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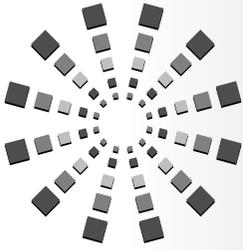
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# Concerns and Needs of Support Among Guardians of Children on Cancer Treatment in Dar es Salaam: A Qualitative Study

## KEY WORDS

Concerns  
 Guardians  
 Needs  
 Pediatric cancer  
 Tanzania

**Background:** Cancer in children in Tanzania is a concerning health issue, yet there is a shortage of information about the experiences of the guardians of children who receive cancer treatment. **Objective:** To explore concerns and needs of support among guardians of children on cancer treatment in Dar es Salaam, Tanzania. **Method:** Using a qualitative design, 3 focus group discussions were held with 22 guardians of children aged 9 to 17 years. Guardians were recruited from Muhimbili National Hospital, Dar es Salaam, where their children were receiving cancer treatment. Data were analyzed using thematic content analysis. **Results:** Guardians experienced several issues during the initial stages of their child's cancer treatment, including the process of seeking a diagnosis, and experiences with care at the peripheral (regional) hospitals and national hospital. They also shared what they felt would lessen their difficult experiences. Seven themes emerged in this study: financial concerns, emotional concerns, barriers to cancer care, need for improved cancer care, need for information, need for tangible support, and gratitude and hope. **Conclusion:** Guardians of children with cancer experience challenges during initial stages when seeking a diagnosis and have concerns and needs related to cancer care and treatment. **Implications for practice:** Improvements are needed regarding care at regional hospitals, the cancer diagnosis, and the recognition of early signs of cancer and quick referral to diagnostic centers, compassionate caring behaviors by healthcare workers, budgetary support from the government to meet the medication supply demands, and meeting stakeholders' support needs.

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Childhood cancer is the second leading cause of mortality among children between 1 and 14 years old in high-income countries.<sup>1,2</sup> Unfortunately, such data are unavailable for Sub-Saharan Africa.<sup>3</sup> The World Health Organization estimates the overall incidence of childhood cancers to be approximately 300 000 children per year.<sup>4</sup> The burden of cancer-related morbidity and mortality disproportionately occurs in low- or middle-income countries, where the resources to provide diagnosis, treatment, and care are minimal. As a result, more than 90% of children in Africa who develop cancer die without access to adequate treatment, compared with an 80% survival rate for children in high-income countries.<sup>4-6</sup> The poor survival rate in African countries is due to numerous factors including poverty<sup>7,8</sup>; competing health priorities<sup>9</sup>; poor cancer diagnostic capacity<sup>10</sup>; inability to recognize signs and symptoms, thus leading to no or delayed referral to a tertiary facility<sup>11</sup>; and insufficient access to diagnostic and treatment facilities.<sup>7</sup>

Substantial improvements for cancer diagnosis and treatment have been made in Tanzania over the last decade.<sup>12</sup> Currently, services are available in 5 hospitals; 2 offer pathological diagnostics and a combination of radiotherapy and chemotherapy; 1 offers pathological diagnostics and chemotherapy; 1 offers only pathological diagnostics; and 1, Muhimbili National Hospital (MNH) in Dar es Salaam, offers a comprehensive pediatric cancer treatment.<sup>12-14</sup> Muhimbili National Hospital also offers a program of supportive care “Tumaini la Maisha” (*Their Lives Matter*) to children with cancer and their parents/guardians (from here referred to as guardians). The program includes financial support for medication and food as well as in-hospital education and play therapy for children.<sup>15</sup> However, challenges regarding care and treatment of childhood cancer remain in Tanzania. These include a progressive increase in the number of cancer patients, late presentation at the diagnostic centers, and underfunding of care and treatment.<sup>13,16</sup> Muhimbili National Hospital yearly provides care and treatment to more than 500 children with cancer.<sup>6</sup> There are no data about in which stage of the disease these children are diagnosed; however, among adult cancer patients, approximately 80% of patients reach the hospital when the disease has reached stage III or IV.<sup>17,18</sup>

