

Emotional Distress Among Pediatric Cancer Patients And Their Siblings

Ruqayya Manzoor¹, Nuzhat Yasmeen², Hijab Shaheen³, Nazia Mushtaq⁴

¹ Assistant Professor Pediatric Oncology Department, PIMS.

³ Medical Officer Pediatric Oncology Department, PIMS.

² Professor Pediatric Oncology Department, PIMS.

⁴ Senior Medical Officer, Islamabad Medical Complex Hospital

Author's Contribution

¹ Conception of study

² Experimentation/Study conduction

^{1,3} Analysis/Interpretation/Discussion

^{1,4} Manuscript Writing

² Critical Review

⁴ Facilitation and Material analysis

Corresponding Author

Dr. Ruqayya Manzoor

Assistant Professor

Pediatric Oncology Department

PIMS

Islamabad

Email: ruqayyamanzoor1@gmail.com

Article Processing

Received: 11/09/2022

Accepted: 17/12/2022

Cite this Article: Manzoor, R., Yasmeen, N., Shaheen, H., & Mushtaq, N. (2023). Emotional Distress Among Pediatric Cancer Patients and their Siblings. *Journal of Rawalpindi Medical College*, 27(1).
DOI: <https://doi.org/10.37939/jrmc.v27i1.2037>

Conflict of Interest: Nil

Funding Source: Nil

Abstract

Objectives: Cancer being a serious chronic illness, causes profound effects on the physical and mental health of the individual as well as affects their caregivers and family members' mental health. This study aims to find out the burden of emotional distress in patients with childhood cancer as well as their healthy siblings.

Methods: It was a descriptive cross-sectional study. Parents of the children undergoing cancer treatment or who have completed treatment within the past year were asked to complete an interview proforma (Pediatric Emotional Distress Scale) about their child's behavior over the past month, scoring each behavior on a scale of 1 to 5 according to the frequency of symptoms. The data was then analyzed using SPSS 20. The frequency distribution, central tendencies, and standard deviations were calculated accordingly.

Results: Almost eighty-five% of the patients showed scores above the clinical threshold for emotional distress. Eighteen% of the healthy siblings also had scores above the clinical threshold. Patients as well as their healthy siblings showed high levels of anxiousness in their behaviors.

Conclusions:

- Childhood cancer is a cause of major emotional trauma in patients.
- Age-matched siblings usually cope well with illness.

Keywords: Psychological distress, survivor, childhood cancer

Introduction

Childhood chronic illnesses have a profound effect on the family. It is even more stressful when a family is dealing with childhood cancer. The diagnosis, treatment, and complications disturb normal family life and leave long-lasting effects on the patient, the siblings, as well as the parents.

Due to the improved outcome of childhood cancer over the past 50 years, there are increased numbers of long-term survivors and various studies are being done to identify the long-term adverse effects on the physical and mental health of survivors. It has been seen previously that better family cohesion, support, and expressiveness and lesser conflict within families are associated with better adjustment of the child with cancer treatment¹. A study done on adult survivors of childhood cancers showed that symptoms of emotional distress were more prevalent among those survivors who had any chronic health conditions like cardiac, endocrine, and pulmonary effects of cancer treatment^{2,3}.

Furthermore, a strong predictor of a better quality of life was cancer appraisal among family members. It means if they perceive the illness to be manageable, it will have a positive impact on their quality of life and if they think it to be an uncontrollable disease, it will have a negative impact on their emotional health as well as the quality of life after diagnosis⁴.

The disease has a well-recognized effect on the siblings of the patient in the form of; parents being absent from home, having to deal with the ill sibling's suffering, having impaired school performance⁵, and enduring sadness⁶.

Although multiple studies have been done about the psychological impact of cancer diagnosis and treatment on the survivors and their families in other parts of the world, there is a limitation of data in our country. As more new Pediatric Oncology Units are being established in different cities of Pakistan, we need to address the psychological impacts of this disease as well. This study looks into the emotional aspects of childhood cancer treatment from the patient's as well as the family's perspective. Proper steps toward the solution of a problem can only be taken when the magnitude of the problem is first identified.

This study can help identify the emotional stress faced by children with cancer and their siblings during and after the treatment. The statistical data obtained by

this study can be useful in preparing strategies and guidelines for mental health interventions for patients and families diagnosed with Pediatric Cancers. Rehabilitation programs and follow-ups are necessary for these children during and after the course of treatment for a better quality of life¹³.

