Section: Paediatrics

Original Research Article

PREVALENCE AND CLINICAL DETERMINANTS OF TREATMENT DENIAL AND NON-ADHERENCE IN PEDIATRIC ONCOLOGY: A CROSS-SECTIONAL STUDY FROM CENTRAL INDIA

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Received : 20/03/2026
Received in revised form : 11/05/2026
Accepted : 27/05/2026

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DOI: 10.70034/ijmedph.2026.2.558

Source of Support: Nil,
Conflict of Interest: None declared

Int J Med Pub Health
2026; 16 (2); 3374-3378

ABSTRACT

Background: Despite notable global advancements in pediatric oncology, treatment denial and non-adherence remain formidable barriers to optimal survival, particularly in resource-limited settings. Identifying the specific clinical and socioeconomic drivers of these behaviors is crucial for institutional policy reform. **Objectives:** To evaluate the prevalence and determine the clinical, demographic, and socioeconomic factors associated with treatment denial and non-adherence among children with malignancies at a tertiary care hemato-oncology unit.
Materials and Methods: A cross-sectional observational study was conducted over one year, encompassing 145 pediatric cancer patients (<18 years). Data were collected using a structured proforma. Caregivers of non-adherent children were interviewed to ascertain the primary causes of treatment interruption.
Results: The overall treatment adherence rate was 75.2%. However, 14.5% of patients were non-adherent, and 10.3% outright denied therapy. Critical illness at presentation was significantly associated with treatment discontinuation (p=0.020); critically ill children demonstrated a non-adherence rate of 26.7% compared to 9.0% in stable patients. The primary reasons for non-adherence included competing family crises (19.0%) and inadequate family support (14.3%), while financial constraints (20.0%) were the leading cause of initial treatment denial.
Conclusion: Treatment abandonment remains a critical challenge driven by a complex interplay of clinical severity, psychosocial stressors, and financial burdens. Early targeted counseling and comprehensive socioeconomic support are imperative to sustain treatment engagement.
Keywords: Pediatric Oncology, Treatment Adherence, Treatment Denial, Malignancy, Treatment Abandonment.

INTRODUCTION

Pediatric oncology has witnessed remarkable progress, with five-year survival rates now exceeding 75-80% globally due to risk-adapted protocols and enhanced supportive care.[1-3] However, this success is largely isolated to high-income nations, where survival often surpasses 85-90%.[4] In low- and middle-income countries (LMICs) like India, survival remains disproportionately lower.[5] This disparity is heavily influenced by treatment denial and non-adherence, which account for nearly 40-60% of therapeutic failures in these regions.[6] Even when curative-intent therapies and supportive care are provided entirely free of cost, abandonment persists.[6,7] Globally, over 80% of pediatric cancer cases and the vast majority of abandonment events occur in LMICs.[8]

The etiology of non-adherence is multifactorial. It is deeply rooted in financial hardship, fear of chemotherapeutic adverse effects, reliance on alternative medicine, and profound misconceptions regarding the curability of cancer.[9] The prolonged nature of oncological treatment imposes severe indirect financial burdens—such as travel expenses and wage loss—which profoundly compromise long-term compliance.[10,11] Additionally, health system barriers, including inadequate provider communication, lack of psychosocial support, and vast geographic distances, exacerbate caregiver fatigue.[12,13] The World Health Organization categorizes these adherence barriers into socioeconomic, health-system, therapy-related, condition-related, and patient or caregiver factors.[14] Notably, financial toxicity during intensive phases remains a paramount driver of non-adherence.[11,15] Therefore, this study aims to evaluate the prevalence and clinical determinants of treatment denial and non-adherence among children with malignancies at a tertiary care center in central India.

MATERIALS AND METHODS

Study Design and Setting

A cross-sectional observational study was conducted over a continuous one-year period at the pediatric oncology department of M.G.M. Medical College and M.Y. Hospital, Indore, a prominent tertiary care referral center serving central India.

Study Population

The cohort comprised 145 children (aged under 18 years) diagnosed with various malignancies who were either newly registered or actively receiving chemotherapy during the study timeframe. Patients who had initiated cancer-directed therapy at external institutions prior to registration, those who could not be contacted for follow-up, and families who declined informed consent were strictly excluded from the analysis.

