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Research Article

The double burden of COVID-19 and cancer at the Uganda Cancer Institute

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Background

Cancer is increasingly diagnosed in Africa, with more than one million new diagnoses annually. In Uganda, the Uganda Cancer Institute (UCI) is the primary cancer care facility, with patients travelling long distances to this facility to receive care. During the COVID-19 pandemic, cancer care was disrupted on several levels, including prevention, screening, diagnosis, treatment, and follow-up. National lockdowns impeded patient access to UCI and halted cancer screening.

Methods

This study used qualitative interviews to obtain primary data from professionals working at UCI. Interviews were conducted from April 2022 to January 2023. KI (key informants) 's were purposively selected, identified by colleagues at UCI and recruited through email and WhatsApp messaging. Verbal consent was obtained. Thirty to 60-minute open-ended interviews conducted virtually and in person were audio recorded and transcribed verbatim. Transcripts were coded via MAXQDA software and analyzed to identify themes.

Results

Thematic analysis revealed three major challenges to cancer care during COVID-19. First, UCI experienced logistical barriers such as travel restrictions, staff shortages, and insufficient protective gear. Second, staff adapted to the inflexible national lockdown policy for chronic health care with modifications to treatment regimens. Third, KI reported a significant mental health burden and reflected on how care should be improved.

Conclusions

As colleagues got infected, UCI staff organized their training, discussed treatment plans with colleagues, and continued to care for patients at personal risk. Resilience characterized UCI's response to COVID-19. They adapted treatment protocols to their setting, many of which remain the standard of care today. At the same time, there is a need for capacity building tailored to the Ugandan context to provide cancer care effectively in case of another pandemic.

As of March 2023, the global incidence of COVID-19 had surpassed 676 million cases.[1] Cancer patients are not only at a higher risk of contracting COVID-19 but also of developing complications.[2,3] In the face of the COVID-19 pandemic, the cancer care continuum has been interrupted on several levels, including prevention, screening, diagnosis, treatment, and follow-up. These disruptions can be attributed to a variety of factors, including a lack of personnel and PPE, cancer therapy and medication shortages, and patients' inability to visit cancer centers due to restrictions, fear of COVID-19, or economic hardship. One study of 356 centers across the globe found that some cancer treatment centers estimated that up to 80% of their patients were exposed to harm from interruption of care.[4]

One study from China was among the first to evaluate cancer patients' rate of complications from COVID-19. Zhang and colleagues found that cancer patients with COVID-19 receiving active anticancer therapy were four times more likely to experience severe complications than those receiving no cancer treatment.[2] Preliminary guidelines suggested prioritizing surgery for only the most aggressive cancers, withholding or postponing palliative care

for those with poor prognoses, and recommending oral treatments.[5]

At the beginning of the pandemic, amidst the uncertainty of COVID-19, health professionals worldwide responded resiliently, even as they watched colleagues and patients alike get sick. Preliminary guidelines on cancer treatment in the context of COVID-19 were applied in developed countries via strategies such as telemedicine. Unfortunately, the ability to modify treatment protocols was not a possibility in many low- and middle-income countries (LMICs), where waiting lists are incredibly long, implementing telemedicine is a challenge due to limited internet services, and cancer patients are already challenged to keep scheduled appointments due to long travel distances, social stigma, and lack of resources.[6] Prior to COVID-19, many cancer facilities in LMICs were already strained; COVID-19 placed an unprecedented burden on these facilities.[7] In one study of oncology providers from 18 African countries, more than 75% of providers reported a decrease in patient volume, and one-third reported modifications of cancer treatment, resulting in treatment delays.[8]

Cancer is increasingly diagnosed in Africa, with more than one million diagnoses annually.[9] The number of Africans projected to die from cancer is predicted to increase by 106% between 2018-2040.[10] In Uganda, the Ugandan Cancer Institute (UCI) is the primary cancer care facility in the country; patients have to travel between 13 and 212 km to a medical facility.[11] In one county in Uganda pre-pandemic, an alarming 89% of breast cancer patients presented with stage III/IV disease and about 80% of cervical cancer patients presented with stage III/IV disease.[12] During COVID-19, the Ugandan government implemented strict lockdowns and curfews that severely interrupted access to UCI and halted cancer screening.[13] In order to adjust cancer activities moving forward, it is imperative to ascertain how cancer prevention and control activities in Uganda have been impacted, as well as document how Ugandan health professionals problem-solved with innovative adaptions. This study was conducted to identify perceived limitations and barriers to cancer care presented by COVID-19 among key informants (KI) who are health professionals at UCI.

