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The burden of care and its correlates in family caregivers of breast cancer patients undergoing chemotherapy in Sari, Iran, in 2020

Mehrooz Alishah[1], Masoumeh Bagheri-Nesami [2,3], Seyed Robabe Babaei [1*], Jamshid Yazdani-Cherati [4], Mehrnoosh Alishah [5]

[1] Nasibeh School of Nursing and Midwifery, Mazandaran University of Medical Sciences, Sari, Iran

[2] Traditional and Complementary Medicine Research Center, Addiction Institute, Mazandaran University of Medical Sciences, Sari, Iran

[3] World Federation of Acupuncture-Moxibustion Societies (WFAS), Beijing, China

[4] Health Sciences Research Center, Mazandaran University of Medical Sciences, Sari, Iran

[5] Information Science, Mazandaran University of Medical Sciences, Sari, Iran

Abstract

Introduction: Caring for patients with cancer can often give rise to numerous physical and mental health problems or even exacerbate them among family caregivers. The present study aimed to reflect on the burden of care and its correlates affecting family caregivers of breast cancer (BC) patients undergoing chemotherapy.

Materials and Methods: This descriptive-analytical cross-sectional study of correlational type was conducted on a total number of 163 family caregivers of patients with BC undergoing chemotherapy at Imam Khomeini Teaching Hospital and Baghban Specialized Center based in the city of Sari, Iran, in 2020. For this purpose, the study samples were selected through the available sampling technique. As well, the demographic characteristics information form and the Caregiver Burden Inventory (CBI) were employed for data collection. The data were ultimately analyzed using the SPSS Statistics software (ver. 21).

Results: The study results revealed that 72 family caregivers (44.17%) were experiencing high levels of burden of care (>36). Moreover, caregivers' level of income, number of chemotherapy sessions, duration of disease, and patients' insurance coverage status were significantly correlated with caregiver burden, which were evaluated in the multiple logistic regression analysis. This model could further explain 25.2% of variance in the burden of care severity in these informal caregivers ($p<0.001$, Chi-square [$\chi 2$] statistic=33.9). The multiple logistic regression analysis was also utilized to determine the effect of the most important dimensions of the burden of care and this model could account for 94.8% of variance in the burden of care severity among these family caregivers, wherein developmental, social, physical, and time dependence dimensions respectively had the greatest impacts on compounding caregiver burden.

Conclusion: The study results indicated high levels of burden of care in family caregivers of patients suffering from BC. Therefore, it was recommended to consider the burden of care correlates and to plan for proper interventions, according to the findings in the present study, in further research.

Keywords: Burden of Care, Breast Cancer, Demographic Characteristics, Patient Companion

