

The Barriers and Facilitators to Achieving Optimal Nutrition for Pediatric Oncology  
Patients in Tanzania: A Mixed Methods Analysis

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  
in the Graduate School of Duke University

2020

ABSTRACT

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## **Abstract**

Background: Each year, approximately 400,000 children are diagnosed with cancer with over 85% of new cases occurring in low- and middle-income countries (LMIC). Survival rates in LMIC are 15 to 25% compared to 85 to 90% in high-income countries (HIC). Undernutrition is a key factor contributing to this disparity. Children diagnosed with cancer are at a higher risk for undernutrition, especially in low resource settings, but nutritional status remains largely unrecognized and unmonitored in many pediatric oncology hospitals in LMICs.

Study aims: This study aims to first determine the prevalence and severity of undernutrition at diagnosis, and second, evaluate existing barriers and facilitators to optimal nutrition among children with cancer at a large specialty referral hospital in Mwanza, Tanzania.

Methods: A mixed methods approach was used including quantitative surveys, and semi structured interviews that were distributed to caregivers and medical providers for children with cancer treated at Bugando Medical Centre (BMC) from May to December 2019.

Results: Quantitative surveys were completed by caregivers(n=65), with a subgroup completing a second Knowledge, Attitudes, and Perceptions survey (n=51). Both caregivers (n=10) and stakeholders (n=14) also completed in-depth qualitative

interviews. Using Tanzanian nutrition guidelines, the majority (60%) of pediatric cancer patients (n=65) aged 1 to 17 years were classified as undernourished and 78.4% of caregivers reported being food insecure. Key factors perceived to contribute to poor nutrition included food insecurity and lack of education. Community support was reported as a facilitator towards achieving optimal nutrition. Additionally, parents expressed interest in nutritional education and supplementation programs during treatment.

Conclusions: This is the first study to address a gap in the literature on the prevalence and factors contributing to undernutrition for children with cancer in Tanzania and provides evidence-based recommendations for effective and sustainable interventions.

## Dedication

This thesis is dedicated to my wonderful parents. Amma and Appa, thank you for all the sacrifices you've made that has enabled me to pursue my wildest dreams. Thank you for believing, that I was capable of not just conquering but moving mountains too.

Finally, I'd like to dedicate this thesis to Lyaki and the wonderful children that inspired my work - for teaching me the true meaning of being strong. You have all given me something to fight for, and for that I am eternally grateful. Lyaki, thank you for sharing your joy with me for the little time that we knew each other. I hope you're in a wonderful place now, wearing colorful kitenge dresses and taking amazing selfies.

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## Acknowledgements

I will never be able to truly express how grateful I am to my mentor, Dr. Kristin Schroeder. This thesis and the last 18 months at DGHI would not have been possible without her unparalleled support, guidance, and sense of humor. It has been a true honor to have had her as my mentor, but more so to call her a friend, I would like to thank her for inspiring me every day through this process and beyond. I am thankful to my committee member and mentor, Dr. Tamara Fitzgerald for her support, expertise, and fondness for a great cup of tea. I'm grateful to have gotten the opportunity to learn and work with her. Thirdly, I would like to share my gratitude to Dr. Mary Story whose warm support, feedback and expertise has been invaluable to the success of this thesis.

I'd like to thank my teams both at Duke and Tanzania, for their relentless support, this work would not be what it has evolved to be without them.

Laura Mkumba and Jacob Stocks, our friendship has been the best blessing to come from our time at Duke. Thank you for opening your hearts, homes, and keeping the light through the dark times.

Lastly, I owe my soul sister, Victoria Nevel and a village of amazing humans for their unconditional love. Tori, if it wasn't for you, this thesis and degree would have been a mere dream. Thank you for believing in me when I didn't believe in myself.

## Foreword

The work that I completed for this thesis was coordinated by me, a cis-Sri Lankan Tamil woman in my mid-twenties working and studying in an elite university in a high-income country. I would like the reader to recognize this as they read through this work, it is important that my privilege is recognized when reading through this work that would not have been possible without the support of the community that welcomed me to conduct this research and guided me throughout the process to ensure it was as equitably done as possible.

I am fortunate to have had the opportunity to conduct my thesis research in the beautiful town of Mwanza, Tanzania but I must acknowledge the power dynamics that were in play, whether intentional or otherwise. I manifested this work as a foreigner in a foreign land, but I tried to the best of my ability to write this thesis for a local gaze. My hope is that my work can eventually be shared to an audience broader than academics, to include policy makers, medical professionals, and most importantly, the community that participated in my work.

## **1.0 Introduction**

### ***1.1. Global Pediatric Cancer Burden***

Over the last 5 years, pediatric cancer has garnered increased attention as a significant global health concern, most notably in low and middle-income countries (LMIC), where 80% of children diagnosed with cancer live.<sup>1,2</sup> The annual incidence of childhood cancer is estimated to be approximately 400,000 cases in the year 2015, yet only 224,000 cases were reported that same year, indicating a substantial underdiagnosis of childhood cancer globally.<sup>3</sup> What is most alarming however is the disparity in survival rates. Survival rates for cancer in high income countries (HIC) exceed 85 to 90% compared to LMIC, with rates ranging from 15 to 25%.<sup>1</sup>

This disparity is caused by a multitude of factors, but nutrition is a key contributor to pediatric cancer outcomes. Undernutrition has been shown to decrease tolerance to chemotherapy, and is associated with increased comorbidities and infection rates, resulting in poor clinical outcomes and influencing patient's overall survival.<sup>4</sup> Therefore, there is an urgent need for innovative nutrition strategies to close the gap between HIC and LMIC in cancer survival.<sup>5</sup>

## **1.2. Definition and Measures of Undernutrition**

Undernutrition is defined as insufficient intake of energy and nutrients to meet an individual's needs to maintain good health.<sup>6</sup> There are 4 broad sub-forms of undernutrition: wasting, stunting, underweight, and deficiencies in vitamins and minerals, but most recently has also included protein and energy malnutrition (PEM).<sup>7</sup> There are several indicators at various levels of effectiveness, currently being used to measure nutritional status. In clinical settings, the most commonly used anthropometric measures are weight and length/height in combination with age and sex. These measures are then divided into indices or indicators. The most common indices used for children are weight for age Z score (WAZ), length / height for age Z score (LAZ / HAZ) and weight for length / height Z score (WLZ / WHZ). The WHO currently recommends the weight-for-height (WFH) index to assess the nutritional status of children under the age of 5 and body mass index (BMI) for those age 5 and above, with height-for age value <5% reflecting chronic undernourishment.<sup>4</sup>

However, in many LMICs, these indices do not truly reflect the population's nutritional status. In countries, particularly in emergency/crisis settings where there is lack of human capital to reliably measure nutrition status, one cannot rely on weight-for-age as a good determinant of nutritional status. When used alone, this indicator may

underestimate the proportion of children who are undernourishment as some undernourishment can only be detected through more comprehensive indices including height-for-age, and weight-for-height. While weight-for-height is useful in young children when measured independent of age, it is less useful for determining undernutrition in older children and adolescents where the relationship is more dependent on age.<sup>8</sup>

There are additional challenges and a lack of consensus on measuring nutritional status among children with cancer. The WHO recommended weight-for-height (WFH) index may not be accurate due to the severity of illness and often large tumor burden seen in many pediatric cancer patients in Sub-Saharan Africa (SSA)<sup>9</sup>. Many patients present with a large abdominal tumor that can increase the child's recorded weight and falsely indicate a normal WFH index, despite severe undernutrition.<sup>10</sup> Hence, more accurate and reliable indicators such as arm anthropometry to measure mid-upper-arm-circumference (MUAC) or triceps fold thickness (TSFT) have been advocated to replace the WFH measure in LMIC.<sup>10</sup> These are far more feasible, and sensitive indicators that are easily used in clinical settings globally.



### **1.3. Global Burden of Undernutrition**

Most children with cancer live in LMIC, where the baseline prevalence of malnutrition among the overall pediatric population can be greater than 50%.<sup>1,10</sup> Stewart and Howard (2009) further elaborates that from the years 1996 to 2005, the percentage of children younger than 5 years who are moderately or severely malnourished were 39% in LMIC. This is compared to a mere 3% reported in HIC.<sup>1</sup> Nutrition-related comorbidities were together responsible for approximately 35% of child deaths and 11% of the total global disease burden.<sup>5</sup> Black et al. (2013) reported that East Africa had the second highest prevalence of stunting among UN subregions, with 42%.<sup>11</sup>

In Tanzania, one of the largest East African countries by population- the most recent Tanzania Demographic and Health Survey (DHS) of 2015-16 described that 34% of children under the age of 5 were stunted, 5% were wasted, and 14% were underweight. Of those surveyed, 5% were classified as moderate malnutrition ( $\leq 2SD$ ) and 1% of those surveyed were severely wasted ( $\leq 3SD$ ). The Lake Zone of Tanzania, has some of the highest reported undernutrition rates with 39% suffering from stunting.<sup>12</sup> Among those with undernutrition, 3.9% were classified as moderate and 1.3% with severe malnutrition.<sup>13</sup> Hence, we can conclude that undernutrition is a serious

matter of concern globally, but particularly in East Africa where there is a need for more evidence to understand the burden and factors contributing to its growth.

#### ***1.4 Undernutrition and Pediatric Oncology in Sub-Saharan Africa***

Undernutrition has been linked to increased morbidity among children with both communicable and non-communicable diseases (NCDs) worldwide. This is especially noted in children with cancer. In HIC, malnutrition among children with cancer is often correlated to the type of tumor and the extent of the illness. This is further exacerbated in low resource countries, where there is a high rate of baseline protein/energy malnutrition (PEM). While there is limited data on the malnutrition prevalence among children with cancer at diagnosis in LMICs, estimates are as high as 50%.<sup>14</sup>

Most existing data on nutritional status among children with cancer in LMICs and its impact on survival is based on patients diagnosed with leukemias. A recent paper by Lobato-Mendizabal et al. reported a stark survival discrepancy with a 5-year survival rate of 83% in well-nourished patients and 26% in those with under-nutrition in Mexico.<sup>9</sup> However, there is a serious void in the literature on the prevalence of undernutrition among children with cancer in Sub Saharan Africa, where the majority of new diagnoses will be made.