Objectives:

1. To identify emotional distress in patients undergoing chemotherapy or those who have completed treatment within one year.
2. To compare the emotional distress scores of patients with their normal siblings.

Materials and Methods

It was a descriptive cross-sectional study. Approval from the institutional ethical review board was taken prior to starting the study and consent was taken from the parents for enrolment in the study.

Inclusion Criteria:

- 1) All patients from 2 to 12 years of age who are undergoing chemotherapy for any type of cancer in the Pediatric Oncology Unit PIMS along with their one healthy sibling from the same age group.
- 2) All patients of pediatric cancer who have completed chemotherapy within the past one year along with one of their healthy siblings.

Exclusion Criteria:

Patients whose parents weren't willing to be included in the study were excluded.

Data Collection:

The Pediatric Emotional Distress Interview¹¹ proformas were filled by asking questions from the parents about their child's behavior over the past few weeks.

Analysis:

Data analysis was done using SPSS version 20. The data was then analyzed using SPSS 20. The frequency distribution, central tendencies, and standard deviations were calculated accordingly.

Results

A total of thirty-three sets of patients along with their age-matched siblings were surveyed.

Twelve patients out of thirty-three had completed their treatment within the past year while the rest (n 21) were still receiving cancer treatment (chemotherapy).

Seventeen out of the total thirty-three patients (51.5%) had a diagnosis of Acute Lymphoblastic Leukemia (ALL), four patients (12%) had Wilm’s tumor, four (12%) had Non-Hodgkin’s Lymphoma (NHL), two patients each (6.1%) had Germ cell tumor, Hodgkin’s Lymphoma and Non-rhabdoid soft tissue sarcoma (NRSTS), while one patient each (3%) was of Rhabdomyosarcoma and Langerhan’s cell Histiocytosis (LCH).

Eighteen (54.5%) of the patients were males and fifteen (45.4%) were females. Among the healthy siblings, seventeen (51.5%) were males and sixteen (48.4%) were females.

The ages of patients and siblings ranged from two to seventeen years. (Figure 1)

Age Groups

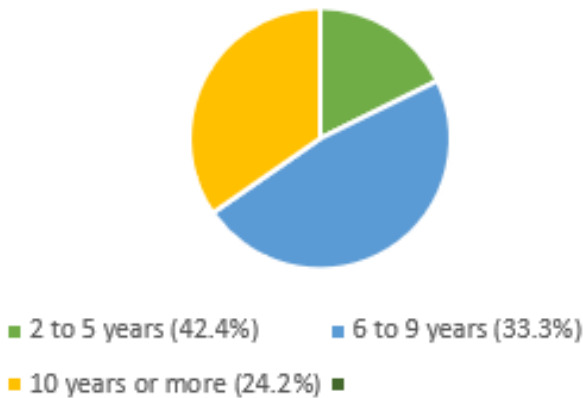


Figure-1: Age Group of Patients

A Pediatric Emotional Distress (PED) scale score of 28 or more was taken as above the clinical threshold. The mean PED score among the group of patients was 35.6 with only five out of the thirty-three patients showing scores below the clinical threshold (<28). Whether patients were still on treatment or completed their treatment didn’t make much difference as far as emotional distress was concerned.

Among the healthy siblings, the mean score was 23.63 with only six children showing scores above the clinical threshold level (Figure 2).

Two out of these six had siblings who had completed cancer treatment over the past year and the rest were still undergoing treatment.

The patients who were either younger than six years age or older than ten years showed more symptoms of emotional distress than the age group of six to nine years (Table 1).

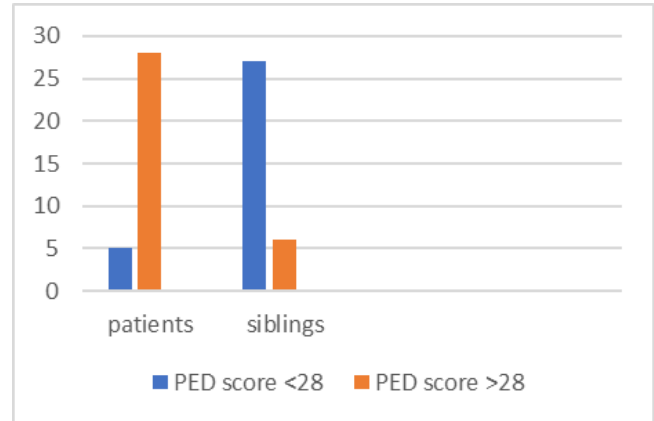


Figure-2: PED Scores of Patients & Siblings

The PED scale also has some subscales within the measure:

- Anxious/ withdrawn (items 6, 7,8,9,14,15, and 16). The clinical cut-off is 9.5.
- Acting out (items 1, 2,11,12,13, and 17). The clinical cut-off is 13.5.
-

While items 18 to 21 relate to a specific trauma the child has experienced (in our case, cancer diagnosis and treatment) and so these questions weren’t asked about the healthy siblings.

