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Caregiver-Reported Reasons and Outcomes of Treatment Default among Pediatric Oncology Patients at a Tertiary Care Hospital in Pakistan

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ABSTRACT

Despite the availability of free care, many children in Pakistan fail to complete cancer therapy, leading to poor outcomes and increased mortality. **Objective:** To determine reasons and outcomes of pediatric cancer patients defaulting treatment at tertiary care hospital in Pakistan. **Methods:** This descriptive cross-sectional study was conducted at Pediatric Hematology/Oncology unit of Children Hospital, Lahore. Total 82 pediatric oncology patients (<16 years) who started treatment but defaulted at any stage between 1st January and 30th June 2024 were included. Caregivers were interviewed regarding default reasons, and relevant clinical data were analyzed using SPSS version 27.0 for descriptive statistics. **Results:** Most frequently reported contributing factors were financial issues (100%), out-of-pocket expenses (98.8%), long travel distance (92.7%), and poor socioeconomic status (91.5%). Family-related challenges included other responsibilities (89%), parental job issues (84.1%), poor understanding of disease (81.7%), and lack of family support (63.4%). Additional reasons included large family size (72%) and family pressure to abandon treatment (29.3%). Patient-related causes were faith-based healing (50%), perceived long treatment duration (31.7%), consent withdrawal (25.6%), and fear of surgery (18.3%). System-related barriers included treatment unavailability (11%) and dissatisfaction with care (7.3%). Upon return, 54.3% were eligible only for palliative care, 25.6% resumed curative treatment, 14.8% expired, 3.7% were cured, and 2.5% were lost to follow-up. **Conclusion:** Treatment default in pediatric oncology is driven by financial, social, and systemic challenges. Overcoming these obstacles is essential to enhance treatment adherence and improve patient outcomes.

INTRODUCTION

Cancer is a leading cause of death among both adults and children globally [1]. Each year, approximately 400,000 new cases of cancer are diagnosed in children aged 0–19 years [2]. A significant proportion of these cases arise in Low- and Middle-Income Countries (LMICs), where outcomes are markedly poorer compared to High-Income Countries (HICs) [3]. The prognosis of childhood cancer varies significantly, often depending on geographical location [4]. While HICs report cure rates exceeding 80% due to advancements in diagnosis, treatment, and supportive care, LMICs lag behind with survival rates ranging from 20% to 70%, and in some regions, such as East Africa, as low as 10% [5]. This disparity is largely attributed to multiple systemic challenges in LMICs, including limited access to specialized pediatric oncology services, inadequate supportive care infrastructure, shortage of trained healthcare personnel, poor social support, late-stage presentation, and most critically, high rates of treatment abandonment [6, 7]. Treatment default is preventable but remains a significant cause of treatment failure, leading to increased morbidity and mortality due to uncontrolled disease progression [8]. Despite the availability of free treatment and specialized pediatric oncology centers in Pakistan, more than 20% of children with cancer still

discontinue therapy [9]. Globally, treatment default jeopardizes the survival of nearly one in every seven children with cancer each year [10]. Although issue of treatment default in pediatric oncology is well-recognized in LMICs, it remains significantly under-quantified and under-addressed, particularly in Pakistan. There is notable lack of local data regarding the specific reasons for treatment abandonment and the outcomes associated with defaulting therapy. Without such contextual evidence, efforts to design effective interventions remain hindered. To reduce abandonment rates and improve survival outcomes at the centre, it is essential to generate baseline data and identify the social, economic, and healthcare-related risk factors contributing to treatment default. Therefore, this study conducted to determine the reasons and outcomes of pediatric cancer patients defaulting treatment at a tertiary care hospital in Pakistan. Addressing this gap would support the development of targeted strategies to enhance treatment adherence and overall pediatric cancer outcomes in resource-limited settings.