Treatment of childhood cancer involves painful procedures including invasive diagnostic procedures, radiation therapy, chemotherapy, surgery, blood draws, and bone marrow aspirations.<sup>19,20</sup> Additionally, treatment may cause a decline in immunity, fatigue, hair loss, nausea, pain, and symptoms of depression. Seeing the child suffer is stressful for guardians, who report impaired functioning and health during diagnosis and the initial phases of treatment<sup>21-23</sup> and short- and/or long-term emotional distress.<sup>22,24</sup> Guardians report anxiety, depression, fear, guilt, insecurity, role shifting, and stress, as well as disruption of family relationships, financial difficulties, and loss of recreation and social outings.<sup>21,23</sup> Factors such as acceptance, emotional and instrumental support from extended family members, family cohesion, flexible adaptation to stress, and open communication can facilitate parents’ and siblings’ adaptation.<sup>22,23,25</sup> Available knowledge about the consequences of childhood cancer for guardians is based on findings from studies conducted in Asia, Europe, and North America and may not apply to the African context.<sup>8,26</sup>

Guardians of children diagnosed with cancer in low-income countries may experience concerns and needs such as financial burden, limited availability of diagnostic centers, and an inadequate infrastructure of health facilities.<sup>6</sup> The few studies that have examined experiences of guardians of children with cancer in Malawi and South Africa found that guardians report needs for information, emotional support, psychosocial support, practical support, spiritual support, financial support, and physical support.<sup>27-29</sup> A study from Kenya concluded that guardians of children with cancer reported shock, anxiety, fatigue, and anger.<sup>30</sup> Taken together, the findings indicate that there are unmet needs of care and support among guardians of children diagnosed with cancer in low-income countries, including African countries. The purpose of this study was to explore cancer-related concerns and needs of care and support among Tanzanian guardians of children on cancer treatment.

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## ■ Methods

### Participants and Design

Three focus group discussions (FGDs) were held, 1 with male guardians (MG1) and 2 with female guardians (FG1 and FG2). In the Tanzanian context, guardians include parents, grandparents, uncles, and aunts or other persons who live with and provide care for a child.<sup>31,32</sup> Guardians were recruited at MNH where they stayed with their children while receiving treatment. Some of them, particularly those who did not have a home in Dar es Salaam, were hosted by the hospital at Tumaini la Maisha Ujasiri house.<sup>15</sup> Muhimbili National Hospital has the capacity to provide care and treatment to approximately 50 children at the same time.<sup>6</sup>

The inclusion criteria were being a guardian of a child receiving cancer treatment at MNH, able to speak Kiswahili, and willing to participate in a 1-hour FGD when approached. Thirty-six guardians (22 women and 14 men) were present with their child at MNH during the study period. Sixteen women were invited to participate; 15 agreed. Fourteen men were invited to participate; 7 agreed. Reasons for declining participation included conflicting interview schedules with physicians’ appointment time and not wanting to leave their children who were on chemotherapy. Gender-specific FGDs were conducted to allow freedom during discussions if gender-specific issues would arise and to allow freedom of expression for women because of patriarchal structures in Tanzanian society.

### Procedure and Data Collection

An interview guide was developed by the research team and piloted with 5 guardians before the study started. Data from these interviews were not included in the results presented below. The interview guide was modified based on initial feedback, and the final version includes 7 questions as shown in the Table. Ethical approval was obtained from the National Institute of Medical Research in Tanzania, and permission to conduct the study was granted by the MNH (ref. MNH/TRC/2015/630). Data collection started in September 2015. Participants were fully



**Table • Interview Guide Questions**

1. Please tell us what happened to you from the time you began following up for cancer treatment of your child until now.
2. Were you bothered of anything because your child has cancer? Please tell us more about that.
3. Has your child's cancer disease affected your life? If so, how? Can you talk more about that?
4. Do you think the hospital or hospital staff were/are in the position to do anything to help you? What could they do?
5. Could anyone outside the hospital do anything to help you? Who? What could they do?
6. Do you think the hospital staff could do anything to help your child? If so, what could they do?
7. Could anyone outside the hospital do anything to help your child? If so, what could they do?

informed about the aims of the study and the voluntary nature of their participation. All participants provided written consent and demographic data including their child's diagnosis and stage of cancer. Those who could not read and write received oral information and signed by thumb printing. Focus group discussions were held in a comfortable room at MNH, which allowed all participants to be seated in a circle. A moderator led the FGDs, and an observer took notes during discussions. Focus group discussions lasted approximately 60 minutes, were conducted in Kiswahili, and were audio recorded.