METHODS

STUDY DESIGN

Semi-structured individual interviews with key informants (KI) (n=25) were conducted. According to their expertise, interviews assessed KI's perceptions regarding how COVID-19 impacted cancer prevention and control services. The study was approved by Institutional Review Boards at the Medical College of Wisconsin, Makerere University School of Public Health, and the Uganda National Council for Science and Technology.

STUDY POPULATION AND SAMPLING PROCEDURE

KI included health professionals at UCI. UCI, located in Kampala, Uganda, is owned by the Uganda Ministry of Health. As a tertiary care center, they have an 80-bed capacity and average about 200 patients daily; UCI offers cancer research, training, consultation, prevention, and treatment services, as well as palliative care and rehabilitation.[14] KIs were purposively selected and identified by colleagues at UCI and recruited through email, telephone calls, and WhatsApp messaging. Inclusion criteria required the respondent to be a UCI staff member who was employed with UCI before March 1, 2020, and who maintained their employment after March 1, 2020, or who started employment at UCI after March 1, 2020. All KI were conversant in English, 18 years or older, and provided informed consent.

DATA COLLECTION

A semi-structured list of open-ended questions was internally validated to guide interviews before data collection. Interviews explored KI's perceptions of cancer services: access, fears, and perspectives during the COVID-19 pandemic. KIs were provided with the objectives, methodology, advantages and disadvantages of participation. KI interviews were conducted from April 2022 to January 2023 and audio recorded if participants consented. Interviews were conducted by 3 females (NA, MB, and CJ), one of whom is African. The three authors who conducted the research all had experience in carrying out research, and the protocol was internally validated to align the interviewing style (see **Online Supplementary Document**). All authors completed CITI Training: Research, Ethics and Compliance Training. Interviews took place in person and virtually, either on Zoom or WhatsApp. KI were informed that all information they provided was confidential. Interviews took 30 minutes to 1 hour to complete. Field notes were made during interviews. Incentives of 30,000 Ugandan shillings (the equivalent of $9) were given to thank KI for their time after completing the interviews.

QUALITATIVE DATA ANALYSIS APPROACH

All interviews were transcribed verbatim. Text data was coded line-by-line and analyzed for key themes and patterns of response using MAXQDA 2020 with a thematic analysis approach in an inductive manner by authors NA and MB. Keywords and quotes were identified in an iterative process as themes and subthemes evolved surrounding facilitators and barriers to cancer care throughout COVID-19. The research team met and discussed the coding framework as themes and subthemes evolved. Authors NA and MB applied the final codebook to all transcripts.

RESULTS

Twenty-five participants were identified as KIs and agreed to be interviewed, 52% male. Of the KIs, 2 were administrators, 8 were physicians, and 15 were nurses. Thematic analysis revealed three major challenges to cancer care during COVID-19. These were[1]: logistical challenges[2] a blanket national lockdown policy with little allowance for chronic

health care, and[3] mental health impacts and lessons learned.

LOGISTICAL CHALLENGES

Although UCI remained open throughout the course of the pandemic, KIs mentioned an array of logistical challenges impacting their ability to offer care, including limited transportation due to the national lockdown and curfew, staff shortages due to COVID-19 infection, and shortages in personal protective equipment (PPE) and medication.

LIMITED TRANSPORTATION

When asked how COVID-19 impacted cancer care, almost every KI mentioned how the national lockdown and strict 7 pm curfew severely limited the ability to travel to UCI.

