Exploring Cancer Stigma Experienced by Pediatric Cancer Patients and Their Caregivers in Mwanza, Tanzania

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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ABSTRACT

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Abstract

Background: Childhood cancer is grossly underreported and underdiagnosed in Sub Saharan Africa, as only an estimated 57% of childhood cancers are thought to be diagnosed with survival rates often below 20%. The cause of the 60% survival gap between high income countries and low- and middle-income countries in Sub Saharan Africa is multifactorial, but a key factor is the negative beliefs or stigma towards childhood cancer. The research objective of this paper was to explore the types of stigmas faced by pediatric cancer patients and their families to inform interventions that can reduce cancer stigma and increase survival rates of pediatric cancer patients in Tanzania.

Methods: This qualitative study was conducted using structured focus group discussions (FGD) and in-depth interviews (IDI) at Bugando Medical Centre (BMC) in Mwanza, Tanzania. Patients who completed cancer treatment and their caregivers were divided into 4 groups based on their age and asked about their experiences and perceived stigma. Trained interviewers collected recordings of the FGDs and IDIs and then transcribed and translated into English. NVivo12 was used for qualitative data analysis and coding through an inductive and deductive approach. This study received ethical clearance from Institutional Review Boards at Duke University, the National Institute of Medical Research in Tanzania and the Catholic University of Health and Allied Sciences at Bugando Medical Center.

Results: A total of 27 participants were interviewed in this study, 12 patients and 15 caregivers. 8 IDIs and 4 FGDs (with number of participants ranging from 5-6) were conducted. The factors frequently reported in both the FGDs and IDIs were severity of condition, avoidance, financial

discrimination, beliefs about causes of cancer and stigma due to physical changes. These themes were found among all age groups and were experienced by both caregivers and patients.

Conclusions: The results and data gathered from this study showed that cancer stigma is still an issue faced by pediatric cancer patients and their families. It also revealed that, although some aspects of stigma have been described and addressed in the literature through adult stigma studies, there are aspects of stigma for pediatric cancer patients specifically that should be addressed. The data gathered here can be used to develop interventions targeted towards cancer stigma for pediatric populations, to reduce cancer stigma and increase survival rates of pediatric cancer patients in Tanzania. More efforts and strategies are needed to increase community awareness about childhood cancer such as establishing education programs for the public and in schools.

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1. Introduction

Africa is home to 1.2 billion people and has the youngest population of any continent, with the estimated percentage of children under 18 being close to 50% (UNICEF, 2017). Many of these youth face a diverse array of health problems, one of which is the rising prevalence of cancer. However, cancer is still grossly underreported and underdiagnosed in Africa, and only an estimated 57% of childhood cancers are diagnosed (Force et al., 2019). Even when children do get diagnosed, survival rates for children are very low; it is estimated only 20% of children survive cancer in Africa as compared to 80% of children in high-income countries (Gupta et al., 2015). This low survival rate can be in part attributed to delays in being diagnosed, accessing cancer care and the discontinuation of treatment for various reasons.

Several factors can lead to delays in treatment and discontinuing treatment such as lack of knowledge about cancer, cost of cancer care, access to transportation to healthcare facilities, poor coverage of physicians and treatment facilities, high costs of cancer care, and negative beliefs or stigma about cancer (Ngwa et al., 2022) (Ward et al., 2019). Although there is some data on most of these factors, the effect of stigma is contextually specific. Despite evidence that stigma is a concern among children diagnosed with cancer, little research has been done in pediatric populations in Africa (Kohi et al., 2019). This paper seeks to explore the perceived stigma that pediatric cancer patients and their caregivers face from their community. This data will be used to help develop educational tools to raise awareness about pediatric cancer in communities in the Mwanza region of Tanzania to decrease community stigma and encourage families to seek out and continue treatment for cancer.

1.1 Childhood cancer in Tanzania

Tanzania is a country in Africa that is currently classified by the World Bank as a lower-middle income country (*The World by Income and Region*, 2023). In Tanzania, the national poverty line is US $1.30 per day. According to the World Bank, in 2018 more than a quarter of Tanzanians lived in poverty (Swinkels, 2022). As the population of Tanzania grows, following the trend of population growth in Africa, this population is likely to increase. There is also no national health insurance plan in Tanzania and only 32% of Tanzanians have health insurance (Durizzo et al., 2022). This is significant because the average cost of pediatric cancer treatment is US$218, meaning it can send many families into bankruptcy (Saxton et al., 2017). Additionally, there are only five pediatric cancer treatment centers in Tanzania and many of these centers do not include all services needed for diagnosis and treatment. One center is located in Dar es Salaam, one in Kilimanjaro, one in Dodoma and one in Mwanza (Kohi et al., 2019). This also makes it difficult for families to have their children diagnosed or treated. These, as well as other barriers, contribute to a low diagnosis rate for pediatric cancer.

Patients are considered to have pediatric cancer if they were diagnosed with cancer before the age of 18. Although there is no national cancer registry in Tanzania, it is estimated that the current pediatric cancer incidence in Tanzania is 134 cases per million people (Ribeiro et al., 2008). Bugando Medical Center (BMC), which is in Mwanza, provides care for the Lake Zone which includes several regions of Tanzania and has a population of around 18 million people. In the Lake Zone, using the estimated pediatric cancer incidence, the predicted annual incidence of childhood cancer would be 1,089, however BMC sees about 250 patients per year (Schroeder et al., 2018). These cases account for only 20% of the estimated pediatric cancer population in the area (Schroeder et al., 2018). This can reasonably be applied to other regions in the country,

meaning pediatric cancer is grossly underdiagnosed. With such a large gap in diagnoses, it is important to investigate other barriers to care that may be affecting presentation delays.

1.2 Cancer Stigma in Tanzania

One factor that has been brought up in literature as a barrier to care in Tanzania but not studied in-depth is cancer-related stigma in Tanzania. This includes stigma experienced by both adult and pediatric patient populations. Several studies have found that cancer patients experience stigma in Tanzania regarding their diagnosis. One study done in Kilimanjaro among all cancer patients found that "disclosure of a cancer diagnosis was seen as more ominous and stigmatized in the Northern Tanzanian setting… because of patients' awareness of the lack of therapeutic options and their associated loss of hope" (Harris et al., 2003).

Similarly, in another study based in Tanzania, for women with breast cancer "societal stigmatization of cancer led some participants to fear revealing their symptoms to others, contributing to delay in seeking medical care" (Sakafu et al., 2022). Another study amongst female cervical cancer patients in Tanzania also found stigmatization was a barrier to seeking care, where women felt that "once diagnosed with cervical cancer, she would most likely be stigmatized, left by her husband/partner, and isolated" (Bateman et al., 2019). Additionally, some cancers result from HIV or can lead to HIV co-infection. HIV is often also stigmatized, there is an increased risk of cancer in these populations. Having both pediatric cancer and HIV together results in another level of stigma that might arise. Although these studies illustrate stigma faced by cancer patients

is a barrier to care-seeking, most studies on this topic have only been conducted among adults with cancer.

There are a handful of studies that discuss stigma among pediatric cancer populations, but these mention it only briefly. One study done about cancer-related concerns among young people in Tanzania found that "young adults expressed experienced stigmatization," but did not examine this stigmatization further. Another study done about pediatric cancer care specifically highlighted the need for further research to find if "community-based cancer stigma poses barriers" (Schroeder et al., 2021). This lack of information about cancer stigma faced by pediatric populations in Tanzania contributes to a gap in literature about barriers to pediatric cancer care and research in this area may contribute to reducing the underdiagnosis of pediatric cancer.

1.3 How stigma contributes to treatment delays

Stigma and negative beliefs about cancer can affect time to cancer diagnosis and lead to treatment delays. According to the American Psychological Association, stigma is defined as: "the negative social attitude attached to a characteristic of an individual that may be regarded as a mental, physical, or social deficiency… it implies social disapproval and can lead unfairly to discrimination against and exclusion of the individual" (VandenBos, 2007). In the context of cancer, stigma can manifest in several ways including believing the patient did something to deserve cancer, actively avoiding people with cancer because they are uncomfortable or believe cancer is contagious and social isolation (Squiers et al., 2021). These can lead to lower screening rates for cancer, turning to traditional medicine first which delays seeking help at medical facilities or believing cancer is fatalistic and medicine cannot help (Weiss & Ramakrishna, 2006).

One study showed that due to some of these factors, most patients present to health facilities late, with an estimated 50% to 80% of patients presenting with an advanced stage of cancer (Stefan et al., 2017). This leads to negative outcomes as those presenting to medical facilities at later stages tend to have higher mortality outcomes (Orem et al., 2011). Cancer stigma from the community can also lead to patients leaving treatment early and lower medication adherence, further increasing mortality rate (Weiss & Ramakrishna, 2006).

