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Challenges faced by cancer patients in Uganda: Implications for health systems strengthening in resource limited settings

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ABSTRACT

Background: Uganda Cancer Institute (UCI), the only comprehensive cancer treatment center in Uganda, registers about 4000 new cancer patients a year. However, many cancer patients in Uganda never receive treatment due to a variety of challenges. We therefore conducted a study to identify and assess the challenges faced by cancer patients in Uganda.

Methods: A cross-sectional study conducted in April-May 2017 among adult cancer patients. 359 participants participated in an interviewer-administered survey. We used stratified random sampling to select the study participants. Data was analyzed in SPSS Statistics 24.

Results: 35 % of the patients delayed initiating cancer treatment and 41 % missed medical appointments along their care journey. Delayed and missed appointments were mainly due to lack of money for cancer medicines, transportation and accommodation. Patients also expressed challenges with side effects of cancer treatment: 52 % sought help from health workers when they experienced side effects; 14 % used alternative medicine; and 21 % did not inform anyone. In addition, 55 % of the participants had limited knowledge about their disease and treatment. Other challenges when at UCI included: being hungry and thirsty throughout the day, long waiting hours, not having a resting place, not understanding what comes next, and having their records lost by hospital staff.

Conclusion: Challenges faced by cancer patients in Uganda result in enormous delays in initiation and continuation of cancer treatment. These challenges are often a result of the poor social-economic status of the patients; inadequate infrastructure for cancer care; and inefficiencies in the health care system.

Policy Summary: To improve the experience of patients, the National Cancer Control Plan should consider establishing regional cancer centers; creating a reliable supply of cancer medicines; and integrating navigation programmes into cancer care. Strengthening the whole health system, in relation to cancer service delivery, should remain a top priority for Uganda and other resource limited settings.

1. Introduction

Cancer is a major cause of suffering and death throughout the world [1]. It's predicted that there will be 21 million new cancer cases per year in 2030 globally, and 75 % of the cancer burden will be in the developing world [2–4]. In Uganda, about 32,617 new cases and 21,829 cancer deaths were registered in 2018 [5]. The cancer estimates for Uganda, come mainly from one population-based cancer registry, Kampala Cancer Registry, established in 1954 in Kampala capital city and covers about 8% of the total population [6]. There is a second upcoming cancer registry in Northern Uganda, Gulu Cancer Registry, established in 2013 which may soon supplement the cancer estimates for Uganda [7]. However, the infrastructure for cancer research and control in Uganda is still developing including; cancer surveillance and registration; prevention and early detection; treatment and diagnosis; and medical records management systems [8]. Hence, the actual cancer burden in other regions of the country and for the whole country is yet to be determined.

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Uganda Cancer Institute (UCI), the only comprehensive public cancer center located in the central region of the country (in Kampala capital city), registers about 4000 new cancer cases annually [9]. UCI offers all cancer services including: prevention and early detection; diagnosis; treatment; and palliation [10,11]. Cancer care at UCI is mainly offered for free including; cancer screening; diagnosis; oncologist consultations; surgery; and all cancer medicines available in the UCI pharmacy. Due to recurrent stock-outs, patients may have to buy medicines that are not available in the pharmacy, and due to the limited number of surgical-oncologists in the country, most patients seek specialized cancer surgery from private practices [12,13]. In addition, patients cost-share for radiotherapy services by paying a standard fee of about $85USD before accessing all the prescribed radiation cycles. Although the general social economic status of cancer patients at UCI is not known yet, Anderson et al. (2017) found that 46 % the patients at one regional referral hospital in Uganda, met the World Bank's definition of extreme poverty ($1.90/person/day) [13]. This study also found that 53 % of the households had to borrow money to pay for care, 21 % had to sell possessions, and 17 % lost a job as a result of the patient's hospitalization [13].

Although most cancer services are provided free of charge, many cancer patients in Uganda are never referred, may never seek treatment, and hence face many challenges along their cancer journey [11,14–16]. The public health service structure in Uganda is organized in several levels from Health Centers (mainly III and IV) to district hospitals, regional and two national referral hospitals [8,17]. Since there are no organized cancer screening programs in Uganda, most cancer patients enter the care pathway by self-referral, due to alarming symptoms, and consult with their primary health care professionals several times before a cancer diagnosis or referral is made [18]. As result, patients may face enormous challenges and delays for cancer care due to several factors including; lack of knowledge and awareness about cancer signs and symptoms; poor access to health care and diagnostic facilities; stigma about the cancer disease; and financial constraints [19].

