Challenges Faced by Post-Treatment Childhood Cancer Patients and Families; The Children's Hospital, Lahore Experience

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ABSTRACT

Objective: To assess challenges faced by post-treatment childhood cancer patients and families in a developing country.
Study Design: cross-sectional study.
Place and Duration of Study: The Children's Hospital and the Institute of Child Health Lahore, from Jul to Dec 2020.
Methodology: 105 children and their parents were enrolled on OPD of the Department of Paediatric Hematology and Oncology. The parents were questioned regarding the duration of follow-up after treatment and the challenges they faced during this interval in association with socioeconomic dynamics, education and awareness of parents, travelling distance from the hospital, behavioural changes in children, toxicities/disabilities due to treatment, effect on other siblings, and various factors.
Results: In this study, the mean age of children was 9.40 ± 2.90 years. There were 55 (52.4%) males while 50 (47.6%) females. There were 35 (33.3%) children who had acute lymphocytic leukaemia, while 15 (14.3%) with Hodgkin Lymphoma, 12 (11.4%) with Wilms tumour, 10 (9.5%) with Non-Hodgkin Lymphoma, 9 (8.6%) with germ cell tumour and 7 (6.7%) with acute myeloid leukaemia. Mostly, 89 (84.8%) children received chemotherapy, while 12 (11.4%) children received chemotherapy as well as radiotherapy, and 4 (3.8%) children underwent surgery along with other treatments. The distance from the hospital was more than 50 km in >90 cases. Moreover, 42 (40.0%) children were found malnourished. Out of 105, 71 parents reported that the treatment affected their jobs, while 52 (49.5%) parents had to change their residence. The family's economic status was affected in 77 (73.3%) cases because of the treatment of the child.
Conclusion: Thus, several challenges significantly affect post-treatment childhood cancer patients and their families. So, strategies should be made to lessen the disease burden on parents to improve the follow-up and outcome of treatment.

Keywords: Cancer, Challenges, Children, Developing countries, Families.

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INTRODUCTION

Early detection, advanced treatments and aggressive supportive care have dramatically increased the overall 5-year survival rates in childhood cancer patients approaching 80% and above since the 1970s.[1,2] In the United States, an estimated 1 out of 530 individuals in their 20s or 30s is a childhood cancer survivor.[3] While improved cure rates are encouraging, intensified treatments for childhood cancer equally affect healthy tissues with late-onset physical and psychosocial impacts.[4] More than 70% of survivors will experience a chronic medical ailment in upcoming years.[5,6]

With the concomitant upsurge in the number of cancer survivors, the proportion of those seek ing medical care declines with an increase in time from diagnosis. A study proposed that only 42% of childhood cancer survivors attended hospitals while the majority did not receive risk-based care after completion of treatment.[6] Essentially, every organ system can be affected by the chemotherapy, radiation, and/or surgery required to achieve a cure for paediatric malignancies. Late complications of treatment may include problems with organ function, growth and development, neurocognitive function and academic achievement, and the potential for additional cancers.[7,8] This necessitates a comprehensive follow-up care strategy for efficient monitoring and timely management of late effects.[9]

In our Pediatric Hematology/Oncology unit, which is the largest in the country, we receive around 1000 new cases of malignancies every year. After completion of treatment, these patients are referred to a long-term follow-up clinic for five years from the end of therapy. Unfortunately, there is a paucity of data available about follow-up care clinics, so the study aimed to compute the challenges faced by cancer patients and their families. The objective of our study was to assess

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challenges faced by childhood cancer patients and families in a developing country.

METHODOLOGY

This cross-sectional study was conducted at the OPD of the Department of Paediatrics Oncology for 6months, from July 2020 to December 2020.

Inclusion Criteria: All children of age 1-17 years, of both genders, on post-treatment follow-up after completion of cancer treatment, along with their parents were included in the study.

Exclusion Criteria: Only children with disease relapse or recurrent disease were excluded from the study.

Informed consent was taken from parents to use their and their child's personal information for research purposes. Demographics like age, gender of the child, type of cancer and treatment, duration of treatment etc., were noted, and parents were asked about the duration of follow-up after treatment. Parents were also inquired about the challenges they were facing during follow-up after treatment in association with distance from the hospital, education of parents, change in child behaviour, disability due to treatment, effect on another sibling, economic status, parents' job, residence and various factor. All the information collected was recorded on the proforma.

Statistical Package for Social Sciences (SPSS) version 20.0 was used for the data analysis. Quantitative variables were summarized as Mean ± SD and qualitative variables were summarized as frequency and percentages.