With the rising prevalence of cancer in Africa, and its large population of young people, it is important to understand how stigma can affect treatment seeking among pediatric patients. With this information, interventions to reduce cancer stigma in Africa can be created, targeting negative and false beliefs about cancer, and encouraging children experiencing symptoms to come to a medical facility to be screened for cancer and be diagnosed sooner, stay in treatment, and adhere to their medication. As a result, these interventions will decrease barriers to treatment which will lead to decreased mortality for children facing cancer.

1.4 Study Objectives: Why Explore Childhood Cancer Stigma in Tanzania?

The large disparities in survival rate of pediatric cancer patients in Mwanza, Tanzania as compared to the survival rates in high-income countries, makes it an important topic to study in this location. Additionally, one of the known barriers to treatment in Tanzania is the negative effect of stigma, however this barrier has not been researched extensively in this location, or with pediatric cancer populations. The research objective of this paper is to explore the types of stigmas faced by pediatric cancer patients and their families to inform interventions to reduce cancer stigma and increase survival rates of pediatric cancer patients in Tanzania.

2. Methods

This study was a qualitative study done using structured focus group discussions (FGD) and in-depth interviews (IDI) with participants. These qualitative methods were used to allow participants to share their experiences in a narrative format. It was also helpful for discovering specific aspects of their experience of stigma from the community that would be helpful to target when developing community education and interventions in the future. Participants included individuals previously diagnosed with pediatric cancer and their caregivers. At the time of the FGDs and IDIs, participants who had been diagnosed with pediatric cancer had finished treatment and were in remission. Participants were recruited from a cohort of pediatric cancer patients treated at Bugando Medical Centre in Mwanza, Tanzania and divided into four groups. The first group was patients who were aged younger than 13. The second group was patients ages 13-17 who had completed treatment less than 2 years ago. The third group was patients ages 13-17 who had completed treatment more than 2 years ago. The last group was patients aged 18 and older.

Both FGDs and IDIs were used to elicit different information. FGDs were used to explore commonalities or differences between experiences of participants from different regions. IDIs were used for participants to discuss more sensitive or personal issues such as fertility and romantic relationships. FGDs were used with all groups except the patients and caregivers in the age 13-17 & >2 years off treatment group because there were not enough participants for an FGD. For patients age <13, only caregivers were asked to participate in an FGD because patients under 13 years of age were determined to be too young for the discussion content of cancer diagnosis and treatment.

2.1 Setting

The study took place at Bugando Medical Centre (BMC) in Mwanza, Tanzania. The city of Mwanza is located on the north-western side of Tanzania, on Lake Victoria. It is Tanzania's second largest city, with a population of 3.6 million people (*Census Information*, 2023). BMC is a faith-based tertiary referral hospital for the Lake Zone, which comprises 8 of 31 regions in Tanzania and has a referral population of around 14 million people. It is owned by the Episcopal Conference of the Catholic Bishops of Tanzania and works with Tanzania Ministry of Health and Social Welfare (*Bugando Medical Centre—Mwanza, Tanzania*, 2022). Therefore, almost all the patients treated for pediatric cancer at BMC live in the Lake Zone region, with a few patients traveling from other regions to receive cancer treatment. The Bugando Cancer Centre has an inpatient capacity of 120 beds.

2.2 Participant Recruitment

Participants were recruited from a cohort of pediatric cancer patients who had been treated at Bugando Medical Centre. To recruit participants, first a contact list was compiled of the names of all patients who had been treated for pediatric cancer at Bugando Cancer Centre and had completed treatment. This list included more than 300 names. Information for each patient included their sex, age, diagnosis, region of Mwanza and contact number. Exclusion criteria included if the patient that was still undergoing treatment, had no contact information on file or was deceased.

After all patient information was compiled, patients were grouped by age at time of completion of treatment. The first group was patients who were aged younger than 13. The second group was patients ages 13-17 who had completed treatment less than 2 years ago. The

third group was patients ages 13-17 who had completed treatment more than 2 years ago. The last group was patients aged 18 and older. As these patients were diagnosed with cancer when they were under the age of 18, they are still considered pediatric cancer survivors as they finished treatment before they turned 18. Caregivers' names were listed with their respective child. Patients were divided into these age rankings because of their possible shared experiences of school and personal lives, and so participants would be more comfortable speaking amongst people their own age.

Within age groups participants were then divided by diagnosis type, then age and sex. According to literature about qualitative methods, the number of participants in a focus group may vary, but for a small focus group four to eight participants is suggested (Rabiee, 2004; Wong, 2008). For each overall age group, a preliminary list of 10 names was created using a mixture of patients of each diagnosis type, exact age, and sex. A list of alternates was created using this same procedure. Using a mix of diagnoses, age and sex was done amongst each age group to ensure a range of diverse experiences would be represented during the study. Having an initial list of 10 people for each group was done to ensure that if some participants did not show up on the day of the focus group, there would still be enough patients for a representative sample size.

At the beginning of the week of the FGDs and IDIs, patient care navigators, who work in the pediatric cancer department of Bugando Cancer Centre, called patients according to the contact list and asked if they could come in at the end of the week, either Thursday or Friday. They first called all patients on the preliminary list. If they finished calling patients on the preliminary list but still did not have 10 participants who could participate, they would move on to the alternate list until a group of 10 available participants was identified. Patient care

navigators were the ones to contact the patients because they were able to communicate to patients in Swahili, and many of the patients were already familiar with them as they had met them in the clinic. This was done to make the patients more comfortable with the study. Research was conducted over 4 days, one day for each age group, and patients in each age group and their caregivers came in on the same day. For the participants in the age 18+ group, 3 of the IDIs were conducted before the FGD and 1 was conducted a week afterwards so their IDI would be conducted by an interviewer of the same gender, for privacy reasons. One patient aged 13-17 >2 years from treatment and their caregiver participated in IDIs instead of their age group's FGD because they arrived to the clinic after the FGD had been completed and were therefore scheduled for an IDI the next day.

Table 1: Schedule for FGDs and IDIs

Day	**Schedule**
Day 1	FGD #1 – Caregivers for patients age <13
Day 2	IDI #1, 2, 3 – Patients age 18+ FGD #2 – Patients age 18+
Day 3	FGD #3 – Caregivers for patients aged 13-17, <2 years from treatment FGD #4 – Patients aged 13-17, <2 years from treatment
Day 4	IDI #4 – Caregiver for patient aged 13-17, <2 years from treatment IDI #5 – Patient aged 13-17, <2 years from treatment IDI #6 – Caregiver for patient aged 13-17, >2 years from treatment IDI #7 – Patient aged 13-17, >2 years from treatment IDI #8 – Patient age 18+

2.4 Interview Guide Development

To develop both the FGD and IDI interview guides, a literature review was first conducted about the types of stigmas associated with all types of cancer in all patient populations. In the literature, the types of stigmas experienced by individuals with cancer were found to be the following: personal responsibility, self-stigma, perceived stigma, label avoidance and stigma by association (Carter-Harris & Hall, 2014; Cataldo et al., 2011; Marlow & Wardle, 2014).

One preliminary guide was drafted based on these five types of stigmas and questions were framed in reference to pediatric cancer. Several questions were created to target each type of stigma individuals with cancer face. This preliminary guide was used as a starting point for FGD and IDI guide development. Due to the differences in age and population of each FGD, each FGD had an individual guide. All guides asked questions about each type of stigma in an age-specific context. IDI guides were created by using the FGD guide for that respective age and population but asked follow-up questions that went more in-depth or brought up topics that were more sensitive in nature.

In total, there were 4 FGD guides, one for each FGD group, and 3 IDI guides, one for participants 18+, one for patients aged 13-17 and one for caregivers of patients age 13-17. The guide for patients framed questions as it related to them, while the guide for caregivers framed questions as it related to them or their children. Similarly, amongst each age group, the guides included age-relevant questions. The guides for the younger groups focused more on treatment in grade school, while the guides for the older group focused on relationships, work, and family

plans. For age 18+, the IDI guide included more sensitive questions related to family planning and relationships.

All guides were sent to Dr. Kristin Schroeder, a pediatric oncologist and the primary investigator on the study, to review for content and scope of questions. Guides were also sent to Dr. Erica Sanga, a Tanzanian researcher and interviewer working with the National Institute for Medical Research (NIMR), to review for cultural sensitivity and clarity. Focus group discussion guide and in-depth interview guides were similar, but IDI guides had some questions that were more personal including questions about dating and pregnancy.