## Data Analysis

The audio recordings were first transcribed verbatim in Kiswahili and then translated to English by an experienced translator who was fluent in English and Kiswahili. English transcripts were reviewed by the authors G.M.M. and T.W.K. (both fluent in English and Kiswahili) against the audio recordings. Participants' demographic data are reported with descriptive statistics. Data from FGDs were analyzed using thematic content analysis<sup>33,34</sup> whereby the entire transcribed text was read and reread, with notes made in the margins of transcripts to identify initial codes. The codes were reviewed, and highly similar codes were combined. Thereafter, codes were grouped in themes. Finally, the transcripts were reread, and codes were relabeled and/or regrouped if necessary.<sup>34</sup> The analysis was done by coauthors J.S.D. and T.W.K. and confirmed by the other coauthors.

## ■ Results

### Participants

Participants' mean age was 38 (SD, 10) years, and they had a mean of 5 (SD, 3) children. They lived 20 to 1300 km from MNH. Most had completed standard 7 classes (n = 13), 6 were illiterate, and most were farmers (n = 16). Their children were 3 to 12 years and were diagnosed with various types of cancer including leukemia (n = 5), eye cancer (n = 5), cancer of the glands (n = 5), kidney cancer (n = 2), and 1 each of stomach cancer,

thyroid cancer, and liver cancer. All children were receiving chemotherapy at study start, with 2 children scheduled for surgery.

## Identified Themes Around Concerns and Needs of Care

Guardians had experienced several concerns and needs, and these were categorized as financial concerns, emotional concerns, barriers to cancer care, need for improved cancer care, need for information, need for tangible support, and gratitude and hope.

### FINANCIAL CONCERNS

Several financial concerns were reported, these were linked to multiple hospital appointments or admissions and traveling long distances to MNH in Dar es Salaam for confirmatory diagnosis, care, and treatment, forcing guardians to leave their economical engagements and other children unattended. Concerns regarding lack of diagnostic centers and cancer experts in the home regions were expressed. These circumstances resulted in repeated hospital admissions because of a misdiagnosis or incorrect treatments, which caused delays in diagnosis and contributed to cancer progression. Elevated costs of care also resulted. A female guardian mentioned:

They did not discover what kind of disease it was, until I came to this hospital, they discovered blood cancer. However, I had already spent a lot of money, and they were injecting my child, even though they didn't know what disease he had. (FG1 #2).

Another female guardian said:

You go to the first hospital, but you are told to go to another hospital... We went around to 5 hospitals. The last one told us to come to Muhimbili. Then you find that the disease spreads simply because of the cycle of referrals and a lot of money spent to pay for the tests. (FG1 #5)

The financial burden had a significant impact on the lives of guardians and their families, and some families had to trade off their belongings to afford the cost of caring for their children. A male guardian expressed how deeply his child's cancer had impacted him and his family financially: "I had to put my plot on sale as a resource. Thinking about fares and those whom I have left at home, I sold the land, so I could manage the costs" (MG1 #4).

### EMOTIONAL CONCERNS

Guardians expressed negative feelings and self-blame about the child's diagnosis. Some believed that cancer was genetically transmitted, leading them to think that one or both parents may have passed it on to the child. That guilt caused emotional stress. They also reported being afraid of having cancer themselves and fearing for their own and their child's survival. For instance, a woman said:

I was stressed very much when they said the child has cancer. I asked myself many questions, ...where has the child got cancer? One doctor told me, it is familial, someone, perhaps in the past had the disease. So, I thought a lot, and I felt in my mind I had cancer. I heard, cancer people do not survive, so I suffered a lot. (FG1 #2)

Guardians also mentioned that healthcare workers did not attend appropriately to the children's needs and expressed a need for compassionate and high-quality care, including a supportive environment: "Doctors and nurses should be quicker in responding to children ...my son had completed the drugs received through the drip, but she was playing on her phone" (MG1 #7) and "... for those scheduled for night duty, they should not sleep as they should care for the children whose conditions change at night, including fever" (MG1 #2).