Seventeen out of thirty-three (51.5%) patients scored positive on the Anxious/ withdrawn subscale while among the siblings, this percentage was 30.3% (ten out of thirty-three). For the Acting out subscale, 24.2% (eight patients) scored above the clinical threshold, while for the siblings this percentage was 6% (two children) only. (Figure 3)

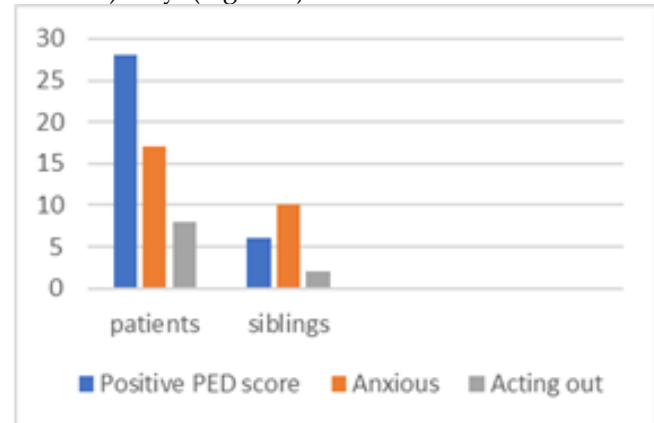


Figure-3 PED Score, Anxiety and Acting Out

Table 1

	Patients (n=33)		Siblings (n=33)	
	PED score <28	PED scores of 28 or more	PED score <28	PED scores of 28 or more
Age 2 to 5 years (n=28)	1 (3.5%)	16 (57%)	8 (28.5%)	3 (10.7%)
Age 6 to 9 years (n=22)	1 (4.5%)	5 (22.7%)	14 (63.6%)	2 (9%)
Age > 10 years (n=16)	3 (18.7%)	7 (43.7%)	5 (31.2%)	1 (6.2%)

Discussion

We found a very high incidence of emotional distress among the patients with pediatric cancer with almost 85% of patients showing scores above the clinical threshold. Being on active cancer treatment or having completed treatment did not have much effect on the emotional distress of patients. This agrees with studies done previously on long-term pediatric cancer survivors which showed a high incidence of emotional problems long after the completion of therapy^{2,3,9,10,13}. But some studies have also shown no difference in anxiety and depression scales among long-term survivors and control groups except for those patients who had received CNS radiation during treatment⁷. The reason behind this difference in observation may be the time passed since the completion of treatment as most studies we found were done on long-term survivors 10-15 years post-treatment while our patients were interviewed within a year of completing treatment.

Another reason for increased emotional distress may be the lack of psycho-social support facilities in our country. Most patients come from faraway places with a lack of basic health facilities and awareness about chronic illnesses. As another study pointed out that better cancer appraisal among the family led to better emotional well-being and quality of life⁴, therefore the lack of awareness about cancer and the taboos associated with it may be contributing to poor coping mechanisms in patients and families with childhood cancer.

One interesting finding in our study was the lower emotional distress levels among the age-matched siblings of the patients. The siblings showed overall better emotional well-being and less anxiety and distress. The reason may be that the family structures in our society are mostly joint family systems with grandparents also involved in childcare. So the siblings left at home may not be alone or missing out

on their routines and school as much as if they were in a nuclear family setup in Western countries⁵. This may help in better coping with healthy siblings with the sickness in the family. Even after considering all these factors, the anxiety score among the siblings was still high showing about one-third of siblings having scores above the clinical threshold. This again emphasizes the importance of psycho-social and emotional support to all family members as well as the patient suffering from childhood cancer^{12,14,15}.

Conclusion

Childhood cancer continues to be a cause of major emotional trauma in patients even after being cured.

Age-matched healthy siblings usually cope well emotionally with the disease.

This study again emphasizes the role of good psychosocial support for childhood cancer patients and their families.

