

# A STUDY ON CAREGIVER BURDEN AND THEIR COPING STYLES AMONG PRIMARY CAREGIVERS OF CANCER PATIENTS ON CHEMO/RADIOTHERAPY: A CROSS SECTIONAL ANALYTICAL STUDY FROM A TERTIARY CARE HOSPITAL IN VISAKHAPATNAM

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## Abstract

**BACKGROUND:** Care services for cancer mainly focus on palliative care, where family members serve as informal caregivers. Caregivers are impacted by the care they offer, resulting in a burden. Higher levels of burden may be associated with increased morbidity and mortality among caregivers. There are several coping methods that may be used by people to get through their burdens. The purpose of this study is to estimate the primary caregiver burden and determine the factors associated with that burden. In addition, the primary caregivers' coping mechanisms were assessed.

**METHODS:** This study was a hospital-based cross-sectional analytical study done among 100 primary caregivers of cancer patients admitted to both the radiotherapy and oncology departments of a tertiary care hospital. Data was collected using the Zarit caregiver burden assessment scale and the Brief COPE scale questionnaire.

**RESULTS:** 43% of the caregivers had a mild to moderate burden. The caregiver adopted a problem-oriented coping style. Male caregivers relied on denial, whereas female caregivers relied on religion.

**CONCLUSION:** By measuring their burden and coping mechanisms, interventions may assist people in managing their physical, emotional, and social demands.

**KEYWORDS:** Cancer, Caregiver burden, chemo radiotherapy, coping mechanism.

## INTRODUCTION

According to GLOBOCAN 2020, developing countries will account for the majority of the increase in global cancer incidence during the next 50 years.<sup>1,2,3</sup>

Cancer care services for patients were limited in India and other low- and middle-income countries, which mainly focused on palliative care for advanced cancer patients, which pushed family members to serve as informal caregivers. A caregiver is defined as "someone who regularly helps and provides care for a person who is disabled or ill with tasks like dressing, shopping, or household tasks, or who offers other sorts of practical or emotional support".<sup>4</sup> Informal caregivers are vulnerable to difficult circumstances and a lack of rapid problem-solving abilities, which can lead to improper emotional adjustment, resulting in caregiver burden or stress.<sup>4,5</sup> Caregiver burden has been described by Zarit et al.<sup>6</sup> as "a state resulting from necessary caring tasks or restrictions that cause discomfort for the caregiver". According to a US report on caregiving, 58% of caregivers were in their productive age group, and the main problem they perceived was mental and emotional illness.<sup>7</sup> Furthermore, higher levels of burden may be associated with increasing morbidity and mortality among caregivers.<sup>8</sup> One should be equally concerned about the physical and

emotional well-being of the caregivers as well.

There are several coping methods that may be used by people to get through their burdens or stressful situations. Coping is defined by Folkman and Lazarus<sup>9</sup> as the "cognitive and behavioral efforts that are implemented to solve problems and reduce the stress that these problems may cause." The type of a person's coping mechanisms can have a direct influence not only on their own quality of life but also on the patient's quality of life. The various coping strategies are classified as problem-focused, emotion-focused, and avoidance-focused. A problem-focused coping strategy indicates that efforts are being made to solve problems in a practical manner. A coping strategy that is emotion-focused aims to control the feelings brought on by the stressful circumstance. Avoidant coping involves making physical or mental efforts to disconnect from the stressor.<sup>10</sup>

Studies have been done separately on the stress of



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caregiving, caregivers' quality of life, and coping strategies. There has been relatively limited study on the combination of caregiver load and coping techniques. This study aims to estimate the primary caregiver burden and identify the factors associated with that burden. In addition, the primary caregivers' coping strategies were assessed. This will assist them in enhancing their patient-care strategies and coping mechanisms, as well as in meeting the physical, financial, and emotional needs of the caregiver.

