

## Childhood cancer – Angst and impact among the parents A cross-sectional survey

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### Abstract:

**Background:** Cancer is spotted as a major public health concern. It is prevalent among all age groups; even during the childhood. Childhood cancer burden is increasing day by day and presenting unpredictable impacts in the society. Despite of the prognosis of childhood cancers, it wields a significant impact on the family. The present study is intended to identify the anxiety and the impact of childhood cancer among the parents.

**Materials and Methods:** A cross-sectional survey design was used to identify the anxiety and its impact among the parents of children with cancer. Total 111 parents were recruited for the study by using quota sampling from selected hospitals with sophisticated pediatric oncology unit. Hospital Anxiety and Depression Scale, and Impact of Event Scale – Revised were used to collect data from the Parents. Data was analyzed using SPSS (SPSS v25) with the level of significance  $\alpha = 0.05$ .

**Results:** Majority of the study participants were mothers of the children with cancer. Most of the parents participated in the study had a borderline level of anxiety ( $9.4 \pm 2.6$ ) with an impact score of  $37.3 \pm 12.6$ . The score revealed that the parents had a probable diagnosis of post-traumatic stress disorder. There is strong correlation was noticed between the anxiety scores of the parents and the impact scores. A significant association was seen with age, employment status, number of children ( $p < 0.01$ , type of cancer and duration of illness of the children ( $p < 0.05$ ) with anxiety scores of the parents.

**Conclusion:** The anxiety level and the associated impact among the parents of children diagnosed with cancer is more than the anticipated level. Hence a compact and collaborative support care interventions should be articulated for enriching the life quality of the parents.

**Key Word:** Childhood cancer; Angst; Impact; Parents.

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### I. Introduction

Cancer in children is distinctly differing in its physiognomies from adults' varieties. The recent GLOBOCAN (2020) estimate, the global cancer burden has levitated to 19.3 million, and 10 million deaths were reported across the globe<sup>1</sup>. Childhood cancer was the sixth most common cause of total cancer burden and the ninth most common cause of childhood disease burden worldwide<sup>2</sup>. Every year almost 40, 0000 children (0-019 years) were diagnosed with cancer in a year<sup>3</sup>. Leukemia and brain tumors are the leading types of cancers reported among the children<sup>4</sup>. The overall prognosis of childhood cancers were more among the high income countries, but a low cure rates were reported in low income countries. Unfortunately, the early screening and prevention is not much effective in childhood cancer diagnosis<sup>5</sup>.

During the period of treatment and diagnosis the travails of children with cancer are unthinkable and it will impede the quality of life among the children. The trajectories of cancer treatment and diagnosis will affect the family functioning too<sup>6</sup>. When the child has been diagnosed with cancer the stress and strain among the parents will be heightened in the initial period of diagnosis, and in the later phase it may leads to traumatic stress reactions<sup>7</sup>. The stress is the major cause for the family conflicts among the parents of children diagnosed with cancer, and it may persist for a long period<sup>8</sup>. The painful phases of treatment and diagnosis among the children exert a huge responsibilities and care demand on the parents compared to the normal children of the same age. This extra burden on the parents will decline their quality of life and affect the routine function of the family. The treatment of the child's cancer has an adverse impact on the social and professional life of the parents<sup>9</sup>. The increased survival rates of childhood cancer impart a high level caring burden over the parents during the time of tenement as well as during period of survivorship<sup>10</sup>.

Parents are the key source of emotional support for the children, and the dependability on the parents is more among children with cancer as compared to normal children. The parental attention is more on the diseased child that will leads to marital conflicts, problems family communication, snags in relationship with

other children<sup>11</sup>. The economic impact of the pediatric cancer on the families are more devastating and that will cause alteration in family functioning<sup>12</sup>. The major stressors among the parents of children diagnosed with cancer include treatment and its related side effects, disturbing emotions, interruption in daily routines, and social dares<sup>13</sup>. The studies were reported that, there is change in cohesion, normality, and values in the family has been changed after the diagnosis of child with cancer<sup>14</sup>. These changes will exert an undue pressure on the parents and make their caregiver ship more stressful and in turn they are more prone to get stress related physical or psychological ailments.

Addressing the stress and strain among the parents of children diagnosed with cancer is an important area of pediatric cancer care. Parents are the key support for the children during the crisis situation. The support care intervention and the selection appropriate coping strategies have a dynamic impact on the treatment outcome. Therefore the agonies among the parents and the impact of pediatric cancer on them should be studied with utmost importance. A number of studies have been conducted in developed countries to identify the level of anxiety among the parents of children diagnosed with cancer; unfortunately compact evidence on this matter cannot be traced in India, especially south India. Hence the present study aimed to examine the anxiety among the parents of children with cancer and its related impact.

