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ORIGINAL ARTICLE

Addressing Treatment Abandonment in Pediatric Oncology: The Role of Missed Appointment Call-Back Systems in a Pakistani Setting

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ABSTRACT

Objective: To evaluate the effectiveness of a missed appointment call-back system in reducing treatment abandonment rates at a tertiary care hospital in Pakistan.

Methods: This cross-sectional study was conducted in the Pediatric Hematology and Oncology Department of Indus Hospital and Health Network from April to September 2023. The study included children aged 1 month to 16 years diagnosed with cancer and receiving curative treatment. A call-back system was introduced, contacting patients within 48 hours of a missed appointment to address their absence and reschedule. Treatment abandonment was defined as missing clinic visits for 4 weeks.

Results: Of 389 children, the mean age was 6.8 ±4.0 years. There were 258 (66.3%) males and 131 (33.6%) females. Treatment abandonment was observed in 26 (6.7%) patients. The likelihood of treatment abandonment was 6 times significantly higher in children who did not respond to the call than those who did respond (cOR 6.27, 95% CI 2.69 to 14.59, p-value <0.001). Similarly, children who missed rescheduled appointments had 8 times higher chances of treatment abandonment than those who attended (cOR 8.11, 95% CI 3.30 to 19.92, p-value <0.001). Among 26 treatment abandonment children, the most common reason of missed appointment was financial issue 10 (38.5%) followed by forget appointment 7 (26.9%), attending school 6 (23.1%), and long distance 3 (11.5%).

Conclusion: Treatment abandonment was low as 6.7%. Children who did not respond to call-backs or missed rescheduled appointments were significantly more likely to abandon treatment. The call-back system is effective in reducing abandonment rates in pediatric oncology.

Keywords: Follow-Up Studies, Patient Compliance, Pediatric Oncology, Treatment Refusal.

INTRODUCTION

Globally the Incidence of childhood cancer is reported to be 14.1 cases per 100,000 children.[1] As per a study from Pakistan, the annual incidence of childhood cancer is 5.6%.[2] In 2015 total childhood cancers occur worldwide is 360,114, 54% in Asia and 28% in Africa.[3] The survival of childhood cancer is becoming better with ongoing rapid development in the field. In higher income countries it has exceeded 80%.[4] However, despite free of cost treatment facilities and availability of specialized pediatric oncologic centers in Pakistan, over 20% of children with cancer still abandon therapy.[5] Abandonment of cancer treatment comprises the survival of approximately one in seven children worldwide every year.[6] Alarmingly, the adjusted estimated number of pediatric patients in low-middle income countries (LMICs) worldwide affected by abandonment of therapy nearly equals the total annual number of childhood cancer cases diagnosed in high-income countries (HICs).[6] The abandonment of treatment working group, established by the International Society of Pediatric Oncology (SIOP) in 2010, defines abandonment of treatment as either failure to initiate therapy or discontinuation of ongoing treatment with an absence of 4 or more weeks, applicable only to patients who are treated with curative intent.[7] It is important to distinguish abandonment of therapy from patients who are lost to follow-up, the latter referring to those who transfer care elsewhere or do not follow-up after completion of curative treatment.[6-15] The reasons behind treatment abandonment in pediatric oncology are multifaceted, but imperative to investigate to bridge the survival gap between LMICs and HICs.[6] A combined effort with involvement of hospital team, non-governmental

organization and government organizations as well as tracking systems has a significant effect in declining abandonment rate in resource constrained countries.[16]

One of the effective ways to decrease abandonment rate is tracking missed appointments in pediatric oncology. At the Pediatric Oncology Department of Indus Hospital & Health Network (IHHN), Karachi, we register nearly 1,000 new cancer cases every year. However, despite free of cost treatment facilities and availability of specialized pediatric oncologic centers in Pakistan, over 20% of children with cancer still abandon therapy. This study will explore the effects of timely intervention such as missed appointment call back systems in affecting rates of treatment abandonment. Using this knowledge, interventions can be implemented to improve the health care of pediatric cancer patients. In this way, early interventions can be executed for better outcomes.

METHODS

The cross-sectional study was conducted in IHHN from April to September 2023. Ethical clearance was obtained from the Ethics Committee of IHHN (Ethical Clearance Number: IHHN_IRB_2023_03_007).

