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Research Article

**INVESTIGATING LEVELS OF CARE BURDEN IN FAMILY  
CAREGIVERS OF PATIENTS WITH CANCER IN THE CITY OF  
ILAM IN 2017****Milad Borji<sup>1</sup>, Hassan Nourmohammadi<sup>\*2</sup>, Akbar Mohammadi<sup>3</sup>, Asma Tarjoman<sup>3</sup>, Safoura  
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Sciences, Ilam, Iran<sup>3</sup> Student Research Committee, Ilam University of Medical Sciences, Ilam, Iran<sup>4</sup> Prevention of Psychosocial Injuries Research Center, Ilam University of Medical Sciences, Ilam, Iran.**Abstract:**

**Background:** Since patients within a community are in need of help from caregivers, the health status of caregivers is of utmost importance. Thus, the purpose of the present study was to determine the levels of care burden among family caregivers of patients with cancer. **Materials and Methods:** In this descriptive cross-sectional study, a total of 220 caregivers of patients with cancer in the city of Ilam in 2017 were surveyed. The instruments used in this study included a Demographic Characteristics Questionnaire and the Zarit Caregiver Burden Interview. The data obtained from this study were analyzed using descriptive statistics [means and standard deviations] and inferential statistics [Chi-square test and paired and independent t-tests].

**Findings:** Of the 220 caregiver participants in our study, 102 were male [46.4%], 116 were non widowed [52.7%], 77 were housewives [35%], 87 were parents [39.5%], and 135 were high school graduates [61.4%]. The average income level was 145 [65.9%] and none of the caregivers were caregivers without pressure. Most of the patients [201; 91.4%] had received intensive care. The average perceived caring pressure of caregivers was above 63.64% [17.77]. **Conclusion:** Considering the high levels of care burden in caregivers of patients with cancer and given the different effects of care burden on quality of life and health status of the caregivers, it is necessary to administer interventions in order to reduce levels of care burden among caregivers of patients with cancer.

**Keywords:** Care Burden, Caregivers, Cancer

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**INTRODUCTION:**

Cancer refers to cell masses characterized as malignant. The given term was first used to describe more than 100 diseases in which cells multiply without limits or destroy normal and healthy tissues [1]. Thus, knowing about cancer diagnoses can be physically and psychologically stressful for patients and their families [2]. Anxiety and other mood disorders may occur in patients immediately after the diagnosis of cancer [3].

Since patients within a community are in need of help from caregivers, care health status is of utmost importance [4]. In most cases, families are responsible for maintaining and caring for patients. As one of the family members suffers from a serious injury, their needs increase and family members need to make efforts to meet them [5]. In addition, patients who benefit from family support have much more ability to adapt to the disease and they are endowed with increased survival rates compared with patients lacking family support [6].

In fact, informal caregivers are those individuals giving help to patients to perform their daily living activities such as feeding, movement; psychological, emotional, and social support, interactions with medical teams about changes, medication therapy, and provision of financial help. These people are extremely involved in providing care for patients and helping them to adjust to the illness and manage chronic diseases. Since these informal caregivers spend most of their time with patients, they tend to forget their own needs and their lifestyles are also changed. Indeed, the effects of the disease on patients are not only physical and psychological; they also profoundly impact the lives of their caregivers [7, 8]. In this respect, care burden refers to the level of distress one feels as a result of patient care, which can have different dimensions [9]. In fact, care burden is an issue that is problematic both for patients and caregivers, and they both can suffer because care burden is not regarded as a disease and its nature is not well understood [8, 10]. It should be noted that care burden is quite personal. Understanding this concept is also personal and inherent and it includes components such as a time-dependent, developmental, physical, social, and emotional care burden [11]. Among the effects of care burden are; disrupted patient care activities, recreation, and social interactions associated with care or even disabilities or diseases [12].

In general, caregivers are faced with two major problems related to patient care: treatment problems and compatibility with care responsibilities [13]. When a person is under the influence of stressful situations, the use of coping methods to deal with stress is essential because effective adaptation can protect them from damage as well as physical and mental problems [14]. Therefore, this study aimed to determine the levels of care burden in family caregivers of patients with cancer.

**MATERIALS AND METHODS:**

This descriptive cross-sectional study was approved by Ilam University of Medical Sciences with the code of ethics in research [ir.medilam.rec.1396.72] In this study, 220 caregivers of patients with cancer in the city of Ilam, in 2017 were recruited. The inclusion criteria for caregivers in this study were meeting a minimum level of reading and writing literacy, falling in the age range of 18 to 75 years, a lack of any diagnosed mental illness, having at least 6 months of patient care, and playing a major role in giving care for the patient as parent, sister, brother, spouse, child, daughter-in-law, or son-in-law. The exclusion criteria from the present study included the response of *Yes* by caregivers to the item “*I have lots of abilities in performing my own personal activities*” and the item “*I never ever need care.*” That is, if the patients answered *Yes* to these two items, they were excluded from the study.

The instruments used in this study were a Demographic Characteristics Questionnaire and the Zarit Caregiver Burden Interview comprised of 22 items [with a score range between 0 and 88] in the domain of care issues. Each item was also scored 0 [never], 1 [rarely], 2 [sometimes], 3 [often], and 4 [always] and the higher the scores obtained by caregivers the higher their level of care burden. The reliability and the validity of the given questionnaire has been confirmed in previous studies [15, 16]. After obtaining permission from the Council of Ethics in Research at Ilam University of Medical Sciences and acquiring informed consent from patients, the researcher began the study. The caregivers were assured that the information obtained from this study would be kept confidential and their privacy would be maintained. The data obtained from this study was analyzed using the SPSS18 software including descriptive statistics [means and standard deviations] and inferential tests [Chi-square tests and paired and independent t-tests].