References

1. Schoors M.V., Caes L., Knoble N.B., Goubert L., Verhofstadt L., Afereder M.A. Systematic Review: Associations between Family functioning and Child adjustment after Pediatric Cancer diagnosis: A Meta-Analysis. *Journal of Pediatric Psychology*,42(L),6-18,2017.
2. Vuotto S.C., Krull K.R., Li C., Oeffinger K.C., Green D.M., et al. Impact of Chronic disease on emotional distress in adult survivors of childhood cancer: A report from Childhood Cancer Survivor Study. (ascjournals.onlinelibrary.wiley.com) Oct 2016. *Cancer* 2017; 123:521-528.
3. Brinkman TM, Zhu L, Zeltzer LK, et al. Longitudinal patterns of psychological distress in adult survivors of childhood cancer. *Br J Cancer*.2013;109:1373-1381.
4. Schoors MV, Paepe AL, Norga K, Cosyns V, Morren H, et al. Family members dealing with childhood cancer: A study on the role of Family functioning and Cancer Appraisal. *Front Psychol*. 2019;10:1405 (published online 2019 June 19)
5. Prchal, Alice, Landolt, Markus A. How siblings of pediatric cancer patients experience the first time after diagnosis; A Qualitative Study. *Cancer Nursing*. March/April 2012-vol 35, Issue2:133-140.

6. Woodgate, Roberta Lynn RN. Siblings' experiences with childhood cancer; A different way of being in the family. *Cancer Nursing*; September 2006;vol 29:issue 5:406-414.
7. Van der G.I, Dorp W, Hop W, Neggers S, de Vries A, et al. *Journal of Pediatric Hematology/ Oncology*: Oct 2013;35:525-529.
8. Lehteenmaki P.M, Sjoblom J, Korhonen T, Salmi TT. The siblings of Childhood cancer patients need early support: A follow-up study over the first year. *Arch Dis Child*; Nov 2004;89(11): 1008-13.
9. Zeltzer LK, Chen E, Weiss R, Guo MD, Robison LL, et al. Comparison of psychologic outcome in adult survivors of childhood acute lymphoblastic leukemia versus sibling controls: a cooperative Children's Cancer Group and National Institutes of Health study. *J Clin Oncol*. 1997 Feb;15(2):547-56.
10. Daniel LC, Wang M, Mulrooney DA, Srivastava DK, Schwartz LA, Edelstein K, Brinkman TM, Zhou ES, Howell RM, Gibson TM, Leisenring W, Oeffinger KC, Neglia J, Robison LL, Armstrong GT, Krull KR. Sleep, emotional distress, and physical health in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Psychooncology*. 2019 Apr;28(4):903-912. doi: 10.1002/pon.5040. Epub 2019 Mar 14. PMID: 30817058; PMCID: PMC6506232.
11. Saylor CF, Swenson CC, Reynolds SS, Taylor M. The pediatric emotional distress scale: a brief screening measure for young children exposed to traumatic events. *J Clin Child Psychol*. 1999 Mar;28(1):70-81. doi: 10.1207/s15374424jccp2801_6. PMID: 10070608.
12. Carlsson T, Kukkola L, Ljungman L, Hovén E, von Essen L. Psychological distress in parents of children treated for cancer: An explorative study. *PLoS One*. 2019 Jun 21;14(6):e0218860. doi: 10.1371/journal.pone.0218860. PMID: 31226159; PMCID: PMC6588250.
13. Linder LA, Hooke MC. Symptoms in Children Receiving Treatment for Cancer-Part II: Pain, Sadness, and Symptom Clusters. *J Pediatr Oncol Nurs*. 2019 Jul/Aug;36(4):262-279. doi: 10.1177/1043454219849578. PMID: 31307323; PMCID: PMC7197222.
14. Tian X, Jin Y, Chen H, Tang L, Jiménez-Herrera MF. Relationships among Social Support, Coping Style, Perceived Stress, and Psychological Distress in Chinese Lung Cancer Patients. *Asia Pac J Oncol Nurs*. 2021 Jan 29;8(2):172-179. doi: 10.4103/apjon.apjon_59_20. PMID: 33688566; PMCID: PMC7934593.
15. Elimimian EB, Elson L, Stone E, Butler RS, Doll M, Roshon S, Kondaki C, Padgett A, Nahleh ZA. A pilot study of improved psychological distress with art therapy in patients with cancer undergoing chemotherapy. *BMC Cancer*. 2020 Sep 22;20(1):899. doi: 10.1186/s12885-020-07380-5. Erratum in: *BMC Cancer*. 2020 Nov 20;20(1):1125. PMID: 32962660; PMCID: PMC7510066.