Burden of Care and Its Relationship with Sleep Quality of Cancer Patients’ Caregivers

Mohammadreza Boostaneh  
Zanjan University of Medical Sciences

Mohammad Zirak (✉ mohammadzirak@gmail.com)  
Zanjan University of Medical Sciences  https://orcid.org/0000-0002-2858-2837

Ramezan Fallah  
Zanjan University of Medical Sciences

Research Article

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Abstract

**Purpose:** This study aimed to assess the burden of care and its relationship with sleep quality of cancer patients’ caregivers.

**Methods:** This descriptive-correlational study was conducted in a referral center of cancer in Zanjan, northwest of Iran. 135 caregivers of cancer patients were recruited through convenience sampling method. The data were collected using a demographic characteristics questionnaire, Novak and Guest’s caregiver burden inventory and Pittsburgh sleep quality index (PSQI). The collected data was analyzed using descriptive and inferential statistics.

**Results:** The mean (± SD) age of the participants was 39.71 (± 10.74) years. The mean (± SD) burden of care and sleep quality of the participants was 45.22 (± 17.75) and 8.88 (± 4.21), respectively. It was found that there is a significant positive relationship between burden of care and quality of sleep scores (r = 0.65, P < 0.001).

**Conclusion:** cancer patients’ caregivers endure a remarkable burden of care and their sleep quality is undesirable. Results indicated that an increase in the burden of care reduces the caregiver’s quality of sleep. High burden of care and poor sleep quality may reduce the quality of the provided care that increase the costs and weakens the disease prognosis. According to the study results, reducing burden of care is an effective strategy regarding improving the caregivers’ quality of sleep that can improve the quality of provided cares by caregivers.

Introduction

Cancer is one the most important leading causes of death around the world [1, 2]. It is estimated that about 10 million cancer related death occurred in 2020 worldwide [1]. Cancer is among the major challenges of health systems and imposes heavy costs on the health system, patients, families, and communities [2, 3].

Recently, due to increase of life expectancy and changes in life style, the incidence of cancer is growing worldwide, especially in developing and less developed countries [2]. It is estimated that the incidence of cancer will be more than 2-fold by 2035[4] and one in 5 will develop cancer during their life [1]. About 19 million new cases of cancer have been reported in 2020 that most of them were related to developing and less developed countries [1]. The age-standardized ratio (ASR) of cancer per 100000 was 222 for male and 186 for female in 2020 globally [1]. In Iran the ASR of 127.7 were reported in general population, 134.7 for males and 120.1 for females [4]. Compared to the global statistics, Iran is in a better situation in terms of incidence of cancer; but, the growing incidence rates of cancer in Iran is a worrying issue that needs more attentions[4, 5].

In recent years, due to advances in diagnostic and therapeutic techniques and improved quality of cares, a large number of the cancer patients survive from cancer and the number of the cancer survivors is
increasingly growing [6]. The chronic nature of cancer and treatment-related complications create numerous new physical and psychological needs in patients that increase patients’ demand for care [7–9]. So, most of the survivors need long-term cares and follow-up [10].

Therapeutic advancements, changes in attitudes towards treatment and care, economic and political transformations in recent years have led to the development of outpatient and in-home care plans. Transferring of care plans to homes, shifts the burden of care from medical staff to informal care provider that include family members, patient’s spouse, friend or relative [11–13]. Burden of care is the load that caused by caring for a patient that includes some physical, psychological, and social strains experienced by caregivers [13, 14]. Previous studies showed that cancer patients’ caregivers endure moderate to high levels of care burden [15, 16]. High burden of care can threaten the caregiver's physical and mental health status and negatively affect various aspects of their life [17]. Caregivers should provide the patients demands beside their daily tasks and responsibilities. So, caring of a cancer patient is a stressful task for informal caregiver that may interrupt their daily living [18].

Sleep quality is one of the most important aspects of life that may be affected by burden of care and most of the cancer patient’s caregivers complain of poor sleep quality. Previous studies showed that there is a significant relationship between burden of care and sleep quality; as an increase in the burden of care reduced the sleep quality of the caregivers [15, 19]. Poor sleep quality can lead to several physical and psychological problem including psychiatric disorders, irritability, disturbed or negative thoughts, decreased concentration, poor decision-making, low motivation, cardiovascular diseases, immunodeficiency disorders and memory impairment [20].

