

CAREGIVER'S BURDEN AND MEASUREMENT OF RESILIENCE AMONG THE CAREGIVERS OF CHILDREN SUFFERING FROM HAEMATOLOGICAL MALIGNANCIES

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Abstract

Background: Caregivers' burden is the physical, economic, social, and psychological exhaustion experienced by sick individuals and is a significant predictor of negative outcomes in home care situations. Understanding the current situation is crucial for designing health promotion programs and prioritising knowledge of parental caregiver burden in children's oncology research. This study aimed to determine the burden on caregivers of children diagnosed with haematological malignancies and measure their level of resilience. **Materials and Methods:** This cross-sectional study included 200 children with haematological malignancies who provided consent for the study and met up in the Department of Hemato Oncology, Institute of Child Health and Hospital for Children, Chennai, from September 2021 to July 2022. The scale of the questionnaire was applied to both the primary caregiver (mostly the mother) and another close relative (father or grandparents). The questionnaire was framed based on the Caregivers' Difficulty Rating Scale (CDRS). **Result:** Caregivers aged over 40, single, less educated, low-income, and unemployed faced a higher burden due to physical exhaustion, health concerns, and uncertainty about their children's future. The most affected children were born second, and caregivers from different districts and states experienced a higher burden. The parents of children with AML, frequent hospital visits, and fearful parents experience a higher burden. There was a significant negative moderate correlation between resilience and burden scores. Resilience increased as the burden score decreased. **Conclusion:** This study concluded that there is a significant burden experienced by parents of children with haematological malignancies. Most of them suffer from two or more physical, psychological, economic, and social burdens.

INTRODUCTION

Caregivers of sick individuals experience a significant burden encompassing physical, economic, social, and psychological aspects.^[1] This burden can negatively impact their well-being and family dynamics. Resilience, on the other hand, refers to the ability to adapt positively despite challenges to physical and mental health.^[2] It involves developing skills to overcome the negative effects of diseases like cancer.

The World Health Organization (WHO) reports a rising incidence of childhood cancer globally, including developing countries like India.^[3] According to the Population-Based Cancer Registry (PBCR) report, childhood cancer accounts for 0.7-4.4% of total cancer diagnoses in India.^[3] Leukemia

is the most common type, with Acute Lymphoblastic Leukaemia (ALL) being the most prevalent.^[4,5]

Cancer diagnosis disrupts the lives of both children and families. Aggressive treatment regimens and constant care needs place a significant burden on parents at physical, psychological, socioeconomic, and behavioral levels.^[6] This burden can lead to vulnerability, decreased quality of life, emotional instability, and tension within families.^[6,7]

Caregiver burden is a concept based on the Transactional Model (TM), which emphasizes the subjective evaluation of stress.^[8] This model suggests that caregivers appraise their stressors and resources to manage stressful situations. High burden often leads to dysfunctional coping strategies.^[8] The balance between burden and resources determines the consequences of caregiving.

While survival rates for childhood cancer have improved, this progress comes with challenges. Long hospital stays, high expenses, and psychological problems in patients and families are growing concerns.^[9,10] Understanding parental burden is crucial for designing support programs for families. Research shows that parents of children with cancer often experience distress, but some also exhibit remarkable resilience.^[11] Resilience allows individuals to adapt to adversity and research explores why some parents don't develop stress disorders. Studies suggest a link between higher resilience and better quality of life in parents.^[12] Kumpfer's resilience framework proposes that internal factors like cognitive, spiritual, emotional, and behavioral aspects contribute to resilience.^[13] Limited research exists on how parents can utilize these internal strengths during their child's cancer journey. A deeper understanding is crucial for developing interventions to boost parental resilience and improve coping mechanisms. The specific needs of caregivers differ depending on the illness. Therefore, focused assessment tools are needed to accurately measure burden and resilience in caregivers of children with cancer.

Aim

This study aimed to determine the burden on caregivers of children diagnosed with haematological malignancies and measure their level of resilience.

MATERIALS AND METHODS

This cross-sectional study was conducted on 200 children with haematological malignancies who provided consent for the study and met up in the Department of Hemato Oncology, Institute of Child Health and Hospital for Children, Chennai, from September 2021 to July 2022. The study was approved by the institutional ethics committee before initiation, and informed consent was obtained from all patients.

Inclusion Criteria

Caregivers of children with newly diagnosed leukaemia who had completed the induction and consolidation phases of chemotherapy and stage III and above Hodgkin's lymphoma after completion of two cycles of chemotherapy were included.

Exclusion Criteria

Families with close relatives with chronic illnesses were excluded.