## BARRIERS TO CANCER CARE

Some guardians expressed concerns about long waiting time for diagnostic results and the fact that some of the tests done in their hometowns had to be redone at MNH. Some of the necessary examinations were not available at MNH and had to be done outside the facility. Guardians expressed that it would be timesaving and less costly if diagnostic tests done in their hometowns were used to inform treatment. One male guardian said:

I came from the region, already felt that the child had cancer, but as I arrived here, they started investigations afresh from February to May... until then we were struggling to get results. We spent long time, and we have spent a lot of money to pay for the tests. ...if they could have started the medications directly we could have finished these [diagnostic] rounds, and now we could be in the rounds to take medicines. (MG1 #2)

Appreciation and concerns regarding living conditions at the hospital were mentioned. Both men and women particularly those hosted at Tumaini la Maisha-Ujasiri house declared that healthcare staff at the hospital, and some others helped them to get food, housing, clothes, washing materials, and medicines for themselves and their children. One woman said:

We are helped; we get free food, porridge in the morning and lunch; we are given clothes for women and children; we are given sugar and many other things. Since I came here I have never bought soap, toothpaste; I never buy a toothbrush; I just buy food that I need because here we get porridge. We are given drugs we do not pay; we really thank God, because cancer treatment is costly, but all these are served free. (FG2 #5)

However, a few men mentioned the issue of safety and respect in the environment where they were living, particularly on the wards. One man said:

While there are women and men present, the environment is not very safe. They could set wards for men, and for women, it will be safe and respectful. Small wards could be added here, even 2 or 3 rooms.... (MG1 #6)

## NEED FOR IMPROVED CANCER CARE

Guardians suggested some improvements to the healthcare system including the need for more funds from the government to support cancer treatment supplies and medications. They also stated a need for local cancer care centers and experts in their hometowns, saying:

The government should increase the number of [cancer] professionals in the regional hospitals. They should be at least 3 or 4; they would help us," (MG1 #6).

Additionally, guardians expressed a need for educational opportunities for their children while at the hospital. A male guardian suggested:

Our children who are being treated here also need education according to their class levels, like those who are at schools. If the government would secure many cancer experts, our children would receive treatments and continue with education in our hometowns. (MG1)

## NEED FOR INFORMATION

Guardians were concerned that healthcare workers at the hospital where their children were receiving care and treatment communicated poorly about the disease. Participants explained that the medications for cancer are associated with many adverse effects; however, healthcare workers did not have a culture of providing information to guardians about what adverse effects to expect when the child received medications. That situation left guardians feeling uncertain about knowing what to do for their children when the adverse effects started to manifest. One male guardian said:

When we take care of the children, they may faint because of the medicines. So, if you tell the doctor, he has nothing to tell you because he has already given the dose. So, you are wondering between the patients, a nurse, and yourself not knowing what to do. (MG1 #6)

Lack of proper information about cancer, its occurrence, diagnostic processes, and treatments emerged in the discussions. Guardians expressed the need for community education around cancer, particularly related to a lack of knowledge of causes and signs of cancer, especially in rural areas. A female guardian stated that:

We don't know how this disease started because we saw the child started to be sick, we knew that was a boil. Begins as a boil and then ended in treatment. (FG1 #5)

## NEED FOR TANGIBLE SUPPORT

Guardians expressed needs for tangible support from extended family members, community, healthcare workers, and institutions. One of the important support needs identified by the guardians was provision of care for the children left at home. A female guardian stated:

I felt very bad because I left home a long time ago. I have left my grandchild and my other children who are sick too. But I am caring for this grandchild (at the hospital), but I do not know when I will be home. (FG2 #5)

Guardians expressed the need to generate an income while at the hospital. A female guardian said, "I wish someone can help me get a job so that I can get food to help my child" (FG1 #4). One male guardian mentioned that their stay at the hospital for many months without production was challenging; he suggested alternative ways to being productive to reduce the financial burden due to cancer treatment:

...the government could form groups, and we could join and work based on our skills. The groups could be provided with marketplaces. A group of carpenters produces beautiful furniture and sells them. One percentage comes here another goes to the government... now we ask the government to help us. (MG1 #6)

Guardians also expressed the need for emotional, spiritual, and material support from the community. They were thankful that the community and faith-based institutions were supportive to them; however, they felt that because of the long-term nature of treatment, the community or institutions often could not sustain the support. A female guardian suggested: "The communities can help us by donating blood, but also clothing, and food like flour, sugar, cooking oil, etc" (FG2 #5). A male guardian expressed the challenges with long-term support:

