Cancer Epidemiology 57 (2018) 53–59

Contents lists available at ScienceDirect

Cancer Epidemiology

journal homepage: www.elsevier.com/locate/canep

Prevalence, predictors, causes of treatment refusal and abandonment in children with acute lymphoblastic leukaemia over 18 years in North India. Treatment phase affecting factors: A step towards better focussed counselling

Areesha Alam, Archana Kumar*

Division of Pediatric Hematology-Oncology, Department of Pediatrics, King George's Medical University, Shah Mina Road, Chowk, Lucknow, India

ARTICLE INFO

Keywords:
Abandonment
Refusal
Acute lymphoblastic leukemia
Children
Counselling
Socioeconomic status

ABSTRACT

Background: Treatment refusal or abandonment are among the major causes of the survival gap between developed and developing countries.

Methods: This retrospective observational study analyzed records of children aged < 18 years with acute lymphoblastic leukemia (ALL) registered for treatment at a tertiary-care teaching hospital, North India, between 1995 and 2012. Children who refused or abandoned therapy were tracked, and reasons for refusal/abandonment were recorded by telephone interviews or by surface mail. Sociodemographic parameters were compared using chi-square/Student *t*-test to identify predictors of refusal/abandonment.

Results: Treatment refusal was noted in 16.8% (96/572) of children with ALL; it was statistically higher for infants ($p = 0.004$), girls ($p = 0.04$), children of parents with poor literacy ($p < 0.001$), and those of lower socioeconomic status ($p < 0.001$). Main causes of treatment refusal were financial constraints (59.4%) and a misplaced belief about the incurability of cancer (22.9%). Therapy once started, was abandoned by 139/476 children (29.2%), the majority (41%) during induction, followed by maintenance (17.9%). Major reasons for abandonment were financial constraints (34.5%), false perception of cure (20%), poor general condition of the child (15%), no improvement in the child (13%), and blood donation refusal (3%). The reasons cited were different in different treatment phases. Abandonment was statistically higher in children from rural background ($p < 0.001$) or lower socioeconomic status ($p < 0.001$), and in those with fathers having a lower literacy status ($p < 0.001$). Low hemoglobin ($p = 0.01$) and severe wasting ($p = 0.01$) was greater in children who abandoned treatment.

Conclusion: Treatment refusal or abandonment, noted in 40% of children, was due mainly to monetary difficulties, disbeliefs regarding curability, or false perceptions of cure; these factors need to be addressed to improve survival, particularly in children from rural areas and those of parents with a lower literacy status.

1. Introduction

Acute lymphoblastic leukemia (ALL) is the most common malignancy in children, comprising a quarter of all childhood cancers. In India the age-adjusted incidence rates of pediatric leukemia range from 35.7 to 61.3 per million for boys and 22.3 to 40.2 per million for girls [1]. With the advent of combination chemotherapy and risk-stratified protocols, the current cure rate for childhood ALL in high-income countries (HICs) has improved from about 10% in the 1960s to 85–90% or more [2]. In India, a low- to middle-income country (LMIC), cure rates are still low except in a few centers of excellence, despite the use of treatment protocols similar to those in the West [3,4]. This survival gap between HICs and LMICs is multifactorial and includes different biological profiles, advanced stage of disease at diagnosis, high rates of malnutrition, illiteracy, poor average per-capita income, low government health expenditure, associated co-morbidities, lack of supportive care, severity of toxicities, and inadequate hygiene along with a high incidence of infection-related mortality [4,5]. Another important yet often overlooked cause is the disparities that exist between healthcare infrastructures of these two categories of countries regarding effective pediatric cancer care [6].

Refusal (non-initiation) and abandonment (non-completion) of

* Corresponding author.
E-mail address: archanakumar@kgmcindia.edu (A. Kumar).

https://doi.org/10.1016/j.canep.2018.07.011
Received 16 March 2018; Received in revised form 5 July 2018; Accepted 18 July 2018
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treatment are among leading causes of treatment failure, and studies focusing on the causes of refusal or abandonment of treatment in children with ALL from India are scanty [4]. Thus the current study primarily aims to identify the prevalence and reasons behind treatment refusal/abandonment in childhood ALL in a tertiary-care public-sector teaching hospital situated in North India over a period of 18 years, and to understand the predictors for refusal and abandonment.

2. Methods

King George's Medical University, Lucknow, is a large, public-sector, multispecialty, 3000-bed tertiary-care teaching hospital in North India. This retrospective, observational study was conducted at the Pediatric Hematology–Oncology division, which is one of the major centers dedicated to pediatric oncology in a state with a population of 204 million residing in area of 243,286 km^2 (rural 77.7%, urban 22.3%) [7]. The majority of our patients come from rural areas (villages); they are not well connected with the city, and they use multiple modes of public transport which are available at government-subsidized rates. The hospital is public sector and overcrowded, and most of our population is of lower socioeconomic status. The hospital is a busy center which registers approximately 300–400 new pediatric cancer cases annually. Patients admitted include those who approach the hospital emergency/outpatient department (OPD) directly (the majority) as well as those who are referred from other centers for specialized care. No charges for physician, nursing, bed or diet are exacted in the hospital, but patients have to pay for a few drugs, laboratory services, radiology, admission, and OPD visits, all of which are highly subsidized. Each child is allowed to be accompanied by two attendants at a time in the hospital wards.