The caregivers of all children with haematological malignancies who provided consent for the study were asked to complete a semi-structured questionnaire. The questionnaire was written in the native language (Tamil). If the caregiver had another native language or was illiterate, the principal investigator, along with a translator, aided in filling up the questionnaire.

The scale of the questionnaire was applied to both the primary caregiver (mostly the mother) and another close relative (father or grandparents). A total of 200

primary and 200 secondary caregivers consented to participate in the study and completed the questionnaire. The questionnaire was framed based on the Caregivers' Difficulty Rating Scale (CDRS). The principal investigator assessed the level of burden using the Zarit Caregiver Burden Interview (ZBI) scale, and measured the level of resilience using the Connor and Davidson 25-point resilience scale (CD-RISC 25). The level of burden on primary and secondary caregivers and the subsequent effects on resilience were measured. The major causes of this burden were assessed.

Statistical Analysis: The burden and resilience scores between primary and secondary caregivers were analysed using a chi-square test. Quantitative differences between primary and secondary caregivers were calculated using an independent t-test. The association between the level of the score and demographic variables was assessed using the chi-square test. The correlation between burden and resilience scores was calculated using the Karl Pearson correlation coefficient method. Statistical significance was set at $p < 0.05$. All statistical tests were two tailed. Statistical analysis was performed using the Statistical Package for Social Sciences (SPSS, version 22).

RESULTS

Primary attender's data analysis

Caregivers aged > 40 years perceive more burden, probably due in part to their physical exhaustion and health concerns. Single caregivers experienced a greater burden. This is explained by the need to look after all the needs of the family in a single person [Table 1].

Providers with less education had a higher burden. Caregivers from low-income families perceive a more severe burden. Employment status plays an important role in family income. Thus, caregivers who are on leave without pay and have abandoned their work perceive a higher burden. Uncertainty about the future, added to the uncertainty of their child, contributes to this increased burden.

The most affected children were born second. Caregivers with first-born children have a higher burden. Approximately 44% of caregivers were from districts other than Chennai. They also experienced a higher burden. 21% of caregivers were from states other than Tamil Nadu. Among them, about 67% had their homes shifted to Chennai due to their children's illness and treatment [Table 2].

The parents of children diagnosed with AML have a more severe burden. This may be explained by the more severe AML course. Parents of children diagnosed with malignancy for more than a year have a higher burden. Their parents must live with mental agony for a longer period. Parents of children who visit the hospital frequently have a higher burden. Parents of children who had a longer hospital stay had a higher burden.

Parents who never allowed their children to play outdoors, who always wanted their children to be involved in indoor activities, and those who did not allow their children to go to school had a more severe burden. However, this was completely explainable. All of these answers reflected their mental burden [Table 3].

Those who must spend more than Rs.5000 per hospital visit, those who have a debt of more than Rs.50000 and those who sell their property have a more severe burden. Characteristics such as the amount of debt, expenditure for one visit, and part of savings spent for treatment all have a very significant p-value. Burden severity is higher with parents who reported chemo port insertion as a fearful procedure [Table 4].

There was a significant negative moderate correlation between resilience and burden scores. Resilience increased as burden score decreased [Table 5].

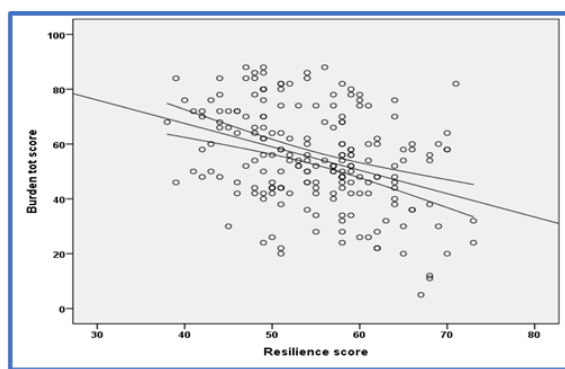


Figure 1: Scatter diagram of burden score and resilience score of primary attendees

The scatter diagram with regression estimates shows a significant, fair, negative correlation coefficient

($r=-0.44$, $p \leq 0.001$) between the resilience score and burden score [Figure 1].

Secondary attender's data analysis: As can be inferred from the above table, most of the secondary caregivers are in the age group of 30-40 years. Of the secondary caregivers, 69.5% were males, and 30.5% were females. This is in contrast to primary caregivers, all of whom were females. This may be attributed to the fact that, in our institution, only female caregivers are allowed as primary caregivers. The secondary caregivers' level of burden score was as follows: 22.50% had no burden score, 37.50% had a mild burden score, 27.50% had a moderate burden score, and 12.50% had a severe burden score. Less educated, manual labourers, caregivers with permanent jobs, and caregivers who continue to work have higher burden scores [Table 6].