In addition to limited data on the prevalence of undernutrition among children with cancer in Sub-Saharan Africa, there is also a significant knowledge gap on the risk factors for increased undernutrition among this population. While there are known influences such as a metabolically active tumor, additional individual and organizational barriers to adequate nutrition may exist such extended hospital stays when caregivers cannot afford food. In addition, there is a lack of emphasis on other proximal determinants of a child's nutritional status such as food security, adequate care, and health.<sup>11</sup>

In Sub-Saharan Africa, the total population is expected to double by 2050 leading to a demographic shift from older age groups to a booming young population that has resulted in pediatric cancer becoming a top priority for Sub-Saharan Africa and more specifically, Tanzania.<sup>15,16</sup> If cancer outcomes could be improved by optimizing nutrition including an evaluation of a variety of factors, then this data could inform cost-effective interventions for future implementation and research.

### ***1.5 Rationale and Aims***

The main rationale for the study is that children diagnosed with cancer are at a higher risk for undernutrition as cancer cells consume calories rapidly, increasing metabolic demands. However, malnutrition continues to be largely unrecognized and

unmonitored in many pediatric oncology hospitals in LMICs. There is currently no data available in LMIC, on current nutritional needs, perceptions of nutrition in relation to pediatric oncology outcomes, and clear, well-defined classifications for malnutrition. This lack of evidence-based research ill informs any possibility of a well-executed implementation of a nutrition supplementation to improve the nutrition and overall, the health of this population.

Hence, my thesis project aims to understand the following two aims:

Aim 1: To determine the prevalence and severity of undernutrition at diagnosis for pediatric oncology patients in Tanzania

Aim 2: To assess the barriers and facilitators towards achieving optimal nutrition for pediatric oncology patients in Tanzania

## **2.0. Methods**

### **2.1. Overview**

This study employed a triangulation mixed methods design using a convergence model. This design involved simultaneous collection and analysis of quantitative and qualitative data for primary purpose of exploration/confirmation of results over an 8 month time period at Bugando Medical Centre (BMC), in Tanzania.<sup>17</sup>

### **2.2. Setting**

This study took place at Bugando Medical Centre in Mwanza, Tanzania. Bugando Medical Centre is one of three cancer consultant hospital in Tanzania serving a catchment area of greater than 15 million people in the Lake Zone of northern Tanzania, with about 200 new pediatric cancer diagnoses per year.<sup>18</sup> The Cancer Centre has a 60-bed inpatient ward which provides care to children and adults, offering services in cancer screening, early diagnosis, staging, chemotherapy, radiation therapy, and surgery. The Bugando Cancer Centre has space for out- and inpatient consultations, administration of chemotherapy and supportive care, radiation therapy simulation and administration, radiology services, laboratory services, conference rooms for tumor board and research presentations, and a library. The patient population is predominantly Black African and speak Swahili.

### **2.3. Study Participants**

All pediatric patients (<18 years old) presenting to BMC with a clinical diagnosis of cancer were eligible for inclusion in the study over an 8-month period from May 2019 to December 2019. Eligibility criteria also included having a caregiver >18 years of age who consented to participation in the study, who was able to understand consent procedure and could communicate in Swahili. A sub-group from this population also answered a second Knowledge Attitudes, and Perceptions (KAP) Likert scale survey that was completed from June 2019 to September 2019.

Additionally, in depth interviews were completed with caregivers of children with cancer (n=10) including 7 mothers and 3 fathers and key pediatric cancer stakeholders at BMC (n=14) including one senior oncologist, one pediatrician, one pediatric resident, two nutritionists, one clinical coordinator, two patient navigators, one social worker, three nurses, one health and food safety officer, and the hostel cook. The interviews were completed from June 2019 to August 2019.

### **2.4. Study Team**

The study team comprised the MSc-GH student, Nutritionist, Research Assistant, and Primary Investigator (PI): Y.R., D.M., R.G., and K.S. respectively. Prior to data collection, the research was explained to each participant by R.G., and informed consent

was obtained. Quantitative data was collected by Y.R, D.M, and R.G. with the surveys being administered orally by R.G. and D.M. The qualitative data was collected, transcribed, and translated by R.G. and Y.R. Both qualitative and quantitative data analysis was handled by Y.R. K.S. gave overall supervision and guidance to the study.

## **2.5. Data Collection**

### **2.5.1. Quantitative Data - Nutritional Status**

At diagnosis, demographic data was recorded including patient age, gender, diagnosis, and stage (if known) as well as place of residence, whether they farmed, number of occupants per household, and travel time from home to the hospital. Standard anthropometric measurements were taken using an intake form (Appendix A). Measurements at admission include weight, height, mid-upper arm circumference (MUAC) and triceps skin fold thickness (TSFT). Based on the collected measurements, the study team then used both WHO's weight-for-height (WFH) index and MUAC/TSFT values to determine severity of malnutrition. Scores falling below 75% of median for WFH and 5th percentile for MUAC or TSFT were indicative of malnutrition. In addition to anthropomorphic measures, nutrition associated laboratory values were collected included serum protein, MCV, hemoglobin, and albumin.

### **2.5.2. Quantitative Data - Caregiver Nutrition Knowledge, Attitudes, and Perceptions (KAP)**

Based on the UN Food and Agriculture's KAP Manual, a 5-point Likert scale survey consisting of 27 items and taking approximately 15 mins to complete was developed by the study team and cross-validated in Swahili. The survey was used to quantitatively evaluate perceptions on child's nutritional status, knowledge understanding, attitudes towards food insecurity and availability, and food insecurity status.<sup>19</sup> (Appendix B)

Twelve statements inquired about the caregiver's perceptions of their child's nutritional status, five statements aimed at understanding the caregiver's nutritional knowledge, and eight items evaluated caregiver attitudes towards food insecurity and food availability to explore what possible barriers existed for the caregivers towards feeding their child. Each item had 5 ordinal responses from 0 to 5, to express their agreement with the statements. These responses included Never (0), Rarely (1), Sometimes (2), Often (3), and Always (4).

Household Food Insecurity status was measured using ChildWatch's Hunger Vital Scale, a two-item screening measure that assesses household food insecurity in LMICs over a period of 12 months.<sup>20</sup> Statements were: " HV1 : Within the past 12 months, we worried whether our food would run out before we got money to buy



more” and “HV2 : Within the past 12 months, the food we bought just didn’t last and we didn’t have money to get more” Responses for both statements were: “Often true(1),” “Sometimes true (2),” “Never true(3),” and “Don’t know or refused(0).” The outcome of the Hunger Vital Scale was dichotomized - those who answered 1 or 2 for either of the two questions were considered Food Insecure and those who answered 3 or 4 were counted as Food Secure.<sup>20</sup> (Figure 1)

Hunger Vital 2-question screener for food insecurity

For each statement, please circle which answer response was closest to what you believe is correct.

HV1	Within the past 12 months, we worried whether our food would run out before we got money to buy more	Often true (1)	Sometimes true (2)	Never true (3)	Don't know or refused (0)
HV2	Within the past 12 months, the food we bought just didn't last and we didn't have money to get more	Often true (1)	Sometimes true (2)	Never true (3)	Don't know or refused (0)

**Figure 1: Hunger Vital Scale**

### 2.5.3 Qualitative Data Collection

The qualitative data collection included a needs assessment to understand what was available in terms of both resources and services for children with cancer seeking treatment at BMC as well as in depth interviews of key stakeholders and caregivers.

The interview guides (Appendices C and D) were developed based on the Consolidated Framework for Implementation Research (CFIR) framework<sup>21</sup> to aid in informing the development of future nutrition interventions. The CFIR model is a framework used to guide needs based assessment for implementation research to identify implementation factors through the following characteristics<sup>22</sup>:

1. Outer setting: External influences on intervention implementation (e.g. cancer/illness specific barriers, access to food - food insecurity)
2. Inner setting: Characteristics within that influence the implementation of the intervention (e.g. feasibility of the intervention, organizational readiness to change)
3. Individual Characteristics: Individual's beliefs, knowledge, and personal attributes that may affect implementation (e.g. knowledge on nutrition both stakeholder and caregiver, societal beliefs on diet)
4. Intervention: Aspects of the intervention that may impact implementation (e.g. Availability and access to nutritional supplements)

Fourteen stakeholders and ten caregivers of patients receiving treatment for cancer were approached using convenience sampling to participate in the study over a three-month period. The interviews were conducted in private offices or clinic rooms in the pediatric or oncology wings. Interviews were audio-recorded with a hand-held recording device with participant permission lasting anywhere from 10 to 45 minutes. The voice recorded files were then simultaneously transcribed and translated from Swahili to English by the trained research assistant R.G. and for the interviews

conducted in English, were transcribed by MSc.GH student Y.R. Following transcription, Y.R. reviewed all the transcripts and edited them for clarity.

## **2.6. Data Analysis**

### **2.6.1. Quantitative**

The data from the intake form was entered into a REDCap (Research Electronic Data Capture) database hosted at Duke University. STATA Version 15, was used to clean, organize and analyze the data.<sup>23</sup> Key information such as socio-demographic characteristics, nutritional status and severity were visualized using simple graphs and tables. (Table 1, Figure 2)

Survey data responses from the KAP survey was also entered into REDCap and subsequently exported as a csv file into R Studio 2018<sup>24</sup>. The first step included cleaning data and organizing it, including making appropriate cutoffs for categorizing variables. A table was then created to display socio-demographic characteristics of the sample (Table 2). As the dataset is not normally distributed, median scores of the survey statements were used for comparative purposes. A Wilcoxon Rank Sum Test was then used to examine the association between the survey statements and food insecurity status based on the Hunger Vital Scale (Table 3). Stacked Bar Plots (Figures 3,4,5) were used to visualize specific statements of interest and their relationship to food insecurity.

A Fisher's exact test was used to determine if there were associations between the socio-demographic characteristics of the participants and their food security status (Table 4). For both tests, significance was concluded if corresponding p values were less than 0.05.

### **2.6.2. Qualitative**

The interview transcripts were uploaded to NVivo, version 12<sup>25</sup> a qualitative analysis software and coded using a content analysis approach. 'Content analysis is a systematic process that involves making inferences by analytically and objectively identifying emerging themes in written transcriptions of recorded data.'<sup>26</sup> The transcripts were coded using a priori structural (Appendix E), and emergent themes were identified and included through an iterative process during analysis. A second coder coded 3/24 transcripts independently, and these were then discussed to ensure inter-coder agreement (ICA) meetings before proceeding with the rest of the coding.

