



## **Perspectives of providers of cancer care in Tanzania: evidence and implications for policy**

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**2023**

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# Perspectives of providers of cancer care in Tanzania: evidence and implications for policy

## Summary

This discussion paper presents findings from interviews conducted in 2019 with 30 healthcare professionals in three regions of Tanzania. Participants included: clinicians and nurses at Ocean Road Cancer Institute, Kitete Regional Referral Hospital, Tumbi Regional Referral Hospital, and Aga Khan Hospital; Regional and District Medical Officers; and Regional and District Pharmacists. The paper considers barriers and facilitators to accessing and providing cancer care in Tanzania.

The research forms part of a larger collaborative project, *Innovation for Cancer Care in Africa (ICCA)*.<sup>1</sup> ICCA brings together researchers from Tanzania, Kenya, India and the United Kingdom to address the opportunities and challenges associated with linking industry and health systems in order to widen access to cancer care in Tanzania and Kenya.<sup>2</sup>

Key findings presented in this paper include the following:

- Availability of medicine and equipment to treat cancer at specialist public sector facilities has increased since 2016.
- The cervical screening programme demonstrates the potential for the extension of low-cost screening and early treatment for cervical cancer across Tanzania, with potentially significant implications for reducing late presentation of patients. However, coverage is still incomplete at present and challenges associated with availability of resources and skilled personnel persist.
- Although cancer patients can access free treatment, many still incur considerable costs due to: costs incurred prior to receiving a diagnosis of cancer; travel and accommodation costs required to access treatment; and costs of purchasing medicine or paying for procedures when they are not available at public sector facilities. Costs can lead to delays in accessing treatment or abandonment of treatment.
- Shortages of skilled staff, particularly nurses and pathologists, affects the ability of health facilities to carry out screening and provide treatment, even when medicines and equipment needed to do so are available.
- It can be difficult for patients to obtain a cancer diagnosis due to limited availability of diagnostic technologies at lower tiers of the health system, the costs of diagnostic procedures and travel to obtain them, and shortages of human resources, reagents and consumables required for pathology where it is available.

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<sup>1</sup> The support of the Economic and Social Research Council is gratefully acknowledged. ICCA is funded under the Global Challenges Research Fund Inclusive Societies initiative (reference ES/S000659/1). The content of this working paper is the sole responsibility of the authors and does not necessarily reflect the views of the UK ESRC. Further information about ICCA is available at: <https://www.open.ac.uk/researchprojects/innovation-cancer-care-africa/>

<sup>2</sup>In Tanzania, ICCA research is led by Fortunata Songora Makene at ESRF. We are very grateful to all those who gave their time to participate in interviews and focus group discussions in Tanzania and participants in a dissemination workshop held at ESRF Dar es Salaam in December 2019, whose insightful contributions have shaped the discussion in this paper.

- Referrals are a key point at which patients leave the system due to the significant costs often associated with pursuing them.
- The importance of palliative care was recognised by participants, however, appropriate pain relief is often unavailable or difficult to access.

## 1. Introduction

Non-communicable diseases (NCDs) are considered a growing problem in Tanzania and are estimated to cause over a quarter of annual premature deaths (URT 2016). Within this, in 2016, cancer made up 29.6% of premature deaths from NCDs in Tanzania. In 2018, there were 42,060 recorded cases of cancer and 28,610 deaths (WHO 2020). Low and middle income countries like Tanzania are expected to account for the majority of increased global cancer burden over the next 10 years (URT 2016). Already, in Tanzania cancer is the second most common cause of death for adult women and the fifth most common for adult men (URT 2020a: 2). There are significant challenges related to late presentation of patients and failure to access treatment at all. Indeed, the national cancer control strategy for 2013 – 2022 estimated at the time that that 80 – 90% of those with cancer do not access diagnosis or treatment within the formal healthcare sector, and of those who do 75 – 80% present too late for curative treatment to be possible (URT n.d.: 2).

A national cancer hospital, the Ocean Road Cancer Institute (ORCI), was established in Dar es Salaam in 1996. ORCI continues to provide specialised cancer screening and treatment, including radiotherapy, chemotherapy, nuclear medicine and hormonal therapy. Muhimbili National Hospital, also in Dar es Salaam, has a paediatric oncology ward, a surgical oncology unit, and provides chemotherapy as well as specialised treatment for adult blood cancers. Treatment is also available in Dar es Salaam within the private sector at the Aga Khan Hospital, Mama Ngoma Hospital, BestaSuperspecialized Polyclinic and Diagnostic Centre, and Tabata Cancer Centre.

Outside of Dar es Salaam, some treatment for cancer is provided at two of Tanzania's zonal referral hospitals.<sup>3</sup> At Bugando Medical Centre in the Lake Zone, an Oncology Centre was inaugurated in 2019 and the hospital has the capacity to offer chemotherapy, radiotherapy, brachytherapy and surgical oncology. Benjamin Mkapa Hospital has a department of oncology that is oncology is responsible for the non-surgical treatment modalities of adult patients with solid tumours. Kilimanjaro Christian Medical Centre (KCMC) in the Northern Zone is providing chemotherapy and a Comprehensive Cancer Care Centre is under development with the support of international non-governmental partners. The government reportedly plans to establish a dedicated cancer facility in Mbeya Region (Nachilongo 2019), and the Good Samaritan Cancer Hospital faith based private hospital, offering radiotherapy and chemotherapy, opened in Ifakara in Morogoro Region in February 2019.

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<sup>3</sup> Zonal referral hospitals are specialized healthcare facilities. Tanzania's healthcare system consists of a tiered structure with primary, secondary, and tertiary levels of care, as well as specialized institutions. Primary healthcare facilities provide basic care, secondary facilities offer more specialized services, and tertiary facilities provide highly specialized care for complex medical conditions.

Once patients are diagnosed with cancer treatment is largely provided free within the public sector. Prevention and screening are also addressed in the National Cancer Control Strategy. Approximately 60 per cent of all cancers in Tanzania are linked to infectious agents (URT 2020a: 14). The Hepatitis B vaccine is included on the routine immunisation schedule in Tanzania. A national HPV vaccination programme for girls aged 14 has also been established and coverage of HPV vaccination was estimated at 15.7% of the population in 2018 (WHO 2020).

The government has also sought to increase availability of screening. Tanzania's National Cancer Treatment Guidelines recommend screening for cervical, prostate, breast, skin and bowel cancers (URT 2020a). The Health Sector Strategic Plan 2015 – 2020 stipulates that by 2020 prostate, breast and cervical screening should be available in all Health Centres (URT 2015). However, at present only cervical cancer screening has been extended systematically and 'with adequate resources for high quality' (URT 2020a: 15), and this service is not yet available in all Health Centres. Additional screening and outreach activities will be conducted in Dar es Salaam and Mwanza regions under the Tanzania Comprehensive Cancer Project, a public-private initiative established in 2019, funded by the Aga Khan Foundation and the French national development agency (Aga Khan Development Network 2019).

## 2. Methods

Permission to conduct this research was obtained from the Tanzania Commission for Science and Technology and the National Bureau of Statistics and the President's Office Regional Administration and Local Government Authorities. Ethical approval was granted by the National Institute for Medical Research. Subsequently, instruments were piloted at Ocean Road Cancer Institute (ORCI) with patients as well as health professionals, the data from the pilot was not used in the final analysis of the study.

Participants were informed of the objectives and content of the study, procedures for maintaining data privacy and security, the voluntary nature of participation and their right to refuse to answer any questions without consequences before an interview took place. All participants signed a consent form prior to their interview. The interviews were recorded in Swahili, eventually transcribed and translated to English.

Interviewers received training regarding ethical data collection and informed consent prior to data collection. This included specific guidance regarding conducting research with healthcare professionals in their place of work. Semi-structured interviews were carried out in three regions of mainland Tanzania: Dar es Salaam, Pwani and Tabora. These regions were purposely selected to enable insights into variation in health worker and patient experiences at different distances from Dar es Salaam. Dar es Salaam is the commercial capital of Tanzania and is where the national specialist cancer hospital, ORCI, is located in addition to Muhimbili National Hospital, which also provides specialised cancer care as outlined above, and major private facilities offering cancer treatment. Participants were purposely selected from public and private institutions within the aforementioned regions, to include senior health

professionals, medical administrators, pharamacists, and clinicians. Pwani Region is located adjacent to Dar es Salaam, and the regional capital, Kibaha, is located approximately 40 kilometres from central Dar es Salaam. Tabora Region is in Tanzania’s Western Zone, and the regional capital, Tabora, is over 800 kilometres from Dar es Salaam. The nearest zonal hospital, Bugando Medical Centre in Mwanza, is located approximately 350 kilometres from Tabora town.

Table 1 below shows those interviewed in the three regions. Interviews were conducted with health professionals at ORCI and the Aga Khan Hospital in Dar es Salaam and at two public regional referral hospitals, Tumbi Regional Hospital in Pwani and Kitete Regional Hospital in Tabora. Regional Medical Officers, District Medical Officers and Regional and District Pharmacists also participated in the study.

