

# Correlation between Supportive Care Needs of Women with Breast Cancer and Quality of Life of their Family Caregivers

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### ABSTRACT

**Background:** Breast Cancer is highly prevalent among women. The supportive care needs of such patients not only affect their quality of life (QoL) but also that of their family caregivers. The present study aimed to assess the correlation between the supportive care needs of women with breast cancer and the QoL of their family caregivers.

**Methods:** The present cross-sectional study was conducted from September 2017 to June 2018. The target populations were breast cancer patients (N=150) and their primary family caregivers (N=150) who attended the Omid Chemotherapy and Radiotherapy Center affiliated with Hormozgan University of Medical Sciences, Bandar Abbas, Iran. Data collection tools included a demographic information form, the Supportive Care Needs Survey-Short Form 34, and the Caregiver Quality of Life Index-Cancer Scale. The data were analyzed using SPSS software (version 22.0) with descriptive statistics and Pearson's correlation coefficient.  $P < 0.05$  was considered statistically significant.

**Results:** The mean age of the patients was  $45.76 \pm 10.44$  years. Of the family caregivers, 99 (66%) were the patients' spouses. Of the different dimensions of the supportive care needs, the score for the physical needs ( $40.60 \pm 23.50$ ) was the highest. In terms of the QoL of the family caregivers, mental and emotional burden scored the highest ( $20.19 \pm 7.38$ ). There was a significant correlation between the caregivers' mental and emotional burden and the physical needs of the patients ( $r=0.19$ ,  $P=0.02$ ).

**Conclusion:** The result of the present study showed that physical needs were the most common supportive care needs of patients with breast cancer. Such needs also significantly undermined the QoL of the caregivers in terms of emotional burden and financial concerns.

**KEYWORDS:** Breast cancer, Caregivers, Needs Assessment, Quality of life

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## INTRODUCTION

Breast cancer is the second leading cause of death globally and highly prevalent among women.<sup>1,2</sup> It is the most common form of cancer with a high mortality rate, affecting 2.1 million female patients annually.<sup>3</sup> More than half of new cases of breast cancer occur in less developed countries.<sup>4</sup> In the same period, 23,300 female cancer patients died in Iran of which 14.2% due to breast cancer.<sup>5</sup> It has been reported that breast cancer is the most common form of cancer among Iranian women and a 3-fold increase in new cases of breast cancer is projected by 2030.<sup>6,7</sup>

Chronic diseases such as cancer not only put a heavy burden on the patients, but also on their family caregivers.<sup>8</sup> At each stage of the disease, supportive care needs may involve any combination of physical needs and daily activities, psychological needs, information and health systems, supportive needs, care needs, and sexual needs.<sup>9</sup> Identifying and addressing these needs allow patients to better manage the symptoms and side effects of the disease, better adapt and cope with illness-related issues, have a better understanding of the condition and make informed decisions, and lessen the impact of impaired functioning.<sup>10</sup> The primary caregivers of women with breast cancer can play an important role in the process of adaptation to and coping with the disease in each stage of the treatment and to support them in making the right decisions.<sup>11</sup> It has been reported that breast cancer patients who tend to seek social support are at a lower risk of morbidity and mortality<sup>12</sup> and have a better quality of life (QoL).<sup>13</sup> Note that cancer negatively affects the QoL of both the patients and their caregivers.<sup>14</sup> The prevalence, severity, and persistence of the burden on caregivers are directly associated with the QoL of both patients and caregivers. The caregivers tend to focus more on the well-being of their loved ones and thereby often ignore their own health. The negative effects of caregiving responsibility manifest itself in psychological suffering of and financial burden on the caregiver.<sup>15</sup> Therefore, preserving

caregivers' QoL is associated with their ability to provide better care to their patients and meet their needs.<sup>16</sup> This can be achieved by supporting them to adapt to changes caused by such troublesome events.<sup>17</sup>

Considering the growing prevalence of breast cancer in Iran and since many sufferers approach a physician mainly at the advanced stage of the disease, it is important to address these issues in order to better facilitate the QoL of not only the patients but also of their caregivers. In addition, cultural diversity across the world and even in different regions of a country has a direct impact on the type of supportive care needs of those affected. Understanding their needs is indeed a step forward toward empowering both the patients and their family caregivers. To the best of our knowledge, there have been no studies on the supportive care needs of women with breast cancer and the QoL of their family caregivers in Bandar Abbas (Iran). Hence, the present study aimed to assess the correlation between the supportive care needs of women with breast cancer and the QoL of their family caregivers.