### **2.7. Ethical Considerations**

The study was approved by Duke University Health System Institutional Review Board, Catholic University Health and Applied Sciences (CUHAS) Institutional Review Board, and the Tanzania National Institute for Medical Research (NIMR). There were no costs to participants or immediate risks associated with participating in the study.

## **3.0 Results**

### **3.1. Needs Assessment**

In order to find the most effective interventions for promoting nutrition, there is a need to look at exactly what current resources are available.

At Bugando Medical Centre, there are four nutritionists to support the 900-bed facility. The pediatric ward of C5 includes a malnutrition unit for supporting severely undernourished children that are referred from other district/referral hospitals in the Zone. Within the malnutrition unit, common nutritional supplements provided include F75 and F100, milk based ready-to-use therapeutic food (RUTF). F75 is used during the stabilization phase, and F100 is used during the rehabilitation phase.<sup>27</sup> Other supplementation includes the Plumpy Nut, another RUTF specifically formulated for nutritional rehabilitation specific to acute severe undernourished children older than 6 years of age.<sup>28</sup> In general, the hospital provides three meals including breakfast consisting of porridge (uji), and subsequent meals include ugali/rice, beans, with the occasional vegetable/fruit. Meat is only served occasionally depending on availability on the weekend.

In terms of oncological support, there is one pediatric hematologist present for 50% of the time, and for the other 50%, the pediatric oncology team of 2 patient

navigators and a clinical coordinator handle day-to-day activities aided considerably by tele-communication between the US and Tanzania. For patients receiving care, a hostel is available where one parent and the child receiving care can stay for the duration of the treatment. A social worker, cook, and nurse oversee caring for the children at the hostel. Meals at the hostel also feature porridge in the morning, and dinner usually featuring rice/ugali, beans, anchovy, vegetables, and the occasional fruit. Lunch is a communal effort, paid for and prepared with help from the caregivers at the hostel to promote community.

### **3.2. Nutritional Status of Pediatric Cancer Patients at BMC**

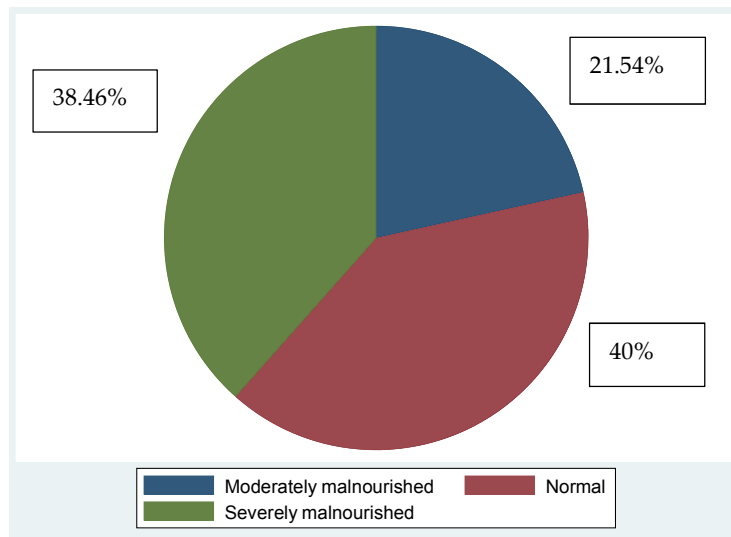
From May 2019 to December 2019, a total of 70 children with cancer aged 0 to 18 years of age were enrolled in the study. Five patients were later excluded due to non-cancer diagnosis. The mean age of the remaining 65 participants was 5.56 years, with almost 73% diagnosed with solid tumors. (Table 1)

**Table 1: Participant Characteristics**

Variable	Classifications	Frequency	Percentage
Sex	Male	30	46.15%
	Female	35	53.85%
	Total	65	100%
Age (years)	Mean	5.56	
	Min	1	
	Max	17	

Nutritional Status	Normal	26	40%
	Moderately malnourished	14	22%
	Severely malnourished	25	38%
	Total	65	100%
Type of Cancer	CNS Tumor	1	8%
	Leukemias/Lymphomas	13	35%
	Solid Tumors	37	73%
	Total	51	100%

As illustrated in Figure 2, 60% were undernourished, with 22% moderately undernourished, and 38% with severe undernourishment.



**Figure 2 : Baseline Prevalence and Severity of Undernutrition (n=65)**

### **3.3. Knowledge, Attitudes, and Perceptions of Caregivers of Pediatric Cancer Patients at BMC**

#### **3.3.1. Caregiver Demographics**

The socio-demographic characteristics of 51 caregivers is described in Table 2. Most of the participants were mothers between the ages of 26 to 35 with daughters between the ages of 6 to 10 who were admitted inpatient. Most caregivers (60.8%) did not complete primary education and were peasants or farmers. Among the 51 participants, 78% reported food insecurity (n= 40), and the proportion of people living in one household with greater than seven people was 24 (47.1%). Most reported that it took up to 5 hours to get the hospital (50.1%, n=26) however almost 30% reported that it took longer than 8 hours to get to the hospital (n=15) (Table 2).

**Table 2: Socio-demographic characteristics**

<b>Variable</b>	<b>Total n (%)</b>
<b>Caregiver's Age:</b>	
0-25	6(11.8)
26-35	16(31.4)
36-45	14(27.5)
>45	15(29.4)
<b>Sex of Caregiver</b>	
Female	29(56.9)
Male	22(43.1)
<b>Child's Age:</b>	
0-5	21(41.2)



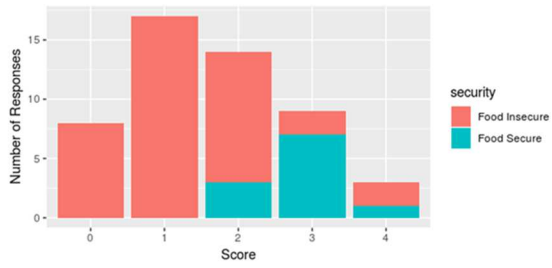
6-10	23(45.1)
11-15	6(11.8)
>15	1(1.96)
<b>Sex of Child</b>	
Female	27(52.9)
Male	24(47.1)
<b>Patient Admittance</b>	
Inpatient	28(54.9)
Outpatient	21(41.2)
<b>Caregiver's Education Level</b>	
No Education	12(23.5)
Primary Education incomplete	31(60.8)
Primary complete	2(3.9)
Secondary and more	6(11.8)
<b>Caregiver's Occupation</b>	
Peasant/Farmer	31(60.8)
Trader/Sales	5(9.8)
Skilled Manual Labor	7(13.7)
Professional	1(1.96)
Household	4(7.84)
Other	1(1.96)
<b>No. of People living per household</b>	
0-5	7(13.7)
5-6	20(39.2)
>7	24(47.1)
<b>Does the family farm?</b>	
Yes	46(90.2)
No	5(9.8)
<b>Setting</b>	
Rural	37(72.5)
Urban	12(23.5)

<b>Duration to hospital</b>	
<b>0-5</b>	26(50.1)
<b>5-8</b>	10(19.6)
<b>&gt;8</b>	15(29.4)
<b>Mode of Transport</b>	
<b>Dala Dala</b>	8(15.7)
<b>Walking</b>	1(1.96)
<b>Car</b>	9(17.6)
<b>Ferry</b>	2(3.92)
<b>Bus</b>	26(50.1)
<b>Piki Piki</b>	4(7.84)
<b>Boda Boda</b>	0(0)
<b>Other</b>	0(0)
<b>Food Insecurity (HV Scale)</b>	
<b>Secure</b>	11 (21.6)
<b>Insecure</b>	40 (78.4)

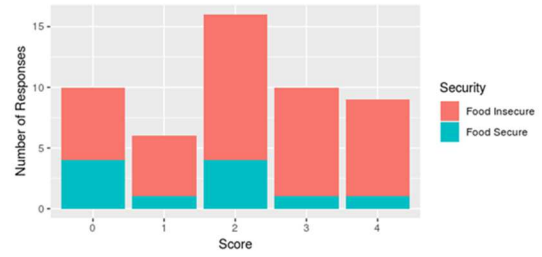
### 3.3.2. Survey Results

There were significant differences in perception about nutrition among caregivers who were food secure versus insecure. For example, when asked if their child is currently getting a well-balanced diet, more food secure caregivers agreed that their child was getting a well-balanced diet, compared to their food insecure counterparts (PER 1 – 3(0.5) vs. 1(1),  $P < 0.001$ ). Likewise, more food insecure caregivers believed their child needed nutritional support compared to food secure caregivers (PER 7 –  $P < 0.001$ ).

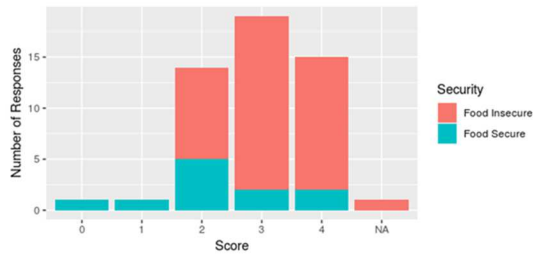
Alternatively, the perception of cancer's effect on overall nutrition varied and did not change by food security status (PER 4 – 2(2) vs. 2(2),  $P < 0.001$ ). Likewise, while most caregivers reported "Always" agreeing with the statement that their community would benefit from learning more about nutrition, there was variance in terms of food security status. (PER 9 – 4(0) vs. 4(1.25),  $P < 0.001$ ) (Figure 3 and Tables 3 and 4)



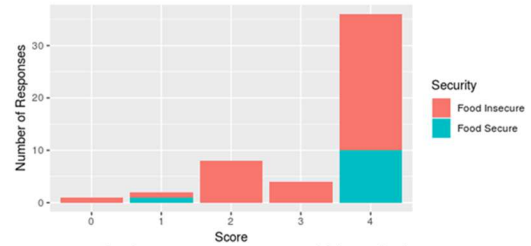
PER1 - My child is currently getting a well-balanced diet.



PER 4- Cancer has affected my child's overall nutrition.



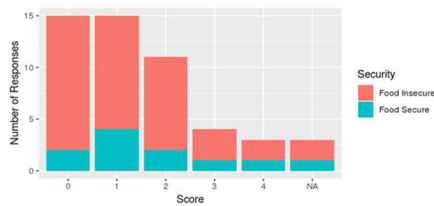
PER 7 - I believe that my child needs additional nutritional support.