## **II. Material And Methods**

### **Study design**

A cross-sectional survey design was used to assess the anxiety among the parents of children with diagnosis of cancer.

### **Study sample and setting**

The study was conducted in selected hospitals in Kerala, which have a sophisticated pediatric oncology unit. Parents of children with the diagnosis of cancer who is seeking treatment from the selected hospitals were included to in this study. A non-probability quota sampling was used to recruit the participants for the study.

### **Participants**

#### **Eligibility criteria**

- Parents of children with recent diagnosis (< 1month) of cancer.
- Parents of children with cancer who aged  $\leq 15$  years.
- Parents of children receiving treatment from selected hospitals.
- Parents of children who have receiving in-patient treatment for the cancer.
- Parents who are willing to participate in the study.

#### **Exclusion criteria**

- The parents with the following criteria were excluded from the study
- Parents of children receiving treatment as outpatient basis.
- Parents of children who are critically ill.
- Parents of children who are receiving specialized treatments such as bone marrow transplantation.
- Parents with widow/widower, or divorced status.
- Parents who have diagnosis of life threatening disorders or psychiatric diseases.

#### **Sample size:**

According to Indian Council of Medical Research (ICMR), national centre for disease informatics and research national cancer registry program population based cancer registry report<sup>15</sup> based on the year 2012-2014 total 326 cancer cases were reported among the children under 15 years of age. Based on this data, the sample size of the present study was derived. The calculated sample size was 104 parents of children with a diagnosis of cancer with 8.84 % margin of error (absolute error) and 95% confidence interval. Considering possible sample attrition, 115 parents were recruited for this study.

#### **Recruitment & ethical considerations**

The investigators have sent a letter for seeking permission to the selected hospitals. After getting the official approval from the concerned authorities, the investigators were visited the facility and conducted the baseline line assessment to recruit the samples for the study.

#### **Outcomes**

The anxieties of the parents of children with cancers during hospitalization were measured using "Hospital Anxiety and Depression Scale (HADS)"<sup>16</sup>. It is an adequate, unswerving, valid tool for detecting depression and anxiety. "HADS" contains 14 items which reveals the mood of participants in the past week. Seven items in the scale assess depression among the study participants, which includes anhedonia and feeling

of slowing down in life. The remaining seven items measures the anxiety. “HADS” was used in the present study to assess the anxiety and depression among the parents of children with cancers during their child’s hospitalization.

The impact of childhood cancer among the parents were measured using “Impact of Event Scale - Revised (IES-R)”<sup>17</sup>. It is a self-report measure to identify the distress experienced by the study participants due to the perceived traumatic event in their life. The tool contains 22 items. Each sub items in the scale has been arranged as 5-point rating scale.

A demographic questionnaire was used to assess the demographic profile of the study participants. The above-mentioned measures of tools were translated and validated in Malayalam (Regional language).

**Data collection**

The data collection was initiated after getting the formal approval from the administrative heads of the selected hospitals. An Informed consent was obtained from the study participants. An assurance was given regarding confidentiality before the data collection procedure. The translated version of the Hospital Anxiety, Depression Scale and Impact of Event Scale - Revised (IES-R), and a demographic questionnaire was used to collect the data from the study participants through a semi structured interview session.

**Statistical methods**

The statistical analysis of the collected data was made using SPSS (SPSS v25) with the level of significance  $\alpha = 0.05$ . Chi square was used to identify the association between parental anxiety and depression with selected demographic variables. A p value of  $< 0.05$  was considered statistically significant. The parent’s anxiety, depression, and impact of childhood cancer were determined with the help of descriptive statistics.

**Ethical considerations**

The present study was conducted with ethical approval by the Institutional Research Board (IRB) of National College of Nursing (IRB/2018/A/02) by abiding the principles of Declaration of Helsinki. The data collection was initiated after getting the formal approval from the administrative heads of the selected hospitals. An Informed consent was obtained from the study participants and an assurance was given regarding confidentiality. The participants were informed of their right to withdraw from the study at any time.

**III. Result**

**Demographic characteristics of the study participants**

The mean age of the study participants was 31 ( $\pm 3.5$ ) years. Majority of the subjects were mothers (62.16 %). Other demographic characteristics of the study participants were presented in the Table 1.

