Evaluation of the Quality of Life of Female Family Caregivers of Patients with Breast Cancer in Iran (2013)

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ARTICLE INFO	ABSTRACT
Article type: Original article	**Background & aim:** Family caregivers of cancer patients are at a high risk of physical, psychological and emotional problems, which could adversely affect their quality of life. This study aimed to evaluate the quality of life of the female caregivers of breast cancer patients in Sabzevar, Iran.
Article History: Received: 25- Oct -2015 Accepted: 25- Sep -2016	**Methods**: This cross-sectional study was conducted on 105 participants in Sabzevar, Iran in 2013. Subjects were selected via purposive sampling, and required data were collected using the Caregiver Quality of Life Index-Cancer (CQOLC) scale, which was completed by the family caregivers of breast cancer patients through interviews. Data analysis was performed in SPSS version 20 using independent t-test, analysis of variance, Pearson's correlation-coefficient, and stepwise multiple regression analysis.
Key words: Breast cancer Family caregivers Quality of life	**Results:** Mean age of the participants was 36.9±10.9 years, and total mean score of quality of life was 55.48±10.87. The highest score was observed in the subscale of "lifestyle disruption" (mean: 66.14±17.31), while the lowest score belonged to the subscale of "emotional/mental burden" (mean: 49.43±18.49). Total mean score of quality of life in the sisters of breast cancer patients was 4.678 units higher compared to the caregivers who were the daughter of the patients. Moreover, total mean score of quality of life in breast cancer patients with no insurance was 5.457 scores lower compared to those with insurance. **Conclusion:** According to the results of this study, emotional and psychological needs of the female caregivers of patients with breast cancer (as informal caregivers) must be considered in developing related educational programs for the formal caregivers of these patients, especially mental health nurses.

Introduction

According to the report published by the American Cancer Society, cancer is currently one of the most devastating health problems across the world, and about one in eight women (12%) in the United States develop invasive breast cancer during their lifetime. Furthermore, statistics suggest that approximately 40,450 women die due to breast cancer each year (1). Among different types of cancer, breast cancer is of utmost importance due to its rising prevalence in many countries, especially Iran.

Breast cancer is known as the most common type of cancer, accounting for 24.4% of all cancers among Iranian women (2). In the majority of cases, patients diagnosed with breast cancer need the support and care of their family members. Recently, this trend has gained greater importance since many patients are opting for continuing their treatment at home with the care of their family members (3).

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Family plays a pivotal role in the support of chronic patients, and family members are considered as "informal caregivers" to offer physical, psychological and spiritual care for cancer patients (4, 5). Considering the process of cancer diagnosis and initial awareness of the disease, family caregivers of these patients might require adequate emotional support as well (6).

According to the literature, family caregivers of cancer patients are at a high risk of physical and emotional disorders, including stress, depression, fatigue, loss of self-confidence, and numerous physical health issues (7, 8). In addition, previous studies have reported other problems in these individuals, such as social role conflict, restriction of routine activities, and disruption of family relations (9), all of which could adversely affect the quality of life.

Quality of life is considered a prominent outcome in health care, and its measurement is essential to research and experimentation in this field (10). According to the World Health Organization (WHO), quality of life is defined as the personal perception of individuals toward their life status in terms of cultural and social values, as well their goals, expectations, standards, and needs (11).

Caregivers of cancer patients play a major role in the decision-making regarding the treatment process, patient care requirements, and recovery of the patients (12). Therefore, adequate support and preventing the occurrence of physical and emotional problems in these individuals significantly influence their quality of life, which is also of great help to the health and wellbeing of cancer patients.

Previous studies denote that women have greater involvement in the care of cancer patients compared to men (13, 14), especially in the Iranian culture. This study aimed to evaluate the quality of life of the female caregivers of breast cancer patients in Sabzevar city, Iran. It is hoped that our findings contribute to the implementation of effective interventions for these individuals in accordance with their status in order to enhance their quality of life.