## MATERIALS AND METHODS

The present cross-sectional study was conducted from September 2017 to June 2018 in Bandar Abbas, Iran. The target populations were breast cancer patients and their primary family caregivers who attended the Omid Chemotherapy and Radiotherapy Center affiliated with the Hormozgan University of Medical Sciences, Bandar Abbas, Iran. In accordance with a previous study<sup>18</sup> and based on the below formula, the sample size was determined at 140 participants. However, considering the probability of sample attrition, a sample size of 150 was used.

$$\frac{z_{1-\alpha/2}^2 \times \sigma^2}{d^2}$$

$$\alpha=0.05, z=1.96, \sigma=6, d=1$$

The convenient sampling method was used to recruit a total of 300 participants (150 women with breast cancer and 150

primary family caregivers). The inclusion criteria for patients were: aged 18 years and older, confirmed diagnosis of breast cancer (at any stage between stage 1 and stage 4) by pathological testing, diagnosed at least 3 months prior to the start of the study, no presence of any psychological disorders based on the medical record, the ability to respond to the questionnaires, willingness to participate, and being an Iranian national. The inclusion criteria for family caregivers were: aged 18 years and older, no physical and mental disabilities requiring treatment, the ability to respond to the questionnaires, and willingness to participate. The exclusion criterion for both the patients and family caregivers was the unwillingness to fully complete the questionnaire.

The data collection tools consisted of a demographic data sheet, the Supportive Care Needs Survey-Short Form 34 (SCNS-SF34), and the Caregiver Quality of Life Index-Cancer (CQOLC) scale. Demographic characteristics included age, marital status, education level, employment status, number of children, place of residence, duration of the illness, disease stage, treatment type, the relationship between the patient and caregiver, duration of caregiving, the number of caregiving hours per day, and monthly income.

*The Supportive Care Needs Survey-Short Form 34:* SCNS-SF34, developed by Bonevski and colleagues in 2000, contained five factors and 34 items, namely physical (5 items: questions 1 to 5), psychological (10 items: questions 6-14, 17), information (11 items: questions 23-30, 32-34), supportive (5 items: questions 18-22), and sexuality (3 items: questions 15, 16, 31). Using the 5-point Likert scale, each item had a possible response of 1 (not applicable), 2 (satisfied), 3 (low need), 4 (moderate need), and 5 (high need). The scores were calculated based on the below formula:

$$((N-M) \times 100) / (M \times [K-1])$$

N: Sum of the individual items for each dimension

M: The number of questions in a dimension

K: The value of the maximum response for each item

The scores ranged from 0 to 100 in each dimension such that a higher score indicated a higher level of unmet need. The construct validity for all factors with eigenvalue >1 accounted for 64% of the total variance. Internal reliability of items within each factor was assessed using the Cronbach's alpha ranging from 0.87 to 0.97.<sup>19</sup> The Persian version of the questionnaire was developed by Abdollahzadeh and colleagues in 2014. The face validity and content validity of the questionnaire were confirmed by 12 academic members of Tabriz University of Medical Sciences, Tabriz, Iran. The reliability of the questionnaire was calculated using Cronbach's alpha coefficient (0.9).<sup>18</sup> In the present study, we determined the reliability of the questionnaire using the test-retest method with an intraclass correlation coefficient (ICC) of 0.98.

*Caregiver Quality of Life Index-Cancer:* The CQOLC questionnaire, developed by Weitzner and colleagues in 1997, contained 35 items that examined four dimensions, namely mental and emotional pain (14 items), disintegrated lifestyle (9 items), positive adaptation (8 items), and financial concerns (3 items). Note that one extra item was related to the family interest in caregiving, which was not included in these dimensions, but included in the calculation of the total score of the life quality. Each item was scored based on a 5-point Likert scale and had a possible response of zero (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit), and 4 (very much). The scores for each subscale of the Persian version of the CQOLC were 0-56 (mental/emotional burden), 0-36 (lifestyle disruption), 0-32 (positive adaptation), 0-12 (financial concerns), and 0-4 (family interest in caregiving). The score for each dimension was calculated by adding the item scores for each dimension. The total score ranged from 0 to 140; higher scores indicated a better quality of life.