**Table 1 Interviews conducted.**

| <b>Region</b>        | <b>Interviewees</b>  |
|----------------------|--|
| <b>Dar es Salaam</b> | 2 Senior Medical Officers<br>1 x pharmacist<br>5 x clinician ORCI<br>2 x clinician Aga Khan Hospital |
| <b>Pwani</b>         | 2 Senior Medical Officers<br>2 x pharmacist<br>3 x clinician Tumbi Regional Hospital                 |
| <b>Tabora</b>        | 2 Senior Medical Officers 1 x pharmacist<br>2 x clinician Kitete Regional Hospital                   |

In addition to the interviews, focus group discussions (FGDs) with 7 – 9 participants were conducted at ORCI, Kitete Regional Hospital and Tumbi Regional Hospital. Participants were selected with the support of the head of the institution, who had experience in provision of health care service and who readily able to provide some insights .The respondents included a combination of doctors, medical assistants and nurses. The team held FGDs with health workers who were off shift so as to minimise disruption in routine service provision.

The semi-structured interviews and focus group discussion guides aimed to establish the participants’ roles in provision of cancer care and services provided within their facility and/or district/region. Questions explored: factors participants saw as enabling provision of cancer care; challenges faced in providing cancer care; and the impact of availability of human resources, medicines, medical devices and consumables on cancer care.

### 3. Findings

### 3.1 Improved availability of medicine and equipment

Many participants commented favourably on availability of specialised cancer medicines and equipment. Clinicians interviewed at ORCI gave estimates of medicine availability ranging from 80 per cent to ‘almost 100 per cent’ of the time.<sup>4</sup>The situation in 2019, when these interviews were conducted, was often compared to the more challenging situation prior to 2016, when the current administration took office. As one oncologist explained:

*Currently about 80% of medicines are available at the hospital [ORCI]. This situation is not like it was before [the current administration]. At that time patients prescribed three consecutive rounds of treatment often could not get the drugs on time as the hospital used to run out of stock, forcing patients to look for other alternative drug stores. Patients who couldn't afford to buy medicine had to wait for one to two months for the hospital stock to arrive and by this time their health would have already deteriorated.*<sup>5</sup>

Between 2015 and 2019, the budget for medicines, medical devices, reagents and other equipment increased from 31 billion TZS (13.4 million USD) to 269 billion TZS (116 million USD) (URT 2020b: 14). The government claimed in June 2019 that availability of essential medicines in health facilities was at 94.4% in April 2020, up from 36% in the 2014/15 financial year (URT 2020b: 14). The amount spent specifically on purchasing cancer drugs increased from 700 million (301,804 USD) to 10 billion TZS (4.3 million USD) in 2018/19. In February 2019 the government stated availability of drugs patients receive without charge at ORCI was 92%, with 95% of non-exempted drugs also available (Mwangonde 2019).

Prior to this the Medical Stores Department (MSD) had reported significant shortfalls in funding that prevented purchase of adequate supplies of medicines. The majority of public sector procurement, storage and distribution of medicines and medical supplies is centralised and carried out by MSD, which is funded through the Ministry of Health, Community, Development, Gender, Elderly and Children. The then director of MSD claimed in 2016 that the 2015/16 budget allocated only 80 billion TZS (34.5 million USD) of over 500 billion TZS (215.75 million USD) that would be required to adequately meet needs (Buguzi 2016a), and the shortfall was compounded by debts owed by the government to MSD (Lee et al. 2016). Indeed, shortages of medical supplies was a key issue during the 2015 election campaign. Newly elected President Magufuli attributed problems to health worker corruption and closed private pharmacies located near hospitals (Buguzi 2016a). As participants in the research described, at ORCI, underpayment of government funding allocated to the institution had prior to 2016 reportedly meant large proportions of patients were required to pay for medication privately in 2016, leading many to abandon treatment (Buguzi, 2016b). The Minister for Health acknowledged in 2019 that in the financial year 2015/16 availability of anti-cancer medicines at ORCI was only 4% (Mwangonde 2019). Thus, the current improvement in the situation was widely welcomed and often attributed to the government, which one clinician noted ‘has tried a lot compared to the previous government’.<sup>6</sup>

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<sup>4</sup> Clinician 1

<sup>5</sup> Clinician 2. This contrast between the situation prior to 2016 and the present was also identified by Clinician 3, Clinician 5 and in the ORCI FGD (Participant 6).

<sup>6</sup> Clinician 3

Availability of equipment required for specialist cancer care was also largely considered to have improved in recent years.<sup>7</sup> Of particular note, radiotherapy capacity has been considerably improved. Two linear accelerator (LINAC) radiotherapy machines were installed at ORCI in March 2019, access to which had previously only been available at one private sector outpatient clinic in Dar es Salaam. One clinician also highlighted the purchase of a cesium-137 teletherapy machine, to treat skin cancer patients, and a CT simulator, for radiotherapy treatment planning, since 2016.<sup>8</sup> Since these interviews were conducted ORCI received 14.5 billion TZS (6.26 million USD) from the government in late 2019 for the purchase of further equipment, to include a cyclotron and a PET-CT scanner, the first in Tanzania (Namkwahe 2019a).

Outside of specialist cancer facilities, participants also noted improvements in the budget available for purchase of medicines by facilities and availability of medicines.<sup>9</sup> Some of the facilities at which interviews were carried out were also included within a larger programme of hospital construction and facility upgrading. Where District Hospitals or upgraded Health Centres were under construction, interviewees anticipated greater potential to diagnose or at least suspect cancer as they would have ultrasound and x-ray machines, and in one case, in Dar es Salaam, mammography.<sup>10</sup> One Regional Medical Officer, for example, having described challenges of late presentation of patients due to limited capacity to diagnose at lower tiers, noted ‘now I have some confidence, because we see basic health facilities are being constructed which will have X-rays’.<sup>11</sup>

In addition to increased budget and construction, one clinician in Tabora Region also emphasised the contribution of improved procurement processes to reducing stock outs, including the ‘prime vendor’ system that facilitates facilities going to the private sector when MSD is out of stock, reducing delays, and a new web-based system that enables MSD to better oversee monitor stock in facilities, which is ‘very efficient, and quite different from what we used to do before.’<sup>12</sup>

### 3.2 Screening and prevention programmes

Participants working at all of the hospitals included in the study reported that cervical cancer screening was carried out at their facility. At the two regional hospitals, screening was provided with the support of international or local non-governmental organisations (NGOs) working on reproductive health and/or HIV, which has high rates of co-morbidity with cervical cancer, which provided budgets for clinics and training of staff. Different organisations provide such support for services in each region.<sup>13</sup> Nurses participating in focus group discussions at regional hospitals reported having attended trainings on cervical screening organised by a range of Tanzanian and international NGOs. Regional and District Medical Officers also reported that screening was available at some Health Centres within their jurisdictions. In the public sector, with the exception of ORCI, screening is conducted using visual inspection with acetic acid (VIA) or Lugol’s iodine. At ORCI, while visual inspection is available free of charge, pap smears are also available for a fee of 60,000 TZS (26 USD).<sup>14</sup>

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<sup>7</sup> Clinician 3; Clinician 4; Clinician 5.

<sup>8</sup> Clinician 3.

<sup>9</sup> Pharmacist 4; Regional Medical Officer 2.

<sup>10</sup> Pharmacist 3; District Medical Officer 2.

<sup>11</sup> Regional Medical Officer 1.

<sup>12</sup> Clinician 6.

<sup>13</sup> RMO 2.

<sup>14</sup> Clinician 3.



Regional hospitals included in the study (Kitete and Tumbi) also provided early treatment to remove pre-cancerous cells. Both hospitals were performing cryotherapy and loop electrosurgical excision procedures (LEEP) were also performed at Tumbi, the only facility providing this service in Pwani Region.<sup>15</sup> One FGD participant thus lamented the absence of LEEP and the problem with having to refer patients, when ‘this is something which could be treated in just one day and provide relief’.<sup>16</sup>

Some interviewees suggested it had been possible to combine screening and provision of advice on prevention with existing services for which there is an established and regular demand. For example, the cervical screening clinic at Kitete is located within the maternal health unit, and several participants noted other examples of integration of cancer education into maternal health appointments, such as women being shown how to check their own breasts or told about HPV and Hepatitis B vaccination programmes. However, it is difficult to know how systematic such practices are. Indeed, there appears to be considerable variation in availability of screening across Tanzania. In a district in central Dar es Salaam, for example, 4 of 27 Health Centres were reported to be providing screening at the time of the interviews. In Tabora Region, in contrast, only 5 of 329 Health Centres were reported to be providing screening, and some districts had no screening provision at all.<sup>17</sup>

The low cost of equipment and consumables required to carry out visual inspection with acetic acid (VIA) and financial support from NGOs meant participants did not usually identify challenges in affordability of stock to carry out screening. Despite the relatively affordable nature of equipment and consumables and the availability of donor support, one interviewee from a largely rural district in Tabora Region reported that although one member of staff had been trained to carry out screening, they did not have any equipment with which to do so.<sup>18</sup> Occasional shortages of speculums were reported at the district level and in a regional hospital,<sup>19</sup> which one pharmacist attributed to procurement challenges, adding ‘there is a very bureaucratic procurement process.’<sup>20</sup> The more expensive equipment required for early treatment is more difficult to maintain and replace. At Tumbi hospital, for example, one of two cryoguns was reported to be broken and too expensive to repair.<sup>21</sup> The gas cylinders required for cryotherapy could also be difficult to obtain.<sup>22</sup>

Hospitals and local government are also involved in outreach events to increase awareness and conduct cervical and breast screening, often in collaboration with local and international non-governmental organisations. These events were reported to be very popular. One participant in the FGD at ORCI described, ‘when they hear Ocean Road doctors and nurses are going to be there response is very high. For example in Singida... we managed to screen almost one thousand people who attended for cervical and breast screening.’<sup>23</sup> It can be easier to encourage people to come forward for screening at such events rather than attending the hospital, which people can be reluctant to do, fearing ‘they might be asked to contribute a bit [of

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<sup>15</sup>Clinician 7.