Children aged 1 month to 16 years with cancer and undergoing treatment with curative intent were included in the study. Patients with metastatic or advanced disease, counseled for palliative intent or referred to other centers, were excluded. Data were collected using a study proforma, and a daily list of newly registered patients was obtained from the electronic medical records department.

The sample size was determined using the WHO sample size calculator, considering the frequency of treatment abandonment among pediatric oncology patients 45.7%,[17] level of confidence 95%, 5% margin of error. The estimated sample size was 382. However, we enrolled 389 patients.

Information on patients' gender, socioeconomic status, educational background, household size, residential status, treatment phase, treatment status, and cancer type were gathered from electronic medical records. Patients were monitored during their outpatient department (OPD) appointments. Those who have missed their scheduled OPD were called back for reminder and to know the reason of missing OPD. Their appointments were rescheduled with the consultants and psychosocial team to address the sensitivity of issue of treatment delaying. If they again missed their appointments, they were again called to know the reasons of missing appointments.

The study adhered to operational definitions established by the SIOP in 2010,[17] including terms such as "treatment abandonment," "left before treatment," and "missed appointment." A missed appointment call-back system was introduced, where patients who failed to attend clinic appointments were contacted within 48 hours to inquire about their absence and to reschedule their appointments as soon as possible. The primary physician and the multidisciplinary team were informed about the reasons for missed appointments for further intervention and counseling by the Psychosocial department. Efforts included offering transport and incentives to patients facing financial and transport issues, especially those from remote areas. Persistent absence from the clinic for 4 weeks was labeled as treatment abandonment.

Data entry and analysis were performed using the Statistical Package for Social Sciences (SPSS) version 20.0. Quantitative variables such as age was expressed as Mean ±SD, while frequencies & percentages were calculated for gender, socioeconomic status, educational status, household size, residential status, treatment phase, treatment status, response to call, reschedule appointment, and type of cancer. Associations between treatment abandonment and the general characteristics of adolescents were examined using the Chi-square test, with a p-value of ≤0.05 considered statistically significant. Moreover, binary logistic regression was applied to all those variables found significant in the Chi-square contingency table. Both univariable and multivariable logistic regression were applied.

RESULTS

Of total 389 children, the mean age was 6.8 ±4.0 years. There were 258 (66.3%) males and 131 (33.6%) females. Majority of the children were from lower socio-economic class 252 (64.8%), educated up to secondary school 270 (69.4%), came from large households 272 (70.0%), resided outside Karachi 242 (62.2%), and had brain tumor/retinoblastoma cancer 202 (51.9%). Most of the children were in late treatment phase 280 (71.9%), had brain tumor/retinoblastoma cancer 202 (51.9%), they responded to call 288 (74.0%), attended rescheduled appointment 279 (71.7%), and had active treatment 253 (65.0%).

Treatment abandonment was observed in only 26 (6.7%) patients. Treatment abandonment found insignificantly higher in children age below or equal to six years (p-value 0.858), male children (p-value 0.745), from lower socioeconomic class (p-value 0.898),

educated up to secondary school (p-value 0.075), large household size (p-value 0.601), and resided outside Karachi (p-value 0.730) (Table 1). However, a significant association of treatment abandonment found with early treatment phase (p-value 0.010), response to call (p-value <0.001), attended reschedule appointment (p-value <0.001), and leukemia/lymphoma type of cancer (p-value 0.010) (Table 2).

Table 3 reveals binary logistic regression analysis for predicting treatment abandonment among children of cancer patients. At the univariate level, all variables presented in Table 3 showed significant odds ratios. The likelihood of treatment abandonment was 6 times significantly higher in children who did not respond to the call compared to those who did respond (cOR 6.27, 95% CI 2.69 to 14.59, p-value <0.001). Similarly, children who missed rescheduled appointments had 8 times higher chances of treatment abandonment compared to those who attended (cOR 8.11, 95% CI 3.30 to 19.92, p-value <0.001). Furthermore, the findings of the multivariable analysis were presented after adjusting the variables that were significant in the univariable analysis. At this stage, variables like response to call and patient attend rescheduled appointment showed significant odds ratios.

The most common reason of missed appointment in treatment abandonment was financial issue 10 (38.5%) followed by forget appointment 7 (26.9%), attending school 6 (23.1%), and distance 3 (11.5%) (Table-4).

