do investigations and get chemo on Thursday. When I go back, my boss tells me I have to pay back the days I didn't work while in the hospital. So, instead of resting, on Saturday and Sunday I've to work to compensate...

(#3, Clinical Officer)

You can't perform effectively. You're getting treatment the patients are also here waiting. When you are on chemo, you're sick, you have headache, you are what (...)! You cannot perform accordingly. That is a problem to my patients. Sometimes, when I get treatment, I get sick for a week...

(#4, RN)

Some professionals were battling social and psychological stigma, resulting from cancer itself, or toxicities of its treatment:

The whole skin became dark, the face... People started seeing me, now I had long skirts (...). I was kind of stigmatized. Everyone would say, are you (her name)? What has happened? Of course that made me to feel bad about myself. Sometimes I would be forced to go out of Eucharistic mass before anyone sees me. It was very hard for me

(#2, RN)

Some sought traditional and herbal cures due to influence from their social networks, including family and friends, and also after modern medicine seemed unrewarding and very slow:

My family was upset, they said this is not the right treatment, come and we take you to Nairobi, others said India. Then I said no, you people, I'm under a superior and I must obey her. Others advised herbs, that they treat and cure cancer. I accessed it for two weeks, but it was very expensive, A Sacket was 250,000/=. At first, I thought I was getting better, and the side effects of methotrexate were disappearing, but after the first week, they came back. I said this doesn't work... I had paid spent 1.5 Ugandan million (\$417) ...

(#2, RN)

#### 4.2.2 | Economic challenges

Participants grieved the financial problems arising from huge out-of-pocket expenditure on cancer investigations and treatment, and these exacerbated psychological suffering. Those whose treatments were covered by insurance reported lesser financial hardships:

Every day I ask myself; people get sick and are able to walk around, but me I fell sick once and got disabled. I can't walk or get myself up... I was very enterprising; rearing chicken, pigs, that's no more. I had a private clinic, but I closed it. You can't receive patients when you're like this! I need to eat this; I can't afford it. All the money got finished on the pain and the disease. Even now I'm on loans. I have sold off almost everything I had. I feel so bad. My children (two) were at the university but now they are seated home. I have real suffering

(#7, Midwife)

Everything has gone down. I was a bread winner for my family. I was working at other places where I was getting some upkeep, that one I stopped. It's challenging and I would not want to go deep in those things

(#4, RN)

#### 4.2.3 | Theme 3: Coping and support strategies

Finally, they narrated how they had to 'relocate' and accept the patient-hood identity and learn to cope with cancer, and the support networks that assisted them on this journey, that is, family, friends and work colleagues:

After getting a diagnosis of cancer, it became so hard for me to counsel myself. I'm a health worker, but it became difficult for me to accept that I have a cancer and accept to start treatment. It became very, very difficult for me...I thought of committing suicide...

(#3, Clinical Officer)

If it was not that my aunt loves me, I would have done a bad thing to myself

(#7, Midwife)

Those who had a history of working in cancer and PC settings reported easier coping as they were supported by their colleagues:

My friends were visiting me, and being in the PC circle, people were coming from all over to visit me; from the ministry, from hospitals... People would really encourage me, and I felt supported. My daughter was there for me; my colleagues within PC were all there for me.

(#8, RN)

Difficulty coping was also observed among those with poor, and/or inadequate social support from their loved ones, especially their family. A 29-year-old patient shared how marital relationship issues with his wife, who he felt did not support him enough, affected his coping:

My appeal is to home care givers of cancer patients, to give a conducive environment to the cancer patients. When you get stress from your family, stress from the cancer (...). Cancer patients should not get any other external stress. In a conducive environment, you might even forget that you have cancer.

(#3, Clinical Officer)

## 5 | DISCUSSION

This study presents findings of an understudied topic, with particular emphasis put on examining how the psychosocial and emotional well-being of HCPs are affected when HCPs are confronted with and become cancer patients. Findings show that, HCP cancer patients, just like other cancer patients, experience considerable, or even higher emotional and psychosocial morbidities than their counterparts non-HCP patients. The HCPs experienced varying degrees of emotional suffering including shock, anxiety, hopelessness, worries about the costs of treatment and fear of the unknown, fear of loss of control and death. These findings confirm the available anecdotal evidence from the lived experiences of other HCPs who became cancer patients (Campbell, 2012; Granger, 2012) or suffered other chronic and mental health illnesses like depression and bipolar



affective disorder (Klitzman, 2007; Singh, 2003). Some participants' knowledge around cancer and its prognosis also influenced its psychological impact, for example, even after being declared cancer free, they continued to worry about recurrence. For some, the emotional and psychological disturbances started even before they received the diagnosis and worsened after the news was broken. Similar experiences on how having a professional background exacerbates individual emotional reactions have been reported in previous studies on HCP cancer patients (Fox et al., 2009; Prekert et al., 2017). This finding corroborates that of an earlier study in which 71% of doctors reported feeling embarrassed about becoming a patient (Davidson & Schattner, 2003).