> *KI10 – "The other thing that hindered me was transport, because there was no transportation. We had to walk to work... So at times I get in early and at times leave early not to get curfew...the daily working hours were really affected."*

KI reported that staff were given stickers for their vehicles and that patients were given clearance letters from local administrative units so that they could travel outside curfew. While some KI said these were helpful, some KI said there was insufficient stickers and, in some cases, reports of stickers intended for healthcare workers landing in the wrong hands and extortion of patients to obtain these letters.

> *KI19 – "There was no proper provisions for health workers to travel. They were supposed to provide stickers to put on our vehicles... the stickers were mishandled and went to the wrong people. So the clinical people could not get the stickers....[patients] had to go to local authorities to get letters of clearance...there were reports of extortion from local authorities for as high as about $3 to get that letter...even when the provision for patients to travel were available, the cost of travel was prohibitive."*

Most patients and providers rely on public transport to come to UCI, which was not widely available during the height of the pandemic. The select few who had access to private vehicles reported a higher chance of being able to travel. In addition to limited transport, gas prices were exorbitant, and staff reported fear of being caught outside curfew by police. UCI did provide transportation via buses for patients and ambulances for staff, although it was logistically challenging coordinating rides and drop-off times so that they could get home before curfew.

> *KI6 – "By the time they drop you [it's] after curfew time. So by the time you remove your ID to explain to the policeman, sometimes they've already beaten you up. So it was really hard."*

Given the transportation barrier, KI were asked if telehealth was utilized. A few noted that patients and staff communicated via WhatsApp for brief follow-up or scheduling appointments. Some clinicians coordinated care for their patients with colleagues at remote health facilities and through a toll-free line. Virtual appointments are currently not available, although one KI noted that telemedicine could be viable in the future.

> *KI19 – "I've been to many parts of Uganda in health facilities. The infrastructure [for telehealth] is there. Because you'll find every hospital that has been linked to HIV care has had such equipment installed."*

STAFF SHORTAGES DUE TO COVID-19 SICKNESS

In addition to trouble transporting to UCI, many staff could not come to work due to falling sick with COVID-19 themselves or being quarantined. KI reported that most staff fell sick at some point, temporarily closing some wards. Some surgeries were canceled due to sick anesthesiologists, and radiotherapy was limited for a period of time because a radiotherapist contracted COVID-19.

> *KI10 – "Almost all our nurses got sick from covid. We had to make do with some of the temporary arrangements... and managed to limp along."*
> *KI13 – "Some of the staff fell ill...our cancer patients had contracted COVID, and we didn't have enough protective equipment, everything was just, it was very confusing. Most of the staff fell sick... that was very stigmatizing and traumatizing in the beginning."*

An institutional policy that reduced staff by 30% was also in place to enable social distancing. After travel restrictions were lifted and patients were able to travel again, staff shortages increased workload; at times, staff had to take on new responsibilities.

> *KI5 – "The work would be overwhelming...the work of six nurses could be done by one person."*

> *KI10– "The staff administering the chemotherapy- they were mostly nursing staff who were disrupted by the transport, so you find in the day instead of finding four in the chemotherapy room, sometimes there was one person, and they might not have mixed the chemotherapy- not everyone had administered the chemo."*

SHORTAGES IN PPE AND MEDICATION

There were numerous challenges in acquiring PPE, medication, and equipment; KI reported that patients had difficulty obtaining laboratory tests, including COVID-19, due to price and supply issues. There were shortages of N95 masks, and patients had to buy materials for their procedures. There were also reports of staff working extended periods without pay.

> *KI6 – "Then, with the diagnosis, it was hard for the patients to do the investigations (labs) for us to diagnose. Some of them could not travel from their villages to come for histology or those who already diagnosed, you know, for doing investigations for staging and management."*
> *KI19 – "You would subject them to the covid test. But even if you would request for one, not many centers would do the test, and by then it was, if you can't get it from the*

> *government facility, you pay. And the cost then was quite high."*
> *KI20 - "Schools were in a lockdown, so they could not collect blood. So patients would need, for example, blood so they get chemotherapy; there was no blood. It was that bad. So I believe quite a number of patients died out of preventable emergencies."*
> *KI25 – "You need at least N95, a face shield, and those things were barely available....drugs, sanitizers, heavy metal axe filters, breathing circuits, tubes, all those things were not there...most of the costs ended up being transferred back patients to buy N95 for the care providers. To buy filters for their protections... most things ended up being out of pocket."*

BLANKET NATIONAL LOCKDOWN POLICY WITH LITTLE ALLOWANCE FOR CHRONIC HEALTH CARE

A recurring theme among KI was how UCI policy adapted to the national policy, which was namely the hard lockdown. Several KI expressed frustration at the lack of suitable cancer care policy during COVID-19.