While health workers observe some challenges faced by cancer patients in Uganda, there is no method to effectively assess the magnitude and nature of these challenges at the moment. For example, of the 4187 cancer patients admitted at UCI in 2017, only 56% (2347) started/initiated cancer treatment of any type. And of those who initiated cancer treatment, only 45% (1057) completed their treatment. This implies that there are still a lot of challenges to accessing cancer care, despite the provision of free cancer services and treatment. Hence, the primary objective of this study was to examine the challenges of patients' access to transportation, accommodation, treatment, and health literacy resources during cancer treatment in Uganda and to generate strategies for mitigation of the identified challenges. This provides evidence for planning and addressing these challenges, to improve cancer care services in Uganda.

2. Materials and methods

2.1. Study population and design

A cross-sectional survey was conducted in April-to-May 2017 among adult UCI patients who received at least one dose of cancer treatment for any cancer type, within the year 2016−2017. All forms of cancer treatment were considered including: surgery, radiotherapy, chemotherapy, and palliation, defined as supportive care and pain management. 359 participants participated in the study. The initial sample size ($n = 357$) was computed based on an average annual estimate of $N = 4000$ patients seen at UCI and the number needed to have a power of 95%. The total number of participants seen at UCI in the study period was 3283 and they formed our sampling frame. This sampling frame was stratified by sex and location (central or upcountry). Using stratified random sampling, simple random samples were drawn from each stratum using different sampling fractions. To have 100% response rate, a top-up sample was drawn from the sampling frame, using the same sampling method to cater for non-respondents. The study coordinator contacted the selected participants via phone, using a Research Ethics Committee (REC) approved oral script. The study was approved by Uganda Cancer Institute Research and Ethics Committee; Morehouse School of Medicine Institutional Review Board USA; and Uganda National Council for Science and Technology. Written informed consent was obtained from all participants prior to study participation.

2.2. Data collection

Participants were interviewed by well-trained, bilingual (English and Luganda) research assistants, using interview-administered questionnaires. The questionnaire was developed through an iterative collaborative process, among public health experts and researchers at UCI and American Cancer Society (ACS). The study questionnaire was piloted prior to the launch of the study and adjusted accordingly.

2.3. Data management and analysis

Data was entered using an online database developed by ACS. Data was protected by a firewall and access was limited to only study staff, using well-protected passwords. Data was analyzed in SPSS Statistics 24. All analyses were based on responses received and there was no extrapolation of missing data. Prevalence of the main challenges was obtained by quantifying the proportion (frequencies) of patients experiencing a certain challenge.

3. Results

3.1. Participant social-demographic information

The average age of participants was 43 years and over half were female. Most of the participants were Baganda, one of the dominant tribes in Uganda that lives in the central region of the country, where UCI is located. More than one third of the participants reported primary education as their highest level of education attained and only a quarter reported attaining college or university education level. While half of the participants were employed, a quarter had lost their jobs because of cancer disease. The most common types of cancers among the participants were cervix and Kaposi's sarcoma, followed by breast and prostate, Table 1. Most participants (55 %) were receiving chemotherapy and/or surgery (16%); palliation (16%); radiotherapy (12%); and some were using alternative medicine (6%) including traditional and Chinese herbs (data not shown).

3.2. Delays in treatment initiation and adherence to cancer treatment

Participants were asked if they had delayed initiating their cancer treatment after diagnosis and whether they had missed or delayed any medical appointments after initiating treatment. 35% (106) reported having delayed initiating cancer treatment and 41% (123) indicated that they have missed or delayed medical appointments after initiation of treatment. Delayed or missed appointments were mainly due to lack of money for treatment, medicines and transportation. Other reasons included: family responsibilities; not healthy enough to continue treatment; and failure to find accommodation in Kampala.

3.3. Side-effects of cancer treatment

Participants reported experiencing many side effects due to their cancer treatment including: general weakness; loss of appetite; darkening of some body parts; loss of hair; and/or vomiting, Fig. 1. Participants indicated that oral wounds (61%); weakness (48%); vomiting (45%); and constipation (42%) were the most worrying side effects (data not shown). One-third of participants also found diarrhea, hair loss and

Table 1
Participant sociodemographic information and cancer related variables. (N = 359).

