

Level of Anxiety and Depression and Its Clinical and Sociodemographic Determinants among the Parents of Children with Cancer Undergoing Chemotherapy

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Abstract

Objective The aim of this study was to find the level of anxiety and depression and its clinical and sociodemographic determinants among the parents of children with cancer on chemotherapy.

Materials and Methods Hamilton-A (HAM-A) and Hamilton-D (HAM-D) scales were used to assess anxiety and depression, respectively, in this cross-sectional study. The assessed parents were administered the questionnaire along with collection of socio-demographic and clinical data through a structured data collection proforma between August 2018 and November 2018.

Statistical Analysis The sociodemographic factors and the clinical characteristics were analyzed and have been expressed descriptively and associations between the sociodemographic characteristics, clinical characteristics of the children, and the calculated scores obtained from HAM-A and HAM-D scales were analyzed using chi-squared test. A *p*-value of <0.05 was considered statistically significant.

Results Out of 101 parents, 86 (85.14%) were found to have a mild, moderate, or severe depression score. Parents of children with solid tumors undergoing chemotherapy had higher frequency of severe and very severe depression. Majority of the parents (56.4%) assessed with HAM-A scale had mild level of anxiety that was significantly affected by the level of education.

Conclusion This study confirmed a very high frequency of depression and anxiety in the parents of children affected with cancer undergoing chemotherapy. Type of cancer (solid or hematological) was found to be a predictor of depression, while education level was found to be a predictor of anxiety in the parents.

Keywords

- ▶ cancer
- ▶ pediatric
- ▶ parents
- ▶ depression
- ▶ anxiety

Introduction

About 1.6 to 4.8% of all the cancers in India are diagnosed in children below 15 years of age with an overall incidence of 38 to 124 per million and the rate is increasing according to population-based cancer registry survey 2009 to 2011.^{1,2} Compared with population norms, the parents of children with cancer have reported worse psychosocial and physical quality of life in all psychological domains.³ These parents face the psychological effects of cancer indirectly in the form

of invasive, expensive, and long chemotherapy treatment given to their child that causes a large number of distressing and unavoidable side effects.⁴

Depression is one of the major causes of poor health and disability in the world and caring for a child with cancer has been associated with increased chances of development of depressive symptoms in parents that are clinically relevant.^{5,6} According to a study conducted by Ghufraan et al in Aga Khan University among mothers of pediatric cancer patients, 78% were found to be depressed.⁷ Parents of children who are

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newly diagnosed or on active cancer therapy report higher levels of anxiety than those of children who are off active cancer therapy.⁸ They also report significant deterioration of their own health due to worse diet and nutrition, decreased physical activity, and less time spent doing enjoyable activities.⁹ It has been found that the depression found in the patients is linked to the depression in their caregivers.¹⁰ Hence, there is a need to assess levels of anxiety and depression in the parents and find its associated factors to help plan appropriate interventions that may mitigate caregiver distress and possibly promote mental health in the children as well.

Parents of children with cancer have also reported levels of anxiety higher than that present in the cancer patients themselves.¹¹ All these evidences suggest that cancer is a disease that affects the entire family as opposed to only the child suffering from it.

Few studies have been done to find the association of various sociodemographic and clinical variables with the levels on anxiety and depression of parents with children undergoing chemotherapy, especially in India. No such study has been conducted in the population being studied to the best of our knowledge. Depression is one of the biggest hidden issues plaguing the society due to the stigma that comes associated with it. To bring to light the mental health being faced the parents, this study was conducted.

Materials and Methods

The cross-sectional study was conducted in the Department of Medical Oncology, Jawaharlal Nehru Institute of Medical Education and Research (JIPMER), Puducherry, at the Regional Cancer Centre (RCC) between August and November 2018. The inclusion criteria of the study included parents (21–50 years old) of children (0–18 years old) who had been receiving chemotherapy as the primary treatment for cancer at the RCC, JIPMER. The parents with prior clinical depression or psychiatric illness, with any significant family death in the past 6 months, and with chronic illnesses and malignancies were excluded from the study.