There was a significant negative moderate correlation between the resilience score, increased burden score, and decreased burden score [Table 7].

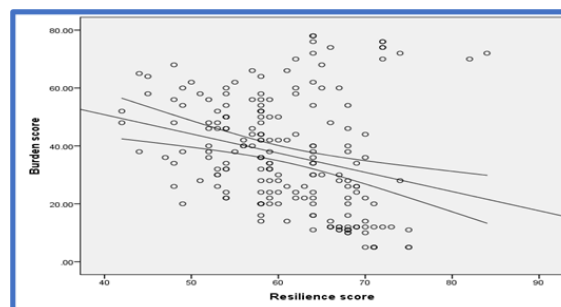


Figure 2: Scatter diagram of burden score and resilience score of secondary attendees

The scatter diagram with regression estimates shows a significant, fair, negative correlation coefficient ($r=-0.34$, $p \leq 0.001$) between the resilience score and burden score [Figure 2].

Table 1: Association between burden score and demographic variables

		Burden			P value
		Mild burden	Moderate burden	Severe burden	
Age	20-30 years	9(29.03%)	15(48.39%)	7(22.58%)	0.05
	30-40 years	24(18.46%)	64(49.23%)	42(32.31%)	
	>40 years	3(7.69%)	16(41.03%)	20(51.28%)	
Gender	Male	36(18%)	95(47.50%)	69(34.50%)	1
	Female	0(0%)	0(0%)	0(0%)	
Marital status	With spouse	27(16.67%)	84(51.85%)	51(31.48%)	0.001
	Spouse died	0(0%)	2(20%)	8(80%)	
	Separated	9(32.14%)	9(32.14%)	10(35.71%)	

Table 2: Association between burden score and education, monthly income, and place of residence

		Burden score			P value
		Mild burden	Moderate burden	Severe burden	
Education	Middle school	0(0%)	45(54.22%)	38 (45.78%)	0.001
	High school	35(36.84%)	32(33.68%)	28(29.47%)	
	Graduate	1(4.55%)	18(81.82%)	3(13.64%)	
Profession	Manual labourer	5(16.13%)	16(51.61%)	10(32.26%)	0.17
	Skilled/Professional	21(29.58%)	34(47.89%)	20(36.62%)	
	Unemployed	10(11.36%)	45(51.14%)	(37.50%)	
Monthly income	Less than 10000	4(25.00%)	2(12.50%)	10(62.50%)	0.03
	10000-20000	17(16.67%)	50(49.02%)	35(34.31%)	
	20000-30000	15(18.29%)	43(52.44%)	24(29.27%)	
Type of job	Permanent	10(21.74%)	27(58.70%)	9(19.57%)	0.2
	Temporary	16(28.57%)	23(41.07%)	17(30.36%)	

Condition of job	On leave with pay	1(8.33%)	11(91.67%)	0(0.00%)	0.02
	Leave without pay	19(25.68%)	33(44.59%)	22(29.73%)	
	Left the job	6(37.50%)	6(37.50%)	4(25.00%)	
Order of birth	First	8(13.56%)	30(50.85%)	21(35.59%)	0.75
	Second	18(19.35%)	41(44.09%)	34(36.56%)	
	Three or more	10(20.83%)	24(50.00%)	14(3.57%)	
Address	Chennai	18(26.09%)	37(53.62%)	14(20.29%)	0.001
	Outside Chennai but in Tamilnadu	10(11.36%)	33(37.50%)	45(51.14%)	
	Other than Tamilnadu	8(18.60%)	25(58.14%)	10(23.26%)	
Reason for address change	For the child	12(13.48%)	37(41.57%)	40(44.94%)	1
	Any other	0(0%)	0(0.00%)	0(0.00%)	

Table 3: Association between burden score and diagnosis of children, duration of treatment and daily activities of children