Characteristic	n	Percentage
Average age (in years)	43.2	
Sex (female)	199	55%
Cancer type		
Cervix	72	20%
Kaposi's sarcoma	71	20%
Breast	46	13%
Prostate	19	5%
Esophagus	16	4%
Tribe (Ethnicity)		
Baganda	172	48%
Munyankore	36	10%
Ateso	21	6%
Musoga	20	6%
Munyoro	17	5%
Mugishu	14	4%
Others	79	21%
Marital Status		
Married	143	43%
Single	77	21%
Living together but not married	61	17%
Separated/divorced	47	13%
Widow/Widower	31	9%
Religion		
Catholic	133	37%
Protestant	105	29%
Muslim	54	15%
Pentecostal	51	14%
Other	16	5%
Occupation		
Self Employed	87	24%
Unemployed	82	23%
Stopped working due to cancer	70	20%
Casual employment	61	17%
Formal employment	39	11%
Other	20	6%
Education		
Primary level	147	41%
Secondary level	97	27%
College/University education level	71	20%

loss of appetite very troublesome. These side effects were most worrying because they affected participants' ability to perform normal duties, like eating or drinking. In addition, participants did not know if the side effects would disappear; they feared worsening of the side effects and facing death; and being embarrassed and ashamed in public because of their appearance (data not shown). When experiencing these side-effects, most participants (52%) sought help from health workers; 14% used alternative medicine; and about 21% did not inform anyone about their side effects (data not shown).

3.4. Health information challenges

285 participants (94%) indicated that they were told the type of cancer they were suffering from and the type of treatment being given (Data not shown). In addition, more than 90% of the participants indicated that they were comfortable asking questions about their treatment. However, many participants were not told what to do before initiating treatment and lacked information on length of treatment schedule and how long they would come to UCI for treatment. Similarly, participants were often not told about the side effects of the treatment and what to do in case of side effects, Fig. 2.

An extremely important finding from this study is that more than 97% of the participants wanted to know how long they would come to UCI for treatment; what to do before initiating treatment; and the side effects of treatment (data not shown). Of those who received this

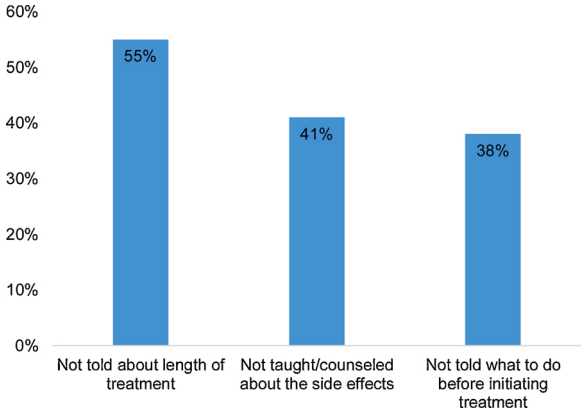

Fig. 2. Challenges faced in accessing health information (n = 302).

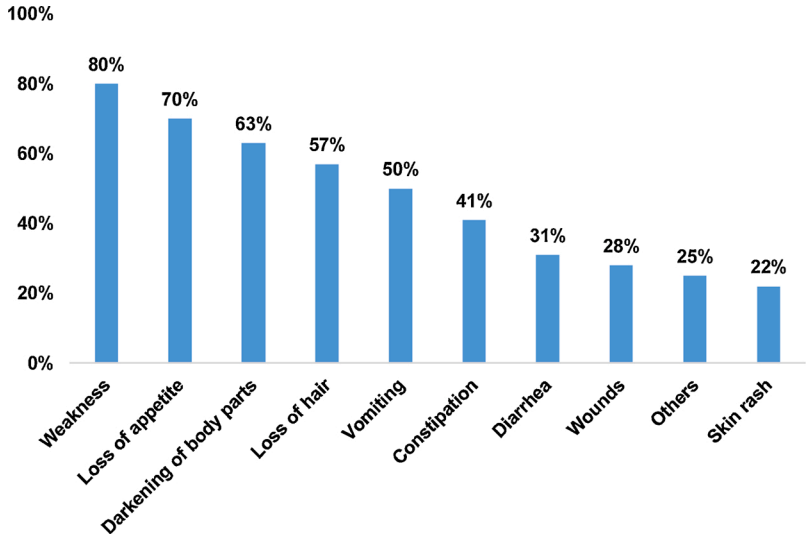

Fig. 1. Side effects experienced since starting cancer treatment (N = 359). Participants indicated as many side effects as experienced.

information, 84% got the information orally from health workers and 53% received information in a written form, like brochures and/or books (data not shown). A small number (4%) were told by their caregiver and none got information from a video. When asked about the preferred source of information, 56% preferred getting the information orally and/or in written form (37%) (data not shown).