RESULTS

In this study, a total of 105 patients were studied. The mean age of children was 9.40 ± 2.90 years. There were 55 (52.4%) male children while 50 (47.6%) females. The mean height of children was 126.58 ± 11.83 cm. The mean weight was 30.59 ± 10.83 kg, while the mean duration of treatment was 15.0 ± 13.13 months. There were 35 (33.3%) children who had acute lymphocytic leukaemia, 15 (14.3%) with Hodgkin Lymphoma, 12 (11.4%) with Wilms tumour, 10 (9.5%) with Non-Hodgkin Lymphoma, 9 (8.6%) with germ cell tumour, 7 (6.7%) with acute myeloid leukaemia, 6 (5.7%) with Ewing sarcoma, 5 (4.8%) with Rhabdomyosarcoma, 2 (1.9%) with Hepatoblastoma while remaining children had other rare types of carcinoma. Mostly 89 (84.8%) children received chemotherapy, while 12 (11.4%) children had undergone treatment through radiotherapy, and 4 (3.8%) children underwent surgery/or had surgical excision. The follow-up duration after the end of treatment was less than one year in 8 (7.6%) cases, 1-5 years in 87 (82.9%) children and more than five years in 10 (9.5%) children. There were 41 (39.0%) children who were regular for routine follow-ups, while 64 (61.0%) children showed irregular follow-ups due to different challenges faced by parents (Table-I).

Table-I: Demographics of children treated.

Features	n (%)
n	105
Age (years) Mean ± SD	9.40 ± 2.90
Male	55 (52.4%)
Female	50 (47.6%)
Height (cm) Mean ± SD	126.58 ± 11.83
Weight (kg) Mean ± SD	30.59 ± 10.83
Duration of treatment (months) Mean ± SD	15.0 ± 13.13
Diagnosis	
Acute lymphocytic leukemia	35 (33.3%)
Hodgkin Lymphoma	15 (14.3%)
Wilms tumor	12 (11.4%)
Non-Hodgkin Lymphoma	10 (9.5%)
Germ Cell Tumors	9 (8.6%)
Acute myeloid leukemia	7 (6.7%)
Ewing Sarcoma	6 (5.7%)
Rhabdomyosarcoma	5 (4.8%)
Hepatoblastoma	2 (1.9%)
Burkitt Lymphoma	1 (1.0%)
Nasopharyngeal carcinoma	1 (1.0%)
Osteosarcoma leg	1 (1.0%)
Retinoblastoma with Enucleation	1 (1.0%)
Type of Treatment Given	
Chemotherapy	89 (84.8%)
Radiotherapy	12 (11.4%)
Surgery	4 (3.8%)
Time Duration Since End of Treatment	
<1 year	8 (7.6%)
1–5 years	87 (82.9%)
>5 years	10 (9.5%)
Follow-up Visits as Per Protocol	
Regular	41 (39.0%)
Irregular	64 (61.0%)

The description of the challenges was given in Table-II. The distance from hospital was <50 km in 12 (11.4%) cases, while >50km in rest of the cases i.e., 17 (16.2%) cases travelling from a distance of 50-100 km, 21 (20.0%) cases from 100-200 km, and 55 (52.4%) from >200km. It has been found that 75 (71.4%) children attended school at the time of cancer diagnosis, but only 31 (29.5%) children resumed/started studying after the treatment. About 98 (93.3%) parents reported that their child's academics got affected due to cancer and its course of treatment. About 98 (93.3%) parents reported that their child manifested social withdrawal, 93 (88.6%) parents stated that their relation/

interactions with peers had been affected, while 67 (63.8%) parents described elements of anxiety they noticed in their child.

Table-II: Challenges faced by parents during follow-up with children treated for cancer.

Challenges		n (%)
Distance from hospital	<50 km	12 (11.4%)
	50–100 km	17 (16.2%)
	100–200 km	21 (20.0%)
	>200 km	55 (52.4%)
Was the child attending school at time of diagnosis	Yes	75 (71.4%)
	No	30 (28.6%)
Has child restarted schooling post-treatment	Yes	31 (29.5%)
	No	74 (70.5%)
Academics of child affected due to gap in schooling	Yes	98 (93.3%)
	No	7 (6.7%)
Any social withdrawal noted in child by parents	Yes	88 (83.8%)
	No	17 (16.2%)
Relation / interactions with peers affected	Yes	93 (88.6%)
	No	12 (11.4%)
Any anxiety noted in child by parents	Yes	67 (63.8%)
	No	38 (36.2%)
Any disability due to illness or treatment	None	35 (33.3%)
	Amputation	4 (3.8%)
	Hearing loss	2 (1.9%)
	Foot drop	1 (1.0%)
	Fatigue	60 (57.1%)
	Persistent disability	3 (2.9%)
Effect on nutritional status	Malnourished	42 (40.0%)
	Obese	30 (28.6%)
	Normal	33 (31.4%)
Father's education	Under matric	7 (6.7%)
	Matric	24 (22.9%)
	Intermediate	18 (17.1%)
	Graduate	38 (36.2%)
	Post-graduate	18 (17.1%)
Mother's education	Under matric	41 (39.0%)
	Matric	26 (24.8%)
	Intermediate	14 (13.3%)
	Graduate	16 (15.2%)
	Post-graduate	8 (7.6%)
Effect on parent's job	Lost	11 (10.5%)
	Changed	60 (57.1%)
	No	34 (32.4%)
Residence changed	Yes	52 (49.5%)
	No	53 (50.5%)
Effect of health and education of other siblings	Yes	57 (54.3%)
	No	48 (45.7%)
Treatment expenses borne by	Self	1 (1.0%)
	Hospital	7 (6.7%)
	Self + Hospital	90 (85.7%)
	Hospital + Donations	7 (6.7%)
Economic status of family affected	Yes	77 (73.3%)
	No	28 (26.7%)

