

The Impact of a Hostel on Outcomes for Pediatric Cancer Patients in Northern Tanzania

by

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Thesis submitted in partial fulfillment of
the requirements for the degree of
Master of Science in the Duke Global Health Institute
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2019

ABSTRACT

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Abstract

Background: There is a significant disparity in survival rates for pediatric cancer in low and middle-income countries compared to high-income countries. A variety of factors contribute to this disparity including late stage disease at presentation, high rates of abandonment of care, and lack of supportive care. In Mwanza, Tanzania, a residential hostel was created to reduce these barriers among patients being treated for childhood cancer at Bugando Medical Centre (BMC). This study explores the potential benefit of the hostel in terms of event free survival and quality of life and examines the barriers and facilitators for completing care and the perceptions of the hostel. **Methods:** The study had three major components. A medical record review was conducted for 229 patients who presented to BMC in 2016-17, looking at survival outcomes. Surveys were collected from patients and caregivers who presented in 2018. In-depth interviews were conducted to explore patient/caregiver experiences. Data was collected at BMC and was analyzed with survival curves, hazard models, logistic regression, t-tests and applied thematic analysis. **Results:** One-year EFS was not significantly different for patients who presented to BMC before the hostel opened compared to those that presented after the hostel opened. However, a proportional hazard model showed a significantly lower hazard for patients that stayed at the hostel compared to patients that did not. Participants that stayed at the hostel also scored significantly higher in emotional functioning compared to patients that did not stay at the hostel. In-depth interview participants highlighted barriers and facilitators for completing care and described the benefits of the hostel including psychosocial support and reduced financial burden. **Conclusions:** Higher one-year event free survival and better scores in emotional wellbeing were observed for patients that stayed at the hostel. Caregivers and patients shared positive perceptions of the hostel as a facilitator for completing care. Key supportive care programs such as a hostel can be beneficial for improving pediatric cancer outcomes in LMICs.

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1. Introduction:

1.1. Pediatric Cancer in LMICs

Globally, an estimated 400,000 children are diagnosed with cancer each year (Ward et al., 2019). Low and Middle-Income countries (LMICs) bear approximately 80% of the burden of pediatric cancer, however only 5% of the global resources for pediatric cancer are spent in LMICs (Howard et al., 2007). The burden of non-communicable diseases such as cancer, is increasing in low and middle-income countries (LMICs) (Rodriguez-Galindo et al., 2013). This is due to a variety of factors including an epidemiological transition as infectious disease are brought under better control. Although pediatric cancer does not share the same risk factors as the major adult NCDs such as cardiovascular disease and diabetes, epidemiologists still expect increases in pediatric cancer as detection improves and infectious diseases decrease.

Health systems in LMICs are poorly prepared to respond to the rising tide of NCDs, including cancers. Partnerships between hospitals and universities in high-income and low-income countries can be utilized to set up centers of excellence in pediatric cancer treatment. Implementation science research is needed to determine the best practices to treat cancer in an efficacious and cost-effective way in LMICs. One such collaboration is between Bugando Medical Centre (BMC) and the Duke Global Health Institute to improve quality and capacity for pediatric cancer treatment in Northern Tanzania.

1.1.1 Pediatric Cancer Outcomes

There is a large disparity in survival rates for pediatric cancer in LMICs compared to HICs. High-income countries achieve survival rates for pediatric cancer of around 80%, while survival for pediatric cancer in LMICs is between 5% and 25% (Schroeder et al., 2017). Many patients in LMICs do not have access to pediatric cancer treatment. However, even when pediatric cancer care exists, the disparity in treatment outcomes remains. There are a variety of reasons for this gap including late stage disease at presentation, high rates of abandonment of

care, high rates of malnutrition, lack of supportive care, lack of palliative care, and limited access to curative therapies (Rodriguez-Galindo et al., 2013). Among patients who access pediatric cancer care, abandonment of care is one of the most significant factors leading to poor treatment outcomes. According to Galindo-Rodriguez et al. (2013), abandonment of care affects 50-60% of pediatric cancer patients on average in LMICs, but abandonment rates vary between treatment centers. Socioeconomic factors, healthcare providers attitudes and communication and availability of supportive care are major contributors to treatment abandonment in LMICs as shown by Galindo-Rodriguez (2013).

1.1.2 Interventions to Improve Pediatric Cancer Outcomes

Several studies have examined the impact of programs aimed to reduce treatment abandonment in LMICs. A study in Guatemala showed that the patient support provided by a multidisciplinary psychosocial team resulted in a significant reduction in abandonment of care (Alvarez et al., 2017). Another study in India found that financial assistance coupled with focus group counselling lead to a significant decrease in abandonment of care for pediatric cancer patients. The intervention was rolled out in phases. Financial assistance alone did not results in a significant reduction in abandonment, but financial assistance along with counselling did (Alam & Kumar, 2019).

Research was conducted at Ocean Roads Cancer Institute (ORCI) in Dar es Salaam looking at strategies to improve treatment outcomes for pediatric cancer (Kersten, Scanlan, DuBois, & Matthay, 2013). A variety of improvements were made in pediatric cancer care at ORCI from 2008 to 2011 including standardization of treatment regimens, improved staffing, and the opening of a hostel for patients and caregivers. These improvements resulted in higher EFS and a low level of treatment abandonment of 8% during the study period. Findings from Kersten et al. (2013) suggest that a hostel may decrease treatment abandonment, however, it is difficult to disentangle the effect of the hostel from other changes that were made during the study period.

Malnutrition has also been identified as a contributor to poor treatment outcomes for pediatric cancer patients in LMICs. A study conducted in six Central American countries found that 50-70% of pediatric cancer patients were malnourished at diagnosis and that malnourished children were more likely to abandon care and have lower event-free survival (Sala et al., 2012). Nutritional support may be necessary to improve treatment outcomes for childhood cancer in LMICs.

1.2 Supportive Care

To bridge the gap between treatment outcomes for pediatric cancer in high resource countries compared to low resource countries, both biomedical considerations and the social determinants of health need to be addressed. Thus, supportive care programs are a crucial component of improving pediatric cancer outcomes. The supportive care framework is a resource for cancer care providers to identify and meet patients' supportive care needs (Fitch, 2008). The supportive care framework defines supportive care as, "the provision of the necessary services for those living with or affected by cancer to meet their informational, emotional, spiritual, social or physical need during their diagnostic treatment or follow-up phases encompassing issues of health promotion and prevention, survivorship, palliation and bereavement (Fitch, 2008)." There is significant diversity in supportive care programs depending on what area of patient wellbeing they are targeting.

An important example of a supportive care program for childhood cancer patients is The Ronald McDonald House Charity (RMHC). RMHC is an international non-profit organization which provides free accommodation for childhood cancer patients and their families during cancer treatment. Ronald McDonald houses serve patients in many countries around the world, however there is only one RMH in Africa and it is in South Africa. Studies have shown a number of positive impacts from Ronald McDonald houses including reduced financial burden, improved

access to care by meeting accommodation needs, improved psychological wellbeing reported by the family, and enhanced patient quality of life (“Impact Statement”).

1.3 Setting

Bugando Medical Centre (BMC) in Mwanza, Tanzania is one of three hospitals in Tanzania that treat children with cancer. Mwanza is located on the southern shore of Lake Victoria in Northern Tanzania, is the second largest city in Tanzania with a population of approximately 440,000 (“Population of Cities in Tanzania (2018)”). Tanzania is a low-income country with 26.9% of its population living on less than \$3.20 (World Bank).

BMC is a 900-bed regional referral hospital serving a catchment area of more than 15 million people in the Lake Zone of Tanzania (Esmaili, Stewart, Masalu, & Schroeder, 2018). In 2009, BMC opened a new oncology center and began an effort to strengthen oncology services. Approximately 200 new pediatric cancer patients are seen each year at BMC. Basic diagnostic testing is available at BMC and chemotherapy and surgery are used to treat pediatric cancer (Schroeder et al., 2017). Radiation services are not yet available for children at BMC. The oncology department at BMC plans to continue building capacity to improve the medical care provided. Based on previous research conducted at BMC the following are the most common types of pediatric cancer diagnosed in Tanzania: Burkitt’s Lymphoma, Hodgkin’s Lymphoma, Non-Hodgkin’s Lymphomas, Acute Lymphoblastic Leukemia (ALL), Retinoblastoma (Schroeder et al., 2017).

1.4 The Intervention

A study conducted at BMC in 2017 identified abandonment of care as a major impediment to achieving successful treatment outcomes (Schroeder et al., 2017). The study also found that greater distance traveled by patients was significantly associated with increased treatment abandonment. To address this specific barrier, a hostel was introduced in collaboration with ICCARE (The International Cancer Care and Research Excellence Foundation), a non-

government organization (NGO) that provides assistance for pediatric cancer care in Tanzania ("ICCare"). ICCARE identified a hostel as an intervention which would supporting patients, particularly patients who traveled long distances to receive care, with the goal of improving treatment outcomes.

A hostel has been opened to support patients being treated for childhood cancer at BMC. The hostel is a house where pediatric cancer patients and a parent or guardian can stay for free during treatment. The hostel was opened in May of 2017 and is supported by ICCARE. Similar to a Ronald McDonald House, the hostel provides accommodations and support for parents or guardians for free while children are undergoing outpatient treatment. The hostel has capacity for 9 patients and caregivers and has four bedrooms, a kitchen and living room. The hostel is staffed by a full-time in-house nurse, a cook and a social worker. Informal education and counseling occur at the hostel.

When pediatric cancer patients are first received at BMC, they are asked if they have a place to stay locally and if not, they are referred to the hostel. Patients and parents are provided basic information about cancer, and the children participate in art projects two days per week and review of school subjects 3 days per week (for example, math and reading). The length of stay at the hostel varies depending on the patient's and family's situation. The hostel is located about a kilometer away from BMC.

1.5 Study Goal and Aims

The overall goal of this study was to explore the impact of a hostel on outcomes for pediatric cancer patient at Bugando Medical Centre. The study had three specific aims. The first aim was to compare pediatric cancer survival rates for patients who presented before the hostel opened to patients who presented after the hostel opened, as well as to compare survival between patients that stayed at the hostel and patients that did not. Outcomes for this aim included one-year event free survival (EFS) as the primary outcome, and nutritional status as a secondary

outcome. The second aim was to assess the impact of the hostel on quality of life and knowledge of pediatric cancer for patients and their parent or guardian as compared to patients who did not use the hostel services. The third aim was to examine barriers and facilitators for completing cancer treatment and participants perceptions of the hostel. In-depth interviews were used to explore the third aim. The study aims, and their corresponding methods and measures are summarized in *Table 1*.

Table 1: Study aims, methods and outcomes

| Aims | Methods | Measures |
|---|-----------------------|---------------------------|
| Aim 1. Estimate the impact of a hostel on pediatric cancer health outcomes. | Medical Record Review | Health Outcomes |
| Aim 2. Assess the impact of the hostel on quality of life and cancer knowledge for pediatric cancer patients and their parent or guardian. | Surveys | Patient Reported Outcomes |
| Aim 3. Examine barriers and facilitators to completing care, and the perceived role and impact of the hostel. | In-depth Interviews | Patient Reported Outcomes |

2. Methods

2.1 Overview

This study used a mixed methods approach. The impact of the hostel on health outcomes was examined through a medical record review and the impact of the hostel on patient reported outcomes was explored through surveys and in-depth interviews. Medical record review was conducted for patients who started treatment in the year before the hostel started, compared to patients who started treatment in the seven months after the hostel opened.

