

# BMJ Open Impact of COVID-19 on delivery of oncology services in Northern Tanzania: a cross-sectional study of community health workers and patients undergoing cancer treatment at the Kilimanjaro Christian Medical Centre

India Pumphrey ,<sup>1</sup> Furaha Serventi,<sup>2</sup> Atukuzwe Kahakwa,<sup>2</sup> Anna Massawe,<sup>2</sup> Antje Annaliese Henke,<sup>2,3</sup> Oliver Henke <sup>2,4</sup>

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For numbered affiliations see end of article.

## Correspondence to

Dr India Pumphrey;  
[indiapumphrey1@gmail.com](mailto:indiapumphrey1@gmail.com)

## ABSTRACT

**Objective** To ascertain how the COVID-19 pandemic was perceived by oncology patients and community health workers (CHWs) and whether this contributed to disruptions in cancer care.

**Design** Cross-sectional study using (1) structured telephone interviews with patients and (2) structured questionnaires completed by CHWs.

**Setting** Outpatient and community care at Kilimanjaro Christian Medical Centre's Cancer Care Centre (KCMCCC), Northern Tanzania.

**Participants** 300 oncology patients (158 men and 142 women) who had attended KCMCCC between January and April 2020 and 78 CHWs (16 men and 62 women) in the KCMC regional palliative care network who conducted home visits to patients with cancer during the period January to April 2020.

**Primary outcome measures** For patients, missed appointments and fear of COVID-19 more than postponement of their treatment. For CHWs, no primary outcome (a broad range of questions on perception of the pandemic were asked).

**Results** 30% of patients said they missed appointments due to the pandemic, the most commonly cited reasons being financial problems (37%) and fear of acquiring COVID-19 infection during travel and/or in the hospital (37%). Only 12.7% of patients said they feared COVID-19 more than postponement of cancer treatment. 88% of CHWs noticed differences in delivering home care since the start of the pandemic, with 58% saying they had noticed more patients dying and 74% saying that more patients were relying on local healers. 31% of CHWs said they feared home visits because of COVID-19 and 46% perceived patients feared home visits due to COVID-19. However, 92% felt home visits should continue.

**Conclusion** These results indicated that while there was a significant degree of disruption and fear around the COVID-19 pandemic, the majority of patients and CHWs did not fear of COVID-19 more than disruption to cancer care. This highlights the importance to these groups of maintaining access to vital cancer services.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ An almost complete cohort of patients attending the hospital at the time of the study (300) were interviewed individually by a clinician, and all community health workers (CHWs) were invited to participate.
- ⇒ We were able to capture patient's and CHW's viewpoints at a particular moment in time.
- ⇒ However, the methodology was subject to a degree of bias and there are limits to the generalisability of the findings beyond the time and place of the study.

## BACKGROUND

COVID-19 has caused significant morbidity and mortality worldwide since its emergence, with patients with cancer particularly at risk of severe illness and death from the SARS-CoV-2.<sup>1 2</sup> In addition, disruption to cancer services has been particularly challenging in low resource settings, where individual and system-wide barriers to accessing cancer care were already substantial.<sup>3 4</sup>

In 2020, the WHO estimated that Tanzania had a 5-year prevalence of 73 300 cancer cases,<sup>5</sup> in a country with a population of nearly 60 million.<sup>6</sup> Before the COVID-19 pandemic, there were significant barriers to accessing cancer care in Tanzania, with high out-of-pocket expenses, lack of access to treatment centres, lack of knowledge about cancer and fear of cancer diagnosis and treatment contributing to difficulty in accessing specialist oncology services.<sup>7-9</sup>

Kilimanjaro Christian Medical Centre's Cancer Care Centre (KCMCCC) is one of three cancer treatment centres in Tanzania. Its catchment area covers around 15 million people in the Northern Region of Tanzania.<sup>10</sup>

KCMCCCC is a zonal public referral hospital and generally covers a more rural population than the other two major cancer centres in Dar es Salaam and Mwanza city. KCMC has a regional palliative care network, which brings together community health workers (CHWs) and the medical team at KCMCCCC. CHWs provide vital care to patients in their communities and are trained to monitor symptoms, advise holistically on palliative care and are often the first point of contact for patients with cancer in the community.<sup>11</sup>

Tanzania had its first reported case of COVID-19 on 16 March 2020<sup>12</sup> and the government initially responded by closing schools and universities and banning public gatherings (although gatherings at places of worship could continue).<sup>13</sup> However, the Tanzanian government stopped releasing official figures for COVID-19 cases in April 2020 and subsequently declared Tanzania free of COVID-19 in June 2020 following 3 days of national prayer and fasting.<sup>14</sup> At this point, all measures to contain the virus ceased and no diagnosis of COVID-19 outside of the national laboratory (let alone reporting) was permitted.<sup>14</sup> As a result, evidence of the impact of the COVID-19 pandemic in Tanzania as a whole, and more particularly on cancer services, is lacking.