<sup>16</sup>Kitete FGD (participant 8).

<sup>17</sup>Pharmacist 1.

<sup>18</sup> Pharmacist 1.

<sup>19</sup>Kitete FGD (participant 3); District Medical Officer 1; Pharmacist 3.

<sup>20</sup> Pharmacist 3.

<sup>21</sup> Tumbi FGD (participant 2).

<sup>22</sup> Pharmacist 3.

<sup>23</sup> ORCI FGD (participant 8).

money]’.<sup>24</sup>There are also attempts to work with existing local government structures to share information about screening, for example through participation in public meetings at village and ward levels.<sup>25</sup>

However, as one participant in a focus group at Kitete Hospital noted, ‘when we take screening to the community people respond positively. The problem is that it doesn’t reach them a lot.’<sup>26</sup>An ORCI clinician explained that their screening outreach programmes were conducted once or twice a year, noting:

*All these efforts [outreach] aren’t enough because the programmes reach a very small population....the programme is not frequently conducted...Even when they go to a particular region they don’t visit all the [districts] of the region, just a portion. The coverage is very small.*<sup>27</sup>

The facilities themselves were dependent upon funding from NGOs to conduct these activities, as they did not have sufficient budget within the institutions.<sup>28</sup>

Health professionals also discussed people’s reluctance to attend screening or lack of familiarity with the principle of screening. Fear of a diagnosis due to the belief cancer cannot be treated reportedly deters some from attending screening,<sup>29</sup> as well as a wish to protect their livelihoods. One DMO explained, ‘People are still afraid of screening. They think if I am diagnosed how am I going to do my job?’<sup>30</sup> More broadly, health professionals felt many lacked awareness of the purpose of or opportunities associated with screening, and did not seek treatment until symptoms developed.<sup>31</sup> In the words of one participant in the Kitete FGD, ‘only women who suspect they have a problem attend the [cervical screening] clinic...[by which time] it is difficult to help them... Some women come here telling you “I just accompanied my friend”, while at the same time they also need to be screened. So education hasn’t reached many.’<sup>32</sup> One of their colleagues concluded, ‘we [Tanzanians] need to develop a culture of checking our health often’.<sup>33</sup>

Participants also raised concerns about the sustainability of services provided through donor funding. A partner supporting screening and early treatment at Tumbi Hospital, for example, had indicated cost-sharing would likely be required in the future. One focus group participant there explained that although equipment for screening was currently available ‘[the NGO] claims that we need to be independent because in the future they might not be able to supply us with the necessary equipment’.<sup>34</sup> As noted above, donor provided consumables sometimes did reportedly run out.<sup>35</sup> One Regional Medical Officer outlined potential challenges with the

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<sup>24</sup>District Medical Officer 3.

<sup>25</sup> Pharmacist 3.

<sup>26</sup>Kitete FGD (participant 8).

<sup>27</sup> Clinician 1.

<sup>28</sup> Clinician 5, 6.

<sup>29</sup> Clinician 10.

<sup>30</sup> DMO 2.

<sup>31</sup>Kitete FGD; DMO 3; Tumbi FGD; Clinician 11.

<sup>32</sup>Kitete FGD (participant 3).

<sup>33</sup>Kitete FGD (participant 1).

<sup>34</sup> Tumbi FGD (participant 2).

<sup>35</sup>Kitete FGD (participant 4).

sustainability of screening in terms of more general difficulties in maintaining donor-sponsored initiatives as follows:

*The problem is that this training is part of vertical programmes... for example, people come to a place for research and diagnose many women etc. and incentives are made available. But when they leave, despite the fact they built capacity, when the programme ends those who are left don't continue...I have seen this in [my previous posting]. You realise [the work has stopped] after you see the number of people who visit the centre going down. Their argument is that they don't have money to keep it going...these vertical programmes make our health providers lazy because they think this is the way of doing things that should continue while in reality these are their responsibilities...[when sponsored projects happen you know they come with funding and you will achieve the objective]. The problem arises when it comes to sustainability. When they leave is when we see gaps. You made this guy feel comfortable with the programme, when you ask them to start walking by themselves they start going backwards.<sup>36</sup>*

Others also reflected more broadly on the influence of donors in shaping priorities within the health system, comparing the relative lack of support for cancer to that available for HIV or for maternal and child health.<sup>37</sup> One pharmacist concluded, 'we only prioritize things that will be supported by our partners.'<sup>38</sup>

### 3.3 Cost of treatment

Treatment for cancer is provided free of charge to patients in Tanzania at public facilities. This exemption is certainly welcomed by many patients and is effective in protecting many lower income patients from otherwise prohibitive costs of receiving care at ORCI. Patients' experiences of and perspectives on free treatment are discussed further by Makene et al. (2020). Health professionals who participated in this research also largely welcomed the free treatment policy, being keenly aware of the financial difficulties that health problems could cause for many Tanzanians. At ORCI, clinicians explained that the majority of patients, 90 per cent in one estimate, treated there do not have health insurance.<sup>39</sup> One doctor expressed their gratitude for the policy, stating:

*I would like to thank the government because cancer treatments are so expensive all over the world, but the government are covering all those expenses to enable people to be treated free of charge. This has increased patients' willingness to come here for treatment because they know it is free of charge...<sup>40</sup>*

Despite this, however, there are a range of reasons why patients can incur very significant costs. As one RMO noted, 'treatment is free, but people pay'.<sup>41</sup> The cost of care can sometimes cause patients to abandon treatment, influenced delays to diagnosis, and was acknowledged by many participants to generate considerable additional distress.

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<sup>36</sup> Regional Medical Officer 1.

<sup>37</sup> Kitete FGD (participant 8).

<sup>38</sup> Pharmacist 2.

<sup>39</sup> Clinician 4. See also Clinician 1.

<sup>40</sup> Clinician 5.

<sup>41</sup> Regional Medical Officer 1.

Firstly, although free treatment is available to patients who have been diagnosed with cancer, many incur significant costs prior to diagnosis. One DMO noted:

*Cancer patients receive free medical treatment from dispensary level up to referral level, including palliative care. However, anybody who hasn't been diagnosed with cancer would find it almost impossible to get free treatment, even if they have all the symptoms of cancer.*<sup>42</sup>

This research included interviews with patients currently undergoing treatment, caregivers for those undergoing treatment and former patients who have completed treatment. The research design thus did not capture those who were never diagnosed or who abandoned treatment. The interviews with healthcare providers, however, suggested that the costs incurred prior to diagnosis and anticipated further costs cause a significant number of patients to exit the formal healthcare system before diagnosis.

As discussed further below in section 3.5, outside of zonal and national facilities, there is limited capacity to diagnose cancer. Therefore, ‘the patient is treated as a normal patient and only later when they suspect they have symptoms of cancer they refer them to [a zonal or national hospital] for treatment which means many people incur high costs.’<sup>43</sup> Sometimes patients may spend money on multiple consultations and inappropriate or unnecessary treatment before cancer is suspected (Kohi et al. 2019; Makene et al. 2020). As one RMO outlined, ‘the bad thing is that when people [at lower tiers] can't detect [cancer] early, in most cases they just offer medication and give [patients] prescriptions to use them for three weeks and come back for a check up again.’<sup>44</sup>

Diagnostic procedures themselves can also be costly. Table 2 includes a sample of reported costs for a range of procedures and pathology services in public hospitals as reported by interviewees and FGD participants. These costs can also affect follow up rates when abnormalities are detected during screening. At Tumbi Regional Hospital, for example, biopsies are extracted when necessary following cervical screening. However, interviewees reported that some patients complain they cannot afford the costs of analysis, for which patients must take their sample to a national hospital (Muhimbili National Hospital or Mlonganzila) in Dar es Salaam.<sup>45</sup> Paying for biopsy analysis can be particularly challenging because samples must be used within a short period of time, meaning that funds must be found quickly.<sup>46</sup> Several of those interviewed thus suggested analysis of biopsies should be provided free of charge, ‘because if you tell a normal person to go with 60,000 or 80,000 shillings [to pay for analysis] it becomes difficult. If they could test for free it would really help.’<sup>47</sup>

**Table 2 Cost of selected diagnostic procedures and pathology (in public sector)**

| <b>Procedure</b>   | <b>Cost (TZS)</b> | <b>Cost (USD)</b> |
|--------------------|-------------------|-------------------|
| Analysis of biopsy | 60 – 80,000       | 26 - 35           |
| CT scan            | 150 – 200,000+    | 65 – 86+          |

<sup>42</sup> District Medical Officer 1.