One-year event-free survival was the primary outcome. Event free survival (EFS), includes death and abandonment of care as events. For this study we defined abandonment of care as leaving active treatment for more than 4 weeks. For one-year EFS, the first event is used. Patients may abandon care and then die sometime later, or they may abandon care and still be alive. Vital status after abandonment is sometimes know but usually unknown. Although not considered an event for 1-year EFS, loss to follow up is also important to consider. Loss to follow up is defined as completing treatment but not coming to follow up appointments and being unreachable by phone. Overall survival (OS) only counts deaths as events.

Quality of life and cancer knowledge and nutrition were secondary outcomes. A pediatric quality of life survey (PedsQL) and cancer knowledge survey were used. These patients were diagnosed and started treatment in 2018. In-depth interviews were also conducted. The comparison group for surveys and interviews was 2018 patients who have not stayed at the hostel. Data was collected at BMC and at the Pediatric Cancer Hostel from May of 2018 to December of 2018. *Figure 1* shows how participants were selected for the retrospective medical record review and surveys.

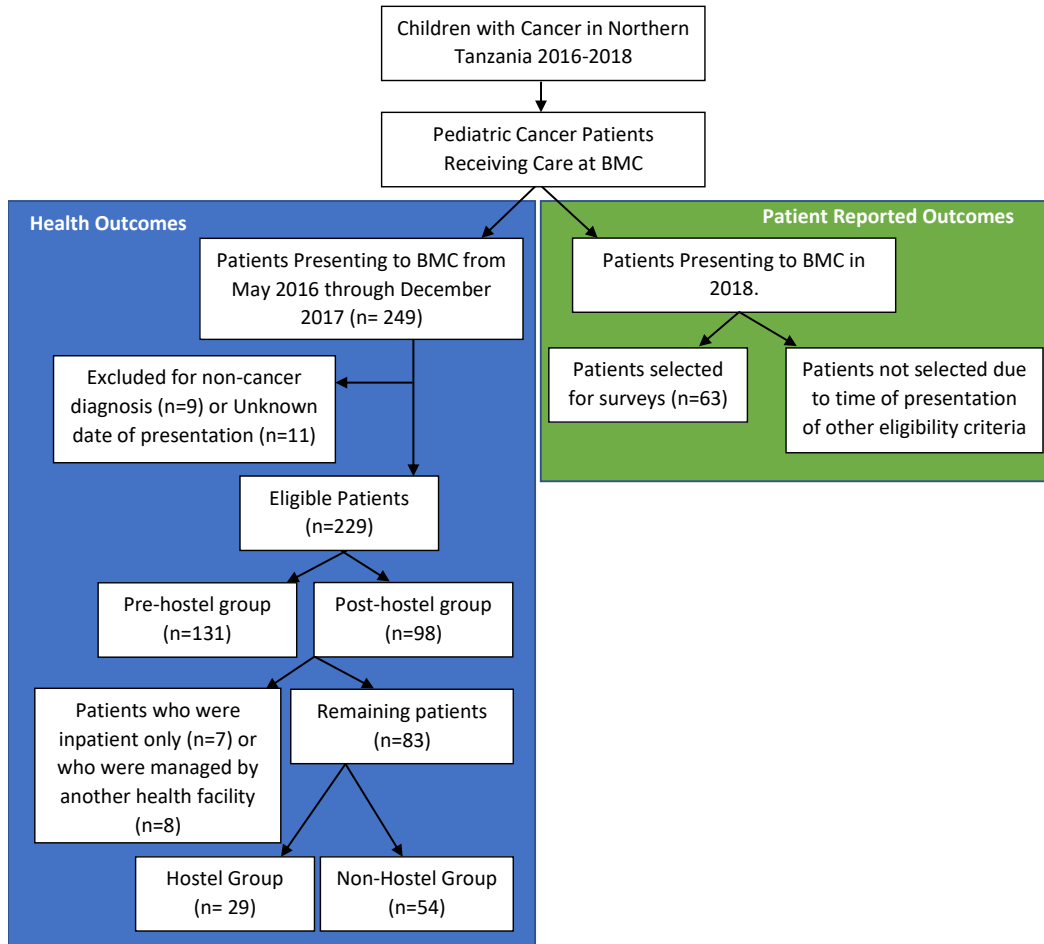


Figure 1: Participant Selection for Aims 1 and 2

2.2 Medical Record Review: Aim 1

2.2.1 Sample for Medical Record Review

A medical record review was conducted to determine the 1-year EFS for patients seen at BMC directly before and after the hostel was opened. Records were reviewed for all patients seen for pediatric cancer at BMC between May of 2016 and December of 2017. The hostel was opened in May of 2017. The pre-hostel group consists of patients who presented to BMC between May of 2016 and April of 2017. The post-hostel group consists of patients who presented to BMC between May of 2017 and December of 2017. This timeframe was chosen to reduce the likelihood of confounding over time and we are not aware of any other changes made to pediatric

cancer care at BMC during this period. Patient outcomes were assessed during the first year. Eligibility criteria for the medical record review included a physician confirmed cancer diagnosis and receiving care at BMC during the study period. 229 patients were included in this analysis; 131 in the pre-hostel group and 98 in the post hostel group. Of the 98 patients in the post hostel group, 29 patients stayed at the hostel and 69 did not. A power calculation was done using Stata 15 during the research design stage, assuming 80% power, and an alpha of 0.05.

Demographic information such as sex, age and diagnosis were collected from medical records. Diagnoses was confirmed through a clinical and diagnostic exam by a physician or histology and pathology findings when available. The village, district and region of residence of each patient was recorded as part of the standard of care by the pediatric oncology support team at BMC. Using GIS mapping, the distance from a patient's home village by roads was calculated and the associated travel time (courtesy of Luke Maillie). When the only available route was by ferry, such as for Ukerewe Island, distance was calculated based on the ferry route. If the patients home village could not be located, the geographic center of their district of residence was used.

2.2.2 Medical Record Data Extraction

Data extraction was done by the primary investigator (PI) and entailed reviewing medical charts at BMC, as well as other records compiled by the pediatric oncology team at BMC. Data on date of presentation, vital status after one year, time of event, as well as demographic information were collected. Data on height, weight, hemoglobin and MCV were also collected. Hostel records were reviewed to obtain data on patients use of the hostel. Data was triangulated between sources whenever possible to ensure accuracy.

2.3 Surveys: Aim 2

2.3.1 Sample for Surveys

Individuals were eligible for the surveys if they had a physician confirmed cancer diagnosis, were receiving cancer care from BMC, within 1-6 months after the date of presentation

to BMC for cancer care and spoke English or Swahili. Surveys were conducted between June and November of 2018. A convenience sample was used where all eligible participants who presented to the oncology clinic during the study period were asked to complete a survey. Surveys were primarily completed by the patients' parent or guardian. Caregivers were asked about their knowledge of cancer and their child's quality of life. Patients between the ages of 13 and 18 were asked to complete the survey themselves if they felt comfortable doing so. A power calculation was done using Stata 15. A sample size of 63 survey responses allows the detection of a meaningful difference in cancer knowledge and quality of life at the levels of 80% power and 95% significance level.

2.3.2 Survey Data Collection

Data collection for surveys was done by two research assistants who were fluent in Swahili and English and were trained in the data collection procedure. Their knowledge of local culture as well as clinical care enabled them to engage participants respectfully and ethically and brought useful insight to the study. The quality of life survey (PedsQL) was developed by Dr. James Varney and is a commonly used survey for assessing quality of life for pediatric patients ("PedsQL TM"). The PedsQL SF15 was translated into Swahili for use in Kenya by Terer et al. (2013), and it was adapted to Tanzanian Swahili by a skilled translator at BMC. The PedsQL asks about how often the patient has had problems with a variety of activities. Responses are recorded using a 5-point Likert scale from 0 (never) to 4 (almost always). Five version of the PedsQL were used including parent-proxy report for children ages 2-4, 5-7, 8-12 and 13-18 as well as a patient self-report survey for patients 13-18.

The cancer knowledge survey was a 10-question survey covering basic information on the characteristics of cancer as well as cancer signs, symptoms and treatment. The survey was adapted from a survey used by Kathryn McHenry, a researcher who had previously studied cancer knowledge in Mwanza Region. The cancer knowledge survey is included in the appendix.

Survey participants provided demographic information at the start of the survey. Demographic information collected included patients age and sex, caregivers age and sex, patient's diagnosis, caregiver's occupation, the number of children in the household, and frequency of hospital visits.

2.4 In-depth Interviews: Barriers and Facilitators

2.4.1 Overview of In-depth Interviews

Semi-structured in-depth interviews were conducted to explore patients' journey to receiving cancer treatment, barriers and facilitators to completing cancer treatment, and perceptions of the hostel. Interviews were conducted between May and August 2018. Three groups of participants were included: pediatric cancer patients who have stayed at the hostel, pediatric cancer patients who have not stayed at the hostel, and healthcare workers involved in caring for pediatric cancer patients at BMC in Mwanza. In-depth interviews were used to gain a more nuanced understanding of the experiences of pediatric cancer patients, including challenges and facilitators to completing treatment, and perceptions of the hostel.

2.4.2 Sample for In-depth Interviews

Eligibility criteria for interview participants included a physician confirmed diagnosis of cancer, the patient being 18 years of age or younger, receiving treatment at BMC and speaking Swahili or English. If the patient was under the age of 12 then the parent would be interviewed in place of the child. Participants under the age of 12 were excluded because of ethical and developmental considerations. Children between the ages of 13 and 18 are considered in early adolescence and are more cognitively developed and less vulnerable than younger children and thus were included in interviews ("The Child Interview"; Williams et al., 2012). For children over the age of 12, parents and the child were interviewed as a dyad.

A non-random sampling was used to select interview participants. In the study proposal, a sampling strategy was developed where every third eligible patient/caregiver would be

interviewed after their clinic visit at BMC. However, due to the simultaneous demands facing research assistants of providing medical services as well as working on data collection, this sampling frame was not feasible; instead, a convenience sample of patients was interviewed. When the interviewer was not busy with other clinical tasks, they would conduct an interview. Caregivers and patients were asked to participate after their regular scheduled clinic visit. The interviewer strove to interview both patients who had stayed at the hostel, and patients who had not stayed at the hostel. Interviewing was stopped when preliminary transcript review showed that thematic saturation had been reached.

To gain different perspectives we interviewed different types of healthcare workers who are involved in pediatric cancer care. Inclusion criteria for healthcare workers included being regularly involved in the medical or supportive care of pediatric cancer patients. Several participants were selected from BMC including nurses and doctors as well as staff at the hostel. Healthcare providers that work consistently with pediatric cancer patients were selected for interviews.

2.4.3 In-depth Interview Data Collection

Interviews were conducted by a research assistant who was fluent in Swahili and trained in qualitative methods. The interviewer was also trained on using the interview guide. Unique but overlapping interview guides were used for each of the three groups: patients staying at the hostel, patients not staying at the hostel, and healthcare providers involved in pediatric cancer care. Interview guides were developed based upon a literature review of factors effecting pediatric cancer patients in low-income countries. Guides were structured around the domains of challenges faced by patients in completing treatment, facilitators for completing treatment, perceptions of the hostel, and social support. Interview guides included open ended questions followed by several possible follow-up questions or probes. Interview guides were translated into Swahili by an experienced member of the research team. Interviews were audiorecorded with

participant consent, transcribed in Swahili, and then translated into English. Interviews were conducted in private, in the research office in the oncology building at BMC, or in a private room in the hostel. All translations were done by a member of the research team. Interviews lasted from 15 to 30 minutes.

