"Money was the Problem": Financial Difficulty is the Main Reason for Treatment Abandonment by Children with Cancer in South West Uganda

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Text word count 2531;

Abstract word count: 235;

Brief running title: Treatment Abandonment by Children with Cancer in Uganda

Key words: treatment abandonment, children, cancer, financial difficulty, low-middle-income countries, Uganda

Tables: 3

Figures: 1

List of abbreviations

HIC	High-income countries
LIC	Low-income countries
MRRH	Mbarara Regional Referral Hospital
MUST	Mbarara University of Science and Technology
REC	Review and Ethics Committee
UNCST	Uganda National Council of Science and Technology

Abstract

Introduction - Treatment abandonment contributes significantly to poor survival of children with cancer in low-middle-income countries (LMICs). In order to inform an approach to this problem at our Cancer Unit, we investigated why caregivers withdraw their children from treatment.

Methods – In a qualitative study, in-depth interviews were conducted with caregivers of children who had abandoned cancer treatment at the Paediatric Cancer Unit (PCU) of Mbarara Regional Referral Hospital (MRRH) in South Western Uganda, between May 2017 and September 2020. Recorded in-depth interviews with caregivers were

transcribed and analyzed to identify themes of caregiver self-reported reasons for treatment abandonment.

Results - Seventy-seven out of 343 (22.4%) children treated for cancer at MRRH abandoned treatment during the study period; 20 contactable and consenting caregivers participated in the study. The median age of children's caregivers was 37 years and most (65%) were mothers. At the time of this study, eight (40%) children were alive and 5 (62.5%) were males; with a median age of 6.5 years. Financial difficulties, other obligations, the child falsely appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child's death was imminent and chemotherapy side-effects were the caregivers' reasons for treatment abandonment.

Conclusions and Recommendation – Treatment abandonment among children with cancer in Uganda is, most times, as a result of difficult conditions beyond the caregivers' control and needs to be approached with empathy and support.

Introduction

Treatment abandonment is defined as the failure to either begin or complete cancer curative therapy and/or missing treatment appointments for more than one month[1]. It is recognized as a major contributor to therapeutic failure in paediatric cancer patients[2,3,4] and is particularly a challenge in low-income countries (LIC) where only 10-20% of children diagnosed with cancer are cured compared to the 80% in the high income countries (HIC)[5,6].

Worldwide, treatment abandonment rates range from 3% to 30% in HIC and LICs, respectively, and are predicted by lower Gross National Product per capita, absence of

national health insurance schemes and high prevalence of economic hardship[7]. Others include, low socio-economic status, poor literacy, increased travel time and lack of affordable local treatment.[8,9,10] Caregiver self-reported reasons for treatment abandonment in LIC include: financial constraints, misplaced incurability of cancer, false perception of cure, preference for alternative medicine, fear of adverse treatment effects and perceived poor prognosis for cancer.[3,4,7,11,12]

In Uganda, treatment abandonment rates range from 10-33%[13,14], however the reasons for abandonment have not been studied. Cancer diagnosis and treatment at the Paediatric Cancer Unit (PCU) of Mbarara Regional Referral Hospital (MRRH) are provided free by the Uganda government and philanthropy. However, a quarter of the children diagnosed with cancer do not start or complete therapy[15]. This study was therefore designed to find out why caregivers at our unit abandon therapy in order to design mitigating interventions for this problem.

Methods

Study setting.

This study was conducted at the PCU of MRRH, located in Mbarara City, south western Uganda, about 260km from the capital, Kampala. The PCU is a 16-bed capacity ward and an outpatient clinic. It is one of the four paediatric cancer treatment facilities in Uganda and the only one in South Western Uganda, serving a population of about 6 million people[16]. On average, 120 children (aged below 16 years) are enrolled with newly diagnosed cancer annually (Unpublished Cancer Unit medical records).

At the unit, all caregivers, upon a new cancer diagnosis of their child, have a private counseling session with a paediatric oncologist. During this session, the diagnosis of the child is revealed, the treatment plan discussed, the side-effects of the treatment revealed and the child's expected chances of survival explained. Caregivers who abandon treatment are routinely followed up with phone calls from the clinic staff until either they return, indicate they are not willing to return, or reveal that the child is dead.

Study design

We conducted a qualitative study in, October and November 2020, of caregivers whose children had been diagnosed with cancer from May 2017 to August 2020 and had abandoned treatment. Telephone contacts of the caregivers of children who abandoned treatment were retrieved from the medical records. Telephone calls were made to them to make appointments for home visits, without revealing the reason for the visit. The research team visited the caregivers who accepted the home visits and conducted in-depth interviews with them.