[*] **Corresponding Author:** Seyed Robabe Babaei

✉ Email: robabe.babaei@gmail.com

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Introduction

Cancer is known as one of the most important diseases in the 21st century (1), so a significant share of health care programs has been allocated to this condition (2). Asia also has the highest prevalence rate of cancer (48% of the cases over the world) among all continents. In this respect, 1 out of every 8-10 women across the world and 1 out of every 10-15 women in Iran, have a higher chance of developing breast cancer (BC) (3). As well, this type of cancer in Iran accounts for 21.4% of all reported cases (4). The incidence of this condition in this country, particularly in central and Northern provinces is considerably on the increase (5). The onset age of developing BC in Iran is also one decade lower than that in Western countries (6). This disease can thus affect various aspects of life in women. Diagnostic tests and medical procedures, complications induced by treatments such as nutritional problems, fatigue, nausea, vomiting, and pain, as well as disruptions of social relationships and care/treatment costs are among other consequences of this condition (7). Given the debilitating nature of cancer and its related care/treatment, most of those suffering from this disease need more support by informal caregivers (1), who might have a sense of despair, loneliness, and failure in assuming their own duties due to no education with regard to the disease and receiving no information support in this domain (8). As 55% of care is provided by informal caregivers, such people mostly fail to meet their own needs in daily living and even ignore them to provide care for their loved ones (9). The mean time of care for cancer patients has been estimated by 8.8 hours per day (10) and family caregivers are required to fulfill not only their daily routine activities but also their obligations in the workplace (11). Under such conditions, if family caregivers fail to manage the time of care for patients and that allocated to their own personal issues, they will progress towards the burden of care (10). Here, caregiver burden is a general term to describe physical, emotional, and socioeconomic costs of care. It has been also defined as the product of the imbalance between costs of patient care and those for care facilities (12). Although the caring role in caregivers can raise a sense of affection and love in these individuals and bring some benefits such as a meaningful life, more intimacy in family relationships, respect for oneself and others, as well as a sense of satisfaction (13), it might be accompanied by problems such as burnout, anxiety, depression, insomnia, decreased appetite, and hypertension (14, 15). Studies have further shown that factors such as duration of care, family economic status, social support, number of caregivers, type of disease, increased duration of disease, and clinical symptoms in patients can have significant effects on the burden of care (16, 17). Given the high importance of caregivers in support of patients to deal with BC and considering the growing population with this condition and little research on the burden of care, this study aimed to evaluate the burden of care and its correlates in family caregivers of patients with BC undergoing chemotherapy.

Materials and Methods

This descriptive-analytical cross-sectional study of correlational type was conducted in the chemotherapy wards of Imam Khomeini Teaching Hospital and Baghban Specialized Center based in the city of Sari, Iran, in 2020. The statistical population included all caregivers of BC patients referred to these centers, of which 163 caregivers of the patients undergoing chemotherapy were selected.

The sample size was further estimated to be 163 individuals based on the study by Adili and Dehghan Araie (18), using the following calculation formula:

$$n = \frac{(1.96)^2 \delta^2}{d^2} = \frac{(1.96)^2 (26)^2}{4^2} = 163$$

Of note, this research project was approved by the Research Ethics Committee of Mazandaran University of Medical Sciences, Sari, Iran (IR.MAZUMS.REC.1399.6442). During 11 months (from April to January 2020), the convenience sampling technique was performed after providing explanations and obtaining written consent from the family caregivers. Ethical considerations in this study were also met by observing the confidentiality of information, voluntary participation in the research, possibility of withdrawing from the project without time restrictions, and explaining the objectives and the research procedure to the study samples.

The primary family caregivers of the patients included spouse, sibling, and parent. As well, the inclusion criteria were literacy (i.e., reading and writing ability), age over 18 years, no mental illnesses, and approvals that these individuals were the primary caregivers and companions. Moreover, those receiving counseling and psychology services, taking sedatives and tranquilizers, or caring for patients with underlying diseases or the ones with metastatic progression were excluded.

The data in this study were collected using two-part questionnaire. The first part contained the demographic characteristics information form about the family caregivers (including gender, age, marital status, level of education, occupation, and kinship) and the patients (such as gender, age, marital status, level of education, occupation, housing, level of income, duration of disease, insurance coverage status, and number of chemotherapy sessions).

The second part of the questionnaire was the 24-item Caregiver Burden Inventory (CBI), developed by Novak and Guest (1989), which was utilized to evaluate the level of burden of care perceived by the caregivers in an objective and subjective manner. This questionnaire measured the burden of care in five dimensions, i.e., time dependence, developmental, physical, social, and emotional (18). The total score could be also from zero to 96, in which scores of <35 indicated lower level of burden of care and the scores of ≥36 represented higher levels of burden of care. The participants could further determine the degree of their experiences with each situation in a five-point Likert-type scale - completely false (0 point) false (1 point), to some extent (2 points), true (3 points), and completely true (4 points).