Prior to data collection, three pilot interviews were conducted and transcribed. The interview guides were revised in an iterative process with revisions occurring after the pilot interviews and then again after conducting five interviews. When revisions were needed the PI and interviewer discussed the transcript and made changes to improve the clarity and focus of questions and the guide structure. Feedback was also given to the interviewer on interviewing technique. A sample interview guide can be found in the appendix.

Children over the age of 7 years were asked to do a simple drawing activity during the interview. Body mapping is a way for people to visually show aspects of their lives, like experiences and identity. A modified version of body mapping was used where a sheet of paper with an outline on it was provided and participants were asked to fill in the figure. After completing the drawing, the interviewer asked the participant to explain what they had drawn. The researcher took notes on the participant's explanation. Nine body-map drawings were collected and analyzed to support themes that emerge from the in-depth interviews.

2.5 Data Analysis

2.5.1 Medical Record Review: Health Outcomes

Health outcome data including the survival data and nutrition data were analyzed using R studio. Data was examined using Kaplan-Meier curves and cox proportional hazard models. A logistic regression was also used to examine factors contributing to death or abandonment of care. A sub-analysis was done looking at survival rates for patients in the post-hostel group who stayed at the hostel versus those that did not. An exploratory analysis of nutritional entailed calculating descriptive statistics and visualizing data trends.

A second sub-analysis was done with the post-hostel group to examine potential confounders. This analysis excluded patients who only received inpatient care and never had a chance to stay at the hostel. Patients who were transferred to Muhimbili national hospital or whose care was received at Sengerema hospital were also excluded from this sub-analysis.

2.5.2 Surveys: Patient Reported Outcomes

Data from surveys were analyzed using R studio. Two sample t-tests were used to compare the scores for the knowledge survey and PedsQL for patients that stayed at the hostel compared to those that did not. Surveys were analyzed by overall score and by section. The PedsQL scores were transformed so the highest possible score is 100 indicating the highest quality of life and the lowest score is 0 indicating the lowest score on quality of life ("PedsQL").

2.5.3 Qualitative Analysis: Barriers and Facilitators

In-depth interviews were analyzed in NVivo 12 using applied thematic analysis (Guest, MacQueen, & Namey, 2012). Based upon review of the first ten transcripts, five domains were identified. These domains included linking to cancer care, challenges in completing cancer treatment, facilitators for completing cancer treatment, perceived role of the hostel and suggestions from participants. Within each domain, an inductive approach was taken to identifying themes and corresponding codes. The resulting codebook included domains as parent codes and associated child codes. The coded data was then queried to synthesize the data and compare between groups. Analytic memos were written for each domain. Peer-feedback was received in developing the codebook. After discussion of the specific aims, interview guides and codebook structure, three transcripts (one from each participant group) were independently coded by two researchers and inter-coder agreement was assessed. From the initial coding, a kappa value of 0.7 was achieved and the remaining transcripts were coded by the primary investigator.

2.6 Ethics

Prior to commencing the study, approval was received from the Institutional Review Boards of Duke University (Protocol ID: 2018-0432), Catholic University of Health and Allied Sciences (CUHSAS), the National Institute for Medical Research (NIMR) in Tanzania, and the Ethics Committee at Bugando Medical Centre (MR/53/100/547). Participants' responses were de-identified, and each participant was assigned a study ID. Data were kept secure on an encrypted computer. Survey and Survival analysis data were compiled in excel and saved in a secure folder on Box. The recordings from the interview were uploaded to a password protected computer, transcribed in Swahili, and then translated into English.

The consent process for surveys and interviews entailed explaining the study and interview process to each participant and providing an opportunity for questions. Written informed consent was obtained before conducting surveys or interviews. Interviews were conducted in a private room, in the oncology building at BMC, or in a private area at the hostel. An observation study design was used because of ethical concerns with randomly selecting which patients are able to stay at the hostel and which are not. Data was de-identified by removing names and patient IDs before analysis to protect patients information.

3. Results

Study findings are grouped into the impact of the hostel on health outcomes from medical record review and the impact of the hostel on patient reported outcomes from surveys and interviews.

3.1 Impact of the Hostel on Health Outcomes

3.1.1 Participant Characteristics

Health outcomes were assessed based on data from 229 patients who received care at BMC for pediatric cancer, including 131 patients who presented to Bugando before the hostel opened, and 98 patients who presented after the hostel opened. Pediatric cancer is a heterogeneous group of diseases with different characteristics, treatments and clinical progressions. *Figure 2* shows the most common types of cancer for patients who received care at BMC from May of 2017 to December of 2017. Of the 229 patients included, 23% were diagnosed with Burkitt Lymphoma, followed by 15% with Wilms tumor, 11% with Non-Hodgkin Lymphoma, 11% with acute leukemia, and 8% with retinoblastoma. Rhabdomyosarcoma, germ cell tumor and hepatoblastoma were also present.

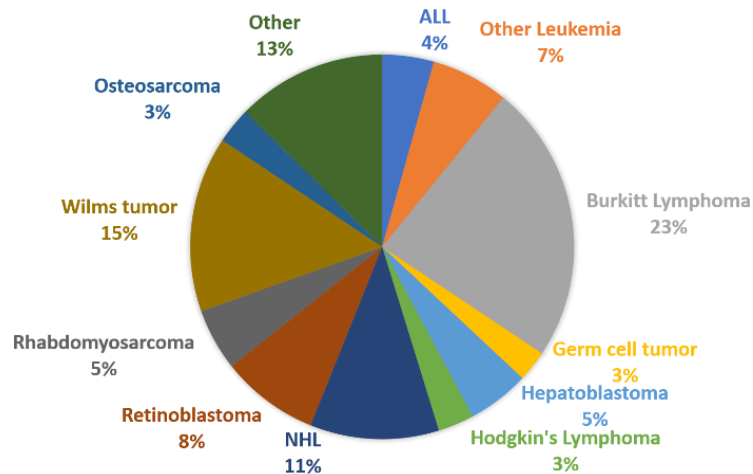


Figure 2: Types of Pediatric Cancer seen in Patients at Bugando Medical Centre from May 2016 to December 2017.

The demographic characteristics of participants in the pre and post hostel groups can be seen in *Table 2*. The average age was 6.68 years in the pre-hostel group and 6.55 years in the post-hostel group and this difference was not significant. The proportion of patients with each type of cancer was also not significantly different between the two groups. There was a higher proportion of females in the post hostel group (64%) compared to the pre-hostel group (49%) and this difference was statistically significant ($p=0.04$). This difference was adjusted for in the analysis.

The average distance traveled for the 229 participants included in the survival analysis was 213.8 km with an average travel time of 3.54 hours. As can be seen in *Table 2*, the distance traveled, and travel time did not differ significantly between the pre and post groups.

Table 2: Demographic Characteristics for Patients Included in the Survival Analysis

| | Pre-Hostel Group (n=131) | Post Hostel Group (n=98) | P-value |
|--------------------------------|-------------------------------------|-------------------------------------|----------------|
| Age (mean) | 6.68 | 6.55 | 0.82 |
| Sex (number of females) | 64 (49%) | 64 (64%) | 0.04 |
| Diagnosis | | | 0.30 |
| Burkitt Lymphoma | 28 (21%) | 26 (26%) | |
| Acute Leukemia | 21 (16%) | 13 (13%) | |
| Wilms tumor | 11 (8%) | 14 (14%) | |
| Non-Hodgkin’s Lymphoma | 13 (10%) | 6 (6%) | |
| Retinoblastoma | 10 (8%) | 9 (9%) | |
| Other | 48 (37%) | 31 (31%) | |
| Distance Traveled (mean in Km) | 218.6 | 207.5 | 0.6 |
| Travel Time (mean in hours) | 3.59 | 3.47 | 0.7 |

3.1.2 Survival for Pre and Post Groups

Health outcomes for the pre and post groups are summarized in *Table 3*. One-year overall survival for all patients included in the study was 39%; 38% in the pre-hostel group and 40% in the post-hostel group. The difference between one-year overall survival was assessed with a chi-

square test and found to be insignificant ($p=0.91$). The one-year event free survival was 29% in the pre-hostel group and 26% in the post hostel group.

For all patients included in the survival analysis, 30% abandoned care. Specifically, 26% of patients in the pre-hostel group and 35% of patients in the post hostel group abandoned care. Abandonment of care was not statistically different between the two groups ($p=0.2$). Overall, 40% of patients died in the first year and 6% of patients were lost to follow up. These results suggest that potential benefits of the hostel are not the results of survival trends over time since one-year EFS is not significantly different for the pre and post hostel groups.

Table 3: One-year survival and abandonment for pre-hostel vs post-hostel groups

| | Pre-Hostel (n=131) | Post-Hostel (n=98) | P-value |
|---------------------|-----------------------|-----------------------|---------|
| Alive | 50 (38%) | 39 (40%) | 0.91 |
| Died | 57 (44%) | 42 (43%) | 1.00 |
| Abandoned | 34 (26%) | 34 (35%) | 0.20 |
| Lost to follow up | 11 (8%) | 7 (7%) | 0.92 |
| Event free survival | 38 (29%) | 26 (27%) | 0.77 |

One-year event free survival for all participants is shown in a Kaplan-Meier curve in *Figure 3*. Consistent with the definition of event-free survival, this survival curve includes death and abandonment as events. From the curve in *Figure 3* it was observed that events tend to occur in the first 150 days after presentation, at which point the curve becomes less steep.

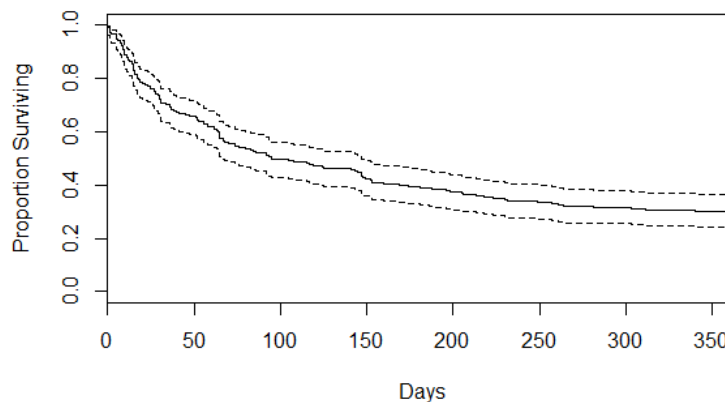


Figure 3: One-year Event Free Survival for 2016 and 2017 patients

Event free survival curves for the pre-hostel and post-hostel groups were compared and can be seen in *Figure 4*. Overall survival curves can be seen in *Figure 5*. The trends seen in each group are very similar. A cox proportional hazards model was used to examine the difference between the survival trends for the pre-hostel group and the post-hostel group. The Proportional Hazard model included one-year event free survival as the outcome. Predictor variables included whether they presented to BMC before or after the hostel opened (prepost), the patients sex (sex) and the patients age (age). Based on visual inspection of the survival curves in *Figure 4*, the proportionality assumption was met. The results of this model are summarized in *Figure 6*. The model yielded a hazard ratio of 1.14 comparing one-year EFS in the pre and post groups along with a p-value of 0.42, suggesting the EFS does not differ significantly between the two groups.