A cross-sectional study in neighbouring Kenya has shown that COVID-19 lockdown measures resulted in 88% of oncology patients having a reduction in household income, with high levels of concern that they would not be able to afford cancer treatment as a result.<sup>15</sup> Similarly, in Uganda, the cost of public transport doubled when national COVID-19 restrictions (including strict lockdowns and curfews) were in place, which significantly increased the financial burden of accessing cancer care at specialist centres.<sup>16</sup> In addition, changes to service provision, such as suspending cancer screening and limiting the number of patients at outpatient appointments, are suspected to have increased barriers to diagnosis and treatment.<sup>16</sup>

In Tanzania, the absence of intensive measures to prevent the spread of COVID-19 may have resulted in less disruption to patients accessing cancer services; on the other hand, the lack of COVID-19 testing may have put patients with cancer at excessive risk, not to mention facilitated the unchecked spread of the virus among clinical staff and allied health professionals, reducing a work force which was already severely overstretched.<sup>17</sup> Comparisons based on surveys with oncology care providers in Sub-Saharan Africa have provided some insight,<sup>18 19</sup> but more information is needed on how COVID-19 has affected patients with cancer in Tanzania.

This study aimed to improve our understanding of how cancer care at KCMCCCC was impacted by the COVID-19 pandemic. Specifically, we wanted to explore (a) whether the pandemic impacted patients' behaviour in attending outpatient clinics and (b) whether delivery of home care by CHWs was impaired.

## METHODS

This is a cross-sectional analytical study of two populations, oncology patients and CHWs, at Kilimanjaro Christian Medical Centre (KCMC). Separate structured questionnaires were used for each population (see online supplemental appendices). Data was collected in June 2020.

The questionnaires were developed by the researchers at KCMC and tested on a small cohort of patients and CHWs before use in the study. The pilot questionnaires and responses were reviewed by a group of clinicians at the facility. We used our own questionnaire, rather than a validated pre-existing questionnaire, due to it being both early in the pandemic (when no validated questionnaires existed) and also, the unique situation in Tanzania where high levels of taboo around COVID-19 meant that only specific questions around COVID-19 could be directly asked. The questionnaire did not undergo formal validity testing due to time constraints.

### Patients

Hospital oncology clinic records were used to identify patients who had attended the oncology department at KCMC between January and April 2020 inclusive. The sample size was chosen on the basis of convenience (these patients had records readily available and were still under treatment at KCMC). All patients with a cancer diagnosis who had attended for any reason were included. Patients were from regions throughout Tanzania. Patients were excluded if too seriously ill to participate, under 18 years of age, no telephone number was available and if they did not consent. Structured questionnaires were administered by telephone interview by a registered doctor at the oncology unit in English or Kiswahili. Answers in Kiswahili were translated back into English.

### Community health workers (CHWs)

CHWs who carried out home care to patients with palliative cancer within the KCMC regional palliative care network were asked to complete structured questionnaires, which they self-completed in paper format, in Kiswahili or English. Answers in Kiswahili were translated back into English. All CHWs who conducted home visits in one of the regional teams during the period January to April 2020 were included. The sample size was therefore limited to the number of CHWs. CHWs who did not consent were excluded.

### Variables

#### Patients

Sociodemographic data on age, gender, district, level of education and occupation were collected. The questionnaire collected further data on type of cancer and current treatment type. Outcome data was collected on whether the patient missed appointments because of the pandemic and if patients feared COVID-19 more than postponement of cancer treatment. Reasons for

missed appointments were also ascertained. The patient questionnaire responses were treated as quantitative variables.

### Community health workers

Sociodemographic data on age, gender, level of education and district were collected. The questionnaire collected further data (in the form of yes/no answers with additional space for expanding on answers in free-form) on whether the CHWs had noticed any differences in delivering home care since the start of the COVID-19 pandemic, whether CHWs or patients feared home visits, whether they would recommend continuing home visits, whether they had noticed more patients dying, if patients had experienced difficulties in obtaining pain medication and whether they had observed patients relying more on traditional healers since the pandemic. The CHW questionnaires provided a mixture of quantitative and qualitative data, with some open-ended questions (see online supplemental appendices).

### Statistical analysis

We used descriptive statistics to provide a clear distribution of the data. Age (as a numerical variable) was expressed as mean and standard deviation (SD), and categorised for further analysis. Categorical variables were expressed as frequency and percentages. The  $\chi^2$  test (or Fishers exact test where frequencies for a variable were  $<5$ ) was used to examine the differences between the categorical variables for outcome variables. Missing data was excluded from statistical analysis. Finally, ORs were calculated to determine the effect size of the sociodemographic variables on the outcome variables (missed appointments, fear of COVID-19 more than postponement of treatment and fearing home visits). ORs and 95% CI are reported. A  $p$  value  $<0.05$  is considered statistically significant. STATA BE V.17.0 was used for statistical analysis. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) cross-sectional reporting guidelines were used.<sup>20</sup>

### Qualitative analysis

There were four questions in the CHW questionnaire that gathered both quantitative (yes/no answers) and qualitative responses: (1) 'Have you noticed differences in home care since the pandemic? If yes, what were these differences?' (2) 'Do you observe more or different symptoms in your patients than before the pandemic? If so, which symptoms are these?' (3) 'Have you experienced that patients or relatives have problems in receiving pain medication or other medication? If yes, what are the reasons?' (4) 'Do the community members talk about the COVID-19 pandemic? If yes, what are the most common questions?' The open-ended responses were analysed by two different researchers who used content analysis to draw themes from the answers.

