Published in final edited form as:

Support Care Cancer. 2018 March ; 26(3): 967–973. doi:10.1007/s00520-017-3917-z.

Risk factors and reasons for treatment abandonment among children with lymphoma in Malawi

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Abstract

Purpose—Lymphoma is the commonest pediatric cancer in sub-Saharan Africa (SSA). Frequent treatment abandonment contributes to suboptimal outcomes. We examined risk factors and reasons for treatment abandonment for this population in Malawi.

Methods—We conducted a mixed methods study among children <18 years old with newly diagnosed lymphoma, prospectively enrolled during 2013–2016. All children received standardized diagnosis and treatment, and were followed for up to two years. treatment abandonment was defined as failure to attend prescribed chemotherapy within four weeks, or post-treatment visit within three months. Child, guardian, and household characteristics associated with treatment abandonment were assessed. Semi-structured interviews were conducted with primary caregivers of children experiencing treatment abandonment.

Results—Of 121 children with newly diagnosed lymphoma, 72 (60%) had complete information regarding child, guardian, and household characteristics. Of these, 56 (78%) had Burkitt and 16 (22%) Hodgkin lymphoma. Forty-nine (68%) were male, median age was 10.6 years (interquartile range [IQR] 7.9–13.0), and 26 (36%) experienced treatment abandonment. Lack of guardian education and travel time ≥4 hours to clinic were independently associated with treatment abandonment, with adjusted hazard ratio (aHR) 3.8 [95% confidence interval (CI) 1.5–8.9, p=0.005] and aHR 2.9 (95% CI 1.2–6.9, p=0.019), respectively. Commonest reasons for treatment abandonment endorsed by 15 guardians were community influence, suboptimal clinic

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Conflict of interest

We declare no conflicts of interest. The authors have full control of all primary data and agree to allow the journal to review these data if requested.

environment, logistical challenges, transport costs, treatment toxicities, loss of hope, alternative healers, and beliefs about cure.

Conclusions—These findings highlight families at risk for treatment abandonment, underlying reasons, and opportunities to improve retention in care for pediatric cancer patients in SSA.

Introduction

Lymphoma is the commonest pediatric cancer in sub-Saharan Africa (SSA) [1, 2]. Long-term cure rates of 90% or more are achievable in developed countries. However, survival rates in SSA are substantially lower, ranging from 30 to 75% [3–5]. While poorer outcomes in SSA can be partly attributed to weak health systems with late diagnosis and limited treatment options, other factors influenced by patients, providers, or both also contribute, like poor adherence to prescribed therapy [6, 7]. Reflecting this, treatment abandonment rates in pediatric cancer studies from SSA are high, often ranging from 30 to 60% [8–10]. Thus, in addition to better diagnosis and treatment, improving pediatric cancer outcomes in the region requires elucidation of underlying risk factors and reasons for treatment abandonment in this vulnerable population, to inform interventions to improve retention.

In HIV programs from SSA, socioeconomic factors and social support are key determinants of treatment abandonment [11]. However, treatment abandonment determinants may be different for pediatric lymphoma patients, given their need for more specialized treatment, typically requiring long travel distances to tertiary facilities and often long hospital stays. For pediatric patients, guardians' knowledge and beliefs about cancer might also influence likelihood of treatment abandonment. Given the scarcity of regional literature examining treatment abandonment among children with cancer, the aim of this mixed methods study was to assess risk factors for treatment abandonment among pediatric lymphoma patients in Malawi, including patient, guardian, and household characteristics. In addition, we conducted semi-structured qualitative interviews with guardians to better understand treatment abandonment at the individual family level.

