

DESCRIPTIVE STUDY TO ASSESS THE LEVEL OF CARE BURDEN AMONG CAREGIVERS OF LEUKEMIA PATIENTS

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Abstract: In India hematological malignancies as a group were the sixth most common with 8.77% patients. Serious illness has an adverse effect on patients, family, relatives and friends. Leukemia patients suffer from multidimensional experience related to physical symptoms, psychological distress, existential concerns, and social-relational worries. Unfortunately, many of these caregivers are risking their own personal wellbeing and sometimes their family life in the process. Many caregivers are not fully aware of the short and long term consequences of doing it all alone because they are so overwhelmed with managing their daily tasks and responsibility.

Quantitative approach using descriptive design was adopted for the present study. The sample for the present study was comprised of the caregivers of leukemia patients who were regularly attending OPD with patient in selected hospitals under study and is main family caregiver. One hundred fifty caregivers of patients suffering from leukemia were included in member. Paper and pencil techniques were selected to collect data regarding knowledge of caregivers of leukemia patients. Data collection was done using standardized Care burden (Novak and Guest's) Caregiver Burden Inventory. Results shows that majority of caregivers of leukemia patients had sever care burden. The study found that mean care burden score was high and thus required intervention. As observed in findings, maintaining and improving the health care status of the caregiver of leukemia patients is very important and thus caregivers need support to take care of their near ones.

Keywords: Caregiver, leukemia and care burden.

1. INTRODUCTION

In India hematological malignancies as a group were the sixth most common with 8.77% patients. In males, these malignancies comprised fourth most common group forming 10.6% of all patients while in females, it was the seventh most common system involved with 6.2% cases.⁹ A diagnosis of leukemia dramatically affects the lives of caregivers and all others who have a relationship with the patient. The patient and the entire family experience an emotional, physical and financial impact. Both patient and caregiver usually need to rearrange daily activities to some degree changes that may not come easily.⁵

Serious illness has an adverse effect on patients, family, relatives and friends. Leukemia patients suffer from multidimensional experience related to physical symptoms, psychological distress, existential concerns, and social-relational worries. As family care providers have become an integral part of the health care system, assessing them in terms of their knowledge, practice, care burden and attending to their needs can improve their outlook and competencies in caring by making them aware of their weaknesses and limitations, thus they become more open for assistance and help from health care professionals.³

Leukemia patients require assistance, including home nursing care, help with transportation, homemaking services, and personal care; that the care giver of leukemia patients take on substantial burdens in caring for them. Unfortunately, many of these caregivers are risking their own personal wellbeing and sometimes their family life in the process. Many caregivers are not fully aware of the short and long term consequences of doing it all alone because they are so overwhelmed with managing their daily tasks and responsibility. Supports and guidelines for caregivers can improve the quality of life of leukemia patients. Nurses are in communication with the patients and their families for a long period of time. Therefore, they have a unique position to identify stress and the psychological burden of caregivers.

The objective of the study:

1. To assess level of care burden among caregiver of leukemia patients.

2. MATERIALS AND METHODS

Quantitative approach using descriptive design was adopted for the present study. The study was conducted at selected hospitals of district Mohali, Punjab, they were, Fortis Hospital, Max Super specialty Hospital, IVY hospital, Sri Guru Harkrishan Sahib multi-specialty Hospital. The population for the present study was comprised of the main/primary caregivers of leukemia patients who were taking care for last three months and are accompanying leukemia patients to OPD of selected hospitals. The sample for the present study was comprised of the caregivers of leukemia patients who were regularly attending OPD with patient in selected hospitals under study and is main family caregiver i.e. father, mother, spouse, daughter or son. One hundred fifty caregivers of patients suffering from leukemia were included in study. Written consent was taken from the caregivers of leukemia patients. Caregivers were assured of the confidentiality of their data. Five caregivers of leukemia patients were interviewed per day. Data collection from one patient took on an average of 50-60 minutes. The researcher gathered data between 9am to 5pm in OPD of selected hospitals.

Data Collection Techniques and Tools: Paper and pencil techniques were selected to collect data regarding care burden of caregivers of leukemia patients. Data collection was done using Standardized Care burden (Novak and Guest's) Caregiver Burden Inventory. It consists of two sections:

Section I: comprised of eleven items seeking information on demographic variables of leukemia caregivers such as age, gender, marital status, educational status, religion, type of family, occupation, total family income per month, residence and time since care has been provided.

Section II: Standardized Care burden (Novak and Guest's) Caregiver Burden Inventory was used to assess burden of caregivers of leukemia patients. Prior written permission was taken from author to use Caregiver Burden Inventory.

Care burden inventory was composed of twenty four item multi-dimensional questionnaire measuring caregiver burden with five subscales: (a) Time Dependence (b) Developmental (c) Physical Burden (d) Social Burden (e) Emotional Burden.