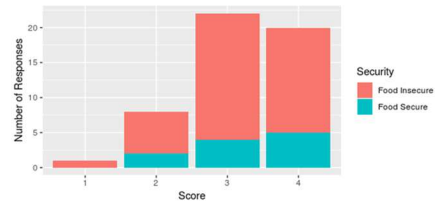
PER 9 - I think my community would benefit from learning more about nutrition.

**Figure 3: Stacked Bar Plots of Perceptions towards Nutrition Survey statements**

The Knowledge Understanding portion of statements visualized in Figure 4, were meant to evaluate existing nutritional knowledge. When asked if patient received adequate nutrition, there was no difference by food insecurity with 58% reporting “never” or “rarely” received adequate nutrition education (KU2). Likewise, when asked if they believed that it was good to give different types of food to my child (KU4), a significant number of participants despite reporting food insecurity still identified that it was good to have variety in their children’s diet indicating that this was a mutually accepted fact.



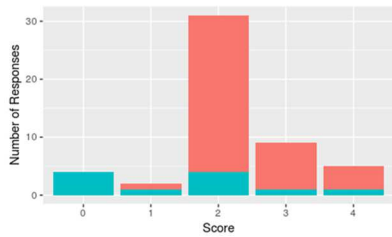
KU2 - I received adequate nutrition education from my child's care team.



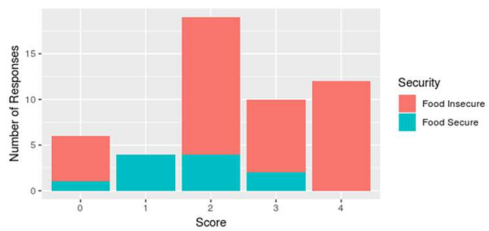
KU4 - I believe it is good to give different types of food to my child.

**Figure 4: Stacked Bar Plots of Knowledge Understanding Survey Statements**

When evaluating food security and availability, distance was an issue across the board with significant numbers reported in the food insecure population, over 30 responses reporting “sometimes” to being asked if the kind of food they wanted to give their child was available where they lived or at the hospital during treatment (FIA2). A second statement questioning if money impacted their ability to provide adequate nutrition for their child reinforced that money was a significant contributor to food insecurity, with large values reported scoring higher than 2 or “sometimes”.



FIA2 - The kind of food I want to give my child is not available where I live/at the hospital



FIA6 - Money impacts my ability to provide adequate nutrition for my child.

**Figure 5: Stacked Bar Plots of Food Insecurity/Availability Survey Statements**

**Table 3: Perceptions, Knowledge, and Food Insecurity Patterns Related to Nutrition using Wilcoxon Rank Sum Test (n=51)**

Variable: Statement	Total Median (IQR)	Food Secure Median (IQR)	Food Insecure Median (IQR)	Wilcoxon rank sum test P-value
PER1: My child is currently getting a well-balanced diet.	2(1)	3(0.5)	1(1)	p<0.001
PER2: My child has a healthy weight and height.	2(2)	3(1.5)	2(2)	p<0.001
PER3: My child has trouble eating well.	0(2)	0(0)	1.5(2)	0.8217
PER4: Cancer has affected my child's overall nutrition	2(2)	2(2)	2(2)	p<0.001
PER5: I believe that good nutrition will help improve my child's cancer treatment outcome.	3(1)	4(1)	3(1)	p<0.001
PER6: BMC is providing enough food for my child's nutrition	2(2)	3(3)	2(1)	p<0.001
PER7: I believe that my child needs nutritional support	NA	2(error)	NA(error)	p<0.001
PER8: In my community, it's believed that certain foods should not be eaten if you have cancer.	2(2)	0(0)	2(2)	0.182
PER9: I think my community would benefit from learning more about nutrition	4(1)	4(0)	4(1.25)	p<0.001
PER10: My child is currently getting all the necessary nutrients	2(1)	2(1)	2(1)	p<0.001
PER11: Sometimes, I feel like I'm a bad parent because I'm not able to provide my child with enough food	2(1.5)	1(1)	2(1)	0.0004

PER12: I believe my child is getting adequate food.	2(2)	3(2)	2(2)	p<0.001
KU1: I believe I have adequate nutritional knowledge to take care of my child	1(2.5)	2(2)	1(2)	0.028
KU2: I received adequate nutritional knowledge to take care of my child	NA	NA	NA	0.061
KU3: My child received follow up care regarding their nutritional status	2(2)	1(2.5)	2(2)	p<0.001
KU4: I believe it is good to give different types of food to my child	3(1)	3(1)	3(1)	p<0.001
KU5: It is enough to feed my child three times a day	3(2)	3(1.5)	3(2)	p<0.001
FIA1: It is difficult for me to give different types of food to my child	2(1)	0(2)	2(1)	p<0.001
FIA2: The kind of food I want to give my child is not available where I live/at the hospital	2(1)	2(2)	2(1)	p<0.001
FIA3: It is difficult for me to feed my child three times a day	2(1.5)	0(0)	2(1)	p<0.001
FIA4: There's not enough food to feed my entire family	2(2)	0(1.5)	2(1)	p<0.001
FIA5: I can't afford to buy fruit and/or vegetables	2(1)	0(2)	2(1)	p<0.001
FIA6: Money impacts my ability to provide adequate nutrition for my child	2(1)	2(1)	2.5(2)	p<0.001
FIA7: The distance of my home from BMC impacts my ability to feed my child	2(3)	0(1)	2(2)	0.002



FIA8: I am worried that my child does not get enough food to be healthy.	2(1)	0(1.5)	2(1)	p<0.001
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**Table 4: Predictors of Food Insecurity using Fisher's exact test (n=51)**

Variable	Total n (%)	Food Secure n	Food Insecure n	Fisher's exact test P-value (95% conf interval)
DEM1 : Caregiver's Age				0.72 (-)
0-25	6 (11.8)	1	5	
26-35	16 (31.4)	5	11	
36-45	14 (27.5)	3	11	
45+	15 (29.4)	2	13	
DEM2 : Caregiver's Sex				1 (0.19, 4.35)
Male	22 (43.1)	5	17	
Female	29 (56.9)	6	23	
DEM3 : Patient's Age				0.73 (0.15, 3.56)
0-5	21 (41.2)	5	16	
6-10	23 (45.1)	0	6	
11-15	6 (11.8)	5	18	
15-20	1 (1.96)	1	0	
DEM4 : Patient's Sex				1 (0.23, 5.29)
Male	24 (47.1)	6	21	
Female	27 (52.9)	5	19	

DEM8: Caregiver's Occupation				0.41
Household	4 (7.84)	1	3	
Peasant/Farmer	31 (60.8)	5	26	
Professional	1 (1.96)	1	0	
Trader/Sales	5 (9.8)	1	4	
Skilled Manual Labor	7(13.7)	2	5	
Other	1 (1.96)	0	1	
DEM10: Caregiver's Education				0.05
No Education	12 (23.5)	1	11	
Primary Incomplete	31 (60.8)	6	25	
Primary Complete	2 (3.9)	0	2	
Secondary and more	6 (11.8)	4	2	
DEM11: No. of household occupants				0.41
0-5	7 (13.7)	3	4	
5-6	20(39.2)	4	16	
7+	24(47.1)	4	20	
DEM14: Does your family farm?				0.29 (0.20, 27.26)
No	5	2	3	
Yes	46	9	37	
DEM15: Residential demographic				0.25 (0.46, 192.45)
Rural	37	10	27	
Urban	12	1	11	
DEM19: Duration to hospital				0.67
0-5	26	7	19	
5-8	10	2	8	
8+	15	2	13	

### 3.3. Qualitative Results

#### 3.3.1. Characteristics of Participants

Fourteen stakeholders and 10 caregivers of children with cancer participated in the interviews. The key stakeholders were identified based on their direct involvement with pediatric cancer care at BMC. The 10 caregivers all identified as Black African with various levels of literacy who were caregivers of children receiving cancer treatment at BMC. Half of the caregivers had children admitted inpatient, and the remaining half were receiving outpatient treatment.

**Table 5: Survey Statement Agreement Summary**

	Do they practice farming?	With <5 people living in household	Receives three meals a day	Received/Gave dietary recommendations	Gave correct/close enough definition of nutrition	Have heard of nutrition supplements
Participant Type						
Caregivers	70% (7/10)	80% (8/10)	100% (10/10)	30% (3/10)	40% (4/10)	50% (5/10)
Stakeholders	-	-	-	78.5% (11/14)	100% (14/14)	92.8% (13/14)

### **3.3.2. Identified Barriers to Achieving Optimal Nutrition:**

Both caregivers and stakeholders expressed a variety of reasons as to why pediatric patients were unable to maintain optimal nutrition. The following themes were identified as barriers contributing to achieving optimal nutrition.

#### **3.3.2.1. Cancer/Illness specific issues**

Among the respondents, 80% of caregivers and 93% of stakeholders identified cancer/illness specific issues as a key barrier playing a role in achieving optimal nutrition for their child. (Table 6) While, the caregivers expressed concern that the cancer/other illness had an impact were not always able to articulate exactly how, compared with the stakeholders who understandably were able to discuss how disease influences nutrition.

*“I do try to give nutrition, but it becomes difficult for her to eat after chemotherapy injections.” - Caregiver 05, Female*

*“the pediatric cancer [patients] are actually under risk of malnutrition because – before even having cancer, under 5 are at risk of (malnutrition) due to low immunity, so, when combined with cancer, the risk is very high.” -Nutritionist, Female*

Based on the cancer diagnosis, caregivers were either encouraged or discouraged by providers at the hospital to avoid or consume certain foods. Some common foods to avoid that were recommended by the providers included red meat, soda, and oily/fried food while, fruit and vegetables were encouraged.

*"I avoid red meat. [Why do you avoid red meat?] I was taught that by oncology providers." - Caregiver 04, Female*

*"Soda has a lot of sugar, and if you feed a lot of sugar to cancer patient, you will make progress of tumor. They will grow faster, as we know cancer cells eat more than normal cells, if you add a lot of sugar, a lot of red meat and a lot of fat. Though the kids need fat, protein and energy for growing and all these processes, there are some nutrients which is not so good for them."- Nutritionist, Female*

### **3.3.2.2. Food Insecurity**

This broader theme of *Food Insecurity* discusses a variety of reasons impacting achieving good nutritional status with 100% of the caregivers interviewed claiming it as the biggest barrier. (Table 6) Within these broader themes, there were many sub-themes that were distinguished during analysis. The first: Finance and secondly, Access.

