



PARENTAL DISTRESS AND IT'S CONTRIBUTING FACTORS AMONG MOTHERS OF CHILDREN WITH LEUKAEMIA.

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ABSTRACT

Background: Leukemia is a cancer of the body's blood - forming tissues, including the bone marrow and the lymphatic system. Caring for a child with leukemia(cancer) necessitates heavy parental involvement, with caregivers having to take their child for frequent appointments, administer medications, and provide emotional support through painful procedures. Alongside trauma and worry elicited by their child's diagnosis, it is unsurprising that a significant proportion of parents of paediatrics cancer patients experience heightened psychological distress during their child's cancer diagnosis and treatment. **Objective:** To assess the parental distress and it's contributing factors among mothers of children with leukaemia. **Materials and Methods:** In a quantitative descriptive correlational study, mothers of children with leukaemia were recruited via convenience sampling during their child's inpatient admission or outpatient appointment. They were asked to complete a self-administered demographic survey, distress thermometer for parents (DT-P), and questionnaire to assess contributing factors. **Results:** Among 100 mothers 32% had mild stress,60% had moderate stress and 8% had severe stress. The cognitive domain of caregiving problems on the DT-P was found to correlate with distress. Parents most frequently reported cognitive problems (77%) and, least often, social problems (17.4%). **Conclusion:** Notable levels of distress and proportions of distressed parents highlighted the heavy burden of caregiving. This may also be attributed to the differences in caregiving challenges. The psychological effects of parental caregiving highlight the need for supportive measures for pediatric cancer caregivers.

KEYWORDS: Leukaemia, Cancer, caregivers, child, pediatrics, parents, psychological distress.

INTRODUCTION

Leukaemia is the most common cancer diagnosed in children and adolescents younger than 20 years and accounts for all 25.1% of all cancer in the age group. It is the second leading cause of cancer death among children and adolescents younger than 20 years. This accounts for 26.1% of all cancer - related deaths among the age group (AML). The Prevalence rate of Leukemia in most populations in the world ranges from 75 to 150 million children per year. However, the reported rate of standardized incidence rate in India ranges from 38 to 124 million children per year. In India, the highest incidence is reported in Chennai, and the lowest in rural Ahmedabad.

The incidence from urban areas like Bangalore, Bhopal, Chennai, Delhi, and Mumbai is generally higher than from rural area like Bashir and Ahmedabad districts and

are more comparable with the average world incidence. Leukemia is the most common childhood cancer in India with a relative proportion varying between 25 to 40%, and 60 to 85% of all Leukemias. Within a population of 882 million, 6000 children will develop acute lymphoblastic leukemia each year in India. Acute lymphoblastic leukemia is the most form in children and represents 78% of cases of leukemia. All reaches its greatest frequency in children between 2 and 6 with a peak of more than 80 cases per million children per year at the age 3- 4, rates then decline to age 20.

Caring for a child with cancer can be profoundly distressing to parents and in turn, parental psychological distress (PD) can affect the child and sibling's wellbeing. Caring for a child with advanced cancer is likely to be even more distressing, yet very few prospective studies have evaluated parental distress among these families.

Not only do parents witness their child's protracted physical and emotional suffering they also must contend with the ultimate threat to their child's life¹⁵, which is heightened among children with more advanced stages of the disease. Prolonged changes in employment and financial challenges may also exacerbate parental distress.

³Our study aimed to explore the levels of psychological distress and the contributing factors among parents of children with cancer, findings of which would arm health-care professionals with crucial knowledge about specific family needs. This may in turn enable them to provide referrals to the appropriate support systems, as well as aid in the early identification of parents who may be at risk for distress. Similarly, the results could shed insights on whether the current efforts to support caregivers are sufficient, and propose consequent areas for improvement.

MATERIALS AND METHODS

A descriptive correlational method was used in our study. The study was conducted among 100 mothers of children diagnosed with Leukaemia. The Sampling technique used for the study was convenience sampling.

Sample selection criteria. Inclusion Criteria

- ✓ Parents between the age group of 20-55 years.
- ✓ Parents with children in the age group 0-18 years undergoing treatment for Leukaemia.

Data Collection Instruments.

TOOL 1: Socio- Demographic Data.

Self-developed Semi - structured questionnaire to assess

the socio - demographic variable. It consists of the age of the mother, marital status, type of family, educational status, occupation of father and mother, and the number of children in the family. It also includes details of the child such as the age of the child, gender of the child, birth order, type of leukaemia, duration of diagnosis and treatment, and family history of leukaemia.