DISCUSSION

The study aimed to assess the effectiveness of a call-back system in reducing treatment abandonment among pediatric cancer patients. The results demonstrated that the overall treatment abandonment rate was relatively low, indicating the potential success of the intervention. Children who failed to respond to call-back efforts or missed rescheduled appointments were significantly more likely to abandon treatment, with odds ratios of 6.27 and 8.11, respectively. These findings highlight the critical role of proactive follow-up in mitigating abandonment, particularly in resource-limited settings. Our study revealed a substantial variation in treatment abandonment rates based on the type of cancer, echoing findings from Slone *et al*. who also identified the type of malignancy as a significant factor influencing abandonment.[18] Another study found that children with retinoblastoma in Peru were more likely to abandon treatment.[14] The variance in abandonment rates by cancer type underscores the necessity of tailoring intervention strategies to specific

Table 1: Association of treatment abandonment with demographic characteristics of the patients (n=389)

Variables	Total	Treatment Abandonment		p-value
		Yes (n =26)	No (n= 363)	
Age (years)				
≤ 6	216	14 (6.5)	202 (93.5)	0.858
>6	173	12 (6.9)	161 (93.1)	
Gender				
Male	258	18 (7.0)	240 (93.0)	0.745
Female	131	8 (6.1)	123 (93.9)	
Socioeconomic Status				
Lower Class	252	16 (6.3)	236 (93.7)	0.898
Middle Class	114	8 (7.0)	106 (93.0)	
Upper Class	23	2 (8.7)	21 (91.3)	
Educational Status				
Illiterate	119	12 (10.1)	107 (89.8)	0.075
Up to secondary school	270	14 (5.2)	256 (94.8)	
Household Size				
Small	117	9 (7.7)	108 (92.3)	0.601
Large	272	17 (6.2)	255 (93.8)	
Residential Status				
Karachi	147	9 (6.1)	138 (93.9)	0.730
Outside Karachi	242	17 (7.0)	225 (93.0)	

- Household size categorized as large if ≥4 members in the family and small if <4 members in the family

***** p-value ≤ 0.05 (Chi-Square test)

Table 2: Association of treatment abandonment with treatment related characteristics of the patients (n=389)

Variables	Total	Treatment Abandonment		p-value
		Yes (n =26)	No (n= 363)	
Treatment Phase				
Early	109	13 (11.9)	96 (88.1)	0.010^*
Late	280	13 (4.6)	267 (95.4)	
Treatment Status				
Active Treatment	253	19 (7.5)	234 (92.5)	0.405^
Post-Treatment/Surveillance	136	7 (5.1)	129 (94.9)	
Response to Call				
Yes	288	9 (3.1)	279 (96.9)	<0.001^*
No	101	17 (16.8)	84 (83.2)	
Attended Reschedule Appointment				
Yes	279	7 (2.5)	272 (97.5)	<0.001^*
No	110	19 (17.3)	91 (82.7)	
Type of Cancer				
Brain Tumor/ Retinoblastoma Cancer	65	3 (4.6)	62 (95.4)	0.010~*
GCT Tumor/ Kidney Tumor/ Sarcomas	96	7 (7.3)	89 (92.7)	
Leukemia/ Lymphoma	131	10 (7.6)	121 (92.4)	
Others	97	6 (6.2)	91 (93.8)	

* p-value ≤ 0.05 (^Chi-Square test/~Fisher Exact test)

Table 3: Binary logistic regression analysis for predicting treatment abandonment among children of cancer patients (n = 389)

Variables	Univariable analysis		Multivariable analysis	
	cOR (95% C.I)	p-value	aOR (95% C.I)	p-value
Treatment Phase				
Early	1		1	
Late	0.36 (0.16 to 0.80)	0.013*	0.43 (0.17 to 1.05)	0.065
Response to Call				
Yes	1		1	
No	6.27 (2.69 to 14.59)	<0.001*	4.67 (1.79 to 12.11)	0.002*
Attended Reschedule Appointment				
Yes	1		1	
No	8.11 (3.30 to 19.92)	<0.001*	5.16 (1.95 to 13.61)	<0.001*
Type of Cancer				
Brain Tumor/ Retinoblastoma Cancer	1		1	
GCT Tumor/ Kidney Tumor/ Sarcomas	3.82 (1.25 to 11.67)	0.018*	3.30 (0.94 to 11.56)	0.062
Leukemia/ Lymphoma	1.80 (0.67 to 4.80)	0.238	1.63 (0.57 to 4.65)	0.359
Others	7.27 (1.67 to 31.68)	0.008*	11.41 (2.02 to 64.36)	0.006*

cOR: Crude odds ratio, aOR: Adjusted odds ratio, CI: confidence interval, *p-value ≤ 0.05