Focus group discussion and interview guides were sent to one of two interviewers conducting the FGD or IDI before the study took place. Training and pre-test of the interview guide was done by the data collection team before beginning formal data collection. The interviewer translated the questionnaire into Swahili and looked over the questions for clarity. Backtranslation was not incorporated, and this limitation will be discussed further in the Discussion section. The question guide was reviewed with interviewers before the FGDs and IDIs were conducted in case there were any questions or clarifications were needed.

Focus group discussion guides and in-depth interview guides for caregivers and patients of all age groups are included in the Appendices.

2.4 Procedures

During the focus group discussions and in-depth interviews, audio data was collected by the interviewer using a voice recorder. All FGDs and IDIs were conducted in Swahili. Both interviewers work at the National Institute for Medical Research (NIMR) in Tanzania and were

trained in qualitative research methods, including conducting focus group discussion and interviews.

Both FGDs and IDIs took place in conference rooms on the Bugando Medical Centre campus. Before the discussion or interview took place, each FGD group or IDI participant reviewed consent forms with the interviewer and asked any questions they had. Consent forms were signed before discussions took place. All in depth-interviews took 45 minutes to 2 hours, with an average time of 1 hour. All focus group discussions took 1.5-2 hours.

In the focus group discussions, each participant was given a number that they would repeat before giving their response to a question. This was done to make the process of transcription and translation more straightforward for the interviewer. Interviewers followed the discussion and interview guides most of the time, straying from the guide when it was necessary for more detail or to rephrase a question if the interviewee did not understand. During each FGD, I took observational notes to document the overall flow of conversation. As I am not fluent in Swahili, I mainly documented which questions participants seemed to have a hard time understanding and which participants spoke the most and least.

Lunch and transportation costs were provided for each participant who participated in the study. All study procedures were approved by the ethical review boards at Duke University, Bugando Medical Centre, and the National Institute for Medical Research in Tanzania. All caregivers and participants 18+ provided and signed consent forms and all participants under 18 signed assent forms with their caregivers.

2.5 Analysis

Interviews and discussions were transcribed in Kiswahili and translated into English by a professional from NIMR and cross-checked by Erica Sanga who is fluent in both languages. Then the transcripts were sent to the researcher for analysis. NVivo12 was used for qualitative data analysis and coding (Ltd., 2020). Analysis was done through both an inductive and deductive approach. An inductive codebook was created using the five types of individual stigmas people with pediatric cancer face. As transcripts were coded, emerging themes were added to the codebook, resulting in deductive coding. The final codebook, including inductive and deductive codes is included in the Appendix.

For analysis post-coding, data reduction tables were created to identify common themes amongst FGDs and IDIs. For each common theme identified, a few quotes were used as examples for the results. A coding report was also extracted through NVivo for all FGDs and IDIs to identify frequency of themes.

3. Results

3.1 Summary Demographics

Data collection occurred between July 14th- 22nd, 2022. In total, 8 IDIs and 4 FGDs (with number of participants ranging from 5-6) were conducted (see Table 2). For every patient age 13-17, their caregiver also participated in the study and there was one caregiver of a patient age 13-17 that had a child that did not participate. Only 4 participants in the age 18+ group participated in both an FGD and an IDI, all other participants either participated in either an FGD or an IDI.

Among the caregivers, there were 6 females and 9 males. Among the patients, there were 8 females and 11 males. Most participants lived in rural regions, 12 total, while 8 lived in urban regions. There was also an even distribution of liquid versus solid cancers. Liquid cancer is comprised of Hodgkin lymphoma, non-Hodgkin lymphoma or leukemia. Solid cancers include sarcomas and carcinomas. Among patients, 8 had liquid tumors while 12 had solid tumors. The significance of this is solid tumors may be visible to people, while liquid tumors are often not visible.

Table 2: Demographics from four FGDs

Patient Age Group	**FGD #1: Caregivers for patients age <13**	**FGD #2: Patients age 18+**	**FGD #3: Caregivers for patients age 13-17 <2 years from treatment**	**FGD #4: Patients age13-17, <2 years from treatment**
Number of Participants				
Patients	0	5	0	5
Caregivers	7	0	6	0
Gender of Participant				

Female	4	1	2	2
Male	3	4	4	2
Type of Cancer				
Liquid	3	1	3	3
Solid	4	4	4	4
Region				
Rural	5	0	5	5
Urban	2	5	1	1

Table 3: Demographics from eight IDIs

Patient Age Group	**Patient age 13-17, <2 years from treatment (IDI #4, 5)**	**Patient age 13-17, >2 years from treatment (IDI #6, 7)**	**Patient age 18+ (IDI #1, 2, 3, 8)**	**Total**
Number of Participants				
Patients	1	1	5	7
Caregivers	1	1	0	2
Gender of Patients				
Female	1	0	1	2
Male	0	1	4	5
Gender of Caregiver				
Female	0	0	0	0
Male	1	1	0	2
Type of Cancer				

Liquid	1	1	1	3
Solid	0	0	4	4
Region				
Rural	1	1	0	2
Urban	0	0	5	5

3.2 Overview of Results and the Identified Themes

Six themes were identified in the study as follows: 1) Severity of Condition 2) Avoidance 3) Financial Discrimination 4) Beliefs about Causes of Cancer 5) Stigma due to Physical Changes 6) In the focus groups and in-depth interviews, several key themes emerged. Some themes were mentioned only within either the FDG or IDI, and some were mentioned in one age group while others were mentioned in multiple age groups. There were also differences in the themes that caregivers focused on versus the themes that the patients themselves focused on.

3.3 Severity of Condition

One aspect of stigma that was experienced by all age groups and brought up in every FGD and several IDIs was the aspect of cancer severity. In the literature, this refers to the degree to which others perceive the patient's symptom burden or severity. In almost all cases where this was mentioned, participants reported that others, including relatives, believed that cancer was incurable and once a patient had cancer there was no treatment available and they would die.

In the FGD with caregivers of cancer patients age <13, one parent said: "Many rushed to tell me that he won't get cured, that cancer doesn't get better, that have you ever seen someone with cancer get healed? Even relatives gave up, not willing to assist me." Other parents also had

similar experiences, with much of the cancer stigma coming from other family members. One mother in the FGD said her child's father did not believe cancer could be cured: "When my child was diagnosed with cancer even her father ran away leaving me at Bugando. He claimed that someone with cancer cannot be cured, so he left."

This theme also arose in the other FGDs. In the FGD with patients age 18+, one participant said others in their community had "…wrong beliefs, someone believes… if you are diagnosed with cancer you will die." In the FGD with patients age 13-17, many patients heard these beliefs from their neighbors. One patient reported:

> *"When I was from Bugando to home, most of them did not believe that I have been cured, as they were looking and me and asking each other if am the real child who was brought to hospital with that situation, they thought I would die till when they saw me yesterday returning home with fine health, so they were only wondering."*

Similarly, in the FGD with caregivers of patients age 13-17, multiple caregivers mentioned this stigma being perpetuated by family members. One caregiver said:

> *"I also went through a tough time because even the father of the child when he heard that the child has cancer he discouraged me. He said that this child will not get better this disease is not curable, I said it is curable we are trained at the hospital and we are told if we go for the treatment the disease is curable. He said now do you have properties to sell so that you can take him/her to Bugando for treatment? Seeing that he does not believe me that the disease is curable I had to take trouble and ask for help so that my child get the treatment."*

Although there was a mention of cancer severity in each of the focus groups, one aspect that differed between the FGDs with patients versus caregivers is that patients often mentioned they heard this type of stigma from their neighbors or other community members while caregivers

more often mentioned they heard this type of stigma from relatives or the other parent of their child.

Severity of a cancer diagnosis as a type of stigma was also brought up in a few IDIs in different age groups and with caregivers and patients. In both IDIs with caregivers of patients age 13-17, this type of stigma was mentioned, with one caregiver saying: “Many people did not believe and most are saying this child was not suffering from cancer, because they say if it could be cancer she would not be able to return cured.” The other caregiver echoed a similar sentiment, bringing up that: “I have been hearing, people were talking, saying that cancer cannot be cured. That it is known that there are diseases that cannot be cured... cancer is one of the diseases that cannot be cured.”

There were also differences in who the caregivers heard this stigma from versus the patients. In the IDIs, the caregivers mainly mentioned hearing this stigma from the community, versus the patients said most of the stigma came from their friends and classmates. One age 18+ patient said about their diagnosis: “Some of my friends understood and I described to them that I have cancer, some were saying and surprised by saying “We know that cancer is incurable.’” Another age 13-17 patient, when asked how their friends treated them after they were diagnosed with cancer, said: “They told me that cancer is untreatable… All this was because, I was in a bad situation as a victim and my entire body swollen.”