Iran is a developing Islamic Middle Eastern country. According to Iran's latest National Census of Population, this country has a population of about 85 million people [21]. Iran's healthcare system is less developed than those of developed countries. Moreover, lack of hospital beds, large number of patients, shortage of nursing staff and care centers, and the COVID-19 pandemic crisis [22] imposed heavy care burden on caregivers. In addition, due to high patient-to- nurse ratios, nurses are unable to meet all the care needs of patients in Iran's medical centers [23]. These conditions may put enormous pressure on informal caregivers. Considering the important role of caregivers in speeding up patient recovery and lack of information on burden of care and its effect on sleep quality of cancer patients’ caregivers in Iran, this study aimed to assess burden of care and its relationship with sleep quality of cancer patients’ caregivers in Zanjan Province, which has been recognized as a most important north-western province of Iran in the treatment, diagnosis, and prevention of cancer.

**Methods**

This descriptive-correlational study was conducted in oncology wards of teaching hospitals affiliated to Zanjan University of Medical Sciences, Zanjan Province of Iran in 2020.

**Participants**
The participants consisted of caregivers of cancer patients. In this study cancer patients were those who had been diagnosed by an oncologist based on specific clinical and paraclinical examinations and tests. The researchers enrolled the main caregivers (i.e. caregivers who participated in most patient care activities and spent most of their times with the patient in comparison with others) who were over 18 years of age, had at least three months of caregiving experience and had no underlying disease. Caregivers of patients who had been hospitalized in intensive care units due to aggravation of their clinical conditions were excluded.

**Sample size and sampling**

The sample size was determined as 113 based on the findings of similar studies [15, 24] (90% power, 95% CI), and using the related statistical formula (Figure 1). In this study considering potential attrition rate and uncompleted questionnaire rate of 20%, the final sample size was calculated at least 135 eligible participants. In this study the eligible participants were selected using a convenience sampling method. In this regard one of the researchers (MB) was present at the research setting and assessed the potential participant according the inclusion criteria and then invited them to the study. Sampling continued until reaching to 135 participants and it lasted from July to September 2020.

After obtaining the approval of the Ethics Committee of Zanjan University of Medical Sciences and necessary permissions, as well as permissions from authorities of the selected hospitals and wards, the researchers distributed the questionnaires among the eligible participants by observing necessary health protocols to prevent COVID-19 infection. In addition, the researchers tried to schedule the questionnaire distribution process in a way to prevent the disruption of treatment and caregiving activities. In addition, the researchers completed the questionnaires for caregivers who were unable to fill out the forms themselves.

**Data collection**

A demographic questionnaire, Novak and Guest’s Caregiver Burden Inventory and Pittsburgh Sleep Quality Index (PSQI) were used to collect the data.

**Demographic questionnaire**

This questionnaire was used to collect information about the age, gender, educational status, marital status, job status, monthly income, relationship with the patient, duration of care, type of patient’s disease and duration of diagnosis. Content validity of the questionnaire was assessed and approved by 10 faculty members of Zanjan University of Medical Sciences.

**Novak and Guest’s caregiver burden inventory**

This inventory was developed by Novak and Guest (1989) to measure the burden of caregiving activities[25]. This 24-item questionnaire consists of 5 subscales including a) Time-dependent burden (5 items), b) Developmental burden (4 items), c) Physical burden (5 items), d) Emotional burden (5 items),
and e) Social burden (5 items). Each item is scored on a five-point Likert scale ranging from not at all (score 0) to very much (score 4). The total score ranges from 0 to 96 and higher scores indicate greater burden of care. Novak and Guest reported a good validity and reliability for this standard inventory. They reported the Internal consistency reliability (Cronbach's alpha) for the 5 domains ranging from 0.73 to .85[25]. Shafeizadeh et al. reported a Cronbach's alpha of 0.96 and Abbasi et al. reported a Cronbach's alpha 0.80 for this scale. [26, 27]. In the present study, Cronbach's alpha was 0.88, which indicates good reliability of the research tool.

**Pittsburgh sleep quality index (PSQI)**

The Pittsburgh sleep quality index was used to assess the sleep quality of cancer patients' caregivers in this study. This scale has been designed by Buysse et al.[28]. In this study the Persian version of the scale was used [29]. This scale comprised of 18-item that categorized in 7 subscales including subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbance, sleeping medication use, and daytime dysfunction. Each subscale is rated on 0 to 3 score. The scores of seven subscales are then summed up to yield a total score which ranges from 0 to 21. Scores more than 5 considered as disturbed sleep quality and higher PSQI scores indicate more poor sleep quality. Boyce et al. reported an acceptable validity and reliability for this standard index (Cronbach's alpha = 0.83)[28]. Cronbach's alpha of the Persian version of this index was 0.77 [29]. In this study, a Cronbach's alpha of 0.76 was calculated.

