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Original articles

Exploring the experiences of individuals with cancer in Uganda during the COVID-19 pandemic

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Background

Individuals with cancer in low- and middle-income countries face significant barriers to care, which were exacerbated by the COVID-19 pandemic. Limited research exists on the pandemic's impact on cancer care in these settings. This qualitative study examines the experiences of individuals with cancer at the Uganda Cancer Institute (UCI) during the COVID-19 pandemic to inform future policy and emergency preparedness.

Methods

Thirty individuals with cancer (11 male, 19 female, aged 18-71) receiving care at UCI were purposively sampled and interviewed between June – July 2022. Semi-structured interviews, conducted in English or Luganda, explored impacts of COVID-19 on treatment, access, and vaccination. Thematic analysis was completed on verbatim transcripts.

Results

Participants reported significant delays in treatment and appointments, some rescheduling up to four times, due to staffing shortages, travel bans, and loss of income. Transportation costs increased up to eightfold for rural patients, while lack of affordable accommodation and personal protective equipment further strained resources. Overcrowding at UCI forced some to sleep outside, and 41% of participants were not vaccinated, citing concerns about side effects. Misinformation, fear of infection, and reliance on social connections to access care were common.

Conclusions

COVID-19 exacerbated longstanding inequities in cancer care access at UCI, disproportionately affecting rural and low-income patients. Policy responses must address subsidized transportation, expanded UCI infrastructure and low-cost accommodations, provision of PPE, and investment in telehealth. Policymakers should prioritize cancer patients in emergency preparedness to ensure continuity of care for vulnerable populations during future public health crises.

INTRODUCTION

Individuals with cancer across low-and-middle-income countries (LMICs) face multiple barriers to healthcare access, including long travel distances to care facilities, limited transportation, and strained finances barriers, among others.[1] The COVID-19 pandemic safety related guidelines, including mobility restrictions, implemented in some countries exacerbated the situation by disrupting cancer service delivery, causing delays and cancellations of cancer screening and treatment in many regions of the world including in sub-Saharan Africa (SSA).[2] There remains limited research examining the pandemic's impact on cancer care from the perspective of the patient.

In Uganda, cancer is a major public health issue with 34,008 new cases and 22,992 deaths recorded in 2020.[3] The most prevalent cancers in Uganda include cervical cancer, Kaposi's sarcoma, breast cancer, prostate, and non-Hodgkin lymphoma.[3] The first case of COVID-19 in Uganda was reported on March 21st, 2020.[4] From January 3, 2020 to November 8, 2023, there were 171,983 COVID-19 cases and 3,632 confirmed COVID-19 deaths.[5] In Uganda, na-

tional pandemic guidelines included lockdowns, travel restrictions, masking, and hygiene measures, and suspension of markets and all non-essential activities.[6] Previous research suggests that these restrictions and measures coalesced to create more health inequity as underutilization and suspension of critical cancer services, including screening, diagnosis, and treatment, became even more pronounced during the COVID-19 pandemic.[7-9] Unfortunately, school and non-essential business closures and stay-at-home mandates that were intended to protect the health of the public, greatly disrupted the cancer care landscape and inconvenienced individuals with cancer. For instance, many individuals with cancer in Uganda rely on public transportation to access treatment services, but during the COVID-19 lockdown, transportation fares nearly doubled, making it difficult to afford.[9]

UCI is the primary cancer care provider in Uganda and is located in the capital city of Kampala, requiring some patients to travel long distances to access cancer services. Even before the COVID-19 pandemic, individuals with cancer in Uganda faced barriers to treatment. Some of those barriers include long travel distances to cancer care facilities, high transportation costs, inadequate health information, accommodation challenges, social support challenges, and system and facility-based challenges such as medicine stock-outs, not having access to clean toilets and waiting long hours to be seen by a doctor.[10] To lessen the cancer burden in Uganda, preventive measures have been undertaken including enhancing routine cancer screening for early detection and improving public health messaging around individual behaviours such as encouraging individuals with cancer to adhere to treatment, engage in physical activity, and eat healthy diets.[9] However, due to the COVID-19 public health measures, many preventative cancer care services were interrupted including screening which disrupted early detection campaigns and increased the risk for late-stage cancer diagnoses.[9]

