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Establishing Childhood Cancer Registry Status in 3 Pediatric Oncology Units of Pakistan - A Low Middle Income Country

Raza MR[1*]

Maqsood S[1]

Habib MA[1]

Rana ZA[2]

Arif A[3]

Hamid H[4]

Ashraf MS[1]

[1]Department of Pediatric Oncology, The Indus Hospital, Karachi, Pakistan

[2]Department of Pediatric Hematology-Oncology, Children hospital and institute of child health, Multan, Pakistan

[3]Department of Pediatric Hematology-Oncology, Lahore General Hospital, Lahore, Pakistan

[4]Department of Pediatric Oncology, Mayo Hospital, Lahore, Pakistan

Article Information

*Corresponding Author:

Muahammad Rafie Raza,
Department of Pediatric Oncology, The Indus Hospital, Plot C-76, Sector 31/5, Opposite Darussalam Society Korangi Crossing, Karachi -75190, Pakistan, Tel: +923002230389, Fax: +92 (21) 35112718, E-mail: muhammad.rafie@tih.org.pk

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ABSTRACT

Introduction: There is marked disparity in infrastructure and standard of care among various Pediatric oncology units in Pakistan. Estimation of childhood cancer incidence is important for policy makers for planning and priority setting. With the help of grant from My Child Matters, The Indus Hospital launched a project for holistic improvement in existing Pediatric Oncology Units of different hospitals; Children Hospital and Institute of Child Health, Multan (CH&ICH), Lahore General Hospital (LGH) and Mayo Hospital. Aim of this study was to establish a hospital based childhood cancer registry which could provide estimation of childhood cancer burden.

Method: This is a retrospective study. Data was collected on web based database from January 2016 to December 2018. The five steps of our study which we followed; developed tumor registry software i-e Pakistan society of pediatric oncology (PSPO) cancer registry software, trained data operators, data was updated monthly, audit of data monthly and analysis of data.

Results: Among 722 patients, 66% were male; mean age was 7.4 ± 3.6. Frequency of Leukemia (58%), Lymphoma (19%), Retinoblastoma (9%), Renal tumors (4%), Soft tissue sarcomas and Neuroblastoma were observed in 2% of patients while CNS and Intraspinal tumors, Bone tumors, Epithelial Neoplasms and Melanomas, Germ cell tumor, Hepatic tumors and LCH tumors were observed in 1% of patients. Stage IV tumor was observed in 34.2% of patients. 14% of patient's left before treatment, 10% left during treatment. 29% were on palliative treatment while 71% were on curative treatment. Treatment related mortality was 16%.

Conclusion: With the help of cancer registry among different cities centers we found that 77% patients with leukemia and lymphoma. Advanced stage disease and abandonment are common problems faced in these units.

BACKGROUND AND RATIONALE

Research into the origins and determinants of childhood cancer is difficult. Although the reported incidence of childhood cancer has increased over the past decades [1], It remains rare: fewer than 1% of all cancers in industrialized countries occur in children younger than 15 years of age [2]. Nevertheless, research is important. Despite dramatic therapeutic improvements, cancer remains the second most common cause of death in childhood in developed countries [3]. Childhood cancer also accounts for a high burden of long-term disability caused by late effects of the cancer itself or its therapy [4].

Absence of a National Cancer Registry in Pakistan makes it difficult to determine the incidence of childhood cancers. However whatever data is available, the trends coincide with the international data. Due to inadequate available facilities and expertise in the field, it is estimated that 50% children do not get properly diagnosed and treated. 40% report only at very advanced stages of disease. Among the treated, only 50% survive after completion of treatment with an overall survival of 15% in childhood cancers [5, 6].

Average annual incidence rate of all cancers per million children aged 0-14 years was recorded by cancer registries in Karachi (96/1000,000) whereas distribution of various cancers is given as such: lymphoid and hematopoietic tissue (45%), brain tumor (60%) and bone cancer (70%) [7]. In Jamshoro, the cancer studies carried out showed that the most common cancers are retinoblastoma (38.9%), Wilm's tumor (13.2%), brain tumor (10.6%), Hodgkin lymphoma (9.7%). According to a study, 669 patients of cancer were reported under the age of 0 - 14, where 92% of these suffered from leukemia and 54% from lymphoma. Leukemia is the most prevalent cancer in age group of 1 - 12 years all over Pakistan which accounts for 21% of total pediatric cancers [8].