**Data analysis method**

The data were analyzed using SPSS ver.16 software. Descriptive statistics (number, percent, mean, standard deviation, and descriptive tables) were used to analyze the participants’ demographic characteristics, burden of care, and sleep quality. Also inferential statistics (Independent t-test, analysis of variance, multiple regression analysis, and Pearson correlation) were used to compare means and to investigate the relationships of burden of care with the participants’ demographic characteristics and sleep quality.

**Results**

135 cancer patients’ caregivers participated in this study. The mean (± SD) age of the participants was 39.71(± 10.74) years (ranged 19 to 70). Of the participants, 71 (52.6%) were female, 111 (82.2%) were married and the most common cancer was carcinoma (57.8%). Full characteristics of the participants are presented in table 1.

Analyses showed that the mean (± SD) of burden of care was 45.22 (± 17.75). The mean (± SD) of the subscales of burden of care were as follow: time-dependent burden (13.54 ± 5), developmental burden (10.64 ± 4.97), physical burden (7.51 ± 4.70), emotional burden (4.90 ± 3.96), and social burden (8.62 ± 4.61). Results showed that about 80% of the participant had PSQI score above 5 and the mean (± SD) sleep quality of the participants were 8.88 (± 4.21).
A significant relationship was found between burden of care and sleep quality scores of the caregivers \( (r = 0.65, P < 0.001) \), as an increase in the burden of care reduced sleep quality of the caregivers. Also, Caregiver’s educational status and patient’s care needs had significant relationships with caregiver’s burden of care. So that, Illiterate people and individuals who stated that their patients have higher care needs experienced greater burden of care than others. More information is provided in Tables 2 and 3.

In this study a multiple linear regression analysis model was designed to accurately investigate the relationships between the research variables and to predict burden of care based on the demographic variables. Based on the results, the model predicted 52% of changes in burden of care and patient’s care needs predicted the highest percentage of changes in burden of care \( (F=23.53, P<0.050, R^2=0.52) \). More details are presented in Table 4.

**Discussion**

This descriptive-correlational study aimed to measure burden of care and investigate its relationship with sleep quality of cancer patients’ caregivers in Zanjan, 2020. It was found that cancer patients’ caregivers endured a substantial burden of care and their sleep quality is remarkably poor. Also, a relatively strong relationship was found between burden of care and sleep quality of the caregivers, as an increase in the burden of care reduced the sleep quality of the caregivers.

This study revealed that cancer patient caregivers experienced a remarkable burden of care. This result is similar to previous studies that indicted cancer survivors’ caregivers endure a moderate to high level of burden of care [15, 16, 19, 27]. So, cancer patients’ caregivers as a neglected group need more attention. High burden of care increases susceptibility to physical, psychological, and financial problems, and at the societal level, it leads to various occupational problems. These problems finally may decrease the quality of the care provided by caregivers [30, 31]. Given the burden of care carried by cancer patients’ caregivers, healthcare systems need to take necessary interventions to support these individuals by creating a balance between the care needs of patients and available caregiving resources [32]. These caregivers must be supported financially, psychologically, and socially. Also, distribution of the burden of care among different family members, close friends, and relatives can also mitigate the caregiver burden.

A worrying result was that the sleep quality of cancer patients’ caregivers is not desirable and most of them suffered from poor sleep quality. Sleep disturbance is a common problem within cancer patients’ caregivers so that using similar tools, Wong et al. [15]/Lee et al. [33], and Al-Daken et al. [19] reported PSQI scores of 8.50, 9.09, and 9.1, respectively. These findings indicate that the sleep quality of these caregivers is remarkably disturbed. Disturbed sleep can decrease the caregivers’ quality of life and on the other hand, it may adversely affects the quality of provided care by caregivers [34, 35].

Results revealed that sleep quality of caregivers decreased along with increasing of burden of care. This result is consistent with previous studies [15, 19, 33]. Poor sleep quality may lead to numerous problems. Besides increasing the risk of psychological disorders and reducing the quality of care and quality of life, poor sleep quality can also result in the adoption of negative coping techniques such as alcohol use,
excessive use of certain medications, and drug abuse, which may in turn exacerbate sleep problems and may even create new problems and increase burden of care [36]. Therefore, improving the sleep quality of cancer patients’ caregivers is essential, and reducing their caregiving burden is an effective strategy in this regard. Psychological interventions, exercise programs, acupressure, reflexology, music therapy, and massage therapy are also suggested to improve the sleep quality of these individuals [37].