Churches and mosques helped, but it will reach a point they might be unable to help anymore. ...the first time they assisted and was glad to help, but not all the time of treatment, because treatment takes 3 to 4 years. (MG1 #4)

## GRATITUDE AND HOPE

While guardians expressed concerns and needs in most of their discussions, a theme regarding gratitude and hope also emerged. Guardians expressed that faith in God had strengthened them to go through the painful experiences associated with caring for their children with cancer. One female guardian said, "It is very painful to me, but I left it in the hands of God, because now the situation is different from the beginning. Now he is getting well, I thank God" (FG2 #5). Guardians also expressed thankfulness to God for improvement in their children's conditions:

I asked them [some cargo workers] to help my son by going there to donate blood. Some accepted, but others did not accept, but all I had is to thank God, as well as the communities." (FG2 #2)

I thanked God after they gave me a referral to this hospital with a hospital ambulance 2 months ago. ... [Recently] they tested and said to me the disease has been greatly reduced." (FG1 #2)

Guardians expressed gratefulness for emotional support (encouragement), transport to MNH, and treatment provided by healthcare workers and hospitals in their regions. One female guardian said, "...I was not able to go to Muhimbili. I was told, as you were transferred from that health center, we will join hands [help you] to transfer you to Muhimbili" (MG1 #1). Guardians also expressed thankfulness for receiving care and support from the staff at MNH. A female guardian said, "...I thank our doctors and nurses for supporting us well, I am very grateful" (FG2 #3).

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## ■ Discussion

To the best of our knowledge, this study is the first to explore cancer-related concerns and needs of care and support among guardians of children receiving cancer treatment in Tanzania.

Guardians expressed financial burden, emotional concerns, barriers to cancer care, need for improved cancer care, need for information, need for tangible support, and gratitude and hope.

The guardians expressed many concerns related to financial burden. Lack of diagnostic centers and experts in cancer care in the regional hospitals resulted in multiple hospital visits and long travels to Dar es Salaam often involving many expenses. While similar concerns have been shown for the population in other studies around the world,<sup>35,36</sup> the financial burden experienced by guardians in this population may have been aggravated by low and unstable incomes as well as lack of health insurance coverage for most rural families, which could have reduced the initial costs at the regional hospitals.<sup>37</sup> Revitalization and expansion of affordable health insurance to rural families may help to reduce the burden of healthcare costs including costs for preliminary hospital visits at regional hospitals.

Emotional concerns were expressed and have previously been reported by parents of children diagnosed with cancer.<sup>21,23</sup> However, guilt of carrying the disease to the child and fear of oneself being diagnosed with cancer found in this study are novel findings that may occur due to guardians' insufficient knowledge of the disease due to poor communication between healthcare workers and guardians. Guardians mentioned lack of communication as a concern.

Barriers to cancer care, including long waiting times due to unavailability of some diagnostic tests at MNH and lack of accommodation for some guardians at the child oncology unit, were mentioned and represent structural barriers to quality child cancer care. Guardians perceived these barriers as the primary cause of delays in initiating cancer treatment, costs, and lack of safety and respect. The barriers may at least partially be caused by the low allocation percentage of the national budgets for cancer care and treatment.<sup>13</sup> Overall, the barriers and the slow progress in addressing them due to lack of adequate resources are the same in many African countries.<sup>6,13,30,38</sup> However, programs such as "Tumaini la Maisha"<sup>15</sup> help lessen the burden of cancer care for guardians, improve access to treatment and supportive care, and may ultimately improve cancer survival.<sup>15,39</sup>

While information is viewed as key to keeping guardians aware of their children's state of cancer and treatment progress, lack of information is frequently reported as one of the barriers to guardians' satisfaction with care.<sup>40,41</sup> Guardians in this study mentioned that poor communication about the disease's adverse effects and treatments left them uncertain about their child's progress and caused difficulties in helping their children when adverse effects occurred. Poor communication has also been reported in studies from Sweden and Malawi related to needs of guardians to speak with healthcare workers and receive information about their child's cancer condition and treatment,<sup>41</sup> as well as the time the treatment will take.<sup>27</sup>

One of the main challenges identified in this study was poor knowledge among guardians related to causes of cancer, its early signs, and treatment process. As reported in other studies conducted in Africa, guardians' failure to recognize early cancer signs in their children causes delays in seeking healthcare services, which in turn reduces cancer survival among children.<sup>42</sup> This finding highlights the importance of strengthening guardians'

awareness about causes of cancer, early signs, and prevention. This could, for example, be done via community programs.