		Burden score			P value
		Mild burden	Moderate burden	Severe burden	
Diagnosis	All	38(20.9%)	74(40.8%)	69(38.10%)	0.001
	AML	3(6.25%)	31(29.1%)	14(29.16%)	
	Others	4(36.36%)	6(54.54%)	1(9.09%)	
No. of blood transfusions	< 5	16(15.5%)	56(54.36%)	31(30.09%)	0.65
	> 5	16(16.49%)	44(45.36%)	37(38.14%)	
Duration of treatment	3-6 months	6(31.58%)	9(47.37%)	4(21.05%)	0.001
	6months to 1year	27(40.30%)	33(49.25%)	7(10.45%)	
	>1 years	3(2.63%)	53(46.49%)	58(50.88%)	
Hospital visit	Less than once	27(20.30%)	70(52.63%)	36(27.07%)	0.01
	1-5 times	9(13.43%)	25(37.31%)	33(49.25%)	
Hospital stays	Less than 10days	24(58.54%)	16(39.02%)	1(2.44%)	0.001
	10-25 days	11(11.70%)	53(56.38%)	30(31.91%)	
	25-75 days	1(1.54%)	26(40.00%)	38(58.46%)	
Sick frequency	Less than or once a week	4(4.12%)	62(63.92%)	31(31.96%)	0.001
	Once a month	6(46.15%)	3(23.08%)	4(30.77%)	
	Twice or more than twice a month	26(28.89%)	30(33.33%)	34(37.78%)	
Playing outdoor	Sometimes	26(32.50%)	24(30.00%)	30(37.50%)	0.001
	Rarely	9(11.39%)	39(49.37%)	31(39.24%)	
	Never	1(2.44%)	32(78.05%)	8(19.51%)	
Want to do	Play outdoors	24(54.55%)	11(25.00%)	9(20.45%)	0.001
	Play indoors	11(8.40%)	66(50.38%)	54(41.22%)	
	Not play	1(4.00%)	18(72.00%)	6(24.00%)	
Thought on attending school	Very happy	33(30.28%)	36(33.03%)	40(36.70%)	0.001
	Fearful	3(6.98%)	38(88.37%)	2(4.65%)	
	Won't allow to school	0(0.00%)	21(43.75%)	27(56.25%)	

Table 4: Association between burden score and financial status and fearful procedure

		Burden score			P value
		Mild burden	Moderate burden	Severe burden	
Expenditure	Less than 2500	12(31.58%)	18(47.37%)	8(21.05%)	0.01
	2500-5000	22(19.13%)	52(45.22%)	41(35.65%)	
	More than 5000	2(4.26%)	25(53.19%)	20(42.55%)	
Major expenditure	Transport	17(11.41%)	83(55.70%)	49(32.89%)	0.001
	Food/others	19(37.25%)	12(23.53%)	20(39.22%)	
Amount from saving	All	1(2.70%)	21(56.76%)	15(40.54%)	0.001
	More than half	15(13.04%)	55(47.83%)	45(39.13%)	
	A little	20(42.55%)	18(38.30%)	9(19.15%)	
In debt	Yes	10(8.77%)	47(41.23%)	57(50.00%)	0.001
	No	26(30.23%)	48(55.81%)	12(13.95%)	
How much	Less than 40000	10(23.26%)	19(44.19%)	14(32.56%)	0.001
	40000-50000	0(0.00%)	13(76.47%)	4(23.53%)	
	More than 50000	0(0.00%)	15(27.78%)	39(72.22%)	
Sold Property	Yes	11(20.37%)	28(51.85%)	15(27.78%)	0.47
	No	25(17.12%)	67(45.89%)	54(36.99%)	
Fearful procedure	BMA	23(32.39%)	23(32.39%)	24(33.80%)	0.001
	Chemo port insertion	0(0.00%)	38(45.78%)	45(54.22%)	
	IT injection	13(27.66%)	34(72.34%)	0(0.00%)	

Table 5: Correlation between mean Burden score and Resilience score

Mean ± SD		r value	P value
Burden score	Resilience score		
54.74±17.71	54.96±7.62	-0.42	0.001

Table 6: Association between burden score and demographic variables

		Burden score			P value
		No burden	Mild burden	MOD/severe burn	
Age	20-30 years	6(13.64%)	29(65.91%)	9(20.45%)	0.001
	30-40 years	30(26.79%)	42(37.50%)	40(35.71%)	
	>40 years	9(20.45%)	4(9.09%)	31(70.40%)	
Gender	Male	26(57.78%)	66(88%)	47(58.75%)	0.001
	Female	19(42.22%)	9(12%)	33(41.25%)	
Education	Up to middle school	5(12.82%)	6(15.38%)	28(71.79%)	0.001
	High school	22(18.64%)	54(45.76%)	42(35.59%)	
	Graduate	18(41.86%)	15(34.88%)	10(23.26%)	
Profession	Manual labourer	0(0.00%)	13(35.14%)	24(64.86%)	0.001
	Skilled	25(24.04%)	51(49.04%)	28(26.92%)	
	Unemployed	20(33.90%)	11(18.64%)	28(47.46%)	
Type of job	Permanent	25(26.60%)	26(27.66%)	43(45.74%)	0.001
	Temporary	20(18.87%)	49(46.23%)	37(34.91%)	
Condition of job	Continuing to work	42(29.79%)	36(25.53%)	63(44.68%)	0.001
	Leave with/ without pay	2(6.06%)	20(60.61%)	11(33.33%)	
	Left the job	1(3.85%)	19(73.08%)	6(23.08%)	
Child to do	Play outdoors	11(23.91%)	14(30.43%)	21(45.65%)	0.001
	Play indoors	28(20.00%)	55(39.29%)	57(40.71%)	
	Stay at home and not play	6(42.86%)	6(42.86%)	2(14.29%)	
Attending school	Very happy	28(20.29%)	56(40.58%)	54(39.13%)	0.001
	Fearful	5(14.71%)	14(41.18%)	15(44.12%)	
	Won't allow to school	12(42.86%)	5(17.86%)	11(39.29%)	