**Table no 1: Demographic profile of the study participants**

Variables		N (%)
Age (years)		31 $\pm$ 3.5
Gender	Male	42 (37.84)
	Female	69 (62.16)
Domicile	Urban	68(61.26)
	Rural	43(38.73)
Employment status	Employed	47(42.34)
	Unemployed	64(57.66)
Type of family	Nuclear	72(64.86)
	Extended	39 (35.14)
Number of children (Alive)	One	22(19.81)
	Two	65(58.55)
	More than two	24(21.62)
Unhealthy Habits	Yes	25(22.52)
	No	86(77.48)

*Data are presented as mean  $\pm$  standard deviation or number (percentage).*

**Clinical profile of children of the study participants**

The mean age of the children of the study participants was 5 ( $\pm 2$ ) years. Majority (44%) of the children were diagnosed with Leukemia. Most of the children (59%) have duration of illness more than 2 weeks. More

than half(65%) of the children were second child of their parents. and Most of the children (51%) are getting chemotherapy alone as the treatment for cancer and they (72%) are seeking treatment from the government institutions

**Table no 2:** Clinical profile of children of the study participants

Variables		N (%)
Age (years)		5± 2
Gender	Male	53 (47.75)
	Female	58 (52.25)
Diagnosis	Leukemia	44(39.63)
	Lymphoma	09(08.10)
	CNS cancer	30 (27.02)
	Peripheral nervous system tumors	3(2.70)
	Nephroblastoma including Wilms' Tumor	10(9.00)
	Hepatic tumors	1(0.90)
	Osteosarcoma/Ewing's sarcoma/other bone related tumors	8(7.20)
	Rabdomyosarcoma	3(2.70)
	Germ cell/gonadal tumors	2(1.80)
	Others	01(0.90)
	Duration of illness	≤ 2 weeks
> 2 weeks but less than one month		59(53.15)
Birth order	First	28(25.22)
	Second	65(58.56)
	Third or more	18(16.22)
Type of Treatment	Chemotherapy alone	51(45.95)
	Radiation therapy alone	8(7.20)
	Chemotherapy and Radiation therapy	44 (39.64)
	Surgery alone	5(4.50)
	Palliative treatment	1 (0.90)
	Others	2(1.80)
Type of treating hospital	Government	72(64.86)
	Private	39(35.14)

Data are presented as mean ± standard deviation or number (percentage).

**Level of anxiety among the study participants**

Majority (82.89%) of the parents having a borderline anxiety scores, and 8.11 % of the parents have abnormal scores in the anxiety scale. The mean anxiety scores of the parents are 9.4±2.6.

**Table no 3:** Anxiety scores of the study participants

Score	Category	N (%)	Mean Score	Standard deviation
0-7	Normal	10 (9.00)	9.4	2.6
8-10	Borderline	92(82.89)		
11-21	Abnormal	9(8.11)		

Data are presented as number (percentage).

**Impact of childhood cancer on the parents**

The mean score of the impact of event scale among the parents of children with cancer is 37.3±12.6.

**Association between the demographic variables and level of anxiety**

The anxiety scores of the study participants have a significant association between the age employment status, and number of children (p=<0.01).

**Table no 4:** Association between the demographic variables and level of anxiety among study participants

Variable	Level of anxiety			Test result	P value
	Normal	Borderline	Abnormal		
<b>Age</b>					
≤30 years	2	72	5	$\chi^2=16.09$	< 0.01
>30 Years	8	20	4		
<b>Gender</b>					
Male	7	32	3	$\chi^2= 4.84$	0.08 (NS)
Female	3	60	6		
<b>Employment status</b>					
Employed	1	82	7	$\chi^2= 32.77$	< 0.01
Unemployed	9	10	2		
<b>Type of family</b>					
Nuclear	4	68	6	$\chi^2= 5.026$	0.08 (NS)
Extended	6	24	3		
<b>Number of children</b>					
One	1	36	5	$\chi^2= 12.49$	0.01
Two	3	41	2		
More than two	6	15	2		

<sup>a</sup> Chi-square tests.

**Association between the clinical variables of the child and parent’s anxiety**

The anxiety scores of the parents have a significant association with type of cancer and duration of illness of their children (p= < 0.05)

**Table no 5:** Association between the child’s clinical variables and level of anxiety among study participants

Variable	Level of anxiety of parents			Test result	P value
	Normal	Borderline	Abnormal		
<b>Age</b>					
≤10 years	6	48	5	$\chi^2=0.24$	0.88(NS)
>10 Years	4	44	4		
<b>Gender</b>					
Male	8	47	5	$\chi^2= 3.04$	0.21(NS)
Female	2	45	4		
<b>Type of cancer</b>					
Hematological malignancies	2	50	3	$\chi^2= 11.73$	0.01
CNS cancers	3	30	5		
Others	5	12	1		
<b>Duration of illness</b>					
≤ 2 weeks	3	65	6	$\chi^2= 6.70$	0.03
>2 weeks	7	27	3		
<b>Birth order</b>					
First	5	42	4	$\chi^2=0.07$	0.99(NS)
Second	3	30	3		
Third or more	2	20	2		
<b>Type of treatment</b>					
Chemotherapy	3	32	2	$\chi^2= 8.62$	0.19(NS)
Radiation	1	12	1		
Chemo& radiation	4	45	4		
Others	2	3	2		

<b>Type of treating hospital</b>					
Government	3	48	6	$\chi^2=2.69$	0.25(NS)
Private	7	44	3		

<sup>a</sup> Chi-square test NS- not significant

### Relationship between the parent’s anxiety level and impact of event score

There is a positive correlation between the anxiety scores of the parents and the impact of the event scores (  $r=0.80, p < 0.001$ ).