### Patient and public involvement

There was no patient and public involvement in the design, conduct, reporting or dissemination plans in this study.

## RESULTS

### Patients

A total of 300 patients participated in the study. Sociodemographic and clinical characteristics are shown in [table 1](#). The mean age was 55.7, with about one-fifth less than 40 years ( $n=56$ , 18.7%), one-third between 40 and 59 ( $n=99$ , 33%) and the majority ( $n=141$ , 47%) over 60 years of age. There were slightly more men ( $n=158$ , 52.7%) than women ( $n=142$ , 47.3%). Most patients were from the surrounding Kilimanjaro region ( $n=175$ , 58.3%) with the rest distributed throughout Tanzania, with 1 just over the border in Kenya. The highest proportion had completed primary education ( $n=125$ , 41.7%), although nearly a third had also completed secondary education ( $n=93$ , 31%). The majority of patients were farmers ( $n=110$ , 50.9%), with business the second most common employment ( $n=61$ , 28.2%).

The most common cancer was breast ( $n=68$ , 22.9%), followed by prostate ( $n=56$ , 18.9%) and then haematological cancers ( $n=49$ , 16.5%). The majority ( $n=142$ , 47.3%) were having intravenous cancer treatment, either with traditional chemotherapy agents or antibody treatment. Overall, 21.7% were having oral treatment with tyrosine kinase inhibitors or hormonal treatment, while just over a quarter were under follow-up (not currently receiving treatment) ( $n=80$ , 26.7%).

Only 12.7% ( $n=38$ ) of patients said they feared COVID-19 more than the postponement of cancer treatment. Nearly a third ( $n=90$ , 30%) stated that they had missed an appointment because of the COVID-19 pandemic. The most frequently cited reasons for this were financial problems due to the pandemic (36.7%,  $n=33$ ) and fear of acquiring infection during travel and/or in hospital (36.7%,  $n=33$ ). These were followed by falling sick (15.6%,  $n=14$ ), transport problems (10.0%,  $n=9$ ) and others (13.3%,  $n=12$ ) (see [figure 1](#)). Overall, 33/300 (11%) stated that they had missed an appointment due to fear of COVID-19.

We conducted bivariate analysis to look for association between sociodemographic and treatment variables and outcome variables (online supplemental table 1). Regarding the question of whether patients feared COVID-19 more than postponement of cancer treatment, we found that female patients were less likely to agree than male patients (7.8% vs 17.2%), which was statistically significant (OR 0.40, 95% CI 0.19 to 0.86,  $p=0.01$ ). There were no other significant associations between demographic/treatment characteristics and fearing COVID-19 more than postponement of treatment.

Patients who were not under treatment were significantly more likely to miss appointments than those who were currently under treatment, but this only just met

**Table 1** Sociodemographic and clinical characteristics of patients

Characteristic	N (%)
Age (years)	(Mean=55.7 years, SD 17.8)
<40	56 (18.7)
40–59	99 (33)
60+	141 (47.3)
Missing	4 (1.3)
Sex	
Male	158 (52.7)
Female	142 (47.3)
Region of residence	
Kilimanjaro	175 (58.3)
Other regions	123 (41.0)
Missing	2 (0.7)
Highest level of education	
No formal	39 (13)
Incomplete primary	8 (2.7)
Primary	125 (41.7)
Secondary	93 (31)
College/university	22 (7.3)
Missing	13 (4.3)
Occupation	
Farmer	110 (50.9)
Business	61 (28.2)
Semiprofessional	9 (4.2)
Professional	19 (8.8)
Other (eg, retired, student)	17 (7.9)
Missing	84 (27.7)
Cancer type	
Breast	68 (22.9)
Prostate	56 (18.9)
Colorectal	30 (10.1)
Haematological	49 (16.5)
Upper gastrointestinal	27 (9.1)
Kaposi's sarcoma	13 (4.4)
Gynaecological	11 (3.7)
Head and neck	13 (4.4)
Other	30 (10.1)
Missing	3 (1)
Current treatment status	
Intravenous treatment (chemotherapy or antibody)	142 (47.3)
Oral treatment (tyrosine kinase inhibitors and hormonal)	65 (21.7)
Both intravenous and oral	1 (0.3)
Treatment not started or not specified	12 (4)

Continued

**Table 1** Continued

Characteristic	N (%)
Under follow-up (not currently receiving treatment)	80 (26.7)
Missed appointment due to pandemic	
Yes	90 (30)
No	210 (70)
Fear of COVID-19 more than postponement of cancer treatment	
Yes	38 (12.7)
No	261 (87.3)
Missing	1 (0.3)

SD, standard deviation.