The CBI was translated by Abbasi et al. into Persian and its validity was further confirmed through content validity method. In a study on patients with end-stage cancer, the Cronbach's alpha coefficient had been similarly calculated by 0.90 (2). In order to analyze the data, they were firstly summarized using descriptive statistics including mean and standard deviation (SD) for the quantitative data and frequency tables for the qualitative ones. Then, descriptive statistics, independent-samples t-test, Chi-square test, and Spearman's rank-order correlation were employed to examine the relationships. The final analysis of the relationships was done through the multiple logistic regression analysis at a significance level of 0.05, using the SPSS Statistics software (Ver. 24). After the normality of data was examined, the Kolmogorov-Smirnov test was used for inferential analysis.

Results

A total number of 163 primary family caregivers, most of them as the spouse of 85 patients (52.1%), with a mean age of 43.6±11.7 years were studied. The results also revealed that 55.83% and 44.17% of the family caregivers had low and high levels of burden of care, respectively. Given the demographic characteristics information, most of the family caregivers in this study were male caregivers (n=97, 59.5%), married individuals (n=136, 83.4%), those holding university degrees (n=66, 40.5%), homemakers (n=45, 27.6%), the ones owning a house (n=132, 81%) and cases with a moderate-to-high level of income (n=129, 79.2%). According to the demographic characteristics of the patients, majority of them in this study were married (n=141, 86.5%), had high school diploma and lower degrees (n=118, 72.4%), owned a house (n=128, 78.5%), and a moderate level of income (n=77, 47.2%) as well as insurance coverage (n=150, 92%). Of these patients, 149 cases (91.4%) also had chemotherapy-induced complications (Table 1). The mean age of the patients in this study was 46.7±10.6 years old, the mean length of chemotherapy was 6.26±4.3 sessions, and the mean duration of disease from diagnosis was 7.86±6.7 months.

The logistic regression analysis was further used to determine the correlates affecting the burden of care in family caregivers. First, the univariate mode of the logistic regression analysis was implemented and the variables whose values were <0.3 were selected for the multiple logistic regression model. Next, employing the multivariate logistic regression analysis and the backward stepwise selection method, the given variables were considered for the model with the probability of excluding each variable by 0.1. The variables of the family caregivers' level of education, occupation, level of income, and kinship along with the patients' marital status, occupation, level of income, number of chemotherapy sessions, chemotherapy-induced complications, duration of disease, and insurance coverage status whose univariate p-values were <0.3 were also taken into consideration for the final model of the multiple logistic regression analysis. Within the final model, the four variables of family caregivers' level of income as well as number of chemotherapy sessions, duration of disease, and patients' insurance coverage status remained.

Table 1. Demographic characteristics of family caregivers along with demographic/clinical characteristics of BC patients.

Groups	Variables	Categories	Descriptive indices	
			Frequency	Percentage
Family caregivers	Gender	Male	97	59.5
		Female	66	40.5
	Marital status	Single	22	13.5
		Married	136	83.4
		Divorced	5	3.1
	Level of education	Lower than high school diploma	46	28.2
		High school diploma	51	31.3
		University degree	66	40.5
	Occupation	Unemployed	9	5.5
		Employed	43	26.4
		Worker	7	4.3
		Farmer	13	8
		Self-employed	37	22.7
		Retired	9	5.5
		Homemaker	45	27.6
	Housing	Owner	132	81
		Tenant	31	19
	Level of income	Low	34	20.9
		Moderate	103	63.2
		Good	26	16
	Kinship	Spouse	85	52.1
		Child	37	22.7
		Brother or sister (sibling)	22	13.5
		Father or mother (parent)	8	4.9
		Others	11	6.7
Patients	Marital status	Single	5	3.1
		Married	141	86.5
		Divorced	8	4.9
		Widowed	9	5.5
	Level of education	Illiterate	10	6.1
		Lower than high school diploma	45	27.6
		High school diploma	63	38.7
		University degree	45	27.6
	Housing	Owner	128	78.5
		Tenant	35	21.5
	Level of income	Low	54	33.1
		Moderate	77	47.2
		Good	32	19.6
	Chemotherapy-induced complications	Yes	149	91.4
		No	14	8.6
	Insurance coverage status	Yes	150	92
		No	13	8