The COVID-19 pandemic and associated public health policies posed significant and unique challenges for Ugandan individuals with cancer. This qualitative study aims to examine and contextualize the perspectives and experiences of Ugandan individuals with cancer during the COVID-19 pandemic to better assess the extent to which COVID-19 has interrupted cancer services at UCI. Previous studies have examined the challenges that the COVID-19 pandemic posed on the Ugandan healthcare system.[11-16] However, few studies focus on the unique challenges of individuals with cancer and their experiences. This work fills a critical knowledge gap that will help guide and inform future public health emergencies and interventions.

METHODS

Semi-structured individual interviews were conducted with individuals with cancer seeking care at UCI (n=30). Interviews assessed patients' perceptions regarding how COVID-19 has impacted the provision and use of cancer treatment and preventive services, COVID-19 vaccination access and distribution to individuals with cancer and fears about how COVID-19 impacted their cancer diagnosis and prognosis. Institutional Review Board approval was obtained from the Medical College of Wisconsin and the Uganda Cancer Institute prior to data collection.

RECRUITMENT AND ELIGIBILITY

Potentially eligible patients were identified and informed of the study by UCI physicians/staff. Eligibility criteria included: new or established cancer patients who sought care from UCI after March 1, 2020, age 18+ and conversant in English or Luganda. Thirty eligible individuals provided verbal consent to participate prior to being interviewed. Interviews were conducted in-person in June and July of 2022 at UCI. All interviews were audio recorded with participants' consent. Interviews were conducted in English or Luganda, according to the patient's preference, by a team of two female interviewers. Interviews lasted between 15 and 40 minutes. Field notes were made during interviews. Interviewees received 30,000 Ugandan shillings (the equivalent of $9) for their participation. This amount was selected based on guidance from local researchers and the IRB.

DATA COLLECTION

A semi-structured list of open-ended questions was prepared and used to guide interviews before data collection. Interviews explored participants' perceptions regarding access to cancer services during the COVID-19 pandemic, their fears, and their access to COVID-19 vaccination.

QUALITATIVE DATA ANALYSIS APPROACH

All interviews were transcribed verbatim. Interview transcripts were coded line-by-line and analysed for key themes and patterns of response using computerized qualitative data analysis software (MAXQDA 2022). We selected this software because of its flexible coding structure and its ability to facilitate collaborative work. Two of the authors (MB and NA) coded the interviews after which they used an inductive approach to uncover themes. The research team collaborated as a group to assess the coding and emerging themes and subthemes. To establish inter-rater reliability and harmonization, a team-based approach to coding was used. Discrepancies in codes were discussed between reviewers until agreement was reached.

RESULTS

A summary of participants is shown in Table 1. Nineteen participants were female and eleven were male. The most common type of cancer among the females interviewed was cervical cancer followed by vulva and low-risk gestational trophoblastic neoplasia. The most common type of cancer among interviewed males was prostate followed by pancreatic, lymphoma, and bone marrow cancers.

The three primary themes identified from the interviews were lack of resources, fears, and transportation. Below, we discuss each theme in detail and present illustrative quotes. It should be noted that while these questions were asked

Table 1. Participant characteristics (N=30)

Characteristics	Values	Sample size N (%)
Gender	Male Female	11 (36.7) 19 (63.3)
Cancer diagnosis	Cervix Lymphoma Bone marrow Low-risk GTN Prostate Vulva Pancreas Esophagus Colon	16 (55.2) 2 (6.9) 1 (3.4) 1 (3.4) 4 (13.8) 1 (3.4) 1 (3.4) 1 (3.4) 1 (3.4)
COVID-19 Vaccination Status	Vaccinated Not vaccinated	17 (58.6) 12 (41.4)
Age (Mean (SD), [Min, Max])	53 (15) [18, 71]	

in the context of COVID-19, many participants described challenges that have always accompanied cancer treatment well before the COVID-19 pandemic.