The study sample consisted of parents directly involved in the care of the child. They were invited to participate in the study when visiting the hospital along with their children for treatment or follow-up. The parents fulfilling the inclusion criteria were informed about the study, written consent was taken, and the validated Hamilton-A (HAM-A) and Hamilton-D (HAM-D) questionnaires in Tamil language (due to preponderance of Tamil-speaking patients at the center) were administered by a clinicosocial worker.

One-hundred eight of the 191 parents eligible for the study participated in it. Out of the 108 samples collected, 7 forms were disregarded from the study due to incomplete data or due to errors in collection of information. A total of 101 samples were considered.

Sociodemographic and Clinical Variables

Information on the age of the parents, economic status, education, occupation, distance of home from the treatment center, number of children in the family, gender, and age of

affected child is collected at the time of administration of the questionnaire through a structured data collection proforma. The clinical details of the case were obtained through the departmental case records.

HAM-A and HAM-D Scales

To assess the anxiety and depression, HAM-A and HAM-D scales were administered.

HAM-D is a questionnaire consisting of 17 items. It helps to assess depression by rating the severity of depression in terms of insomnia, somatic symptoms, mental retardation, weight loss, agitation, and feeling of guilt. It is designed for adults. There are eight questions that are scored from 0 to 4 0 being “not present” to 4 being “severe.” Nine are scored from 0 to 2.¹² The scoring is classified into different categories as follows: 0–7 = normal; 8–13 = mild depression; 14–18 = moderate depression; 19–22 = severe depression; more than 23 = very severe depression.

HAM-A is used to rate the severity of anxiety in a patient. It consists of 14 items. There are 14 questions containing several symptoms, and each symptom is rated on a scale ranging from 0 to 4 with 0 being “least severe” and 4 being “most severe.” All these scores help to calculate an overall score that indicates the severity of a person’s anxiety. There’s a total score range of 0 to 56, where <17 indicates mild severity, 18 to 24 indicates mild-to-moderate anxiety, and 25 to 30 indicates moderate-to-severe anxiety levels.¹³

Statistical Analysis

The data collected was analyzed using Stata Version 12. The sociodemographic variables and the clinical characteristics were analyzed and have been expressed descriptively in frequency and percentages. Associations between the sociodemographic characteristics, clinical characteristics of the children, and the calculated anxiety and depression scores obtained from HAM-A and HAM-D scales were analyzed using chi-squared test. A *p*-value of <0.05 was considered statistically significant.

Results and Discussion

A total of 108 people took part in this study. However, due to missing information and incomplete filling of the questionnaire, only 101 responses were considered. Out of the 101 parents, most (78.2%) were mothers. The median age of the parents participating in the study was 31 with a range of 23 years to 47 years. The distribution of the age is given in ►**Table 1**. Sixty-six (65.4%) of the parents were unemployed with all the unemployed mothers being homemakers by profession, while majority of the employed parents were self-employed as daily wage laborers. The median number of people living at homes of the parents was 4 with a range of 2 to 12. The median age of the children associated with the study was 4 years with a range of 1 to 18 years of age. This information is summarized in ►**Table 1**.

Out of the 101 parents studied, sixty-two (61.4%) had some form of suicidal tendencies. Eighty-seven (86.1%) parents reported insomnia present as difficulty in falling

Table 1 Sociodemographic characteristics of parents and children

Variables	n (101)	Percentage
Gender of parents		
Fathers	22	21.78
Mothers	79	78.22
Age distribution of parents		
21–30 y	49	48.51
31–40 y	38	35.64
>40 y	14	13.86
Education of parents		
No formal education	16	15.84
Primary/Secondary	51	50.50
Intermediate/Higher education	34	33.66
Occupation of parents		
Unemployed	66	65.35
Employed	35	34.65
Distance of home from cancer center		
<20 km	13	12.87
21–100 km	41	40.59
>101 km	47	46.53
Economic class of family		
Lower	81	80.20
Middle	12	11.88
Upper	8	7.92
Number of children in family		
1	23	22.77
2	50	49.50
>2	28	27.72
Gender distribution of children		
Male	62	62.6
Female	39	39.3
Age distribution of children		
0–4 y	35	34.6
5–9 y	29	28.7
10–14 y	28	27.7
15–19 y	9	8.9

asleep, waking during the night, or waking in early hours of the morning and difficulty in falling asleep again. Thirty-three (32.7%) parents reported somatic form of anxiety with gastrointestinal symptoms such as indigestion and cardiovascular symptoms such as palpitations, headaches, and respiratory symptoms.