All 10 caregivers and over 90% of stakeholders interviewed expressed very clearly that their biggest concern when it came to provide good nutrition for the children in their care was affording the food. (Table 6)

*"I can't afford to buy her fruits because I have to pay rent. And another problem is that she's not able to attend school fully because of the clinics and side effects of medication." - Caregiver 08, Female*

*"It's mainly finances and distance from home. It would have been different if they were at home where they could collect everything in their surrounding and utilize with nutritional knowledge. Also, the illness, stress on parental side in cases where the parents are hopeless and thinks that no efforts can salvage the patient." - Nutritionist, Female*

*"So, most of our patients come from very poor conditions, like poor environment. Most of them come from the villages, most people from the villages don't have a great idea concerning nutrition, so, just whatever they get, that's what they eat. Sometimes due to poverty, it also brings*

*about poor nutrition so, it's financial. Generally, it's financial stability yea." -Patient Navigator, Female*

When discussing access to food as a barrier, we found that 70% of all caregivers interviewed practiced farming with many growing staple crops such as maize, cassava, and potatoes.(Table 5) However, external factors like lack of rain, has an impact on their livelihood and so, impacting their ability to source for food.

*"We do farm but this year the situation is bad. We just buy." – Caregiver 06, Male*

Another aspect that affects sourcing food, is being away from their farmland because of their child's cancer treatment process. Caregivers are unable to farm while residing in Mwanza near the hospital for their child's treatment and can go up to 6 months without being able to farm, severely impacting their ability to access food.

*"The main problem is not being able to afford because I don't have source of income. I spent most of the times at Bugando for clinic." (Caregiver 08, Female)*

*"I can add by saying that funding is the biggest problem. Especially due to the lengthy course of treatment." -Caregiver 10, Female*

A point of interest when discussing access was that a few of the children receiving treatment at BMC were refugees from Burundi, who were originally situated in the UNHCR Camp based out of Kigoma district that borders Burundi. This unique situation was expressed by a father who felt that they did not have a choice in food selection but had to feed his child whatever they were provided within the camp.

*“Life is very hard at the camp. [What’s making it hard?] It is hard to get money and be able to afford food. We only eat what we are given because we don’t earn income.” - Caregiver 01, Male*

During the interviews, it was also expressed that being able to afford food didn’t necessarily mean that they could access the food based on their geographical location.

*“I’ll have to go all the way to Sengerema from my village just to buy food. And even milk should be bought.” -Caregiver 06, Male*

Almost all (49/51) of patients reportedly lived in households with >5 people, confirmed by the qualitative interviews with 80% of caregivers interviewed that reported having >5 people living in their house. (Table 5) While the caregivers did not explicitly note this as a barrier, stakeholders made a point to highlight this as a potential causal factor in poor nutrition.

*“...maybe issues related to social factors maybe a big family, family size very big, (inaudible) many children to take care of..” - Head Oncologist, Male*

### **3.3.2.3. Diet and Eating Behavior**

To gain insight into population diet norms and identify interventions that would match the local context, caregivers were asked to describe typical food consumed by the children as well as food preparation.

As referenced in Table 5, all caregivers reported being able to provide their children with 3 meals. However, the quality of the three meals differed, some considered

a cup of tea as a meal, while others consumed other types of foods that were more substantial such as bread or porridge.

*“She drinks tea for breakfast, ugali for lunch and rice for dinner.”*

*-Caregiver 02, Female*

*“He eats porridge in the morning. In the evening we eat ‘ugali’. And the same at night.”*  
*-Caregiver 03, Male*

#### **3.3.2.4. Lack of Resources**

The theme of lacking resources was emphasized as a barrier especially on an institutional level taking the hospital into account. Human capital, and time were some of the more common elements that were reported to having been serious concerns to facilitating nutritional support. Lack of staff such as nutritionists were a major concern, but other providers and even caregivers were emphasized as playing a major role when participants were questioned on who should play a key role in promoting nutrition.

*“Nutrition officers; nurses so that they create more awareness among patients due to them spending more time with each other; doctors as well as patients’ relatives including parents and other care takers.” - Nurse, Female*

There were also several responses that mentioned the need to provide more resources such as nutrition education for the providers but also, the cancer drugs and nutrition supplements themselves.

*“I think they can at least try to build capacity in terms of knowledge, and the management of patients who are malnourished in terms of facility by increasing the nutritionist in the ward. So that will be very helpful. And if it’s possible to accommodate some of the drugs,*



*especially for our cancer patients, which can serve as an additional component, if they can be exempted, like if you want to give them an anti-emetic drug, they shouldn't be charged for it or something like that. Or if they are charged maybe the price to be lowered. So, they can afford, that will be very helpful." -Pediatric Resident, Female*

### **3.3.2.5. Access and Availability of Nutritional Supplement**

Out of the 10 caregivers interviewed, as referenced in Table 3, only 50% had heard of nutritional supplements, and only one had received supplements yet, the child was only able to consume one type of supplement, purely based on taste. (Table 5)

*"Right now, he's not fond of milk, but only takes the nut." (Caregiver 07, Female)*

*"Yea, it is important because the supplements even for the diagnosis of what supplements are missing, in the hospital is very difficult. [yes] We need to know which supplements are missing in the patient, so, there is no harm by giving supplements in a blanket manner to all patients, I think that is the best approach." - Head Oncologist, Male*

However, access and availability of the nutritional supplement is a concern with 57% of stakeholders foreseeing this as a barrier. (Table 6)

*"We need to have enough supplement for everybody... we need to have enough supplement first, and at least the people to support." - Nutritionist, Female*

### **3.3.2.6. Nutrition Knowledge**

Nutrition knowledge serves as both a barrier and facilitator when evaluating the knowledge of stakeholders to make nutritional recommendations or carry out processes like evaluating nutritional status. There were discrepancies between the two participant groups. Despite lead providers at BMC having adequate knowledge to make

recommendations, only 3/10 caregivers were provided counselling, including one at another hospital. The majority (11/14) providers claimed to be involved in providing nutritional recommendations yet, there is a disconnect, which may be explained by a lack of training/education. (Table 5)

*“The barrier that I can talk about for now from what I know is that there is inadequate training of the nutritional officers. I’m not sure about the rest but for me as a nutritionist, I have never received any kind of training on nutrition supplements. And it was introduced while we are already in the system.... Thirdly, it’s the need to train the consumers on the benefits so that they don’t get resistant.” (Stakeholder 02, Nutritionist, Female)*

Nutrition knowledge also serves as a barrier when trying to explore the caregiver’s nutrition literacy understanding. When asked to define nutrition, only 40% of caregivers were able to define or come close to a correct definition of nutrition. (Table 5) Many claimed not to know what the term meant, and the study team had to provide a definition to move forward with the interview. Additionally, knowledge was lacking in understanding nutrition’s link to their child’s health.

*“I can’t define that (nutrition). Please define it for me.” -Caregiver 01, Male*

Table 3 illustrated that 90% of caregivers and 100% of stakeholders referred to lack of nutritional knowledge as being a barrier to achieving nutrition for the pediatric cancer patients at BMC. Some caregivers pointedly asked for more education:

*“I would ask for more education about nutrition”- Caregiver 04, Female*

*“I think the most important thing is to educate parents so that they know what to give their children.”- Caregiver 08, Female)*

Stakeholders were unanimously in agreement that lack of nutritional knowledge was a huge matter of concern both on the provider front and in terms of the caregivers.

*“Sometimes, it’s not like people forget. It’s just to refresh. Yeah, okay. Because if someone has not managed a malnourished kid for a while, they are different, the guidelines themselves change the current one might be different from the one they knew before. So, you just do a refresh even a one-day refresh or something like that. That will be helpful.”- Pediatric Resident, Female*

*“The barriers especially on hospital’s side, is the absence of better way of providing the required diet to these patients. And other times they lack money to buy food due treatment charges. For outpatients we can say it’s the lack of awareness on the appropriate food to eaten and at what time. In general, they lack awareness on nutrition.” - Nurse, Male*

**Table 6: Percentage of Caregivers & Stakeholders that identified specific themes as barriers**

	<b>% of Caregivers (Freq)</b>	<b>% of Stakeholders (Freq)</b>
<b>Themes</b>		
Food Insecurity	100% (10/10)	93% (13/14)
Nutritional Knowledge	90% (9/10)	100% (14/14)
Cancer/illness specific	80% (8/10)	93% (13/14)
Access and Availability of Nutritional Supplements	30% (3/10)	57% (8/14)
Lack of Resources	90% (9/10)	100% (14/14)

### **3.3.3. Identified facilitators to achieving optimal nutrition:**

#### **3.3.3.1. Nutrition Knowledge**

Nutrition knowledge acted as a facilitator as many caregivers and stakeholders were able to understand what nutrition was, and its importance to improving cancer outcomes. In addition, both groups of participants were encouraged to ask for more guidance.

*“Okay. Would you teach me what to buy for nutrition in pediatric cancer patient?”- Caregiver 06, Female*

#### **3.3.3.2. Community Support**

One of the key facilitators is community support. If the community was more involved, both caregivers and stakeholders agree that it would help boost nutrition amongst the population.

*“Community-based interventions are very important [okay, interesting] think of the hospital-based interventions and then, go to the community. [okay] The moment you don’t go to the community, you will remain combatting the facility based and then you’ll see the number increasing. They’re increasing because they know, when they come they will get help, when they go back they will go back to square one.” -Head Oncologist, Male*

*“I think maybe, if you have a big team, a huge team, I think you should also think about going into the community, or the [community intervention] you should go around there because that’s the start. Because even when these kids are sick, they just don’t come directly to Bugando, they start to a health centre and stuff. So, I think even the clinicians and the health professionals at these clinical centers should also be given this knowledge about nutrition.” -Patient Navigator, Female*

### 3.3.3.3 Feasibility of Intervention

From both an organization readiness perspective to the caregiver's support, both groups of participants expressed interest and support for the setting up of future nutritional interventions specifically when questioned about potentially setting up a nutrition supplementation program.