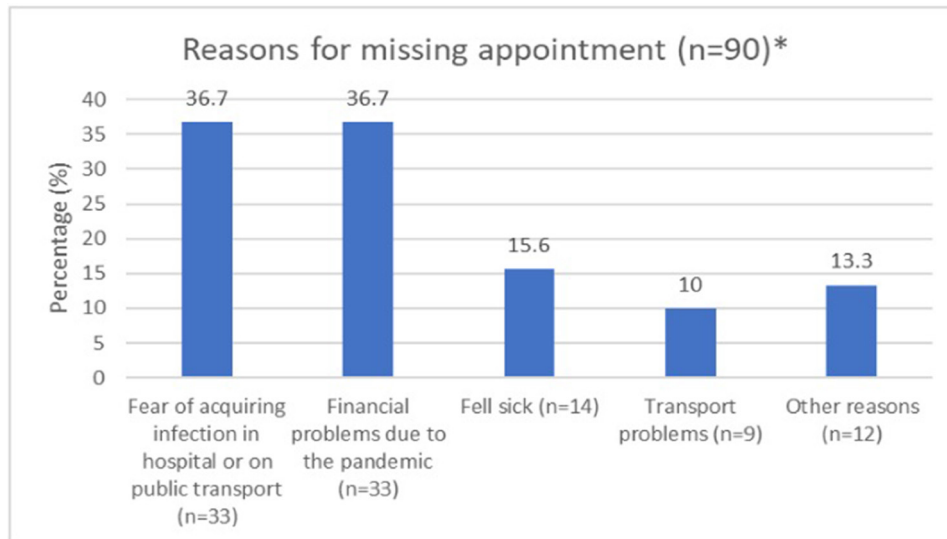
significance, with lower end of the 95% CI only just above 1 (OR 1.73 (95% CI 1.002 to 2.98,  $p=0.046$ ). The odds of missing an appointment were nine times higher for those who said they feared COVID-19 more than postponement of treatment compared with those that did not (OR 9.18 (95% CI 3.97 to 21.2,  $p=0.000$ ). No other significant associations were found.

### Community health workers

A total of 78 CHWs completed the survey. Sociodemographic characteristics are shown in [table 2](#). The majority ( $n=60$ , 76.9%) were 40–59 years old and most were women ( $n=62$ , 79.5%). Most had primary level education ( $n=63$ , 80.8%). CHWs were spread among Moshi municipal district ( $n=21$ , 26.9%), Moshi rural district ( $n=28$ , 35.9%), Rombo ( $n=15$ , 19.2%) and Hai ( $n=14$ , 17.9%). These areas are all geographically close to KCMC in the Kilimanjaro region (in contrast to the patient group, some of whom were from distant regions).

CHWs answered further questions regarding experience of home visits, patients dying, problems with medication and reliance on local healers (see [table 3](#)). Overall, 88.5% ( $n=69$ ) said they had noticed differences in delivering home care since the start of the pandemic. When asked to expand on the differences in free-form written answers, 38.5% ( $n=30$ ) mentioned that either they or their patients were afraid of catching COVID-19, while 44.8% ( $n=35$ ) mentioned differences were related to using preventative measures such as wearing masks, social distancing and hand washing. When asked if they had noticed their patients had different symptoms since the pandemic started, most said they had not noticed any difference ( $n=43$ , 56.6%). However, 34.4% ( $n=26$ ) mentioned an increase in anxiety or fear, while few mentioned an increase in cough ( $n=4$ , 5.3%) or influenza-like symptoms ( $n=3$ , 3.9%). Over half ( $n=45$ , 57.7%) said that they had experienced more patients dying since the pandemic started.

About 31% ( $n=24$ ) of CHWs reported that they feared carrying out home visits, while 46% ( $n=36$ ) said that their patients were afraid of having home visits due to



**Figure 1** Reasons for missing appointment. \*Some patients had more than one reason for missing an appointment.

COVID-19. However, 92.3% (n=72) responded they would recommend that home visits continue.

About a quarter (n=20, 25.6%) of CHWs responded that their patients or their relatives had problems in obtaining medication. Overall, 50% (n=7) of CHWs from Hai district reported that there were problems obtaining medication, compared with 40% (n=6) and 33.3% (n=7) from Moshi municipal and rural districts and none from Rombo. These differences were statistically significant using the Fishers exact test (see online supplemental table 2). Of those who reported patient difficulties obtaining medication, the reasons given were most commonly that

their patients were afraid of catching COVID-19 (n=12, 60%) but also that their patients had financial difficulty (n=4, 20%), drugs were not available (n=2, 10%) or that the hospital had stopped offering treatment (n=2, 10%).

Almost three quarters of CHWs (n=58, 74.4%) responded that their patients were relying more on local healers than before the pandemic. There was a significant difference in CHW responses, depending on which district they were from (see online supplemental table 2). Overall, 100% of CHWs from Moshi municipal district reported an increased reliance on local healers, compared with 75% from Moshi rural, 40% from Rombo and 71.4% from Hai. When asked to state reasons for the increased reliance, CHWs most frequently reported statements such as patients 'believe steam inhalation can cure COVID-19' or 'they heard from radio and television traditional medicine can cure COVID-19'. Equally some referenced the fact that there was no mainstream medical treatment for COVID-19 at that time, for example, 'because COVID-19 has no cure of modern medicine'.

There was no significant association between whether CHWs had noticed more patients dying and the district they worked in (p=0.46) (online supplemental table 2). No significant associations were found between CHWs who stated they feared home visits and age, sex, education or district (online supplemental table 3).