Out of 101 children, sixty-five (64%) had been diagnosed with a hematological cancer, while thirty-six (35.6%) children had been diagnosed with a solid cancer. Most of the parents (46.53%) studied had children diagnosed more than 6 months ago from the date of assessment. The distribution of time since diagnosis and time since initiation of chemotherapy has been shown in ► **Table 2**.

Out of 101 parents assessed, eighty-six (85.14%) parents were found to be depressed. The mean HAM-D score was 14.88 that falls within the range of moderate depression (standard deviation [SD] = 6.63). Eighteen (17.82%) parents were mildly depressed with a score range of 8 to 13, thirty eight (37.62%) parents were moderately depressed with a score range of 14 to 18, eighteen (17.82%) parents were severely depressed with a score range of 19 to 22, and twelve (11.80%) parents were very severely depressed with a score of more than 23. For calculation of anxiety levels, the mean HAM-A score was 17.64 that falls within the range of moderate anxiety (SD = 10) with the majority (56.44%) of the parents having mild anxiety with a score of <17, 17 (16.83%)

Table 2 Clinical characteristics of pediatric cancer patients studied

Variables	n = 101	Percentage
Type of cancer		
Solid	36	35.64
Hematological	65	64.36
Time since diagnosis		
<1 mo	19	18.81
1–6 mo	33	32.67
>6 mo	49	48.52
Number of outpatient/inpatient visits in previous month		
0–5	54	53.47
6–10	34	33.66
>10	13	12.87
Time since initiation of chemotherapy		
<1 mo	26	25.74
1–6 mo	28	27.72
>6 mo	47	46.53

Table 3 Incidence and distribution of depression and anxiety by severity

Variables	n = 101	Percentage
Depression		
Present	86	85.14
Absent	15	14.85
Depression grade		
Absent	15	14.85
Mild/moderate	56	55.45
Severe/very severe	30	29.70
Anxiety grade		
Mild	57	56.44
Moderate	17	16.83
Severe	27	26.73
Anxiety		
Present	101	100
Absent	0	0

of the parents having moderate anxiety with a score range of 18 to 24, and twenty-seven (26.73%) of the parents having severe anxiety with a score range of more than or equal to 25. The above information is summarized in ►Table 3.

It was observed that the frequency of severe and very severe depression is seen more in parents of children diagnosed with solid cancer as compared with parents of children diagnosed with hematological cancer ($p = 0.04$). A significant p -value of 0.013 was also found in the association between the education of the parents and the level of anxiety seen in them. The frequency of severe anxiety was found to be more in the parents with lesser education

as compared with parents with higher level of education (►Tables 4 and 5).

Discussion

Parents of pediatric cancer patients are the main source of emotional support to them.¹⁴ Hence, it is essential to evaluate and assess their mental health to ensure proper care of the children. This study found the frequency of depression among the biological parents of pediatric cancer patients to be 85.14% that is significantly higher than prevalence of 15.4% found in the general population according to the largest population-based study in South India to determine the prevalence of depression done in Chennai among 26,001 subjects.¹⁵ A study conducted in Iran showed the depression rate in mothers of leukemia-diagnosed children to be 91%.¹⁶ Ghufuran et al conducted a study that showed the depression rate in mothers of cancer-diagnosed children to be 78% which is relatively lower than the depression rate found in this study.⁷ The study found that the majority of parents (69%) had mild level of depression, as opposed to this study in which majority of the parents (37.62%) had moderate level of depression. About 61.4% of the parents reported having some form of suicidal thoughts. They were referred to a clinical psychologist in the institute.