3.5. Transportation challenges

On average, participants traveled about 132 km to and from UCI. Those who were residing in the central region traveled an average of about 13 km, while those from upcountry traveled an average of 212 km to and from UCI (data not shown). 85% of the participants indicated that they used public transportation to travel from their permanent home to Kampala, Fig. 3. When in Kampala (i.e. from the Kampala accommodation to UCI), 56% used public transport; 21% indicated using motorcycle (commonly known as boda-boda) and 16% used other means, such as walking or taxi.

3.6. Accommodation challenges

When asked about where they stayed when receiving cancer treatment, participants' accommodation options included: staying at their own homes; staying with relatives; staying in a rented apartment; staying at a friend's house; staying at hostels; and some had no accommodation apart from staying in the corridors or grounds of the cancer center (UCI), Fig. 4. Of the 133 participants responding, 63% indicated that they needed to stay around Kampala to receive cancer treatment for about 1–7 days; 8% needed to stay for about 8–18 days; 13% stayed between 15–30 days; and 16% needed to stay in Kampala for more than a month to receive cancer treatment (data not shown). 17% (60) of the participants indicated that they were paying for the place where they stayed during treatment, which cost them about $2−4 USD per night (data not shown). While 28% (101) felt they were a burden to others, more than 80% indicated that the place they were staying in was comfortable and/or safe, clean, and they could take a bath/shower; received food; and slept comfortably (data not shown). During treatment breaks, 63% of the participants returned to their permanent homes and 37% continued to stay where they stayed when on treatment.

3.7. Social support challenges

67% (n = 243) of participants came to UCI unaccompanied; 30% (n = 108) were accompanied by an adult family member; and 3% accompanied by small children (data not shown). 59% (68) were accompanied by relatives or friends from Kampala while 41% (47) were accompanied by people from their permanent home, outside Kampala (data not shown). 36% of the participants indicated that their caregivers were not staying in the same place with them. When asked about the most needed assistance since they started treatment, 78% of the participants indicated that talking to someone with a similar disease was the most needed assistance, as that helped them cope better with their situation (data not shown). Other types of assistance identified were: getting information about their disease (90%); and getting help with transportation to and from the hospital (75%) (data not shown).

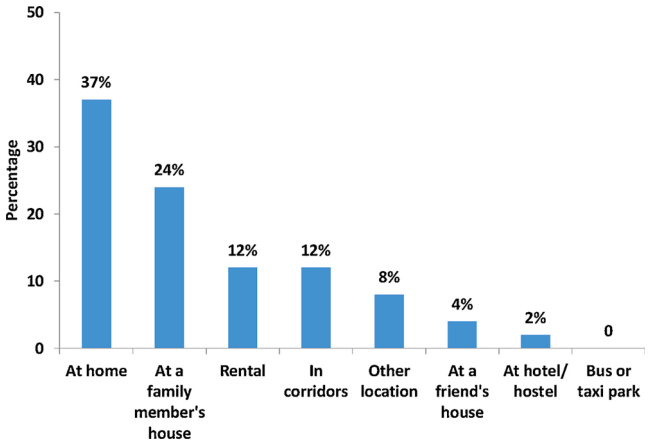

Fig. 4. Places where cancer patients stay when receiving treatment (N = 357).

3.8. System and facility-based challenges

The most frustrating challenges included: medicines stock-outs; not having access to clean toilets; being hungry and thirsty throughout the day; waiting for long hours to be seen by the doctors; not having a place to rest throughout the day; not understanding what comes next; and having their records lost by hospital staff (data not shown).