<sup>43</sup> Regional Medical Officer 3.

<sup>44</sup> Regional Medical Officer 1.

<sup>45</sup> Tumbi FGD (participant 1); Clinician 8.

<sup>46</sup> Tumbi FGD (participant 2).

<sup>47</sup> Clinician 7. See also Tumbi FGD.

|                                 |        |    |
|---------------------------------|--------|----|
| Fine needle aspiration cytology | 50,000 | 22 |
|---------------------------------|--------|----|

It is important to note that the costs in Table 1 refer only to the procedure itself. When potential cancer symptoms are identified following screening or examination by a healthcare provider, patients must also often pay travel costs to reach higher tier healthcare facilities where diagnostic procedures are available. Healthcare workers in Tabora Region were particularly aware of the challenge that travel costs and logistics could pose for patients. Patients at Kitete Regional Hospital must travel much longer distances to reach a zonal referral hospital, where diagnostic procedures such as biopsy extraction and analysis can be conducted, than those attending the other facilities included in the study. Thus, although cervical screening at Kitete Regional Hospital is provided free of charge, patients suspected of having cancer are sometimes deterred from attending referrals for further investigations due to the cost. As one FGD participant in Tabora explained, ‘sometimes we lose patients. Sometimes you know that this patient will go home with no follow up and finally they will die, because although you have discovered the signs they cannot afford financially [to continue with investigations]’.<sup>48</sup> These challenges are compounded when there is high demand for procedures, such as biopsy extraction, meaning that patients may be asked to return to the hospital on multiple dates, which can be prohibitively expensive for patients residing at significant distances from the facility.<sup>49</sup>

Secondly, after a cancer diagnosis, when free treatment is available, patients from outside of Dar es Salaam continue to incur costs of travel and accommodation in order to receive treatment because cancer treatment capacity is concentrated in national hospitals, primarily ORCI in Dar es Salaam, and to a lesser extent at zonal referral hospitals in the Lake Zone and Northern Zone, as outlined above. The challenges faced by cancer patients in affording travel and accommodation are evident in existing literature from Tanzania (Esmaili et al. 2018; Kohi et al. 2019) and elsewhere in eastern and southern Africa (e.g. Mulemi 2010; Livingston 2012). Many health professionals were acutely aware of the difficulties that these costs posed for patients. At ORCI for example, FGD participants described discharged patients remaining on wards for several months as they tried to raise funds for the bus fare home, which could lead to overcrowding and increase workload for staff.<sup>50</sup> Healthworkers often went beyond their official roles to try to support such patients, as one nurse at ORCI described:

*Say a patient is admitted for 4 months. Whatever money they had with them is finished [by the end]. [Hospital staff] start to brainstorm how to help the patient. If somebody volunteers to help her with the transport fare she tells other patients that we are giving out transport fare, but in reality we don't.*<sup>51</sup>

The nature of chemotherapy and radiotherapy, which must be administered regularly over an extended time period, made challenges with paying for transport more acute. One caregiver described having asked ORCI management to admit her mother during her chemotherapy, as daily transport costs of TZS 50,000 (22 USD) were unaffordable.<sup>52</sup>

<sup>48</sup>Kitete FGD (participant 8).

<sup>49</sup> Tumbi FGD (participant 1).

<sup>50</sup> ORCI FGD (participant 7).

<sup>51</sup> ORCI FGD (participant 4).

<sup>52</sup> Caregiver 1. See also Caregiver 9.

Thirdly, when medicines are out of stock, equipment is not available or not working, or staff with required expertise are not available in public facilities, patients must access services through the private sector or purchase medicine in private pharmacies or face delays. Although a perceived significant improvement in availability of medicine and equipment for cancer care at ORCI was discussed above, some challenges remain. Participants attributed stock outs to factors including importation delays, budgetary constraints at facility level, and delays in disbursement of government funding to facilities.<sup>53</sup> Literature also highlights challenges in calculating usage and needs within health facilities and weak accountability and oversight (Wales et al. 2014; Strong 2017).

When medicines are out of stock at ORCI, patients without insurance could face very high prices in private pharmacies (see also Kohi et al. 2019). Chemotherapy drugs are typically very expensive and must be administered in combination and in multiple doses. One doctor explained that:

*It might be the case that a certain drug costs TZS 300,000. But actually, cancer treatment entails a combination of more than one sort of drug. To administer the dose, you need to use each drug frequently, more than six times per month. Can you imagine how many Tanzanians have the ability to pay such a big sum of money just for the sake of medicine? Although these drugs are provided free, if one type of drug is missing for the required combination, the patient is told to go and buy it at the pharmacy. This becomes very burdensome to the patient and their family.<sup>54</sup>*

Patients might thus have to choose which medication to purchase based on its cost, rather than clinical advice. As one FGD participant at ORCI described:

*If the patient doesn't have insurance and the medicine is expensive we advise them about availability of other medicines that perform the same function and talk to them about the side effects. Based on their financial status they decide on the best option for them.<sup>55</sup>*

For many patients even cheaper options are likely to be unaffordable. One participant in the FGD in Tabora Region recalled a woman who had been referred to ORCI following cervical screening returning to Tabora when medicine was unavailable and she was unable to purchase her own.<sup>56</sup> Even patients with insurance can face prohibitive costs when insurance packages do not include a particular drug.<sup>57</sup> When it is not possible to purchase medicine privately, treatment could be delayed or a patient might be required to restart a course of treatment from the beginning.<sup>58</sup>

Participants at ORCI also noted challenges in maintaining some equipment. In particular, the conventional simulator, used in planning radiation therapy, had reportedly been out of use for over six months in June 2019.<sup>59</sup> Some machinery, notably radiotherapy machines, can only be serviced by technicians from overseas (ORCI clinician 3).<sup>60</sup> Absence of equipment or broken

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<sup>53</sup>Regional Medical Officer 1; Clinician 3; Clinician 9.

<sup>54</sup> Clinician 1.

<sup>55</sup> ORCI FGD P4.

<sup>56</sup>Kitete FGD P3.

<sup>57</sup> Clinician 3.

<sup>58</sup> District Medical Officer 2.

<sup>59</sup> Clinician 1.

<sup>60</sup> Clinician 3

equipment means patients must be referred to Muhimbili where possible, which can delay treatment,<sup>61</sup> or are obliged to seek care in the private sector if they can afford to do so (e.g. Lugongo 2020). Although as discussed above capacity has increased, particularly to provide radiotherapy, one clinician at ORCI noted, ‘I can’t say the equipment and tools [we have] are completely sufficient’, rating adequacy at 60 to 70 per cent.<sup>62</sup>

Fourthly, there are some services that are not included within Tanzania’s free cancer treatment policy. Notably, surgery is not provided at ORCI and patients must be referred to Muhimbili where they are charged.<sup>63</sup> A mastectomy could be carried out at Tumbi Hospital, for example, for TZS 50,000 (24 USD), however, additional costs of hospitalisation and possibly medicine would also be incurred.<sup>64</sup> A survey of patients conducted for this study thus found the median cost of hospital admission where surgery was performed to be much higher, at TZS 611,800 (264 USD) (Makene et al. 2020). CT-scans, which may be regularly required as part of treatment, cost 150,000 at ORCI.<sup>65</sup> These additional costs could be challenging and frustrating for patients and caregivers. One participant in the Kitete FGD reflected on their experience of supporting a relative with cervical cancer, saying:

*When we say treatment is free I think it’s just politics. It’s very expensive, because once treatment is missing you will lose the patient. There’s nothing for free. It could run from 200,000 to one million [TZS] because there are a lot of things involved in the treatment and therefore a lot of costs.*<sup>66</sup>

Finally, the indirect costs of being treated for cancer or caring for a cancer patient are significant. The impact on illness and travelling for treatment on patients’ livelihoods and household income is discussed further in Makene et al. (2020). Interviews with caregivers also illustrate the very challenging financial impact of cancer. Being distant from home to access treatment meant those who relied on agriculture struggled to tend their land and harvest crops, and other business owners lost out or had stopped businesses due to their absence.<sup>67</sup> One carer who had previously had a small business selling cloth door to door, which was no longer viable due to lack of capital, stated ‘financially, I have gone broke, because whatever we had in savings has been spent and we’ve made no income since businesses were shut down’.<sup>68</sup> Families shared they had been obliged to sell a range of assets to cover the costs of treatment, costs of travelling with the patient, and to cover family expenses over sometimes very long periods of time. One family for example had sold cattle and a motorbike over eight years of treatment.<sup>69</sup> Some of the sacrifices made related to future aspirations and are thus difficult to quantify, but were felt very significant by caregivers in explaining the impact of the disease on their family. One caregiver explained that his sister had been unable to study medicine as course fees were too high ‘because 70 per cent of our income was used for [our father’s] treatment.’<sup>70</sup>

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<sup>61</sup> Clinician 1.