With the help of grant from My Child Matters (MCM), The Indus Hospital launched a project to improve survival in these Pediatric Oncology Units of three different hospitals; Children Hospital and Institute of Child Health, Multan (CH&ICH), Lahore General Hospital (LGH) and Mayo Hospital. Web-based childhood cancer registry software named Pakistan Society of Pediatric Oncology (PSPO) has been established with the help of MCM grant to collect baseline statistics of childhood cancers enrolled in these units. The aim of the study was to establish a childhood cancer registry which provides the total estimation of childhood cancer in Pakistan.

MATERIALS AND METHODS

Study design: This is a retrospective multicenter study; Patient's data was collected in PSPO cancer registry software. Pediatric Oncology Units (POU's) that are involved in our study are POU's of CH&ICH, LGH and Mayo Hospital. Data was collected from January 2016 to December 2018 after approval of proposal by institutional review board of TIH.

Flow chart (Figure 1) shows the five steps of our study which we followed: developed tumor registry software (PSPO), trained data operators, data was updated monthly, audit of data every month and analysis of data. Our study sample was children between age 1 and 16 years diagnosed with cancers in the three centers.
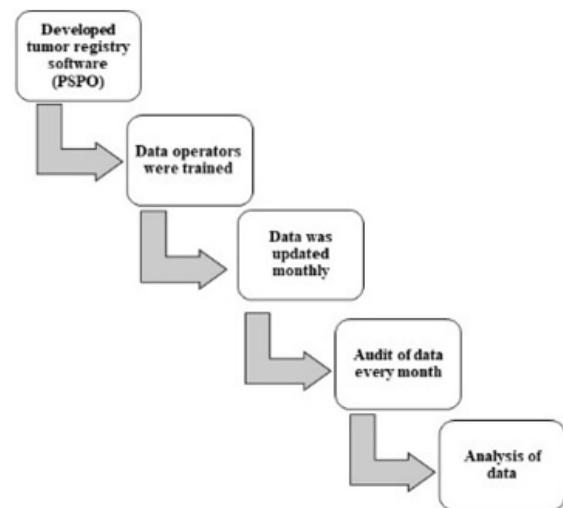

Figure 1: Flow chart

STATISTICAL ANALYSIS

Data was entered and analyzed by using SPSS version 21.0. Descriptive statistics i-e mean, standard deviation, median, range were computed for age. Frequency and percentage will be evaluated for qualitative variables.

RESULTS

Total 722 patients were registered during study period, male were 478 (66%) while female were 244(34%) i-e male is to female ratio was 2: 1, overall mean age was 7.7 ± 3.6, whereas the median age (range) of CH&ICH, 7(1-16), LGH were 6(1-16) and Mayo hospital were 7(2.0-16). Distribution of cancers in individual units is shown in (Table 1).

Stage IV tumor was observed in 11% of patients. Curative and palliative treatment were given to 512 (70%) and 66 (10%) respectively. While 144 (20%) were abandoned and 15 (3%) were referred out.

Out of 512 patients 288 (56%) were alive with diseases, 76(15%) were alive with no disease, 199 (38%) were dead.

Institute wise distribution of following characteristics like gender, treatment, abandonment and the status of patients were shown in (Table 2).

Year wise data of the patients who has given curative treatment were shown in (Table 3).

Table 1: Different cancers distribution of individual units.

	CH&ICH	LGH	MAYO
Leukemia and MDS	325(66%)	36(56%)	60(35%)
Lymphomas	111(22%)	5(8%)	24(13%)
Retinoblastoma	8(1%)	19(29%)	42(24%)
Soft tissue Sarcoma	4(1%)	0	11(7%)
Renal Tumors	19(4%)	1(1%)	14(8%)
Neuroblastoma	11(2%)	0	4(3%)
CNS and Intraspinal	0	0	5(4%)
Germ Cell Tumors	10(2%)	2(3%)	2(2%)
Malignant Bone tumor	1(1%)	0	4(3%)
LCH	1(1%)	2(3%)	0
Epithelial Neoplasms and Melanomas	0	0	1(1%)

(CH&ICH) = Children Hospital and Institute of Child Health, Multan, LGH= Lahore General Hospital

Table 2: Detailed data analysis of different POUs.