Methods

Our study was nested within the prospective Kamuzu Central Hospital Lymphoma Study observational cohort in Lilongwe, Malawi, which has been previously described in detail [4, 5, 12]. These analyses focused on children less than 18 years of age with newly diagnosed lymphoma at our center, enrolled between June 2013 and March 2016. Patients received standardized diagnosis and treatment according to institutional protocols within a dedicated pediatric oncology unit. Children were seen for all chemotherapy visits, and every three months for the first two years after completing treatment. Transport reimbursements were provided to families who attended clinic to encourage retention throughout care. We have also previously described successful use of cell phone tracing to ascertain vital status in nearly all children [4, 5, 12]. For this study focused on risk factors and reasons for defaulting from care, treatment abandonment during treatment was defined as failure to attend clinic within four weeks of a prescribed chemotherapy appointment [6]. treatment abandonment after treatment was defined as failure to attend clinic within three months of a scheduled follow-up visit appointment. However, given relatively small sample size and frequent cooccurrence of treatment abandonment during and after treatment within the same families, in these analyses treatment abandonment during and after treatment were considered together as a single outcome. This composite outcome approach combined two clearly distinct but related outcomes. However, we felt this composite outcome provided the optimal framework for this initial in-depth exploratory study of treatment abandonment among pediatric lymphoma patients in Malawi. For any missed clinic visit, dedicated staff made up to three attempts to reach families by phone. If phone contact was not successful, home visits were attempted.

Baseline categorical data with respect to patient, guardian, and household characteristics were descriptively summarized using proportions with percentages, and compared between families with and without treatment abandonment using Fisher's exact test. Continuous data were summarized using medians with ranges, and compared between groups using the Kruskal-Wallis test. Follow-up time was calculated from enrolment until the first occurrence of treatment abandonment, death, or administrative censoring on 31 August 2016. Risk factors for treatment abandonment were assessed using Cox proportional hazard model. The final adjusted model retained only variables with significant associations in unadjusted models at a two-sided α-level of <0.1. All analyses were performed using STATA IC version 14.1 (Stata Corp., College Station, TX). Statistical significance was considered at a two-sided α-level of <0.05.

For families experiencing treatment abandonment who could be subsequently reached and were willing to participate, detailed semi-structured interviews were conducted to qualitatively assess reasons for treatment abandonment. These interviews were conducted with the child's primary caregiver, and whenever possible, the same individual who provided consent for the child's initial participation in the study. An interview guide was designed based on similar studies in the region [10, 13], and the clinic team's experiences interacting with patients and guardians in Malawi. After initial development, the interview guide was cognitively tested with two guardians and subsequently improved based on this experience and their feedback. Interviews were conducted by trained study staff in the local language, Chichewa. Guardians were interviewed by phone or face-to-face, and interviews were conducted until saturation of information was reached [14]. All interviews were recorded, translated into English, and transcribed by study staff fluent in both Chichewa and English. A codebook was developed based on literature and previous experience, and adapted based on content elicited during the interviews. Double coding was done by one Malawian (CCS) and one expatriate investigator (TvdG) to ensure reliability and consistency. A five-step framework analysis approach was used for interpretation of interviews [15]. All qualitative data coding and analysis was done using Nvivo Pro 11 (QSR International, Melbourne, Australia).

The study was approved by the Biomedical Institutional Review Board of the University of North Carolina at Chapel Hill, the Protocol Review Committee of the Lineberger Comprehensive Cancer Centre and the Malawi National Health Sciences Research Committee.

Results

Quantitative results

From 1 June 2013 to 31 March 2016, 121 children less than 18 years of age were enrolled with a new pathologically confirmed diagnosis of lymphoma. Treatment course, toxicities, follow-up, and outcomes for the overall cohorts of children with Burkitt and Hodgkin lymphoma have already been reported [4, 5]. Of these 121 children, complete patient, guardian, and household information were available for 72 (60%) children who comprised the final analytic population. Most had Burkitt lymphoma (n=56, 78%), followed by 16 (22%) with Hodgkin lymphoma. Twenty-six children (36%) met the treatment abandonment study definition (n=19 with treatment abandonment during treatment only; n=6 with treatment abandonment during and after treatment; n=1 with treatment abandonment after treatment only). Patient, guardian, and household characteristics for the analytic population overall, and also stratified by treatment abandonment occurrence, are shown in Table 1. Overall, 49 children (68%) were male and the median age was 10.6 years [interquartile range (IQR) 7.9–13.0]. Four patients (6%) were HIV-infected, 45 (63%) had stage III/IV disease, and 55 (76%) had impaired performance status defined as Lansky performance score less than 70. Sixty-four children (89%) were currently attending school at the time of study enrolment. There was a trend toward treatment abandonment patients being more frequently male than patients without treatment abandonment (81% vs 61%, p=0.068), but patient characteristics were otherwise not clearly associated with treatment abandonment.

