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Original Research Article

Posttraumatic stress symptoms during treatment in parents of children diagnosed with cancer

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ABSTRACT

Background and Objectives: The study aimed to study the presence of PTSS in parents of children with cancer currently on treatment and the association of PTSS in parents with cancer during treatment with length of time since diagnosis and treatment intensity.

Materials and Methods: The study was conducted on 360 parents at a Tertiary Care Government Medical College and Cancer Hospital. The participants were subjected to the questionnaire PTSD Checklist Civilian Version (PCL-C) scale, to assess PTSS and Oncologists rated the intensity of each child's treatment.

Result: The most common age group in the parents was of young adults 25-34years [255(71%)]. Majority of parents were male 288(80%). It was found that PTSD was present in majority of parents [235(65.27%]. On statistical analysis, no significant relationship was found between PTSS in mothers and fathers (p=0.1664). There was no significant relationship between PTSS and the length of time since diagnosis in both mothers (P=0.85) and fathers (P=0.32). No significant relationship was found between the intensity of treatment and PTSD in mothers on statistical analysis (p<0.3). While PTSD in fathers showed significant correlation with the intensity of treatment of the child (p<0.05).

Conclusion: There are very few studies regarding examining emotional distress of parents of children with malignancies in our country. Hence, studying PTSS in parents of children with cancer seems to be significant and more research needs to be done in this area.

1. Introduction

Nearly 300,000 children aged 0 to 19 years old are diagnosed with cancer each year and it is a leading cause of death for children and adolescents globally.[1,2] Low- and middle-income countries account for more than 80% of all childhood cancer cases.[3] In India, cancer is the 9th most common cause for the deaths among children aged 5-14 years,[4] where the survival rate for paediatric malignancies is only 20-30%. The causes for such low rates being inadequate facilities, lack of awareness, late detection of cancer and high cost of treatment. The experience of having a child diagnosed with cancer can be overwhelming and extensively distressing for parents.[5]

For offering optimal support to families of children with malignancies, a profound knowledge of parental distress is important.[6] Findings show that often, the anxiety was detected to be even higher in parents of children with cancer than that in adult cancer patients and children suffering from cancer themselves.[7] During treatment, parents are exposed to many events that are potentially traumatic like learning of the diagnosis, emergency hospitalizations, invasive procedures, seeing their child in pain during treatment, adverse effects of treatment and deaths of other patients.[6] These traumatic events may lead to Post-traumatic Stress Symptoms (PTSS) which include physiologic arousal, intrusive thoughts, and avoidance of

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treatment-related procedures and events. The DSM-IV defines PTSD as a serious mental condition which follows an individual who is experiencing, being confronted with or witnessing a traumatic event/events which involved death, actual or threatened, or serious injury, or threat to physical integrity of themselves or others.[8]

PTSS is likely to emerge at some point during the treatment for cancer where, variables such as the intensity of treatment and the length of time since diagnosis may correlate with PTSS in parents. For example, PTSS might decrease with time, like anxiety, in a natural course of adjustment to the cancer.[6] Also, intense treatment regimens, more likely of having immediate adverse effects, might be more likely to harbour PTSS during the treatment period.[6,9] Following exposure to a traumatic event, a number of factors are considered to increase risk of PTSS and PTSD. In adults, it includes sociodemographic factors such as young age, socio-economic status, female gender, lower intelligence levels, cognitive and personality features such as neuroticism, avoidant coping and external locus of control.[10] Positive correlation has been found between psychosocial functioning of parents and psychosocial functioning in children. In children with cancer, the most important source of emotional support are their parents, and the parents with PTSD and distress may face difficulty in caring for the children.[11] Because of PTSS there has been wider cases of failure and defaulting of treatment in patients.

Nowadays, there has been improved access to affordable and essential medicines and technologies.[1] However, there are very few studies regarding examining emotional distress of parents of children with malignancies in our country.[7] Hence, this study aims to examine PTSS in parents of children with cancer.

2. Material and Methods

This is a Cross-sectional study conducted at Tertiary Care Cancer Hospital in Maharashtra from 01 February 2021 to 31 March 2021 over the period of 2 months. Institutional ethical committee approval was taken. The Study population were parents of children on treatment for paediatric malignancy in cancer hospital. After written and informed consent, total of 360 parents were enrolled in the study.

The inclusion criteria were parents of children with cancer in age group of 0-12 years and parents of children with cancer whose duration of diagnoses is more than one month. We excluded the parents of children with cancer of age more than 12 years, parents of children with cancer with relapse, parents of children with cancer with duration of diagnosis less than one month and parents not willing to participate in the study.

