

A pilot study to assess stress and coping among primary caregivers of patients with leukemia

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ABSTRACT

Background: Caring hematologic cancer patients by the caregivers is very stressful. Aim of the study was to assess stress and coping among the caregivers. **Materials and Methods:** In this descriptive pilot study, stress and coping was assessed with Perceived Stress Scale (PSS) and BRIEF-COPE scale respectively in 30 primary family caregivers of hematologic cancer patients. **Results:** Among caregivers 63.33% had moderate stress, 33.33% had mild stress and 3.33% had severe stress. Also 93.33% had average while 6.67% had good coping skills. While stress was significantly related to government job employee and to nuclear families, no significant relation of coping with any demographic variables was seen. Caregivers adopted both active and passive coping. **Conclusion:** Most of the caregivers of hematologic cancer patients experience moderate stress and had average coping skills. It is important to establish a care program, so that caregivers can maintain their own health and provide the best care to the patient.

Keywords: Leukemia, Primary family caregiver, Stress, Coping, Cancer, Behavior

The diagnosis of cancer is devastating in all aspects of patient's life. It affects not only individual's physical and psychological integrity but also the function of family system (Hodges, Humphris & Macfarlane, 2005). A caregiver is someone who provides physical and emotional care to the person suffering with an illness. In modern era, role of the caregivers of cancer patients have been increased. First, patients now spend more time with their family due to decrease in hospitalization period with the advances in medical technology (Given, Given & Kozachik, 2001). Second, now the medical policies are to focus on non-professional care than on professional for which patients are getting discharged earlier from hospital (Nijboer, Tempelaar, Triemstra, Van & Sanderman, 2001). Third, more cancer patients are getting outpatient treatment by the family caregivers than earlier times.

Caregivers experience various changes in many aspects of their life including physical, emotional, social, financial, and spiritual (Palos, Mendoza, Liao et al. 2011). The complexity of care given in cancer ward can provoke additional stress. Among all the diseases the most feared diseases are cancer, it is viewed as being synonymous with pain, disfigurement and

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death. Family caregivers receive little preparation, information and support to perform their vital role. There are some studies which investigated the different aspects of cancer care burden on family caregivers. A review found that the most prevalent physical problems were reported by caregivers included fatigue, sleep disturbance, back problems, heart problems, high blood pressure, arthritis, pain, weight loss. (Girgis, Lambert, Johnson et al. 2013) Depression, anxiety, helplessness and fear of death of loved ones are the most important psychological effects of cancer on family caregivers (Mary, 2004)

To combat against cancer care burden, caregivers adopt several behavioral and cognitive strategies, which is called coping. Coping means the way of dealing with stress. It aims at eliminating the stressor and reduction of stress responses (Ben-Zur, 2005). To cope with the fear of cancer, the patients and caregivers experience different behavioral patterns such as shock, anger, denial, bargaining and other defence mechanisms. Good coping behaviors can decrease the damage brought about by stress. Bad coping behaviors have an unfavorable influence on the mind and body, including direct damage to the body, psychological problems such as depression, animosity and even suicidal behavior (Chellappan & Rajamanikam, 2016).

The degree of burden and stress experienced by the caregivers has been the focus of a considerable amount of research. In addition, hematologic neoplasms impose more problem for the patient and their family members due to high mortality and frequent hospitalizations (Bakhshi, Mortazavi, Taherkhani et al. 2014) So assessing the cancer care burden on family caregivers of hematologic cancer patients is utmost important to establish any care program, so that they can maintain their own health and provide the best care possible to the patient. In literature, in India there is sparse data regarding it.

MATERIALS AND METHODS

This descriptive study was carried out at Nehru hospital, PGIMER, Chandigarh, India. The participants of this study were primary family caregivers of hematologic cancer patients. Total 30 caregivers of leukemia patients were enrolled in the study with the following inclusion criteria: age 20-60 years; definite members of the family, being chiefly responsible for taking care for patient, mentally and physically able to be enrolled in the study. Caregivers suffering from any mental illness were excluded from the study. The objective of the study was to assess stress and coping among caregivers of hematological cancer patients and to acquire a deeper understanding of their lived experiences.