Due to this stigma, several caregivers reported that their relatives or neighbors told them to either not bring them to the hospital to get diagnosed, or if their child was diagnosed with cancer, others told them to bring the child back home. In an IDI with a caregiver of a child age

13-17, the caregiver mentioned: “And because I was told that cancer is incurable I lost hope and all my relatives told me to take my child back home.”

3.3 Avoidance

Avoidance was another aspect of stigma that came up during the interviews that was mentioned in the literature. Avoidance in the literature refers to a chronic social and physical avoidance of a person by others. This aspect of stigma was evidenced by a few patients and caregivers discussing how community members or relatives avoided or isolated them after their diagnosis. All the patients who mentioned isolation, only discussed feeling isolated from their family or relatives. One patient age 18+ mentioned in an IDI that they “felt isolated because I did not get any support from my relatives apart from my caregivers at home, so I really felt isolated.” Another age 13-17 patient said their relatives “were isolating me” before he got better with treatment. Another patient age 18+ talked about experiencing stigma while living with their aunt: “I experienced stigma from my aunt… She was doing all those because she knew that I have cancer… she was only caring her children and isolating me.”

Although all patients mentioned feeling isolated in the context of their home and family life, the caregiver who mentioned isolation in their IDI, mentioned it in the context of their child’s schooling. They discussed how their child’s teacher treated their child differently after their diagnosis, saying “teachers were refusing to accept my child at their school.”

Another aspect of avoidance was some participants mentioned that others believed cancer was contagious. One participant in the age 13-17 FGD talked about how their classmates “discriminate and ran away from me they said that my disease was infectious.” Another

participant age 18+ in the FGD had a fear of being discriminated against "because people would think that it a contagious disease."

3.4 Financial Discrimination

Both caregivers and patients also reported facing financial discrimination from their communities. Financial discrimination refers to the degree to which people believe cancer patients should have access to financial support. Most examples of this from the interviews were family members or community members refusing to support caregivers financially when asked. In an IDI with a patient age 13-17, they reported their relatives "were isolating me, because there was a time when my father asked them for money and they refused. They were telling him, 'Bring the child home.'" Similarly, in an IDI with a patient age 18+, they were asked why they did not receive support from their relatives. The participant answered that they "think it is because of the costs used for cancer treatments, so they did not want to involved in covering of some expenses."

A caregiver of a child age <13 said in the FGD "personally I didn't get any assistance from friends and relatives." Similarly, another caregiver in this FGD talked about how they needed to sell their belongings to afford treatment as "my relatives told me to sell my things on my own that they wouldn't support because the disease is incurable."

3.5 Beliefs about Causes of Cancer

One aspect of stigma mentioned by several participants was about others' beliefs about the cause of cancer. This topic was brought up in three of the four FGDs. Multiple participants talked about how their relatives and neighbors believed that symptoms of cancer were a result of "bewitchment" and that caregivers should seek traditional treatment to treat the symptoms. This

also resulted in stigma towards the child and their diagnosis. One caregiver of a patient age 13-17, talked about this in a FGD, saying: “When my child was sick, I was told that she was bewitched… that she will not be cured.” Neighbors and relatives encouraged them to go to someone “who said that they are capable of doing the operation… the witch doctors.” Another caregiver in this FGD brought up how people in their village believed the symptoms of the cancer were a result of revenge, saying those “who saw me suffer with the child from the village after seeing me going back there they said this is a revenge that is inherited… they said maybe it is a revenge from people you do not even know.”

Additionally, a patient in the age 13-17 FGD shared a similar experience, saying “because I had a swollen part, so everyone was thinking why do I have that or maybe I have been bewitched, so I had to tell them.” Finally, a caregiver in the patient age <13 FGD brought up how even the father of the child did not understand the cause of cancer and treatment and stigmatized the child. The caregiver said:

> *“He wasn’t eating, he wasn’t even excreting, and we were wondering what it was. So, we started tests here, the tests took at least two weeks, we were hospitalized then we started treatment. After a month the swelling started decreasing. So, we used to come to the clinic to this moment we still come to the clinic. But others were saying that he was bewitched, his biological father was saying that this isn’t my child they have brought me a clone. When he got well, he (father) was happy.”*

3.6 Stigma due to Physical Changes

One aspect of stigma that was brought up by multiple caregivers and patients in the interviews but not addressed to a great extent in literature is the response of the patients’ classmates to their physical cancer symptoms and changes. Some patients found support from

their classmates, with one saying their fellow students "treated me well. We were studying and playing together."

However, others had different experiences and experienced teasing from their classmates. This aspect of stigma was mentioned in all four FGDs and one caregiver IDI. In the FGD with caregivers of patients age <13, multiple caregivers reported their child being teased about their condition. One caregiver discussed how their child's classmates treated them:

> *"But the effects he got because of the way he was weak – there is a time when chemo weakens them and all his hair was gone, his fellow kids would make fun of him. But because my child loves going to school, he still went and when they made fun of him, he'd come to report them. But it was hard for me to face the entire class to explain that he was sick and that they shouldn't make fun of him."*

Another caregiver in the same FGD said their child had a similar experience at school:

> *"In fact, he had already begun to be fearful after hair started falling. He loves school. When he went to school kids would mock him, what saloon did you shave from? You can take us there as well. So, he would remove his sweater and put it on his head."*

This experience was shared by individuals in all age groups and across caregivers and patients. In the FGD with caregivers of patients age 13-17, several mention their child struggled at school. One parent discussed how their child's classmates "were laughing at him/her during that period when she changed because of the medicine… they said that he/she is infected (HIV/AIDS)." Another caregiver in this group discussed how their child's "relation with his/her fellows were cut off" after they started displaying symptoms of cancer.

A participant in the age 13-17 FGD also shared a story of being teased by their classmates for their condition. The participant talked about how some classmates "discriminate and ran away from me, they said that my disease was infectious." In the age 18+ FGD, two

participants also mentioned facing comments from their classmates in school. One participant said that in response to their physical changes, “interacting with my fellow children, playing, they used to tell me inappropriate words… that affected me a bit.” Another participant echoed the same experience, saying “I was still young and at school they would make fun of me… so, it affected me to an extent.”

Finally, a caregiver of a patient age 13-17 discussed how their child’s classmates teased her in school:

> *I: Apart from teachers stigmatizing, did she report stigma from her fellow students?*
>
> *P: Yes, they interact with her but there are verbal attacks, unwanted verbal advances made her not to put logo on her shirt, she says I was attacked in school.*
>
> *I: Mm*
>
> *P: They see me as a person who will die soon, but I told her if you don’t put a red logo, you can get problems with teachers because they would not be able to identify you easily and know how to treat you.*
>
> *I: Mm*
>
> *P: I have tried to convince her, but she doesn’t want to put that logo because her colleagues are stigmatizing her and attacking her.*

3.7 Anticipated Stigma

One stigma discussed by multiple participants was anticipated stigma they thought they may experience from their community. Although this type of stigma was not directly experienced from community members, the anticipation of stigma from the public about their diagnosis led some participants to take certain actions including not informing their relatives or friends about their diagnosis or avoiding certain situations because of their diagnosis.

Avoiding telling others about their cancer diagnosis is termed “Label Avoidance” in the literature. Label avoidance refers to when people avoid associating with a label such as “cancer”

for fear of what others might think or say about them. Although participants did not directly experience stigma from their community, many chose to keep their diagnosis to themselves for fear of stigma. In the FGD with participants age 18+, one participant said: "On my side, after I was diagnosed with cancer, I think it was a period where I lived with many secrets. After I was diagnosed with cancer, I never told anyone apart from those who knew." Another participant in this group discussed how "I was scared that if I openly told my friends, relatives, and neighbors I would probably be discriminated… Maybe because there was no awareness, I thought I would be discriminated because people would think that it a contagious disease." A third participant echoed the same experience, saying:

> *"Only a few family members not all knew, even the neighbors, we weren't open to them, it was later that we were open. We couldn't give them the picture, as in tell them what was I suffering from, so they assumed whatsoever they assumed. We didn't tell them."*

In an IDI with a participant age 18+, they detailed a similar experience, saying:

> *"After I was diagnosed with cancer, we did not tell the family members, it was a secret between I and my parents only, until today no one knows about my cancer diagnosis… Because people who are looking after you when you sick are only people who should know what you are suffering from, so my family who were living with me know but other family members like relatives who don't live with me doesn't know."*

However, this experience was not limited to only patients age 18+. Another participant in the FGD with participants age 13-17 also discussed not sharing their diagnosis with others. They talked about how they were "afraid that if I will tell other people…. But I had to tell them." In the FGD with caregivers of patients age 13-17, a caregiver mentioned that they did not tell anyone the news of their child's sickness because "since it is my child who is sick it disturbed me."