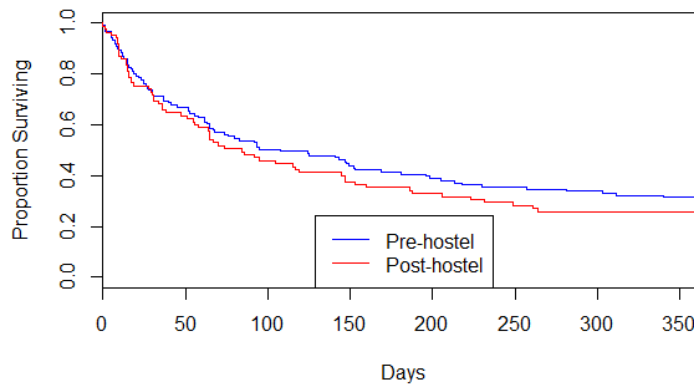


Figure 4: One-year Event Free Survival for the pre-hostel and post-hostel groups

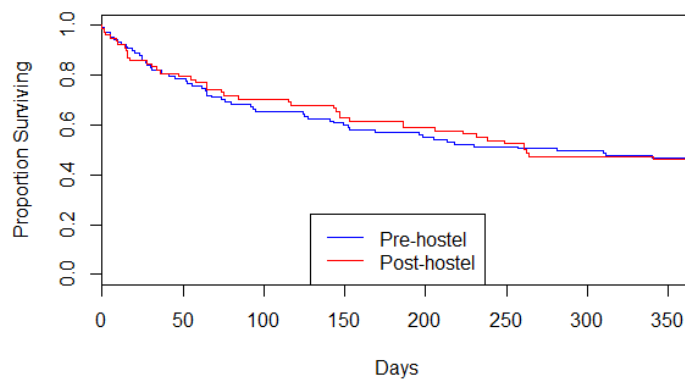


Figure 5: One-year Overall Survival for Pre and Post Groups

Although the pre and post hostel groups differed in the proportion of males and females, we did not find a difference between males and females for one-year EFS, as can be seen in survival curves separated by sex in *Figure 7*. In addition, the cox proportional hazard model showed that sex was not a significant predictor of survival, with a p-value of 0.34 as can be seen in *Figure 6*. Lower age was associated with fewer events but this difference was not significant ($p=0.08$).

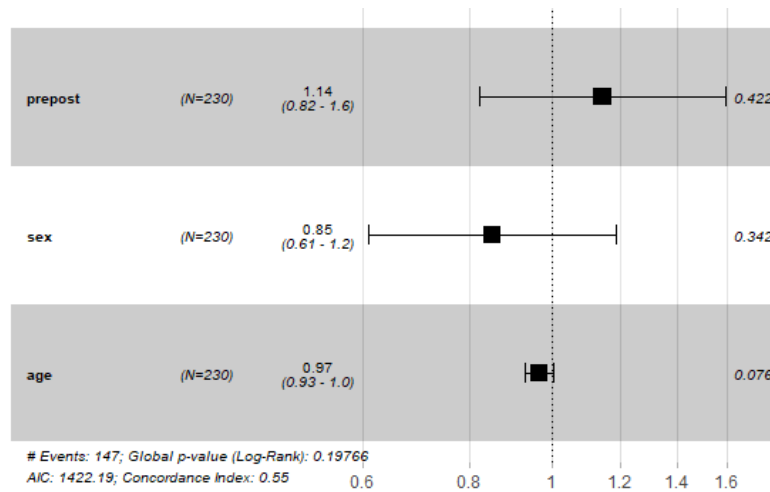


Figure 6: Summary of the proportional hazard model for one-year event free survival

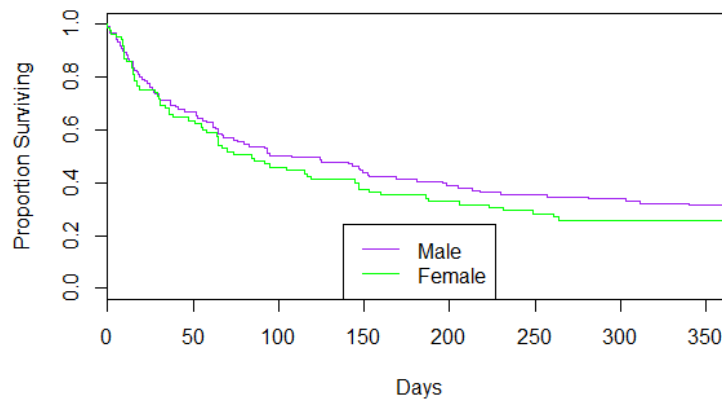


Figure 7: One-year Event Free Survival by Sex

A logistic regression model was used to look at possible predictors of death or abandonment of care. The model included variables indicating whether patients were in the pre or

post group, whether patients had stayed at the hostel, whether the distance traveled was greater than 3.5 hours and whether the patient was male or female. The odds of having an event were not significantly different for the pre-group compared to the post-group. The odds of having an event were also not significantly different for patients whose travel time was more than 3.5 hours compared to those who traveled less than 3.5 hours to get to BMC. In addition, the odds of an event were not significantly different for males compared to females. However, the log odds of having an event decreased by 0.86 for those who stayed at the hostel compared to those that did not. This finding was significant with a p-value of 0.039.

The average distance traveled and travel time for patient who had an event compared to those that did not have an event was not significantly different overall. The distance traveled, and travel time were also not significantly different for the pre or post groups alone as assessed with a two-sample t-test.

3.1.3 Sub-Analysis of Post-Hostel Group

Of the 98 patients included in the post-hostel group, 29 of these patients stayed at the hostel and 69 did not. *Table 4* shows the demographic characteristics of patients who stayed at the hostel compared to patients who did not stay at the hostel in the post-hostel group.

Table 4: Demographic characteristics of patients in the post-hostel group who stayed at the hostel compared to patients that did not stay at the hostel

| | Hostel Group (n=29) | Non-Hostel Group (n=69) | P-value |
|------------------------|------------------------|----------------------------|---------|
| Age (mean) | 6.49 | 6.57 | 0.91 |
| Sex (# of females) | 12 (41%) | 24 (32%) | 0.66 |
| Diagnosis | | | 0.15 |
| Burkitt Lymphoma | 11 (38%) | 15 (21%) | |
| Acute Leukemia | 4 (14%) | 10 (14%) | |
| Wilms tumor | 5 (17%) | 8 (11%) | |
| Distance Traveled (km) | 268.1 | 181.7 | 0.005 |
| Travel Time (hours) | 4.1 | 3.2 | 0.047 |

The distance traveled, and travel time were significantly different for patients that stayed at the hostel compared to those that did not. Patients who stayed at the hostel traveled an average distance of 268.1 kilometers from their home to receive care at BMC, while patients that did not stay at the hostel traveled an average of 181.7 kilometers. A two-sample t-test showed this difference was significant ($p = 0.005$). Patients who stayed at the hostel traveled for an average of 4.1 hours to reach the hospital, compared to an average of 3.2 hours for patients who did not stay at the hostel. This shows that the hostel tends to serve patients who traveled from greater distances to receive care at BMC.

Patients who stayed at the hostel had a one-year event free survival of 38% while patients that did not stay at the hostel had a one-year event free survival of 22%. 31% of patients abandoned in the hostel group compared to 36% of patients in the non-hostel group. Loss to follow up was 7% in both groups. *Table 5* shows the vital status at one year for patients that stayed in the hostel compared to those that did not.

Table 5: One-year Event Free Survival by Hostel Status

| | Hostel Group (n=29) | Non-Hostel Group (n=69) | P-value |
|---------------------|------------------------|----------------------------|---------|
| Alive | 14 (48%) | 25 (36%) | 0.38 |
| Died | 11 (38%) | 31 (45%) | 0.68 |
| Abandoned | 9 (31%) | 25 (36%) | 0.79 |
| Loss to follow up | 2 (7%) | 5 (7%) | 1 |
| Event free survival | 11 (38%) | 15 (22%) | 0.22 |

Survival curves for patients in the post hostel group who stayed at the hostel compared to patients who did not stay at the hostel are shown in *Figure 8* for overall survival and *Figure 9* for event free survival. The survival curve by hostel status shows a steeper curve for the non-hostel group compared to the hostel group. In addition, we see a higher proportion of patients surviving over the course of one year in the hostel group. A second cox proportional hazard model was used to examine hostel status as a predictor of survival for patients in the post-hostel group. The model included hostel status, age, sex and travel time. Results from the model are summarized in *Figure*

10. Those who stayed at the hostel compared to those that did not gives a hazard ratio of 0.55, suggesting that patients who stay at the hostel are less likely to have an event in the first year and this difference was statistically significant ($p=0.04$).

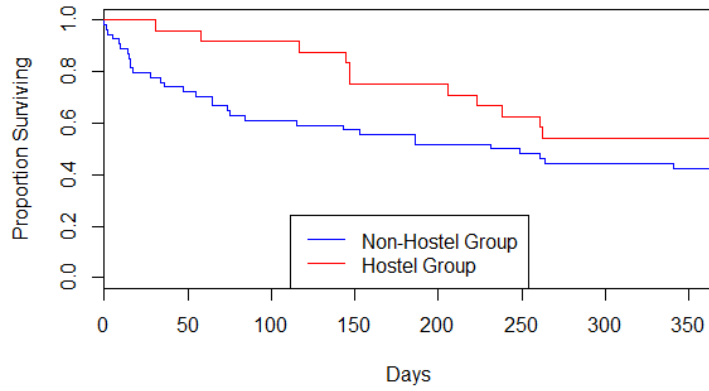


Figure 8: One-year Overall Survival by Hostel Status

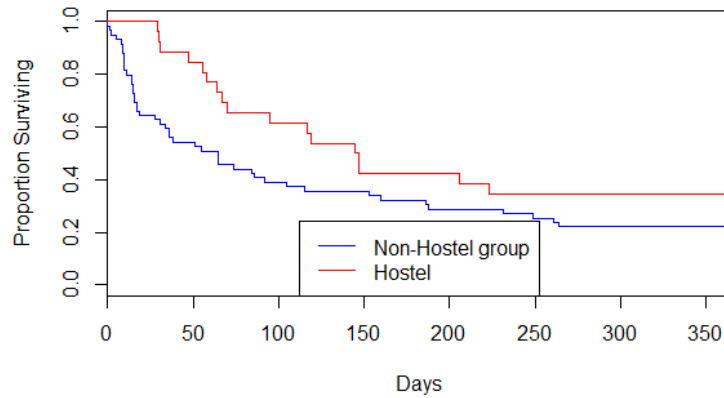


Figure 9: One-year Event Free Survival by Hostel Status

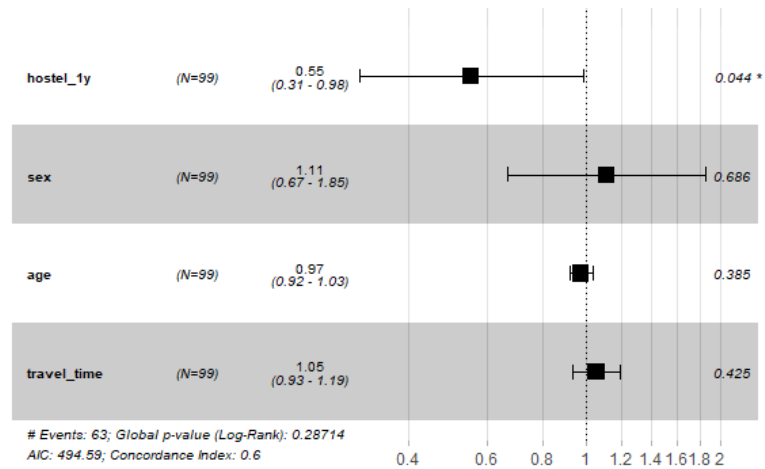


Figure 10: Cox proportional hazard model for post-hostel group only looking at hostel status, sex and age as predictors of one-year event free survival.