Of 72 guardians, 49 (68%) were female with most (n=48, 67%) aged 35–49 years. Fifty-nine (82%) guardians were married, and 39 (54%) were the child’s mother. Fifty-one guardians (71%) had primary education, 14 (19%) no education, and 7 (10%) secondary or higher education. Families with treatment abandonment tended to more frequently have guardians with no formal education (p=0.051). Forty-six families (64%) reported farming as their main source of income. Household characteristics also indicated typically low socioeconomic status, with 43 (60%) having grass roofs, 52 (72%) having mud floors, 45 (62%) having a borehole as the primary water source, and 52 (72%) having firewood as the main energy source. Among these socioeconomic status indicators, lower status as reflected by grass versus iron roof (p=0.067) and primary energy source (p=0.028) exhibited possible associations with treatment abandonment. Median travel time to clinic was 4.0 hours (IQR 2.9–6.0), and was higher among treatment abandonment families than those without treatment abandonment (5.4 versus 3.8 hours, p=0.028).

As of 31 August 2016, median follow-up time among children not known to have died was 10.1 months (IQR 7.4–18.2) from study enrollment. Among families experiencing treatment abandonment, this occurred at a median of 6.7 months (IQR 3.7–11.6) after study enrollment. Risk factors for treatment abandonment are shown in Table 2. In adjusted analyses, treatment abandonment was independently associated with no formal education for the guardian compared to any education [adjusted hazard ratio (aHR) 3.8, 95% confidence interval (CI) 1.5–8.9, p=0.005], and travel time ≥4 hours to clinic (aHR of 2.9, 95% CI 1.2–6.9, p=0.019).

Qualitative results

Of 26 families experiencing treatment abandonment, we conducted qualitative interviews with 15 guardians (n=10 with treatment abandonment during treatment only; n=5 with treatment abandonment during and after treatment), of which 10 interviews were conducted in person and five by phone. Intercoder agreement was 99%, with average Cohen's kappa coefficient of 0.77. Several important thematic reasons for treatment abandonment emerged from the interviews as shown in Table 3.

Community influence was a recurring factor in whether guardians brought their children for treatment or follow-up visits. Community influence could be positive, as expressed through financial help, food donations, or psychological support. Community influence could also be negative, and many guardians were discouraged by neighbors to attend clinic.

> "You are wasting your time and money by going to the clinic" (guardian 1)

Guardians also frequently did not find the clinic and hospital environment to be very family-friendly. Despite substantial recent renovation and infrastructure investments within the pediatric oncology ward including dedicated staff, beds for guardians were often not available, forcing them to sleep on the floor due to hospital overcrowding. Food was provided by the hospital, but was often felt to be insufficient.

> "Sometimes we were sleeping on the floor, when all the beds have been occupied, until some patients are discharged" (guardian 2)

Logistical challenges, including long travel distances with poor road conditions, were also mentioned as key reasons for treatment abandonment. In some instances, guardians resorted to moving in with family members who lived closer to hospital, but this was impossible for those without relatives living in Lilongwe.

> "Travelling was very difficult, it's very far from here, and we live near the Zambian border. It's very difficult to find transport like a vehicle to get to get clinic" (guardian 1)

> "It was very difficult because most of the times, I was arriving at the hospital late at night. Or sometimes I was starting off at night so I could get to the hospital on time" (guardian 3)

In other cases, families failed to make it to the hospital due to scheduling obligations. Often guardians had to take care of other family members, which was most common in single-parent families.

Another recurring theme was that guardians did not always understand the need for specific treatments nor their expected effects, despite standardized education sessions provided by the clinical team to all families at the time of initial diagnosis. Some guardians thought the disease was caused by HIV, or that there was a relationship between the disease and HIV, although all children were tested and very few found to be positive. Misconceptions and lack of understanding about the disease, treatment, and potential for cure among guardians were commonly expressed.