METHODS

This descriptive cross sectional study, conducted at Pediatric Hematology/Oncology unit, of Children's Hospital and University of Child Health Sciences Lahore, for duration of 6 months from April 2024 to September 2024. Ethical approval from IRB was taken before conducting this study [No.816/CH-UCHS]. The sample size of 82 patients was estimated based on a local study conducted in Karachi, which reported a 22% treatment default rate among pediatric cancer patients [11]. The unit of analysis was the patient, while the primary source of information regarding reasons for treatment default was the caregiver, who was interviewed at the time of return or follow-up. The sampling technique used was nonprobability purposive. It included all children diagnosed as having any pediatric malignancy with age range of 12 months to 16 years, who were treatment defaulted during any stage of management were included. Treatment default refers to failure of patient or caregiver to adhere to prescribed cancer treatment plan. This includes not starting the prescribed treatment, missing multiple appointments, or discontinuing treatment for prolonged period (typically more than 4 weeks) without medically valid reason. Children more than 16 years of age, treatment started/taken at other hospitals and those with consent withdrawal were excluded. Written informed consent was taken from parents/guardians before enrolment. Data collection was started with patients demographic (name, age, gender, address, underlying malignany), and parents related characteristics (education, monthly income). The diagnosis of malignancy was confirmed from the hospital's medical records at the time of default and recorded in the proforma to ensure data consistency. Data were collected using a structured questionnaire specifically developed for this study based on a review of relevant literature and expert consultation with pediatric oncology specialists. The questionnaire comprised approximately 30 questions covering multiple domains, including patient-related factors such as age, gender, type of malignancy, and treatment phase; family-related factors like parental education, occupation, family size, and support; socioeconomic aspects including monthly household income, financial constraints, out-of-pocket medical expenses, and travel distance to the hospital; as well as healthcare system factors such as treatment accessibility, satisfaction with hospital services, and medication availability. The reasons for treatment default were also explored, including refusal to start treatment, missed appointments, treatment discontinuation, fear of procedures, use of alternative therapies, and social or cultural pressures. Data collection was conducted through face-to-face interviews with the primary caregivers of the patients during their follow-up visits or return to the hospital. Trained research assistants administered the questionnaire to ensure consistency and completeness, and responses were recorded on paper forms before being entered into a digital database for analysis. These outcomes included treatment resumption, whether curative or palliative; disease progression as evaluated through clinical assessment and medical records; mortality, with cause of death documented when available; and loss to follow-up if patients did not return or could not be contacted. Outcome data were obtained from hospital records and caregiver interviews during follow-up visits. Patients were followed for 1 month to see outcomes. The collected data were entered and analyzed in SPSS version 27.0. Age was presented as median and range. Data regarding gender, education of parents, causes of treatment default, and outcomes were presented as frequency and percentage.

RESULTS

Among 82 patients included, median age found was 6 years (1–16years). Fifty-two (63.4%) were male and thirty (36.6 %) were females with male-to-female ratio of 1.7:1. Median duration of default was 16 weeks (Range 1-156). Forty-six (56.1%) patients were from the village and 36 (43.9%) from the city. Fathers were uneducated in 45 (54.9%) patients, mothers were uneducated in 43 (52.4%) patients. Seventy-five (91.5%) patients had monthly income <50,000 PKR/month, while only 7 (8.5%) patients had family income >50,000 PKR/month.

Table 1: Demographic of Patients and Parents Related Characteristics of Study Participants(n=82)

Patient Age: Median (Minimum –Maximum)	Categories	6 Years (1-16 Years) Frequency (%)
Gender	Male	52 (63.4)
	Female	30 (36.6)

Residence	Rural	46 (56.1)
	Urban	36 (43.9)
Malignancy	Hematological	47 (57.31)
	Sarcomas	8 (9.7)
	Neuroblastoma	2 (2.4)
	Retinoblastoma	3 (3.7)
	Wilms tumor	10 (12.2)
	CA colon	1 (1.2)
	Nasopharyngeal carcinoma	1 (1.2)
	Hepatoblastoma	3 (3.7)
	Germ cell tumour	7 (8.5)
Parents Educational status	Mother	Educated	-
		Uneducated	43 (52.4)
	Father	Educated	-
		Uneducated	45 (54.9)
Monthly income	<50,000 PKR/month	75 (91.5)
	> 50,000 PKR/month	7 (8.5)

The most frequently reported factors contributing to treatment default among pediatric oncology patients included financial issues (100%), poor socioeconomic status (91.5%), long travel distance to hospital (92.7%), and out-of-pocket expenses (98.8%). Family-related challenges were also prominent, with 89% citing other responsibilities, 84.1% facing parental job issues, 80.5% needing to borrow money, 81.7% having poor understanding of disease, and 63.4% lacking adequate family support. Additionally, large family size was noted in 72% of cases, while 29.3% experienced family pressure to abandon treatment. Among patient-related reasons, 50% turned to spiritual or faith-based healing, 31.7% cited long duration of therapy, 25.6% withdrew consent, 18.3% feared surgery, and 8.5% refused to initiate treatment. System-related issues were less common but included treatment unavailability (11%), overburdened healthcare services (9.8%), dissatisfaction with hospital care (7.3%), and witnessing death of other patients in the ward (2.4%). Language barriers were reported by 15.9% of families, and 11% of children came from broken families or had single parent.