This fear or anticipated stigma also deterred some patients from doing certain actions for fear of stigma from the community. One participant in the FGD for age 18+ patients discussed how they stopped going to church because they had "absolutely had no desire to do such things after I was diagnosed with cancer. I think it was fear because I could see my condition at that time." Another age 18+ participant in an IDI said the following about their diagnosis and symptoms:

> *"It little affected my relationship with my friends and relatives, my close friends who we were doing things together before, our closeness reduced… my limbs had crashes and produced wets all the time, so my body conditions also may be the reasons why they reduced closeness."*

4. Discussion

This study sought to explore the types of stigmas experienced by pediatric patients and their caregivers. The results and data gathered from this study show that cancer stigma is still an issue faced by pediatric cancer patients and their families. It also revealed that, although some aspects of stigma have been described and addressed in the literature through adult stigma studies, there are aspects of stigma for pediatric cancer patients specifically that should be addressed. The aspects of stigma most brought up by these participants were: cancer severity, avoidance, financial discrimination, beliefs about causes of cancer and stigma due to physical changes. Cancer severity, avoidance and financial discrimination were aspects of cancer stigma that have been discussed in the literature, while beliefs about causes of cancer and stigma due to physical changes were not found in the literature.

In other studies that utilized exploring cancer stigma according to the six domains of cancer stigma, often statements about severity, financial discrimination and avoidance had the highest levels of agreement (Akakpo et al., 2023; Vrinten et al., 2019). This correlates to the findings in this study and illustrates that these fears are not limited to this population. For these widely established types of stigma, there are interventions that have been developed that may be translated to this context and used for this population.

Beliefs about the causes of cancer affecting cancer stigma were briefly addressed in literature such as in the Vrinten et al., 2019 study where they found that “individuals who show stigma towards cancer do not believe it can be treated” (Akakpo et al., 2023). However, these studies were done in the adult populations. This study shows that many aspects of stigma that affect adult patient populations can affect pediatric patient populations as well.

The aspect of stigma due to physical changes, especially in the context of school and education was not widely addressed in cancer literature. One study done by Gomez, 2007, discussed stigma of cancer in schools in Portugal (Gomez, 2007). In this study, Gomez used in school plays to dispel cancer stigma and educate children about the symptoms of cancer. This could be an intervention that could be applied to schools in this region, as a way of increasing knowledge and decreasing teasing from peers. Many participants in the study also discussed wanting to share their experiences with their communities and using their stories as educational tools. These testimonials can be used to reduce stigma and increase knowledge about pediatric cancer among youth and children in schools.

4.1 Study strengths and limitations

There are several strengths of this study. The first is that there is difference in time window between receiving treatment and participating in the study, meaning there can be an assessment of changes in stigma experience over time. Also, there is a diverse pool of study participants, through including both caregivers and patients, including different locations, ages and time after treatment. Finally, having similar guides between the FGDs and IDIs means that there is a wide range of data while also making sure that themes are consistently represented in both formats.

Limitations of this study include the lack of inter-coder reliability, as only one researcher coded the data. Similarly, the surveys were written in English and then translated into Swahili but there was no formal back-translation of the survey. This means there may have been questions asked in Swahili that were different to the intended meaning in English.

4.2 Implications for policy and practice

For policy and practice, these results have significant implications. At the national level, there should be more education on cancer symptoms to reduce cancer stigma nationally. This study also shows the need for local educational initiatives, where survivors can speak about their experiences and educate others.

4.3 Implications for further research

Further research should be done in this region but also concerning this topic nationwide. This study was only done in a small subsection of the population, with those who are already familiar with cancer and cancer stigma. Larger studies should be done with community members who are not familiar with cancer to gather more data about what types of interventions would increase awareness and knowledge about cancer. Interventions should also be developed to curb cancer stigma both in cities and villages but also in schools with young children.

5. Conclusion

This study found that among pediatric cancer patients and their caregivers, they experienced stigma from their communities towards pediatric cancer. The main themes of stigma found through FGDs and IDIs were severity of condition, avoidance, financial discrimination, beliefs about causes of cancer and stigma due to physical changes. Similar themes were found to be experienced both among caregivers and patients. Additionally, similar themes were experienced amongst most age groups and among other similar demographics. This data illustrates that stigma is a problem experienced by pediatric cancer populations, and it can dissuade people from seeking treatment for cancer symptoms. It also shows that, although some aspects of stigma have been described and addressed in the literature through adult stigma studies, there are aspects of stigma for pediatric cancer patients specifically that should be addressed. The data gathered here can be used to develop interventions targeted towards cancer stigma for pediatric populations, to reduce cancer stigma and increase survival rates of pediatric cancer patients in Tanzania.

Appendix A: Focus Group Discussion Guides

Caregiver Focus Group Discussion Guide

1. We want to first talk about your child's diagnosis.
    a. Before coming here to BMC, what did you know about cancer?

        Probe: What had friends and family told you about cancer?

    b. What did you think about the treatment and curability of cancer when your child was first diagnosed ? Follow up - how has that changed now?

    c. From where and how did you receive support during your child's cancer diagnosis and treatment?

        Probe: Mentally/psychologically, financially, socially? Do you feel you had enough support to take care of your child during their treatment? Was there anyone who didn't support you bringing your child for treatment?

2. We would like to discuss life after finishing treatment:

    a. Now that your child has finished treatment, can you tell us what you understand about why they still come for visits in the oncology clinic?

    b. Sometimes patients who were treated with cancer as children have side effects later in life. Have you heard about any of these side effects? Probe: which have you heard discussed?

    c. Does your child have any side effects that are atill there after finishing treatment that you know about? Probe: Anything that is visible (ie: scars, difficulty using limb)? Anything that is not visible (hearing changes; fatigue; changes in menstruation) Does it affect the way you live your life?

    d. Do you have any concerns for your child's future because they received treatment for cancer? Probe: what types, relationsips, being around others, recurrence.

    e. Since it is very important to monitor for side effects that may occur after treatment, what is the best way to provide this information to patients and parents? when should this be provided?

    f. What challenges do you have to bring your child back for follow up visits, after completing their therapy?

3. Now we will talk about your child's social interactions after being diagnosed with cancer:

    a. When your child was diagnosed how did you explain cancer to your child? What language did you use?

b. Did you tell other family members about your child's cancer diagnosis? Why or why not?

Probe: How did they react? Did you have fears about how they would react? Did their interaction with your child change?

c. Did your child's friends or their families know about their diagnosis?

Probe: If yes, what was their reaction? Did you have fears about how they would react?

Did it change the way they interacted with your child (**was it the friend or the caregiver that changed the interaction pattern)?

d. How did being diagnosed with cancer affect your child's ability to go to school?

Follow up: If they did go to school, do you feel that they were treated any differently because they had cancer? If so, how?

e. Were there any traditions/customs that your child did not participate in because they were diagnosed with cancer? Why ?

f. Did you feel your child was treated differently by health providers (outside of BMC) after being diagnosed with cancer?

Probe: If yes, how? Were you concerned this would happen?

g. How can the government help support children diagnosed with cancer? Probe: screenings, financial, transport etc

4. Any other comments about how your child was treated by others after their cancer diagnosis that you would like to discuss today, to help us educate others in the community?

Patient Focus Group Discussion Guide

1. Now let's talk and share about your experience of being diagnosed with cancer;
   a. Before treatment, what did you know about cancer?

      Probe: Causes, treatment, curability? What had friends and family told you about cancer?
      How have those beliefs changed?
   b. Did you have any negative thoughts when you found out you had cancer? What were they?

      Probe: Did you believe your personal actions had an impact on your cancer diagnosis? Did you accept the cancer diagnosis when you first found out or did you avoid speaking about it? why?
   c. After being diagnosed, did you tell people you had cancer?

Probe: How did they react? Did you have fears about how they would react? Did their interaction with you change?

d. Were there any traditions/customs in your age group or the community that you were concerned that you wouldn't be able to participate in? Why or why not?

2. Let's discuss how being diagnosed with cancer affected your daily life;

   a. From where and how did you receive support during your cancer diagnosis and treatment?

      Probe: Mentally/psychologically, financially, socially? Do you feel you had enough support?

      Are there other ways that you wish that you were supported?

   b. How did being diagnosed with cancer affect life in general, such as going to school, finding jobs or work?

      Probe: How difficult or easy was it for you to find work? Did employers or co-workers know you had cancer when they hired you or treat you differently?

   c. What are some of the other challenges you have faced as a result of your cancer diagnosis?

      Probe: What kinds of stressors? How did your diagnosis affect you psychologically/mentally? Did you have any other worries about your future?

      i. If someone was dealing with depression/anxiety/mental health after diagnosis and treatment, what would you say to them or how would you help?