## METHODOLOGY

This hospital-based cross-sectional analytical study included 100 primary caregivers of cancer patients admitted in both radiotherapy and oncology departments at a tertiary care hospital in Visakhapatnam, Andhra Pradesh. The inclusion criteria were as follows: primary caregivers of cancer patients admitted for chemo or radiation who offer the majority of care on a daily basis; 18 years old or older; taking care of the patients for at least 3 months; able to speak vocally. The following were the exclusion criteria: caregivers with no history of any psychiatric disease and who were paid to care for the patients. We achieved a sample size of 84 with 10% non-response using the formula  $4pq/l2$ , where  $p$  is 70% (in Mishra et al. study,<sup>8</sup> and the relative error was 14%. The final sample size was 97, rounded off to 100.

As a result, the study included caregivers who met the inclusion criteria and were willing to take part from August to October 2022. Ethics approval was obtained from the institutional ethics committee, and written informed consent was taken. The questionnaires were filled out by the researcher using the interview method.

## STUDY TOOLS

The social demographic details of the patient and their primary caregivers were collected. The socioeconomic status of the caregivers was classified using the Modified Kuppusamy socioeconomic scale for 2022. The Zarit Burden Interview (ZBI), a validated, short 12-item version<sup>11,12</sup> was used to assess caregiver burden. The caregiver's coping mechanism was measured using the modified 28-item Brief COPE scale.<sup>13</sup>

### Statistical analyses :

All statistical analyses were performed using IBM SPSS Statistics 21. Descriptive data were expressed in proportion or mean and SD. The normality of the data was tested and a parametric test was applied. Multivariate linear stepwise regression analysis was done to determine the predictors of caregiver burden. Pearson correlation was used to analyze the

relationship between the components of coping and burden.

## RESULTS

### DEMOGRAPHIC DETAILS:

The demographic information for the patients and the caregivers is shown in Table 1. The mean (SD) age of patients was 49.85 (12.5) years (19 to 76 years), and the mean duration of the illness was 20 months. In terms of caretakers, their mean (SD) age was 41 (16) years. The majority of caregivers (88%) said that their patients were cooperative with their caretakers or doctors.

### FACTORS ASSOCIATED WITH THE BURDEN OF CAREGIVING:

In this study, the mean ZBI score was 15.7 (7.3) (min 5; max 33). This study revealed that 43% had a mild to moderate burden, 30% had a no to mild burden and 27% had a high burden.

The analysis of the burden score with patient and caregiver characteristics is shown in Tables 2 and 3.

### DETERMINANTS OF THE BURDEN OF CAREGIVING:

A stepwise multiple regression analysis was done to determine the predictors of the burden of caregiving. The variables that showed significance in univariate analysis were taken for regression. The residuals were normally distributed, and the linearity was assessed. There was independence of residuals as assessed by the Durbin-Watson statistic of 2.03. There was evidence of homoscedasticity but no evidence of multicollinearity. The values were found to be within acceptable limits for studentized deleted residuals, Cooks distance, and leverage values.

The burden on caregivers was found to be higher in this study for caregivers who were working and caregivers of patients who were illiterate and had completed a primary level of education ( $R^2 = .162$ , adj  $R^2 = .144$ ,  $p = .001$ ), which accounted for 16% of the total variations (Table 4).

### COPING SCALE:

The mean coping score was 56.7 (7.1), which ranges from 40 to 72. The mean score for males was 56.3 (7.5), and for females, it was 57.1.<sup>7</sup> Problem-solving styles were preferred by caregivers over avoidant styles (Table 5).

Religion, acceptance, informational support, and emotional support were among the coping techniques used by respondents, according to our findings. Humor, self-blame, substance use, and denial were almost never employed by the caregivers (Fig 1-3).

Men were more likely to use denial strategies ( $p = 0.019$ ), whereas women used religion strategies ( $p = 0.026$ ) (Table 6).

Caregivers in their early adulthood used denial strategies more than those in their middle adulthood ( $p = 0.021$ ).