> *KI10 – "The lockdown was really a blanket intervention...no one critically looked at specific areas of cancer care."*
> *KI19 – "Transportation was never thought about critically to make sure that most health workers could access their workplace."*
> *KI6 –"They did not think about these people with chronic illnesses...how many people with chronic illnesses in that district and how many are going to be allowed to come to the hospital? So, it impacted us negatively. Most of the people who didn't come for the treatment for their appointments. It was really sad."*

One KI explained how cervical cancer screening, an already stigmatized procedure, was completely halted during the lockdown.

> *KI19 – "It becomes even harder if someone has to go through the stress of getting a letter, and paying some money for a letter and paying very expensive transport costs for screening. So, for screening, it came to zero. And also, the mindset was like we're in an emergency situation... So we were only able to attend to emergency problems. And that was policy. Yeah, so the president used a phrase. Like if you bring things that are not attached to immediate survival, then you are like someone who gets to a home when the house that is bad and you ask where will I sleep."*

One KI in a leadership role remarked that early on, UCI decided that health services had to continue and that all clinicians were motivated to work through the pandemic, though they knew the potential risk.

> *KI11 – "If you shut down services, you'll be doing more harm than good because there will be other patients who will have COVID who need care, and you will just be escorting them to their grave sooner."*

KI spoke about the uncertainty throughout the pandemic, especially regarding treatment. The operating room was shut down for a few months except for emergencies. Clinicians expressed uncertainty about how to define surgical emergencies, what to do if surgery was not an option, whether the COVID-19 vaccine was an option for immunosuppressed patients, outcomes of COVID-19 in cancer patients, and treatment plans for patients who had missed their chemotherapy or radiotherapy.

> *KI19 – "Everything was like in shambles ...theaters were not operational, so patients were scheduled ahead, but ahead till when? Nobody knew when... then say someone has ovarian malignancy– they keep deteriorating. So what do you do? Do you start them on chemotherapy? So that they don't get worse than they were. So you had to think of such scenarios to make sure by the time we open up, these patients can be managed better than waiting here."*

Cancer patients were discussed as case studies during online tumor boards that examined new treatment regimens. Chemotherapy regimens were modified to deliver larger doses over a shorter amount of time to account for curfew. Clinicians organized training and workshops to simulate working on a COVID-19 patient with proper protective gear. For surgeries, while it was extremely difficult to define "emergencies", certain procedures like feeding gastronomies were prioritized; thoracic spinals were utilized in these situations to avoid airways.

> *KI24 – "We had to work out regimens that were shorter, so we delivered the same doses of the term over a period of time. And what that meant is that patients received bigger doses of radiation, something which was relatively new in the world of oncology. And since then, it is now becoming more standard of care... a good thing on our wards where patient numbers are many."*
> *KI23 – "Those patients, they have starvation literally and if just putting a feeding tube would change a lot of that. So those took a lot of our priority and we devised so many ways including doing through thoracic spinals to try to avoid the airway and since then thoracic spinals have become like normal here; we no longer put patients to sleep for feeding tubes."*

MENTAL HEALTH IMPACTS AND LESSONS LEARNED

On top of logistical challenges and changes in cancer treatment, KI emphasized the immense psychological burden of COVID-19. Staff watched, traumatized, as colleagues died from COVID-19; they feared getting the disease themselves and bringing it home to loved ones. Staff feared for their patients, who were at risk of opportunistic infection as well as COVID-19. For patients, developing COVID-19 on top of an already overwhelming cancer diagnosis was a real fear.