Prior to the interviews, the caregivers provided written informed consent to participate in the study and to have their responses tape-recorded. Interviews were conducted by 2 research assistants in the commonly used local language, and recorded with tape recorders. One research assistant interviewed the caregiver and the other took notes about his/her non-verbal communication. Each interview took about 60 minutes and a maximum of 4 interviews were conducted each day. Team debriefing sessions were

held the day after the interviews to discuss the important findings from the data collected.

The recorded interviews were transcribed verbatim for analysis. Data was analyzed using NVivo software (version 12, QSR International, Burlington, Mass.). Thematic content analysis was used to analyze the data and a code book was generated comprising all of the major themes. The emerging themes were organized into an explanatory logic that provided a succinct conceptual model of treatment abandonment.

The research proposal was approved by the Review and Ethics Committee of MUST (39/01-20) and registered with Uganda National Council of Science and Technology (HS966ES).

Results

Three hundred and forty-three children below 16 years of age were diagnosed with cancer from 1st May 2017 to 30th September 2020 and 77 (22.4%) of them abandoned therapy. Sixty-eight of those who abandoned therapy (88.3%) had some chemotherapy while 9 (11.7%) did not start treatment. The phone contacts of 51 out of these 77 caregivers were either not available (22), switched off (25), or calls were answered by someone who claimed not to know the child in question (4). Caregivers of 26/77 (33.8%) children were reached by phone to request a home visit by the research team and 20 (76.9%) accepted, as shown in Figure 1.

Demographic characteristics caregivers

The demographic characteristics of the primary caregivers are shown in table 1. Their ages ranged from 24 to 65 years, with a median age of 37 years. Thirteen (65%) were the children's mothers, six (30%) were their fathers while one (5%), a grandfather. The children of 8 (40%) caregivers were alive while those of 12 (60%) had died.

Demographic and clinical characteristics of the living children

The demographic and clinical characteristics of the 8 children who were still alive at the time of the study are shown in table 2. Their ages ranged from 4 to 15 years, with a median age of 6.5 years and 5 (62.5%) were males. Their diagnoses were as follows: 2 nephroblastoma, 2 Hodgkin lymphoma, 2 lymphoblastic lymphoma, one chronic myeloid leukemia, and one acute lymphoblastic leukemia. Three (37.5%) had cancer disease symptoms.

Reasons for Treatment Abandonment

Several important thematic reasons for treatment abandonment emerged from the in-depth interviews with the caregivers who had withdrawn their children from care and are shown in Table 3.

Financial difficulty was overwhelmingly, the most commonly cited reason for treatment abandonment. Caregivers reported experiences of struggling to raise money to buy food

and other necessities during the often prolonged and repeated hospital stays that characterize cancer treatment.

“My husband used to borrow money from a saving group, which we’re still paying back up to now. One time when I called him, he told me he didn’t have money and that I should take the child home”, said caregiver number 15, tears running down her cheeks.

Some caregivers reported selling their property to meet the repeated costs after which they had nothing else to sell.

“For us, we did our best. We sold almost everything, including goats, cattle and land. After that, we did not have any more money and gave up. So, money was the problem”, said caregiver number 9, folding her arms and beginning to cry.

Money was also required for transport to repeated hospital visits. When caregivers could not raise money for transportation anymore, they stopped coming.

“We did not go back because we failed to get money for transport; haven’t you seen that our place is very far?” said caregiver number 6.

Caregivers reported feeling conflicted about exhausting all the money on one sick child at the expense of the needs of the other children and family members.

“The father had a small piece of land and we considered selling it but wondered where we would put the rest of the children. We therefore decided to leave him,” caregiver number 19.

For some caregivers, other responsibilities and social obligations competed with the care of the child.

“My wife was almost due and she needed to go to the hospital so I became confused and left”, said caregiver number 1, looking away and silent for a moment.

Many caregivers said they regarded traditional and spiritual healers as alternatives to the medical care, especially in the context of disease progression and perceived poor prognosis.

“Ever since we left the hospital, we have been giving him herbal medicine and that’s what is keeping him healthy. We even planted it ourselves and so it doesn’t run out”, caregiver number 4.

Some caregivers reported feeling discouraged at the thought that cancer is incurable, often from conversations with other caregivers and observing other children who relapsed or progressed and died.

“This disease does not cure; so even when we were taking care of him, we knew that he was going to die”, said caregiver number 17, shaking her head.