<sup>62</sup> Clinician 5.

<sup>63</sup> Clinician 5.

<sup>64</sup> ORCI clinician 4.

<sup>65</sup> Clinician 3.

<sup>66</sup> Kitete FGD (participant 7).

<sup>67</sup> Caregiver 5; Caregiver 6; Caregiver 4; 7; 1; 10.

<sup>68</sup> Caregiver 10.

<sup>69</sup> Caregiver 2.

<sup>70</sup> Caregiver 4.

Others had delayed or abandoned plans to invest in business opportunities or had been obliged to stop sending their children to school.<sup>71</sup>

Further data regarding the sums spent by patients on treatment and travel is reported in Makene et al. (2020), but one caregiver reported close relatives had contributed 1.3 million TZS (561 USD), but even this was inadequate to cover the costs of caring for their family member.<sup>72</sup> Having to ask friends and relatives for financial support to access care has an important, and often damaging, impact on patients' and carers' social relationships. As one patient's daughter explained, 'between us relatives we are sometimes not on good terms because not everyone is willing to help my mother.'<sup>73</sup> Several caregivers felt that this was particularly challenging because the treatment did not always seem to be helping, and many believed cancer was not curable. In the words of one participant, 'sometimes if relatives take care of the patient for a long time without any hope, they start to discriminate against them.'<sup>74</sup> Another recalled:

*...a relative called my brother [the patient] on the phone and told him "you will not be healed as cancer is incurable." Unfortunately this relative then refused to give financial support for [my brother's] treatment. Others didn't answer the phone when we called to ask for support or hung up.<sup>75</sup>*

The high costs of providing cancer treatment also had implications for health professionals facilities. One oncologist estimated that the cost of treating a patient with a form of widely used and easily available chemotherapy to cost an average of 5 to 10 million TZS (2,156– 4,312 USD) and radiation to range between 5 and 8 million TZS. This cost could rise even further, to approximately 200,000 USD per cycle of treatment, if more expensive specialised treatment was required, such as monoclonal antibodies.<sup>76</sup> Thus, even at the largest faith-based private facility in Tanzania, some drugs were not purchased due to their high cost.<sup>77</sup> Some more specialised and very costly treatments are also not available at ORCI or typically elsewhere within the private sector in Tanzania, meaning they are available only to the wealthiest patients who can afford to travel abroad.<sup>78</sup>

Although the free treatment policy was widely welcomed, a few health professionals did highlight the challenges of managing to provide treatment without charge. This could generate difficult budgeting decisions for professionals, as 'when these people are exempted there are costs'.<sup>79</sup> One Regional Medical Officer insisted the policy needed to be 'realistic and implementable', as at present it was not always possible to implement it and some contributions were needed from those who could afford to do so.<sup>80</sup> A clinician at ORCI explained in further detail:

*Limited budget [is a challenge to providing adequate services], especially with the policy of free treatment for those who don't have health insurance. It's not sustainable and not feasible.*

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<sup>71</sup> Caregiver 8; caregiver 5; caregiver 13.

<sup>72</sup> Caregiver 13.

<sup>73</sup> Caregiver 9.

<sup>74</sup> Caregiver 3.

<sup>75</sup> Caregiver 13.

<sup>76</sup> Clinician 10.

<sup>77</sup> Clinician 10.

<sup>78</sup> Clinician 4.

<sup>79</sup> District Medical Officer 3.

<sup>80</sup> Regional Medical Officer 1.



*Because, at times hospital machines break and there's nobody to do cost sharing and sometimes it takes time to make repairs... to make matters worse some radiation machines need technicians from overseas to perform repairs as local technicians lack the required expertise...The big challenge is the policy of free medications for patients who don't have health insurance. There should be cost sharing to meet the running costs and maintenance and repair of machines to ensure future sustainability and to purchase additional drugs and fund expansion of hospital services....At least [patients] should pay TSH 2000 for hospitalisation a day or 20000 for opening a registration file.<sup>81</sup>*

### 3.4 Human resources

Shortages of skilled personnel emerged as a key challenge from interviews with health professionals. At ORCI, participants emphasised shortages of general doctors,<sup>82</sup> specialist doctors,<sup>83</sup> surgical oncologists (patients are referred to Muhimbili for surgery),<sup>84</sup> physicians,<sup>85</sup> and nurses.<sup>86</sup> The shortage of nurses was described as a nationwide problem.<sup>87</sup> Recruitment of nurses is centrally controlled. One ORCI oncologist attributed this to some nurses having been removed during a purge of those deemed to have fake certificates as well as those who left for other reasons not being replaced.<sup>88</sup>

In recent years as screening programmes and awareness campaigns have expanded the number of patients attending ORCI has increased significantly. ORCI had 30 oncologists in 2020, in comparison to 13 in 2015, but the facility treated 72,712 patients between July 2019 and March 2020, of which 14,504 were inpatients (URT 2020c: 71 – 4). This is a significant increase from approximately 30,000 patients in 2015 (Namkwahe 2019b). This means that doctors who might previously have expected to attend to 10 – 15 patients could be responsible for 60 – 70.<sup>89</sup> One clinician estimated that cervical cancer patients had tripled since 9 years ago, from 500 each year to 1500.<sup>90</sup> Although medical students play an important role in supporting provision of care, when they are on leave 'we realise we don't have enough doctors'.<sup>91</sup> One general doctor could thus be seeing 80 patients in one day.<sup>92</sup> Thus, a doctor at Aga Khan Hospital expressed fulsome praise for ORCI's achievements, but noted 'the only challenge... is they have been overwhelmed. In a country with a population of over sixty million we have only one hospital specialised in oncology and that is a challenge.'<sup>93</sup>

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<sup>81</sup> Clinician 5.

<sup>82</sup> Clinician 1, ORCI FGD (participant 8).

<sup>83</sup> Clinicians 1 2; 5

<sup>84</sup> Clinician 4; 5.

<sup>85</sup> Clinician 3.

<sup>86</sup> Clinician 1; 3 4

<sup>87</sup> Clinician 9.

<sup>88</sup> Clinician 1.

<sup>89</sup> ORCI FGD (participant 7).

<sup>90</sup> Clinician 5.

<sup>91</sup> ORCI FGD (participant 3).

<sup>92</sup> ORCI FGD (participant 8).

<sup>93</sup> Clinician 9.

The high patient load also put significant pressure on nurses. Three nurses might be required to care for 100 patients, many of whom are in a critical condition and require additional care due to pain.<sup>94</sup> One nurse explained how this impacted their work in providing chemotherapy:

*We...educate [patients] that ...they should check, if they got three drips [the first time] but when they come again there is a change, for instance instead of three drips you have two drips, it is good to ask so that we can double check the files because patients are so many that you can't keep track of all of them and their needs.*<sup>95</sup>

Therefore, one ORCI doctor concluded, 'human resource here at ORCI is not enough'.<sup>96</sup>

In the private sector, at Aga Khan Hospital, an oncologist explained that 'all those involved in oncology are very few,'<sup>97</sup> noting the need for additional radiation and clinician oncologists, oncology nurses, diagnostic doctors, physicists and palliative care specialists.

At lower tiers of the health system, participants also highlighted challenges arising from shortages of skilled staff. In all three regions, shortages of people to carry out screening were raised at regional hospitals and lower tiers of the health system as, for example, trained staff also have other duties to manage. This issue was discussed in the Kitete FGD, where participants noted that the four people trained to perform screening were insufficient as this was the only facility within Tabora municipality where it was carried out and they also had other responsibilities. As one participant outlined, 'we are not sufficient. Sometimes women go back home without accessing a service because we might be dealing with other responsibilities'.<sup>98</sup> If demand for screening were to increase, as is intended, interviewees anticipated additional challenges could arise.<sup>99</sup>

Shortages of pathologists, in addition to lab technicians to support them, was frequently identified as a major challenge at regional hospitals, where pathology is not available as discussed below, and at ORCI.<sup>100</sup> The private sector facility included in this study also had only one pathologist, meaning samples had to be sent to Muhimbili when this individual was on leave. As observed in other African contexts, shortages of pathology services hinder early diagnosis and can lead to delayed or inappropriate treatment (Adesina et al. 2013). In 2013, there were 22 pathologists in Tanzania, approximately one per 2,187,545 people (Nelson et al., 2016). Where pathologists are present, they face great demands on their time due to responsibility for very large geographic areas which means results can be significantly delayed (Schroeder et al. 2017).

Nurses in FGDs frequently commented that they desired more training or more regular training in specialist cancer care, emphasising that methods of screening and treatment changed regularly and thus training needed to keep up with that. As one explained:

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<sup>94</sup> ORCI FGD (participant 7).

<sup>95</sup> ORCI FGD (participant 6).

<sup>96</sup> Clinician 3.

<sup>97</sup> Clinician 10.

<sup>98</sup> Kitete FGD (participant 3).