*"... I think that the patients really need nutritional supplements, I hope the data which you will get will help to get help." -Pediatrician, Female*

*"I can see that, it (nutritional supplement) will help in getting good treatment outcome."- Caregiver 02, Female*

**Table 7: Percentage of Caregivers & Stakeholders that identified specific themes as facilitators**

	<b>% of Caregivers (Freq)</b>	<b>% of Stakeholders (Freq)</b>
<b>Themes</b>		
Nutritional Knowledge	70% (7/10)	64.3% (9/14)
Community Support	10% (1/10)	42.9% (6/14)
Feasibility of Nutritional Support	90% (9/10)	85.7% (12/14)

## 4.0. Discussion

Among pediatric cancer patients in Mwanza, Tanzania, our study found a 60% prevalence rate of undernutrition. Through mixed methods analysis, the study discovered contributing factors of undernutrition among children living with cancer that included both cancer/disease barriers but beyond that other barriers such as food insecurity, lack of resources, access and availability of nutritional supplements, and nutritional knowledge. Facilitators included community support, nutritional knowledge, and feasibility of nutrition supplementation.

The overall pediatric cancer burden of undernutrition globally is 50%<sup>1</sup> yet our study population exceeded this at 60% indicating a high prevalence of undernutrition. In a similar study in Central America that evaluated baseline undernutrition in six Spanish speaking countries in the region, 63% of children with cancer had undernutrition similar to the numbers on our study. Due to limited literature on children living with cancer in the Sub-Saharan region, it is hard to ascertain if these values are similar to Tanzania, however, values are consistent when looking at the general pediatric population. A similar study to ours was conducted at Bugando Medical Center and corroborated this data with 55.8% of children under-5 years of age seeking treatment at Bugando reported as being undernourished.<sup>29</sup> This 5% gap between the pediatric cancer population and the general pediatric population does not seem significant but brings attention to the question of the lack of structural support for nutrition for the pediatric population at

large in LMICs indicating that while nutrition is a problem in general for the pediatric population, it is more of an issue among children with cancer.

The value of 60% prevalence reported was greater than regional, national, and district-level values of undernutrition among pediatric patients. East-Africa reported 42% prevalence of undernutrition. Likewise, according to the most recent Tanzanian national survey one-third (34%) of children under the age of 5 were reported as being stunted, 5% wasted, and 14% as underweight. On a regional level, data from a study conducted in Arusha, Tanzania indicated that 50%, 28%, and 16.5% of children were stunted, underweight, and wasted respectively, corroborating with our results.<sup>30</sup> When comparing these different values, the high prevalence of undernutrition reported in our study suggests that poor nutrition is a concern in children with cancer, but more importantly, many LMICs are already facing high rates of undernutrition in their pediatric population that is only being further exacerbated by cancer. In addition, our study showed a high diagnosis of solid tumors, for which weight-for-height (WFH) and BMI would not be accurate measures of nutritional status as the weight of the tumor is also being taken into account. Hence, MUAC was a more reliable measure for this population and in this setting, to provide an accurate portrayal of nutritional status. It is imperative that measures be taken to both understand what is contributing to the high prevalence of undernutrition but also, to set up interventions to combat the high proportion of undernourished children with cancer.

The main factors associated with undernutrition among children with cancer in this study had to do with suffering from symptoms such as nausea, mouth sores, and a loss of appetite as a result of their chemotherapy treatment. The presentation of these symptoms is commonly associated with leading to difficulties in eating, and hence, is attributed to causing undernutrition amongst this population. A decreased appetite for example, can impair nutritional status and in turn, is associated with lower tolerance to treatments and to a higher prevalence of infections.<sup>31</sup> While tailored nutrition support can help with improving symptoms and eating behaviors, often times, these are unavoidable. Other more general factors, however, can be tackled more efficiently through effective interventions that prioritize the factors on a country basis.

The key factors brought up through the mixed methods analysis design of this study includes food insecurity, nutrition knowledge, community support, and large family size. While not specific to children with cancer, these are key factors that should be prioritized for future interventions. Similar data was reported in other studies looking at factors influencing nutrition such as a recent study conducted in BMC itself, that concluded risk factors such as caregiver's education, lower socio economic status, and single parents were more likely to have malnourished children.<sup>29</sup>

One key barrier is food insecurity. Quantitative data indicates approximately 78% of the sample were food insecure and caregivers believed that money had a significant impact (Figure 5). Our data indicated that there are many causal factors



leading to food insecurity such as large numbers of people per household, financial barriers, and access to food. Financial barriers and access posed the largest burden on food insecurity. Many caregivers were farmers who produced the food that they and their families consumed. However, when confined to the hospital/hostel for their child's cancer treatment, they were unable to source food and hence, not only lost income but also, access to food, with a few attributing this to shortage of food based on poor climate conditions. A large proportion of those surveyed, also attested to having more than 6 family members in their household and hence, reported being more food insecure, as there were more people to provide for. This was further corroborated in a study among Zambian children examining environmental and other demographic factors associated with malnutrition,<sup>32</sup> as well as, in a study conducted among the Chagga of Tanzania, where socio-economic causes such as high birth rates, poverty, lack of education, and disease prevalence were identified as being the biggest barrier of childhood nutrition.<sup>33</sup>

Nutrition knowledge served as both a barrier and facilitator towards achieving optimal nutrition. Lack of education of the caregiver was a concern corroborated between both types of data. From the Fisher's exact test in Table 4, the survey data wasn't significant except for caregiver's education with a p-value of 0.005. Qualitative data also corroborated this finding as more than 90% of caregivers and 100% of stakeholders simultaneously agreed that nutritional knowledge was a key barrier to achieving optimal nutrition. Results indicated that many caregivers were unable to

define nutrition, but also understand its influence on their child's health. Likewise when examining other literature specific to Tanzania's 2015/16 DHS survey, including over 10,000 respondents, that evaluated the nutritional status of those under the age of 5, it found that increased maternal education correlated with decreased rates of stunting, wasting, and reported underweight in children.<sup>12</sup> Similarly, other studies in both Brazil and India identified a relationship between parent education and malnutrition.<sup>34,35</sup> This is likely due to the increased economic power to provide quality food and services for the family.<sup>36</sup>

The current study highlighted the discrepancy in nutritional knowledge between the key pediatric cancer medical providers. Accurate understanding on nutritional recommendations for the pediatric cancer population was centered on the nutritionists of the hospital alone, with a lack of understanding detected among the higher leadership personnel and the more patient-facing roles of nurses and patient navigators. This is further exacerbated by the fact that only four nutritionists were responsible for covering the needs of the 900-bed facility of the Bugando Medical Centre. While leadership insisted that nutritional counseling was conducted for every patient entering the facility, the nutritionists who were involved in the process insisted that the burden was too great to cover all patients. They suggested innovative solutions like training more nurses and facilitating more education workshops as possible methods to bridge this gap in knowledge and ability to provide proper training to patients and their families.

Many of those surveyed were able to recognize the importance of nutrition for their child's health, and hence, were more invested and interested in asking for more help and/or tools towards educating themselves. Awareness seminars, and trainings, were some suggestions that were made based on promoting better nutrition. Previous research on nutrition also supports that if the population is open to asking for more support, that these interventions could prove effective.<sup>37</sup>

A major facilitator that could help influence improvements in nutritional status amongst children living with cancer in Tanzania is community support. Both food secure and insecure groups supported the statement that their community would benefit from learning about nutrition. This was further confirmed by the stakeholder's, who believed that the greatest nutrition intervention impact and potential sustainability would involve the community rather than on an institutional or individual level. Tanzania is a country exhibiting collectivist ideals; hence, it is vital to uphold community involvement for more long-term, sustainable development. Community involvement should involve increasing awareness about the topics of nutrition and cancer, but also participation by promoting interventions that involved groups of people. This has been demonstrated effectively in India, via the impact of integrated child development scheme (ICDS) program, where authors agreed that focusing on feeding alone is not enough, and there needs to be a holistic approach including education, nutritional awareness, and hygiene behavior in order to be more effective.<sup>38</sup>

#### 4.1. Implications for Future Interventions

The Tanzanian Ministry of Health has been active in trying to reduce child undernutrition, with many nutritional interventions being developed and implemented. These include infant and young child feeding (IYCF) protocols, sanitation, deworming, vitamin A supplementation, and health education. However, nutrition continues to be a problem.<sup>30</sup> There is a need for more feasible, sustainable, and locally contextualized nutritional interventions to drive positive change in tackling undernutrition. The CFIR framework<sup>21</sup>, provides us with a framework to visualize, and explore what components would contribute to developing effective interventions to combat undernutrition in Tanzania.

**Table 8: Areas for intervention development based on CFIR domains<sup>21</sup>**

Barriers/Facilitators	Food Insecurity	Cancer/Illness Specific	Nutritional Knowledge
CFIR Domain			
Outer Setting	Policies need to be put in place by both the government and other institutions to promote better access to food such as food rations for those below a certain level e.g. those below the poverty line.	Promote community-based cancer awareness campaigns	Promote community-based nutrition awareness campaigns

Inner Setting	Help offset nutrition related expenses such as ensuring better sources of nutrition while in treatment at the hospital, provide stipend for caregivers unable to make an income while child is receiving treatment etc.	Host training seminars to educate the providers on how best to provide for cancer patients in terms of nutrition.	Host training/workshops for both assessing nutrition and making recommendations for the providers
Individual	<p>Promote workshops encouraging caregivers on using simple ingredients to prepare nutritious meals.</p> <p>Facilitate interventions such as home farming/gardening to encourage more sustainable food-sourcing options.</p> <p>Provide nutrition supplements to patients receiving treatment for cancer to help boost treatment adherence and reduce illness-related toxicity.</p>	<p>-Ensure nutritional counseling is mandatory for all patients diagnosed with cancer, and if required facilitate additional supplementation.</p> <p>Partner with the hospital canteen so, that they are equipped to handle cancer-related nutrition dietary recommendations.</p>	Nutrition educational materials for both the providers and caregivers
Intervention	Ensure that the intervention is sustainable and contextualized to the local setting.	Ensure that interventions are designed with the expertise of pediatric oncologists who can confirm safe, and individualized nutritional recommendations for the patients.	Ensuring counseling is provided to both the providers and caregivers so that accurate information is relayed about the interventions benefits and concerns.