In about 35 (33.3%) children, no disability was observed. However, amputation was documented in 4 (3.8%) cases, hearing loss in 2 (1.9%) cases, foot drop in 1 (1.0%) case, while fatigue and persistent disability in 60 (57.1%) and 3 (2.9%) cases, respectively. Out of the total of 105 children, 42 (40.0%) children were found malnourished, 30 (28.6%) children were obese, and 33 (31.4%) children had normal physiques. The education level of both parents was noted. There were 7 (6.7%) fathers who were under grade 10, 24 (22.9%) up to matric, 18 (17.1%) up to intermediate, 38 (36.2%) graduates while 18 (17.1%) post-graduates. There were 41 (39.0%) mothers who were under grade 10, 26 (24.8%) up to matric, 14 (13.3%) up to intermediate, 16 (15.2%) graduates while 8 (7.6%) post-graduates. Out of 105, 11 (10.5%) parents lost their job, while 60 (57.1%) changed their job. Nevertheless, treatment did not affect the jobs in 34 (32.4%) cases. There were 52 (49.5%) parents who had to change their residence because of their child's treatment. The health and education of about 57 (54.3%) siblings were affected. The expenses of treatment were borne mostly by the hospital, and only one (1.0%) case paid all the treatment expenses, while donations were involved in 7 (6.7%) cases. The family's economic status was affected in 77 (73.3%) cases because of the treatment of the child.

DISCUSSION

Early identification of factors leading to non-compliance of cancer survivors during post-treatment follow-up can be related to a lower risk of long-term morbidity and mortality. Considering the facts like limited data about the survivors, the variability of their treatment exposures, and the delayed appearance of many late effects, more and more clinical studies need to be conducted to establish optimum screening techniques. Furthermore, therapybased risk stratification while treating childhood cancer can also help us to decide about the intensity of follow-up after completion of treatment, thus allowing for the identification of individuals at the greatest risk of acquiring therapy-specific problems.[11,12,13]

In our study, we observed that mostly 89 (84.8%) children received chemotherapy, while 12 (11.4%) children had undergone treatment through radiotherapy, and 4 (3.8%) children underwent surgery or had surgical excision. The distance from the hospital was <50 km in 12 (11.4%) cases, while >50 km was noted in >90 cases, 42 (40.0%) children were found malnourished.

Out of 105, 71 parents reported that the course of treatment affected their jobs. 52 (49.5%) parents needed to change their residence. The family's economic status was affected in 77 (73.3%) cases because of the treatment of the child.

Childhood cancer survivor patients and their families face substantial emotional and financial difficulties during and after treatment. Therefore, providing medical therapy and psychosocial support coordination is key to cancer treatment effectiveness. Starting from the moment they get diagnosed with the condition, the patient and family will require psychosocial support throughout their lives. 10 In our country, we need to develop national social assistance programs and legislative rules to serve as a foundation for them.

In Turkey, recovery rates for paediatric malignancies have been reported to be as high as 70%.[14] Paediatric malignancies have various emotional and economic effects on patients, families, and the community throughout the treatment process, beginning with the diagnosis. In paediatric malignancies, the illness process can cause issues that might significantly impact the patient, such as treatment interruption, psychological issues, and a lack of social support, in addition to the family's challenges. As a result, in addition to medical therapy, providing emotional and economic support to patients and their families and harmonizing these treatments is critical in cancer treatment.[15,16]

According to Chino *et al,* cancer-related families experience significant financial difficulties, resulting in unfavourable psychological consequences. They found that individuals exposed to this stress were three times as likely to develop depression.[17] Likewise, economic and psychological issues are also inextricably linked.[18]

Parents identified numerous hurdles and facilitators impacting the reintegration process into nursery/school and leisure time activities, according to Inhestern *et al.* Although many children successfully reintegrate, the process takes considerable work on the part of both parents and children. After extensive treatment, childhood cancer survivors and their families should be supported to help them reintegrate into society.[19]

Inhestern *et al,* also said that the groundwork for effective reintegration might be laid during treatment, such as allowing for further education or maintaining contact with peers. Parents who are concerned about potential barriers and so overprotect their children may obstruct the reintegration process.[19]

Affected families and children face a decline in social support and care, particularly after therapy ends. As a result, it may be critical to talk openly with classmates and staff at school or in the nursery to organise a social support network.[20,21] The patients' and their parents' main concerns remained lack of awareness and spiritual issues. If the children and their mothers are provided with the essential information regarding the disease, its treatment, and consequences at the time of diagnosis, as well as spiritual care interventions throughout treatment, their psychological difficulties can be significantly minimized.[22]

CONCLUSION

Thus, there are several challenges which have to face by the parents. So few strategies should be made to lessen the burden and effect of treatment from parents to improve the follow-up and outcome of treatment.

Conflict of Interest: None.

Authors' Contribution

MK:, MS: Data collection, MF: Literature, manuscript , HZ; Manuscript, FS: Data analysis.

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