The participants were subjected to the questionnaire PTSD Checklist Civilian Version (PCL-C) scale which comprises of 17 items, to assess PTSS in parents.[5,12] Based upon this scale presence or absence of PTSD in parents were decided (questions will be asked in the mother tongue of parents). Oncologists will rate the intensity of each child's treatment as per the Intensity of treatment scale as shown in Table 1 .[6] A four-point rating scale was used to rate the intensity of the cancer treatment protocols based on Children's Oncology Group protocol number, medications, and treatment modalities.

For socioeconomic status modified Kuppuswamy scale was used.[13]

The data analysis was done using SPSS (Statistical Package for Social Science.) descriptive statistic will be calculated and appropriated statistical test will be used. All the statistical tests were considered statistically significant whenever $p<0.05$.

3. Results

During this study period, we enrolled 360 parents of children with cancer as per criteria.

Table 2 shows demographic profile ofparents. Most common age group in the parents was between 25-34 years (young adults) in 255 (71%) parents. Males were 288 (80%) while females were 72(20%) with male to female ratio 4:1. Majority of parents were staying in urban area [216(60%)] and were free from addiction [328 (91%)]. 180 parents [50%] were belonged to lower middle class according to Modified Kuppuswamy Socioeconomic Scale.

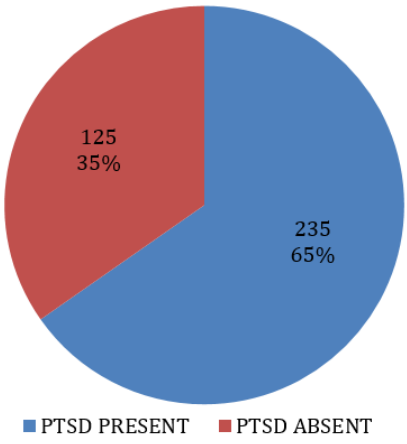

Figure 1: Distribution of PTSD findings in parents

Figure 1 shows presence or absence of PTSD in parents. PTSD was present in 235 (65.27%) parents and was absent in 125(34.72%) parents.

Table 3 shows PTSD in parents. Amongst 288(80%) fathers, PTSD was seen in 183 (50.83%) while amongst 72 (20%) mothers PTSD was seen in 52(14.4%) mothers. On statistical analysis by chi-square test, no significant correlation was found between PTSD in mothers and fathers ($p=0.1664$).

Table 1: Intensity of treatment scale

Level 1	Included minimally intensive treatments (ex, surgery only, less than 6 months of chemotherapy with one or two drugs, unilateral enucleation)
Level 2	Moderately intensive treatments (ex, more than or equal to 6 months of chemotherapy with more than or equal to three chemotherapeutic agents plus limited dose and single-field radiation, craniotomy)
Level 3	Intensive regimens such as those including higher doses or larger volumes of radiation, some metastatic tumours, and brain tumour protocols with two or more modalities
Level 4	The most intensive and in this study represented protocols involving bone marrow transplantation or acute myeloid leukaemia therapy.

Table 2: Demographic profile of parents

Characteristics	**No. of parents**	**Percentage**
Age Distribution (Years)		
Young Adult (18-34 Years)	255	71%
Middle Aged (35-44 Years)	97	27%
Old Aged (45-54 Years)	8	2%
Gender Distribution		
Male	288	80%
Female	72	20%
Distribution of region of residence		
Urban	216	60%
Rural	144	40%
Distribution of Addiction		
Addiction Present	32	9%
Addiction Absent	328	91%
Distribution of socioeconomic class as per modified kuppuswamy socioeconomic scale		
Upper (I)	0	0%
Upper Middle (Ii)	4	1%
Lower Middle (Iii)	180	50%
Upper Lower (Iv)	152	42%
Lower (V)	24	7%
Total	360	100%

Table 3: Distribution of PTSD findings in fathers and mothers

	PTSD Present (%)	**PTSD Absent (%)**	**Total (%)**	**P Value**
Fathers	183 (50.83)	105 (29.17)	288 (80)	Chi Square Value =1.974,degrees of freedom (d.f)=1, p =0.1664
Mothers	52 (14.44)	20 (5.55)	72 (20)	
Total	235 (65.28)	125 (34.72)	360 (100)	