TOOL 2: Modified Distress Thermometer for Parents (DT-P). It is the thermometer used to assess the distress in mothers. The mother is instructed to mark in the thermometer provided which has a scoring of 0-10 (0-no distress; 1-3 mild distress; 4-6 moderate distress 7-10 severe distress).

TOOL 3: It is a self-administered questionnaire that contains contributing factors. It contains six problems (physical, social, emotional, cognitive, practical, and parenting) potentially contributing to their distress. The items are scored dichotomously (yes or no), based on whether parents deemed them as problematic.

Ethical Clearance

Ethical clearance was obtained from the Institutional Ethical and Scientific Review Committee. Permission was taken from the Head of the Department, Paediatrics of the tertiary care hospital. Informed written consent was obtained from each subject before data collection.

Data Collection Procedure and Data Analysis.

A pilot study was conducted among ten subjects according to the sample selection criteria to find out the feasibility of the study, after which the data collection for the main study was done. The subjects took around 20-30 minutes to complete the questionnaire. The data analysis was done using SPSS version 20.

RESULTS

Table 1: Frequency and percentage distribution of mothers based on the socio-demographic variables.

Table I. Shows that the majority of mothers (66%) belong to the age group of > 40. 96% of the mothers are married and 51% of them are from nuclear families. 24% of the subjects are graduates. Most of the subjects have private jobs.

SL. No	Demographic Variable	Frequency (f)	Percentage (%)
1.	Age of mother		
	• 20 – 30	14	14.0
	• 31- 40	20	20.0
	• >40	66	66.0
2.	Marital status		
	• Married	96	96.0
	• Divorced	4	4.0
3.	Type of family		
	• Nuclear	51	51.0
	• Joint	44	44.0
	• Extended	5	5.0
4.	Educational status		
	• Primary	13	13.0
	• Secondary	31	31.0
	• Higher secondary	24	24.0
	• Graduate	24	24.0
		8	8.0

	<ul style="list-style-type: none"> • Post graduate 		
5.	Occupation of mother		
	<ul style="list-style-type: none"> • Government job 	13	13.0
	<ul style="list-style-type: none"> • Private job 	36	36.0
	<ul style="list-style-type: none"> • Daily wages 	16	16.0
	<ul style="list-style-type: none"> • Unemployed 	33	33.0
	<ul style="list-style-type: none"> • Self employed 	2	2.0

(n=100)

Table 2: Distribution of children with leukaemia based on sociodemographic characteristics and clinical data.

SL.No	Sociodemographic Variables	Frequency (f)	Percentage (%)	
1	Gender of the child			
	<ul style="list-style-type: none"> • Male • Female 	42 58	42.0 58.0	
2	Birth order of the child			
	<ul style="list-style-type: none"> • First • Second • Third 	17 56 27	17.0 56.0 27.0	
	Diagnosis- Type of leukaemia			
3.	<ul style="list-style-type: none"> • AML • ALL 	7 93	7.0 93.0	
	Duration since treatment			
4.	<ul style="list-style-type: none"> • Less than one year • 1-2 years • 2-3 years • 3-4 years 	18 49 29 4	18.0 49.0 29.0 4.0	
	Duration since diagnosis			
	5	<ul style="list-style-type: none"> • Less than one year • 1-2 years • 2-3 year • Above 3 years 	20 47 28 5	20.0 47.0 28.0 5.0
		Family History		
6		<ul style="list-style-type: none"> • Yes • No 	1 99	1.0 99.0
		History of any other cancer		
7	<ul style="list-style-type: none"> • Yes • No 	1 99	1.0 99.0	

The above table shows that majority of the children with leukaemia were female (52%). Most of the children (47%) were suffering from leukaemia over the past 1-2 years. Majority of the children (49%) were taking treatment for the past 1-2 years. In this, about 7% of the children were having Acute Myeloid Leukaemia and 93% were having Acute Lymphoblastic Leukaemia. In addition, 1% has a family history of cancer.

Table 3: Frequency and Percentage distribution of parents based on Parenteral Distress score. (n=100)

SL. No	DT-P THERMOMETER SCORE	Frequency (f)	Percentage (p)	Mean	Standard Deviation
1	No Distress	0	0	5.09	2.78
2	Mild Distress	32	32		
3	Moderate Distress	60	60		
4	Severe Distress	8	8		

Table 3: Shows that the mean DT-P thermometer score of parents was 5.09 (standard deviation [SD] = 2.78, range = 0–10). Among 100 mothers 32% had mild stress, 60% had moderate stress and 8% had severe stress.

Table 4: Frequency and Percentage distribution of the sample based on care giving problems.