#### **4.1.1. Intervention No. 1: Complementary Nutritional Supplementation**

Sala et al. discusses how dietary supplementation particularly the parenteral route, can reverse malnutrition, and improve the tolerance of chemotherapy - however, this is not a sustainable option for a country like Tanzania, with 67.9% living below the poverty line.<sup>4,39</sup>

Complementary nutrition supplementation is one sustainable approach to improving the nutritional status of pediatric cancer patients. Black et al, discusses how improvements of complementary feeding can be made by using strategies such as counselling about nutrition for food-secure populations, and for food-insecure populations - strategies such as nutritional counselling, food supplementation, conditional cash transfers or a combination of these can substantially aid in reducing stunting and related burden of disease. Carefully designed interventions that take into consideration local context during development can have a positive effect on feeding practices.<sup>40</sup>

Additionally, specific to the pediatric cancer population, there have been many favorable clinical outcomes associated with nutrition supplementation interventions. Undernutrition has been found to significantly decrease tolerance to chemotherapy, increased infectious complications, and decreased overall survival. However, nutrition support can prevent this by decreasing bone marrow recovery time, which in turn, aids in diminishing toxicity associated with chemotherapy.<sup>41</sup> This is particularly the case

when the supplement's target is the restoration of lean body mass to combat protein-energy malnutrition (PEM).<sup>37</sup> Several studies have reported the beneficial effects of PEM dense oral nutritional supplements like Plumpy Nut that prevent weight-loss in pediatric cancer patients.<sup>41</sup> In the US, in a paper published in as early as 1983, 17 children with Stage IV neuroblastoma, who were committed to a favorable nutritional course during the first 21 days of therapy were reported to have had significantly fewer treatment delays and fewer drug dose reductions throughout the first 10 weeks of treatment.<sup>42</sup> In Malawi, the use of 'chiponde', a ready-to-use-therapeutic food (RUTF), appeared to enhance the pre-operative nutritional status of children with Wilms tumor during chemotherapy and seemed to improve tumor response significantly.<sup>37</sup>

Hence, a nutrition supplement targeted towards this population should be appropriately designed to the local context as evidenced in the qualitative results where Caregiver 07 mentions not being fond of therapeutic milk F75/F100. This can be achieved by either resembling taste of local food, or as an addition to staple meals like incorporating nutrient-rich flour in *uji* (porridge). In addition, based on the qualitative results - it is vital that this intervention is complemented by either educational materials or sufficient training to the providers, and awareness-based counselling to the caregivers so, that the intervention is appropriately implemented.

#### **4.1.2. Intervention No. 2: Nutrition Education materials & training**

As seen in the results of the qualitative data, lack of nutrition education is a leading factor contributing to undernutrition in the pediatric cancer population. This barrier is a concern for both caregivers and key stakeholders at BMC and is further supported by other literature globally. Our study described discrepancies in terms of nutrition knowledge within the stakeholders, while hospital and department leadership claimed to provide recommendations to all pediatric patients coming into the hospital, the nutritionists making the recommendations described that it was impossible to cater to the everyone considering their limited human capital. Likewise, there were discrepancies described between the caregivers and the stakeholders, while 78.5% of stakeholders self-reported that they gave nutrition-related recommendations, only 30% of caregivers reported receiving these recommendations. A report put together by the International Society of Pediatric Oncology (SIOP) PODC Nutrition Working Group discussed the importance of having optimal nutritional status as a child with cancer, as it can have a serious influence on clinical outcomes. The survey encompassed both institutions and stakeholders and reported that only 35% of institutions provided nutrition education to patients and their families. According to the nutritionists interviewed at these institutions, lack of nutrition resources and lack of nutritional knowledge of staff were the main barriers to providing nutrition care in LMIC.<sup>37</sup>



One key evidence-based intervention that can prove effective in the pediatric cancer population are nutritional education materials. Many sources claim that improved nutrition education and assessment tools for doctors and nurses as well as increased availability of nutrition education resources for families and patients can go a long way in alleviating low levels of nutritional literacy in communities worldwide.<sup>43</sup> Specific effects have been seen promoting linear growth when matched with interventions that highlight specific educational messages such as e.g. on consumption of animal source foods that emphasize energy density of the diet.<sup>5</sup>

In a recent paper by Bhutta et al. (2008) Nutritional education in food-secure populations produced an increase in height-for-age Z score of 0.25 (95% CI 0.01-0.49) compared with the control group. In Food-insecure populations, the increase was more effective showing a height-for-age Z score increase by a weighted mean difference of 0.41 (0.05 - 0.76) in the group given nutrition supplements (with or without education) compared with the controls. In areas of food insecurity, where there is often times low consumption of micronutrients - food supplements fortified with micronutrients can have a positive impact on promoting sustainable growth.<sup>5</sup> This evidence showed that education strategies alone were of immense benefit, however, saw substantial results in effectiveness for food-insecure populations when paired with a supplementation program.<sup>40</sup>

### **4.1.3. Intervention No.3: Household Farming**

According to Stakeholder 15, 80% of the population of Tanzania relies on farming for their sources of food. This is also evidenced by the Food and Agriculture Organization of the United Nations, which further iterates that 26.7% of the country's GDP is reliant on agriculture. From the qualitative interviews, 7/10 reported engaging in farming practices for sourcing food. (Table 2) and the quantitative data collected further backed this up as 90.2 % of participants reported that they farm. (Table 4).

Hence, a viable intervention to help combat food insecurity would be to encourage caregivers to engage in home gardening/farming practices specifically for nutrient rich yet hard to access foods like fruits and vegetables. A recent study looked at evaluating home gardening as a promising start for promoting food security in post-conflict Sri Lanka. This paper did a literature review of over 100 publications to develop a theoretical framework for approaching food security, studies mentioned included a research study on home gardens conducted in the early 1930s in java Indonesia, which showed a 18% caloric and 14% protein consumption increase in households in Kutowinangun, Indonesia.<sup>44</sup> Likewise, similar reports were found in Zimbabwe<sup>45</sup> and Bangladesh that discussed how effective home gardens were in fulfilling nutritional needs for those of lower socioeconomic status, and importantly helped to boost diversity of food items and promote overall increase in dietary intake.<sup>46</sup>

One interesting element to promotion of home gardening is the facilitator of community support. Home gardening can prove to be an effective intervention on a community level encouraging food security and comradery not just on an individual level but also on a community level. Hence, home gardens are an eco-friendly, sustainable option for aiding in achieving more optimal nutrition for the pediatric cancer population, by improving overall food security of the community, and while, more time-consuming option, the rewards that can be reaped outweigh the costs.

#### ***4.2. Implications for Policy***

There is clear evidence in literature highlighting the need for more interventions that are accountable for the various risk factors that are associated with nutrition. However, in order to successfully carry out these policies, there is a need for more broader governmental and institutional support by way of policies. In 2013, WHO published a booklet reviewing global nutrition policy, discussing the question of “What does it take to scale up nutrition action?” One of the key takeaways that supports this study discusses that existing nutrition policies do not adequately consider or address underlying and basic causes of malnutrition (e.g. food insecurity, inadequate health service and inadequate care for women and children). One key example of this was that while most countries has relevant policies that included direct interventions yet do not address bigger structural issues such as gender inequality.<sup>47</sup>

One of the bigger takeaways from this study was that one key underlying contributor to undernutrition was the large number of family members per house. Larger families can be linked to poorer socio-economic status and in turn, food insecurity. This is especially true in communities afflicted with gender inequalities where there were limited breadwinners supporting many family members. In addition, with limited education, the income does not often cover the combined expenses of the entire family. This was reaffirmed in a similar study in South Sudan, evaluating prevalence and determinants of undernutrition amongst under-5s, that confirmed large family size and lack of family spacing and two key determinants affecting child nutrition in the region.<sup>48</sup> There are many policies that could be in place to tackle this. In Tanzania, one solution would be the implementation of family planning policies. As of 2015/16, contraceptive prevalence rate in Tanzania is 38.4% which is an incredibly low rate of uptake.<sup>49</sup> Action taken on a policy level to improve family planning services and education may have a positive impact on stabilizing family sizes, improving gender inequality, and hence as a result boosting undernutrition among children. This was corroborated by the WHO global nutrition policy paper that called for the need for “A comprehensive set of interventions addressing the life-course” to be implemented and in addition, many “countries have inadequate coordination mechanisms to address existing nutrition challenges.”<sup>47</sup> Hence, it is vital that nations consider both formulating

but also adopting key policies that landscape reproductive, maternal, and child health as a whole.

### **4.3. Study strengths and limitations**

Although the results were limited to a single institution, the mixed methods approach and simultaneous data collection provides strength to the interpretations, highlighting the need and feasibility of implementing nutritional supplementation, educational materials, and household gardening interventions to improve nutrition in Tanzania. Qualitative data was ample, with the sample size interviewed reaching thematic saturation, and contributed rich context to the issue at hand. The main interviewer for the qualitative interviews: R.G. was the same cultural background as the participants and hence, may have contributed to aiding in making the participants feel more open, and willing to participate in the study and share their opinions.

There are several limitations that may have impacted the results of this study. Firstly, the small sample size of the quantitative group made it difficult to draw any solid conclusion for analysis. The main limitation being that with the sample size of 65 for baseline prevalence, and then 51 from the surveys, it was too small a sample size to derive any significance from. The large p-values reported in tables 3 and 4 indicate either that there is no significance or there is potential significance, but the sample size is too small to detect significance. The small p-values reported on the Wilcoxon Rank Sum Test (Table 3) could suggest alternatively that there is high variance. This limitation was

unfavorable for the application of a logistic regression model due to the low sample size giving inflated odds ratios and 95% confidence intervals. Secondly, the structured nature of the questions together with the lack of knowledge from the caregiver participants, may have prompted response bias during data collection as they required additional prompting and explanation. Power dynamics of having the MSc-GH student in the room during the qualitative interviews, may have also resulted in desirability bias and influenced the responses that were given. In addition, some of the other limitations in the study include not having a control group to compare the prevalence rate with, and a lack of data on the staging info of the pediatric cancer patients at diagnosis.

## **5.0. Conclusion**

The current study is the first to address a gap in the literature on the prevalence and factors contributing to undernutrition for children with cancer in Tanzania and provides evidence-based recommendations for effective and sustainable interventions. Firstly, this study contributes by filling a gaping hole by delivering prevalence data associated with undernutrition for the niche population of pediatric cancer patients in Tanzania. Secondly, the study elaborates on what factors function as barriers and facilitators towards achieving optimal nutrition and informs interventions that could also prove more effective and sustainable when upscaled for the rest of Tanzania and Sub-Saharan Africa as a whole.