The regression analysis was similarly performed to determine the effect of family caregivers' level of income on chemotherapy sessions, duration of disease, and insurance coverage status of the patients and the burden of care in family caregivers (Table 2). The logistic regression model was also statistically significant (p<0.001, Chi-square [$\chi 2$] statistic=33.9). This model could determine 25.2% of the variance of the burden of care severity on family caregivers and correctly explained 67.5% of the effects of the burden of care on these individuals. The study results revealed that the family caregivers with higher levels of income had experienced lower levels of burden of care in different aspects of life. For example, in family caregivers with good levels of income, the burden of care for their patients had reduced by 1.194 times compared with low-income cases. Each additional chemotherapy session had correspondingly resulted in higher levels of burden of care for the BC patients as much as 1.229 times (p<0.001). Moreover, the results of this study showed that an increase in the duration of disease from the time of diagnosis (namely, months) had decreased the family caregivers' burden of care in different aspects of life (p=0.005). In addition, in patients who benefitted insurance coverage, the caregivers' level of burden of care had significantly reduced (p<0.001).

Table 2. Logistic regression analysis results to investigate the relationship between burden of care and its correlates.

Variables	Beta coefficient	Standard error (SE)	Wald statistic	Degree of freedom (DF)	P-value	Exponentiation of the B coefficient (Exp [B])	95% confidence interval (CI) for EXP (B)	
							Lower bound	Upper bound
Y-intercept	-2.12	0.697	9.255	1	0.002	0.12	-	-
Family caregivers' level of income (low)	-	-	11.81	2	0.003	-	-	-
Family caregivers' level of income (moderate)	-1.177	0.457	6.63	1	0.01	0.308	0.126	0.755
Family caregivers' level of income (high)	-1.61	0.586	7.85	1	0.005	1.194	0.062	0.611
Patients' number of chemotherapy sessions	0.207	0.059	12.17	1	<0.001	1.229	1.095	1.38
Duration of disease	-0.108	0.039	7.75	1	0.005	0.898	0.832	0.969
Insurance coverage status (No)	2.188	0.883	6.145	1	0.013	8.921		
Insurance coverage status (Yes)	-3.214	0.892	12.968	1	<0.001	0.04	1.581	50.33

The logistic regression analysis was also employed to identify the most important dimensions of the burden of care among family caregivers. Accordingly, time dependence, developmental, physical, social, and emotional dimensions were considered. Initially, the univariate model of the logistic regression analysis was implemented and the variables whose p-values were <0.3 were selected for the multiple logistic regression model. Afterward, using the multivariate logistic regression analysis and the backward stepwise selection method, the given variables were considered for the model with the probability of excluding each variable by 0.1. All the given dimensions whose univariate p-values were <0.3 were taken into account in the final model of the multiple logistic regression analysis. In the final model, time dependence, developmental, physical, and social dimensions remained.

The regression analysis was also performed to determine the effect of time dependence, developmental, physical, and social dimensions on the burden of care in family caregivers (Table 3). The logistic regression model was also statistically significant (p<0.001, χ2 statistic=200.4). This model could account for 94.8% of the variance of the burden of care severity on the family caregivers and correctly explained 96.3% of the effects of the burden of care on caregivers. The study results revealed that the increase in each unit in the values of time dependence (p<0.021), developmental (p<0.006), physical (p=0.005), and social (p=0.005) dimensions led to a growth in the caregivers' burden of care by 1.71, 3.8, 2.2, and 3.39, respectively.

Table 3. Results of logistic regression analysis to investigate the relationship between burden of care and its dimensions.