## IV. Discussion

In the present study, the investigators were reconnoitered the anxiety among the parents of children diagnosed with cancer and its impact on their life. According to the study results, the parents had a moderate level of anxiety and this level of anxiety has been increased their susceptibility towards post-traumatic stress disorder. The present findings brought out the evidence in suggesting that the childhood cancers will escalate the anxiety level among the parents and intensify the occurrence of post-traumatic stress disorder among them.

A study conducted by Shivayan Srivastava et al were reported that parents of children with cancer experienced moderate level of anxiety (56.4%)<sup>18</sup>, where as in the present study 82.89% of the parents have a borderline anxiety scores and 8.11% were reported an abnormal anxiety scores. The majority of the study participants have children with more than two weeks duration of illness from diagnosis. Alves et al were explored that the parents of children with cancer suffering with high level of anxiety if they have young children and short duration of illness<sup>19</sup>.

Van Warmerdam J was identified that the prevalence of post-traumatic stress disorder is more among the parents of children with cancer and it is in line with the findings of the present study. In the present study majority of the parents were susceptible to post traumatic stress disorder<sup>20</sup>. A study conducted among Lithuanian Parents by Irina Baniene was showed that the prevalence of post-traumatic stress symptoms is more among the parents caring cancer children<sup>21</sup>.

In the present study there is a positive correlation was noticed among the anxiety scores and impact of event scores of the parents of children with cancer. The results has showcased that when anxiety increases the vulnerability for post-traumatic stress disorder also increases among the parents. Pöder U et al. were reported that parents with higher acute stress scores showed an escalation in experiencing post-traumatic stress symptoms<sup>22</sup>. Fuemmeler, B. F etal. were reported that the parents with cancer children have an increased risk of experiencing symptoms of post-traumatic stress disorder<sup>23</sup>.

As mentioned earlier there is a significant relationship between the parent’s anxiety scores with employment status and number of children. In a study by Azad Rahmani et al. in Iran, there is a significant difference between the mean anxiety scores of the fathers and their job status<sup>24</sup>. In the present study there associations between the anxiety score among the parents with duration of child’s illness and type of cancer. The results showed that there is an upward trend has been seen among the anxiety score of the parents of children with recent diagnosis of cancer and the severity of the diagnosis. Nurse managed patient and family education clinics should be formulated in each intuition level to support the parents and family during the treatment and diagnosis. The nurse led clinics are the best solution to handle the psychological problems of children as well as their family<sup>25</sup>. The study finding highlighted the need for offering support services for the parents according to the child’s diagnosis and duration of illness.

### Implications

The findings of the present study uncovered the level of anxiety among the parents of children with cancers and its associated impact on their psychological life. The study has portrayed the need for support services for the parents during the time of diagnosis, treatment and survivorship phases. Most of the parents with cancer children are anxious about the outcome of the child’s diagnosis and they are vulnerable to post traumatic stress disorder. The nurses are the key person to associate with the parents during their crisis period and they can effectively recognize the problems of parents during the period of diagnosis and treatment. The study has implicated the need for a nurse led support group for the parents of children with cancer to alleviate their anxiety and reduce the susceptibility of post-traumatic stress symptoms among the parents.

### Limitations

The findings of the present study should be interpreted with caution, because study was conducted in the single region of India. Hence, the generalizability of the findings should be done with great care. Multicentric studies with enormous sample are necessary for more generalization of the study findings. In the present study the investigators were examined the anxiety and its impact level among the parents of children with cancer, unfortunately no other psychological constrains were assessed. Responder bias also likely happens in this study. Moreover, the major participants of this study were the mothers of children with cancer.

## V. Conclusion

The findings of the study revealed the apprehensions among the parents of children with diagnosis of cancer. Anxiety and the associated impact of that event will hamper the quality of life of the parents and make their life more miserable. The present study warrants the need for effective support interventions for the parents of children with the diagnosis of cancer in a multicentric perspective irrespective of the cancer type and treatment phase. However, the investigators suggest further studies with a larger sample size and a multicentric approach for the better generalization of the study results.

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