# Appendix A: Intake Form for Aim 1

RedCap Survey

**Form: Intake**

1. Enter Patient Identifier [free text box]
2. Enter the Study Site:
  - Mulago Hospital
  - Bugando Medical Centre
3. Completing Form
  - Navigator / Coordinator
  - Research assistant
  - Nutritionist
  - Medical provider
4. Date of intake
5. MRN
6. Age [num]
7. Sex
  - M
  - F
8. Duration of symptoms in months [# ]
9. Abdominal Distention
  - Yes
  - No
10. Other visible mass
  - Yes
- i. Location: \*\*can select multiple
  1. Eye
  2. Face
  3. Extremity
  4. Other [free text]
  - no
11. Patient Height today in centimeters [XXX]
12. Patient Weight today in Kg [XXX]
13. Upper Arm Circumference in centimeters [XX]
14. Triceps skin fold thickness in centimeters [XX]
15. Abdominal circumference in centimeters [XX]
16. Head circumference (<1 yo) in cm [XX]
17. Albumin level [XX , units of measurement]
18. Protein level [XX , units of measurement]
19. Hemoglobin [XX , units of measurement]
20. MCV [XX , units of measurement]



21. Primary Tumor Measurement
- Tape Measure in centimeters
    - i.Measurement 1 [XX]
    - ii.Measurement 2 [XX]
  - Ultrasound Tumor Measurement in centimeters (leave blank if no recent ultrasound) [free text box]
    - i.Measurement 1 [XX]
    - ii.Measurement 2 [XX]
  - CT Tumor Measurement in centimeters (leave blank if no recent CT) [free text box]
    - i. Measurement 1 [XX]
    - ii. Measurement 2 [XX]
22. Best Diagnosis [free text box]

## Appendix B : Quantitative Survey

Participant ID# \_\_\_\_\_

Age of caregiver \_\_\_\_\_ Sex of caregiver: Male | Female

Age of child \_\_\_\_\_ Sex of child: Male | Female

What is the patient's status : Inpatient Outpatient

What is the caregiver's relationship to the child? 1. Mother 2. Father 3. Sibling 4. Grandparent 5. Aunt/Uncle 6. Other \_\_\_\_\_

What is the caregiver's primary occupation? 1. Peasant/Farmer 2. Trader/sales 3. Skilled manual labor 4. Professional 5. Household  
6. Student 7. Other \_\_\_\_\_

How much education has caregiver completed? 1. No Education 2. Primary education incomplete 3. Primary complete 4. Secondary  
and more

How many people live in the same house at least half the time? \_\_\_\_\_

How many adults? \_\_\_\_\_ How many children <18 yrs \_\_\_\_\_

Does the family farm? Yes No

Where does patient live? Village : \_\_\_\_\_ District: \_\_\_\_\_ Region: \_\_\_\_\_ Select Applicable: Rural / Urban

How long does it take you to access Bugando Medical Centre from your home? \_\_\_\_\_ hours

How do you get to the hospital? 1.Dala Dala 2.Walking 3.Car 4.Ferry 5. Bus 6.Piki piki 7. Boda Boda

PER1	My child is currently getting a well-balanced diet.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER2	My child has a healthy weight and height.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER3	My child has trouble eating well.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER4	Cancer has affected my child's overall nutrition.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER5	I believe that good nutrition will help improve my child's cancer treatment outcome	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER6	BMC is providing enough food for my child's nutrition.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER7	I believe that my child needs additional nutritional support.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER8	In my community, it's believed that certain foods should not be eaten if you have cancer.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER9	I think my community would benefit from learning more about nutrition.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER10	My child is currently getting all the necessary nutrients.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER11	Sometimes, I feel like I'm a bad parent because I'm not able to provide my child with enough food.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
PER12	I believe my child is getting adequate food.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
KU1	I believe I have adequate nutritional knowledge to take care of my child	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
KU2	I received adequate nutrition education from my child's care team.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
KU3	My child received follow up care regarding their nutritional status.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)

KU4	I believe it is good to give different types of food to my child	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
KU5	It is enough to feed my child three times a day.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA1	It is difficult for me to give different types of food to my child	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA2	The kind of food I want to give my child is not available where I live/at the hospital	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA3	It is difficult for me to feed my child three times a day	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA4	There's not enough food to feed my entire family.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA5	I can't afford to buy fruit and/or vegetables	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA6	Money impacts my ability to provide adequate nutrition for my child.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA7	The distance of my home from BMC impacts my ability to feed my child.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)
FIA8	I am worried that my child does not get enough food to be healthy.	Never (0)	Rarely (1)	Sometimes (2)	Often (3)	Always (4)

## Appendix C: Patient Interview Script

### Patient Evaluation: Interview Script

I'd like to start by thanking you once again for participating in this interview for my study. As I have mentioned before, we are trying to understand what people know about nutrition, where people get their food from, and what types of food our patients typically eat. We are trying to understand this so that we can see what type of nutrition support might be most helpful for our patients. This interview will last approximately an hour and will be recorded using this voice recorder.

Do you have any questions before we begin? Please feel free to stop me at any time if you have any questions.

To start, where are you from (what ward/ district)?
Do you live with your child?
How many people live in your household with your child?
At home, where do you normally get the food that you eat? <ul style="list-style-type: none"> <li>• If answer is farm: What do you grow? If answer is market/other: How often do you purchase/what do you buy?</li> <li>• How do your friends, other families, and neighbors get food the same way too?</li> </ul>
How many meals do you have in a day? -how many meals does your child have in a day?
How many meals would you like to try to eat per day?
Are there any foods that your child eats on most days of the week?
What are their favorite foods to eat? -What foods do they not like to eat? – Why?
Are there certain foods that you avoid feeding your child because of their cancer diagnosis?
Are there certain foods that you eat more of because of your child's cancer diagnosis? - (if yes to either question above) What influenced/motivated this change?
Did the doctor or someone else make recommendations for your child's diet/nutrition? What were these recommendations?
How would you describe the word "nutrition"?
How would you define "good" nutrition?

Do you think receiving “good” nutrition is a problem for your child? If yes, why? If no, why not?
Are there any things that make it more difficult for you to have good sources of nutrition for your child? Prompt: Do you have problems getting food? Financially?
Do you think your child’s recovery is affected by nutrition? If yes, explain more? If no, why do you think your child’s recovery is not impacted by nutrition? Have you ever been admitted to BMC?
If yes, What types of food did your child eat while admitted? How often / day did they received meals?
Have you heard about nutritional supplements? -If yes, what do you know about nutritional supplements? If no, explain that a nutritional supplement will consist of a small meal such as a bowl of ugali etc. rich in essential nutrients to supplement the child’s diet.
Have you used, or do you know someone who has used a nutrition supplement before? If yes, why did you/he or she take it? What do you know about it? Did your/they’re child like it?
Would you be interested in us providing your child with a nutritional supplement? Why or why not?
How might a nutrition supplement help your child?
Do you have any concerns about giving your child a nutrition supplement?
Who do you think are the key people that need to be involved to implement this nutrition supplement?
What do you think will make this nutrition supplementation intervention successful at Bugando?
We’ve come to the end of the interview. Thank you so much for your participation. Is there anything else that you’ll like to add?

## Appendix D: Stakeholder Interview Script

### Stakeholder Evaluation: A semi-structured questionnaire

I'd like to start by thanking you once again for being willing to participate in this interview for my study. As I have mentioned before, my study seeks to understand what your perceptions are about nutrition, and looks at how you access food, what food is available, and your opinions on the acceptability of a nutrition supplement etc. The aim of this study is to help in understanding the feasibility of the implementation of a nutritional supplement for pediatric cancer patients at Bugando Hospital. This interview will last approximately an hour and will be recorded using this voice recorder.

Do you have any questions before we begin? Please feel free to stop me at any time if you have any questions. I would be more than happy to answer them.

Could you please start out by sharing what you do here at Bugando Medical Centre?
In your role do you provide nutrition/diet recommendations for the patients?
How would you define nutrition?  If adequate definition is provided, then proceed to next question. If not, then define nutrition as [providing food or nourishment necessary for life] for the next few questions.
In your opinion, what leads to poor nutrition for pediatric cancer patients? (If only disease is mentioned, prompt additional question) - Are there any factors outside of their disease that might influence their nutrition?
Do you think nutrition is a problem with the patients that are being seen at Bugando? If yes, why? If no, why not?
What kind of food is currently served at Bugando for the patients who are admitted? How often is food served? What is the typical food that our patients might eat if they were not admitted?
Are there certain foods that are encouraged or discouraged from being consumed by the patients on account of their cancer diagnosis? What exactly?
What barriers do these children have to access nutrition-rich foods - <ul style="list-style-type: none"> <li>• While admitted at Bugando hospital?</li> <li>• As an outpatient?</li> </ul>
What do you think Bugando can do to make this it easier for patients to have better nutrition – <ul style="list-style-type: none"> <li>• While admitted at Bugando hospital?</li> <li>• As an outpatient?</li> </ul>

Have you heard about nutritional supplements? If yes, what have you heard about them? If no, provide definition “A nutritional supplement will consist of a small meal such as a bowl of ugali etc. rich in essential nutrients to supplement the child’s diet” and then, proceed with questions.
Are you aware of any current nutrition supplements/specialized diet plans available for the pediatric cancer patients? If yes, what are they?  What are your thoughts on providing a nutritional supplement for all patients?
What are some things that might prevent an intervention for a nutritional supplement at BMC? (availability of food, resources, time).
What are the resources needed to start a nutrition supplementation intervention here for patients? (people, time, money, equipment, space)?
Are you aware of any government incentives for BMC to provide a nutritional supplement to patients?
Who are the key people that need to be involved to conduct this nutrition supplementation intervention?  Do you think people at BMC would be interested in having a nutrition supplement? Why?
Would additional training be required to start a nutritional supplement program? If yes, what kind and for who?
What do you think will be the best way to measure the effectiveness of the nutrition supplementation?
Thank you for your participation, do you have any other questions/comments?



## Appendix E: Codebook Matrix for Qualitative Interview

Themes	Description	
Food Insecurity	Having no/poor access to food, not being able to afford food/nourish child. Food not being available (whether specific or not). Not having enough food for the family/said person whether through institutional, personal barrier.	
Illness/Cancer-specific	Cancer-specific matters/issues.	
Nutritional Knowledge	B - Lack of understanding of nutrition/appropriate knowledge on nutrition/food choices/practices	F - Good Understanding of gaps/need for proper nutritional knowledge/access to good sources or foods
Diet and Eating behaviors	Food-specific - mentions of food, food choices, issues, dietary matters.	
Resources	Discussion of resources, whether time, space, human capital etc.	
Access and Availability of NS	NS and details to do with access, availability	
Feasibility of NS	Effectiveness, Acceptability, and potential application of NS	
Community Support	F- Support for better nutritional steps	
Annotate for Emerging Topics		

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