About 56.4% of the parents were found to have mild level of anxiety, 16.8% were found to have moderate level of anxiety, and 26.7% were found to have severe level of anxiety. According to a study conducted among male adults in India, the rate of mild anxiety was found to be 24.4% that is significantly lower than the rate found for the male parents in this study (54.5%).¹⁷ There were no significant differences between the levels of anxiety in mothers and fathers. A statistically significant association was found between the level of anxiety and the education level of the parents. The parents with lesser level of education were found to have higher frequency of severe anxiety when compared with parents with higher level of education. This could be possibly due to difficulties in understanding the disease in parents with no formal education. There were no other significant associations found. Prior literature with a significant association between education and anxiety in case of caregivers of cancer afflicted children could not be found. However, a separate study done on caregivers of mentally ill patients noted that caregivers with less education were found to have more anxiety as compared with the caregivers with primary and secondary levels of education.¹⁸

There are multiple factors responsible for the presence of high rates of depression among parents of pediatric cancer patients. A study conducted in 2015 by Halina Sklenarova found that more distress was present in parents with unmet information and healthcare needs and unmet psychological needs.¹⁹ Hence, the lack of information, uncertainty, and lack of access to proper psychological counselling might be important factors causing high depression levels in the parents. It is also due to the presence of low social support. Chemotherapy leads to a variety of side effects such as nausea, hair loss, and vomiting that have been described as the

Table 4 Associations between sociodemographic and clinical factors with level of depression

Variable	No depression		Mild/moderate depression		Severe/very severe depression		Total		p-Value
	Frequency	%	Frequency	%	Frequency	%	Frequency	%	
Gender of parents									p = 0.59
Male	2	13.3	12	21.5	8	26.6	22	21.7	
Female	13	86.7	44	78.5	22	73.4	79	78.3	
Age of parents									p = 0.84
21–30 y	7	46.6	29	51.7	13	43.3	49	48.5	
31–40 y	5	33.4	21	37.5	12	40.0	38	37.6	
>40 y	3	20.0	6	10.8	5	16.7	14	13.9	
Education of parents									p = 0.29
No education	1	6.7	11	19.6	4	13.3	16	15.8	
Primary/secondary	10	66.7	23	41.1	18	60.0	51	50.5	
Inter/higher	4	26.6	22	39.3	8	26.7	34	33.7	
Occupation of parents									p = 0.37
Unemployed	12	80.0	34	60.7	20	66.7	66	65.3	
Employed	3	20.0	22	39.3	10	33.3	35	34.7	
Economic class									p = 0.23
Lower	10	66.6	35	62.5	17	56.7	62	61.4	
Lower middle	3	20.0	6	10.7	10	33.3	19	18.8	
Middle	1	6.7	9	16.1	2	6.7	12	11.9	
Upper middle	0	0	4	7.1	1	3.3	5	4.9	
Upper	1	6.7	2	3.6	0	0	3	3.0	
Distance from cancer center									p = 0.42
<20 km	1	6.7	9	16.1	3	10.0	13	12.9	
21–100 km	9	60.0	19	33.9	13	43.3	41	40.6	
>100 km	5	33.3	28	50.0	14	46.7	47	46.5	
Number of children									p = 0.51
1	6	40.0	12	21.4	5	16.7	23	22.8	
2	6	40.0	28	50.0	16	53.3	50	49.5	
>2	3	20.0	16	28.6	9	30.0	28	27.7	
Age of children									p = 0.23
0–4	3	20.0	24	42.8	8	26.7	35	34.6	
5–9	4	26.7	13	23.2	12	40.0	29	28.8	
10–14	7	46.7	15	26.8	6	20.0	28	27.7	
15–19	1	6.6	4	7.2	4	13.3	9	8.9	
Children gender									p = 0.90
Male	10	66.7	34	60.7	18	60.0	62	61.4	
Female	5	33.3	22	39.3	12	40.0	39	38.6	
Time since diagnosis									p = 0.37
<1 mo	6	40.0	9	16.1	4	13.3	19	18.8	
1–3 mo	2	13.3	8	14.3	5	16.7	15	14.8	
3–6 mo	4	26.7	10	17.8	4	13.3	18	17.8	
6–12 mo	1	6.7	12	21.4	8	26.7	21	20.8	
>12 mo	2	13.3	17	30.4	9	30.0	28	27.8	