It was found that burden of care had significant relationships with some sociodemographic characteristics of the participants. Based on the regression model results, the independent variable of patient’s care needs predicted the highest percentage of burden of care, as high care needs intensified the burden carried by a caregiver. Jafari et al. [38] and Mirhosseini et al. [39] reported similar results in their studies. Increasing a patient’s needs dramatically decreases his/her independence in daily activities [7], and thereby increases the responsibilities of the caregivers, as well as the care burden carried by the caregivers [15]. Therefore, special attention must be paid to caregivers of cancer patients with greater caring needs.

Educational status of caregivers had an indirect relationship with burden of care. This is in line with the findings of Bakım et al. [40]. Caregivers with low levels of education cannot use modern information and communication tools, are unable to effectively communicate with others, and typically come from low social class backgrounds; therefore, they cannot easily handle various problems [40, 41]. Unlike the present findings, Schwartz et al. [42] reported that caregivers with higher levels of education experienced greater burden of care. The difference may be due to socio-cultural differences between the two communities. Therefore, healthcare systems must expand their training programs on the nature of cancer and relevant care practices, especially for less educated people. Providing caregivers with educational packages in the form of films, booklets, pamphlets or group training programs (e.g. seminars and workshops) seem to reduce part of the care burden experienced by these individuals.

In contrast with the researchers’ assumptions, a caregiver income level was not associated with his/her burden of care. This is inconsistent with the findings of previous studies [15, 37, 41]. This may be attributed to differences in the study samples and populations. Unlike similar studies, in this study most of the costs were covered by insurance and charity institutions. Patients and caregivers did not have to pay much for the services they received; therefore, it seems appropriate financial, psychological, and social supports are vital for reducing levels of burden of care.

**Conclusion**

Cancer patients’ caregivers endure a remarkable burden of care. Patient’s care needs increase burden of care, and less educated caregivers experience greater burden. Sleep quality of cancer patients’ caregivers is undesirable, and an increase in the burden of care reduces the sleep quality of the caregivers. Besides reducing the quantity and quality of services provided by caregivers, high burden of care and poor sleep quality may also exacerbate the disease, impose heavy costs on families and health systems, and result in poor prognosis.
Clinical implications

This study showed that cancer patient caregivers endure a remarkable burden of care and their sleep quality is interrupted. The present findings can help medical and research communities to develop suitable plans for supporting caregivers. The findings also provide nurses with a holistic view to extend their services beyond patients by supporting caregivers, and thereby substantially improve the quality of their services.

Research limitations and suggestions for future studies

Using three questionnaires and credible methods, the researchers attempted to collect accurate and valid data; however, due to using a non-probability sampling, the findings may not precisely reflect all facts about the research variables and concepts; therefore, the results are suggested to be carefully generalized to other populations. Researchers are suggested to carry out studies on different populations and using other methodologies such as qualitative approaches.

Declarations

Funding

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Conflict of interest

The authors declare that they have no conflict of interest.

Availability of data and material

The authors attest that, if requested by the editors, they will provide the data/information or will cooperate fully in obtaining and providing the data/information on which the manuscript is based.

Code availability

Not applicable

Authors’ contributions

At the present paper MZ and MB are responsible for design, data gathering, analyzing and draft of the article. MZ and RF read and reviewed the analyzing process and had given main comments during the analyzing and writing process to improve the scientific quality.

Ethics approval

The study was approved by the Research Council and the Ethics Committee of Zanjan University of Medical Sciences. The research conforms to the provision of the Declaration of Helsinki in 1995.
Ethical code

IR.ZUMS.REC.1399.257

Consent to participate

Before collecting the data, the participants were provided with information about the research and its objective and each participant completed a written informed consent prior to participation. They were also assured about the confidentiality of their information, and their right to leave the study at any stage.

Consent for publication

All authors approved the manuscript content and consented to publish it.

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Tables
Table 1: Demographic characteristics of participants

| Variable                        | Number (%)   |
|---------------------------------|--------------|
| **Type of patients’ disease**   |              |
| Carcinoma                       | 78(57.8)     |
| Leukemia                        | 22(16.3)     |
| Sarcoma                         | 12(8.9)      |
| Lymphoma                        | 14(10.4)     |
| Metastatic                      | 9(6.7)       |
| **Caregiver’s gender**          |              |
| Female                          | 71(52.6)     |
| Male                            | 64(47.4)     |
| **Caregiver’s marital status**  |              |
| Single                          | 24(17.8)     |
| Married                         | 111(82.2)    |
| **Caregiver’s educational status** |          |
| Illiterate                      | 17(12.6)     |
| Under diploma                   | 55(40.7)     |
| diploma                         | 40(29.6)     |
| Above diploma                   | 23(17.1)     |
| **Caregiver’s relation to the patient** |        |
| Spouse                          | 28(27.7)     |
| Parents                         | 10(7.4)      |
| Child                           | 82(60.7)     |
| Other                           | 15(11.1)     |
| **Caregiver’s job status**      |              |
| Housewife                       | 60(44.4)     |
| Unemployed                      | 9(6.7)       |
| Self-employed                   | 58(43)       |
| Employee                        | 8(5.9)       |
| **Patient’s care needs**        |              |
| Low                             | 13(9.6)      |
| Moderate                        | 69(51.1)     |
| High                            | 53(39.3)     |
| **Caregiver’s income**          |              |
| low                             | 70(51.8)     |
| moderate                        | 48(35.6)     |
| high                            | 18(12.6)     |
| **Duration of care**            |              |
| < 1 year                        | 69(51.1)     |
| 1-3 years                       | 56(41.5)     |
| > 3 years                       | 10(7.4)      |
| *Caregiver’s age (M±SD)         | (39.71 ± 10.74) |
**Duration of diagnosis**(M±SD) (16.37 ± 19.04)