To ensure that the hostel and non-hostel groups were comparable, a sub-analysis was done where patients who only received in-patient care and did not have a chance to stay at the hostel were censored (7 patients removed). We also censored patients who were transferred to Muhimbili National Hospital for further treatment, and patients whose care was managed at Sengerema hospital (8 patients removed). *Table 6* shows the health outcomes for the remaining patients. One-year overall survival and one-year EFS remained almost unchanged after censoring these patients. *Figure 11* shows survival curves using the censored data comparing the non-hostel group to the hostel group. The hostel group appears to have a higher event free survival, particularly in the first 150 days.

The same proportional hazard model from *Figure 10* was run with the censored post-hostel sample and results can be seen in *Figure 12*. The hazard ratio comparing patients that stayed at the hostel to patients that did not was 0.55 for the original post-hostel group, and 0.62 for the censored post-hostel group. The sample size was smaller for the censored group (n=83), and the difference in survival was no longer statistically significant (p=0.115). However, because of the similarity in the hazard ratios, this finding seems to be trending towards significance.

Table 6: Health outcomes for patients who stayed at the hostel compared to those that did not excluding patients who did not have an opportunity to stay at the hostel

| | Hostel Group (n=29) | Non-Hostel Group (n=54) | P-value |
|---------------------|------------------------|----------------------------|---------|
| Alive | 14 (48%) | 21 (39%) | 0.55 |
| Died | 11 (38%) | 24 (44%) | 0.73 |
| Abandoned | 9 (31%) | 22 (41%) | 0.53 |
| Loss to follow up | 2 (7%) | 3 (6%) | 1 |
| Event free survival | 11 (38%) | 12 (22%) | 0.24 |

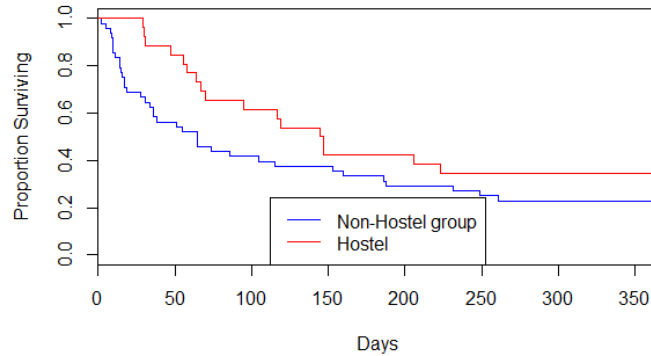


Figure 11: Survival Curve by hostel group excluding patients who were never discarded or who were referred elsewhere to receive care

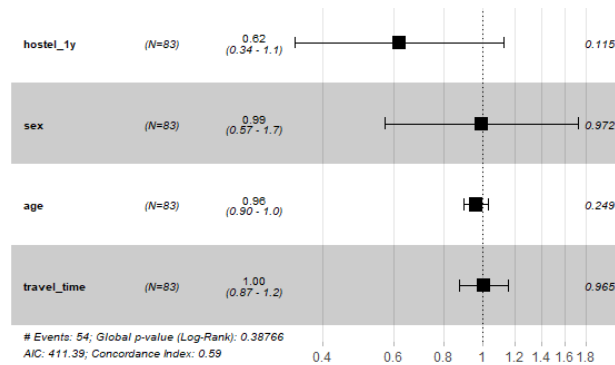


Figure 12: Cox proportional hazard model for censored post-hostel group

On average patients stayed 46.8 days at the hostel over the course of their treatment. Some patients only stayed at the hostel once while most patients returned to the hostel several times. The average patient who used the hostel stayed 3.6 times. Length of stay at the hostel ranged from 1 day to 176 days. The hostel has served 85 unique patients for a total of 309 stays since it opened in May of 2017 through the end of 2018. Summing up all patients and the length

of each of their stays, patients have spent a total of 2,883 days at the hostel from May of 2017 to the end of 2018.

Patients who stayed at the hostel and did not have an event had a significantly longer hostel stay compared to patients with an event. The average hostel stay for patients without an event was 82 days compared to 25 days for patients who died or abandoned in the first year ($p=0.01$). Data suggests a dose response relationship with longer hostel stay being associated with more exposure to the potential benefits of the hostel. However, this may be biased by longer survival times for patients that did not have an event.

3.1.4 Nutrition

Height, weight, body mass index (BMI), hemoglobin (Hb) and mean corpuscular volume (MCV) values were analyzed as a proxy for nutritional status. Nutritional data was collected for patients who presented from May 2016 through December of 2017. The nutritional analysis was exploratory. When the study was planned, we intended to collect data on height and weight each month for 12 months after the date of presentation, but due to a very high percentage of missing heights and weight, that data could not be used. Instead height, weight and BMI at presentation will be used to explore the baseline nutritional status of patients.

The average initial BMI, Hb and MCV, as well as the percentage of patients who were undernourished or anemic at presentation are shown in *Table 7*. There were 53 missing values for initial height and 47 missing values for initial weight, resulting in 53 missing BMI measures. Nutritional status was assessed using WHO growth standards. For children under the age of 5 years, weight for height was used. For children over the age of 5 years, BMI for age was used ("Tanzania NACS Job Aids "). 76% of patients in this study are anemic based on the lower limit of normal for hemoglobin of 11 used by Bugando Medical Center.

Table 7: Nutritional Indicators for 2016 and 2017 Patients

| | |
|--------------------------------|-----------------------------|
| | All participants (n=229) |
| Initial BMI | 15.4 |
| Initial Hb | 8.8 |
| Initial MCV | 72.7 |
| Undernourished at presentation | 27% |
| Anemic at presentation | 76% |

Hemoglobin and MCV levels for the hostel and non-hostel groups were plotted over time. Hemoglobin levels over the first year of treatment can be seen in *Figure 13*, and MCV levels for one year after presentation can be seen in *Figure 14*. The trends in hemoglobin levels for the pre-hostel group and post-hostel group are similar over time, with a slightly larger positive slope in the post-hostel group.

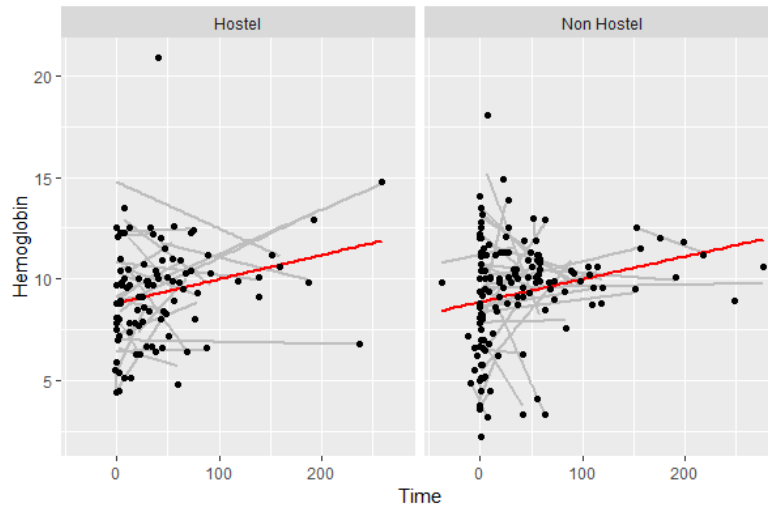


Figure 13: Plot of Hb levels over time by Hostel Group

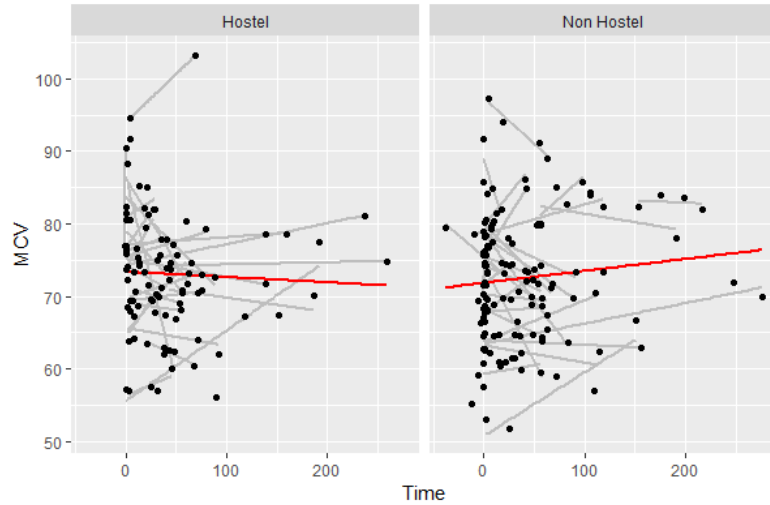


Figure 14: Plot of MCV levels over time by Hostel Group

3.2 Patient Reported Outcomes

3.2.1 Quality of Life and Knowledge Surveys: Aim 2

Surveys and interviews were used to assess the impact of the hostel on the patient reported outcomes of quality of life, cancer knowledge.

3.2.2 Participant Characteristics for Surveys

63 surveys were conducted with patients who presented to BMC in 2018. Caregivers-proxy report was used for 62 surveys and 1 survey was filled out by the patient themselves. *Table 8* shows the demographic characteristics of survey participants. The average patient age in the hostel group was 4.9 years while the average age in the non-hostel group was 6.5 years. The most common profession of caregivers was working as a farmer, with 67% of caregivers in the hostel group and 58% of caregivers in the non-hostel group working as farmers. The most common diagnosis in both the hostel and non-hostel groups was Wilms tumor, followed closely by Burkitt lymphoma. Although some small differences in demographic characteristics did exist between the groups, none of these differences were statistically significant.

Table 8: Demographic Characteristics for Survey Participants

| | Hostel Group (n= 18) | Non-Hostel Group (n= 45) | P-value |
|------------------------------|-------------------------|-----------------------------|---------|
| Caregiver Age (mean) | 36.4 | 36.8 | 0.81 |
| Caregiver Sex (# female) | 9 (50%) | 30 (66%) | 0.42 |
| Patient Age (mean) | 4.9 | 6.5 | 0.13 |
| Patient Sex (# female) | 9 (50%) | 28 (62%) | 0.35 |
| Diagnosis | | | 0.61 |
| Burkitt Lymphoma | 3 (17%) | 10 (22%) | |
| Acute Leukemia | 2 (11%) | 4 (9%) | |
| Wilms tumor | 5 (28%) | 11 (24%) | |
| Occupation | | | 0.88 |
| Farmer | 12 (67%) | 26 (58%) | |
| Business person | 3 (17%) | 9 (20%) | |
| Household work | 2 (11%) | 2 (4%) | |
| # of Children (mean) | 5.1 | 4.9 | 0.84 |
| Frequency of Hospital Visits | | | 0.79 |
| One or more times a week | 7 (39%) | 20 (44%) | |
| Once every two weeks | 6 (33%) | 16 (35%) | |
| Once a month | 5 (28%) | 9 (20%) | |

Note: P-values are based on t-tests for continuous variables and chi square test for categorical variables.

