



Unexpected changes and associated factors of care burden among caregivers of cancer patients one year after COVID-19 outbreak

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ABSTRACT

Purpose: The study aimed to evaluate the changes in the care burden and quality of life of caregivers of cancer patients and correlates of care burden during the COVID-19 pandemic.

Methods: This cross-sectional study used the census sampling technique with 260 cancer patients and their caregivers during January to March 2020 in northeast Iran. Data collection tools included the Novak and Guest Care Burden Scale, the SF-36 Quality of Life Questionnaire, and the Stress, Anxiety, and Depression Scale (DASS-21). Data were analyzed using descriptive and inferential statistics (independent *t*-test and multiple linear regression analysis).

Results: Baseline scores of care burden and quality of life in caregivers suggested mild to moderate care burden and a reasonable quality of life and moderate levels of stress, anxiety, and depression in patients. The post-outbreak mean scores of care burden and quality of life significantly decreased and increased, respectively ($p < .001$). Regression analysis showed that 39.3% of the changes in the care burden score during the pandemic could be predicted by studied variables. In exchange for increasing the quality-of-life score and daily care hours, the care burden score decreases and increases. The burden of care in caregivers was also related to the type of cancer. Care burden in the caregivers of patients with breast and neurological malignancies was lower than the caregivers of patients with gastrointestinal cancer ($p < .05$).

Conclusion: Despite the results obtained, supportive and educational interventions are needed to reduce the caregiver burden and improve the quality of life of caregivers and measure its impact on levels of psychological distress in their patients clinically.

1. Introduction

Patients with cancer in the active phase of treatment, under special treatment and care programs, have been more affected by the COVID-19 pandemic than other patient groups [1]. The COVID-19 outbreak has imposed burden on health institutes [2] and also

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changed the course of treatment for cancer patients; for example the delay rate in chemotherapy has increased significantly, with rates reported at 11.6% prior to and 14.2% following the outbreak [3]. Fear of disease progression, anxiety, and depression have been high in cancer patients during the COVID-19 pandemic [4]. Immunosuppression in cancer patients (due to the nature of their disease and treatment effects) has increased vulnerability to the effects of a COVID-19 infection. The multidimensional effects of COVID-19 was higher in cancer patients than in other type of patients [5].

Before the outbreak, patients faced several challenges associated with the psychological, social, economic and emotional consequences of cancer, along with physical problems [6]. Furthermore, patients with various cancers experience co-morbid psychological distress. For example, a study conducted in Iran showed that depression, anxiety, and stress prevalence in cancer patients was 28.4%, 43.2%, and 14.7%, respectively [7]. Cancer affects not only the patient, but also the family members who care for them who experience adverse outcomes [8]. Cancer treatment requires frequent periods of hospitalization in short-term care units, regular follow-up, and repetitive care in short or medium-term periods at home. Family caregivers are more stressed during the caring process for their loved-one, leading to stress, depression, and reduced quality of life [9,10]. The chronic nature of cancer causes patients and caregivers to lose control of their lives, with severe effects on social activities, work, marital, and family life, reducing their health status and quality of life [11]. The experience of high stress, burnout, and significant challenges associated with fatigue [12] negatively affects the coping ability of family caregivers and reduces the quality of care [13]. Before the outbreak, a study showed a significant level of care burden and its inverse association with quality of life [14]. There are several reasons why caregivers have experienced higher stress levels during the COVID 19 crisis; as cancer patients were immunocompromised and at higher risk for complications after contracting the virus, many were reluctant to seek medical treatment in hospitals, and delayed requesting medical care because these places are considered "dangerous" places for the disease [15]. The resulting disruption to communication with health care providers and postponement of appointments has resulted in keeping patients at home, which increases the strain and further decline of family economic conditions are among potential causes [16].

Given the new challenges faced by cancer patients and their families during the COVID-19 pandemic, the psychological barriers to the caring process needs to be considered more specifically. Therefore, this study aimed to determine the changes in care burden and quality of life and correlates of care burden among family caregiver's patients with cancer during the COVID-19 pandemic.