LACK OF RESOURCES EXACERBATED BY COVID-19 LOCKDOWN IN UGANDA

Several participants described insufficient resources at UCI during the COVID-19 pandemic, specifically an inadequate number of beds and available seating in the waiting area. Due to overcrowding and COVID-19 outbreaks, most patients wait outside on the veranda for several hours before being seen. Several of the participants had to travel from outside of Kampala, and they were responsible for finding and paying for accommodation near the hospital, which proved to be impossible for some because of the lockdown, travel restrictions, and loss of income caused by the COVID-19 pandemic. Participants who travelled long distances noted challenges related to cost of travel, timely treatment, and accommodation needs, and these challenges were worsened by the COVID-19 pandemic lockdown in Uganda.

"*So verandas became shelters for patients, at that time. Wards would be closed, because I remember on our ward, the solid tumour ward, they found 2 patients with covid, all patients were ordered out of the ward. But to where? There was no easy way out.*" (Participant 20)

"Now for me, I sleep here, on the veranda because I come from very far. Imagine the doctor gives you your next appointment two weeks from now, you go and come back, where do you get that money, even today, you come in the morning and are leaving in the evening, where will you find the vehicle to take you back, so you just sleep here. If you are bedridden, they give you the bed, but if not, you care for yourself." (Participant 14)

"I slept here Musaawo [doctor] for a full month, outside on the veranda, and it would rain on us Musaawo, you could go back if you had means of returning, but now for me I didn't have so I had to stay, in fact for two months and I received my radiation and went back when they had finished and they had released the lock down." (Participant 8)

"There were no beds, they were all full, people were sleeping on the floor." (Participant 18)

"The only problem I had was failure to find nearby shelter, so I waited until they released the lockdown, and I came. In fact, when I came back, I was told that the cancer was back." (Participant 3)

Participants mentioned that their treatments and appointments were delayed due to staffing shortages. Some patients had to cancel appointments and others were rescheduled. COVID-19 exacerbated these preexisting issues. One participant indicated that they had to reschedule their appointments approximately four times, resulting in a delay of one month.

"Originally, I would see the doctor at 6:30 am. But when COVID came, I had to change it completely. I had to see him after 9 am. He would come when he feels like coming. It changed the setup of what we know." (Participant 11)

"All patients missed their appointments. Even patients that were undergoing treatment that was schedule sensitive. Like those with GTM they missed." (Participant 20)

In addition to being in an overcrowded hospital, many participants shared that they were responsible for purchasing personal protective equipment, PPE, such as hand sanitizers and masks. Most participants shared that masks were readily available at UCI, but hand sanitizers were not provided, and several participants described the difficulties they experienced with having to purchase these items on their own due to financial constraints and loss of income during the pandemic. COVID-19 sanitary requirements put an extra financial pressure on individuals with cancer, who already had limited resources as one participant described:

"It was difficult for us to get them. We had to buy them, but we did not have any money." (Participant 24).

Participants found ways to get reusable masks but had to bear the cost of sanitizers, which was not affordable considering their income levels and other cancer related competing essential needs.

"We don't use disposable masks. We wash them and reuse, also for the sanitizer we use soap and water, and the difficulty is that these sanitizers are expensive." (Participant 7)

Table 2. Coding tree utilized for the qualitative analysis

Lack of resources
Use of telehealth services
Changes to surgery, chemotherapy, or radiation
Food insecurity
Lack of telehealth services
Communication barriers
Change of residence
Insufficient resources
Loss of income
Delays
Rescheduled/canceled appointments
Delayed treatment/appointment
unavailability of face masks and hand sanitizers at UCI
Lack of access to face masks and hand sanitizers
Lack of access to medication/treatment
Financial difficulties/barriers
COVID-19 fears and misconceptions
Death of a family member/friend
Need for education
Changes to the quality of services
Negative changes
Positive changes
UCI covid-19 policies
Vaccine hesitancy
Vaccination and cancer diagnosis
Feelings about the vaccine from family and friends
Reasons for vaccine acceptance
Reasons for vaccine hesitancy
Fears
Lack of fear/worries
Fear of delays in care/treatment
Fear of worsening cancer
Fear of infecting others
Fear of infection
Transportation barriers
Distance from hospital
Distrust of drivers
Missed/delayed treatment due to transport
Traffic jams
High cost of transportation
COVID-19 lockdown/travel restrictions