A written consent was taken from all the subjects. Anonymity and confidentiality of the subjects was maintained. Objectives, activities and duration of their involvement in the study were properly explained to them. In this study two scales were used and were translated to Punjabi language and both English and Punjabi written forms were given to the caregivers, they filled the form according to their understandable language.

For data collection a questionnaire consisted of three parts were used. The first part gathered some sociodemographic characteristics of participants like name, age, sex, central registration number, bed number, ward of the patient, name of caregiver, age, address, educational status of caregivers, occupation of caregivers, monthly family income, type of family, residence and religion etc.

Second part was to assess stress among caregivers with Perceived Stress Scale (PSS), stress assessment instrument that was originally developed in 1983 by Cohen (Cohen, Kamarck

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and Mermelstein, 1983). It is a measure of the degree to which situations in one's life are appraised as stressful. The ten questions in this scale ask about caregiver's feelings and thoughts during the last month. PSS scores are obtained by reversing responses (e.g., 0=4, 1=3, 2=2, 3=1 & 4=0) to the four positively stated items (items 4, 5, 7, & 8) and then summing across all scale items. Individual scores on the PSS can range from 0 to 40 with higher scores indicating higher perceived stress. Scores ranging from 0-13, 14-26 and 27-40 was considered low stress, moderate stress and high perceived stress respectively.

The third part was to assess coping behaviours of caregivers with a validated standardised Brief COPE scale (Carver, 1997) (Carver, Scheier & Weintraub, 1989). It is a 28 item self-report questionnaire designed developed by Carver, Scheier, and Weintraub in 1997 to measure effective and ineffective ways to cope with a stressful life event. The minimum score was 28 and maximum score was 112. The scale can determine someone's primary coping styles as either approach coping or avoidant coping. In addition, following subscales are reported: self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioral disengagement, venting, positive reframing, planning, humor, acceptance, religion, & self-blame. For each item, respondents indicate whether they have used the coping response on four-point likert scale: 1 =I haven't been doing this at all; 2 = I've been doing this a little bit; 3 = I've been doing this a medium amount; 4 =I've been doing this a lot. Rating for Brief COPE was as follows: Poor coping <35 %; Average coping 36-70 %; Good coping 71-100 %.

Calculation was carried out with the help of SPSS. Data was analyzed by applying descriptive statistics (mean, standard deviation) and independent t test and ANOVA was used to describe the variables.

RESULTS

Table 1: Socio demographic profile of caregivers (n=30)

Variable	Group	Frequency	Percent
Sex	Male	14	46.7
	Female	16	53.3
Education of caregivers	Senior Secondary	13	43.3
	Graduate or above	17	56.7
Occupation of caregivers	Government job	12	40
	Private job	18	60
Age	20-40 yrs	14	46.7
	40-60 yrs	16	53.3
Family	Joint	14	46.7
	Nuclear	16	53.3
Residence	Rural	14	46.7
	Urban	16	53.3
Religion	Hindu	16	53.3
	Muslim	1	3.3
	Sikh	13	43.3

Table no 1 shows socio demographic profile of caregivers. Caregivers were in the age range of 20-60 years. 46.7% of subjects were in the age group of 20-40 years; 53.3% of them were of 40-60 yrs. 46.7% of subjects were males and 53.3% were females. 43.3% completed their senior secondary school education, 56.7% of subjects were graduate. 40% of the subjects were government employee 60% were doing private job. Majority of subjects were having

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per capita income between 10000-20,000 and above. 46.7% were residing in joint families and 53.3% in nuclear family and urban area. Maximum (53.3%) of subjects were Hindu by religion and very few were Muslims (3.3%). Regarding patients, more than half (53.33%) of patients were in age group of 50-80 yrs and 46.67% were in age group 20-50 yrs. 53.3% of them were males rest 46.67% were females.