## DISCUSSION

This study was conducted to understand how the SARS-CoV-2 pandemic impacted oncology patients' attendance at outpatient clinics and CHWs' delivery of palliative care in Northern Tanzania. At the time of the study (June 2020), the inability to diagnose COVID-19 at the point of care meant there was an absence of data from which to assess the spread of COVID-19 in Tanzania. The impact on cancer care, for both patients and healthcare workers, was therefore difficult to assess.<sup>13 14</sup> For this reason, we

**Table 2** Sociodemographic characteristics of community health workers (n=78)

Variable	n (%)
Age (years)	Mean 51.2, SD 10.1
<40	7 (9)
40–59	60 (76.9)
≥60	11 (14.1)
Sex	
Male	16 (20.5)
Female	62 (79.5)
Education	
Primary	63 (80.8)
Secondary	13 (16.7)
College/university	2 (2.6)
District	
Moshi (municipal)	21 (26.9)
Moshi (rural)	28 (35.9)
Rombo	15 (19.2)
Hai	14 (17.9)

SD, standard deviation.

**Table 3** Community health workers' experience of patients dying, recommendations and communications about COVID-19 (N=78)

Variables	Frequency	Percentage
Have you noticed any differences in delivering home care since the start of the pandemic?		
Yes	69	88.5
No	9	11.5
Do you fear home visits because of COVID-19?		
Yes	24	30.8
No	54	69.2
Do patients fear receiving home visits due to COVID-19?		
Yes	36	46.1
No	42	53.9
Do you observe more or different symptoms in your patients than before the pandemic?		
None	43	56.6
Anxiety/fear	26	34.4
Increase in cough	4	5.3
Increase in influenza-like symptoms	3	3.9
Missing	2	2.6
Have you experience of more patients dying since the pandemic started?		
Yes	45	57.7
No	33	42.3
Would you recommend to continue home visits or to stop home visits?		
Continue	72	92.3
Stop	6	7.7
Have you experienced that patients or relatives have problems in receiving pain medication or other medication?		
Yes	20	25.6
No	58	74.4
Do you recognise that patients rely more on local healers than before the pandemic?		
Yes	58	74.4
No	20	25.6

used interviews with patients and CHWs to ascertain their perspectives and experience, at a time when there was much uncertainty around the true extent of the COVID-19 pandemic in Tanzania.

### Patients

The results from our patient questionnaire showed that there was a fairly low prevalence of fear regarding catching COVID-19, with only 12.7% of patients saying that they feared COVID-19 more than the postponement of treatment. This suggests that while fear existed, it was not particularly common. Other studies that have asked the question of whether patients feared COVID-19 more

than cancer have tended to find higher proportions of those fearing COVID-19—in Beirut 55% of patients with cancer feared COVID-19 more than their disease,<sup>21</sup> in Italy 21% of patients with lung cancer feared COVID-19 more than their cancer<sup>22</sup> and in Korea 29.9% of the general population were more afraid of COVID-19 than lung cancer.<sup>23</sup> Equally, overall, 11% of our participants responded that they missed appointments due to fear of contracting COVID-19 either in hospital or on transport. This compares with a scoping review of 87 published articles globally which found that 60.9% of oncology patients deferred treatment due to fear of contacting COVID-19.<sup>24</sup> It is likely that messaging from the Government and Ministry of Health impacted patients' perceptions as, at the time of this study, it was stated that the pandemic was over, all lockdown restrictions had been lifted and Tanzanians were able to live their lives as normal.<sup>14 25</sup> Therefore, it would not be surprising if there was a lower degree of risk perception than in other countries which had national policies in place to control the spread of COVID-19. Corresponding to this, a study comparing general population levels of anxiety around the COVID-19 pandemic in 23 countries found that Tanzania had the lowest percentage of people with the highest levels of anxiety, along with Iran.<sup>26</sup>

Our study found that female patients with cancer were significantly less likely to fear COVID-19 more than postponement of treatment, compared with male patients with cancer. This contrasts to studies in Italy and Poland, where female patients with cancer were more likely to fear COVID-19 than male patients with cancer<sup>22 27</sup> and a recent meta-analysis which found that in general populations, women had greater COVID-19 related fear and anxiety.<sup>28</sup> A small qualitative study of women (without cancer) in Tanzania found that they many had 'normalised' COVID-19 as an illness such as seasonal malaria or influenza, and some believed that God had answered their prayers in protecting Tanzania against COVID-19.<sup>29</sup> While the study did not compare women with men, a possible interpretation is that women were more likely than men to believe these narratives which were circulated by the government and media.

Regarding overall missed appointments, 30% of patients said they had missed an appointment at the Cancer Care Centre due to the pandemic. Other studies in sub-Saharan Africa, which have looked at access to oncology care, have suggested that this is a comparatively low rate—data published from Botswana gynaecology oncology outpatients showed the median number of unattended appointments increased by five times during the lockdown<sup>30</sup> and in Kenya, a cross-sectional study found that 50% of patients with cancer were limited in their ability to travel for treatment by curfews and lockdowns.<sup>15</sup> In Nigeria, 51% of patients reported difficulty in accessing cancer care due COVID-19.<sup>31</sup> The financial impact of lockdowns and infection control measures is significant for patients with cancer in low-income and middle-income countries (LMICs)<sup>32</sup> and indeed 36.3%

of our patients responded that they missed appointments due to pandemic-related financial problems. In neighbouring Kenya, however, 79% of patients with cancer were worried that the financial impact of COVID-19 made it harder for them to afford cancer care.<sup>15</sup> While some of our patients were affected by financial loss due to the pandemic (most likely those working in tourism or in sectors influenced by imports and international trade), the fact that relatively few patients reported this as a factor in them missing appointments may reflect the relative lack of disruption to local economies, given the lack of lockdown measures.