In addition to inadequate access to face masks and hand sanitizers, participants shared that the COVID-19 pandemic made it more difficult to access and afford their treatment and medications. One participant reported that each medication costs around 6,000 Ugandan shillings (about $1.62) monthly for six months.

"It is difficult because I cannot afford it in many cases. At times, I buy half drugs, and the drugs are too expensive…if I'm unable, I consult my children. In most cases, I can't afford it. I ask them to contribute…other times, I go home and sell the animals if they are there." (Participant 25)

CANCER PATIENTS FEARED THE COVID-19 VIRUS AND LACKED ACCESS TO CLEAR INFORMATION

Participants mentioned that they not only feared getting infected with the COVID-19 virus but also feared transmitting the virus to other people such as friends, family, and healthcare workers they interacted with.

"I was worried because of my cancer status. COVID-19 killed my first doctor. It was so sad." (Participant 24)

"COVID is a very dangerous disease yet hard to tell that you have it. By the time you know you are down with it, there is no one or transport to bring you to the hospital and you die." (Participant 23)

"It is a very terrible disease that doesn't fear even a health worker, so if you kill a health worker that should treat you, or your colleague, then it affects the nation." (Participant 5)

While some participants shared that they received the COVID-19 vaccine due to fear that the COVID-19 virus would worsen their cancer, others were hesitant to get the vaccine for fear of it worsening their cancer symptoms and side effects from chemotherapy and radiation. One participant shared that she was open to getting the vaccine once she completed chemotherapy. In some cases, participants shared that their healthcare providers advised them against being vaccinated due to the treatment services they were receiving at the time.

"Some say it is always dangerous, some say it is not. Some say it is dangerous if you are sick from other diseases…I have not talked to him (her oncologist). But those nurses and doctors who were handling in my village said to get it when you are not suffering." (Participant 25)

"I was afraid of mixing it with chemotherapy. I wanted to first complete the chemotherapy then go, but I tested twice, and I was negative, having heard from my friends that are on chemotherapy they said it treated them really badly." (Participant 16)

UCI created COVID-19 guidelines and policies that patients had to abide by in an effort to reduce the spread of COVID-19. Policies included suspension of all outreach and cancer screening services, restricting services to only patients with cancer, mandatory hand washing with soap or alcohol-based hand sanitizer at all entrances, and people keeping 2 meters distance from each other.21 Compliance with UCI COVID-19 safety requirements added extra financial pressure to individuals with cancer, who were already overburdened with the cost of care.

"They tell us to always wear a mask, and to wash our hands properly, to make sure the mask covers well the nose and lips, to wash the hands properly with soap and water not just plain water, or the sanitizer if you have it. They would also encourage us to maintain social distance, keep four meters apart so

that at least you don't come into contact with your friend." (Participant 7)

One participant reported the lack of education regarding COVID-19 at UCI and expressed concern that this lack of information could impact their behaviors and increase their risk for COVID-19, given that they were immunosuppressed.

"I don't think the majority of people particularly those in rural areas have adequate information on the disease let alone adequate information on the safeguards. Those things that we must do to avoid catching COVID-19. The citizens lack that information. Different people understand things differently based on their level of education. UCI was not providing education." (Participant 29)

TRANSPORTATION BARRIERS WERE HEIGHTENED DUE TO THE LOCKDOWN IN UGANDA

Transportation was an important factor discussed by several of the patients, including issues of cost, distance, and restrictions associated with the lock-down and curfews. Some participants shared that the cost of transportation to UCI dramatically increased due to COVID-19. This dramatic rise in transportation costs, coupled with reduced availability of public transport, made it incredibly difficult for patients to attend their treatment appointments. Patients from rural areas were disproportionately affected, with some having to rely on private transport, which further increased costs.