> "I didn't really understand what would happen if I don't give her (child) all the medication" (guardian 4)

Costs of transport were also cited as a major reason by many guardians for treatment abandonment, despite transport reimbursement for all study participants.

> "The big problem is transport money, if we don't have the money then we can't come to the hospital for treatment, while the patient is in need to receive treatment" (guardian 5)

Treatment side effects and toxicities were also a concern for guardians and children. Families were demotivated when their children experienced discomfort, which was often a reason for parents to abandon treatment and stay at home.

> "Each time she takes the medication, she starts vomiting and feeling fever and we were worried about that" (guardian 6)

Some guardians lost hope when their children showed no signs of improvement or disease progression.

> "When he started treatment there at the clinic, there was an improvement, but when we went back home, he started feeling unwell again. We went back to the hospital; the clinicians tried everything but there was no improvement, so we went home. After 3 months he died" (guardian 7)

Use of non-allopathic medicine was another commonly occurring theme. Many families regarded traditional healers as a viable alternative, especially after losing hope due to disease progression, and some were spurred on by their peers. Some guardians mentioned that they tried treatment from traditional healers even before children were enrolled into the study, and others used hospital medication only as supplement to treatments obtained from traditional healers.

> "We failed to come to the hospital after our child had high fever and we went to a nearby traditional doctor and once we came back from there, the child seemed to be better" (guardian 4)

Some guardians indicated that their children did not need further treatment, since they looked cured. This feeling was justified especially by financial and logistical challenges associated with attending clinic simply to document that the child was alive and well.

> "Now he is better although sometimes he complains about having a headache but we do just go to nearby clinic to get analgesic drugs" (guardian 8)

Discussion

Given the frequency and importance of treatment abandonment within pediatric populations in SSA, and few studies specifically examining it, we conducted a mixed methods study to assess risk factors and reasons for treatment abandonment among children with lymphoma in Malawi. treatment abandonment was common in our cohort and associated with low guardian education and long travel distances. No child characteristics seemed to be clearly associated with treatment abandonment. Emerging themes from qualitative interviews highlighted community influence, suboptimal clinic environments, logistical challenges, transport costs, treatment side effects and toxicities, loss of hope due to disease progression, use of alternative healers, and beliefs about cure as recurring reasons for treatment abandonment in the Malawi context.

Low guardian education has been previously associated with treatment abandonment in the region [10, 16]. In our cohort, guardians exhibited a significant lack of knowledge and understanding about their child's disease and treatment, despite dedicated efforts by the clinical team to educate all families at the time of initial diagnosis. These efforts included senior clinicians, but diverse messaging from various providers in the hospital and non-standardized educational content may nonetheless have led to persistent misconceptions among patients and families. This lack of knowledge was also evident and important at the community level, with neighbors frequently advising guardians that their children were bewitched and recommending traditional healers. These findings highlight the immense continued need for community and patient education, together with efforts to improve cancer diagnosis and treatment [10, 16, 17]. In order for guardians to be effective therapeutic allies in the care of pediatric cancer patients, it is vital that they better understand diagnostic and treatment procedures, and benefits of adherence to medication.

Educating patients, families, and communities also depends on strong therapeutic relationships between providers and guardians, which should include a focus on anticipated side effects and interventions to prevent and manage these, like anti-emetics. Although there is clearly a need to better engage families in the treatment process [18], it must be emphasized that this can be practically very challenging in SSA environments, even within dedicated pediatric oncology programs as at our center. This may be due to time limitations in clinics with few staff and overwhelming patient numbers, low education levels within many families, and historically paternalistic doctor-patient relationships in SSA settings, which require significant cultural shifts and resetting of expectations among both providers and patients.