<sup>99</sup> District Medical Officer 3.

<sup>100</sup> Insert refs here from conclusion, Clinician 5, 6.

*It's true that things change every day and technology changes. The ministry had advised people should be trained annually. At times you are taught the same thing [as previously] and practice it just to notice that the process and procedures have changed.*<sup>101</sup>

### 3.5 Diagnosing cancer

Late presentation of cancer patients is a significant challenge in Tanzania (URT 2016: 25). This frequently limits treatment options once patients do arrive at a specialised facility. As one FGD participant at ORCI described, 'Around 80% of our patients come in when their disease is at a late stage. Only 10 or 20 percent come at an early stage when their cancer might be curable'.<sup>102</sup> Participants in the research identified a number of factors that they believed cause people to delay seeking treatment for possible cancer in the formal health system, including: limited awareness of cancer and potential symptoms; a preference for alternative medical providers; fear of undergoing cancer treatment, particularly radiotherapy; lack of access to diagnostic procedures outside of national and zonal hospitals, and consequently patients' inability to afford to travel to access services; and the cost to patients of diagnostic procedures.

All 13 caregivers who were interviewed felt awareness of possible cancer symptoms among the population was very limited, particularly in rural areas. One participant, for example, explained that her mother had only been advised to investigate her symptoms further when a nurse spotted a growth on her throat while treating her for malaria.<sup>103</sup> When asked about stigma attached to suffering from cancer, 6 of the 13 responded that they had not observed stigma to be a significant problem in their local area because people had typically not encountered anybody known to have cancer before. For 3 caregivers, their relative was the first person they had heard of being diagnosed with cancer.<sup>104</sup> The limited visibility of cancer care outside of Dar es Salaam was also noted by one interviewee from Dodoma, who noted 'there are no cancer hospitals, that is why cancer patients aren't known about.'<sup>105</sup>

Others did feel cancer was stigmatised, largely because of a perception that it cannot be treated and 'once you have cancer you will die'.<sup>106</sup> The impact of the belief that cancer patients will not survive on the willingness of extended family members to provide financial support was noted above. One caregiver explained that misconceptions that cancer could be communicated by touch led people 'to stay away from patients as much as possible',<sup>107</sup> and others noted that very noticeable symptoms, such as a strong odour, caused people to avoid the patient or increased reluctance to provide support.<sup>108</sup> Symptoms that affected intimate body parts could be difficult for those affected to talk about, especially for older people. As one District Medical Officer recalled of her aunt who had suffered from cervical cancer, she did not feel able to tell

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<sup>101</sup> Tumbi FGD (participant 2).

<sup>102</sup> ORCI FGD (participant 8). See also Clinician 5.

<sup>103</sup> Caregiver 3.

<sup>104</sup> Caregivers 2; 5; 12.

<sup>105</sup> Caregiver 4.

<sup>106</sup> Caregiver 9. Also caregivers 3, 13.

<sup>107</sup> Caregiver 7.

<sup>108</sup> Caregivers 2; 11.

anybody about vaginal bleeding because ‘at her age she considered it shameful... [people] hide it because of our norms and traditions’.<sup>109</sup> Stigma can be compounded by co-morbidity with HIV, which is common in the case of cervical cancer. One doctor at a regional hospital explained that HIV-positive people with suspected cervical cancer sometimes did not get diagnosed as their HIV status made family members less willing to contribute support travel and treatment costs.<sup>110</sup>

Several of the patients whom carers were supporting had initially blamed witchcraft for their affliction and sought alternative healing to resolve this, rather than going to a formal health facility.<sup>111</sup> Health professionals also noted beliefs in non-bio medical causes of illness and preferences for alternative healing in explaining why people delayed attending health facilities or abandoned treatment after referral.<sup>112</sup> One doctor at ORCI commented on the cost of alternative treatment, which they believed incurred ‘higher fees than the hospitals’, continuing, ‘once the patient gets to hospital they have lost most of their income and the situation has worsened to an advanced stage.’<sup>113</sup>

Fear of treatment, and particularly radiotherapy, was also raised by health professionals as a reason why people did not seek treatment or abandoned it. Four of five clinicians interviewed at ORCI alluded to fear of radiotherapy and the perception it could cause death. This led some to abandon treatment when radiotherapy was prescribed, preferring to ‘wait for the mercy of God’.<sup>114</sup> Discussion in the ORCI focus group connected these fears to some sense of wider distrust in the medical system. One nurse outlined that they and their colleagues tried to educate patients and discourage them from spreading false information about radiotherapy, but also recounted suspicions of chemotherapy, stating ‘there are some medicines which have a colour and others that don’t...So they think those who get the medicine with a colour are being treated, while those who have the colourless medicine are getting water not medicine.’<sup>115</sup>

However, participants also recognised that even when people did seek care, there are systemic challenges that limit the likelihood of timely diagnosis and early treatment. Some participants mentioned cases whereby patients had been wrongly diagnosed due to limited diagnostic capability at lower tiers and prescribed inappropriate treatment, delaying their access to cancer care (see also Kohi et al. 2019; Makene et al. 2020). In other cases, clinicians recalled partial diagnoses, whereby, for example, a patient might have surgery to remove a tumour at a regional hospital, prior to imaging or diagnostic pathology that might have provided further information about the cancer. This can mean that patients arrive at ORCI having deteriorated since their treatment started.<sup>116</sup>

The need for many to travel to access diagnostic procedures that are not available near their homes, emerged as a key reason participants felt diagnosis was often delayed, with the cost of doing so sometimes leading patients to abandon treatment before diagnosis, as discussed above. In accordance with the tiered structure of the health system, many diagnostic tests cannot be performed until a patient reaches a zonal or national hospital and diagnostic pathology is not

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<sup>109</sup> DMO 3; Also DMO 2.

<sup>110</sup> Clinician 11.

<sup>111</sup> Caregivers 6, 9.

<sup>112</sup> DMO 1; ORCI FGD; Clinician 2; Kitete FGD; Clinician 6; Tumbi FGD.

<sup>113</sup> Clinician 4.

<sup>114</sup> Clinician 4. Also clinicians 1, 2, 3.

<sup>115</sup> ORCI FGD (participant 6).

<sup>116</sup> Clinician 5.

available until this level. While possible indicators of some cancers can be identified through a physical examination at lower tiers of the health system, such as cervical, breast, skin and advanced oesophageal cancers, others, such as blood cancers, are ‘very difficult to identify because it needs laboratory diagnosis.’<sup>117</sup> As one District Medical Officer explained, ‘We only provide physical examination services to patients suspected to have cancer. For example, a woman who comes with a history of vaginal bleeding who reached the menopause three years ago and reports pain during sex with her husband; a man who is coughing up blood – we suspect these people have cancer and they are referred to referral hospitals.’<sup>118</sup>

One of the most common ways in which participants at regional hospitals felt cancer care provision at their facility could be improved was through having the capacity to perform additional diagnostic procedures without having to refer patients. Doctors and nurses recognised the financial burden frequent referrals placed on patients and the increased likelihood that patients would abandon formal treatment. Although the fact that nearly all regional hospitals have a good ultrasound enabling identification of some swellings requiring further investigation was welcomed,<sup>119</sup> the absence of pathology services below national and zonal levels was frequently raised as a challenge.

Participants at Kitete Regional Hospital reported that biopsies could not be extracted or analysed at the hospital. This meant that sometimes patients must be referred to a distant zonal hospital for a diagnostic procedure before they could have surgical treatment that was available at the regional level. One doctor gave the following example:

*‘...you cannot plan to start treatment before you know whether it [prostate swelling] is benign or malignant. There is a very small tool we use called a true cut needle. It’s something we insert to take a flesh sample to take to the laboratory. But our laboratory isn’t equipped to do such a test which is very basic. If we could get such a tool and get a pathology lab... At least in every regional hospital there must be a small pathology unit so that small operations like that can be carried out. We wouldn’t need to make a large number of referrals, because sometimes you get a patient with an enlarged prostate. We can remove it, but we aren’t allowed to do this before confirming the type. So you have to send people to Bugando in Mwanza or Muhimbili in Dar es Salaam or Benjamin Mkapa in Dodoma just for a biopsy so that they can bring back the results as a go ahead. But if regional hospitals could be empowered in terms of supplies and equipment, as well as personnel, and have the capacity to do all those basic cytological investigations, I think we would have made a very big step within cancer care... If we have a pathologist in every regional hospital and good laboratory infrastructure we will move forward.’<sup>120</sup>*

In cases where a tumour had been identified, without the ability to stage the patient’s cancer and ascertain whether it had spread, it was not possible to provide surgical treatment that was available at Kitete.<sup>121</sup>

At Tumbi Hospital, it was possible for a biopsy sample to be removed, however, as discussed above, patients then had to transport their sample to a national hospital in Dar es Salaam for analysis. Thus, one doctor, described the benefits having a pathologist at the hospital would

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<sup>117</sup>Clinician 6.

<sup>118</sup> DMO 1.

<sup>119</sup> Clinician 6.

<sup>120</sup> Clinician 6. A surgeon at Tumbi Hospital also reported their desire for a true cut needle.