2. Materials and methods

Baseline data was collected in this cross-sectional study in two stages before the COVID-19 pandemic (from December 20, 2018 to May 10, 2019) and follow up data approximately one year after the outbreak (from January 3 to March 7, 2020) in caregivers of cancer patients in Shahroud, Iran. The first phase of the study was performed before the outbreak and the second was conducted during the sixth wave of COVID-19 which was the one of largest waves with the highest incidence and mortality of previous waves in Iran. Patients' psychological distress (including stress, anxiety, and depression) was measured at the second data collection point to assess whether this was associated with caregiver burden.

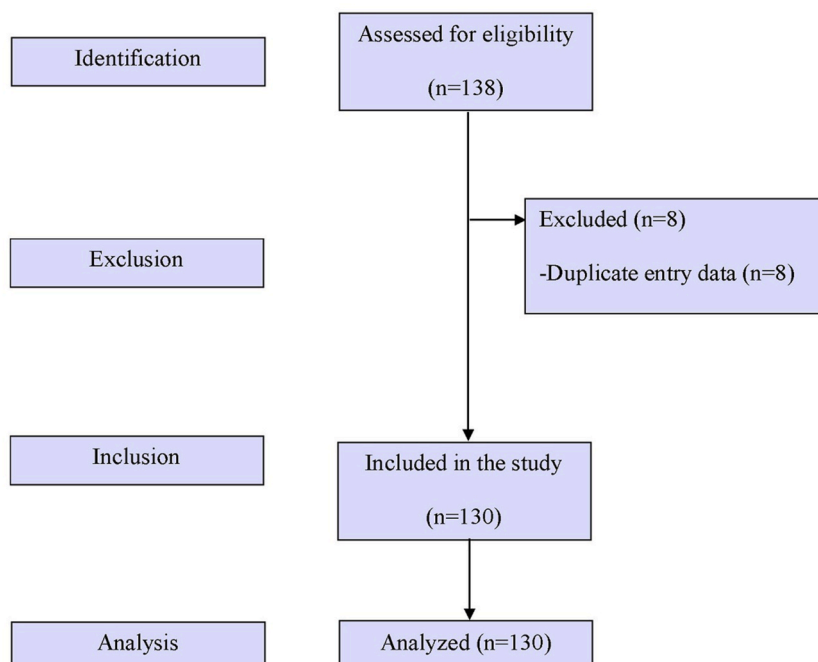


Fig. 1. STROBE Flow diagram shows the number of participants that were excluded and included in the study.

Two hundred sixty participants (130 patients and 130 caregivers) were recruited; eight were excluded from the study due to non-completion (Fig. 1). Inclusion criteria included age greater than 15 years (patients and caregivers), a definitive diagnosis of cancer by a physician with determined cancer stage, patient undergoing chemotherapy, full consciousness (GCS = 15), internet access and cyberspace, and no mental disorders and neuroleptic medications. Eligible caregivers and patients were selected by census sampling method and informed about the nature and procedure of this study by sending an invitation message to participate in the survey using WhatsApp. After obtaining the necessary permits, demographic information and care burden and quality of life in caregivers, and psychological distress in cancer patients were measured.

2.1. Instruments

2.1.1. Demographic information

Patient and caregiver age, gender, education level, marital, economic, secondary support courses and employment status were obtained along with caregiver-patient relation. Patient specific data was collected relating to type of cancer, stage of cancer, presence of underlying disease and patient's insurance coverage status. COVID-19 related items included history of COVID-19 in the caregiver, history of COVID-19 infection or death in the patient and caregiver relatives, follow-up news about COVID-19.

Outcome measures were the care burden and quality of life in caregivers and psychological distress in their patients, which were measured using self-report questionnaires.