The CQOLC questionnaire was evaluated

using the official psychometric testing for convergent and divergent validity, reassurance of the confidence level of the test, and for internal consistency. Convergent validity was measured by measuring the correlation between the score of the CQOLC questionnaire and the following questionnaires: Medical Outcomes Study Questionnaire Short Form 36 Health Survey (SF-36), Beck's Depression Inventory (BDI), State-Trait Anxiety Inventory (STAI-S), and Caregiver Burden Scale (CBS). The CQOLC questionnaire had a high correlation with the subscales (emotional role, mental health, social functioning, and vitality) of the SF-36 questionnaire ( $r=0.49-0.61, 0.50, 0.49; P<0.0001$ ). It also had a high correlation with the scores from the BDI questionnaire ( $r=-0.50, P<0.0001$ ), STAI ( $r=-0.52, P<0.0001$ ), and the CBS questionnaire ( $r=-0.65, P<0.0001$ ). Divergent validity was measured by the correlation between the score of the CQOLC questionnaire and questionnaires such as the Multidimensional Scale of Perceived Social Support [MSPSS] ( $r=0.20, P<0.001$ ), and the Marlowe-Crowne Social Desirability Scale [MC-SDS] ( $r=0.08, P<0.001$ ). The reliability of the questionnaire, using the test-retest method over 2 weeks, was 0.95. Its internal consistency using the Cronbach's alpha was 0.91.<sup>20</sup>

The Persian version of the questionnaire (CQOLC-P) was developed by Khanjari and colleagues in 2012 using the translation and re-translation method. They confirmed the face validity, content validity, and construct validity of the CQOLC-P. The CQOLC-P questionnaire was used to assess 166 family caregivers of breast cancer patients. The confirmatory factor analysis, using the LISREL statistical software, was performed to test the validity of the scale construct; the RMSEA=0.06 (CI: 0.053-0.068), SRMR=0.07,  $X^2/df=1.60$  (864.88/539,  $P<0.001$ ), CFI=0.95, NNFI=0.94, and IFI=0.95. The convergent validity was assessed using scales such as Sense of Coherence (SOC), Spirituality Perspective Scale (SPS), Health Index (HI), and the Brief Religious Coping (RCOPE).

The CQOLC-P questionnaire was reported to have satisfactory internal consistency (0.9-0.72). The convergent validity test showed that all hypotheses were approved. Multi-factor regression analysis of the convergent validity between the score of the overall indicator of the total CQOLC score and the sense of coherence ( $\beta=0.34$ ), negative religious coping ( $\beta=-0.21$ ), education ( $\beta=0.24$ ), and the more severe stage of breast cancer ( $\beta=0.23$ ) explained a total of 41% variance. Its reliability based on Cronbach's alpha was 89%.<sup>21</sup> In the present study, we determined the reliability of the questionnaire using the test-retest method with ICC ranging from 0.93 to 0.98.

Data were analyzed using SPSS software version 22. Descriptive data were expressed as frequency and percentage. The Pearson correlation coefficient was used to correlate the data.  $P<0.05$  was considered statistically significant.

The study was approved by the Ethics Committee of Shahid Beheshti University of Medical Sciences, Tehran, Iran (code: IR.SBMU.PHNM.1395.574). The purpose of the study was explained to the patients and their primary family caregivers, and the confidentiality of any disclosed information was guaranteed. Written informed consent was obtained from all participants.

## RESULTS

A total of 150 women with breast cancer and 150 primary family caregivers participated in the study. The mean age of the patients and the family caregivers was  $45.76\pm 10.44$  (range of 27-78 years) and  $43.46\pm 9.5$  years (range 21-68 years), respectively. The mean duration of the disease was  $16.35\pm 9.34$  months and the mean patient care time per day was  $2.34\pm 0.75$  hours. Of the study participants, 118 (78.7%) were married and 125 (83.3%) lived in urban areas. The majority of the family caregivers 99 (66.6%) were patients' spouses. The mean number of children of the patients and their family caregivers was  $2.96\pm 1.80$  and  $2.57\pm 1.51$ , respectively. Demographic characteristics of the

patients and their family caregivers are shown in Table 1.

Among the different dimensions of patients' supportive care needs, the highest and the lowest mean value was associated with physical needs (40.60±23.50) and sexuality (23.10±30.37), respectively. The other three dimensions had similar mean values. Higher scores indicated greater supportive care needs of the patients. In terms of the QoL of the family caregivers, the highest and lowest mean value was associated with mental and emotional burdens (20.19±7.38) and financial concerns (5.72±3.35), respectively (table 2) the total quality of life score of carigivers was 52.49±13.03.