Unmarried caregivers were more likely to engage in self-distraction style (p 0.042). Working caregivers considerably adopted the denial strategy (p 0.001), whereas non-working caregivers largely utilized religion as a strategy (p 0.004). The behavioral disengagement method was more commonly used by caregivers with secondary education (p 0.023) and degrees (p 0.037) than by caregivers without education. Caregivers who cared for patients for 6 months to a year were more likely to use the self-distraction mechanism (p 0.023) than caregivers who cared for patients for less than 6 months. Lower-income caregivers were more likely to use a behavioral disengagement method (p 0.003).

Table 7 demonstrates the relationship between coping components and caregiver burden. The assumption of normality was found to be supported by the Q-Q plot prior to computing the correlations. A visual inspection of the box plot revealed outliers in some subscales, which were taken for analysis. Among the coping strategies, self-distraction, active coping, and venting were significantly positively correlated with burden, while religion was negatively correlated.

## DISCUSSION

In this study, 41% of care providers were between the ages of 35 and 64, and 50% of them were female. The majority of caretakers were married, employed, and uneducated. The majority of the patients were cared for by their children or parents, who were then followed by their spouses, and the majority of them are upper middle-class. Only 17 percent of the patients were working, and almost two-thirds were married, which was comparable with the study by Mishra et al.<sup>8</sup> and the Bekdemir study.<sup>14</sup>

Both Mishra<sup>8</sup> and our study discovered that a high majority of individuals had a mild to moderate burden. This might be due to the way Indian families are living. The caregiver's social support system is a key measure of their improved physical and emotional well-being. According to the literature, family support decreases caregiver burden and improves quality of life for caregivers who care for patients with chronic conditions.<sup>14</sup>

The mean ZBI score in our survey was 15.7 (7.3), with 27% experiencing high burden. In the Likhmana et al. study<sup>6</sup>, 43.5% of participants reported a moderate-to-severe burden, which contrasts with our findings. In the Mirsoleymani et al. study<sup>15</sup>, a higher proportion (48.1%) of caregivers indicated a high burden when the caregiver burden assessment questionnaire was used. The mean score was higher in the Mishra<sup>8</sup> and Harding et al.<sup>16</sup> studies because the study participants were from intensive care or high dependency

units.

According to our findings, the spouse faces a greater burden than in other relationships, which is consistent with the Zuo et al. study.<sup>17</sup> This may be due to the fact that they are emotionally attached to their life partner, and the whole responsibility gets shifted to their partner.

Furthermore, the burden of care in our study was much higher for caregivers who were working. This may be due to the fact that employees must adjust to their shift patterns, take extra time off for frequent hospital visits and hospitalizations, and complete their tasks. In contrast to our findings, unemployed caregivers in the Bekdemir study.<sup>14</sup> had a larger burden.

Additionally, caregivers who provided care for between one and five years had a greater strain than those who provided care for less than six months. Studies by Bekdemir,<sup>14</sup> Chiou et al.<sup>18</sup> and Zuo<sup>17</sup> show that providing care for a person over a longer period of time causes a greater burden.

When care was provided for 5 to 10 years, the mean burden score was lower. Caregivers who offer care for longer periods of time, according to Huang et al.<sup>19</sup> may experience less stress and anxiety because they have more time to customize their caregiving work to their priorities. The burden and its psychological impact might vary based on disease stage, caregivers' social assistance, and disease duration.

The burden was not significantly associated with the caregiver's age group, gender, marital status, degree of education, or socioeconomic situation. This is also true in Mishra<sup>8</sup> and Bekdemir<sup>14</sup> studies. Furthermore, male caregivers, caregivers with higher levels of education, and married caregivers had a larger burden, which was similar to the Zuo study.<sup>17</sup> When the wife becomes ill, the husband is suddenly burdened with increased care responsibilities. The circumstances exacerbate his emotional, financial, and time constraints significantly. Other researchers, including Orak<sup>20</sup> and Sanuade<sup>21</sup>, have discovered no significant relationship between gender and caregiver burden, which is consistent with our findings.