2.1.2. The SF-36 Quality of Life Questionnaire

The SF-36 questionnaire (Appendix A) was used to assess the quality of life. The questionnaire has 36 items and evaluates eight subscales of emotional role, social function, physical function, vitality, physical role, general health, mental health, and physical pain. It also assesses two general measurements of a person's physical and mental dimensions. The total score of this scale was equal to sum of its subscales. The higher scores of SF-36 indicate higher levels of quality of life [17]. The SF-36 has a standard reliability coefficient of 77%–90% [18,19]. In the present study, Cronbach's alpha coefficient was evaluated equal to 0.88 for this scale.

2.1.3. Caregiver burden inventory (CBI)

Novak and Guest (1989) designed the CBI to measure objective and subjective care burden (Appendix B). This questionnaire has 24 items and five subscales (time-dependent, development, physical, social, emotional care burden). Caregivers' responses are measured on a 5-point Likert scale (Did not apply to me at all = 1 and applied to me very much or most of the time = 5), with scores ranging between 24 and 120 (24–47 mild, 48 to 71 moderate, 72 to 95 severe, and 96 to 120 very severe care burden). Total score of this scale obtained from sum of all item scores [20]. The reliability of this questionnaire was assessed by Abbasi et al. (2013), with Cronbach's alpha coefficient of CBI reported as 0.90, and the Cronbach's alpha coefficient of the subscales ranging from 0.76 to 0.82 [21]. In the present study, Cronbach's alpha coefficient was assessed as 0.91 for the total score and the range of this coefficient was 0.73–0.79 for its subscales.

2.1.4. Depression, anxiety, and stress scale (DASS-21)

The DASS-21 (Appendix C) is an abbreviated version of DASS-42 introduced in 1995 by Lovibond [22]. This scale is a standard tool with each item scored from 0 to 3, with seven items measuring stress, anxiety and depression. In DASS-21, seven items related to stress (2,6,8,11,12,14, and 18), seven items related to anxiety (1,4,7,7,15,19, and 20), and seven items related to depression (3,5,10,13,16, 17, and 21). Higher obtained scores indicate higher levels of each subscale symptom of psychological distress (anxiety, stress and depression). Scores on each subscale between 0 and 4 are considered normal, 5 to 11 moderate and more than 12 severe. Psychometric testing confirmed the validity and reliability of the scale with Cronbach's alpha values in a normative sample of 717 people for stress (0.81), anxiety (0.73), and depression (0.81). Antony et al. (2012) reported Cronbach's alpha coefficient for these factors for stress, depression and anxiety as 0.95, 0.92 and 0.97, respectively [23]. Mirhosseini et al. (2022) assessed its reliability in Persian version, with Cronbach's alpha values for stress (0.86), anxiety (0.87) and depression (0.92) reported [24]. The reliability of this tool was assessed according to Cronbach's alpha coefficient estimation for depression, anxiety, and stress subscales equal to 0.78, 0.82, and 0.77.

2.1.5. Statistical analysis

Data were analyzed using descriptive (frequency, percentage, mean, and standard deviations) and inferential statistics by independent sample *t*-test (to measure the changes in the scores of quality of life and care burden in two phases of sampling) and Multiple Regression Analysis by backward method (to evaluate the predictor factors of care burden during the pandemic). The significance level was considered 0.05.

3. Results

The majority of caregivers were married (85.5%) and just under half (45.5%) reported a moderate level of daily care. COVID affected a substantial number of caregivers, with 10.8% reporting that their relatives had a history of COVID-19 and 4.6% reporting a COVID-related family death. Most (94.6%) caregivers reported moderate monthly income. 36% of caregivers had a child-parent relationship. Caregivers followed COVID-related news for 1.1 ± 0.3 h a day. In this sample 31.5% of patients had gastrointestinal cancer, 20% had Grade G1 malignancy, and 33.1% had stage 2 disease. The majority of patients were covered by health insurance

(97.7%). On average, patients had been diagnosed with cancer for 1.7 ± 0.9 years. Additional demographic characteristics are listed in Table 1.

A proportion of patients reported moderate levels of stress (25%), anxiety (22.8%), and depression (21.7%). Additional information is shown in Table 2.