Another prominent risk factor and reason for treatment abandonment was long travel distances to clinic with often poor road conditions. This is consistent with other reports from SSA [10, 16]. Higher-level diagnosis and treatment for cancer patients in Malawi is largely restricted to two referral centers, Kamuzu Central Hospital in Lilongwe and Queen Elizabeth Central Hospital in Blantyre. However, even with centralized cancer services, retention may be improved by providing reimbursements for transport and other costs associated with clinic visits. Notably, in our study, guardians cited transport costs as a challenge even despite receiving reimbursements. Other solutions might include providing residential short-term housing adjacent to clinics for families throughout treatment, and ultimately providing more decentralized services closer to where children reside. The latter solution will of course require major infrastructure investments to address human capacity and infrastructure especially in rural areas, before specialized pediatric oncology care can be safely delivered outside urban health facilities. In the short term, the potential impact of residential housing for families was highlighted recurrently in interviews, during which guardians frequently reported displeasure at sleeping on the hospital floor due to bed shortages, as well as inadequate nutritional support for children and their families while admitted.

Strengths of our study include a mixed method approach to assess factors associated with treatment abandonment both quantitatively and qualitatively, thus providing a detailed understanding of treatment abandonment at the individual family level. Secondly, we considered patient, guardian, and household factors, which allowed us to comprehensively assess risks for treatment abandonment and the overall environment for these children. Our study is limited in that comprehensive patient, guardian, and household data were available only for a subset of all enrolled patients in the study, and qualitative interviews were conducted only with guardians who could be reached and were willing to participate. Lastly, treatment abandonment during and after treatment were considered together in our analyses as a composite outcome, although existing literature suggests these have different implications and underlying reasons. Examining these differences in depth should be an important focus of future studies.

In conclusion, we assessed risk factors and reasons for treatment abandonment among pediatric lymphoma patients in Malawi and found treatment abandonment to be driven more by guardian or household characteristics than child characteristics, in particular low guardian education and long travel distances. Interviews with guardians highlighted several recurring reasons for treatment abandonment, emphasizing many opportunities to improve retention including possibly targeted interventions for families at highest risk of treatment abandonment. Specific opportunities for intervention raised by our work include providing more thorough standardized education for families and communities about cancer care and treatment, and possible mitigation of transportation difficulties through short-term residential housing for families until cancer treatment is complete. These efforts can ultimately help increase survival for all children with cancer in SSA, irrespective of distance traveled, family education level, or socioeconomic status.

Acknowledgments

The authors would like to thank the patients and their families for agreeing to participate in the study. We are also grateful to leadership of Kamuzu Central Hospital, Malawi Ministry of Health, UNC Project-Malawi, Lineberger Comprehensive Cancer Center, and Baylor College of Medicine Children's Foundation Malawi for support of this study. This work is supported by grants from the National Institutes of Health (K01TW009488, U54CA190152, and P30CA016086-40S4).

References

1. Msyamboza KP, Dzamalala C, Mdokwe C, et al. Burden of cancer in Malawi; common types, incidence and trends: national population-based cancer registry. BMC Res Notes. 2012; 5:149. [PubMed: 22424105]
2. Mwanda OW, Rochford R, Rainey J, et al. Challenges in the epidemiological and clinical aspects of Burkitt's lymphoma in Kenya: Linking evidence and experience. East Afr Med J. 2004; 8(Suppl):S111–6.
3. Kazembe P, Hesseling PB, Griffin BE, et al. Long term survival of children with burkitt lymphoma in Malawi after cyclophosphamide monotherapy. Med Pediatr Oncol. 2003; 40:23–25. [PubMed: 12426682]
4. Stanley CC, Westmoreland KD, Heimlich BJ, et al. Outcomes for paediatric Burkitt lymphoma treated with anthracycline-based therapy in Malawi. Br J Haematol. 2016; 173:705–712. [PubMed: 26914979]

