ISSN: 0975-833X

Available online at http://www.journalcra.com

International Journal of Current Research
Vol. 11, Issue, 06, pp.4615-4617, June, 2019

DOI: https://doi.org/10.24941/ijcr.35655.06.2019

INTERNATIONAL JOURNAL OF CURRENT RESEARCH

RESEARCH ARTICLE

BARRIERS IN ENSURING ADHERENCE TO TREATMENT IN PEDIATRIC ONCOLOGY: EXPERIENCE FROM A TERTIARY CARE CENTER IN A DEVELOPING COUNTRY

Padma, M., *Pooja Gujjal Chebbi, Jyothi, M., Nuthan Kumar, M.K., Arunkumar, A.R., Arunakumari, B.S. and Appaji, L.

Department Pediatric Oncology, Kidwai Cancer Institute, Dr. M.H. Marigowda Road, Bangalore-560029, India

ARTICLEINFO

Article History:
Received 11th March, 2019
Received in revised form
21st April, 2019
Accepted 09th May, 2019
Published online 30th June, 2019

Key Words:
Barriers,
Treatmentaherence,
Pediatric Oncology

ABSTRACT

Background: Treatment adherence is a complex phenomenon, which has a significant impact on therapeutic success especially with respect to pediatric oncology patients in developing countries like ours where socioeconomic factors have an important bearing on treatment. To gain an insight into the factors that affect adherence in pediatric oncology we conducted this study in a tertiary care center. **Methods**: Retrospective analysis of case records of children <15 years of age who visited the pediatric Oncology out-patient department at Kidwai Cancer Institute between June -2018 and Jan-2019 was carried out to assess their adherence to treatment and in case of non-adherence to treatment the factors responsible were identified. **Results**: Of the 600 case records that were screened 115 of them had poor adherence to treatment. These patients were then studied in detail with respect to their demographic details and the factors responsible for poor adherence. The commonest causes for poor adherence that emerged from the study were those pertaining to socio-economic factors and caregiver issues. **Conclusions**: Socioeconomic factors and caregiver issues are important barriers to treatment adherence. Targeted interventions in the form of social support systems and shared care models have the potential to improve treatment adherence and consequently overall survival in developing countries

***Citation: Padma, M., Pooja Gujjal Chebbi, Jyothi, M., Nuthan Kumar, M.K., Arunkumar, A.R., Arunakumari, B.S. and Appaji, L.* 2019.** "Barriers in ensuring adherence to treatment in pediatric oncology: Experience from a tertiary care center in a developing country", *International Journal of Current Research*, 11, (06), 4615-4617.

INTRODUCTION

Abandonment of therapy, defined as either missing at least 4 consecutive weeks of scheduled treatment or not starting therapy after a cancer diagnosis (Mostert *et al.,* 2011), is a major cause of pediatric cancer mortality in low- and mid-income countries (Spinetta *et al.,* 2002; Lam *et al.,* 2012; Arora *et al.,* 2010; Mostert *et al.,* 2012). Although less clearly documented, more general non-adherence to treatment (such as intermittently missing medication doses or appointments) can also reduce the effectiveness of therapy (Butow *et al.,* 2010) and may predict a greater risk of treatment abandonment. The World Health Organization defines adherence as "the extent to which a person's behavior... corresponds with agreed recommendations from a health care provider." (World Health Organization, 2003) With respect to pediatric oncology parents and caregivers are generally responsible for adherence to their child's therapy appointments and therefore can provide insight into the causes of non-adherence and abandonment of therapy. We undertook this study with the intent of analyzing factors which affect adherence to treatment in pediatric oncology in a tertiary care cancer center in India.

Corresponding author:* **Pooja Gujjal Chebbi,

MATERIALS AND METHODS

From June 2018 to January 2019 a total of 600 case records of patients visiting our hospital between the ages of 1 year to 15 years were reviewed. Of these only those patients which were following up with us for the sixth time or more were included in the study. This constituted about 400 patients. We analysed the case records in these patients to assess their compliance. The allotted dates for the last 4 visits were analysed and the compliance assessed as to on how many visits they had arrived on the allotted dates. A compliance of 75% and above was considered as acceptable, while anything less than that was considered unacceptable. In patients who had less than 75% compliance factors which prevented adequate follow up were recorded in a systematic manner and analysed. The data collected was then divided into various broad categories which included Socio-economic factors, patient/caregiver related factors and health system related factors

WHO definitions

- **Social/economic factors** as to how socio-economic status affects adherence

- **Therapy-related factors** as complexity of the medical regimen, duration of treatment, previous treatment failures, frequent changes in treatment, the immediacy of beneficial effects, side effects and the availability of medical support to deal with them
- **Patient-/caregiver-related factors** as the resources, knowledge, attitudes, beliefs, perceptions and expectations of the patient;
- **Health system factors** as the effects of healthcare team and system-related factors on adherence

RESULTS

Of the 400 patients in the above mentioned time period 285 (71.5%) the compliance was more than 75% while in 115 (28.75%) patients the compliance was less than 75%. For the purpose of this study only the demographic characteristics and other details of patients who were non- compliant were recorded and analysed. Table 1 shows demographic and treatment characteristics. There was no sex predeliction in the non compliant group and in accordance with the expected distribution of cases leukemias followed by lymphomas and CNS tumors were the most common diagnoses which were observed. Most of the patients belonged to the lower socioeconomic strata. In the analysis of factors for non adherence it was noted that in most cases there was more than one factor that was present and the commonest cause was socio-economic factors and caregiver issues. The details of all factors are shown in Table 2.