The mean scores of care burden and quality of life one year after the COVID-19 outbreak were 45.6 ± 9.5 and 75.7 ± 9.7 , which had a significantly decreased and increased compared to before the outbreak ($p < .001$) (Table 3).

A multiple linear regression model by the backward method showed that 39.3% of the variance of the care burden score is explained by the variables of quality of life, type of cancer and duration of daily care. Accordingly, for each unit increase in quality-of-life score and duration of daily care in caregivers, 0.17 and 1.26 units of care burden score decrease and increase, respectively. The care burden in the caregivers of patients diagnosed with neurological and breast malignancies was 6.94 and 3.53 units lower than caregivers of patients with gastrointestinal cancer (Table 4).

4. Discussion

The COVID-19 pandemic has widely affected patients and caregivers with negative psychosocial consequences [25]. Delays in cancer screening and treatment, lack of medication, and inadequate nursing care are commonly experienced by patients. Hospital closures, resource constraints, nationwide quarantines, and patients' reluctance to use health services due to infection concerns have contributed to the delay. Financial and social problems, isolation and emotional distress have also been reported. In addition to patients, their caregivers also have specific pandemic concerns about the possibility of cancer patients being infected with COVID-19 [26]. The present study showed that about a quarter of patients reported stress, and a fifth of them reported moderate anxiety and depression at moderate levels. The findings showed significant levels of psychological distress in cancer patients during the pandemic [27]. In line with the findings of the present study, Alrubai et al. (2021) also showed that about a quarter of patients (22.2%) experienced stress, and 36.4% and 43.2% of them experienced depression and anxiety at moderate levels [28].

The COVID-19 pandemic has also challenged caregivers about the conditions they face daily. Family caregivers became aware of the increased risk of COVID-19 for those they cared for and for themselves. During the COVID-19 pandemic, family caregivers care for patients without proper training in care, adequate medical equipment, support, and other resources [29]. Therefore, it is expected that the care burden experienced by these individuals will increase during the pandemic. Contrary to this expectation, the present study results showed that the burden of care reported by caregivers had decreased significantly compared to the pre-pandemic period. Also, well-being improvements are likely to result from the combined consequences of declining face-to-face clinical care and rigorous physical treatments, increased informal home care due to quarantine and protection measures, and the availability of remote psychosocial care [30]. Family caregivers are a valuable human resource during the current pandemic, which increases the health care capacity of the community overall [29].

The results of the present study showed that the quality of life among caregivers of cancer patients increased significantly one year after the outbreak. Contrary to the present finding, the results of the study by Suzuki et al. (2021) showed that the quality of life of caregivers of patients with dementia decreased during the pandemic [31]. In line with the possible explanations of the previous findings, it can be considered that caregivers may have adopted appropriate coping strategies to deal with the negative consequences of the pandemic and to deal with significant long-term daily constraints in their social life without deteriorating quality of life during this time. Nevertheless, the pandemic and the resulting quarantines have certainly affected the parameters of the present study. The

Table 1
Demographic characteristics of cancer patients and their caregivers.

Variable		Caregiver	Patients
		n (%)	n (%)
Gender	Male	69 (53.1)	60 (46.2)
	Female	61 (46.9)	70 (53.8)
Educational level	Primary school	15 (11.5)	47 (35.6)
	Secondary school	58 (44.7)	58 (44.6)
	Academic degree	57 (43.8)	25 (19.2)
Employment status	Housewife	50 (38.5)	63 (48.5)
	Self employed	37 (28.5)	28 (21.5)
	Employed	25 (19.2)	7 (5.4)
	Student	1 (0.8)	1 (0.8)
	Retired	17 (13.1)	31 (23.8)
Underlying disease	Yes	20 (15.4)	31 (23.8)
	No	110 (84.6)	99 (76.2)
Need for supporting associations	Yes	4 (3.1)	1 (0.8)
	No	126 (96.9)	129 (99.2)
History of COVID-19 infection	Yes	10 (7.7)	11 (8.5)
	No	120 (92.3)	119 (91.5)
	Mean (SD)	45.2 (10.5)	55.1 (10.7)

n: frequency; %:percent; SD: Standard deviation;

Table 2
Mean and standard deviation scores of stress, anxiety and depression in patients.