- **Time Dependence:** Objective burden (which corresponds to the amount of time devoted to care giving): the burden on the caregiver due to shortage of time (items 1-5).
- **Developmental burden:** The caregiver's sense of being left behind, unable to enjoy the same expectations and opportunities as his or her peers (items 6-10).
- **Physical burden:** Feelings of fatigue and chronic health problems (items 11-14).
- **Emotional burden:** Emotional burden which originates from awareness of negative feelings towards the patient that can be induced by the patient's bizarre and unpredictable behavior (items 15-19).
- **Social burden:** Social burden results from a perceived conflict of roles (items 20-24).

Scoring – Caregivers were asked to rate each item on a five point Likert scale ranging from zero (not at all disruptive) to four (very disruptive). The responses were quantified by giving a score. Statements were scored four for nearly always, three for quite frequently, two for some time, one for rarely and zero for never. The minimum score was zero and maximum score was ninety-six. Total score on caregiver care burden inventory ranges from 0 to 96. Based on the method of scoring, the check list was categorized into four categories i.e. no burden (0-24) mild burden (25-48), moderate burden (45-72) and severe burden (73-96).

3. RESULTS

TABLE 1: Frequency and Percentage Distribution of Caregivers of Leukemia Patients According to Demographic Variables

Sr.no	Demographic Variable	n	(%)
N=150			
1	Age in years		
	20-30	30	20
	31-40	33	22
	41-50	46	31
	>50	41	27
2	Gender		
	Male	57	38
	Female	93	62
3	Marital Status		
	Single	33	22
	Married	90	60
	Widow/Widower	21	14
	Divorced/Separate	6	4
4	Education status		
	Illiterate	0	0
	Primary	15	10
	Matric	39	26
	Sr. Secondary	63	42
	Graduate & above	33	22
5	Religion		
	Hindu	78	52
	Sikh	48	32
	Christian	15	10
	Muslim	9	6
6	Type of family		
	Nuclear	87	58
	Joint	63	42
7	Occupation		
	Unemployed	27	18
	Laborer	24	16
	Business	45	30
	Government job	24	16
	Private service	30	20
8	Total family income		
	< 10,000	15	10
	10001-20,000	33	22
	20,001-30,000	42	28
	> 30,000	60	40
9	Residence		
	Rural	84	56
	Urban	66	44
10	Duration as Caregivers		
	3-6 month	21	14
	6-12 month	60	40
	1-3 years	48	32
	>3years	21	14

Table 1 depicts frequency and percentage distribution of caregivers of leukemia patients according to demographic variables. Among 150 caregivers of leukemia patients 46(31%) were in the age group of 41-50 years, followed by 41(27%) in the age group of above 50 years, 33(22%) in the age group of 31-40 years and 30(20%) were in age group of 20-30 years. When differentiated on the basis of gender it was found that majority of caregivers of Leukemia Patients were female 93(62%). On the basis of marital status, majority of caregivers of leukemia patients 90(60%) were married.

As per education status of the caregivers of leukemia patients 63(42%) were having senior secondary education, 39(26%) had passed matric, 33(22%) were graduate and above, 15(10%) had primary education. When caregivers of leukemia patients were divided on basis of religion, majority of caregivers of leukemia patients belonged to Hindu religion 78 (52%). The data also shows that out of 150 caregivers of leukemia patients 87(58%) were living in nuclear family and 63(42%) were living in joint family. Apart from it, 27(18%) caregivers of leukemia patients were unemployed, 24(16%) were laborer, 45(30%) were in business, 24(16%) were doing government job and 30(20%) were doing private service. 60(40%) had family income per month >30,000 an 15(10%) caregivers of leukemia patients had total family income per month <Rs10,000. Most of the caregivers of leukemia patients were residence of rural area 84(56%) and 66(44%) were living in urban area. Majority of caregivers of leukemia patients 60(40%) had duration as caregivers for 6-12months, while 48(32%) had duration as caregivers from 1-3years, 21(14%) were taking care from 3 to 6 months and same number of caregivers were taking care from more than three years.

Table 2: Mean, Median, Standard Deviation, Range and Mean Percentage of Care burden Score of Caregivers of Leukemia Patients

N=150					
Mean	Mean %	S.D	Median	Maximum	Minimum
74.93	78.05	8.322	75	89	56

Maximum score: 96; Minimum Score: 0

The data presented in the Table 2, indicates that caregivers of leukemia patients had mean care burden 74.93 and mean percentage (78.05%). The median of the distribution of caregivers of leukemia patients was 75.

Table 3: Frequency and Percentage Distribution of Caregivers of Leukemia Patients in Terms of Level of Care burden

N=150		
Level of care burden	F	(%)
Severe Burden (73-96)	81	54
Moderate Burden (49-72)	69	46

Maximum score: 96, Minimum Score: 0

Table 3, reflects that in 81% of caregivers of leukemia patients had experienced sever burden while the rest of the group had witness moderate burden. Thus, it is evident that majority of caregivers of leukemia patients had sever care burden.