Related to this and in contrast to previous studies in Tanzania which looked at access to cancer care, we did not find a correlation between educational attainment and missing appointments. We also did not find a significant association between educational attainment and fearing COVID-19 more than postponement of cancer treatment. Lower education levels have been found previously to be associated with delay in diagnostic delay for patients with cancer in Tanzania.<sup>33</sup> One possible explanation for the lack of correlation between educational attainment and missing appointments could be that patients with a higher educational attainment were more likely to have a source of income that would be negatively affected by the pandemic (such as in tourism) than those with lower educational attainment (ie, subsistence farmers) and so this would balance out the baseline discrepancy, which was found in .

### Community health workers

Our study found that while a minority (31%) of CHWs were afraid of carrying out home visits, at the same time, 92% responded that home visits should continue. Respondents to a survey of palliative care practitioners from 21 countries in sub-Saharan Africa (not including Tanzania) rated their anxiety about becoming infected with COVID-19 themselves at a median of 9 on a scale of 1–10, suggesting a higher degree of fear and concern around continuing delivery of palliative home care.<sup>34</sup> Similar surveys in India and the Asia-Pacific region also found moderate–high levels of palliative care staff anxiety, both at 7 on a 1–10 scale.<sup>35 36</sup> From the perspective of delivery of home care for patients, these findings were positive, as by far the majority of CHWs wanted home visits to continue, despite the pandemic. However, the relatively low levels of fear also raise concerns that CHWs may not have been taking the necessary precautions to protect themselves. We did not specifically ask about the availability of personal protective equipment (PPE), hand washing practices or infection control measures, but when asked what differences CHWs had noticed since the pandemic, only 44.8% mentioned that they were wearing masks or observed hand washing when seeing patients. We know from our own experience that availability of PPE was sparse and it is unlikely that CHWs could have been adequately protected from infection. Together, these

findings raise concerns that CHWs may have been putting themselves at excessive risk of COVID-19 infection.

CHWs reported fewer patients (25.6%, n=20) had difficulty obtaining palliative medication than was found in Kenya, where 52% of oncology patients reported lack of access to pain relief medication.<sup>15</sup> Interruptions to medication supply were a concern for oncologists globally during the early stages of the pandemic, with LMICs worse affected due to fragile infrastructure and chronic issues with unreliable drug supplies.<sup>37 38</sup> CHWs in our study most commonly reported that patients did not have access to medication because they were afraid of catching COVID-19 (60%) rather than because of problems with drug availability (10%). While we know that there were national problems with importing certain medications (eg, the measles vaccine and certain chemotherapies), we expect the finding that medication supply was largely maintained in the area served by the CHWs was a result of the palliative care network, which ensures palliative medication is delivered free of charge to patients directly by KCMC. KCMC was able to maintain its procurement avenues during the pandemic and was largely not affected by medication shortages. However, fear of catching COVID-19 again arose as a significant problem and suggests that for some patients, a lack of trust in infection control measures may have been a barrier to accessing treatment.

Interestingly, in Rwanda, drones were used to deliver medications to oncology patients during the pandemic, reducing the risk of infection for patients, which is a novel approach to this problem and perhaps one that could have been replicated in Tanzania had there been a robust government level response to COVID-19.<sup>39</sup>

A concerning finding was that over half (57.7%) of CHWs said that they had noticed more patients dying since the start of the pandemic. While this is an unreliable way to assess the burden of illness caused by COVID-19 and is subject to many biases, given the lack of other measures that were available at the time to measure the impact of COVID-19, this provides valuable insight from the perspective of CHWs. As of 16 August 2022, Tanzania has officially recorded 38 454 cases and 841 deaths due to COVID-19,<sup>40</sup> which corresponds to approximately 0.06% of the population having been infected with COVID-19. However, a seroprevalence study conducted in July–October 2021 in Zanzibar, Tanzania found that 58.9% of the participants had evidence of prior COVID-19 infection.<sup>41</sup> While the increase in deaths noted by the CHWs may not necessarily have been attributable to COVID-19 infection itself, and may in part be due to delays and missed cancer treatment, this study adds weight to the evidence that COVID-19 was much more widespread than official figures suggest.

Another significant finding was that so many CHWs (74.4%) reported patients relying on local healers, which is concerning as they described their patients believing false reports such as steam inhalation being an effective cure. This raises concerns that patients may have delayed

seeking care for COVID-19 or their cancer in more appropriate settings. Equally, it highlights again the influence of Government communications at the time, as the benefits of steam inhalation were frequently promoted by the Ministry of Health and the president.<sup>14</sup>

### Limitations

The small sample size resulted in some limitations to our study, as we had low power to detect real differences between groups and had wide CIs where we did find differences. The small sample also meant we were not able to adjust our analysis through multilinear regression to assess for confounding bias between sociodemographic variables. The fact the study was conducted from one facility in Northern Tanzania only, with a relatively rural population, means that results cannot be taken to reflect the situation at all cancer centres in Tanzania and limits the generalisability of our findings. Equally we could not compare our findings on missed appointments to pre-pandemic data, as none was available at our centre or published from elsewhere in Tanzania. Surveys are subject to inherent biases and particularly in this study, social desirability bias is likely to have played a significant part in respondents' answers given the highly political nature of the discourse around COVID-19 at the time and the social and official repercussions of acknowledging the ongoing pandemic.