"COVID affected us. Especially on transport. Coming here for treatment was very difficult for us from the upcountry. Instead of paying little money–we used to pay 25,000–we ended up paying more than 200,000 UGX. From Soroti to the village was 25,000. It takes me about 12 hours to get here" (Participant 25)

As indicated, one patient reported a change from 25,000 Uganda shillings ($6-7) to 200,000 shillings ($50-51) for a 293-kilometer trip. Another referred to high prices for motorcycle taxis (boda bodas) due to lockdown restrictions, fuel prices and the trip to the hospital being essentially an inelastic demand. Patients had to pay double because boda bodas could carry only one passenger due to the COVID-19 restrictions, while prior to COVID-19, they could carry more than one passenger at a time.

"Boda bodas were working but expensive. They were very expensive because now they are supposed to carry one passenger and fuel was expensive. They could charge you any amount they want because you want to go and get treatment." (Participant 21)

All the extra cost was borne by patients, adding extra financial stress. Those who were unable to afford transportation had to find other ways of getting to the hospital. Prior to the COVID-19 pandemic, traffic jams impacted many citizens, and many participants mentioned that they continued to be affected by traffic jams during the COVID-19 pandemic when getting to the hospital.

"The traffic jam is also there, it limits me from arriving here on time. It also costs me money being in the traffic jam for a long time. I am a pensioner, so I do not have much money. It impacts easy access to health services." (Participant 29)

The government also implemented strict travel restrictions that made it even harder for individuals with cancer to get to their appointments on time. Some shared that they missed their treatments because it was unclear how and when they could come.

"The government had stopped people from coming for treatment. People had their appointments, but we were not able to make it because of bans and even transport was not there. Everybody was at home… It was a general announcement that everyone must stay home. And there was no way for us to come here. They would not allow us. I think that's why most people could not come." (Participant 25)

However, one described that those with financial resources or political connections, could still access care.

"Those who have access were able to come. If you have a relative in the president's office or medical staff at your place, those were the people who were able to move. That's how I used to come…. I had government people and police. You give them little money; they will help you. If you have documents from RDC (Resident District Commissioner) and a letter from here requesting that person come to the cancer institute, as long as you can hire a vehicle, you can come up here. Those were the people who were able to come". (Participant 25)

DISCUSSION

This study investigated how COVID-19 has impacted individuals with cancer in Uganda and their access to services at UCI. Our findings reveal that longstanding gaps in access to cancer treatment including transportation challenges, financial constraints, and accommodation shortages were severely intensified during the pandemic. Several aspects of patient's reports offered opportunities for the public health system to address critical gaps in cancer care provision.

Government measures intended to curb COVID-19, such as travel bans and lockdowns, inadvertently made it more difficult for patients to obtain cancer care. Patient narratives highlighted how these policies prevented them from accessing care. Some resorted to paying police officers or relying on personal connections to circumvent restrictions, turning access to care into a privilege dependent on financial means or social capital. Those without resources often missed appointments or went without treatment further widening health inequities. The narratives shared by the participants suggest that the impact of COVID-19 restrictions on individuals with cancer was not well anticipated and potential strategies to mitigate harm from these policies were not identified or were not able to be implemented. These findings were corroborated by a qualitative study of healthcare professionals in Uganda who emphasized having to quickly adapt to changing policies. This illustrates the need for policies that explicitly address the unique barriers and needs of individuals with cancer, as well as those living with other chronic and debilitating diseases that may require ongoing treatment or follow up care.