<sup>121</sup>Kitete FGD (participant 3).

bring as being ‘to reduce the workload on the patients here at the regional level’.<sup>122</sup> Staff at Tumbi Hospital also noted the impact of the requirement to travel on deterring people from pursuing a diagnosis as discussed above. As one doctor explained lack of access to histology and cytology services at a regional level, ‘can lead to a patient not going to the hospital because of financial problems, because once they think about going to Muhimbili for tests they become scared and you find they delay, but if tests could be done from here, at least people from Pwani[Region] could come here because they know they can just come here and get treatment, rather than thinking about going to Muhimbili where they expect expenses to be high.’<sup>123</sup>

In addition to increasing the cost of obtaining a diagnosis, the necessity for many to travel to access pathology services could also lead to delays. One pharmacist from outside of Dar es Salaam felt the care they could provide would be improved: ‘[if] instead of sending biopsies to the national laboratory we could take a biopsy and analyse it here, instead of waiting for fourteen days for results to come, because you never know how many samples are in the queue waiting for analysis where you sent yours’.<sup>124</sup>

Patients who can afford private treatment may be able to access diagnostic procedures more quickly and without travelling so far from their home. Patients at Kitete Regional Hospital, for example, could have a punch biopsy to ascertain a diagnosis of cervical cancer at Nkinga Referral Hospital, a faith-based facility approximately 110 kilometres away by road.<sup>125</sup> While this still represented a significant distance, it is much closer than the public zonal hospitals to which patients would otherwise be referred, such as Bugando Medical Centre in Mwanza, located 350 km away. The laboratory at Nkinga was also reportedly able to test for PSA and for some blood cancers.<sup>126</sup> The cost of having a biopsy and other diagnostic procedures in the private sector is, however, more expensive than at a public hospital.<sup>127</sup> One caregiver reported having spent 1,332,400 TZS (575 USD) on hospitalisation for a CT scan and barium meal procedure at a faith-based facility.<sup>128</sup>

While patients have usually been diagnosed with cancer before they are treated at ORCI, they may still require diagnostic tests. Clinicians noted that patients must be referred to Muhimbili for a surgical biopsy or blood tests, with the potential to cause delays.<sup>129</sup>

Although pathologists were not interviewed as part of this research, other participants noted challenges including shortages of personnel, discussed above, unreliable supplies of reagents and other consumables, such as formalin for preserving samples and containers for transportation of samples.<sup>130</sup>

Some participants did suggest plans were underway to increase diagnostic capacity in their hospitals. One doctor at Kitete, for example, noted that they believed the Ministry planned for regional hospitals to have a pathology unit able to analyse a biopsy with microscopy or other

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<sup>122</sup> Clinician 7.

<sup>123</sup> Clinician 12.

<sup>124</sup> Pharmacist 4.

<sup>125</sup> DMO 1.

<sup>126</sup> Kitete FGD (participant 8).

<sup>127</sup> Kitete FGD (participant 8).

<sup>128</sup> Caregiver 7.

<sup>129</sup> Clinicians 1, 3, 4.

<sup>130</sup> Tumbi FGD; Clinician 1.

machines.<sup>131</sup> One of their counterparts at Tumbi also explained that there had been discussions within the hospitals about increasing lab capacity, including the possibility of acquiring a tumour marker machine.<sup>132</sup>

### 3.6 Referral system

The challenges patients face in obtaining a diagnosis and the high costs that can be incurred in doing so, outlined in sections 3.3 and 3.5, mean that referrals are a key point at which patients discontinue treatment. This was described as follows by one participant in the FGD in Tabora:

*Sometimes you might know that this patient will go home with no follow up and finally they die. Because you identify a problem [abnormal cervical cells] and refer, but they can't afford to go financially. If we could manage to take a biopsy here we could send it ourselves and get the results sent here, but when you ask them to go Bugando or Muhimbili you know they will not go and you just write the referral.*<sup>133</sup>

Tanzania's National Cancer Control Strategy 2013 – 2020 acknowledges that the 'referral system is long and leads to late detection of cancer and delays in treatment' (URT, n.d.: 8). It notes that:

*'In Tanzania, there are no laid-down guidelines for the diagnosis and referral of cancer patients.*<sup>134</sup> *Currently, if a patient is suspected or diagnosed with a cancer at a dispensary level, the patient will be referred to a district or regional hospital for confirmation of the diagnosis. From there, the patient will be referred to a consultant hospital for diagnostic procedures and surgical treatment (if possible) before being referred to ORCI for chemotherapy and/or radiotherapy.'* (ibid.).

The weak referral system is also identified as a weakness by the Strategic Plan and Action Plan for the Prevention and Control of Non-Communicable Diseases in Tanzania 2016 – 2020 (URT, 2016: 10).

Participants described the challenges in persuading patients to follow a referral that requires travel given the often significant costs and inconvenience of doing so. One pharmacist described the response of patients to news they must be referred as follows:

*...the big issue is that when you ask a patient to go for a referral they become resistant....[for two reasons] one is education and another is distance, because if a patient came from far away and had already spent a lot to come here thinking that they will get everything from here and you then ask them to go for a referral...they resist.. [they give] you excuses, even if they have money they get argumentative thinking they can be treated from here.*<sup>135</sup>

Some interviewees recalled occasions when they had been able to refer a patient who was strongly suspected of having cancer directly to ORCI or to a zonal hospital, for example one

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<sup>131</sup> Clinician 6.

<sup>132</sup> Clinician 12.

<sup>133</sup> Participant 8.

<sup>134</sup> National Cancer Treatment Guidelines were published in January 2020 (URT 2020).

<sup>135</sup> Pharmacist 3.

woman who had very visible signs of breast cancer.<sup>136</sup> However, their ability to do so depended on the type of cancer being identifiable without access to pathology or a CT scan. It is possible that, as observed in research with paediatric cancer patients at Bugando Medical Centre and elsewhere in Africa, patients who present with a visible mass or other visually identifiable symptoms are more likely to be referred to higher tier facilities (Schroeder et al. 2017; Stefan 2015). In contrast, cancers such as leukaemia, which require haemopathology for diagnosis, are likely underdiagnosed in comparison with expectations based on international norms (Schroeder et al. 2017).

There may also be constraints on patients being admitted to ORCI without required documentation showing they have completed all necessary investigations elsewhere. One focus group participant explained that:

*You cannot open a file if the documents are not signed to indicate [prior investigations are complete]... If they are not signed it means there is a problem and a patient requires further investigative procedures... If a patient has been referred by a general practitioner we will have to send them to Muhimbili if we think what has been done is not sufficient, but if there is adequate information you can admit them.*<sup>137</sup>

At Tumbi hospital, one nurse described that once a patient who had taken their cervical biopsy sample for analysis at Muhimbili or Mlonganzila hospitals, they would return to Tumbi to receive the results. If these confirmed the patient had cervical cancer, they would first be referred again to Muhimbili, from where they could be referred again to ORCI.<sup>138</sup>

Even once a patient has been admitted to ORCI, they may be referred out again to have procedures that are not available at ORCI, such as blood tests,<sup>139</sup> and especially for surgery. One clinician explained the challenges associated with not being able to perform surgery within ORCI, noting, ‘sometimes you refer a patient to Muhimbili for an operation and expect them to come back afterwards to continue with other stages of treatment, but the patient doesn’t come back after the operation. So this is a problem.’<sup>140</sup>

### 3.7 Palliative care

As noted above, challenges linked to late diagnosis of cancer in Tanzania mean that curative interventions may often not be possible and palliative care is the only way in which patients can be treated. Participants working at national, regional and district levels identified provision of palliation as one of their roles in relation to cancer care. This included both pain relief and mitigating side-effects of radiotherapy, through blood transfusion, for example, and providing oxygen.

It was clear that some research participants took a holistic approach to palliative care, outlining cooperation with spiritual leaders and attempts to help patients in financial distress in order to mitigate ‘social pain’ as well as physical pain (see also Hartwig et al. 2014; Buhl 2018). One

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<sup>136</sup> DMO 3.

<sup>137</sup> ORCI FGD (participant 7).

<sup>138</sup> Tumbi FGD (participant 1).

<sup>139</sup> Clinician 2, 4.

<sup>140</sup> Clinician 5.



participant in the ORCI FGD, for example, when discussing enabling factors and challenges they faced in providing palliative care, explained:

*It depends...if it is social or physical pain. One pain can cause another pain. So we do a holistic assessment and integrate the findings into a plan. So for physical pain we use morphine. For social pain we coordinate with spiritual leaders and they conduct guidance sessions. In certain cases we coordinate with the social worker(s), whereby they then link with the finance department if the issue concerns money... for example if the patient is thinking about costs of tests.<sup>141</sup>*

Their colleague continued, ‘palliative care consists of many caregivers: nurses, psychologists, doctors, religious leaders, social workers and sheikhs. After assessment you will know the area to focus the intervention on.’<sup>142</sup> Several participants also mentioned counselling as an important aspect of palliation. While there were no psychologists employed at ORCI, spiritual leaders played an important role in this.<sup>143</sup> Research from elsewhere in the region highlights the importance of considering therapeutic pluralism in the provision of palliative care (Githaiga 2017, Livingstone 2012; Mulemi 2020). One study of palliative care provided to paediatric cancer patients at Bugando Medical Centre, a zonal hospital in Tanzania’s Lake Zone, identifies several ‘intangible’ resources that staff could draw on in enhancing palliation, including their strong personal faith, which can be a source of comfort for patients and for the healthcare professional working in very difficult conditions (Esmaili et al. 2018).