Table 4: Correlation between PTSD findings and length since diagnosis in parents

Subject	**Duration Of Treatment**	**PTSD Present (%)**	**PTSD Absent (%)**	**Total (%)**	**P Value**
Fathers	Less Than 1 Year	86 (29.86)	43 (14.93)	129 (44.79)	Chi Square Value =0.984, degrees of freedom (d.f)=1, p=0.32
	More Than 1 Year	97 (33.68)	62 (21.53)	159 (55.21)	
	Total	183 (63.54)	105 (36.46)	288 (100)	
Mothers	Less Than 1 Year	17 (23.61)	7 (9.72)	24 (33.33)	Chi Square Value =0.03, degrees of freedom (d.f)=1, p=0.85
	More Than 1 Year	35 (48.61)	13 (18.05)	48 (66.66)	
	Total	52 (72.22)	20 (27.77)	72 (100)	

Table 5: Correlation between PTSD and intensity of treatment in fathers and mothers; **A :** Correlation between PTSD and intensity of treatment in fathers

Subject	**Intensity of Treatment**	**PTSD Present (%)**	**PTSD Absent (%)**	**Total (%)**	**P Value**
Fathers	1	8 (2.78)	0 (0.00)	8 (2.78)	Chi Square Value =5.88, Degrees of Freedom (D.F) = 2, P<0.05 Signifiant
	2	123 (42.70)	80 (27.78)	203 (70.48)	
	3#	52 (18.05)	25 (8.68)	77 (26.74)	
	Total	183 (63.53)	105 (36.46)	288 (100)	

Table 6: Correlation between PTSD and intensity of treatment in mothers

Subject	Intensity of Treatment	PTSD Present (%)	PTSD Absent (%)	Total (%)	P Value
Mothers	1	4 (5.55)	4 (5.55)	8 (11.11)	Chi Square Value =2.33, Degrees of Freedom (D.F)=2, P<0.3
	2	37 (51.39)	13 (18.05)	50 (69.44)	
	3#	11 (15.28)	3 (4.17)	14 (19.45)	
	Total	52 (72.22)	20 (27.77)	72 (100)	

Table 4 shows correlation between PTSD findings and length since diagnosis in parents. PTSD was seen in 183(63.5%) fathers amongst them 97(34%) fathers had PTSD with length of treatment >1 year and 86(30%)fathers had PTSD with length of treatment <1 year. On statistical analysis by chi-square test, no significant correlation was found between PTSD in fathers and length of time since diagnosis of the child (p= 0.32).

PTSD was present in 52 (72%) mothers amongst them 35(48.61%) mothers had PTSD with duration of treatment more than 1year and 17(23.6%) mothers had PTSD with duration of treatment less than 1 year. On statistical analysis by chi-square test, no significant correlation was found between PTSD in mothers and length of time since diagnosis of the child (p= 0.85).

A shows correlation between PTSD and intensity of treatment in fathers. Majority of fathers with PTSD were having Level 2 intensity of treatment [123(43%)]. On statistical analysis by chi-square test, significant correlation was found between PTSD in fathers and intensity of treatment in the child (p< 0.05).

Table 6 shows Correlation between PTSD and intensity of treatment in mothers. Majority of mothers with PTSD were having Level 2 intensity of treatment [37(51%)]. On statistical analysis by chi-square test, no significant correlation was found between PTSD in mothers and intensity of treatment in the child (p>0.05).

4. Discussion

During this study period, we enrolled 360 parents of children with cancer as per criteria. Primary objective of this study was to study the presence of PTSS in parents of children with cancer currently on treatment and secondary objectives were to study the association of PTSS in parents of children with cancer during treatment with length of time since diagnosis and treatment intensity.

In present study, most common age group in the parents was between 25-34 years (young adults) in 255 (71%) parents. Similar results were found in the study conducted by Irina Baniene et al.(2020) ,where 19-39 years was the most common age group(62.1%) in parents.[14] While in a contrast study done by Yiling Yang et al. (2020), the most common age range in the study group was 35-44 years(59.3%), The reason for such variation may be the difference in sample size i.e. n=187 in this study.[15] In our study, majority of parents were male 288 (80%). Contrary to this, in study conducted by Yiling Yang et al.(2020)[15] and Irina Baniene et al.(2020)[14] majority of participants were females. It could be explained based upon difference in sample size i.e. n=187 and n=195 respectively in these studies.

In this study, according to the scoring by modified Kuppuswamy socioeconomic scale, it was found that the most common socioeconomic class was Lower Middle (III) with 180 (50%) parents. Similarly, in study by Madeleine J. Dunn et al.(2012)[16] most common socioeconomic class was lower middle class. In contrast, in study done by Anne E. Kazak et al.(2005)[6] most common socioeconomic class was upper middle and lower middle class. The difference in finding may be due to difference in geographical location of the study i.e. later study conducted at Philadelphia (U.S.A).