### CONCLUSION

Overall, the results suggested that while there were significant disruptions to cancer care, these were not as severe as might have been expected. For the most part, patients and CHWs did not fear COVID-19 more than disruption to cancer care. This indicates that for these groups, there is a delicate balance between protection from emerging infectious diseases and ensuring that cancer services are still accessible. Our findings draw attention to the importance of public health measures (for example infection control measures and education about the pandemic) and how these interacted with the maintenance of cancer services in Tanzania. Acknowledging the risk and ensuring adequate PPE and vaccine availability are important strategies to be considered in the event of further waves of COVID-19 or new emerging infectious diseases. Looking to the future, with the aim of supporting cancer care for patients and health workers during both pandemics and in normal times, our findings reinforce the movement towards a decentralised health system with a hub and spoke model, which could (a) prevent overcrowding and (b) facilitate easier patient access to cancer services.

### Author affiliations

<sup>1</sup>Institute for Tropical Medicine and Public Health, Charité—Universitätsmedizin Berlin, Berlin, Germany

<sup>2</sup>Department of Oncology, Kilimanjaro Christian Medical Centre, Moshi, Tanzania, United Republic of

<sup>3</sup>Institute for Medical Epidemiology, Biostatistics and Informatics, Center of Health Sciences, Martin-Luther-Universität Halle-Wittenberg, Halle, Germany

<sup>4</sup>Institute for Hygiene and Public Health, Section Global Health, University of Bonn, Bonn, Germany

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### ORCID iDs

India Pumphrey <http://orcid.org/0000-0002-8173-2494>

Oliver Henke <http://orcid.org/0000-0002-9838-9805>

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**Appendices:****Appendix Table 1. Factors associated with missing appointments and fear of covid-19 more than postponement of treatment (n=300)**

Variable		Missed appointment		Crude Odds Ratio (95% CI)	P value	Fear covid more than postponement of treatment		Crude Odds Ratio (95% CI)	P value
		Yes n (%)	No n (%)			Yes n (%)	No n (%)		
<b>Age</b>	<40	22 (39.3)	34 (60.7)	1	0.12	9 (16.1)	47 (83.9)	1	0.55
	40-59	31 (31.3)	68 (68.7)	0.70 (0.35-1.40)		10 (10.1)	89 (89.9)	0.59 (0.22-1.55)	
	≥60	35 (24.8)	106 (75.2)	0.51 (0.26-0.99)		17 (12.1)	123 (87.9)	0.72 (0.30-1.74)	
<b>Sex</b>	Male	47 (29.7)	111 (70.2)	1	0.92	<b>27 (17.2)</b>	<b>130 (82.8)</b>	<b>1</b>	<b>0.01</b>
	Female	43 (30.3)	99 (69.7)	1.03 (0.63-1.68)		<b>11 (7.8)</b>	<b>131 (92.2)</b>	<b>0.40 (0.19-0.86)</b>	
<b>Region</b>	Kilimanjaro	51 (29.1)	124 (70.9)	1	0.63	17 (9.8)	157 (90.2)	1	0.10
	Other	39 (31.7)	84 (68.3)	1.13 (0.68-1.86)		20 (16.3)	103 (83.7)	1.79 (0.89-3.60)	
<b>Education</b>	Primary or less	50 (29.1)	122 (70.9)	1	0.69	23 (13.4)	148 (86.6)	1	0.75
	Secondary/ College	36 (31.3)	79 (68.7)	1.11 (0.66-1.86)		14 (12.2)	101 (87.7)	0.89 (0.44-1.82)	
<b>Occupation</b>	Farmer	37 (33.6)	73 (66.4)	1	0.12*	10 (9.2)	99 (90.8)	1	0.57*
	Business	23 (37.7)	38 (62.3)	1.19 (0.62-2.30)		8 (13.1)	53 (86.9)	1.49 (0.55-4.03)	
	Semi-professional	4 (44.4)	5 (55.6)	1.58 (0.40-6.28)		2 (22.2)	7 (77.8)	2.82 (0.51-15.8)	
	Professional	3 (15.8)	16 (84.2)	0.37 (0.10-1.37)		1 (5.3)	18 (94.7)	0.55 (0.07-4.61)	
	Other	2 (11.76)	15 (88.3)	0.26 (0.56-1.24)		1 (5.9)	16 (94.1)	0.62 (0.07-5.22)	
<b>Under Treatment</b>	Yes	<b>59 (26.8)</b>	<b>161 (73.2)</b>	<b>1</b>	<b>0.046</b>	26 (11.9)	193 (88.1)	1	0.47
	No	<b>31 (38.7)</b>	<b>49 (61.2)</b>	<b>1.73 (1.002-2.98)</b>		12 (15)	68 (85)	1.31 (0.63-2.74)	
<b>Treatment Type</b>	Intravenous	45 (31.5)	98 (68.5)	1	0.052	17 (12)	125 (88)	1	0.71
	Oral	12 (18.5)	53 (81.5)	0.49 (0.24-1.02)		9 (13.8)	56 (86.1)	1.18 (0.49-2.82)	
<b>Fear covid more than Treatment Postponement</b>	No	<b>61 (23.4)</b>	<b>200 (76.6)</b>	<b>1</b>	<b>0.000</b>				
	Yes	<b>28 (73.7)</b>	<b>10 (26.3)</b>	<b>9.18 (3.97-21.2)</b>					