In our study and the study by Chiou et al.<sup>18</sup>, it was shown that caregivers with lower socioeconomic status have higher levels of caregiver burden because they may face out-of-pocket costs, such as travel expenses for illness treatment.

Caregivers of patients who were illiterate or had just completed primary school and caregivers of married patients had a significantly higher burden. This was in contrast to our findings in the Bekdemir study<sup>14</sup> in which caregivers of patients with higher education had a higher mean score. Patients with lower levels of education are more likely to

rely on their caretakers for treatment management, which increases the burden on caregivers.

In the regression analysis, the caregiver's working status and the patient's education level were significant, explaining 16% of the total variance. One of the determinants of caregiver burden in the Bekdemir research<sup>14</sup> was caregiver working status.

Problem-solving strategies were preferred by caregivers, while in the Kamarulbahri<sup>10</sup> and Kasi et al.<sup>22</sup> and Suriyamoorthi<sup>23</sup> studies, emotion-focused coping was preferred. According to Fortune et al.<sup>24</sup>, and Ong et al.<sup>25</sup> studies, a problem-focused approach was found to lessen caregivers' psychological distress in general.

According to our findings, respondents utilized positive/effective coping tactics such as religion, acceptance, informational support, and emotional support, whereas negative/ineffective coping approaches such as humor, self-blame, drug use, and denial were practically never used. The research conducted by Ong et al.<sup>25</sup> had similar results. The results of the current study support those of the Antony study<sup>26</sup> and the Mukwato study<sup>27</sup>, which found that the caregivers mostly used religion and informational support. Furthermore, Kamarulbahri<sup>10</sup> and other researchers<sup>28</sup> found that religion and acceptance were the most common coping techniques, whereas substance use was the least common. Religion is usually regarded as the most common coping method used by caregivers. It is thought to be an efficient coping mechanism, independent of religious belief.<sup>29</sup> In other words, spiritual belief enhances health and provides hope.<sup>10</sup> As a result, it has been found that patients who use religion as a coping mechanism are better able to manage and overcome more difficult life situations.<sup>29</sup>

Men mostly employed denial (avoidant), while women primarily utilized religion (emotionally focused), which was consistent with the Suriyamoorthi study.<sup>23</sup> The only characteristic significantly associated with an emotion-focused coping strategy in the Kamarulbahri research<sup>10</sup> was gender.

In contrast to the Suriyamoorthi research<sup>23</sup>, caregivers who were working were significantly more likely to use the denial mechanism. One characteristic that was consistent throughout both studies was that lower-income caregivers used more negative coping mechanisms.

In our study, religion had an inverse relationship with burden (ie, more religious caregivers had less burden), whereas caregivers who adopted self-distraction, active coping, and venting had a positive relationship (ie, a high burden). One component of the maladaptive (emotionally

oriented) coping method was venting, which explained 4% of the variance in the rise in burden score in our study and Ong et al. study.<sup>25</sup> According to the findings of the study by Kausar and Powell<sup>30</sup>, caregivers who used emotion-focused coping methods had more difficulties, resulting in poor adaptation, than those who used problem-focused coping strategies, which provided better results.

Substance use as a coping strategy, on the other hand, was rarely used in our study. This might be due to secrecy or a reluctance to accept the usage. According to a Ministry of Social Justice and Empowerment report<sup>31</sup>, a significant percentage of individuals in India use psychoactive substances, and substance use affects all demographic groups. The long-term effects of substance abuse, such as drinking too much or using other drugs can be stressful and harmful to the caregiver's health.