Needs for tangible support expressed by guardians in this study were also found in a study from Malawi.<sup>27</sup> Guardians in Malawi expressed needs of financial support to cover costs for transportation, medication, and food.<sup>27</sup> Financial challenges during cancer care and treatment to cover costs for food, clothes, water, transportation, and hygienic supplies have also been reported by adults on cancer treatment in Tanzania.<sup>43</sup> The finding underscores the importance of financial support to Tanzanian families with children with cancer and providing these families with opportunities to generate an income while away from their homes. Guardians in this study mentioned gratitude and hope in coping with the challenges of caring for their children with cancer including hope and faith in God. This finding agrees with findings from a study from Malawi showing that guardians conducted morning prayers with nurses as well as individually for the well-being of their children.<sup>27</sup> Hope and faith in the context of caring for children with cancer have been found to be associated with better coping and adjustment with cancer diagnosis of the child and therefore as a resource for better collaboration between healthcare workers and guardians in the care of the child.<sup>44</sup> As evidenced by the guardians' gratitude and hope, receiving support for treatment and being provided good care by staff enhance coping and adjustment when treatment is received.<sup>44</sup>

To address the concerns and needs of guardians of Tanzanian children with cancer, it is essential that guardians receive information from healthcare providers about their children's cancer condition and that improvements related to early diagnosis and care provided at the regional hospitals are made. The progressive and substantial improvements by the government through continually adding more cancer centers should continue, while improving care at the regional hospitals where cancer patients start their initial visits should be made. For example, on-job training to improve physicians' ability to recognize early signs of cancer at rural centers and regional hospitals would make a significant impact for children with cancer and their guardians and thereby address their concerns, particularly high cost due to unnecessary repeated hospital visits, incorrect treatments, and delays in referral to cancer center.

## Limitations

Some participants in the FGDs talked very much whereas others were more silent. This circumstance, which is common when FGDs are used,<sup>45,46</sup> may imply that the experiences of the more silent participants are not reported to the same extent as the experiences of those talking more. A respondent validation could have revealed whether this was the case, but this was not done. Participants who were uncomfortable talking in the focus groups may have opened up more in an individual interview. Another limitation is that only guardians who were available at the hospital where the children were receiving care and treatment participated in the study. Thus, the views of guardians who may have failed to reach MNH for treatment, such as those who may be the poorest, are not represented in these findings. Nevertheless, as the first study exploring the concerns and needs of guardians

who are caring for children receiving cancer treatment in Tanzania, it provides novel findings and a solid base for further investigation with the purpose to improve the situation of guardians of children with cancer in Tanzania. This in turn may positively affect the children receiving cancer treatment as well as other family members.

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## Conclusion

In Tanzania, guardians of children who are diagnosed with cancer are confronted with challenges regarding accessing care, receiving a diagnosis and appropriate treatment, emotional concerns, and financial costs. Challenges in accessing care before diagnosis are often linked to poor care at the regional hospitals. Many of the mentioned concerns and needs such as financial concerns, emotional concerns, barriers to cancer care, need for improved cancer care, need for information, and need for tangible support were experienced during the period when the child received treatment. Guardians also mentioned positive aspects such as supportive care from healthcare workers and community and having hope and faith for good progress of their children. The findings indicate that improvements in cancer diagnosis, particularly recognition of early signs of cancer and quick referral to diagnostic centers, as well as compassionate caring by healthcare workers, are needed. In order to reach these goals, more expertise at regional hospitals, more budgetary allocation to meet the medication supply demands, and tangible support from stakeholders could be necessary. Further, community programs focusing on raising awareness of the community on causes of cancer, early signs, and prevention would be beneficial.

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## Availability of Data

Transcripts from the FGDs are accessible through the corresponding author. Researchers interested in further analysis are welcome to contact the corresponding author for access to transcripts upon securing ethics approval by the National Institute of Medical Research, Tanzania.

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