Variable	Mild	Moderate	Severe	Mean (SD)
	n (%)	n (%)	n (%)	
Stress	57 (62.0)	23 (25.0)	12 (13.0)	5.0 (4.9)
Anxiety	61 (66.3)	21 (22.8)	10 (10.9)	4.6 (4.1)
Depression	62 (67.4)	20 (21.7)	10 (10.9)	5.0 (4.6)

n: frequency; %:percent; SD: Standard deviation;

Table 3
Mean scores of care burden and quality of life before and one year after COVID-19 outbreak.

Variables	Before	After	t	P-value*
	Mean (SD)	Mean (SD)		
Care burden	55.9 (20.3)	45.6 (9.5)	5.56	<0.001
time-dependent	15.5 (5.7)	10.0 (3.3)	10.07	<0.001
Developmental	12.5 (5.5)	11.0 (3.4)	2.86	0.005
Physical	9.3 (4.4)	7.9 (2.3)	3.14	0.001
Social	10.2 (5.0)	8.5 (2.0)	3.79	<0.001
Emotional	8.3 (4.1)	8.2 (2.1)	0.40	0.675
Quality of life	59.8 (19.7)	75.7 (9.7)	8.81	<0.001

*: Independent t-test; SD: Standard deviation

Table 4
The role of independent variables on care burden one year after COVID-19 outbreak in caregivers.

Variables	β	Standard Error	t	P-value	
Constant value	56.02	5.92	9.46	<0.001	
Quality of life	-0.17	0.07	-2.28	0.02	
Duration of daily care	1.26	.22	5.72	<0.001	
Type of malignancy					
	Gastrointestinal	reference			
	Blood cells	3.07	2.60	1.18	0.24
	Neurological	-6.94	2.97	-2.34	0.02
	Respiratory	5.43	2.95	1.84	0.07
	Urological	-1.49	2.22	-0.67	0.51
	Breast	-3.53	1.67	-2.11	0.04

present finding is in line with the study results of Troschel et al. (2021) in patients with brain tumor and their relatives [32]. The results of a study by Hulbert - Williams et al. (2021) also showed that people with cancer reported significantly reduced anxiety and improved quality of life after the onset of COVID-19 but their support network reported decreased quality of life [33].

The current study suggests that quality of life is a significant factor in reducing the burden of care in caregivers of cancer patients. Improving the quality of life can be considered an opportunity to reduce the burden of care. Cengiz et al. (2021) showed that quality of life is a significant factor in predicting the burden of care imposed on family caregivers in supportive care [34]. The findings also showed that the burden of care and quality of life in caregivers have a significant and inverse relationship [35]. Other related factors were identified in caregivers of cancer patients, such as fatigue, depression, social support, and self-esteem [36,37]. Care burden is a multidimensional strain perceived by the caregiver caring for a family member and/or loved one over time according to their caring role, which has negative consequences for the caregiver [38]. The results of the study of Duimering et al. (2020) show that while the patient's health deteriorates, caregivers take on increasing responsibility, which is often associated with psychological distress, harming the caregiver's quality of life [39]. In this regard, the results of the present study showed that one of the possible related factors and predictors of higher care burden is the greater levels of daily care for the patient. Consistent with this finding, the results of the study by Kehoe et al. (2019) showed that caregivers of older adults with cancer who needed more help with daily activities in life experienced a higher care burden [40]. Duration of daily care as a contextual variable in the care process, along with other factors such as age, employment status, help-seeking in caring role and duration of daily care, family dissatisfaction, caregiver distress and patients' memory and behavioural problems while approving the stress process model also affects the quality of life of caregivers [41].