> *KI10 –"There's a mental health aspect to COVID that hasn't been talked about, and it's waiting somewhere in front to explode, and I think that there's trauma, the stress, the disruption, the economic hardships, now the post-pandemic lockdown, the supply chains."*
> *KI24 – "Colleagues got sick to the point of hospitalization and ICU. So it was very emotional for all of us, it was quite disturbing....many colleagues hospitalized. Yeah. And*

> *they were helpless for weeks. So that was really a disaster."*
> *KI13 – "It was really very traumatizing. The patients were scared of the health workers; we were also scared of the patients."*

KI mentioned many cases of cancer progression; in the minds of patients' and staff, deciding whether cancer or COVID-19 posed a more serious risk was a struggle.

> *KI7 – "The time someone comes back, they're in another stage… I don't know the statistics. But I think the institute recorded a lot of deaths."*
> *KI25 – "'If I have cancer and add covid will I survive?' So you find most of your patients were more anxious, they're worried about whether they're going to live or not."*

When asked to reflect on governmental or institutional policies that could have improved care at UCI, many expressed the need for mental health services for staff.

> *KI10 – "You know, I strongly think if there had been a special, some sort of mental and mental health team to address some of those issues. Counselors… then they [could] assist the health workers how they are coping. We did have a ward where at some point, I think, the mortality rate was 50%."*

On the institutional side, staff noted the need for funds, standard operating procedures in case of epidemics, and more organized transportation for patients. On the governmental side, KI mentioned the need for more regional cancer care centers throughout the country, which are currently being built, and national decentralization of COVID-19 testing.

> *KI19 – "A lot could have been done better. If, for example, they'd tasked institutions to come up with ways in which they could adjust their systems to continue giving the care. But these decisions were blanket."*

DISCUSSION

Viewing the challenges to care that UCI faced through qualitative interviews revealed personal, institutional, and governmental barriers. To our knowledge, this study is the first study to date to highlight barriers to cancer care in Uganda during COVID-19. The analysis revealed a dynamic in which UCI continuously adapted to a strict national lockdown with remarkable innovation and resiliency. As shortages in staff fluctuated, treatment regimens were dynamically modified. However, many KI emphasized how mentally grueling it was to watch colleagues and patients die from COVID-19 while working with insufficient PPE amidst fear of bringing the infection to loved ones.

The national lockdown characterized UCI's response to the pandemic; nationwide, there was a sharp decline in all essential health services.[15] In addition, transport costs doubled due to the reduced carrying capacity of vehicles.[12] News articles corroborate KI testimonies of some security persons abusing their power and misinterpreting rules, preventing both patients and providers from accessing UCI.[16]

Barriers to cancer care predated the pandemic; for example, misconceptions and lack of awareness result in low uptake of cervical cancer screening, and most patients present with late stages of cervical cancer.[17] A study in Uganda in 2019 found it took a median of 84 days from the first presentation to consultation and a median of 34 days from consultation to starting treatment.[12] COVID-19 exacerbated barriers to cancer screening; several KI attested to cancer progressing to another stage or not following up at all. Furthermore, before treatment at UCI, patients are required to bring confirmation and staging of their cancer through histology. 56.3% of patients visit a private hospital for histology, and costs would be out of pocket.[18] Both histology services and labs to monitor response were difficult to access throughout COVID. While UCI does cover the costs of cancer care, if there were shortages of PPE, these costs were transferred to the patient, as mentioned by KI.

While data on COVID-19's impact on East African countries is emerging, one article found that in Kenya, cancer care was also limited to a travel ban, but in Tanzania, patients seeking cancer care "rapidly increased back to usual numbers", although due to insufficient data, it is difficult to compare "diametrically opposed policy strategies on the death toll among East African cancer patients."[13] As KI noted, our results signify the need for a coordinated cancer care policy with UCI input at the national level. For example, while exemptions were attempted to allow patients and professionals to travel, corruption and lack of awareness prevented mobility. KI called for streamlined distribution of vehicle stickers and clearance letters.