Table 2: Stress and Coping in relation to demographic variables (n=30)

Variables		Coping			Stress		
		Mean	SD	p-value	Mean	SD	p-value
Gender	Male	67.57	5.70	0.872	21.93	5.73	0.177
	Female	67.88	4.50		25.13	6.76	
Education	Senior secondary	68.46	5.12	0.496	23.69	7.26	0.966
	Graduate and above	67.18	5.00		23.59	5.89	
Occupation	Govt job	66.08	2.57	0.114	27.75	6.64	0.002
	Private job	68.83	5.94		20.89	4.62	
Income	Rs 5000-10000	68.50	6.39	0.622	27.75	4.89	0.283
	Rs above 10000	67.45	4.55		22.86	6.80	
Type of family	Joint	67.21	5.13	0.604	20.88	5.81	0.009
	Nuclear	68.19	5.02		26.79	5.68	
Type of residence	Rural	69.50	6.04	0.070	24.64	5.83	0.429
	Urban	66.19	3.37		22.75	6.92	
Type of religion	Hindu	68.75	5.88	0.488	22.88	5.59	0.619
	Sikh	66.46	3.77		24.85	2.08	
	Muslim	68	-		20.00		
Age	20-40yrs	67.57	5.70	0.872	21.93	5.73	0.177
	40-60yrs	67.88	4.50		25.13	6.76	

Table no 2 shows PSS score and Coping score of caregivers with different demographic variables. The results showed that there is no significant relation of age, sex, education, income, residence and religion with stress but there is more stress among government employee than private employee. Results also showed more stress in nuclear families than in joint families. There is no significant relation of coping with any of the studied demographic variables. PSS and Coping score of whole of the study population is given in table 3 and table 4 respectively.

Table 3: Description of subjects according to the level of stress (n=30)

Level of stress	Stress score	Frequency	Percentage
Mild stress	0-13	1	3.33
Moderate stress	14-26	19	63.3
Severe stress	27-40	10	33.3

It shows 63.33% subjects were moderately stressed and 33.3% were severely stressed and 3.33% were mildly stressed.

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Table 4: Description of subjects according to the level of coping (n=30)

Level of coping	Coping level (%)	Frequency	Percentage
Poor coping	<35	Nil	Nil
Average coping	36-70	28	93.3
Good coping	71-100	2	6.67

It shows that 93.33% of subjects have average coping while only 6.67% of subjects have good coping.

Individual items of PSS scale were studied and individual responses were checked and shown in table 5.

Table 5: Participant's response to items of PSS scale

Items of PSS	MEAN (responses)	SD
In the past month how often have you been upset because of something that happened unexpectedly due to diagnosis of cancer?	3.30	.83
In the past month, how often have you felt unable to control the important things in your life due to diagnosis of cancer?	2.50	1.01
In the past month, how often have you felt nervous or stressed due to diagnosis of cancer?	3.26	.94
In the past month, how often have you felt confident about your ability to handle personal problems due to diagnosis of cancer?	2.50	1.52
In the past month, how often have you felt that things were going your way due to diagnosis of cancer?	1.46	1.25
In the past month, how often have you found that you could not cope with all the things you had to do due to diagnosis of cancer?	2.46	1.13
In the past month, how often have you been able to control irritations in your life due to diagnosis of cancer?	1.80	1.37
In the past month how often have you felt that you were on the top of things due to diagnosis of cancer?	2.60	1.01
In the past month how often have you been angry because of things that happened that were outside of your control due to diagnosis of cancer?	2.10	1.26
In the past month, how often have you felt that difficulties were piling up so high that you could not overcome them due to diagnosis of cancer?	2.40	1.27

Participants had maximum mean score in first item that is “in the past one month, how often have you been upset because of something that happened unexpectedly due to diagnosis of cancer?”

On the other side, participants scored minimum in fifth item “in the past month how often you felt that things were going your way due to diagnosis of cancer?”

Caregivers adopted both approach and avoidant coping behavior.