Occasionally, caregivers withdrew their children from treatment because they felt the child was very sick and death was imminent and preferred the child dies at or near home to avoid the inconvenience of transporting the body. They either took the child

away from hospital without asking for an official discharge or they did not to bring them back when the review dates were due.

"*I saw other children dying and I feared mine too would die from the hospital and I struggle bringing the body. So, I decided to bring him early so he dies from home", said caregiver number 10, keeping silent for some moments and folding her lips.*

Yet, on the other hand, some caregivers said they thought that their children did not need any further treatment, since they looked fine.

"*We saw that she was well and so we decided to stay at home", caregiver number 5.*

Some caregivers also got concerned watching their children suffer treatment side effects and this motivated their decision to abandon treatment.

"From home she would be talking, walking and eating but after giving her drugs, she would fail to eat, get mouth sores and diarrhea. That one made me hate going back", caregiver number 16.

Discussion

Our study found that financial difficulties, other obligations, child appearing cured, preference for alternative treatments, belief that cancer was incurable, fear that the child was about to die, and fear of chemotherapy side-effects were the main reasons for treatment abandonment.

The inadequacy of money for food, transport and other necessities was the most common contributor to treatment abandonment among our children. This is not surprising since Uganda's population is 74% rural[17] with limited economic activities. Most people are subsistent farmers and spend most of their time growing food for survival. Quite often, the family benefactor is the one taking care of the child in hospital, thereby, cutting off family income abruptly with disastrous consequences for the sick child and the rest of the dependents.

Much as meals are provided to sick children and their attendants during their hospital stay and chemotherapy and supportive drugs are free, these do not seem adequate, because money is required to meet other in-hospital costs. Funds are also required for transport and lack of it is likely to discourage families that have to make repeated visits, usually for several months or even years. Financial difficulties have been reported as a reason for treatment abandonment in other studies, especially in the developing world[8,18-20] and low social economic status has been previously identified as the most important predictor of treatment abandonment.[7,21] In Kampala, Uganda, where money for meals during hospital stay and for transport and were provided, treatment abandonments were indeed reduced to below 10%[13].

As in previous studies, [12,22] we found that caregivers had other commitments and obligations and faced difficulty dividing their attention between other responsibilities and the care of their sick children. This was especially so if the other commitments involved

further financial expenses and especially where the parent staying in hospital with the sick child was the family bread winner. Uganda is a country with a high total fertility rate of 5.6 children per woman of child bearing age[17], so families tend to be large, with parents of limited means.

Children with cancer tend to be admitted with severe symptoms which respond to treatment quickly after initial chemotherapy. Most families, who are financially hard-pressed with so many other obligations, may see their children appearing healthier and no longer a priority. This has also been previously described in other studies[8,23,24] as a cause for treatment abandonment as caregivers shift their attention to more obviously immediate obligations.

As in our study, other studies[22,25] have described preference for other modalities of treatment among the commonest reasons caregivers report for abandoning treatment. In this community, as in many others in Africa, sickness is inherently looked at as both a physical and a spiritual problem. Communities are often convinced that there are spiritual explanations for physical disease symptoms and consult spiritual healers and herbalists for answers[26]. Children may be taken for alternative treatment before, during and after visiting the hospital, especially if the former are cheaper and within their vicinity.

In conclusion, seeking care for children with cancer involves a lot of expenses and families with limited incomes find it expensive and out of reach. Consequently,

economic difficulty, which is beyond the caregivers' control, is the cause of most treatment abandonments. Caregivers with limited resources and many dependents and who falsely think that their children are cured, are likely to abandon treatment. They are also likely to choose alternative means of care that are cheaper and procurable closer to their homes.

We recommend that on top of the free meals, diagnosis and treatment that are currently provided free at the PCU, financial support to off-set transport and upkeep costs should also be provided to caregivers. Health-care related costs, like radiological and laboratory investigations should be offered free to the patients by the hospital in order to relieve the burden off the caregivers. A full-time counselor needs to be recruited by the hospital for the PCU to hold on-going counseling sessions with caregivers and explore their coping mechanisms. Such a counselor would particularly identify caregivers with treatment abandonment ideation, so that they can be given empathetic support to avert abandonment.

The study was limited by the failure to make contact with the majority of the caregivers who had abandoned treatment, which likely caused a selection bias. The strength of the study was the success of recruiting caregivers from across a large geographical area who agreed to be interviewed face-to-face in their homes.

Funding

The study was funded by the First Mile Project of Mbarara University of Science and Technology (MUST).

Conflict of Interest

The authors declare no Conflict of Interest.

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Figure 1 Caregiver Tracking Schema