Table 7: Correlation between mean burden score and resilience score

Mean ± SD		r value	P value
Burden score	Resilience score		
36.82±19.37	60.25±8.84	-0.34	0.001

DISCUSSION

In this study involving 200 primary caregivers, the majority (61%) were aged between 30-40 years (Namazzi et al).^[1] Younger parents were found to experience a higher burden as caregivers (Bonin-Guillaume et al., Kim and Spillers).^[16,17] All primary caregivers were mothers, consistent with previous findings (Namazzi et al, Govender et al).^[1,18] However, Thuy et al. found a majority of male caregivers.^[19] About 20% of the mothers were single parents, similar to findings by Namazzi et al.^[1] Regarding education, 47.5% of caregivers had completed high school, 2% were illiterate, and 11% were graduates. This differed from Namazzi et al., who reported higher secondary education for 48.6% of caregivers.^[1] Burden was inversely related to educational status, with graduates experiencing moderate burden and illiterates experiencing severe burden ($p = 0.03$). Employed caregivers faced higher burden if their jobs were temporary ($p = 0.20$). Income also affected burden, with lower income associated with higher burden ($p = 0.03$). This was consistent with findings by Motlagh et al.^[20] Caregivers often faced financial strain due to expenses related to the child's illness, such as transportation and food. The burden was higher for parents of children with AML ($p = 0.001$), as AML treatment is associated with frequent hospital stays and poor outcomes. Longer treatment duration increased caregiver burden ($p = 0.001$), as did total hospital stay exceeding 10 days ($p = 0.001$). Caregivers reported frequent fights with spouses, tiredness, exhaustion,

and lack of sleep, similar to findings by Kazak et al.^[21] Psychological stress was experienced by caregivers providing over 20 hours of care per week, often due to lack of support from other family members. Caregivers struggled with hospital procedures, such as insertion of intravenous cannulas, which increased burden (Shiota et al).^[22] Insertion of a chemo port significantly increased burden ($p = 0.001$), as caregivers witnessed their children's distress during procedures. The mean resilience score was low compared to general populations (Davidson).^[23-25] Resilience was negatively correlated with burden scores, indicating lower coping skills increased burden. Secondary caregivers, mainly aged 30-35, experienced moderate-to-severe burden, with a mean ZBI score of 33.5. Resilience scores for secondary caregivers were slightly higher than primary caregivers (60.25±8.84). Significant differences were found between primary and secondary caregiver burden scores ($p = 0.001$) and resilience scores ($p = 0.001$).^[26]

CONCLUSION

This study concludes that there is a significant burden experienced by parents of children with haematological malignancies. Most of them suffer from two or more physical, psychological, economic, and social burdens. As can be seen from this study, these parents also had a low level of resilience which is a marker of coping skills for the disease. This sheds light on the importance of parental counselling. With a child being the centre of the family, secondary

caregivers also experience a significant burden. In a long-term disease like cancer, the secondary caregivers must also experience all the burdens the primary caregiver has to undergo. Therefore, it is necessary to examine the burden and importance of secondary caregivers. There can be faltering in the continuation of treatment because of the burden felt by the parents. Hence, it is imperative to resort to counselling these parents at all levels and throughout the treatment.

Limitations: The study at the Apex Institute of Tamil Nadu included children from other states, possibly biasing data towards higher burden for out-of-state caregivers. Additionally, there's a lack of resilience scores tailored to pediatric hematological malignancy caregivers, requiring further research. Furthermore, no studies have explored the burden of secondary caregivers in pediatrics, indicating a gap in understanding their experiences compared to primary caregivers. Limited data are available for comparison, with only a few adult-focused studies.

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