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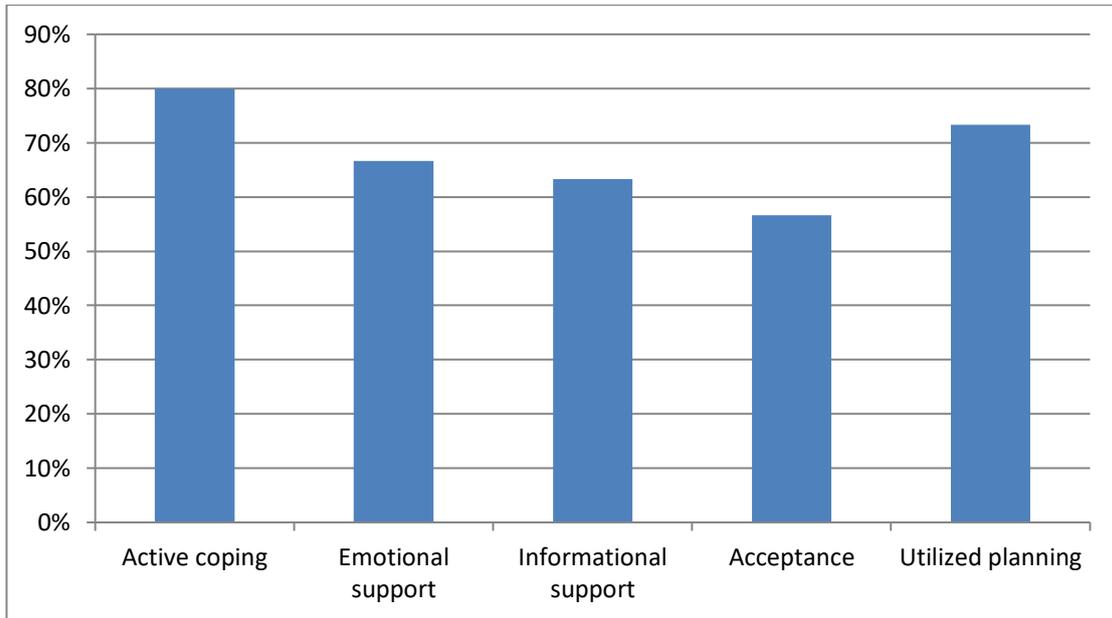


Figure 1: Approach coping behavior (%)

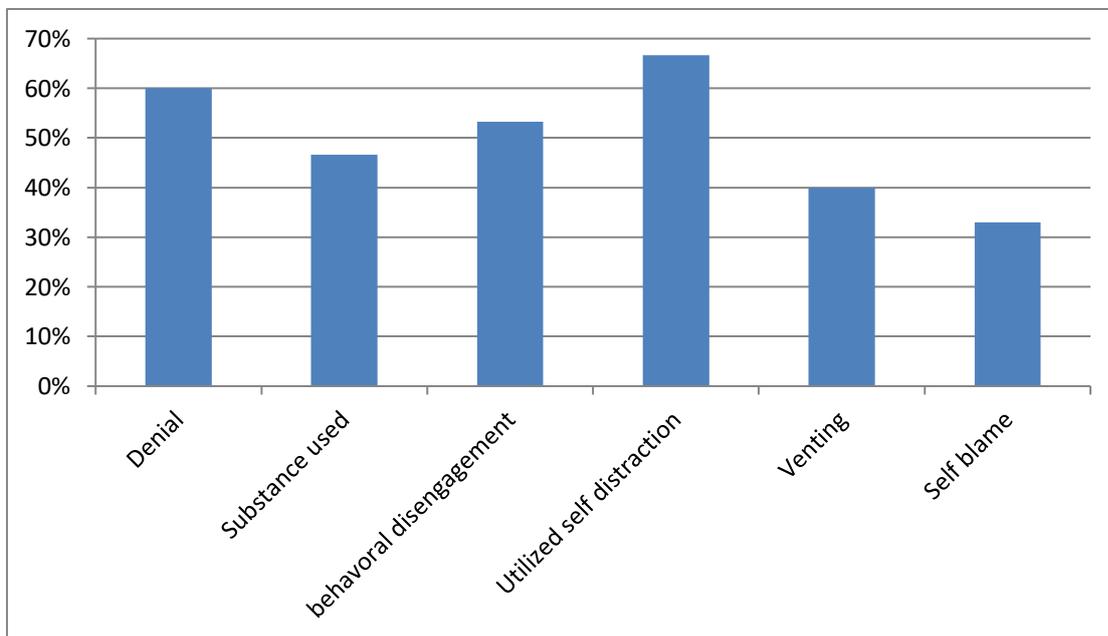


Figure 2: Avoidant coping behavior (%)

Figure 1 show the approach coping adopted by caregivers. Data reveal that, 80% of them used active coping, 66.6% used emotional support and 63.33% used informational support, 56.66 % used acceptance and 73.33% used utilized planning.