Table 2: Factors Associated with Treatment Default

Factors Associated with Treatment Default		Frequency (%)
Patient-Based	Advanced disease	3 (3.7)
	Consent not given/withdrawal	21 (25.6)
	Refusal to start treatment	7 (8.5)
	Fear of surgery	15 (18.3)
	Long duration of therapy	26 (31.7)
	Healing through faith	41 (50)
Family-Based	Poor understanding of disease	67 (81.7)
	Other responsibilities	73 (89)
	Family pressure	24 (29.3)
	Family support NA	52 (63.4)
	Broken family/single parent	7 (11)
	Parental job issues	67 (84.1)

System-Based	Need to borrow money	66 (80.5)
	Death in family	11 (13.4)
	Illness of other member in family	15 (18.3)
	Treatment NA	7 (11)
	Overburden of patients	8 (9.8)
	Not satisfied	6 (7.3)
	Death of other patients in ward	2 (2.4)
Socioeconomic	Poor socioeconomic Status	73 (91.5)
	Financial issues	82 (100)
	Out of pocket expenses	81 (98.8)
	Language barrier	11 (15.9)
	Long Travel Distance	73 (92.7)
	Large family size	59 (72)

Out of 82 pediatric oncology patients who defaulted on treatment, majority (54.3%) were only eligible for palliative care upon their return, 21 patients (25.6%) were able to restart curative treatment, while 12 patients (14.8%) expired and only 3 patients (3.7%) achieved cure after resuming therapy. Two patients (2.5%) defaulted treatment again or were lost to follow-up, leaving their outcomes unknown.

Table 3: Outcome of Defaulted Patients

Outcomes	Frequency (%)
Expired	12 (14.8)
Palliative care	44 (54.3)
Treatment started	21 (25.60)
Cured after treatment	3 (3.7)
Unknown/Defaulted again	2 (2.5)
Total	82 (100)

DISCUSSION

It was observed in the current study that the most common malignancy found among treatment defaulters was hematological. This is in contrast with a previous study conducted in Ethiopia where most treatment defaulters were found to have bone sarcomas and brain tumours [12]. In the current study, the male gender was found to have a greater rate of treatment default. However, one review found that among treatment defaulter cancer children, no gender disparity was found [13]. Furthermore, in India, more treatment failure was noted among the female gender [14]. This study highlights treatment failure as a critical barrier to pediatric cancer care in Pakistan, reflecting trends seen across low- and middle-income countries. Financial constraints (100%) and low socioeconomic status (91.5%) were the most prominent factors. These findings are consistent with recent studies from Ethiopia (financial difficulty: 83%), Uganda (socioeconomic reasons: 78%), and India (poverty-related default: 28.6%), where cost of care was the leading cause of default [12, 15, 16]. Low socioeconomic status (91.5%) and out-of-pocket expenses (98.8%) further compounded the risk, as previously noted in similar LMIC settings, where

65% of parents were found to have borrowed money as a contributing factor to treatment failure [17, 18]. In contrast, one study found assumption of poor disease outcome as the most frequently found factor [19]. Parental illiteracy and poor disease understanding (81.7%) also played a major role, aligning with global reports that caregivers' misconceptions about cancer's curability often lead to treatment discontinuation [15, 19]. According to a study conducted in Karachi, the most commonly reported reason for treatment non-compliance among pediatric oncology patients was "perceived improvement in child's condition" (38.5%), followed by forgotten appointments (26.9%), school commitments (23.1%), and long travel distance to hospital (11.5%) [20]. The burden of long travel distance (92.7%) and out-of-pocket expenses (98.8%) mirrors data from studies where geographic and logistic barriers significantly influenced adherence [16]. Notably, similar patterns have been observed nationally; Tahirkheli et al., in (2023) reduced abandonment to 6.7% at a Karachi center using call-back interventions and travel support [20]. In the current study, outcomes were poor 54.3% of patients returned only for palliative care, and 14.8% died emphasizing that abandonment leads to avoidable morbidity and mortality. These trends affirm previous findings that treatment default significantly lowers survival in LMICs and is a key contributor to global pediatric cancer disparities [6]. Furthermore, Farrag et al., documented that 75% of patients have disease progression after treatment abandonment [21].

CONCLUSIONS

Treatment default in pediatric oncology is driven by financial, social, and systemic challenges. Overcoming these obstacles is essential to enhance treatment adherence and improve patient outcomes.

Authors Contribution

Conceptualization: AG
Methodology: AG, SR, WM, LI, SG
Formal analysis: AG
Writing, review and editing: RUA, MF
All authors have read and agreed to the published version of the manuscript

Conflicts of Interest

All the authors declare no conflict of interest.

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