5. Westmoreland KD, Stanley CC, Montgomery ND, et al. Hodgkin lymphoma, HIV, and Epstein-Barr virus in Malawi: Longitudinal results from the Kamuzu Central Hospital Lymphoma study. Pediatr Blood Cancer. 2016 Oct 26. (2016) [Epub ahead of print]. doi: 10.1002/pbc.26302
6. Mostert S, Arora RS, Arreola M, et al. Abandonment of treatment for childhood cancer: position statement of a SIOP PODC Working Group. Lancet Oncol. 2011; 12:719–720. [PubMed: 21719348]
7. Weaver MS, Howard SC, Lam CG. Defining and Distinguishing Treatment Abandonment in Patients With Cancer. 2015; 37:252–256.
8. Weaver MS, Arora RS, Howard SC, et al. A practical approach to reporting treatment abandonment in pediatric chronic conditions. Pediatr Blood Cancer. 2015; 62:565–570. [PubMed: 25586157]
9. Arora RS, Eden T, Pizer B. The problem of treatment abandonment in children from developing countries with cancer. Pediatr Blood Cancer. 2007; 49:941–946. [PubMed: 17252565]
10. Njuguna F, Mostert S, Slot A, et al. Abandonment of childhood cancer treatment in Western Kenya. Arch Dis Child. 2014; 99:609–614. [PubMed: 24681695]
11. Gwynn RC, Fawzy A, Viho I, et al. Risk factors for loss to follow-up prior to ART initiation among patients enrolling in HIV care with CD4+ cell count ≥200 cells/μL in the multi-country MTCT-Plus Initiative. BMC Health Serv Res. 2015; 15:247. [PubMed: 26108273]
12. Stanley CC, Westmoreland KD, Itimu S, et al. Quantifying bias in survival estimates resulting from loss to follow-up among children with lymphoma in Malawi. Pediatr Blood Cancer. 2016 Nov 28.1–4 (2016) [Epub ahead of print]. doi: 10.1002/pbc.26370
13. Israëls T, Chirambo C, Caron H, et al. The guardians’ perspective on paediatric cancer treatment in Malawi and factors affecting adherence. Pediatr Blood Cancer. 2008; 51:639–642. [PubMed: 18668516]
14. Morse JM. Determining Sample Size. Qual Health Res. 2000; 10:3–5.
15. Srivastava A, Thomson SB. Framework Analysis: A Qualitative Methodology for Applied Policy Research. Journal of Administration & Governance. 2009; 4:72–79. Available at http://joaag.com/Past_Issues.html].
16. Slone JS, Chunda-Liyoka C, Perez M, et al. Pediatric malignancies, treatment outcomes and abandonment of pediatric cancer treatment in Zambia. PLoS One. 2014; 9:1–8.
17. Abratt RP, Vorobiof DA. Cancer in Africa. Lancet Oncol. 2003; 4:394–396. [PubMed: 12850189]
18. Arora RS, Pizer B, Eden T. Understanding refusal and abandonment in the treatment of childhood cancer. Indian Pediatr. 2010; 47:1005–1010. [PubMed: 21220796]

Table 1

Patient, guardian, and household characteristics among pediatric lymphoma patients in Lilongwe, Malawi.

	All (n=72)	**No treatment abandonment (n=46)**	**Treatment abandonment (n=26)**	**p-value**
Patient characteristics				
Male	49 (68.1)	28 (60.9)	21 (80.8)	0.068
Age in years, median (IQR)	10.6 (7.9 – 13.0)	10.6 (8.3 – 13.0)	10.8 (7.7 – 13.0)	0.81
HIV status				
Negative	68 (94.4)	43 (93.5)	25 (96.2)	
Positive	4 (5.6)	3 (6.5)	1 (3.8)	0.54
Clinical stage				
Stage I/II	27 (37.5)	17 (37.0)	10 (38.5)	
Stage III/IV	45 (62.5)	29 (63.0)	16 (61.5)	0.55
Lansky performance status ≤70	55 (76.4)	36 (78.3)	19 (73.1)	0.41
Child in school	64 (88.9)	42 (91.3)	22 (84.6)	0.31
Guardian characteristics				
Female	49 (68.1)	29 (63.0)	20 (76.9)	0.17
Age				
<35 years	14 (19.4)	7 (15.2)	7 (26.9)	
35–49 years	48 (66.7)	30 (65.2)	18 (69.2)	
≥50 years	10 (13.9)	9 (19.6)	1 (3.9)	0.11
Married				
Yes	59 (81.9)	37 (80.4)	22 (84.6)	
No	13 (18.1)	9 (19.6)	4 (15.4)	0.46
Relation to patient				
Mother	39 (54.2)	21 (45.7)	18 (69.2)	
Father	20 (27.8)	16 (34.8)	4 (15.4)	
Other caregiver	13 (18.1)	9 (19.6)	4 (15.4)	0.15
Education				
None	14 (19.4)	6 (13.0)	8 (30.8)	
Primary	51 (70.8)	37 (80.4)	14 (53.8)	
Secondary or above	7 (9.7)	3 (6.5)	4 (15.4)	0.051
Main income source				
Farming	46 (63.9)	28 (60.9)	18 (69.2)	
Irregular job or business	20 (27.8)	14 (30.4)	6 (23.1)	
Regular job	6 (8.3)	4 (8.7)	2 (7.7)	0.86
Household characteristics				
Roof				
Grass	43 (59.7)	24 (52.2)	19 (73.1)	
Iron sheets	29 (40.3)	22 (47.8)	7 (26.9)	0.067
Floor				
Sand/Mud	52 (72.2)	31 (67.4)	21 (80.8)	