In the present study, Maximum number of parents 216 (60%) belonged to urban area. Similar results were found in a study by Irina Baniene et al.(2020).[14] While contrast results were found in study by Yiling Yang et al.(2020),[15] majority of the participants in the study group(54.9%) had rural residence.The difference in location of residence with respect to other studies can be due to difference in study setting and geographical location i.e. Guangzhou, China in later study.

PTSD was present in 235 (65.27%) parents and was absent in 125(34.72%) parents. Similar results were found in a study by Martin Cernvall et al.(2015)[17] where 48% parents had score above suggested cut-off on PCL-C checklist. Also, Nina Oginska-Buliket al. (2017)[18] in their study using IES-R scale (measuring general index of intensity of PTSD) found 80.7% parents with moderate and above moderate level symptoms.

In present study 52(14%) mothers amongst 72 (20%) had PTSD. Similar results were found in a study by Anne E. Kazak et al(2005)[6] where moderate to severe PTSS was reported in 68% mothers. Abdelaziz M Thabet et al.(2017),[19] found that PTSD was absent in 44% mothers. This contrary finding could be because of different geographical area of study.

In our study PTSD was present in 183 (51%) fathers with [n=288(80%)]. Similar results were found in a study by Anne E. Kazak et al(2005)[6] where moderate to severe PTSS was reported in 57% fathers.

However, in our study on statistical analysis by chi-square test, no significant correlation was found between

PTSD in mothers and fathers (p= 0.164). Similarly, Nina Oginska-Buliket al. (2017)[18] found that sex of the parents was not related to the intensity of PTSD.

In our study no significant relationship was found between PTSD in both parents and the length of time since treatment on statistical analysis. The study by Irina Baniene et al.(2020) had found the similar results.[14] While study by Anne E. Kazak et al.(2005),[6] found significant negative association between length of time since diagnosis and PTSS in mothers and no significant association in fathers. The difference in findings in comparison to current study could be due to difference in number of cases enrolled i.e. n= 119 mothers in their study. Also it could be due to the difference in geographical area i.e Philadelphia U.S.A. in their study.

In this present study no significant relationship was found between the intensity of treatment and PTSD in mothers on statistical analysis (p<0.3). Similar results were found in a study by Anne E. Kazak et al.(2005).[6] While, in study by Irina Baniene et al.(2020),[14] expression of PTSS differed in parents with relation to the stage of oncologic disease in the child (IES-R scores were higher in parents of children with stage IV cancer than those with stage III cancer), however no such difference was found on comparing treatment methods. The variation in results may be because intensity of treatment was compared for both the parents in this study.

In the present study, PTSD was present in 183(63.5%) fathers among which level of intensity treatment in children was level 2 in 123(43%). PTSD in fathers showed significant correlation with the intensity of treatment of the child (p<0.05). while study by Anne E. Kazak et al. (2005) showed contrasting results with no significant correlation was found between intensity of treatment and PTSS in fathers.[6]This difference may be attributed to the difference in age groups of study population (mean age for fathers was 41.7 years in later study).

5. Conclusion

The most common age group in the parents was of young adults between 25-34 years. Majority of parents were male 288 (80%), followed by female 72 (20%) with male to female ratio 4:1. It was found that PTSD was present in majority of parents and there was no significant relationship was found between PTSD in mothers and fathers and the length of time since treatment. Also there was not any significant relationship between the intensity of treatment and PTSD in mothers but PTSD in fathers showed significant correlation with the intensity of treatment of the child.

Thus, majority of parents in this study setting were suffering from PTSD, and while intensity of treatment showed correlation with PTSD in fathers, length of time since diagnosis did not show any such relationship in parents.

Management, adjustment and support in parents of children diagnosed with cancer thus forms a crucial part of holistic approach to managing child's condition. A perspective on cancer treatment that considers traumatic stress, opens avenues for multidisciplinary treatment methods and options with the aim to provide trauma-informed medical care for their families along with the patients.[4]

Psychosocial services are not being provided currently, even if present, are not consistent, within or across treatment setups[20] in India. Intervening with mothers and fathers during treatment may help in preventing psychological difficulties, on a long-term basis, for the patient and the family.[6] For facilitation of positive outcomes in cancer, a close partnership paediatric oncologists with psychologists is required, while bringing much-needed attention to the spectrum of issues that emerging in the treatment course.[20] Application of cognitive behavioural theoretical framework techniques can be suggested to the family of such children, followed by internet based guided self-help. Perhaps extending the discussion to the aspect of the public stigma, self-stigma and institutional stigma associated with mental illness, the role of such interventions assumes utmost importance.

6. Source of Funding

None.

7. Conflict of Interest

None.

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