Data Collection

Data encompassing socio-demographic profiles, socioeconomic status, clinical presentation, malignancy type, and adherence status were prospectively collected utilizing a structured, pretested proforma. Patient tracking and follow-up were maintained via hospital medical records and telephonic communication. Caregivers of patients exhibiting non-adherence or denial underwent detailed qualitative interviews to explicitly identify the underlying barriers prompting their decisions.

Operational Definitions

- **Denial:** Defined as families who completely refused to initiate any form of cancer-directed therapy following a confirmed diagnosis.
- **Non-adherence:** Characterized as patients or families who initially accepted therapy but subsequently discontinued or delayed scheduled treatment for a duration exceeding four consecutive weeks, despite institutional reminders [16].
- **Adherence:** Defined as families who strictly followed prescribed therapeutic regimens and follow-up schedules without arbitrary delays or interruptions.

Statistical Analysis

Data were tabulated in Microsoft Excel and statistically analyzed using IBM SPSS Statistics version 25.0. Categorical variables (e.g., gender, malignancy type, adherence status) were expressed as frequencies and percentages. Associations between categorical variables were evaluated utilizing the Chi-square test and Fisher's exact test where appropriate. Statistical significance was established at a threshold of $p < 0.05$.

RESULTS

Table 1 delineates the baseline socio-demographic profile of the 145 pediatric patients enrolled in the study. The cohort was predominantly male (56.6%) and heavily skewed toward the younger demographic of 0-6 years (62.8%). A significant majority of the participants hailed from rural geographic areas (77.2%) and belonged to the lower-middle socioeconomic stratum (37.2%), highlighting a highly vulnerable study population.

Table 2 outlines the overarching therapeutic compliance within the cohort. More than a quarter of the patients experienced a breakdown in care, comprising 14.5% who discontinued ongoing therapy and 10.3% who refused treatment at the outset. While female patients exhibited a slightly higher rate of non-adherence (17.5%) compared to males (12.2%), this gender variance was not statistically significant (p=0.662).

Table 3 and Figure 1 (represented jointly) highlight a profound, statistically significant association (p=0.020) between disease severity and treatment continuation. Children presenting in a critically ill state were almost three times more likely to abandon ongoing therapy (26.7%) compared to hemodynamically stable patients (9.0%), though initial denial rates were comparable between the two cohorts.

Table 4 details therapeutic compliance across major malignancies. B-cell Acute Lymphoblastic Leukemia (B-ALL) constituted the largest subgroup, displaying a 20.3% non-adherence rate. In contrast, solid tumors with generally predictable surgical and medical trajectories, such as Wilms Tumor, demonstrated superior adherence levels (90.0%).

Table 5 and Figure 2 together illustrate the various social, economic, and psychological barriers that lead to treatment failure. The data show that stopping ongoing treatment (non-adherence) is mainly driven by active family struggles, especially competing family crises (19.0%) and a lack of proper family support (14.3%). In contrast, the complete refusal to start therapy (denial) is mostly

caused by immediate financial difficulties, with severe financial constraints accounting for 20.0% of cases. Furthermore, a poor understanding of how serious the disease is significantly contributed to the initial rejection of prescribed cancer treatments (13.3%).

Table 1: Baseline Socio-Demographic Characteristics of Study Participants (n=145)

Parameter	Category	Total n (%)
Gender	Male	82 (56.6%)
	Female	63 (43.4%)
Age Group	0-6 years	91 (62.8%)
	7-12 years	42 (29.0%)
	13-18 years	12 (8.2%)
Place of Residence	Rural	112 (77.2%)
	Urban	33 (22.8%)
Socioeconomic Status	Lower Middle	54 (37.2%)
	Upper Middle	36 (24.8%)
	Lower	33 (22.8%)
	Upper Lower	22 (15.2%)