Table 1. Demographic and treatment characteristics of non-compliant group

Variable	n (%)
Age	
< 5 years	65 (57%)
> 5 years	50 (43%)
Sex	
Female	55 (48%)
Male	60 (52%)
Diagnosis	
Leukemia	60 (52%)
Lymphoma	20 (17.3%)
Central Nervous system tumor	15 (13%)
Renal tumors	04 (3.4%)
Bone tumors	03(2.6%)
Soft tissue sarcomas	04(3.4%)
Germ cell tumor	02(1.7%)
Retinoblastoma	02(1.7%)
Heaptic tumors	01(0.8%)
Other	04(3.4%)

Table 2. Causes for non adherence to treatment

Cause for non adherence	No. of patients (%)
Social /Economic factors	
• Financial Difficulties	35 (30.4%)
• Transportation Issues	20 (17.3%)
• Domestic needs	28 (24.3%)
Patient/care givers related factors	
Care givers issues	32 (27.8%)
Health system factors	
• Failure to understand medical instructions	3 (2.6%)
• Inability to access to health scheme benefits	3 (2.6%)

DISCUSSION

In order to reduce or prevent abandonment it is important to understand the causes of missed therapy appointments. Previous studies (Salaverria *et al.,* 2015) have shown adherence to treatment can be improved with appropriate interventions after detecting missed appointments. In the present study 30 % patients were unable to ensure adherence to treatment due to lack of financial resources although most patients receive free treatment and hospitalization and subsidies for housing, food, and transportation. Similar observations were also made by Carmen *et al.* (Salaverria *et al.,* 2015) where they observed that approximately 23 % of absences during treatment of pediatric cancer were attributable to lack of financial resources. Majority of our patients and caregivers travel large distances to reach the medical facility. In about 17% of cases caregivers were unable to reach for treatment appointments due to non availability of transportation facilities (train reservations not being available, public transport non-availability due to holiday etc.). Other studies (Salaverria *et al.,* 2015) have also reported this as a hindrance to treatment adherence. About 28% of missed appointments were due to caregiver issues such as caregiver was ill, non availability of another attender to bring the child to the hospital or that the caregiver had to take care of another ill family member and there was no one else to bring the child to the hospital. In some instances appointments were missed in order to avoid income loss (e.g., no permission from employer, a job opportunity for the day) .Other causes for missing treatment appointments included other appointments such as (school, community meetings, others) or a caregiver forgetting an appointment date. These causes remain common across most developing nations and have been reported in previous studies (Salaverria *et al.,* 2015; Kumar *et al.,* 2013). The insights gained from this study are that socioeconomic factors and caregiver issues are important barriers to treatment adherence and targeted interventions in the form of social support systems and shared care models have the potential to improve treatment adherence and consequently overall survival in developing countries.

Source(s) of funding : None

Conflict of Interest : None

REFERENCES

Mostert S, Arora RS, Arreola M, Bagai P, Friedrich P, Gupta S, Kaur G, Koodiyedath B, Kulkarni K, Lam CG, Luna-Fineman S, Pizer B, Rivas S, Rossell N, Sitaresmi MN, Tsimicalis A, Weaver M, Ribeiro RC. 2011. Abandonment of treatment for childhood cancer: position statement of a SIOP PODC Working Group. *Lancet Oncol.,* 12:719–720.

Spinetta J, Masera G, Eden T, Oppenheim D, Martins A, van Dongen Melman J, Siegleret M, Eiser C, Weyl Ben Arush M, Kosmidis HV, Jankovic M. 2002. Refusal, non compliance, and abandonment of treatment in children and adolescents with cancer. A report of the SIOP Working Committee on Phychosocial Issues in Pediatric Oncology. *Med Pediatric Oncol.,* 38:114–117.

Lam C, Rossell N, Ribeiro R. 2012. Globalsnapshots of treatment abandonment in children and adolescents with cancer: Social factors, implications and priorities. *J Healthcare Sci Hum.,* 2012;2:81–110.

Arora RS, Pizer B, Eden T. Understanding refusal and abandonment in the treatment of childhood cancer. Indian Pediatrics 2010; 47:1005–1010.

Mostert S, Gunawan S, Wolters E, van de Ven P, Sitaresmi M, van Dongen J, Veerman A, Mantik M, Kaspers G. Socio-

economic status plays important role in childhood cancer treatment outcome in Indonesia. *Asian Pac J Cancer Prev.,* 2012;13:6491–6496.

Butow P, Palmer S, Pai A, Goodenough B, Luckett T, King M. Review of adherence-related issues in adolescents and young adults with cancer. *J Clin Oncol.,* 2010; 28:4800–4809.

World Health Organization. Adherence to long-term therapies: Evidence for action. Sabat_e E, editor. Switzerland: World Health Organization; 2003. p. 194.

Salaverria *et al.* Interventions Targeting Absences Increase Adherence and Reduce Abandonment of Childhood Cancer Treatment in El Salvador. *Pediatr Blood Cancer,* 2015;62:1609–1615

Kumar A, Moulik NR, Mishra RK, Kumar D, Causes. Outcome and prevention of abandonment in retinoblastoma in India. Pediatr Blood Cancer, 2013;60:771–775.

****