It should be noted that the care of cancer patients has changed from hospital-based care to home and community care, which requires more care in the home and community, increasing responsibility and burden on family caregivers [42]. During the COVID-19 pandemic, contacts between patients and caregivers at home, and associated provision of day-to-day care increased. The results of a study in the COVID-19 pandemic confirm such findings [43].

This study suggests that the type of cancer is a predictor of caregiver burden. The caregiver burden in caregivers of patients with neurological and breast cancers was significantly lower than that of caregivers of patients with gastrointestinal cancers. Consistent with this finding, Akpan-Idiok et al. (2020) showed a significant relationship between the type of cancer of the patient and the burden

of care, such that caregivers of patients with prostate and colorectal cancers experienced severe levels of care burden, and caregivers of patients with breast and cervical cancer experienced moderate care burden [44]. It should be noted that caregiver's duties vary with the type of cancer diagnosis of the patient and the change in the patient's needs during the course of cancer treatment [45]. One possible explanation of the present finding could be that patients with gastrointestinal cancers experience more medication, diet, and physical restrictions require more complex support than others [46].

The two stages of the present study were cross-sectional, and there was a substantial interval between the two stages. Future studies during the COVID-19 pandemic should be performed at larger levels and shorter intervals for a more detailed longitudinal examination with larger sample sizes. This study was conducted for faster conclusions and increased access to online participation, so some items such as personality type, personality disorders and other positive and negative aspects of mental health (such as hope, optimism, self-esteem, spiritual health, etc.) were not evaluated due to the increase in the number of questionnaires and the response rate. Finally, recall bias may affect caregiver responses, as they may have incorrectly reported details of pre-pandemic conditions in their family.

This study demonstrated the psychological burden of the COVID-19 pandemic in caregivers of cancer patients. The burden of care decreased and quality of life increased over the study period, which is consistent with some literature. The findings of this study must be considered in clinical settings to help maintain well-being and reduce psychological distress in this post pandemic period. Psychological support should be integrated into a comprehensive intervention based on the culture. The findings of this study cannot be generalized to larger communities (other sub-groups of caregivers) and outside of Western communities, so to investigate the broader aspects of mental health in caregivers of cancer patients during the COVID-19 pandemic, further research with different approaches (such as qualitative studies to explore further directly with the carers and patients with cancer - the factors that contribute specifically to the increase/decrease of care burden/quality of life/psychological distress during and post COVID-19 pandemic) are recommended.

Ethics statement

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. All participants were informed about the objectives and conditions of the present research. The present study was approved by the Ethics Council of the Shahrood University of Medical Science (No. IR.SHMU.REC.1399.158).

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Consent to participate

Informed consent was obtained from all individual participants included in the study. Research objectives, confidentiality, risks and potential benefits were presented to participants in online forms. Researchers also provided contact information to support participants asking questions and to facilitate withdrawal.

Author contribution statement

Seyedmohammad Mirhosseini: Conceived and designed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Samuel Grimwood, Amy Baraniak: Conceived and designed the experiments; Wrote the paper.

Malihe Ameri, Mohammad Hasan Basirinezhad: Performed the experiments; Analyzed and interpreted the data; Contributed reagents, materials, analysis tools or data; Wrote the paper.

Hossein Ebrahimi: Performed the experiments; Wrote the paper.

Data availability statement

Data will be made available on request.

CRedit authorship contribution statement

Seyedmohammad Mirhosseini: Conceptualization, Data curation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Malihe Ameri:** Data curation, Investigation, Methodology, Writing – original draft, Writing – review & editing. **Amy Baraniak:** Conceptualization, Methodology, Writing – original draft, Writing – review & editing. **Samuel Grimwood:** Conceptualization, Data curation, Investigation, Writing – original draft. **Mohammad Hasan Basirinezhad:** Data curation, Formal analysis, Investigation, Validation, Writing – original draft. **Hossein Ebrahimi:** Conceptualization, Methodology, Supervision, Validation, Writing – original draft, Writing – review & editing.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.heliyon.2023.e20504>.

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