3.2.3 Pediatric Quality of Life Survey

The average score on the PedsQL for all survey participants was 66.2 out of 100. Scores on the PedsQL by section and overall can be seen in *Table 9*. A significant difference was not seen for the total score, or the physical or social sections. However, patients that stayed at the hostel scored significantly higher on the emotional section of the PedsQL as seen in *Figure 15*.

Table 9: Pediatric Quality of Life (PedsQL) Score by Hostel status. Score is out of 100, with higher scores indicating better quality of life.

| | Overall (n=63) | Hostel Group (n=18) | Non-Hostel Group (n=45) | P-value |
|-----------|-------------------|------------------------|----------------------------|---------|
| Physical | 60.7 | 58.7 | 61.4 | 0.7 |
| Emotional | 69.7 | 79.3 | 66.1 | 0.03 |
| Social | 70.4 | 68.7 | 71.0 | 0.6 |
| Total | 66.2 | 68.1 | 65.5 | 0.6 |

The PedsQL SF-15 includes a section on school functioning. However, because more than 50% of responses for this section were missing, it was not analyzed. Of the 63 patients represented in the completed surveys, 15 (24%) are attending school, 21 (33%) dropped out of school because of their health, 2 (3%) delayed school because of their health, 20 (32%) were not yet going to school, and 5 (8%) had unknown school status.

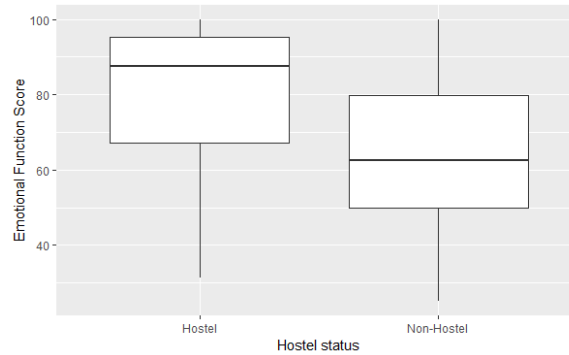


Figure 15: PedsQL Emotional Functioning Score by hostel status

3.2.4 Cancer Knowledge Survey

The average score of caregivers on the cancer knowledge survey was 6.1 (61%) for the hostel group and 5.9 (59%) for the non-hostel group out of 10. The difference between the cancer knowledge scores for the two groups was not significant ($p = 0.69$). Side by side box plots of the average total score for the hostel and non-hostel groups can be seen in *Figure 16*. There was not a significant difference in the average score by question between the two groups.

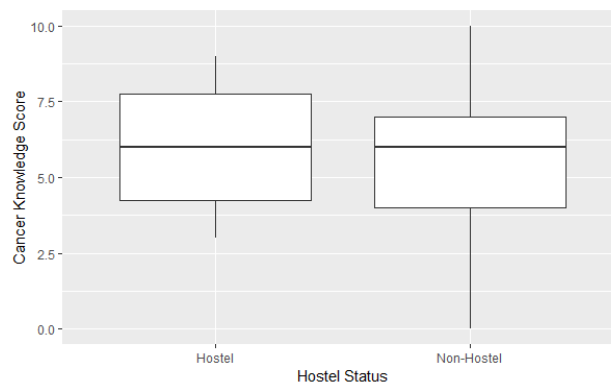


Figure 16: Cancer Knowledge Scores by Hostel Status

3.3 Patient and Caregiver Experiences: Aim 3

3.3.1 In-depth Interviews Participant Characteristics

Demographic characteristics of interview participants can be seen in *Table 10*. Of the 27 interviews conducted, 16 were with patients/caregivers who have not stayed at the hostel, 6 interviews were conducted with patients/caregivers who have stayed at the hostel and 5 interviews were conducted with healthcare workers. Two interviews were conducted with patients themselves, while 20 interviews were conducted with the patient's caregiver. Of the 5 healthcare workers interviewed, 2 were nurses, 1 was a pediatrician, and 2 worked at the hostel.

Table 10: Demographic Characteristics for Interview Participants

| | Number (n) | Percentage (%) |
|--------------------------|------------|----------------|
| Participant Age | | |
| 10-24 | 3 | 11% |
| 25-39 | 11 | 41% |
| 40-54 | 2 | 7% |
| 55+ | 1 | 4% |
| Participant Sex | | |
| Male | 11 | 41% |
| Female | 16 | 59% |
| Patient Diagnosis | | |
| Burkitt Lymphoma | 4 | 15% |
| Wilms Tumor | 5 | 19% |
| Leukemia | 1 | 4% |
| Other | 17 | 63% |
| Participant Group | | |
| Hostel group | 6 | 22% |
| Non-hostel group | 16 | 59% |
| Healthcare worker | 5 | 19% |

3.3.1 Linking to Cancer Treatment

The Patient's journey to cancer treatment was described as long and arduous, involving significant travel and referrals. Misdiagnosis and delays were often part of the journey. In the following quote, a male caregiver for a patient with non-hodgkin's lymphoma described a typical journey to receiving a diagnosis and pediatric cancer treatment:

“It started like a lump above the eyelid and we then took her to Mkome dispensary where they gave her eye drops but we returned for the third time because there was not any progress so we were given referral to Geita district hospital, there they did some tests and said they won't be able to treat her so they referred us to Bugando where she was diagnosed to have cancer. (male caregiver, non-hostel)”

Initial symptoms such as a mass on palpation, pain or nausea prompted parents and guardians to seek treatment for their child. The father of a child with retinoblastoma describes how he first noticed his child's condition: “I realized she had something white under her eye. In the afternoon the eye looks okay, but at night when you shine a torch into her eye it looks like a cat eye” (male caregiver, non-hostel). This patient, like most patients interviewed, first sought care at a local dispensary, then was referred to a district hospital, then a regional hospital, until eventually being referred to Bugando. For this patient who is from the Kigoma region, this series of referrals involved several hundred kilometers of travel.

A variety of logistical challenges emerged from participants' descriptions of their journey to receiving cancer care. First was the limited knowledge and diagnostic capacity at local health centers and dispensaries. Often equipment for imaging or biopsies was unavailable and patients did not receive a diagnosis or sometimes received an incorrect diagnosis and ineffective treatment such as the patient above who received eye drops for an ocular lymphoma.

Another hurdle that faced patients as they sought care was the limited treatment capacity at health centers and dispensaries as well as regional hospitals. A father of a patient with hepatoblastoma describes the health facilities they went to where they were unable to get the needed treatment:

“We started within the refugee camp where the child was admitted. They gave us some treatments, but they said they couldn't treat his disease, so they gave us a referral to Kibondo district hospital where we were admitted for three days and then they did x-ray and said they also can't treat him, so they gave us a referral to Bugando. (male caregiver, non-hostel)”

Lastly, limited knowledge of cancer is expected to lead to delays in seeking treatment. Of the 22 patients/caregivers interviewed, eight caregivers (36%) had never heard of cancer before their child was diagnosed. 14 participants had heard of cancer before their child was diagnosed with cancer, but of those, only 6 had any knowledge of cancer at the time.

3.3.2 Barriers to Completing Treatment

Participants described a variety of challenges they faced in completing cancer treatment as seen in *Figure 17*. Barriers facing patients and caregivers can be grouped into two categories: external and internal challenges. External barriers included financial challenges, accommodation, transportation, conflicting caregiver responsibilities, and navigating care systems. Internal challenges included lack of social support, feelings of hopelessness, misconceptions and side effects. All interview participants were asked what they think is the greatest challenge facing patients in completing cancer treatment. The most common answer, which was mentioned by 9 participants (33%), was side effects and symptoms. Delays and navigating the health system was the second most common answer and was described by 8 participants (30%), and financial challenges was the third most common answer, reported by 6 participants (22%).

In some of the early interviews, participants mentioned that they were not facing any challenges in receiving cancer treatment for their child. As one participant in a pilot interviews mentioned: "I've never failed coming to the hospital for clinic or chemotherapy day nor have I ever faced any challenge." After the pilot interviews this question was rephrased and during subsequent interviews key themes emerged relating to challenges patients and their families faced in receiving and completing treatment.



Figure 17: Barriers to Completing Cancer Treatment

Side effects and symptoms were reported as the greatest barrier to completing treatment by 9 of 27 participants. A male caregiver for a patient with retinoblastoma explained that, “the greatest challenge is when she receives chemotherapy she becomes so weak and loses her appetite to eat and vomits a lot (male caregiver, non-hostel).” A 14-year-old female with Rhabdomyosarcoma explained that the greatest challenge to completing treatment was, “Vomiting, being sick and losing food appetite (female patient, non-hostel).”

Not only are side effects unpleasant for patients, they may also cause delays in treatment. The grandfather of a patient with a type of carcinoma explained that it was a challenge when, “the day for my child to receive chemotherapy has arrived and that same day the child's health condition changes, making it so he cannot get chemo (male caregiver, hostel).” The mother of a child with Wilms tumor mentioned some of the side effects that her child is facing; “Sometimes when she gets chemo she suffers from very high fever and having low blood levels (female caregiver, hostel).”

Participants also mentioned delays in receiving care and navigating the health system as significant barriers to completing care. A male caregiver for a patient with Burkitt lymphoma

described that he felt the greatest challenge in completing treatment was, “the large number of patients, the waiting and the delays in arriving at the hospital (male caregiver, non-hostel).” Delays are very common, particularly for services such as labs and surgery.

Delays can also occur because of issues on the health system side such as not being able to find the patient medical file. When asked about the greatest challenge during treatment, a male caregiver for a patient with Burkitt lymphoma explain that for them the greatest challenge was, “when my child's file can't be found, and she isn't seen in the system either (male caregiver, non-hostel).” In total, 3 participants mentioned this as the greatest challenge to completing treatment. A new system for medical records has been put in place and two participants explained that they felt the greatest challenge for patients was delays due to the new system.

When describing the greatest challenge to completing treatment, another male caregiver explained how there are, “so many cycles within the hospital (male caregiver, non-hostel).” He went on to clarify that there are many different steps and parts of the hospital that patients have to go through such as the clinic, labs and imaging, the pharmacy, etc. to get the care patients need. Delays and challenges in navigating the health system can occur at a variety of levels and can lead to patients becoming frustrated and not getting the care they need in a timely manner.

Difficulties with money overlap with several of the other barriers mentioned by patients, including transportation, accommodations and buying necessities such as food. Although a charitable organization (ICCARE) has begun to cover some of the costs of treatment at BMC, patients still face many additional financial barriers, particularly money for transportation. When asked about the challenges in completing cancer treatment, a female patient with rhabdomyosarcoma said, “Mostly the challenge is the money for transportation (female caregiver, non-hostel).” Other participants mentioned difficulty in paying for lab tests and scans, as well as the cost of the hospital stay.

In addition to the costs of care, caregivers lose income from their normal jobs when they are spending considerable time at the hospital. Caregivers often have multiple responsibilities including taking care of other children and work and these responsibilities can conflict with supporting their child with pediatric cancer. For example, when asked about the challenges in completing treatment, a female caregiver for a patient with Wilms tumor said, “I do have another young child to look after at home and I don't have anyone to look after him while I'm gone... (female caregiver, non-hostel)”

Caregivers and patients mentioned that they sometimes struggle with feelings of hopelessness. Several participants mentioned that these feelings of discouragement come when they see their child's health deteriorate. A female caregiver for a patient with Wilms tumor explained that she gets, “discouraging thoughts that I should just go back home because my daughter's condition just kept being worse (female caregiver, non-hostel).”