Footnotes: Missing values were excluded from analysis. \*p-value calculated using Fishers exact test

**Appendix Table 2. Relationship between District and CHWs reporting more patients dying, problems receiving medication and patients relying more on local healers**

District	Have you experienced more patients dying?		p-value	Have you experienced patient or relatives have problems receiving pain or other medication?		p-value	Do you recognize that patients rely more on local healers?		p-value
	Yes n (%)	No n (%)		Yes n (%)	No n (%)		Yes n (%)	No n (%)	
<b>Moshi Municipal</b>	12 (57.1)	9 (42.9)	0.463	6 (28.6)	14 (71.3)	0.012*	21 (100)	0 (0)	0.000*
<b>Moshi Rural</b>	19 (67.9)	9 (32.1)		7 (25%)	21 (75)		21 (75%)	7 (25)	
<b>Rombo</b>	8 (53.3)	7 (46.7)		0 (0)	15 (100)		6 (40)	9 (60)	
<b>Hai</b>	6 (42.9)	8 (57.1)		7 (50)	7 (50)		10 (71.4)	4 (28.6)	

**Appendix Table 3. Relationship between fear of home visits because of covid-19 by Age, Sex, Education and location**

Variables	Do you fear home visits because of Corona?		Crude Odds Ratio (95% CI)	P-value
	Yes n (%)	No n (%)		
<b>Age (years)</b>				
<40	1(14.3)	6(85.7)	1	0.565
40-59	20(33.3)	40(66.7)	3.0 (0.32-27.6)	
≥60	3(27.3)	8(72.7)	2.25 (0.17-30.3)	
<b>Sex</b>				
Male	4(25.0)	12(75.0)	1	0.575
Female	20(32.3)	42(67.7)	1.43 (0.40-5.04)	
<b>Education</b>				
Primary	20(31.7)	43(68.3)	1	0.632
Secondary	4(30.8)	9(69.2)	0.96 (0.26-3.5)	
College/University	0(0.0)	2(100.0)	-	
<b>District</b>				
Moshi Municipal	9(42.9)	12(57.1)	1	0.503
Moshi Rural	8(28.6)	20(71.4)	1.87 (0.56-6.33)	
Rombo	3(20.0)	12(80.0)	0.62 (0.14-2.89)	
Hai	4(28.6)	10(71.4)	1 (0.23-4.21)	

**QUESTIONNAIRES**Questionnaire for Community Health Workers (English version)

Age: \_\_\_\_\_ sex: \_\_\_\_\_

CHW in which district: \_\_\_\_\_ highest education level: \_\_\_\_\_

Have you noticed any differences in delivering Home Care since the pandemic?

Yes: \_\_\_\_\_ No: \_\_\_\_\_

If yes, which are these differences?

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Do you fear home visits because of Corona? \_\_\_\_\_

Do patients fear to receive home visits due to Corona? \_\_\_\_\_

Do you observe more or different symptoms in your patients than before the pandemic? If so, which symptoms are these?

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Have you experience of more patients dying since the pandemic started?

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—

Would you recommend to continue home visits or to stop home visits? \_\_\_\_\_

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Have you experienced that patients or relatives have problems in receiving pain medication or other medication?

If yes, what are the reasons?

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Do the community members talk about the corona pandemic?

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Do they need more information about it?

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If yes what are the most common questions?

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Do you recognize that patients rely more on local healers than before the pandemic?

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Questionnaire for Patients (English version)**Cancer Patient Questionnaire – Impact of the Corona pandemic**

EHMS: consented: yes no

Age:

Sex: place of residence:

Highest education level: employment status:

Type of Cancer: Stage:

Currently under treatment: yes no

If yes: which kind of treatment: chemotherapy/antibody  
Oral hormonal treatment  
Oral treatment with TKI

Currently under follow up: yes no

Treatment not yet started: yes no

Have you missed an appointment at the Cancer Care Centre because of the current pandemic?

Yes No

If yes: What were/was the reason(s)?

Fear of acquiring infection during travel

Fear of acquiring infection in the hospital

Transport problems

Financial problems due to the pandemic

I fell sick

Duties at home due to a Corona-infected family member

Other reasons:  

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Have you been referred to radiotherapy during your last visits to our centre?

Yes No

If yes, did you travel and received radiotherapy?

Yes

No

If no, what are the reasons for not traveling?

Fear of acquiring infection during travel

Fear of acquiring infection in the hospital

Transport problems

Financial problems due to the pandemic

I fell sick

Duties at home due to a Corona-infected family member

Other reasons:

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Do you fear the Corona virus more than postponement of the Cancer treatment?

Yes

No