Ethical approval was obtained from the Ethics Committee of the King George's Medical University before the start of the study, with reference to code 66th ECM II-B/P17th (# 1257/Rcell 14).

2.1. Study population

All children with ALL aged < 18 years registered for treatment from 1995 to 2012 were followed up to 2015. During this period, the children were treated according to protocols based on the Children's Oncology Group (COG).

2.2. Data collection

The hematology–oncology division maintains a proper cancer registry of all registered patients in the form of patient information sheets (PIS) filled in for each patient during initial registration and updated in detail by the physician at each hospital visit. Sociodemographic, disease-related and laboratory data were retrieved from these patient information sheets retrospectively. The children who abandoned/refused therapy were identified and their families were contacted by telephone by an appointed social worker to assess the status of the children and to counsel them regarding the necessity for resuming treatment. The social worker enquired of parents – or relatives in the absence of parents – about the reasons behind the abandonment using a uniform questionnaire. Letters with pre-stamped reply postcards were sent to families who could not be contacted by telephone [8].

2.3. Definitions

Treatment refusal was defined as rejection or non-initiation of any treatment after diagnosis had been made, and abandonment was defined as the missing of ≥4 consecutive weeks of therapy after initiation of treatment [9].

Parental educational status was categorized as illiterate, low (primary or high-school) or high (intermediate-school, graduate or professional). Socioeconomic status was classified as per the modified Kuppuswamy scale [10]. Area of residence was classified as rural or urban as per census India [7]. Nutritional status was assessed using WFH (weight-for-height) Z scores, HFA (height-for-age) Z scores, and serum albumin levels. Wasting was defined as WFH < –2 SD (moderate: –2 to –3 SD; severe: < –3 SD). Stunting was defined as HFA < –2 SD (moderate: –2 to –3 SD; severe: < –3 SD).

2.4. Analysis

Data were entered into a Microsoft Excel sheet and tested for normality. The prevalence and causes of refusal and abandonment were described as proportion. All collected data – demographic, biological and social – were analyzed using SPSS (Statistical Package for Social Sciences) version 16 software (SPSS, Chicago, IL, USA) to identify predictors of refusal and abandonment. Chi-square and Student *t*-test were used for categorical and parametric continuous data respectively. The Mann–Whitney U test was used for non-parametric continuous data. Statistical significance was defined as two-tailed $p < 0.05$.

3. Results

3.1. Prevalence of refusal and abandonment

Out of 572 children, 96 (16.8%) refused to undergo any treatment, and out of 476 started on induction therapy 139 (29.2%) abandoned therapy during the course of treatment (Fig. 1). The majority of children (41%) abandoned therapy during induction followed by maintenance (17.9%) as shown in Fig. 2.

3.2. Causes and predictors for refusal of treatment

Eighty-seven families (90.6%) were successfully contacted, and reasons for treatment refusal were documented. Nine families could not be contacted and were lost to follow-up for various reasons: phone out of service (3), no reply to letters (3), wrong phone number (1). Two care-givers refused to communicate about the reasons for treatment refusal. The sociodemographic profiles of these 'lost to follow-up' children were as follows: seven out of nine (77.8%) were boys, eight out of nine (88.9%) lived in rural locations, six out of nine (66.7%) were of lower socioeconomic status, and all had illiterate fathers.

In the present study population the main cause of refusal of therapy was financial constraints (59.4%), followed by a belief in the incurability of cancer (22.9%) (Table 1).

The prevalence of refusal was significantly higher in infants ($p = 0.004$) and girls ($p = 0.04$) compared to children aged > 1 year and boys, respectively. Treatment refusal was highest in children from a lower socioeconomic status ($p < 0.001$) and in those whose fathers were illiterate ($p < 0.001$) as compared to middle/upper

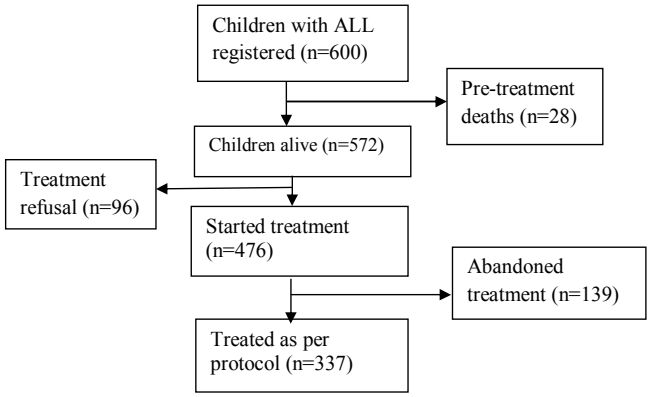

Fig. 1. Flow diagram showing the number of children who refused or abandoned the therapy.

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