Many articles have commented on the fragmented cancer care policy in Uganda.[6,19] Unlike care in other LMICs, the pandemic "pronounced the shortcomings" of an already fragile system.[13] At the beginning of the pandemic, many research articles were published regarding strategies for cancer care in the COVID context. While KI mentioned their reliance on these articles to shape practice, these practices were often tailored to the global north and carried the risk of doing more harm than good.[13] For example, screening was halted in many countries; however, in LMICs, where the burden of late-stage disease is high and was already a problem due to limited resources pre-pandemic, a more tailored approach that prioritized continuation of cancer prevention and screening should have been considered.[13] Many countries also relied on telemedicine when possible throughout the pandemic. While technology was used to communicate with some patients and host virtual tumor boards, there is no infrastructure in Uganda for telehealth; telemedicine must be invested in and organized to build resilience. While there was a recent roll-out of a countrywide 4G network in Uganda and platforms like WhatsApp are ubiquitous and support privacy, "technicalities and costs involved in set-up and maintenance" must be further developed in Uganda for telehealth to be mainstream.[20]

POLICY RECOMMENDATIONS

COVID-19's unprecedented burden highlighted the need for capacity building of Ugandan healthcare infrastructure. Thematic analysis reveals four different priorities for pol-

icymaking for the Ugandan Ministry of Health and UCI: transportation policies, targeted mobilization of funding, investment in health infrastructure, and clear protocol. First, as interviewees noted, our results signify the need for a coordinated cancer care policy with UCI input at the national level that allows exemptions to allow patients and professionals to travel freely between UCI and their home. While exemptions were attempted in terms of clearance letters for patients and vehicle stickers for providers, there appeared to be a lack of awareness and compliance of this policy. A specific policy to streamline distribution of vehicle stickers and clearance letters in case of a national lockdown is warranted. Second, based on interviews with providers, it appears that there was no designated process to mobilize funding to meet needs as they arose. There are several instances throughout the pandemic in which targeted funds could have met specific needs. Third, providers mentioned that many patients returned to UCI with significant cancer progression and poorer prognosis; modernizing infrastructure to allow for telemedicine would result in better outcomes not only in times of decreased mobility like a pandemic, but also improve current access to care. Fourth, as KI shared the unclarity in the beginning of the pandemic, there is a need for a clear protocol for exposed healthcare workers.

LIMITATIONS

Our study investigated the perceptions of UCI staff. Social desirability and response bias were potential limitations in this study as KI may have wished to present themselves and their institution positively. In addition, given the qualitative nature of this study, other limitations might include language barriers, cultural differences, and recall bias. However, KI were assured that they would remain anonymous to enable them to share openly. Future studies should characterize how halted cancer screening and treatment modifications impacted prognosis and how many patients were lost to follow-up during this time.

CONCLUSIONS

During the uncertainty of COVID-19, and even as they watched colleagues succumb to infection and, in some cases, lose their lives, UCI staff organized their training, discussed treatment plans with colleagues, and still showed up to care for cancer patients at personal risk. They innovatively adapted treatment protocols and noted how these practices remain the standard of care today. KI did identify perceived barriers to cancer care presented by COVID-19, noting areas of opportunity of how UCI can improve logistically, how the Ugandan government might change national policy, and how mental health should be prioritized in the future. While there is much-needed capacity building tailored to the Uganda context to provide cancer care effectively in case of another pandemic, resiliency characterized UCI's response to COVID-19.

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ETHICS STATEMENT

The study was approved by Institutional Review Boards at the Medical College of Wisconsin and Makerere University School of Public Health, and the Uganda National Council for Science and Technology.

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AUTHORSHIP CONTRIBUTIONS

NA, KB, and CJ conceived the study. NA, MB, and CJ collected the data, and NA and MB analyzed the data. NA wrote the first draft. All of the authors had access to the data, reviewed manuscript drafts, provided input, and approved the final version.

DISCLOSURE OF INTEREST

The authors completed the ICMJE Disclosure of Interest Form (available upon request from the corresponding author) and disclose no relevant interests.

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SUPPLEMENTARY MATERIALS

ONLINE SUPPLEMENTARY DOCUMENT

Download: https://www.joghr.org/article/92052-the-double-burden-of-covid-19-and-cancer-at-the-uganda-cancer-institute/attachment/191672.docx