*per year

**per month

Table 2: Comparison of burden between qualitative variables

| variables                  | Burden of care | p-value |
|----------------------------|----------------|---------|
| Type of patients' disease  |                |         |
| Carcinoma                  | 47.91 ± 16.53  | > 0.050 |
| Leukemia                   | 39.04 ± 19.10  |         |
| Sarcoma                    | 41.04 ± 13.83  |         |
| Lymphoma                   | 41.11 ± 21.10  |         |
| Metastatic                 | 49.22 ± 21.71  |         |
| Caregiver's gender         |                |         |
| Female                     | 45.83 ± 16.34  | > 0.050 |
| Male                       | 44.56 ± 19.31  |         |
| Caregiver's educational status |         |         |
| Illiterate and under diploma | 52.82 ± 15.57 | < 0.050 |
| Diploma                    | 50.32 ± 18.25  |         |
| Above diploma              | 38.43 ± 17.15  |         |
| Relation to the patient    |                |         |
| Spouse                     | 46.67 ± 18.39  | > 0.050 |
| Parents                    | 51.10 ± 17.01  |         |
| Child                      | 44.59 ± 17.40  |         |
| Other                      | 42.06 ± 19.64  |         |
| Caregiver's job status     |                |         |
| Housewife                  | 45.53 ± 16.29  | > 0.050 |
| Self-employed              | 45.36 ± 19.03  |         |
| Unemployed                 | 39 ± 22.65     |         |
| Employee                   | 49 ± 13.96     |         |
| Patient's care needs       |                |         |
| Low                        | 34.46 ± 13.44  | < 0.001 |
| Moderate                   | 40.15 ± 17.45  |         |
| High                       | 54.47 ± 14.90  |         |
| Caregiver's income         |                |         |
| low                        | 44.94 ± 17.16  | > 0.050 |
| moderate                   | 45.64 ± 18.58  |         |
| high                       | 45.23 ± 18.82  |         |
| Duration of care           |                |         |
| < 1 year                   | 44.78 ± 16.93  | > 0.050 |
| 1-3 years                  | 45.44 ± 18.39  |         |
| > 3 years                  | 41.10 ± 21.31  |         |
Table 3: Correlation of burden of care with quantitative variables

| variable                  | burden of care |
|---------------------------|----------------|
| Caregiver’s age           | r = 0.15       |
| Duration of diagnosis     | r = 0.07       |
| Patient’s age             | r = 0.07       |
| Caregiver’s sleep quality | r = 0.65       |

Table 4: Multiple regression model for predicting burden of care

| Variable                        | B    | SE   | β    | T    | P-value |
|---------------------------------|------|------|------|------|---------|
| Constant                        | 17.46| 6.97 | 2.50 | 0.013|
| Caregiver’s educational status  | -3.73| 1.26 | -0.19| -2.95| 0.004   |
| Patient’s care needs            | 7.23 | 1.78 | 0.25 | 4.05 | 0.000   |
| Duration of diagnosis           | 0.132| 0.08 | 0.14 | 1.56 | 0.120   |
| Duration of care                | -2.55| 2.59 | -0.09| -0.98| 0.327   |
| Caregiver’s income              | 1.82 | 1.60 | 0.07 | 1.13 | 0.260   |

Figures

\[
\begin{align*}
    w &= 0.31 \\
    n &= \frac{(z_{1-\alpha} + z_{1-\beta})^2}{w^2} + 3, \\
    w &= \frac{1}{2} \ln \left( \frac{1 + r}{1 - r} \right) \\
    n &= \frac{(1.96 + 1.28)^2}{(0.31)^2} + 3 = 113
\end{align*}
\]

Figure 1

Sample size formula