Some patients and caregivers mentioned that they did not have anyone to support them through this challenging time. Lack of social support interacts with several of the other challenges already listed. Lack of accommodations, conflicting responsibilities and feelings of hopelessness may be exacerbated by a lack of social support. In addition, misconceptions can combine with the fear of a serious disease to lead to caregivers and patients being left with limited social support. The mother of a child with Wilms tumor describes a misconception which lead to a lack of social support for the patient and caregiver; “I got resistance from his father who was refusing to bring the child to hospital for treatment as he believed the child was sick because of witchcraft” (female caregiver, non-hostel). When the mother took her daughter to the hospital, the father left and has not returned.

3.3.3 Facilitators for Completing Pediatric Cancer Treatment

Many of the challenges faced by patients have a reciprocal facilitator that helps patients on their way to completing treatment. For example, interviews showed that financial challenges

were a barrier to completing treatment, so logically participants responded that financial support was a facilitator for completing treatment. The most common facilitators reported by patients can be seen in *Figure 18* and included social support, provider support, religion and spirituality, ICCARE and the hostel, seeing health improvements during treatment, and help from providers with managing symptoms and side effects.



Figure 18: Facilitators for completing pediatric cancer treatment

Financial support was mentioned frequently as an important facilitator helping patients complete treatment. Financial support helps patients in several ways, for example in help patients get to the hospital as well as paying for drugs, scans, labs and hospital fees. When asked about what makes it easier to continue with treatment, a male caregiver for a patient with Burkitt lymphoma responded, “The ability to have transport money that can bring me to Bugando Hospital (male caregiver, non-hostel).” In addition to being able to afford transportation to the hospital, financial support with paying for medical services was reported as a major facilitator for competing care. A female caregiver for a patient with Rhabdomyosarcoma explained that what makes it easier for her to continue with treatment is, “the way I get the medication for free

(female caregiver, non-hostel).” This is the result of assistance in purchasing medications provided by ICCARE.

Participants also discussed social support as an important facilitator. A male caregiver for a patient with Burkitt lymphoma explained, “I usually talk to my friends and tell them when my child is having a bad health condition. They advise me to go and seek help as well as advice from the doctors (male caregiver, hostel).” Another male caregiver for a patient with retinoblastoma described how, “I usually speak with my family and mostly I talk to them about the actual condition this way and all the hardships (male caregiver, non-hostel).” Caregivers and patients often talk to their family and friends about the challenges of going through cancer treatment and for many patients the support that they get from friends and family is an important factor that helps them continue with treatment.

Closely related to social support from friends and family, patients and caregivers also highlighted support from providers as an important facilitator for completing treatment. The mother of a child with leukemia said that they work through the challenges of treatment by, “getting help from the doctors (female caregiver, non-hostel).” Providers can support patients in several ways, through providing knowledge, counseling, quality medical care and helping patients and caregivers navigate care. A male caregiver for a patient with a type of lymphoma who had previously described how navigating the medical system was a major challenge explained how the, “understanding and hospitality of the doctors” helped in navigating the medical system and enables their continuation of treatment. (male caregiver, non-hostel).

Participants also discussed help with managing symptoms and side effects as a facilitator. A female caregiver explained how the doctors help; “I usually talk to the doctor and my daughter gets blood transfusion or drugs help with increasing blood level as well as drugs for lowering fever (female caregiver, hostel).” Another caregiver mentioned that pain relief medication from the doctors was helpful for supporting her child.

Several patients mentioned religion and spirituality as a facilitator to completing treatment. When asked how they persist through the challenges of cancer treatment, a caregiver explained, “I usually keep heart and have faith in God that all these (difficulties) will be over (male caregiver, hostel).” In response to a question about the greatest challenges in completing cancer treatment, a female caregiver for a patient with Wilms tumor said, “to me God has been so helpful therefore there are not any challenges so far (male caregiver, hostel).”

ICCARE provides assistance to patients who cannot afford treatment as well as employing a patient navigator to help patients. ICCARE also runs the hostel and supports the hostel staff which includes a social worker to support patients. Several participants mentioned this organization as a factor that has helped them continue with treatment. Patients who stayed at the hostel mentioned this program as an important facilitator. Perceptions of the hostel and how it supported patients will be discussed in the next section.

3.3.4 Roles and Perceptions of the Hostel

Participants described several important roles filled by the hostel as described by a male caregiver of a patient with Burkitt lymphoma, “staying at the hostel helps us in many ways (male caregiver, hostel).” Participants stated that the hostel helps them to overcome both external and internal barriers. One of the most important roles of the hostel is as an affordable and convenient accommodation, particularly serving those who come from far away and those who do not have relatives in Mwanza. The hostel has enabled improved access to care for patients that live far away from the hospital. A male caregiver for a patient with retinoblastoma explains that the hostel, “helps me a lot because if it was not for the hostel I would be having so much difficulty in coming here because I come from far away (male caregiver, hostel).”

Participants viewed the hostel as an important source of psychosocial support from hostel staff and interpatient support from others staying at the hostel. Participants reported that the hostel staff as well as other caregivers and patients staying at the hostel provided valuable support

and advice. Caregivers and patients often form strong friendships with others staying at the hostel and these friendships are valuable for gaining knowledge about cancer and for maintaining their psychosocial wellbeing. For example, a caregiver explained that, “the friends that I have made here supports me well in thoughts and gives me good teachings on everything concerning cancer (female caregiver, hostel).” In explaining what he likes about the hostel, another caregiver highlighted the support that comes from hostel staff and friends at the hostel; “what I like is that the hostel gives good teachings about life (male caregiver, hostel).”

In addition to providing accommodations and psychosocial support, participants explained that the hostel helps by providing nutritional support. The hostel provides two meals a day free of charge to support patients who are unable to afford enough food. When describing his view of the hostel, a caregiver for a patient with retinoblastoma explained, “it helps in shelter and food (male caregiver, hostel).”

Participants shared several key perceptions of the hostel. All participants who had stayed at the hostel, as well as all healthcare workers interviewed shared very positive perceptions of the hostel. A male caregiver for a patient with a type of carcinoma explained, “The hostel has so many benefits. First, it makes us feel free, second it has helped us a lot in terms of hospital services and third, it has helped us in terms of food and nutrition (male caregiver, hostel).” The hostel was perceived by this caregiver and others as a convenient, familiar and comfortable place to stay. By functioning as a home away from home, caregivers reported that the hostel helps patients resume normalcy. A caregiver for a patient with Wilms tumor explains, “it is helpful that we get to live here just as how I used to live back at my homeplace (female caregiver, hostel).”

Caregivers and healthcare workers speculated that if the hostel closed, loss to follow up and abandonment of care would increase. When asked what would happen if the hostel closed, a caregiver responded, “I wouldn't be able to bring my child for treatments and I would not be consistent in treatments (female caregiver, hostel).” Another caregiver explained that the hostel

“is beneficial because if it was not for the hostel my daughter would not get her treatment well because I do not have any relatives in Mwanza or any place to stay here in Mwanza (female caregiver, hostel).” In summary, participants shared a very positive view of the hostel and reported that the hostel is an important source of accommodations which help them maintain some normalcy during a challenging time, as well as an important source of psychosocial support and nutritional support.

3.3.5 Suggestions from Participants

Patients expressed their gratitude for the services available such as the drugs available at BMC and the support provided by the hostel. However, patients also recognized that there is still room for growth. After discussing the barriers and facilitators for completing cancer treatment, many participants had suggestions for cancer care specifically at BMC as well as more broadly in Tanzania. Patients that stayed at the hostel as well as healthcare providers also shared some suggestions for the hostel.

Participants provided suggestions for improving pediatric cancer care at Bugando. First, participants highlighted how they see a need for more nutritional support. For example, the caregiver for a patient with Burkitt Lymphoma said, “I would like that there should be a nutrition treatment program available for the patients because when they get chemotherapy it is a must for them to have good nutrition (male caregiver, hostel).” Other participants described how making radiotherapy therapy available to pediatric patients at BMC would be helpful. Currently radiation therapy is available for a limited number of adult patients at BMC but not for pediatric patients. Participants also suggested that treatment for leukemia be supported at BMC. Currently patients with leukemia must travel to Dar Es Salaam to get treatment. One of the healthcare workers interviewed suggested that providers should get training in treating pediatric cancer. Participants also suggested increasing capacity for cancer treatment at BMC. Lastly, participants suggested that BMC should, “have a special unit for pediatric oncology (female pediatrician).” Currently

pediatric cancer patients are mixed in with adult patients, as well as non-oncology patients. This physician explained that this would be particularly beneficial for patients with compromised immune function.

To improve the functioning of the hostel, participants reported it would be helpful if more space could be provided so more patients can stay at the hostel. Participants also discussed a desire for the provision of more regular education and skills trainings for both patients and caregivers at the hostel. It was suggested that patients can be given regular lessons on school subjects and cancer and caregivers can receive trainings to enable them to engage in income generating activities.

To improve pediatric cancer care in Tanzania, participants mentioned the need for educational campaigns to improve peoples' knowledge of childhood cancer. Suggestions also included increased screening and improving access to care through making it affordable and building treatment capacity. Lastly, participants highlighted the importance of organizations that support patients during treatment and suggested cancer care in low-income countries like Tanzania could be improve by, "add(ing) more organizations like ICCARE (female nurse)."

3.6 Body Maps

To further explore the barriers and facilitators for completing care, 9 participants completed body map drawings. Of these patients, 5 stayed at the hostel and 4 did not. Participants were asked to make a drawing of themselves and to include challenges they have faced while going through treatment, as well as factors that have helped during treatment. Two drawings can be seen in *Figure 19*. These drawings highlight challenges such as side effects and missing home and school, as well as facilitators such as emotional support from friends and family.

4. Discussion

Findings from medical record review, surveys and in-depth interviews suggest that patients who stayed at the hostel have higher one-year event free survival and better emotional wellbeing than patients that did not stay at the hostel. However, this benefit is not generalizable to all patients in the post-hostel group. Participants identified several barriers and facilitators to care which will be important to consider in the continued effort to improve pediatric cancer outcomes in LMICs.

One-year event free survival was 38% for patients that stayed at the hostel and 22% for patients that did not stay at the hostel. The cox proportional hazard model looking at hostel status showed that those who stayed at the hostel were significantly less likely to have an event in the first year compared to those that did not stay at the hostel. This finding was further supported by the logistic regression model, which showed that those that stayed at the hostel had a significantly lower odds of death or abandonment. Abandonment of care within the first year was 30% overall. This shows that abandonment is still a major issue requiring further attention.

Although the major difference here comes from a lower proportion of patients dying in the first year in the hostel group, it is also possible that the hostel helps patients to not abandon care. Although we did not see a significant difference in the percentage of patients abandoning care in the hostel and non-hostel groups, participants who stayed at the hostel reported that the hostel helped them continue with treatment. The hostel seems to meet several important needs of patients and caregivers during treatment and this may result in the higher 1-year EFS seen for hostel patients.