Table 1: Sociodemographic Details of Patients and their Caregivers

S.No	VARIABLE	PATIENT		CAREGIVER	
		Frequency (n)	%	Frequency (n)	%
1	<b>AGE:</b>				
	Early adulthood	11	11	46	46
	Middle adulthood	74	74	41	41
	Late adulthood	15	15	13	13
2	<b>GENDER</b>				
	Male	38	38	50	50
	Female	62	62	50	50
3	<b>MARITAL STATUS</b>				
	Married	95	95	78	78
	Unmarried	5	5	22	22
4	<b>EDUCATION STATUS</b>				
	Illiterate	47	47	29	29
	Primary	18	18	6	6
	Middle	16	16	14	14
	High	7	7	24	24
	Intermediate/ diploma	4	4	9	9
	Degree	8	8	18	18
5	<b>WORKING STATUS</b>				
	Working	17	17	69	69
	Not working	83	83	31	31
6	<b>DURATION OF CARE GIVING</b>				
	< 6 months			46	46
	6 months – 1 year			23	23
	1-5 years			26	26
	5-10 years			5	5
7	<b>RELATIONSHIP WITH THE PATIENT</b>				
	Spouse			34	34
	Parent/ Child			47	47
	Others			19	19
8	<b>SOCIOECONOMIC STATUS</b>				
	Upper middle			10	10
	Lower middle			19	19
	Upper lower			63	63
	Lower			8	8

Table 2: Analysis of The ZBI Scores In Relation to the Caregiver Variables

VARIABLE OF THE CAREGIVER	ZARIT BURDEN INTERVIEW SCORE				
	M	SD	F/t (df)	p value	Post Hoc test
<b>AGE:</b>					
Early adulthood	15.7	7.02	0.195 (2,97)	0.824	
Middle adulthood	15.3	7.42			
Late adulthood	16.7	8.04			
<b>GENDER</b>					
Male	16.7	7.54	1.369 (98)	0.174	
Female	14.7	6.90			
<b>MARITAL STATUS</b>					
Married	15.8	7.45	0.403 (98)	0.688	
Unmarried	15.1	6.67			
<b>EDUCATION STATUS</b>					
Illiterate	16.2	7.55	1.989 <sup>#</sup> (5,28)	0.112	
Primary	15.7	9.20			
Middle	12.0	3.80			
High	17.3	8.97			
Intermediate/ diploma	16.6	7.86			
Degree	15.1	4.82			
<b>WORKING STATUS</b>					
Working	17.4	7.55	4.310 (86) <sup>\$</sup>	<b>0.000*</b>	
Not working	11.9	4.87			
<b>DURATION OF CARE GIVING</b>					
< 6 months (1)	14.2	6.26	3.626 (3,96)	<b>0.016*</b>	3 > 1 <sup>@</sup>
6 months – 1 year (2)	15.8	7.32			
1-5 years (3)	19.11	7.85			
5-10 years (4)	10.6	7.16			
<b>RELATIONSHIP WITH THE PATIENT</b>					
Spouse (1)	18.12	7.58	3.577 (2,97)	<b>0.032*</b>	1 > 3 <sup>@</sup>
Parent/ Child (2)	15.02	7.27			
Others (3)	13.0	5.47			
<b>SOCIOECONOMIC STATUS</b>					
Upper middle	13.4	6.42	0.909 (3,96)	0.440	
Lower middle	16.3	8.30			
Upper lower	15.4	6.88			
Lower	18.9	8.74			

# welch value.

\* statistically significant.

\$- equal variance not assumed in t test

@- Tukeys post hoc analysis.