3. Let's discuss your treatment

   a. Now that you have finished treatment, can you tell us what you understand about why you still come for visits in the oncology clinic?

   b. Sometimes patients who were treated with cancer as children have side effects later in life. Have you heard about any of these side effects? Probe: which have you heard discussed?

   c. Do you have any side effects that you know about from your treatment? Probe: Anything that is visible (ie: scars, difficulty using limb)? Anything that is not visible (hearing changes; fatigue; changes in menstruation) Does it affect the way you live your life?

   d. When should the health care team talk about these potential side effects? When diagnosed, during therapy, when you complete therapy?

   e. Since it is very important to monitor for side effects that may occur after treatment, what is the best way to provide this information to patients, especially when they are diagnosed at a young age?

4. Do you feel as if you were able to express yourself fully today about your cancer

diagnosis and that your voice was heard?

a. Probe: Are there other ways you feel would be better to express your experience with cancer such as with photography, videos or skits?

Appendix B: In-Depth Interview Guides

Caregiver In-Depth Interview Guide

1. Before coming here to BMC, what did you know about cancer?
    a. What had friends and family told you about cancer?
2. From where and how did you receive support during your child's cancer diagnosis and treatment? (Mentally/psychologically, financially, socially)?
    a. Was there anyone who didn't support you bringing your child for treatment?
3. Now that your child has finished treatment, can you tell us what you understand about why they still come for visits in the oncology clinic?
    a. Does your child have any side effects that are still there after finishing treatment that you know about? (Anything that is visible (ie: scars, difficulty using limb)? Anything that is not visible (hearing changes; fatigue; changes in menstruation)
        i. Does it affect the way you live your life?
    b. Do you have any concerns for your child's future because they received treatment for cancer? Probe: what types, relationships, being around others, recurrence.
    c. What challenges do you have to bring your child back for follow up visits, after completing their therapy?
4. When your child was diagnosed how did you explain cancer to your child?
    a. Did you tell others about your child's cancer diagnosis and how did they react?
5. How did being diagnosed with cancer affect your child's ability to go to school?
6. Any other comments about how your child was treated by others after their cancer diagnosis that you would like to discuss today, to help us educate others in the community?

Patient In-Depth Interview Guide

1. Before treatment, what did you know about cancer?
    a. What did you think about the treatment and curability of cancer when you were first diagnosed and how has that changed now?
2. Did your parents treat you differently after your cancer diagnosis? How?

a. Did they let you interact with others (such as schoolmates or friends) in the same way as before your diagnosis or did it change?
b. What did they tell you about your diagnosis?
c. Did friends or community members treat you differently?

3. Did you continue attending school after being diagnosed with cancer?

    a. How did the other students treat you?

4. Now that you have finished treatment, can you tell us what you understand about why you still come for visits in the oncology clinic?

    a. Do you have any side effects that you know about from your treatment? Probe: Anything that is visible (ie: scars, difficulty using limb)? Anything that is not visible (hearing changes; fatigue; changes in menstruation) Does it affect the way you live your life?

5. Did you feel isolated after your cancer diagnosis (because of the diagnosis itself or because of treatment/side effects of treatment)?

    a. Did you have any negative thoughts when you found out you had cancer? Did you believe your personal actions had an impact on your cancer diagnosis?

    b. Did you accept the cancer diagnosis when you first found out or did you avoid speaking about it?

6. Did you have any feelings of sadness or stress after your diagnosis or during treatment?
    a. How did you handle those feelings? Did you talk about those feelings to anyone?
7. In what other ways did your cancer diagnosis or treatment affect your life?
8. Looking back, is there anything you would have liked to know about diagnosis or treatment?

9. Is there anything else you would like to add about your experience with cancer?

Appendix C: Consent Forms

Study Title: Barriers to Follow-Up Care for Childhood Cancer Survivors in Tanzania

English:

Information sheet and consent to participate in a research study

Overall Principal Investigator: Dr. Kristin Schroeder, Kristin.schroeder@duke.edu

Local Principal Investigator: Dr. Erica Sanga, esanga2010@gmail.com

CONCISE SUMMARY

We are a group of researchers from Bugando Medical Centre (Tanzania), National Institute for Medical Research (NIMR)- Mwanza Medical Research Centre (Tanzania) and Duke University (United States) who are studying children's cancers. The current research is being done to gain a deeper understanding of the needs for children with cancer after completing therapy. The results from the study will help the researchers and other key players in pediatric cancer to develop post-treatmenet guidelines for childhood cancer in Tanzania.

It is important for you to know that participation in this study is voluntary which means that:

- You can choose whether or not you would like to be in this study.
- You can decide to stop participating in the study at any time.

There are no significant risks to participating in this study. While there is no direct benefit to you from being in the study, the results from this study will be very important to inform the policies and programs that address the needs the needs for pediatrics cancer in Tanzania.

Approximately 50 childhood cancer survivors or their caregivers will participate in this study over a 1 year time period.

The information just described will be discussed in greater detail in this consent form. Study staff will give you a copy of the consent form with a contact phone number to call in case you have questions or concerns about the study. As you decide whether or not to participate in this study, please ask the study staff any questions you have about the study.

INTRODUCTION

Researchers at Duke University have partnered with Bugando Medical Centre (BMC) and NIMR- Mwanza Medical Research Centre in Mwanza to conduct research on children's cancers, with a focus on improving outcomes through the development of guidelines to monitor side effects of the treatment children receive for cancer care. Dr. Erica Sanga from NIMR-Mwanza Centre and Dr. Kristin Schroeder from Duke University will conduct the study. A grant from the National Cancer Institute, USA is funding this study.

Research studies are voluntary and include only people who choose to take part. Please read this consent form carefully or have study staff read to you, and take your time making your decision. As study staff discuss this consent form with you, please ask them to explain any words or information that you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information are listed below.

WHY IS THIS STUDY BEING DONE?

This study is being done because we know that >66% of children who are treated for cancer will experience at least one late effect from their treatment . This study aims to understand the types of late effects, challenges, and potential stigma that children who have completed therapy for cancer have experienced. We will use the information gathered from interviews to help develop guidelines to better monitor for these late effects for children completing cancer treatment in Tanzania.

WHY HAVE I BEEN ASKED TO PARTICIPATE? You are being asked to participate in this study because you (the patient) or your child (caregiver) have completed treatment for cancer. We'd like to get your views concerning issues experienced by children who completed cancer treatment to enhance our understanding of the needs for our patients.

WHAT WILL THE STUDY INVOLVE AND HOW LONG WILL I BE IN THE STUDY? You will be requested to participate in an individual interview or focus group discussion in a group of about 10 people. We will ask you questions about physical, mental or social health issues faced after competing therapy, and potential stigma that you (or your child) have experienced. The group discussions will be audio-recorded and transcribed and you will not be identified by name on the tape or in the transcript. Numbers or nick names will be used during the discussion and we ask that you not refer to other people by their true names, or talk about the information that was shared with people outside of the group.

WHAT ABOUT MY RIGHTS TO DECLINE PARTICIPATION OR WITHDRAW FROM THE STUDY?

Participation in this study is completely voluntary; If you choose to participate you will be asked to complete the Informed Consent Form (ICF) confirming your willingness to participate. You will be given time to read the information sheet and ask all your questions and they will be responded to your satisfaction before signing the ICF. Furthermore, you are free to not answer any questions that might make you feel uncomfortable or withdraw from the study at any time.

WILL MY PARTICIPATION IN THE STUDY BE KEPT CONFIDENTIAL?

All research projects carry some risk that information about you may become known to people outside a study; however the research team will take all the necessary precautions to ensure that confidentiality is well observed. For example, the focus group facilitator will again explain that comments made by others during the group discussion should not be discussed with people outside the group. To protect your identity, all identifying information (such as your names, date of birth, or contact information) will be accessed only by authorized study staff at BMC, NIMR- Mwanza Centre and collaborators at Duke University. In some cases, study records

may be reviewed in order to meet federal or state regulations. Reviewers may include representatives and affiliates of Bugando Medical Centre, the National Institute for Medical Research and the Duke University Health System Institutional Review Board, the National Institutes of Health, and others, as appropriate.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

While there are no direct benefits to participating in the study, the information that you provide will help the researchers and other key players in pediatric cancer to develop effective guidelines to improve the care of children who complete cancer treatment in Tanzania.

WHAT ARE THE DISADVANTAGES TO TAKING PART IN THE STUDY?

Since we cannot guarantee that participants will keep things confidential, you are free not to give information that you feel that are too personal and you would not want other people to know. In our study, you will not be asked to tell us anything personal and your name will not be attached to any of the comments you make during discussion. You may stop participation in this study at any time. If you have experience of having a child with cancer, or cancer yourself, sharing your experience may cause distress but you are free to not answer any questions that might make you feel uncomfortable or withdraw from the study. There are no additional risks as a result of your participation in this study.