Table 4: Reason for missed appointment in treatment abandonment (n= 26)

Reasons	n (%)
Distance	3 (11.5)
Forget Appointment	7 (26.9)
Financial Issue	10 (38.5)
Attending School	6 (23.1)

-All data presented as frequency (percentage)

patient groups, recognizing the unique challenges and perceptions associated with different cancer diagnoses.

The early treatment phase was identified as a critical period with a heightened risk of abandonment. This finding is consistent with Alvarez *et al*. who reported that the timing of abandonment often occurs early in the treatment course, highlighting the importance of intensive support during this initial phase.[19] Initiatives in Guatemala that aimed to reduce abandonment through comprehensive psychosocial support (medicina integral) have demonstrated success, suggesting that early, targeted interventions can mitigate the risk of abandonment during this vulnerable period.[20] Our results demonstrated that active follow-up through call-backs and effectively managing rescheduled appointments significantly reduced treatment abandonment. This aligns with the strategies employed in El Salvador, as described by Salaverria *et al*. where a time-sensitive adherence tracking procedure significantly lowered abandonment rates from thirteen to three percent.[15] The effectiveness of these proactive approaches highlights the critical role of communication and logistical support in enhancing treatment adherence.

The study successfully demonstrates that modest, cost-effective measures such as the missed appointment call-back system can have a substantial positive impact on patient care. This intervention not only mitigated the treatment abandonment rate but also served as a lifeline for those navigating the complexities of cancer care. The effectiveness of such a system highlights the potential for scalable solutions to improve healthcare outcomes significantly. Furthermore, the study sheds light on the profound social issues faced by patients and their families, including poverty and illiteracy, which compound the hardships of battling cancer. Indus Hospital's holistic approach to pediatric oncological patient care-encompassing residence facilities for patients and their families, transportation cost coverage, psychological support, alongside a proactive call-back system-emerges as a beacon of comprehensive care in a landscape marred by multifaceted challenges, including poverty, malnutrition, poor hygiene, high infection rates, and late presentations. The evidence from this study calls for immediate governmental intervention to bridge the gap in cancer care. The establishment of more oncological centers, heightened awareness campaigns, and enhanced training for healthcare providers in rural and smaller city centers are imperative to decrease abandonment rates and elevate the standard of patient care. The positive outcomes of such interventions, as demonstrated by this study, emphasize the critical need for a coordinated response to combat the barriers to cancer treatment in Pakistan, aiming for a future where every child has the opportunity to fight cancer with adequate support and resources at their disposal. However, limitations include its single-center design and the potential for unmeasured confounding variables that might influence treatment abandonment, such as detailed socioeconomic factors and cultural beliefs. Early interventions such as providing patient boarding,[9] educational and awareness programs for parents,[5, 12] nutritional evaluation and support,[12] monitoring missed appointments[13] and timely involvement of a psychosocial team[14] are a few effective ways to improve abandonment rates in LMICs.

CONCLUSION

The study concluded that due to the implementation of a call-back system for missed appointments, treatment abandonment was observed in only a small percentage of patients. Significant associations were identified between treatment abandonment and factors such as treatment phase, response to calls, attending rescheduled appointments, and cancer type. Notably, children who did not respond to calls or missed rescheduled appointments were much more likely to abandon treatment. These findings highlight the crucial role of follow-up communication and appointment adherence in minimizing treatment abandonment in pediatric oncology.

ETHICAL APPROVAL: This was approved by the Institutional Review Board of Indus Hospital Network, Letter no. (IHHN-IRB-2023-03-007, dated: 25 May, 2023).

AUTHOR'S CONTRIBUTIONS: NT, MRF & MSA: Conception and study design, data acquisition, analysis and interpretation. SI & SAH: Data analysis and interpretation. FA & ZK: Drafting of manuscript. SM: data acquisition, analysis and interpretation. All critically authors reviewed and gave final approval of the manuscript.

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