Variables	Beta coefficient	SE	Wald statistic	DF	P-value	Exp (B)	95% CI for EXP (B)	
							Lower bound	Upper bound
Y-intercept	-25.16	8.25	9.29	1	0.002	000	-	-
Time dependence	0.534	0.231	5.35	1	0.021	1.71	1.085	2.68
Developmental burden of care	1.33	0.486	7.54	1	0.006	3.79	0.465	9.84
Physical burden of care	0.79	0.28	7.86	1	0.005	2.197	0.268	3.81
Social burden of care	1.22	0.43	8.04	1	0.005	3..39	1.458	7..89

Discussion

This study aimed to evaluate the burden of care and its correlates in family caregivers of BC patients undergoing chemotherapy. The results showed that almost half of these informal caregivers (44.17%) had experienced high levels of burden of care (>36), which was lower compared with the findings in Salmani et al. (20) who had reported the burden of care in Iranian caregivers of patients admitted to the oncology ward by 81% and in the survey by Gabriel (21) in which the burden of care in the primary caregivers of the patients with BC in Nigeria had been 86.7%. It seems that the metastasis and the underlying conditions could be the main reasons for this discrepancy. It should be noted that the patients in the present study were undergoing chemotherapy, the exclusion criteria were metastatic BC and underlying diseases. In the survey on the patients with advanced cancer, living in Northern England, Higginson (22) had also found that the patient caregivers were experiencing a lower level of burden of care (18.5±11). The researchers had attributed such findings to receiving domestic support services to the caregivers (23). In any case, cancer might put too much mental strain on family members, especially patients' spouses, and the evidence shows that they suffer from the highest levels of burden of care (24) because they are closer to their own patients with regard to emotional and physiological problems and feel more responsible in caring for their patients, which can produce greater levels of burden of care among them.

In the present study, the higher the caregivers' level of income, the lower the level of burden of care, which was consistent with the reported results by Gabriel (21) and Vahidi (25), examining the burden of care among the caregivers of BC patients. They also highlighted the relationship between the low level of income and the increased level of burden of care. Some studies had similarly demonstrated a significant correlation between economic status and low level of income and higher level of burden of care (26- 28). These findings were additionally observed in the research by Hanratty, wherein most caregivers had to quit their jobs to provide full-time care to their patients, leading to further financial problems as well as elevated level of burden of care (29). As a result, more support for low-income caregivers to reduce the levels of burden of care seems necessary.

Besides, this study showed that a rising trend in the number of chemotherapy sessions could produce the burden of care. Given that weakness and disability increase in patients during chemotherapy sessions and the patients might be subjected to new complications at the end of each session, this issue leads to higher level of burden of care among caregivers.

The results of this study suggested that the burden of care reduced as the disease prolonged from diagnosis to treatment. In conflict with the present study, Germain et al. researched the burden of care in the elderly patients with cancer (30). The age of the patients in both studies could be the reason for the different results because older adults might demand more care. On the other hand, the patients in the present study were young or middle-aged, so they could gradually perform many diagnostic tests before treatment on their own, and they needed no constant caregivers.

The study results indicated that the caregivers whose patients were benefiting more support from insurance services had lower levels of burden of care, which was in line with the survey by Hu and Peng (31) on the burden of care in caregivers of patients with lung cancer and the findings by Johnson (32) on the burden of care among caregivers of oncology patients receiving chemotherapy. In these studies, the insurance coverage status and social support had been reported as the factors affecting the burden of care in the caregivers. It seems that the role of authorities committing insurance caregivers to provide medications for these patients has a significant impact on minimizing the level of burden of care. The results of the present study were not in agreement with the reports by Adili (18), exploring the relationship between the burden of care and the patients' quality of life in caregivers of BC patients. The reason for this discrepancy could be in the time of diagnosis, which was only three months in the survey by Adili, when it seems that the financial resources in family could still meet the financial needs of the patients. In the present study, however, this time was longer.