Figure 2 shows the avoidant coping adopted by caregivers. It reveals that 60% of them used denial, 46.6 % were involved in substance use, 53.3% used behavioral disengagement, and 66.6% utilized self-distraction, 40% used venting and 33.33% used self blame.

DISCUSSION

The mental health and perceived stress among the caregivers of leukemia patient is a neglected issue. So, in this pilot study, we tried to explore the level of stress, coping

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behavior and related demographic profile among the caregivers. There are very few studies in India regarding this in the literature.

Major findings of present study were that 63.33% of subjects had moderate stress, 33.33% of subjects had mild stress and 3.33% had severe stress due to terminal illness of the patient. Our finding is similar to the study done by Antony et al in south India where they found maximum number of caregivers (82%) had moderate stress (Antony, George and Jose, 2018) Same finding was obtained from another study in Brazil where moderate level stress 46.21% predominated, followed by the high level 44.70 % and low level 9.09 % (Coppetti, Girardon-Perlini, Andolhe et al. 2019). Therefore, it seems that most of the caregivers experience moderate level stress worldwide. Assessment of level of coping shows that 93.33% of subjects have average coping skills while 6.67% have good coping skills.

In our study, maximum care givers are of 40-60 years of age, female, graduated in education, doing private jobs, belongs to nuclear family and lives in urban area.

Level of stress and coping was assessed in relation to different demographic variables. The results showed that there is no significant relation of age, sex, education, income, residence and religion with stress but there is more stress among government employee than private employee. Results also showed more stress in nuclear families. This result is expected. Study done by Basit Ansari et al revealed that caregivers working in nuclear family system is more likely to feel stress and loneliness than the one working in a joint family system, where there are other people present to share his or her stressful situations (Basit & Sara, 2013). Poor social support is associated with significantly higher stress. These findings are consistent with the existing literature which suggests negative correlation between the social support in joint family and burden experienced by caregivers of patients with cancers (Kumari, Kohli, Malhotra, Grover and Khadwal, 2018) (Fitzell and Pakenham, 2010)

No significant relation of coping with any of the demographic variables is observed.

When analyzing individual item of PSS scale, it was found that caregivers were more distressed by the unexpected situation arising from the occurrence of haematological cancer and maximum time things were not going in favour of patients and caregivers.

Analysing the coping behaviour revealed that caregivers adopted both avoidant and approachable coping. Most prevalent avoidant coping adopted by caregivers was self-distraction (66.6 %) followed by denial (60 %) while most prevalent avoidant coping behavior was active coping (80 %) followed by utilized planning (73.3 %). This finding is similar to the study by Antony et al in south India. (Antony, George and Jose, 2018)

Our study has several limitations. First, study population was small in number, only 30 caregivers were included in our study. Second, only the caregivers of hematologic cancer patients participated in this study and its results cannot be easily generalized to other kinds of neoplasms. Third, this study was conducted in only at one hospital in north India. So, it cannot be generalized.

Despite the limitations, on the basis of findings of the study it is recommended that similar study can be carried out at a larger group to assess the stress level and coping behaviors among caregivers of patients with terminal illnesses.

CONCLUSION

Hematological cancer affects not only the patients but also their caregivers. Caregivers face multiple physical and emotional challenges. Most of the caregivers of experience moderate stress and have average coping skills. It is important for the caregivers to maintain their own health so that they can provide the best care to the patient. So establishment of a care program is essential.

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Conflict of Interest

The author declared no conflict of interest.

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