Malnutrition is an important issue for pediatric cancer patients and our data suggest that malnutrition and anemia are very common among pediatric cancer patients in Northern Tanzania. Research on nutrition for childhood cancer patients has found that BMI may not be the best indicator of nutritional status due to confounding from tumor growth (Schoeman, 2015). Pediatric

hematological reference values for Tanzania have been established by Buchanan et al. (Buchanan et al., 2010) Hb and MCV values for patients in this study are significantly lower than the Tanzanian reference values suggesting important nutritional deficiencies faced by pediatric cancer patients. According to the WHO, in Tanzania 6.6% of children under 5 years are undernourished based on a height for weight z score and 61% of children under 5 are anemic (Abarca-Gómez et al., 2017). In contrast, approximately a quarter of pediatric cancer patients included in this study were undernourished and three quarters were anemic. Improved nutritional support has the potential to improve treatment outcomes for pediatric cancer in Tanzania.

Although we did not find a difference for overall quality of life scores, patients who stayed at the hostel scored significantly higher than patients that did not stay at the hostel on the emotional functioning section. Participants in the hostel group said that they have less of a problem with feeling sad, worried and scared. Based on interview findings in combination with the emotional functioning scores that the social support provided at the hostel enables patients to achieve better emotional wellbeing compared to patients that did not stay at the hostel. No difference was observed between knowledge of cancer between hostel and non-hostel groups. Although the hostel is one place where patients can learn about cancer, there are other important source of information such as healthcare providers.

Interview findings suggested that patients present in late disease stage because of a variety of challenges in linking to cancer treatment, including limited knowledge of the signs and symptoms of childhood cancer, limited diagnostic and treatment capacity, and delays in referral.

Side effects and symptoms emerged as the most commonly reported challenges to completing cancer treatment. Not all patients understood that side effects are a normal part of chemotherapy. Improvements can be made in educating and counseling patients about the side effects of chemotherapy and helping patients manage these side effects. Participants also highlighted delays as a significant barrier. Due to the time sensitive nature of treatment, as well as

other constraints such as financial challenges and other caregiver responsibilities, delays may contribute to high rates of abandonment of care. Capacity building is needed to reduce delays in treatment for cancer patients at BMC. Recent programs have ameliorated many of the financial burdens of cancer treatment, but some financial challenges remain. These barriers faced by patients in completing cancer treatment may suggest why abandonment of care remains at 25% for childhood cancer patients at BMC.

Patients mentioned financial support, provider support, social support, and help with managing symptoms and side effects as important facilitators for completing treatment. Although these factors help patients complete treatment, many patients do not have access to all the support they need. Some participants mentioned that having insurance was an important factor helping with the financial burden of treatment. However, the vast majority of pediatric cancer patients seen at BMC do not have insurance. Participants also mentioned ICCARE as a major help with the financial burdens of treatment. When patients are unable to pay for medical services including medications, tests and hospital fees, ICCARE does its best to help and many participants reported that this was an important factor in helping them continue with treatment.

Participants explained that the hostel was an important source of support helping meet their needs during cancer treatment. Participants who had utilized hostel services shared very positive perceptions of the hostel and highlighted how the hostel provided valuable psychosocial support, help patients maintain some normalcy during treatment, provided convenient accommodations and some nutritional support and reduced the financial burden of care.

Findings from the survival analysis, surveys and in-depth interviews suggest that the hostel has several important impacts on pediatric cancer patients. Patients that stayed at the hostel had a significantly higher one-year event free survival compared to patients that did not stay at the hostel. Patients that stayed at the hostel also had higher emotional functioning as indicated by the PedsQL. The hostel addresses several important barriers to completing pediatric cancer

treatment raised in in-depth interviews and perception of the hostel from in-depth interviews were very positive.

However, the impacts of the hostel were not generalizable to all patients who received care at the BMC after the hostel opened, as we see from the non-significant difference between the pre and post hostel groups. In addition, the hostel did not significantly decrease the proportion of patients abandoning care. Further interventions and research are needed to determine promising practices for decreasing abandonment of care. Although improvements have been made in 1-year event free survival at BMC, a significant gap remains between 1-year survival in high income countries and low-income countries suggesting that additional improvements and interventions are required.

Although context make a difference, previous research on pediatric cancer care in LMICs has shown that many factors contributing to poor treatment outcomes are similar across countries (Rodriguez-Galindo et al., 2013). In situations where patients face similar barriers to completing care, supportive care programs such as a residential hostel are a promising way of improving outcomes. These programs seem to work particularly well when implemented along with improvements in the quality of cancer diagnosis and treatment.

This study had several limitations. Limitations include the limited sample size and the lack of information on cancer stage or socioeconomic status. An effort was made to collect cancer stage information, but this information was not available for most patients included in the study. Due to the observational nature of the study it is necessary to consider any changes in cancer care that occurred during the study. In addition to the hostel opening in May of 2017, a patient navigator started working at BMC in July of 2016. Since recruitment into the pre-hostel group started in May of 2016 we do not suspect that the patient navigator had a differential impact on the pre and post groups. We are not aware of any other changes made to pediatric cancer care during the study period. The risk of confounding by time is decreased by our finding that one-

year event free survival was not significantly different for the pre and post groups, only for the hostel and non-hostel groups. Although efforts have been taken to reduce confounding, it is still a possibility and we cannot be sure that relationship between the hostel and improved 1-year EFS is causative.

There is a potential for confounding by disease severity but since the composition of the two groups did not differ by disease type, we suspect that the two groups also did not differ by disease severity. Ideally disease stage would be used to compare treatment severity, but this information was not available for most patients in the study and as a result diagnosis was used as a proxy for disease severity.

Systematic reviews have found that the barriers to improved treatment outcomes for pediatric cancer patients are similar across many low- and middle-income countries.(Rodriguez-Galindo et al., 2015) Thus, these findings are generalizable to pediatric cancer treatment programs in most low and middle income countries.

Strengths of this study include the mixed methods approach. Findings from medical record review has been clarified and backed up by data from interviews and surveys. In addition, the generalizability of the findings to other LMICs is a strength of the program. Lastly, the utilization of an arts-based method allows unique insight and novel ways of representation patient experiences. This study fills a gap in the research since no other studies that we know of have examined a hostel for pediatric cancer patients in a low-income country. Because this is the first study to focus on this type of supportive care program we believe the study provides novel insight into ways of improving pediatric cancer outcomes in LMICs.

5. Conclusion

This study suggests that the hostel for pediatric cancer patients in Northern Tanzania may improve one-year event free survival and allow patients to maintain better emotional wellbeing. Patients face a variety of barriers to completing cancer care including side effects, delays in medical service provision and financial challenges. Patients reported that social and provider support, financial support and the hostel helped patient's complete cancer treatment. Despite the existence of several supportive factors, significant challenges remain for pediatric cancer patients in completing treatment. Findings suggest that a combination of biomedical and supportive care programs will be needed to bridge the gap between survival outcomes in high-income and low-income countries.

Through addressing patients need for affordable accommodations and psychosocial support and counseling, a significant improvement in 1-year event free survival can be made. Our findings suggest that the hostel may improve 1-year event free survival and emotional wellbeing for pediatric cancer patients. The hostel also seems to meet additional needs of patients and caregivers as reported from in-depth interviews. The hostel is a promising supportive care program for pediatric cancer patients and may be helpful for supporting pediatric cancer patients and caregivers in other LMICs.

6. Appendix

6.1 Cancer Knowledge Survey

Cancer Knowledge Survey

Patient ID: _____

Does your child stay at the hostel? Yes No

For all questions, circle the option that is the best answer.

1. What is cancer?

- a. Cells that change making them grow and divide rapidly
- b. A contagious disease
- c. A disease caused by bacterial infection
- d. A disease caused by a curse

2. What causes cancer?

- a. It is spread through sharing food
- b. It comes from a curse
- c. It comes from animal bites
- d. None of the above

3. Which of the following symptoms would make you suspect that a child may have cancer?

- a. Fast-growing masses
- b. Night sweats
- c. Unintentional weight loss
- d. Discoloration of the pupil
- e. All of the above

4. Can children with cancer be cured?

- a. Never
- b. Yes, sometimes
- c. Yes, always

5. A child with cancer will be cured after a single trip to the hospital.

- a. True
- b. False

6. Which of the following can be used as treatment for cancer?

- a. Medicines
- b. Radiation
- c. Surgery
- d. All of the Above

7. What is chemotherapy?

- a. Drugs used to treat cancer and other diseases
- b. Tools for agriculture
- c. A way of talking to your friends

8. Does chemotherapy have side effects?

- a. Yes. Although chemotherapy can help make you better, it also has some uncomfortable side effects.

- b. No, chemotherapy is free of side effects.
- 9. Which of the following help keep a child healthy during chemotherapy?**
 - a. Washing hands after using the toilet and before eating
 - b. Not seeking medical care for fevers
 - c. Eating lots of greens, meat and beans
 - d. Drinking untreated water
 - e. A and C are both true
- 10. Are there different types of cancer?**
 - a. Yes
 - b. No

6.2 Hostel Group Interview Guide

Hostel Group Interview Guide

Background

1. Tell me about how your child came to be diagnosed with cancer.
 - How did your child come to seek treatment at Bugando?
2. Had you heard of cancer before your child was diagnosed?
 - What did you know about cancer before your child became sick?
 - How did you learn this information?
3. Your child has just had their labs taken, where do you go while waiting to receive chemotherapy?
 - Where do you go in between cycles of chemotherapy?

Challenges of Treatment

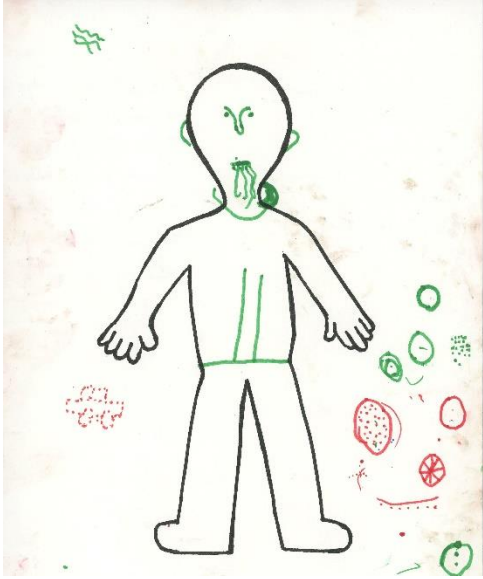
4. What things make it hard to continue with cancer treatment?
 - In what way is this a challenge?
 - (Try to have them list at least 3 challenges)
 - (For each challenge they listed, ask what helps them address this challenge)
 - Is there anything else that makes it more challenging to get treated?
5. What difficulties do you expect to face on the way to completing cancer treatment?
6. What has been the greatest challenge during treatment?
 - How do you work through these challenges?

Facilitators of Treatment

7. What makes it easier for you and your child to continue with treatment?
 - For example, ask about factors that help them get to the hospital, get their medicines, etc.
 - Is there anything else that helps you and your child continue with treatment?
8. What motivates you to continue coming to Bugando for treatment?
9. Are there any service that are not offered that would help you and your child during cancer treatment?

The Hostel

10. How would you describe your experience and your child's experience at the hostel?
 - (Have the staff been helpful? Are the facilities good?)
11. In what ways have you found the hostel to be beneficial?
 - (What needs has staying in the hostel helped you meet?)
12. What do you like about staying in the hostel?
13. Do you feel that the hostel provides a supportive environment?
 - (In what way?)



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