	CH&ICH -490	LGH -65	MAYO -167
Male	339 (69%)	39 (60%)	100 (60%)
Female	151 (31%)	26 (40%)	67 (40%)
Curative	390 (80%)	53 (88%)	145 (88%)
Palliative	29 (6%)	01 (1%)	05 (3%)
Abandonment	44 (9%)	08 (12%)	13 (8%)
Curative			
Alive with disease	238/390 (61%)	12/53 (23%)	26/145 (38%)
Alive with no disease	10/390 (2%)	18/53 (34%)	47/145 (32%)
Died	97/390 (25%)	15/53 (28%)	59/145 (41%)

(CH&ICH) = Children Hospital and Institute of Child Health, Multan, LGH= Lahore General Hospital

Table 3: Yearly data analysis of POUs.

	2016 (121)	2017 (228)	2018 (373)
Male	85 (70%)	153 (67%)	240 (64%)
Female	36 (30%)	75 (33%)	133 (36%)
Curative	119 (98%)	178 (78%)	291 (78%)
Relapse	9/119 (7%)	9/178 (5%)	8/291 (3%)
Died	73/119 (61%)	54/178 (30%)	44/291 (15%)
Left during treatment	7/119 (6%)	16/178 (9%)	42/291 (14%)
Died			
Induction mortality	20/73 (27%)	12/54 (22%)	23/44 (52%)
Treatment related mortality	1/73 (1%)	2/54 (4%)	10/44 (23%)

DISCUSSION

Childhood cancer is rare and the rate at which the new cases reported amongst children increasing day by day every year. For betterment in analyzing and gathering the childhood cancer data in Pakistan there is a requirement of proper National Registry; as registries plays a significant role in reporting the data to local and national governmental administrations. Enabling them to develop effective and relevant future health plans.

In the course of January 2016 to December 2018, we observed that the occurrence of cancer among males in all three units were significantly higher than in females. Our study represents the data of POUs of three units including CH&ICH, LGH and Mayo hospital. Approximately 490 patients were registered in CH&ICH Multan. Out of which frequency of males were found to be 339(69%) and female were 151 (31%).Similarly,65 patients were registered at LGH; males were 39(60%) and females were found to be in least ratio about 26(40%). Whereas, 167 patients were registered at Mayo Hospital. Among which 100 (60%) were males and 67(40%) were females. One of the study carried out by Zhenqiu Liu and coworkers which was published during March 2019 shows that males were more susceptible to cancer than females [9]. Furthermore, an epidemiological study which was conducted in Pakistan by Farhana Badar and Shahid Mahmood between 2010 and 2012 illustrates that ratio of cancer among males (9.3%) were elevated than females (6.1%) [10]. Similarly, study that was conducted at Jamshoro, Pakistan which in cooperates the data from January 2001 to December 2005 also reveals that the ratio of childhood cancer among males were significantly higher than females [7].

Leukemia and MDs shows striking pattern in CH&ICH, LGH and in Mayo. Study conducted in Pakistan also reveals that Leukemia and MDs was the most common diagnosis in children [12]. One of the international study conducted by Dr Eva in which data from 2001-2010 were in cooperated depicts that Leukemia is the most aggressive cancer among children followed by CNS tumors and lymphomas [11]. Lymphomas shows second highest and the third highest was renal tumors in CHM. Whereas, in LGH and Mayo after Leukemia and MDs, Retinoblastoma and Lymphomas are most frequent.

Our study depicts that around 512 patients offered curative treatment, 66 received palliative intent while the frequency of abandonment was found to be 142. Study carried out by Charlotte Burns and coworkers represents about 8 patients received palliative care whereas, 5 patients were abandonment [12].

The data in the current study indicates that rate of mortality during the course of 2016 were significantly higher but afterwards decline in mortality rate were shown in the year 2017 and 2018 respectively. The reason behind this decline was basically the strategies and plans initiated by My Child Matters in collaboration with The Indus Hospital. Trainings of paramedical and non-paramedical staff as well as monthly mortality meetings played a momentous role in this decline. Similarly, study conducted by Martha S. Linet and colleagues in United States depicts dramatic decline in mortality among children which highlights treatment related improvement in survival [13].

CONCLUSION

Cancer registry helps to evaluate and improve outcomes for a pop-

ulation defined by a particular condition, disease, or exposure. In addition to registering cases and using its data, the registry becomes an important data resource for hospital departments and research institutions to whom the cancer registry may provide lists of cancer patients. Intensive and extensive use of the registry's data also tends to maintain and improve their quality. By virtue of, their duties, the cancer registry's staff often have considerable expertise in disease registration, epidemiology and public health questions. This hospital based cancer registry program is very helpful for low middle income country like Pakistan. This will help us to determine the disease burden abandonment rate and mortality. In future it will also be helpful for the treatment plans.

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