WHAT WILL HAPPEN TO THE DATA COLLECTED? Data sharing is only allowed for research purposes and only with de-identified information. Only the Principal Investigator of the study and the study monitors will have access to the consent documents. The study results will be retained at BMC for at least five years after the study is completed. At that time, research information may be destroyed or information identifying you will be removed from study results at BMC. Since this study is conducted with Duke University, all data from the study will be shared with them. All data collected on paper will be stored in locked cabinets in secure offices and all electronic data containing identifiable information will be stored on password-protected devices and/or secure devices as approved by regulatory agencies in Tanzania and the United States.

WHAT WILL HAPPEN TO THE RESULTS?

The de-identified information will be analyzed and included in a research paper that may be published and presented at national and international meetings. The conclusions from the study will inform future policies and programs that address the needs for pediatric cancer awareness campaigns. By agreeing to be in the study, you consent to publication and presentation of study results.

WHAT ARE THE COSTS?

There will be no additional costs to you as a result of being in this study.

WHAT ABOUT COMPENSATION?

You will not receive direct compensation for participating in this study. However, your transportation to BMC will be reimbursed for the focus group particpation.

WHO HAS REVIEWED THIS STUDY? The Tanzanian NIMR-IRB-, NatHREC, BMC-CUHAS Ethical Review Board, and the Duke University Institutional Review Board (IRB).

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

At the end of the interview, if you subsequently feel distressed or if you need any further information, you may contact Dr. Erica Sanga at + 255 658 577041 or Dr. Kristin Schroeder at +1-703-470-2455 or; For questions about your rights as a research participant, or to discuss problems, concerns or suggestions related to the research, or to obtain information or offer input about the research, may be addressed to the Chairperson of NatHREC at Tel: +255-22-2121400.

If you agree to take part in the study, please sign the consent form hereafter

_____

Printed Name of Participant

_____ _____

Signature or Fingerprint of Participant Date (Day/Month/Year). Time

(Witness required if the research participant does not know how to read the consent)

_____

Printed Name of Witness

_____ _____

Signature of Witness Date (Day/Month/Year) Time

_____ _____

Signature of Person Obtaining Consent Date (Day/Month/Year) Time

STATEMENT OF CONSENT

"The purpose of this study, procedures to be followed, risks and benefits have been explained to me. I have read the information sheet and understood the purpose and nature of the study. I have been allowed to ask questions, and my questions have been answered to my satisfaction. I have been told whom to contact if I have questions, to discuss problems, concerns, or suggestions related to the research, or to obtain information or offer input about the research. I have read this consent form and agree to be in this study, with the understanding that I am participating voluntarily and may withdraw without repercussions, at any time, whether before it starts or while I am participating.

I understand that study findings will be published without any identifying information, but that full anonymity cannot be guaranteed. Text, and any pictures or videos published in these reports may be freely available on the internet and may be seen by the general public, including you. The pictures, videos and text may also appear on other websites or in print, and may be translated into other languages or used for scientific purposes. Signing this consent form does not remove my rights to privacy. I have been told that I will be given a signed and dated copy of this consent form."

_____

Printed Name of Participant

_____ _____

Signature or Fingerprint of Participant Date (Day/Month/Year) Time

(Witness required if the research participant does not know how to read the consent)

_____

Printed Name of Witness

_____ _____

Signature of Witness Date (Day/Month/Year) Time

_____

Printed Name of Person Obtaining Consent

_____ _____ _____

Signature of Person Obtaining Consent Date (Day/Month/Year) Time

Kiswahili -Information sheet and consent to participate in a research study

Jina la utafiti: Vizuizi vya Ufuatiliaji wa Huduma kwa Waathirika wa Saratani za Utotoni nchini Tanzania

Mtafiti Mkuu -Tanzania: Dr. Erica Sanga, esanga2010@gmail.com

Mtafiti Mwenza: Dk. Kristin Schroeder, Kristin.schroeder@duke.edu

Maelezo ya utafiti na ridhaa ya kushiriki katika utafiti

MUHTASARI MFUPI

Sisi ni kundi la watafiti kutoka Kituo cha Matibabu cha Bugando (Tanzania), Taasisi ya Taifa ya Utafiti wa Magonjwa (NIMR)-Kituo cha Mwanza (Tanzania) na Chuo Kikuu cha Duke (Marekani) ambao tunatafiti saratani za watoto. Utafiti wa sasa unafanywa ili kupata uelewa wa kina wa mahitaji ya watoto walio na saratani baada ya kumaliza matibabu. Matokeo ya utafiti huo yatawasaidia watafiti na wadau wengine wakuu katika saratani ya watoto kutengeneza miongozo ya baada ya matibabu ya saratani ya watoto nchini Tanzania.

Ni muhimu kwako kujua kuwa kushiriki katika utafiti huu ni kwa hiari ambayo inamaanisha kuwa:

- Unaweza kuchagua kama ungependa kushiriki katika utafiti huu au la.
- Unaweza kuamua kuacha kushiriki katika utafiti wakati wowote.

Hakuna hatari kubwa ya kushiriki katika utafiti huu. Lakini pia hakuna faida ya moja kwa moja kwako kwa kushiriki katika utafiti, ingawa matokeo ya utafiti huu yatakuwa muhimu sana kuwajulisha sera na mipango ambayo inashughulikia mahitaji ya kampeni za uhamasishaji wa saratani kwa watoto nchini Tanzania.

Takriban manusura 50 wa saratani ya utotoni au walezi wao watashiriki katika utafiti huu kwa muda wa mwaka 1.

Habari iliyoelezwa itajadiliwa kwa kina zaidi katika fomu hii ya ridhaa. Wafanyakazi wa utafiti watakupa nakala ya fomu ya ridhaa yenye namba ya simu ya mawasiliano ili uweze kupiga ikiwa una maswali au wasiwasi juu ya utafiti. Unafikiria kushiriki au kutoshiriki katika utafiti huu, tafadhali waulize wafanyikazi wa utafiti maswali yoyote uliyonayo kuhusu utafiti.

UTANGULIZI

Watafiti kutoka Chuo Kikuu cha Duke wameshirikiana na Kituo cha Matibabu cha

Bugando (BMC) na Kituo cha utafiti wa Magonjwa NIMR-Mwanza kilichopo jijini Mwanza kufanya utafiti juu ya saratani za watoto, kwa kuzingatia kuboresha matokeo kupitia uimarishaji wa uelewa wa jamii. Utafiti huu unafanywa ili kupata uelewa wa kina wa imani za jamii, maadili na maarifa juu ya saratani kwa watoto. Dk Erica Sanga kutoka Kituo cha NIMR-Mwanza na Dk. Kristin Schroeder na Nelson Chao kutoka Chuo Kikuu cha Duke watafanya utafiti huo. Ruzuku kutoka Taasisi ya Taifa ya Saratani, Marekani ndiyo inayofadhili utafiti huu.

Kushiriki katika utafiti ni hiari na unahusisha watu tu ambao wamechagua kushiriki. Tafadhali soma fomu hii ya ridhaa kwa makini au usomewe na wafanyakazi wa utafiti, na chukua muda wako kufanya uamuzi wako. Wakati wafanyakazi wa utafiti wanapojadili fomu hii ya ridhaa na wewe, tafadhali waulize wakuelezee maneno yoyote au habari ambayo hauelewi vizuri. Tunakuhimiza kuzungumza na familia yako na marafiki kabla ya kuamua kushiriki katika utafiti huu. Hali ya utafiti, athari, kero, usumbufu, na taarifa nyingine muhimu zimeorodheshwa hapa chini.

KWANINI UTAFITI HUU UNAFANYWA?

Utafiti huu unafanywa kwa sababu tunajua kuwa > 66% ya watoto wanaotibiwa saratani

watapata angalau athari moja ya kuchelewa kutokana na matibabu yao. Utafiti huu unalenga

kuelewa aina za athari za marehemu, changamoto, na unyanyapaa unaowezekana ambao

watoto ambao wamemaliza matibabu ya saratani wamepitia. Tutatumia taarifa zilizokusanywa

kutoka kwa mahojiano kusaidia kutengeneza miongozo ya kufuatilia vyema madhara haya ya

kuchelewa kwa watoto wanaomaliza matibabu ya saratani nchini Tanzania.

KWANINI NIMEOMBWA KUSHIRIKI?

Umeombwa kushiriki katika utafiti huu kwa sababu wewe (mgonjwa) au mtoto wako (mlezi)

mmemaliza matibabu ya saratani. Tungependa kupata maoni yako kuhusu masuala

yanayowakumba watoto waliomaliza matibabu ya saratani ili kuboresha uelewa wetu wa

mahitaji ya wagonjwa wetu.