Table 3: Analysis Of The ZBI Scores in Relation to the Patient Variables

VARIABLE OF THE PATIENT	ZARIT BURDEN INTERVIEW SCORE				
	M	SD	F/t (df)	p value	Post Hoc test
<b>AGE:</b>					
Early adulthood (1)	11.9	4.37	3.7 (2,25) <sup>#</sup>	<b>0.039*</b>	2 > 1 <sup>&amp;</sup>
Middle adulthood (2)	16.2	7.58			
Late adulthood (3)	15.8	6.83			
<b>GENDER</b>					
Male	14.8	6.33	-1.049 (90) <sup>\$</sup>	0.297	
Female	16.3	7.77			
<b>MARITAL STATUS</b>					
Married	15.88	7.40	2.576 (7) <sup>\$</sup>	<b>0.036*</b>	
Unmarried	12.0	2.91			
<b>EDUCATION STATUS</b>					
Illiterate (1)	16.7	7.2	6.331 (5,23) <sup>#</sup>	<b>0.001*</b>	1,2 > 5 <sup>&amp;</sup>
Primary (2)	17.7	7.14			
Middle (3)	14.3	6.7			
High (4)	13.0	9.5			
Intermediate/ diploma (5)	10.0	1.7			
Degree (6)	14.0	4.06			
<b>WORKING STATUS</b>					
Working	16.8	7.69	0.704 (98)	0.489	
Not working	15.5	7.20			

# welch value.

\* statistically significant.

\$- equal variance not assumed in t test

@- Tukeys post hoc analysis.

& Games-howell

Table 4: Predicting Caregiver Burden using Multiple Regression Analysis

VARIABLE	ZBI score			
	B	95% CI	t	p
Constant	24.715	20.3-29.1	11.233	0.000
Caregiver working status	-5.284	-8.17 to -2.34	-3.632	0.000
Patient education level	-0.926	-1.78 to -0.078	-2.167	0.033

Note: R2 = .162, adj R2= 0.144, p < .001, F(2,97) = 9.36

Table 5: The Mean and SD of Primary Coping Styles

PRIMARY COPING STYLES	MEAN (max score 4)	SD
Problem- focused	2.28	0.45
Emotion- focused	2.15	0.27
Avoidant coping	1.63	0.37

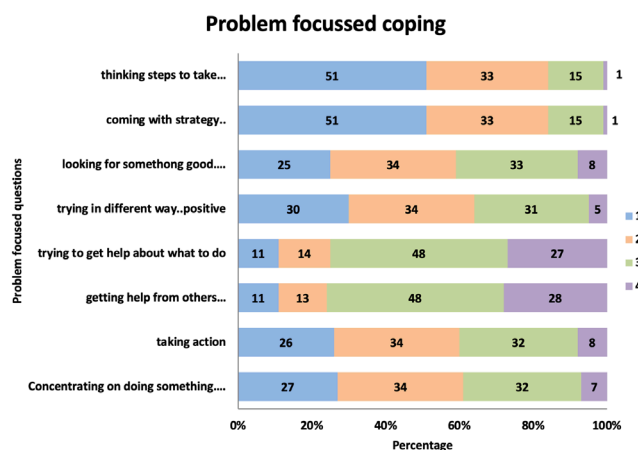


Figure 1: Problem Focused Coping Adopted by Caregivers of Cancer Patients

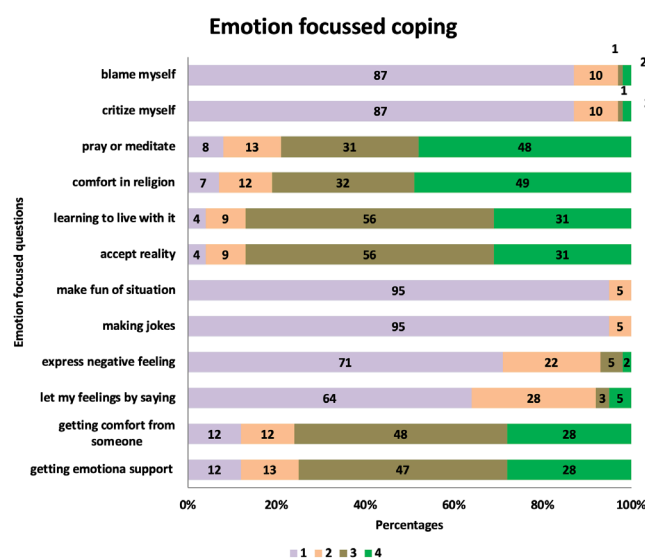


Figure 2: Emotion Focused Coping Adopted by Caregivers of Cancer Patients.