Emotional and psychological suffering were most prevalent and severe in younger and middle-aged HCPs. This was due to concerns about 'unfinished business' and premature loss, including employment and financial, as well as physical disabilities and deformities. On top of the emotional disturbances following diagnosis, inadequate, and/or contradictory information about the illness from HCPs exacerbated the emotional distress of some participants. Disabling psychological symptoms have been reported in studies with non-professional cancer patients (Natuhwera et al., 2022; Van Beek et al., 2021).

The study revealed many HCPs lack the knowledge and skills to handle their colleagues who become cancer patients. Poor or inappropriate communication skills, especially with health providers giving the news of a cancer diagnosis insensitively were common. HCPs who were insensitively given their diagnosis reported greater emotional and psychological suffering. This phenomenon could underline a training gap, and so the need for prioritizing training in communication skills for HCPs working in cancer care, as demonstrated by Moore et al. (2018) and Uitterhoeue et al. (2010).

Participants narrated the challenging experience associated with the transition from being an HCP to being a patient; loss of professional role identity was a common challenge. This finding supports those of previous studies which report how adopting a patient identity is difficult for the HCP patient (Fox et al., 2009; Kay et al., 2004, 2008; Kenny et al., 2010; Lagad et al., 2019; Marsh, 2022), and undesirable (Granger, 2012; Klitzman, 2006a, 2006b; Tuffrey-Wijne, 2015) and heightens feelings of vulnerability among HCP patients. The findings further point to the fact that after becoming a patient, a HCP becomes vulnerable and needs care support from other professional colleagues, contrary to an assumed belief they can help themselves due to their background knowledge and clinical practice. Reporting on his experience of testicular cancer Campbell (2012), a physician, mentioned how he was no longer able to apply his professional knowledge to help himself, but needed the support of fellow HCPs.

Most participants reported significant disruptions in performing their work, and to their family-social domain. Physical symptoms related to cancer and its aggressive treatments, for example, nausea, fatigue were predominant contributors to such disruption. Previous medical literature has reported how health professionals' ill health can adversely affect their performance and functioning,

including the ability to provide compassionate care to their patients (Davies, 2015, Oxtoby, 2015). Some reported fear and stigma of being known and identified as patients. All narrated how getting a cancer diagnosis adversely impacted their psychological and social well-being, and 'metastasized' to their loved ones (family, friends, work colleagues) who also suffered psychological distress, shock, worry, etc. Stigma related to cancer and non-cancer illnesses has been reported in other medical literature and studies conducted with health professional patient populations, and is a risk factor to, and exacerbates psychological morbidity (Fox et al., 2009; Kay et al., 2004, 2008; Marsh, 2022; Natuhwera et al., 2022). There is thus, an urgent need to identify strategies to destigmatize cancer, as stigma could negatively impact healthcare-seeking behaviours, and lead to poor cancer treatment outcome.

Barriers to cancer care access, including prolonged delays before accessing care were reported by most participants. These barriers included limited availability of specialist services, including palliative care (personnel and equipment) for investigations and treatment, unaffordability of cancer care, both investigations and treatments. These barriers have been reported in other studies in the context of LMICs (Arbyn, 2020; IAEA, 2013; Sullivan et al., 2015; WHO, 2015). Participants who had a history of working in palliative care narrated how, in some instances, they were disappointed as they would not be receiving palliative care for their symptoms, or if they did it was late, and this caused them unnecessary suffering; "I knew what I needed for that pain; I needed morphine, but they would not give me morphine", a surprising finding reported by a participant who, at some point, received care in the UK, a HIC. Delays and challenges receiving palliative care for distressing symptoms were also reported by other participants who received care in Uganda. Financial suffering was commonest and greatest in those not covered by insurance, deepening their psychological suffering. Whereas this finding is unsurprising, it is important to understand it in a more generic and broader sense based on the socioeconomic context in Uganda where the financial hardship is not just about paying for treatment but also travel, subsistence and not having a job. For example, agonizingly, one of the participants (a clinical officer) decided to abandon chemotherapy treatment and developed suicidal thoughts due to multi-component stress exacerbated by delays while receiving treatment, financial strain and social and emotional disruptions resulting from cancer. This finding corroborates evidence from previous studies which report increased susceptibility to mental health issues, including increased risk of suicide among doctors (Gerada, 2018; Kay et al., 2004; Learner, 2011; Schlicht et al., 1990).