(Continued)

Table 4 (Continued)

Variable	No depression		Mild/moderate depression		Severe/very severe depression		Total		p-Value
	Frequency	%	Frequency	%	Frequency	%	Frequency	%	
Cancer type									p = 0.04
Hematological	12	80.0	39	69.7	14	46.7	65	64.4	
Solid	3	20.0	17	30.3	16	53.3	36	35.6	
Time since initiation of chemotherapy									p = 0.49
<1 mo	7	46.7	12	21.4	7	23.3	26	25.7	
1–3 mo	2	13.3	9	16.1	3	10.0	14	13.9	
3–6 mo	3	20.0	8	14.3	3	10.0	14	13.9	
6–12 mo	1	6.7	12	21.4	8	26.7	21	21.0	
>12 mo	2	13.3	15	26.8	9	30.0	26	25.5	
Number of visits									p = 0.06
0–5	5	33.3	34	60.7	15	50.0	54	50.5	
6–10	5	33.3	16	28.6	13	43.3	34	33.7	
>10	5	33.3	6	10.7	2	6.7	13	12.8	

side effects causing the most distress.²⁰ The presence of such side effects in their children might be a factor adding to the deterioration of mental health.

There were no associations found between the level of depression and the age of the parents, their education level, their employment status, the number of children in the family, and gender of the child in this study that was consistent to the findings of a study done in Iran among mothers of children with leukemia which also found no associations in these factors.¹⁶ However, there were associations found between the socioeconomic class of the family and the level of depression in that study which were absent in this study. The income data collected in this study was self-declared income by parents, majority of whom are employed as daily wage laborers with high variability in monthly income which could have led to erroneous reporting and could be a reason for the missing association. However, Erkan and Kaplan did not find a statistically meaningful difference when the level of depression was compared with respect to income level.²¹

A significant association was found between the form of cancer and the level of depression in the parents in this study. Parents with children diagnosed with solid cancer were found to have higher level of severe or very severe depression present when compared with parents of children diagnosed with hematological cancer. A similar result was found in a study conducted in Jordan which found that the parental distress was lower in children diagnosed with lymphoma (a hematological tumor) when compared with other diagnosis.²² This could be due to the fact the hematological tumors, even in advanced stages, are more curable than solid tumors. Solid tumors in advanced stages are associated with poor prognosis. The worse prognosis of solid tumors is one possible reason for the association found. A 10-year survival rate for patients with Wilms tumor, Ewing sarcoma, neuroblastoma, osteosarcoma, and

rhabdomyosarcoma was 76.6, 30.6, 54.4, 29.3, and 27.5%, respectively, for children diagnosed in the time period of 2000 to 2010, while the 10-year survival rate for ALL, the most common hematological cancer is as high as 85.5% in the time period of 2000 to 2010.^{23,24} Another reason for the lower frequency of severe and very severe levels of depression in case of hematological tumors could be intensive initial chemotherapy and intensive counseling immediately following the diagnosis that is not seen in case of solid tumors.

Conclusion

This study confirmed a very high frequency of depression and anxiety in the parents of children affected with cancer undergoing chemotherapy. Type of cancer (solid or hematological) was found to be a predictor of depression, while education level was found to be a predictor of anxiety in the parents.

Clinical Implications

It maybe concluded that screening for depression and anxiety followed by early therapeutic interventions by psychologists and psychiatrists in the form of counseling and other clinically relevant methods can help to improve the mental health of the parents and ensure better care of affected children. A further, well designed study with a larger sample size is required to find more clinically relevant associations between the level of anxiety and depression and the sociodemographic and clinical factors.