The pandemic amplified mistrust and misinformation especially surrounding the COVID-19 vaccine underscoring the need for tailored health communication for individuals with cancer. Participants described fears around vaccine

side effects and mixed messages from healthcare providers. These experiences illustrate the need for targeted public health messaging for vaccination decision making for individuals with cancer as well as clear guidelines for health professionals.

Our findings are consistent with additional research published regarding the impact of COVID-19 on cancer care in Uganda. The pandemic not only exposed but deepened these existing problems. A large cross-sectional study of over 350 individuals with cancer across Uganda highlighted similar barriers to care during the pandemic including difficulty accessing treatment and delayed appointments due to lack of financial resources, transportation challenges, and inadequate accommodation.[10] Furthermore, a recently published qualitative study examining the experiences of professionals' working in cancer care in Uganda similarly found travel restrictions and lack of PPE to be major barriers to care during the COVID-19 pandemic. In addition, staff highlighted the need to adapt to changing national policies.[17] The perspectives of both patients and professionals emphasize that future lockdown or emergency policies must explicitly consider the needs of cancer centres, patients, and staff to prevent disruptions in care.

In response, UCI has taken steps to address accommodation challenges by establishing a tent encampment for patients.[18] While this is a temporary solution, it highlights the need for more permanent and resilient infrastructure, especially during public health crisis.

This study was conducted at a single facility (UCI) which, as the only public cancer centre in Uganda, does represent much of the national experience but may not capture perspectives of patients not seeking or unable to access care. The relatively small sample size (n=30) further limits generalizability. Future research should aim for broader and more diverse sampling, potentially including individuals outside of UCI or comparing experiences across different countries and policy environments.

CONCLUSIONS

This study shows that the COVID-19 pandemic deeply disrupted Uganda's healthcare system, profoundly impacting individuals with cancer and derailing routine service delivery. Patients' experiences reveal how existing structural barriers including transportation costs, lack of accommodation, insufficient PPE, and poor access to health information were intensified during the crisis, particularly for rural and low-income individuals.

To mitigate the impact of future health emergencies, policymakers, healthcare institutions, and international partners must implement structural reforms that safeguard continuity of care for cancer patients. Based on the lived experiences captured in this study, we recommend the following policy actions:

- **Subsidized Transportation:** Government and non-profit partners should offer affordable or free transport options, especially for rural patients, during public health emergencies.
- **Expansion of UCI Infrastructure:** Invest in new inpatient wards, outpatient facilities, and waiting areas to reduce overcrowding and improve care.
- **Low-Cost Accommodations:** Establish subsidized housing near UCI for patients requiring prolonged treatment stays.
- **Provision of PPE:** Ensure access to essential items such as masks and sanitizers for all cancer patients to reduce financial burden and exposure risk.
- **Telehealth Services:** Expand virtual consultation infrastructure to reduce unnecessary in-person visits and associated travel costs.

The COVID-19 pandemic exposed and deepened longstanding inequities in cancer care across LMICs. These vulnerabilities will persist unless addressed with urgency and intention. Health systems must act now to prepare for future crises and to build lasting equity and resilience for those who need it most. We must ensure that the future of public health responses protect, not marginalize, those who are already most vulnerable. Immediate, coordinated action is critical to safeguard the health and dignity of vulnerable populations and prevent further widening of health disparities in Uganda and similar settings.

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ETHICS STATEMENT

Provide the number of ethics approval(s) and the name of the body that issued it/them. If the study involved human participants, state the informed consent was obtained from all participants involved in the study or provide reasons why the consent from participants was waived. *(Delete if not relevant)*

DATA AVAILABILITY

Provide details regarding the access to data supporting the reported results. If publicly available data were used, provide the link. *(Delete if not relevant)*

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AUTHORSHIP CONTRIBUTIONS

MB, NA and KMB conceived the study. MB collected the data, and NA and MB analysed the data. MB wrote the first

draft. All authors had access to the data, reviewed manuscript drafts, provided input, and approved the final version.

DISCLOSURE OF INTEREST

The authors completed the ICMJE Unified Competing Interest form (available upon request from the corresponding author) and declare no conflict of interest.

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