However, health professionals often reported their ability to provide effective relief of *physical* pain to patients was limited. As a controlled substance, morphine is heavily regulated in Tanzania and internationally. The Medical Stores Department (MSD), a government body that conducts procurement for all public hospitals in Tanzania is the only institution permitted to import morphine powder to Tanzania. ORCI and two of the four zonal hospitals, Bugando Medical Centre and Mbeya Regional Referral Hospital, which carry out some cancer treatment (Magubira 2019a), are permitted to purchase morphine to compound directly from MSD. Other public and private facilities require a permit issued by the Tanzania Medicine and Medical Devices Authority (TMDA) in order to procure morphine from ORCI. Permits must be renewed annually (United Republic of Tanzania 2011). To obtain a permit facilities are required to estimate their likely annual use, which might be challenging to do and may also lead to difficulties in justifying any increase in demand. As one RMO described ‘they [district and regional hospitals] must be under very keen care as morphine is a narcotic medicine. Therefore it can’t just be left for anyone to prescribe because it might be used for another purpose.’<sup>144</sup> Facilities located a long distance from ORCI are required to collect morphine from Dar es Salaam, which has cost implications that are reflected in the price charged to patients (Magubira 2019a; 2019b).

At the time this research was carried out morphine was reportedly either not available at the regional hospitals included in the study or was irregularly available. The process of obtaining morphine was described as ‘very difficult’ by one pharmacist, who also noted challenges with storing the drug, and the requirements that must be met before it could be prescribed to a patient.<sup>145</sup> At Tumbi Regional Hospital, for example, supplies of morphine had run out and the

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<sup>141</sup> ORCI FGD (participant 7).

<sup>142</sup> ORCI FGD (participant 4).

<sup>143</sup> ORCI FGD (participant 9).

<sup>144</sup> RMO 2.

<sup>145</sup> Pharmacist 4.

hospital did not have at present have a permit in place to order more from ORCI.<sup>146</sup> This meant patients had to be referred to ORCI to receive morphine, or that their relatives would need to travel to collect the drug. One clinician noted that while it would be preferable to have morphine available at Tumbi, ‘there are some drugs that are not allowed to be here’, meaning only ‘normal’ painkillers such as pethidine, tramadol and paracetamol were available.<sup>147</sup> Prescription of paracetamol for cancer pain was mentioned by several participants at lower tiers of the health system, who did not have access to more appropriate pain relief. These findings are consistent with research conducted with staff treating paediatric cancer at Bugando Medical Centre, who similarly indicated challenges in accessing morphine which meant that most staff reported use of paracetamol or diclofenac for pain-relief in terminal patients (Esmaili et al. 2018). Within the private sector, at Aga Khan Hospital, an oncologist also reported it was difficult to procure morphine.

Although it is difficult to infer from this data, research from Tanzania and elsewhere in East and Southern Africa suggests there are other reasons why morphine might not be prescribed even when it is available. Firstly, the challenges linked to human resources discussed above also affect provision of palliative care. The dedicated palliative care team at ORCI, for example, face a very high patient load, which impacts on the care provided (Buhl 2018). Patients at Muhimbili’s paediatric oncology ward reported difficulties in accessing pain relief due to staff shortages (Kohi et al. 2019) and the absence of a dedicated palliative care team at Bugando is discussed by Esmaili et al. (2018). It is also possible that ‘opiophobia’, referring to health professionals’ fear that prescribing opioids will lead to addiction, plays a role in reducing prescription of morphine. Participants in the ORCI FGD also highlighted lack of training in provision of palliative care as an issue, noting that most newer nurses had not had any training in palliative care, and suggesting it should be incorporated in the curriculum at MUHAS.<sup>148</sup>

When morphine was available outside of ORCI patients were charged for it.<sup>149</sup> The cost of morphine was not reported by our participants to be a significant impediment to access,<sup>150</sup> however, evidence from elsewhere in Tanzania suggests costs can cause patients at the end of life to be withdrawn from hospital and access to palliation. Esmaili et al. (2018) identify the cost of morphine and other medicine as well as other costs associated with hospitalisation as a major impediment to paediatric cancer patients at Bugando Medical Centre continuing to receive treatment. The post-mortem fees that would be incurred should a patient die while in hospital were another significant reason why terminal patients were withdrawn from care.

Research elsewhere in the region also illustrates the importance of cultural and social context in shaping attitudes to pain and its relief (Githaiga 2017, Livingstone 2012; Mulemi 2020). Esmaili et al. (2018), for example, report that dying patients on the paediatric cancer ward at Bugando Medical Centre were stigmatised and received less regular care from nursing staff. Other challenges included likely under-reporting of pain by patients, which reduced recognition of pain by staff. Preferences to not disclose poor prognosis to patients at ORCI and patients’ lack of knowledge about what palliative provision is available may also affect how end of life care is provided and how patients experience palliative care (Buhl 2018; see also Mulemi 2013 on Kenya).

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<sup>146</sup> Tumbi FGD (participant 1).

<sup>147</sup> Clinician 7.

<sup>148</sup> ORCI FGD (participants 1, 4).

<sup>149</sup> Pharmacist 4; Tumbi FGD (participant 1).

<sup>150</sup> Tumbi FGD (participant 1).

## 4. Conclusion

The findings explored in this paper identify some enablers of cancer care provision in Tanzania, but also some significant challenges facing healthcare professionals. Participants welcomed increased funding for purchase of medicines and investment in technologies for cancer treatment. Vaccination and screening programmes at lower tiers of the health system have the potential to reduce the proportion of patients who present for cancer treatment at late stages of the disease. However, the costs associated with accessing treatment, limited diagnostic capacity at lower tiers, and shortages of skilled personnel, including nurses and pathologists, continue to contribute to high rates of late presentation and can cause patients to abandon treatment. The high proportion of patients who access specialised cancer treatment when their disease is very advanced, means that there is huge demand for palliative care, of which pain management is an important component. There are a range of obstacles to provision of effective pain relief, including regulation of morphine.

There have been some positive developments that have contributed to overall improvement of cancer care in the country, notably by increasing the health budget very substantially since 2016. A large element of the new funding has gone towards improvements and building of facilities, as well as improved medication supplies that have increased access to medication by about 80% according to medical professionals interviewed. There is high political will to improve health care services in the country as they relate to cancer, most evidently with establishment of cancer facilities in zonal and regional hospitals. Use of the prime vendor system has reduced stock-outs, though instances of stock-remain that have proven financially burdensome for patients who have to pay out of pocket to purchase some medication, notably including pain management.

Success in diagnosis is greater in higher tier facilities than in lower tier facilities, as demonstrate in the preceding report on accessing cancer care treatment (Makene et, 2020). Some lower tier facilities have been able to screen for potential cancer symptoms and provided referrals to higher tier facilities for further processes. There is an opportunity to do more to enhance screening services and some procedures such as the cryotherapy and loop electrosurgical excision procedures (LEEP) at regional level and other cancer screening services at lower tier facilities.

Prevention programmes have been helpful in creating awareness and rallying the population to screen for cancer where services are available. However there is an issue of sustainability and lack of awareness on cancer screening, more so diagnostic services are not readily available. Here lies the opportunity for policy actor to continue to address preventative measures, training of staff in general and ensuring sustainability of the various outreach programmes designed to provide services in the long term. It is also imperative to broaden early screening coverage which would invariably save lives and lower the cost burdens on individuals. Funding in the days ahead, after the building of facilities and their rehabilitation, could be geared more towards ensuring availability of skilled staff and availability of diagnostic technologies.

Cost of cancer treatment has been challenge. As noted by the professionals and by patients in the report by Makene et al. (2020), free treatment policy has exempted patients suffering from certain chronic illnesses including cancer after the point of diagnosis. The policy has been instrumental in allowing people to access advanced treatment services at the national specialised hospitals and national referral hospital. The policy has helped mitigate some of the costs that would have been otherwise have been unmanageable, especially for lower income earners. Yet, there is still significant cost incurred by patient pre and post diagnosis; as illustrated in the discussion in the preceding section, this calls for implementation of the universal health care as advocated for in the Sustainable Development Goals (SDGs).

It is also imperative to enhance coverage by addressing the shortage of general doctors and specialists, such as oncologists and pathologists. This would go a long way, as cancer patients will increase substantially. Enhancing training of human resources at lower facilities would enhance visibility of cancer care. With improvements in human and technical resources, as well as improvement in the referral system it is envisioned to health the case for cancer in the country. Exploration of low cost technological solutions for screen, treatment and care should be heart at redressing shorting comings in the cancer care provision in the country.

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