Study Limitations

This study included patients with different types and stages of cancer. Sample size was not sufficient for association

Table 5 Associations between sociodemographic and clinical factors with level of anxiety

Variable	Mild anxiety		Moderate anxiety		Severe anxiety		Total		p-Value
	Frequency	%	Frequency	%	Frequency	%	Frequency	%	
Gender of parents									p = 0.68
Male	12	21.0	5	29.4	5	18.5	22	21.8	
Female	45	79.0	12	70.6	22	81.5	79	78.2	
Age of parents									p = 0.96
21–30	28	49.1	8	47.0	13	48.2	49	48.5	
31–40	20	35.1	7	41.2	11	40.7	38	37.6	
>40	9	15.8	2	11.8	3	11.1	14	13.9	
Education of parents									p = 0.01
No education	5	8.8	5	29.4	6	22.2	16	15.8	
Primary/secondary	27	47.4	6	35.3	18	66.7	51	50.5	
Inter/higher	25	43.8	6	35.3	3	11.1	34	33.7	
Occupation									p = 0.51
Employed	36	63.2	10	58.8	20	74.1	66	65.4	
Unemployed	21	36.8	7	41.2	7	25.9	35	34.6	
Socioeconomic class									p = 0.51
Lower	33	57.9	10	58.8	19	70.4	62	61.5	
Lower middle	10	17.5	3	17.6	6	22.2	19	18.8	
Middle	9	15.8	2	11.8	1	3.7	12	11.9	
Upper middle	2	3.5	2	11.8	1	3.7	5	2.9	
Upper	3	5.3	0	0	0	0	3	2.9	
Distance from cancer center									p = 0.99
0–20 km	8	14.0	2	11.8	3	11.1	13	12.9	
21–100 km	23	40.4	7	41.2	11	40.7	41	40.6	
>100 km	26	45.6	8	47.0	13	48.2	47	46.5	
Number of children									p = 0.53
1	16	28.1	2	11.8	5	18.6	23	22.7	
2	25	43.8	11	64.7	14	51.8	50	49.5	
>2	16	28.1	4	23.5	8	29.6	28	27.8	
Age of children									p = 0.29
0–4	22	38.6	6	35.4	7	26.0	35	34.6	
5–9	17	29.8	3	17.6	9	33.3	29	28.7	
10–14	15	26.3	4	23.5	9	33.3	28	27.8	
15–19	3	5.3	4	23.5	2	7.4	9	8.9	
Time since diagnosis									p = 0.51
<1 mo	11	19.3	3	17.6	5	18.6	19	18.8	
1–3 mo	7	12.3	4	23.5	4	14.8	15	14.8	
3–6 mo	11	19.3	3	17.6	4	14.8	18	17.8	
6–12 mo	8	14.0	5	29.5	8	29.6	21	20.8	
>12 mo	20	35.1	2	11.8	6	22.2	28	27.8	
Cancer type									p = 0.82
Hematological	38	66.7	10	58.8	17	63.0	65	64.4	
Solid	19	33.3	7	41.2	10	37.0	36	35.6	

(Continued)

Table 5 (Continued)

Variable	Mild anxiety		Moderate anxiety		Severe anxiety		Total		p-Value
	Frequency	%	Frequency	%	Frequency	%	Frequency	%	
Time since initiation of chemotherapy									p = 0.52
<1 mo	14	24.6	4	23.5	8	29.6	26	25.7	
1–3 mo	6	10.5	4	23.5	4	14.8	14	13.9	
3–6 mo	10	17.5	2	11.8	2	7.5	14	13.9	
6–12 mo	9	15.8	5	29.4	7	25.9	21	20.8	
>12 mo	18	31.6	2	11.8	6	22.2	26	25.7	
Number of visits									p = 0.43
0–5	17	29.8	5	29.4	13	48.2	35	34.6	
6–10	20	35.1	5	29.4	5	18.5	30	29.7	
>10	20	35.1	7	41.2	9	33.3	28	27.7	

studies. The factors identified are exploratory and need to be confirmed in larger subsets.

Ethical Approval

The study was conducted according to the Helsinki Declaration. Ethical approval was obtained from the institute ethical committee. Number—JIP/IEC/2018/190. This project was performed under ICMR-STs 2018.

Conflict of Interest

None declared.

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