	All (n=72)	**No treatment abandonment (n=46)**	**Treatment abandonment (n=26)**	**p-value**
Cement	20 (27.8)	15 (32.6)	5 (19.2)	0.17
Main water source				
Open source	19 (26.4)	10 (21.7)	9 (34.6)	
Borehole	45 (62.5)	30 (65.2)	15 (57.7)	
Tap	8 (11.1)	6 (13.0)	2 (7.7)	0.51
Main energy source				
Firewood	52 (72.2)	30 (65.2)	22 (84.6)	
Charcoal	17 (23.6)	15 (32.6)	2 (7.7)	
Electricity	3 (4.2)	1 (2.2)	2 (7.7)	0.028
Number of children				
≤3 children	35 (48.6)	25 (54.4)	10 (38.5)	
>3 children	37 (51.4)	21 (45.6)	16 (61.5)	0.15
Days without food in last week				
None	34 (47.2)	21 (45.6)	13 (50.0)	
≥1 days	38 (52.8)	25 (54.4)	13 (50.0)	0.46
Travel time to clinic in hours, median (IQR)	4.0 (2.9 – 6.0)	3.8 (2.8 –5.0)	5.4 (3.0 – 10.0)	0.028

Data presented as n (%) unless otherwise specified.

Table 2

Risk factors for treatment abandonment among pediatric lymphoma patients in Lilongwe, Malawi.

	Unadjusted		**Adjusted**	
	HR	**95% CI**	**HR**	**95% CI**
Guardian education level				
Any education	1		1	
No education	3.62	1.49 – 8.83	3.61	1.46 – 8.91
Main source of energy				
Charcoal or electricity	1		1	
Firewood	2.32	0.78 – 6.94	2.46	0.76 – 7.90
Travel time				
<4 hours	1		1	
≥4 hours	2.32	1.01 – 5.36	2.86	1.19 – 6.89

HR = hazard ratio. CI = confidence interval.

Table 3

Themes emerging in semi-structured interviews focused on treatment abandonment among pediatric lymphoma patients in Lilongwe, Malawi

Theme	Description	Frequency
Community influence	When guardians are encouraged or discouraged by friends, family, or neighbors to come for treatment	14
Suboptimal clinic environment	When guardians mention suboptimal conditions in the clinic or hospital	13
Logistical challenges	When other responsibilities or non-financial barriers interfere with clinic attendance	12
Knowledge gap	When guardians express lack of knowledge or understanding about the disease, treatment, or association with HIV	11
Transport costs	When guardians cite financial barriers preventing travel to clinic	9
Treatment side effects & toxicities	When concerns or actual side effects of treatment are cited as reasons for missed follow-up appointments	8
Loss of hope	When guardians indicate they didn’t have hope that their child would get better	8
Alternative healer	When guardians mention obtaining treatment from traditional healers or those offering non-allopathic remedies	4
Looked cured	When guardians mention their child does not need more treatment since the child appears cured	3