Since family caregivers must meet their own needs and those of patients, they suffer from additional levels of burden of care in all physical, emotional, and socioeconomic aspects along with disruption in their caring roles (33). This study showed that the most frequent burden of care among the primary caregivers was related to developmental, social, physical, and time dependence dimensions, which was in line with the survey by Ghane et al. (34), reporting the developmental burden of care as the most common dimension in the family caregivers of patients undergoing hemodialysis. However, Abbasi et al. (35) had mentioned the most frequent burden associated with the emotional dimension of care for patients receiving hemodialysis. In a study on colorectal cancer (CRC) patients, Bakim (36) had revealed that aging could lead to higher levels of burden of care in the caregivers. Since the increase in age in the caregivers reduces the emotional dimension of the burden of care following gaining experience (37) and a rise in physical, developmental, and time dependence dimensions (35), this can be justified with regard to the mean age of the caregivers (46.7±10.6 years old). Unsar et al. (38) had also indicated that the caregivers of cancer patients had to care for them all day long, so they had no spare time for themselves. Employment outside the home could similarly create an elevated level of burden of care due to the conflict between work and caring responsibilities (28). As well, Shafie Zadeh et al. (39), investigating the relationship between the burden of care and the demographic characteristics of the caregivers of the elderly with Alzheimer's disease, had found that these caregivers had experienced the maximum level of burden of care related to the time dependence dimension. It seems that the duration of care for such patients, depending on the type of the disease, can be a factor affecting the burden of care severity as the Alzheimer's disease needs constant care, while in this study, the patients did not demand full-time care according to the caregivers.

At the end of the questionnaire and according to the survey conducted among the caregivers to offer their suggestions with regard to the burden of care, financial and insurance support especially for the provision of medications and information on how to take care and deal with the complications in the patients were among the issues noted by most of the caregivers. Studies have further shown an inverse relationship between the burden of care and social support (40, 41). In other words, caregivers may have more time and energy to care for oneself and to meet their own needs whenever they take advantage of higher levels of social support from family and professional institutions.

It seems that the use of different sampling techniques, variations in receiving care services, support services, cultural discrepancies, types of organizations involved in cancer care/treatment, as well as the most recent breakthroughs in BC care/treatment can be among the reasons for inconsistencies in the results of such studies.

Since this study was conducted during the coronavirus disease 2019 (COVID-19) pandemic and some caregivers were reluctant to complete the questionnaires manually, a number of the questionnaires were unavoidably done through interviews, which could increase the possibility of unreal responses by them. It was also possible that the caregivers tended not to talk about the burden of care or underestimate it, and even feel guilty to tell the truth in this regard.

Conclusion

The study results revealed that the caregivers of the BC patients were suffering from the burden of care during chemotherapy. Based on the study findings, caregivers' level of income, number of chemotherapy sessions, duration of disease, and insurance coverage status are significantly correlated with their burden of care. The correlation between some demographic characteristics information and the burden of care among the caregivers of this category of patients is further highlighted. Accordingly, information is provided in order to improve the existing situation of the caregivers and to reduce the burden of care. If the caregivers' burden of care is mitigated, they can play their caring roles better. Given the results of the present study, there is a need to reflect more on the caregivers' developmental and social dimensions of the burden of care. It is also recommended to provide nurses with the outcomes of the most recent studies on caring for cancer patients in the form of training courses to help them meet the educational needs of informal caregivers in order not to feel frustrated and isolated. Caregivers must be also supported by health care providers and a person should be always available as a supporter to respond to the questions posed by these caregivers and help them have lower burden of care. Health care team members should remember that the main respondents to cancer patients are their primary caregivers, whose value should never be overlooked in the health care team. Technology resources including telephone follow-up, virtual care guide, and online support groups can be thus effective in these conditions.

Author contributions

MA, MBN, JYCh and MA wrote and completed the article. SRB designed and edited the manuscript. All authors confirmed the final edited version.

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Conflicts of interest

There are no conflicts of interest.

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