A significant inverse correlation was found

between the total score of QoL and the duration of care (r=-0.23, P<0.001). In addition, there was a significant inverse correlation between caregivers' emotional and mental burden and the duration of caregiving (r=-0.34, P<0.001). A significant correlation existed between caregivers' mental and emotional burdens and the patients' physical needs (r=0.19, P=0.02), and between caregivers' lifestyle disruption and the patients' physical needs (r=0.26, P=0.02). There was also a significant correlation between the overall score of caregivers' QoL and the patients' physical needs (r=0.22, P=0.007). A significant correlation existed between caregivers' financial concerns and the patients' supportive

**Table 1:** Demographic characteristics of the patients and their primary family caregivers

Variables		Number (%)	
		Patients	Caregivers
Marital status	Single	8 (5.3)	25 (16.7)
	Married	118 (78.7)	125 (83.3)
	Divorced	6 (4)	-
	Widowed	18 (12)	-
Education level	Illiterate	38 (25.3)	5 (3.3)
	Primary school	37 (24.7)	26 (17.3)
	Junior high school	13 (8.7)	33 (22)
	High school	34 (22.7)	50 (33.3)
	University	28 (18.7)	36 (24)
Living area	Urban	125 (83.3)	125 (83.3)
	Rural	25 (16.7)	25 (16.7)
The stage of cancer	Stage I	2 (1.3)	-
	Stage II	67 (45)	-
	Stage III	77 (51)	-
	Stage IV	4 (2.7)	-
Relationship with the patient	Husband	-	99 (66)
	Sister	-	13 (8.7)
	Daughter	-	24 (16)
	Son/brother	-	8 (5.3)
	Mother/father	-	6 (4)

**Table 2:** Mean scores for the dimensions of the patients' supportive care needs and the caregivers' quality of life

Dimensions		Mean±SD	Maximum	Minimum
Needs of patients	Physical	40.60±23.50	100	0
	Psychological	28.89±17.32	77.5	0
	Health system and Information	30.74±18.36	90.09	0
	Supportive	37.93±32.62	100	0
	Sexuality	23.10±30.37	100	0
Caregivers	Positive adaptation	15.81±3.76	25	6
	Mental and emotional burdens	20.19±7.38	52	6
	Lifestyle disruption	10.19±3.85	29	2
	Financial concern	5.72±3.35	16	0

**Table 3:** The Pearson correlation coefficient between the dimensions of the supportive care needs of the patient and the dimensions of caregivers' quality of life

Variables		Caregivers				
		Positive adaptation	Mental and emotional burdens	Lifestyle disruption	Financial concern	CQOLC
Needs of patients	Physical	r=0.14 P=0.10	r=0.19 P=0.02	r=0.26 P=0.002	r=0.13 P=0.12	r=0.22 P=0.007
	Psychological	r=0.05 P=0.51	r=0.15 P=0.07	r=0.15 P=0.07	r=0.10 P=0.20	r=0.15 P=0.07
	Health system and information	r=0.04 P=0.63	r=0.04 P=0.61	r=0.04 P=0.66	r=0.10 P=0.22	r=0.05 P=0.55
	Supportive	r=0.01 P=0.86	r=-0.04 P=0.59	r=0.13 P=0.11	r=0.21 P=0.01	r=0.05 P=0.55
	Sexuality	r=-0.11 P=0.18	r=0.01 P=0.89	r=0.12 P=0.14	r=-0.03 P=0.71	r=0.004 P=0.96

care needs ( $r=0.21$ ,  $P=0.01$ ). The caregivers' positive adaptation was not significantly correlated with the different dimensions of the patients' supportive care needs ( $P>0.05$ ). Table 3 shows the correlation between the dimensions of the supportive care needs of the patient and the dimensions of caregivers' QoL.

## DISCUSSION

Out of the different dimensions of the patients' supportive care needs, the results showed that physical needs and sexuality had the highest and lowest mean value, respectively. Psychological, health system and information, and supportive dimensions had nearly similar mean values. Higher scores indicated greater supportive care needs of the patients. In terms of caregivers' QoL, mental and emotional burdens had the highest mean value; indicating the level of unmet needs.