Table 4: Area Wise Mean Score, Mean Percentage and Ranking of Care burden Score of Caregivers of Leukemia Patients

N=150				
Areas of care burden		Mean score	Mean %	Rank
Time dependency	20	15.58	77.90	III
Development	20	15.14	75.70	V
Physical Health	16	12.67	79.21	II
Emotional Health	20	16.07	80.37	I
Social Relationships	20	15.46	77.30	IV
Total	96	74.93	78.05	

Table 4 shows the area wise mean score and mean percentage of care burden of caregiver of leukemia. The data shows that the mean percentage obtained in area i.e. Emotional Health was ranked I with mean percentage 80.37%. Physical Health was having mean percentage score 79.21% and ranked as II. Time dependency was ranked as III with mean percentage obtained was 77.90%. In mean percentage score obtained in Social Relationships was 77.30% and ranked as IV. Mean percentage score obtained in area of Development was 75.70% and ranked as V.

Data further reveals that from above analysis it is evident that caregivers of leukemia patients experience maximum care burden emotionally and lowest related to development.

Table 5: Association of Care burden of Caregiver of Leukemia Patients with Demographic Variables

Demographic Variables			χ^2	P Value	df	Table Value
	Severe Burden	Moderate Burden				
N=150						
Age in years						
20-30	19	11	1.520	0.678	3	7.815
31-40	16	17				
41-50	24	22				
>50	22	19				
Gender						
Male	31	26	0.006	0.941	1	3.841
Female	50	43				
Marital Status						
Single	14	19	7.001	0.072	3	7.815
Married	50	40				
Widow/Widower	11	10				
Divorced/Separate	6	0				
Education status						
Illiterate	0	0	9.799*	0.020	3	7.815
Primary	12	3				
Matric	25	14				
Sr. Secondary	26	37				
Graduate & above	18	15				
Religion						
Hindu	55	23	18.637*	0.000	3	7.815
Sikh	19	29				
Christian	4	11				
Muslim	3	6				
Type of family						
Nuclear	55	32	7.086*	0.008	1	3.841
Joint	26	37				
Occupation						
Unemployed	18	9	11.010*	0.026	4	9.488
Labor	18	6				
Business	24	21				
Government job	9	15				
Private service	12	18				
Total family income						
< 10,000	7	8	4.111	0.250	3	7.815
10001-20,000	21	12				
20001-30,000	18	24				
> 30,000	35	25				
Residence						
Rural	59	25	20.265*	0.000	1	3.841
Urban	22	44				
Duration of time as care giver						
0-6month	11	10	18.319*	0.000	3	7.815
6-12 month	41	19				
1-3 years	26	22				
>3years	3	18				

The data presented in Table 5 indicates that the obtained chi-square values of caregiver of leukemia patients shows association of care burden with, educational status (9.799), religion (18.637) type of family (7.086), occupation (11.010) residence (20.265) and duration as caregivers(18.319) was found to be statistically significant at 0.05 level of significance..

Therefore, it can be concluded that care burden of caregiver of leukemia patient was dependent on their educational status, religion, type of family, occupation, residence and duration as caregivers and was independent of other variables like age, gender, marital status, and total family income.

4. DISCUSSION

The above study was comparable to the studies done by various researchers. In terms of socio-demographic variables, study done by Manal M. El-Sawy et al(2013) shows that more than half (55.8%) of the caregivers aged from 35 to less than 45 with a mean age 37.46 ± 6.56 years, about sixty percent (59.4%) of the caregivers were females and 41.4% had secondary school education, regarding marital status of the caregivers, the majority (90.1%) were married.⁶ Saleem Hasan et al(2012) study results reveals that (31%) of caregiver's age were between (39-48) years.⁴

Results of caregivers of leukemia patients show severe care burden among caregivers. The finding support the data from study by Asadi Noughabi F et al (2015) to assess the effect of instructing care program on the quality of life of the parents of the children suffering from leukemia, Results shows severe care burden among caregivers and after introduction of care program training can be a positive step to help these parents and ultimately lead to improved quality of life of parents.¹ Similarly Pailler ME et al (2015) showed sever care burden and shows significant interaction effects were observed for both caregiver distress and quality of life, whereby those receiving the intervention demonstrated improved quality of life and reduced distress over time.⁷ This result stand in position with Pahlavanzade S (2014) who revealed severe care burden among caregivers thus family need-based program decreased burden in caregivers of leukemia patients and may potentially improve the quality of life of both patients and caregivers.⁸ Also Creedle C et al (2012) reported sever stress among caregivers and shows that standardized patient education helped improve caregivers' overall well-being.²

5. CONCLUSION

Burden of care includes physical, emotional, financial, and social problems, and if unnoticed and untreated, can result in damaging the physical and mental health of caregiver.

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