4. Discussion

This study set out to assess the challenges faced by patients seeking cancer treatment in Uganda. Challenges ranged from socio-economic factors to structural and system factors including lack of money for medicines, transport and accommodation. Other challenges included:

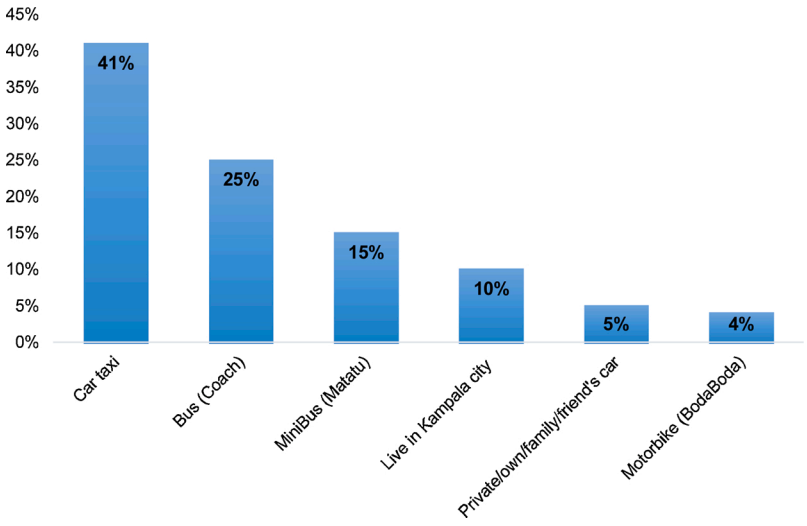

Fig. 3. Main type of transport used from permanent home to Kampala for treatment (N = 358).

recurrent drug stock outs; limited information about their disease and treatment; not having access to clean toilets; being hungry and thirsty throughout the day; long waiting hours; not having a place to rest throughout the day; not understanding what comes next; and having their medical records misplaced by hospital staff.

The results of this study indicate that many participants delayed initiating cancer treatment and missed doctors' appointments during their treatment journey. This may directly affect the outcomes of cancer treatment in this setting, since adherence to cancer treatment and doctor's advice is a key factor to successful outcome of medical treatment [15,20]. The delay in accessing treatment is partly due to the fact that UCI is the only comprehensive cancer treatment center in Uganda, thereby presenting a geographical accessibility challenge. In addition, more than half of the Ugandans live in multidimensional poverty and hence are unable to afford cancer treatment and related costs [21,22].

Lack of money for medicines ranked highest among the reasons for delayed treatment or missed appointments. Although this could be partly explained by the social-economic status of the cancer patients in this population, Uganda is one of the countries that provides free treatment and essential cancer medicines to its patients. This implies that there could be other systemic challenges, resulting in recurrent stock-outs of cancer medicines at UCI. In the event medicines are out of stock, patients have to buy the prescribed treatment from private pharmacies which are frequently unaffordable. Research has shown that these out of pocket expenditures for healthcare have further impoverished patients and their families [23]. Medicine stock-outs in low-middle income countries (LMICs), are thought to be related to the inefficiencies in the procurement and distribution processes, such as lack of planning and forecasting medicine needs, as well as untimely ordering of medicines [24,25]. There is a need to assess and identify such bottlenecks in cancer care, with an aim of strengthening the whole health system to efficiently respond to the rising number of cancer patients in Uganda [26].

Lack of transportation to the cancer center ranked second among the reasons for delayed and missed clinic appointments. According to this study, the average distance travelled by cancer patients ranged from 13 km to 212 km. As consistent with other studies, travelling long distances for cancer treatment imposes financial burden on patients and their families, resulting in poor adherence to cancer treatment and treatment abandonment [15,27]. Two regional cancer centers, one in western and one in northern regions, are being established to increase geographical access to cancer treatment in Uganda. This implies that patients can come to UCI for an initial consultation and for specialized services like radiotherapy but continue to receive ongoing treatment and follow-up at regional centers. Providing a visiting oncologist to these regional centers and use of telehealth are proven innovations for increasing access to cancer care [28–30]. Hence, UCI and other LMICs need to consider such initiatives, as they decrease financial burdens; reduce infections like COVID-19; and save time for patients [28,30].