The study has shown a diagnosis of cancer has far reaching financial ramifications on patients, and their entire social systems and financial suffering was a common emergent theme. Some were forced to sell houses and land to finance their treatment and meet other obligations. This pushed them into extreme poverty, further heightening their psychological distress. This study identified how six of the participants forced themselves to continue working, despite pain and other significant distressing cancer symptoms. One participant reported how unbearable pain made her quit work

without even informing her employer, while another could no longer withstand work demands retired early. A widow who was bedridden with advanced metastatic cancer broke down as she narrated how cancer and constant spending on its treatments (multiple surgeries, radiotherapy and chemotherapy) drove her into heavy debt and the loss of all her possessions. Her two children also had to drop out of university. These findings are not surprising, given that a lack of a national insurance scheme in Uganda dictates that individuals have to suffer out-of-pocket spending on their health care, and HCP cancer patients in this study, in particular, those that lacked insurance cover were not spared. Anderson et al. (2017), in their study, found 46% of cancer patients attending a regional referral hospital in Uganda met the World Bank's definition of extreme poverty (living on US\$1.90/person/day). Out-of-pocket spending on health care is prevalent at 48.1%, 33.3% and 13.7% in LMICs, Upper-Middle Income Countries and HICs respectively (World Bank, 2013). It should be noted that Uganda is one of the poorest countries in the world. According to Multidimensional Poverty Index (MPI) survey report 2022 by the Uganda Bureau of Statistics (UBoS) (2022) and the World Bank data (n.d.) 42% of Ugandans live in multidimensional poverty, while 14.7% (of 45 million Ugandans) are deprived of an income and are extremely poor (UBoS, 2022).

Finally, participants narrated how they had to relocate and accept the cancer patient-hood identity. Support received from friends, work colleagues and family members were utilized in coping with cancer patient-hood. Spiritual and religious structures and systems were also utilized and provided a lever of support. These findings emphasize the role of holistic care in the management of complex needs of cancer patients. Participants who were attending, or working in, PC reported better support and easier coping than their colleagues, in addition to being able to advocate for themselves to be given palliative care for control of their symptoms, including but not limited to pain. This finding supports the active role palliative care in cancer care, as a key component of universal Health Coverage. Participants who had completed treatments reported their hopes for cure were restored after they were assessed and told the cancer was no longer there. However, some of them continued to experience post-traumatic stress disorder-like symptoms such as intrusive thoughts and fears of disease recurrence when they encountered reminders of the disease—a phenomenon reported elsewhere (Campbell, 2012; Granger, 2012; Lagad et al., 2019; Tuffrey-Wijne, 2015).

### 5.1 | Strengths and limitations

No known documented study has been conducted in Africa, to examine the psychosocial and emotional morbidities caused by cancer as lived by HCPs. This study, therefore, provides novel insights into this under-researched area and evidence critical for informing clinical practice, or even policy to some extent.

The COVID-19 pandemic and lockdowns presented practical transport difficulties, meaning some participants were interviewed by telephone which could have limited elicitation of some of their

experiences and the capture of non-verbal cues, so limiting the richness of the data. This also meant it was not possible to observe emotional distress and offer face-to-face emotional support to participants who could have suffered emotional distress and preferred not to disclose it to the interviewer during interviews. Hence, the interviewer had to rely on participant-disclosed emotional distress, and that which was audibly eminent during the telephone interview. Similarly, challenges in accessing health care, as well as socioeconomic, and psychological disruptions due to the pandemic could also have exacerbated some of the participants' experiences. Limited research in the topic also presented a unique limitation, where the researchers did not have adequate available evidence to compare with the results of the current study.

## 6 | CONCLUSION

Many HCPs are now diagnosed with cancer every year. Findings from this study indicate getting a cancer diagnosis and the transition from being an HCP and care provider to being a patient and recipient of care is a unique experience. The patient role identity is associated with significant multidimensional disruption and suffering, including feelings of disempowerment, for example, grieving threatened and/or actual loss of professional role identity, fear of the consequences of disease and recurrence, shock, worry, anxiety and depression. Constant reminders of cancer, financial hardships and challenges in accessing care, pain and other distressing symptoms and toxicities of treatment further exacerbate psychosocial and emotional suffering.

## 7 | RELEVANCE TO CLINICAL PRACTICE

The study findings suggest an urgent need for action to assuage the suffering associated with cancer including the need to: (1) improve access to care; (2) increase the communication training of cancer care specialists and other care providers; (3) intensify cancer awareness campaigns; (4) prioritize and introduce a public health insurance scheme to eliminate out-of-pocket costs for cancer treatment and, (5) develop guidelines for the management of HCP cancer patients. These will lessen the psychosocial, financial and emotional suffering for both HCP, and non-HCP, cancer patients and survivors.

### AUTHOR CONTRIBUTIONS

GN: Conceptualized the study, reviewed literature, collected data, transcribed interviews, analysis and writing up the paper, prepared and submitted manuscript for journal publication. PE: Reviewed literature, transcripts, analysed the data, expert review of the paper, final proofreading and formatting of the manuscript prior to submission to the journal. SWA: Analysis, review of the paper, prepared and proofread manuscript for journal publication. EN: Analysis, proofread and prepared manuscript for journal publication.

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## CONFLICT OF INTEREST

The authors declare no competing interests.

## DATA AVAILABILITY STATEMENT

For access to the data for this study, please contact peteralanellis@aol.com

## NO PATIENT CONTRIBUTION OR PUBLIC CONTRIBUTION

The HCP cancer patients and survivors are participants in the study but did not contribute to the design or undertaking of the study.

## ORCID

Germans Natuhwera  <https://orcid.org/0000-0003-4474-4063>

## TWITTER

Germans Natuhwera  @GermansNatuhwera

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