## Findings

**Table 1: Demographic characteristics of family caregivers of patients with cancer**

Variable		N [%]	M [SD]
gender	Male	102[46.4]	58.79[16.04]
	Female	118[53.6]	67.46[18.45]
Marital status	Has spouse	104[47.3]	60.86[17.32]
	No spouse	116[52.7]	65.75[18.10]
Employment	Employed	53[24.1]	60.71[14.79]
	Unemployed	36[16.4]	50.11[18.24]
	Housewife	77[35]	66.48[15.42]
	Student	54[24.5]	70.68[18.66]
Family relations	Mother	7[3.2]	83.85[6.06]
	Father	6[2.7]	69.16[19.43]
	Sister	6[2.7]	51.83[9.30]
	Brother	19[8.6]	72.89[19.27]
	Spouse	76[34.5]	61.50[15.17]
	Child	87[39.5]	64.05[17.78]
	Son-in-law	12[5.5]	52.91[24.35]
	Daughter-in-law	7[3.2]	54.00[17.86]
Education	Illiterate	37[16.8]	63.75[13.83]
	Diploma and below diploma	135[61.4]	62.88[17.53]
	Academic	48[21.8]	64.79[21.49]
Income	Low	46[20.9]	65.02[18.35]
	Moderate	145[65.9]	62.44[18.61]
	High	29[13.2]	65.96[12.59]

According to the results listed in Table 1, more male caregivers were 102 [46.4%], no widowed 116 [52.7%], housewives 77 [35%], child ratio 87 [39.5%], diploma graduates 135 [61.4%]. The average income level was 145 [65.9%]. In addition,

the level of care was highest in women, non-spouses, students, mothers, college educators and high-income people.

**Table 2: Distribution of samples in terms of levels of care burden**

care burden	N [%]
No or low levels of care burden [0–20]	0[0]
Moderate levels of care burden [21–40]	19[8.6]
Severe levels of care burden [22–88]	201[91.4]
Total[M[SD]]	63.64[17.77]

As can be seen from Table 2, none of the caregivers were caregivers without pressure and most of them had 201 [91.4%] intensive care. Additionally, the average perceived caring pressure of caregivers was above 63.64 [17.77].

### DISCUSSION:

Cancer causes a lot of changes in patients[23]. Cancer is considered to be a disease with unique and severe impacts on patients and their caregivers. Patients with cancer are also in need of long-term care at home, which can lead to changes in life routines [18]. Therefore, the present study aimed to determine the levels of care burden in family caregivers of patients with cancer.

The findings of this study revealed that most caregivers had a high school diploma or lower education level. In the study by Safaeian *et al.*, the majority of caregivers of patients with cancer had only a primary school level of education [8] and the caregivers recruited in the study by Haghgoo *et al.* had undergraduate education [19] which was not consistent with the results of the present study. In the present study, caregivers held high school diplomas or lower degrees. Also in the present study, the bulk of caregivers had a child-parent family relationship that was in line with the findings of the study by Haghgoo *et al.* [19] and Safaeian [8] in which majority of caregivers were patients' children. The results also showed a statistically significant difference between levels of care burden and caregivers' gender. Specifically, women suffered higher levels of care burden than men. In the study by Safaeian *et al.* [8], no significant difference was found between perceived care burden by male and female caregivers, which is inconsistent with the results of the present study.

Moreover, the findings of this study suggest that severe levels of care burden were much more reported among caregivers than in previous studies. The results of the study by Safaeian *et al.* surveying care burden among caregivers of patients with cancer also revealed that more than half of caregivers of patients with cancer had experienced severe and very

severe levels of care burden [8]. In the investigation by Salmani *et al.*, all caregivers of patients with cancer had severe levels of care burden [7]. The findings of the study by Papastavrou *et al.* also revealed that caregivers of patients with cancer had suffered from high levels of care burden [20]. Moreover, care burden perceived by mothers and fathers of children with cancer was more than average as reported in the study by Valizadeh *et al.*

[18]. This is consistent with the results of the present study, indicating high levels of care burden in caregivers of patients with cancer.

However, the results of some studies were not consistent with the findings of the present study indicating high levels of care burden among caregivers; for example, the results of the study by Abbasi *et al.* investigating care burden in caregivers of hemodialysis patients showed that care burden in caregivers was at a moderate level [10]. In the study by Bamari *et al.*, most of the caregivers of patients with diabetes [21] and the bulk of caregivers of patients with mental disorders in the study by Haghgoo [19] had similarly experienced moderate levels of care burden. Furthermore, the findings of the study by Cotelito *et al.* on caregivers of patients with Alzheimer's disease demonstrated that a quarter of caregivers had experienced high levels of care burden [22] which was inconsistent with the results of the present study. The reason for the differences in the results of the present study with those of the mentioned investigations could be that cancer and its impact on caregivers is different from other diseases and could consequently influence the levels of care burden in different ways. Additionally, cultural and demographic conditions as well as demographic characteristic of patients could have their own impacts on levels of care burden.

One limitation of this study was the use of questionnaires [self-report data], which can affect the accuracy of the information reported; therefore, it was recommended to us to conduct qualitative studies or clinical trials in order to investigate levels of care burden among caregivers and provide more accurate information for researchers. Given that the present study was cross-sectional, it was suggested to do further studies with larger sample sizes in other cities in order to investigate levels of care burden in caregivers of patients with cancer and to provide researchers with more complete and accurate information.

### CONCLUSION:

Considering the high levels of care burden in caregivers of patients with cancer and given the fact that care burden can have various impacts on quality of life and health status of caregivers, it is necessary to administer interventions in order to reduce the levels of care burden in caregivers of patients with cancer.

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