Table 2: Prevalence of Treatment Adherence, Non-Adherence, and Denial by Gender

Treatment Status	Total n (%)	Male n (%)	Female n (%)	p-value
Adherent	109 (75.2%)	63 (76.8%)	46 (73.0%)	0.662
Non-Adherent	21 (14.5%)	10 (12.2%)	11 (17.5%)	
Denial	15 (10.3%)	9 (11.0%)	6 (9.5%)	

Table 3: Treatment Status According to Critical Illness at Clinical Presentation

Critical Illness at Presentation	Total (n)	Adherent (n) (%)	Non-Adherent (n) (%)	Denial (n) (%)	p-value
Yes	45	29 (64.4%)	12 (26.7%)	4 (8.9%)	0.020*
No	100	80 (80.0%)	9 (9.0%)	11 (11.0%)	

Table 4: Treatment Behaviour Across Prevalent Malignancies

Malignancy Type	Total n (%)	Adherent n (%)	Non-Adherent n (%)	Denial n (%)
B-ALL	59 (40.7%)	42 (71.2%)	12 (20.3%)	5 (8.5%)
AML	21 (14.5%)	14 (66.7%)	3 (14.3%)	4 (19.0%)
Hodgkin Lymphoma	11 (7.6%)	9 (81.8%)	1 (9.1%)	1 (9.1%)
Wilms Tumour	10 (6.9%)	9 (90.0%)	1 (10.0%)	0 (0%)

Table 5: Primary Caregiver-Reported Reasons for Non-Adherence and Denial

Domain	Reported Reason	Non-Adherence (n=21) (%)	Denial (n=15) (%)
Socioeconomic constraints	Financial constraints (including loss of wages)	1 (4.8%)	3 (20.0%)
	Travelling expenses	2 (9.5%)	0
Family & social support	Inadequate family support	3 (14.3%)	2 (13.3%)
	Competing family crises	4 (19.0%)	1 (6.7%)
	Death of another child	2 (9.5%)	0
Health system barriers	Non-availability of hospital resources	1 (4.8%)	1 (6.7%)
	Dissatisfaction with staff attitude	0	1 (6.7%)
Treatment-related factors	Long duration of treatment	2 (9.5%)	0
	Chemotherapy-related toxicity / painful procedures	2 (9.5%)	1 (6.7%)
Knowledge, beliefs & perception	Perceived incurability of disease	2 (9.5%)	2 (13.3%)
	Poor understanding of disease severity	0	2 (13.3%)
	Disbelief in diagnosis	0	1 (6.7%)
	False perception of recovery	1 (4.8%)	0
Sociocultural factors	Preference for traditional medicine	1 (4.8%)	0
	Gender bias (female child)	1 (4.8%)	0
Communication barriers	Difficulty understanding medical instructions	0	0