UTAFITI UTAHUSISHA NINI NA KWA MUDA GANI NITAKUWA KATIKA UTAFITI?

Utaombwa kushiriki katika mahojiano binafsi au majadiliano ya kikundi katika kikundi cha watu 10 (zaidi ya miaka 18, wanaume na wanawake). Tutakuuliza maswali juu ya imani, uelewa, tabia ya kutafuta afya na matibabu ya saratani za watoto. Katika majadiliano ya vikundi pia tutapitia sampuli ya vifaa vya uelimishaji vyaa lugha ya Kiswahili vilivyotengenezwa kwa matumizi ya kampeni ya elimu ya magonjwa mengine na kujadili muundo

unaopendelewa/utakaofaa kwa kampeni iliyopangwa ya uelimishaji wa cancer ya watoto. Majadiliano ya kikundi yatarekodiwa kwa sauti na kunakiliwa na hautatambuliwa kwa jina kwenye mkanda au nakala. Namba au majina ya utani yatatumika wakati wa majadiliano na tunakuomba kwamba usitaje watu wengine kwa majina yao halisi au kuzungumza juu ya hoja ambayo ilichangiwa na watu nje ya kikundi.

VIPI KUHUSU HAKI ZANGU KUKATAA KUSHIRIKI AU KUJIONDOA KWENYE UTAFITI?

Kushiriki katika utafiti huu ni hiari kabisa; Kama ukichagua kushiriki utaombwa kukamilisha Fomu ya ridhaa uliyofahamishwa (ICF) inayothibitisha nia yako ya kushiriki. Utapewa muda wa kusoma karatasi yenye taarifa na kuuliza maswali yako yote na yatajibiwa hadi utakaporidhia kabla ya kusaini fomu ya ridhaa. Kwa kuongezea, una uhuru wa kutojibu maswali yoyote ambayo yanaweza kukufanya ujisikie vibaya au kujiondoa kwenye utafiti wakati wowote.

USHIRIKI WANGU KATIKA UTAFITI UTAKUWA WA SIRI?

Tafiti zote zina hatari kiasi ya kwamba taarifa kukuhusu zinaweza kujulikana kwa watu nje ya utafiti; hata hivyo timu ya watafiti itachukua tahadhari zote muhimu kuhakikisha kuwa usiri unazingatiwa vizuri. Kwa mfano, msimamizi wa kikundi cha majadiliano ataelezea tena kuwa maoni yaliyotolewa na wengine wakati wa majadiliano ya kikundi hayapaswi kujadiliwa na watu walio nje ya kikundi. Ili kulinda utambulisho wako, taarifa zote zinazotambulisha (kama vile majina yako, tarehe ya kuzaliwa, au mawasiliano) zitafikiwa tu na wafanyakazi walioidhinishwa wa utafiti wa BMC, NIMR- Kituo cha mwanza na washirika katika Chuo Kikuu cha Duke. Kwa namna nyingine, rekodi za utafiti zinaweza kukaguliwa ili kukidhi kanuni za shirikisho au serikali. Wakaguzi wanaweza kujumuisha wawakilishi na washirika wa Kituo cha Matibabu cha Bugando , Taasisi ya utafiti wa magonjwa ya binadamu na bodi ya ukaguzi wa taasisi ya afya ya chuo Kikuu cha Duke, Taasisi za kitaifa za afya, na wengine, kadri itakavyofaa.

KUNA FAIDA ZA KUSHIRIKI KATIKA UTAFITI?

Ingawa hakuna faida ya moja kwa moja ya kushiriki katika utafiti, habari unayotoa itasaidia

watafiti na wahusika wengine muhimu katika kitengo cha saratani za watoto kuandaa

miongozo madhubuti ya kuboresha matunzo ya watoto wanaomaliza matibabu ya saratani

nchini Tanzania.

NINI HASARA ZA KUSHIRIKI KATIKA UTAFITI?

Kwa kuwa hatuwezi kuhakikisha kuwa washiriki watatunza usiri, uko huru kutotoa taarifa

yoyote ambayo unahisi ni ya kibinafsi sana na usingependa watu wengine waijue. Katika utafiti

wetu, hautaulizwa utuambie chochote cha kibinafsi na jina lako halitaambatanishwa na maoni

yoyote unayotoa wakati wa majadiliano. Unaweza kuacha kushiriki katika utafiti huu wakati

wowote. Ikiwa una uzoefu wa kuwa na mtoto mwenye saratani, au saratani yako mwenyewe,

kuchangia uzoefu wako kunaweza kusababisha huzuni lakini uko huru kutojibu maswali

yoyote ambayo yanaweza kukufanya upate na huzuni au ujiondoe kwenye utafiti. Hakuna

hatari zaidi kutokana na ushiriki wako katika utafiti huu.

NINI KITATOKEA KWA TAARIFA ZILIZOKUSANYWA?

Ushirikishaji wa taarifa (data) unaruhusiwa tu kwa madhumuni ya utafiti na taarifa isiyo na utambulishwa tu. Mtafiti Mkuu tu wa utafiti na wasimamizi wa utafiti watapata nyaraka za ridhaa. Matokeo ya utafiti yatahifadhiwa BMC angalau kwa miaka mitano baada ya utafiti kukamilika. Kwa wakati huo, taarifa ya utafiti inaweza kuharibiwa au taarifa inayokutambulisha itaondolewa kwenye matokeo ya utafiti huko BMC. Kwa kuwa utafiti huu unafanywa na Chuo Kikuu cha Duke, taarifa zote kutokana na utafiti watashirikishwa. Takwimu zote zilizokusanywa kwenye karatasi zitahifadhiwa kwenye makabati yaliyofungwa katika ofisi salama na data zote za elektroniki zilizo na taarifa zenye utambulisho zitahifadhiwa kwenye vifaa vyenye ulinzi wa nywila (nenosiri) na / au vifaa salama kama inavyoidhinishwa na wakala wa udhibiti nchini Tanzania na Marekani.

NINI KITATOKEA KWA MATOKEO?

Taarifa ziliyopatikana zitachambuliwa na kuingizwa kwenye karatasi ya utafiti ambayo inaweza kuchapishwa na kuwasilishwa kwenye mikutano ya kitaifa na kimataifa. Hitimisho kutoka kwa utafiti huo litasaidia kufahamisha sera na mipango ya baadaye ambayo inashughulikia mahitaji ya kampeni za uhamasishaji wa saratani za watoto. Kwa kukubali kushiriki katika utafiti huu, unaridhia uchapishwaji na uwasilishaji wa matokeo ya utafiti.

GHARAMA NI ZIPI?

Hakutakuwa na gharama zozote za ziada kwako kwa kushiriki katika utafiti huu.

VIPI KUHUSU FIDIA?

Hautapokea fidia ya moja kwa moja kwa kushiriki katika utafiti huu. Hata hivyo, usafiri wako

hadi BMC utafidiwa kwa ushiriki wa kikundi lengwa

NANI AMEKAGUA UTAFITI HUU?

NIMR-IRB-, Kamati ya Kitaifa ya Tathmini ya Maadili ya Utafiti wa Afya (NatHREC), Bodi ya Ukaguzi wa Maadili ya BMC-CUHAS na Bodi ya Uhakiki ya Taasisi ya Chuo Kikuu cha Duke (IRB).

NITAWASILIANA NA NANI NIKIWA NINA MASWALI AU TATIZO?

Mwisho wa mahojiano, ikiwa una mfadhaiko/mashaka au ikiwa unahitaji taarifa zaidi, unaweza kuwasiliana na Dkt Erica Sanga kwa nambari + 255 658 577041 au Dk. Kristin Schroeder kwa + 1-703-470-2455; Kwa maswali juu ya haki zako kama mshiriki wa utafiti, au kujadili shida, wasiwasi au maoni yanayohusiana na utafiti, au kupata habari au kutoa maoni juu ya utafiti huo, unaweza kuwasilisha kwa Mwenyekiti wa NatHREC kwa Simu: + 255-22-2121400.

Ikiwa unakubali kushiriki katika utafiti, tafadhali saini fomu ya ridhaa inayofuata hapa chini.

_____

Chapisho la jina la Mshiriki

_____ _____

Sahihi au alama ya kidole cha Mshiriki Tarehe (Siku/Mwezi/Mwaka) Muda

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Chapisho la Jina la Shahidi

_____ _____ _____

Sahihi ya Shahidi Tarehe (Siku/Mwezi/Mwaka). Muda

_____ _____

Sahihi ya anayeomba ridhaa Tarehe (Siku/Mwezi/Mwaka) Muda

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