Figure 3 : Avoidant Focused Coping Adopted by Caregivers of Cancer Patients.

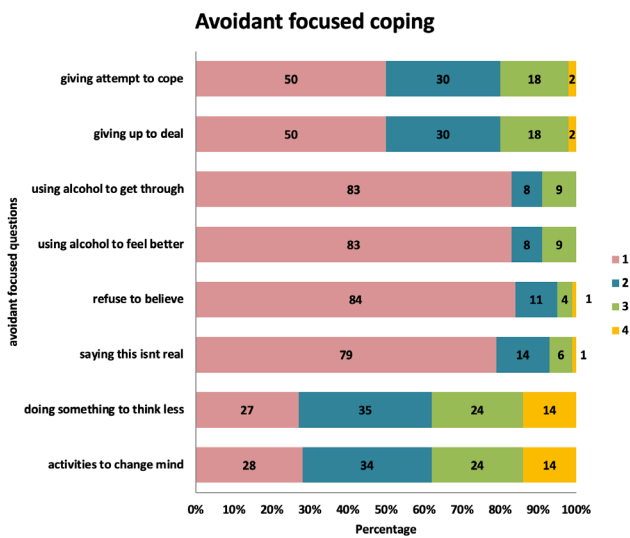


Table 6 : Comparison of the mean and SD of the Brief Cope Components by Gender

COMPONENTS	MEAN (SD)		t (df)	P VALUE
	MALE	FEMALE		
Self-distraction	2.26 (1.1)	2.15 (0.9)	0.542(98)	0.589
Active coping	2.28 (0.9)	2.13 (0.85)	0.833(998)	0.407
Denial	1.41(0.6)	1.19 (0.3)	2.388(92)#	<b>0.019</b>
Substance use	1.36(0.7)	1.20(0.4)	1.458(81)#	0.149
Emotional support	2.99 (0.8)	2.66(0.9)	1.88 (98)	0.06
Informational support	3.0(0.8)	2.8 (0.83)	1.137(98)	0.258
Behavioral disengagement	1.8(0.7)	1.72(0.8)	0.487(98)	0.627
Venting	1.47(0.5)	1.53(0.6)	- 0.548(98)	0.58
Positive reframing	2.26 (0.7)	2.12(0.7)	0.892(98)	0.375
Planning	1.92 (0.7)	1.72 (0.8)	1.303(98)	0.196
Humor	1.10 (0.2)	1.04(0.19)	1.172(98)	0.244
Acceptance	3.22(0.7)	3.14(0.7)	0.546(98)	0.586
Religion	3.0 (0.8)	3.36(0.78)	- 2.263(98)	<b>0.026</b>
Self-blame	1.12(0.3)	1.24(0.6)	- 1.115(98)	0.268

#- welch value.

Table 7: Caregiver Burden's Relationship with Brief Cope Subscale

COMPONENTS	CAREGIVER BURDEN (r)	p VALUE
Self-distraction	0.217	<b>0.030*</b>
Active coping	0.225	<b>0.025*</b>
Denial	0.1	0.324
Substance use	-0.043	0.668
Emotional support	-0.083	0.41
Informational support	-0.037	0.714
Behavioral disengagement	0.088	0.386
Venting	0.205	<b>0.04*</b>
Positive reframing	-0.084	0.408
Planning	0.057	0.574
Humor	-0.117	0.246
Acceptance	-0.109	0.283
Religion	-0.213	<b>0.033*</b>
Self-blame	0.017	0.867

\* Statistically significant p <0.005

## DISCUSSION

This was a cross-sectional study of caregivers of cancer patients receiving chemotherapy and radiotherapy in hospital wards. Data on the kind of cancer, its stage, the patients' socioeconomic situation, and the number of hours per day spent caring for the patients were not collected.

## CONCLUSION

This study suggests that by providing caregivers with community intervention, they can improve their adaptive coping capacities, especially through problem-oriented strategies combined with social support to minimize their burden. More research on the influence of caregiver burden on health is recommended.

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