Another important finding was the challenge of inadequate health and cancer information for patients. Although a majority of the participants were told about the type of cancer and treatment being given, the study showed there were limited opportunities for consistent access to detailed information, such as the duration of treatment and side effects. It is well documented that cancer patients prefer to know as much information as possible about their disease including: the stage of cancer; treatment options; prognosis; and side effects. Such information provides opportunities for patient involvement in decision-makingabout their health and treatment. This leads to satisfaction with treatment choices and enhances adherence to cancer treatment. Ultimately it reduces patients' anxiety, improving their experience and quality of life [31–34]. Although UCI provides patients with pre-medication and post-medication, administered with their chemotherapy to control some side-effects, health workers need to develop ways of providing adequate and detailed information to cancer patients including what to do in case of treatment side-effects.

In addition, many participants lacked social support. It was a striking finding that most of the study participants came to the cancer center unaccompanied and many were not staying in the same place with their caregiver(s). Children accompanied a small proportion of the cancer patients as well. This is a worrying situation given the high levels of health-illiteracy among cancer patients in Uganda, coupled with lack of established follow-up mechanisms and inadequate social care support services in the country. Evidence shows that support received from caregivers, formal or informal, is vital in influencing patients' abilities to process cancer-related information. It also regulates their emotions and helps them cope with medical related decisions and treatment [35]. Hence, more research is needed to assess and understand the social support needs and the extent to which patients receive helpful information and decision-making support in Uganda [35].

Other highly ranked challenges faced by cancer patients are system and facility-based factors including: lack of access to clean toilets; being hungry/thirsty throughout the day; long waiting hours; not having a place to rest throughout the day; not understanding what comes next; and having their records misplaced by hospital staff. Interventions like Patient Navigation programs have been proved effective in addressing such challenges [36]. Patient navigation refers to the provision of support and guidance to patients, accessing the cancer care system to overcome barriers to timely and quality care [37,36,38]. Patient navigation improves the quality of life after cancer diagnosis and enhances patient satisfaction [39–41]. Such approaches could be very helpful for the cancer care system in Uganda and other LMICs.

Strengths and Limitations of the study: This study had a number of limitations as indicated; First, the study recruited cancer patients receiving medical treatment in the public cancer center and findings may not be generalizable to cancer survivors who have completed medical treatment. However, many cancer patients, including survivors in Uganda, may have experienced these challenges during their course of treatment. This was done to mitigate recall bias especially among survivors who had completed treatment. Secondly, this study used data from quantitative methods only, and some of the concepts may not have been explored in detail. The researcher conducted a qualitative analysis of these findings shortly after quantitative data collection to attach meaning and validate these findings. A manuscript about qualitative analysis of the findings is under preparation. Thirdly, the study did not assess the duration between symptom onset to diagnosis since it is known that some of the symptoms are not very specific for a particular cancer although this aspect is important to identify system barriers to healthcare. Fourthly, this study did not conduct patient chart reviews to determine the cancer stage, and neither did we ask the patients their cancer stage. However, the patients in this study were fully aware of their cancer diagnosis and had accessed cancer treatment. The fifth limitation of this study was that the social economic status of the study participants was not assessed. However, there is evidence that a good proportion of Ugandans live below the poverty line and that healthcare out of pocket expenditures, may have further impoverished people [23].

5. Conclusion and recommendations

The evidence from this study shows that many cancer patients delay initiation of cancer treatment and miss medical appointments during their treatment. This is caused by several factors including:

- Social-economic status of the patients: Patients lack social support; they cannot afford many of the costs including; transport, accommodation, medicines, food and drinks.
- Inadequate infrastructure for cancer care: Only one comprehensive cancer center, causing patients to travel long distances; lack of accommodation facilities at the treatment center; lack of access to clean toilets; and lack of resting and waiting places.
- Inefficiencies in the health care system: reflected in recurrent medicine stock-outs; inadequate health information given to patients;

long waiting hours; lack of clear patient flow; and ineffective records management system.

Hence, in addition to establishing regional cancer centers and providing free cancer medicines, UCI should consider establishing a reliable supply of cancer medicines and integrating patient navigation programmes into cancer care. In addition, functional patient support groups should be established, as many patients cited talking to someone with similar disease as one of the most needed assistance. Above all, there is need to assess the whole Health System *(leadership/governance, financing, human resources, equipment/medicines/supplies, health information, and service delivery)* and how it relates to cancer care. This is a critical path to identifying areas of improvement and to comprehensively address the challenges of cancer service delivery in Uganda and other resource limited settings.

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Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:https://doi.org/10.1016/j.jcpo.2020.100263.

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