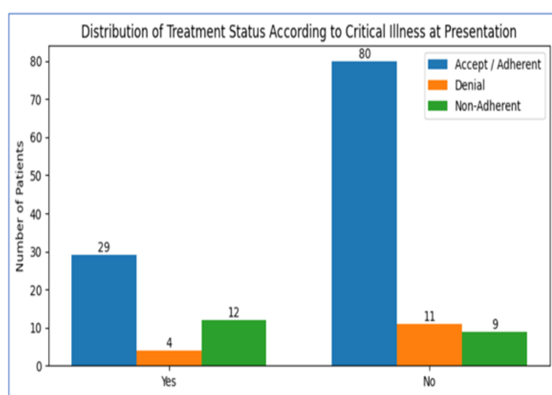

Figure 1: Impact of Critical Illness on Treatment Adherence Outcomes

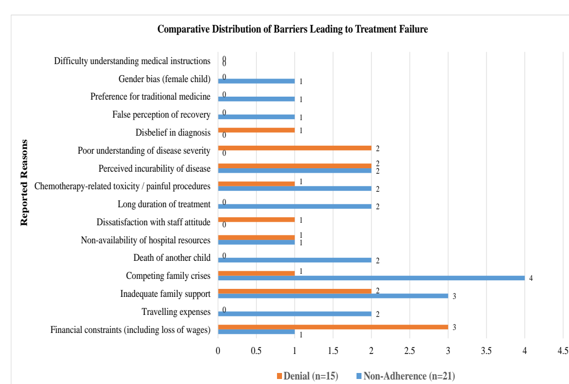

Figure 2: Comparative Distribution of Barriers Leading to Treatment Failure

DISCUSSION

The overall adherence rate in our pediatric cohort was 75.2%, leaving nearly a quarter of patients failing to complete curative therapy (14.5% non-adherent, 10.3% denial). These findings parallel historical global estimates from resource-limited settings. Mostert et al. (2006) reported a combined refusal and abandonment rate of 35% in Indonesia, a phenomenon driven primarily by severe socioeconomic disparities.[16] Similarly, Lan et al. (2019) documented an alarming 45.5% abandonment rate in Vietnam, highlighting how treatment interruption remains a critical systemic barrier in LMICs.[13] Furthermore, Arora et al. (2007) emphasized that abandonment is disproportionately higher in low-resource environments and is strongly linked to poverty, poor healthcare access, and lack of affordable facilities.[17]

A highly significant determinant of non-adherence in our study was critical illness at presentation (p=0.020). Critically ill children exhibited a non-adherence rate of 26.7%, compared to just 9.0% in stable patients. This strongly aligns with findings by Handayani et al. (2022), who demonstrated that delayed diagnosis and advanced disease stages significantly increase the likelihood of treatment abandonment due to the compounding intensity of care required.[18] Similarly, Friedrich et al. (2016) noted that clinical severity drastically alters caregiver perception, often leading to premature discontinuation out of perceived futility or fear of severe toxicity.[9] Sitaresmi et al. (2010) also found that an inherent fear of treatment-related toxicity and misconceptions regarding prognosis were primary drivers of early abandonment.[10]

Although geographic and general socioeconomic variables did not reach independent statistical significance in our cohort, their contextual impact was profound during qualitative assessments. Competing family crises (19.0%) and inadequate family support (14.3%) were the primary reasons for non-adherence, whereas acute financial issues (20.0%) dominated early treatment denial. Sundriyal et al. (2024) identified highly similar logistical and psychosocial hurdles, reporting a lack of social support (26.2%) and financial hardship (20.3%) as the leading causes of default.[19] Padma et al. (2019) corroborated those indirect financial burdens—such as travel expenses and continuous wage loss—critically impair treatment continuation, even when chemotherapy itself is subsidized.[20]

Cotache-Condor et al. (2023) conceptualized these intersecting barriers within a robust Three-Delay Framework, illustrating how structural and economic limitations synergistically delay care.[21] Furthermore, Benedetti et al. (2023) and Goh et al. (2017) emphasized that caregiver misinformation and the sheer psychological burden of complex treatment regimens significantly disrupt sustained therapeutic engagement.[22,12] Ultimately, as noted by Gupta et al. (2017), poor adherence directly and severely correlates with an increased risk of relapse and mortality, making targeted intervention vital.[23]

CONCLUSION

Treatment denial and non-adherence in pediatric oncology are driven by a complex interplay of critical clinical severity at presentation, acute financial distress, and compounding psychosocial burdens. Addressing these formidable barriers requires transitioning to holistic, family-centered care models that integrate early structured counseling, robust psychological support, and targeted financial assistance to ensure sustained therapeutic engagement.

Recommendations

Implement structured psychosocial counseling at diagnosis, decentralize pediatric oncology networks to reduce travel burdens, and expand indirect financial support programs for vulnerable families.

Strengths and Limitations

The study captures real-world adherence dynamics via direct caregiver interviews; however, it is limited by a single-center cross-sectional design and a relatively small sample size.

Relevance of the Study

It provides actionable insights into the non-medical barriers to pediatric cancer survival in central India, guiding localized health policy reforms.

Authors' Contribution

All authors contributed equally to the conceptualization, data acquisition, statistical analysis, and drafting of the manuscript.

Ethical Consideration

The study protocol was approved by the Institutional Ethics and Scientific Review Committee; written informed consent was obtained from all participating caregivers.

Financial Support and Sponsorship: Nil.

Conflicts of Interest: The authors declare no conflicts of interest.

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