A descriptive study in Iran reported that physical dimension was the most unmet needs of women with breast cancer during chemotherapy.<sup>22</sup> Another study found that the dimensions of "health system and information" and "physical needs" were among the highest care needs of women with breast cancer.<sup>23</sup> In another study in Malaysia, physical and psychological needs were among the important needs of such patients.<sup>24</sup> Overall, in line with the findings of the present study, these studies reported that meeting the physical needs was of paramount

importance in patients' supportive care needs. However, another study in Iran indicated that the dimensions of "psychological" and "health and information system" were the most common supportive needs of patients.<sup>25</sup> A previous study in Tabriz (Iran) also reported that the dimension of "health system and information" followed by "daily life activities" was the most common supportive needs of patients with breast cancer. The lowest supportive care needs were again associated with the dimension of "sexuality".<sup>18</sup> The inconsistency between the current study results and those of the other studies stems from the fact that the majority of the study patients were receiving active treatment (chemotherapy and hormone therapy) at the time of the study, which affected the physical supportive care needs of the patients. In line with other studies, we found that sexuality was the least common supportive care needs of the patients. According to the evidence the breast cancer and the treatment process of this disease threat the sexual health of women (26), it seems that best managing the sexual life of women with breast cancer is very important and could affect the quality of life of them.<sup>26</sup>

In the present study, the correlation between physical needs and other dimensions of supportive care needs was indicative of the patients' reduced physical ability over time, which negatively affected patients' QoL. Consequently, they had a greater need for psychosocial, sexual, and supportive care.

Therefore, psychological interventions and the provision of information and knowledge are necessary for such patients.<sup>27</sup> Moreover, there was a correlation between the caregivers' financial concern and the patients' supportive needs. Financial distress leads to a higher level of patients' anxiety, depression, and reduced QoL.<sup>28</sup> It has been reported that caregivers carry the main weight of the financial burden as a result of the cancer disease.<sup>29</sup>

In terms of caregivers' QoL, the highest and lowest mean value was associated with the mental and emotional burdens and financial concerns. The caregivers of cancer patients had a poor QoL due to experiencing fatigue, anxiety, and the pressures of caregiving.<sup>30</sup> We found a significant correlation between the physical dimension of supportive care needs of the patients and the caregivers' mental and emotional burdens and the QoL. A previous study conducted in China reported that the care burden of caregivers inversely affected their QoL and particularly their mental health.<sup>31</sup> In line with the current study results, another study in Iran reported similar mean QoL scores for caregivers. However, the mean score of positive adaptation in female caregivers was higher compared to current study results.<sup>32</sup> This could be due to the fact that the majority of the caregivers in current study were patients' male spouses, whereas the other study included patients' mothers, sisters, and daughters. In that study, with respect to the QoL of the sub-scale "positive adaptation", housewives achieved higher scores than employed women, while the majority of the current study caregivers were patients' male spouses and employed. This could explain the observed difference in the scores between the two studies in "positive adaptation". Furthermore, there was a difference in the mean duration of the disease in both studies; 2 years<sup>32</sup> compared to 16.35 months in the current study.

There was a significant inverse correlation between the total score of QoL of caregivers and the duration of caregiving. The longer the caregiving duration, the lower the QoL score of caregivers. In this regard, a previous study

reported that the QoL score of caregivers varied from the time of cancer diagnosis until the first 1-2 years after diagnosis and beyond the second year. Caregivers experienced greater mental distress during the initial two years after diagnosis. However, beyond the initial 1-2 years, the patient and their caregivers had a better QoL since they adapted more to the conditions of the disease.<sup>33</sup> These findings were consistent with the results of the present study and confirmed the hypothesis that the duration of caregiving affected the QoL of caregivers. Note that the average duration of care provided by the current study caregivers ranged 1-2 years after diagnosis. We also found a significant inverse correlation between the mental and emotional pain of caregivers and the duration of caregiving. This was in line with the findings of a previous study that reported mental and psychological problems arising from caregiving during shorter periods (6 months to 2 years) were more intense compared to that of longer caregiving periods.<sup>34</sup>

The main strength of the present study was the inclusion of all patients with breast cancer from the entire Iranian province of Hormozgan. Note that Omid Chemotherapy and Radiotherapy Center is the only referral center for the 1.8 million inhabitants of the province of Hormozgan. Furthermore, we studied both the QoL of caregivers and the supportive care needs of the patients. The main limitation of the study was the inclusion of a single Iranian province, which undermined the generalizability of the current study findings across the whole country. It is recommended that future studies include a larger sample size from different provinces and perform a qualitative study to assess the supportive care needs of the patients and the QoL of family caregivers.

## CONCLUSION

The result of the present study showed that physical needs are the most common supportive care needs of patients with breast cancer. These needs also significantly undermined the QoL of primary

caregivers in terms of emotional burdens and financial issues. Therefore, it is essential to design supportive care programs for patients with breast cancer and their family caregivers, particularly during the chemotherapy and hormone therapy phase, to reduce the patients' physical needs and to empower their family caregivers.

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