SL. No	Contributing Factors	Frequency (f)	Percentage (p)	Mean	Standard deviation
1	Emotional problems (9 items)	64	64	2.49	2.17
2	cognitive problems (2 items)	77	77	0.72	0.870
3	Family problems (4 items)	46	46	1.51	1.60
4	Physical problems (7 items)	47	47	1.62	1.64
5.	Practical problems (6items)	42	42	2.07	1.79
6	Social problems	17.4	17.4	0.61	1.64

The above table shows that Parents most frequently reported cognitive problems ($n = 77$), and the least often social problems ($n = 17.4$).

Table 5: Association between contributing factors and parental distress. (n=100)

Contributing Factors	No Distress	Mild Distress	Moderate Distress	Severe Distress	X ²	P
Emotional Problems						
• Yes		26	42	6	10.869	0.001*
• No		6	18	2		
Cognitive Problem						
• Yes		24	48	7	10.556	0.001
• No		8	12	1		
Family Problem						
• Yes		25	41	5	3.829	0.050
• No		7	19	3		
Physical Problem						
• Yes		20	33	5	5.617	0.026
• No		12	27	3		
Practical Problems						
• Yes		26	24	2	4.231	0.040*
• No		6	36	6		
Social Problems						
• Yes		22	33	3	3.123	0.170
• No		10	27	5		

Table 5 shows that the practical ($P = 0.040$), emotional ($P = 0.001$), physical ($P = 0.026$), and cognitive problems ($P = 0.001$) from the DT-P caregiving problem list were significantly associated with distress.

Table 6: Association between parental distress, and selected socio- demographic variable

Table 6 shows that there is no significant relationship between parenteral distress and sociodemographic variable

SL. No	Demographic variable	Distress								X ²	P value
		No Distress		Mild Distress		Moderate Distress		Severe Distress			
		(f)	(%)	(f)	(%)	(f)	(%)	(f)	(%)		
1	Age of mother									2.222	0.068
	•20-30yrs			5	5	9	9				
	•31-40yrs			2	2	14	14	4	4		
	41-50yrs			25	25	37	37	4	4		
2	Marital status									3.588	3.102
	•Married			32	32	58	58	6	6		
	•Divorced					2	2	2	2		
	Single parent										
3	Type of family									3.526	0.092
	•Joint			20	20	28	28	3	3		
	•Nuclear			10	10	30	32	4	4		
	•Extended			2	2	2	2	1	1		
4	Educational status										
	Primary			4	4	6	6	3	3		

	Secondary			9	9	20	20	2	2	16.223	1.764
	Higher secondary			4	4	18	18	2	2		
	Graduate			2	2	20	20	2	2		
	Post graduate			1	1	6	6	1	1		
5	Occupation of mother									6.461	0.140
	•Government job			4	4	8	8	1	1		
	•Private job			9	9	23	23	4	4		
	•Daily wages			5	5	10	10	1	1		
	•Unemployed			14	14	17	17	2	2		
	•Self employed					2	2				

DISCUSSION

Parental distress was notably elevated, with the mean distress thermometer score in this study falling above the DT-P cutoff for distress. This was found to be comparable to the results of other studies which utilized the same tool. In Pierce *et al.*'s research, participants from the USA had an average DT-P mean score of 4.9 (SD 2.70). Schepers *et al.* also found higher distress among parental caregivers of pediatric cancer patients than parents of healthy children, in the Netherlands. This may suggest that pediatric cancer caregiving is a universally distressing experience for parents of children with cancer regardless of the cultural context.

Out of six problem lists in the DT-P, only the category of cognitive problem was found to predict distress. The above result could be attributed to the fact that over half of the caregivers were older adults (aged 40 and above), who tend to report difficulties in concentration and memory more frequently than their younger counterparts as a consequence of aging. This is further supported by a study by Xin Wei Isabel Tan *et al.*, which reported that participants faced significantly greater concentration and memory problems on the DT-P as compared to parents of healthy children, highlighting the relationship between the pediatric cancer caregiving burden and cognitive problems for parents of children with cancer.

Previous studies have drawn associations between parental distress and parent-child demographic, medical, and psychosocial factors. However, in our study, none of the caregivers' characteristics were linked with distress, including their utilization of social services. This result may suggest that parents in our study were not distressed by the people or situation surrounding them. Rather, it was having to personally cope with the mental and cognitive strain of caregiving, which remained in spite of external circumstances and supportive measures that contributed to their distress.

CONCLUSION

The present research underscores the substantial burden of pediatric cancer caregiving. Supporting caregivers in their psychological adjustment to their child's disease is consequently emphasized as an imperative cornerstone of providing quality care and improving treatment outcomes for pediatric cancer patients.

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