Materials and Methods

This cross-sectional study was conducted in Sabzevar city, Iran in 2013. Sabzevar is a low-income city located in Khorasan Razavi province in the northeast of Iran with 400,000 inhabitants.

Study population consisted of all the female family caregivers of patients diagnosed with breast cancer.

In total, 213 cases of breast cancer were recorded in Sabzevar during 2008-September 2013. To estimate the average quality of life of the caregivers of these patients (2.5 accuracy, 95% confidence interval, quality of life standard deviation of 15) and considering the number of breast cancer patients, sample size was estimated at 86 subjects, and 105 participants were enrolled in this study.

Inclusion criteria of patients were the diagnosis of breast cancer two years prior to the study (15), having received cancer treatment for a minimum of one year, and having an immediate family member as the caregiver.

Inclusion criteria of the study for family caregivers were as follows: 1) female immediate family members (mother, sister or daughter of patients); 2) age of more than 16 years (considering the cultural values in Sabzevar, the eldest daughter, even if aged less than 18 years, is expected to provide care for patients); 3) absence of cancer and 4) no psychiatric or neuropsychological disorders in the past or present.

Finally, 105 eligible participants were enrolled in the study. With respect to ethical considerations, study objectives were explained to all the subjects, and informed consent was obtained from all the participants before completing the questionnaires.

Data were collected using the Caregiver Quality of Life Index-Cancer (CQOLC) scale to measure quality of life. CQOLC is a validated, multidimensional scale to assess the pers-pectives of cancer patient caregivers, which has been designed and corrected through detailed interviews with caregivers of cancer patients in the United States (16) and successfully applied in many studies in different countries (17-19). Moreover, CQOLC has been translated and adjusted for the Iranian population by Khanjari et al. (20).

In this study, we used the Persian version of CQOLC after obtaining the required permit from related authorities. This scale is composed of four subscales and 35 items, which are scored based on a five-point Likert scale. Subscales in CQOLC include emotional/mental burden (14 items) (example: "I feel sad."), lifestyle disruption (9 items) (example: "The fact that my

life routines have changed bothers me."), positive adaptation (8 items) (example: "The responsibility of taking care of my loved one at home is onerous."), and financial concerns (3 items) (example: "I am under financial pressure.").

In this study, one of the items in CQOLC that was irrelevant to the subscales was evaluated independently. Items of the subscales of CQOLC are replied with five options (Never=zero, Very much=4). Score of each subscale was calculated separately, so that four different scores were obtained for each participant. Total score of CQOLC was determined within the range of 0-140. For matching the scores in different subscales, obtained scores were converted into a range of 0-100. Considering the concept of quality of life, assigning scores to the responses in CQOLC resulted in proper quantitative assessment (20), so that higher scores were interpreted as better quality of life.

Research was carried out through the completion of questionnaires via interviews with the participants, and the provided responses had to be based on the events of the past seven days. In this study, Cronbach's alpha coefficient for the internal consistency of CQOLC was 0.85 for the subscale of "mental/emotional burden", 0.71 for "lifestyle disruption", 0.76 for "positive adaptation", and 0.81 for the subscale of "financial concerns".

Study protocol was approved by the Research Ethics Board of Sabzevar University of Medical Sciences, Iran.

Data analysis was performed in SPSS version 20 using Pearson's correlation-coefficient. Normality of the collected data was measured using the Kolmogorov-Smirnov test, and independent t-test was used to compare the obtained mean scores. Moreover, analysis of variance was applied to investigate the correlations between variables, and stepwise multiple regression analysis was used to identify the variables significantly associated with quality of life. In all statistical analyses, level of significance was considered at 0.05.

Results

In total, 105 women within the age range of 17-64 years and mean age of 36.9±10.9 years were enrolled in this study. Among the participants, 77.1% (n=81) were housewives, and 76.2% (n=80) were married. In terms of education level, the majority of subjects (27.6%; n=29) had high school diploma (1-8 years), and the lowest proportion (9.5%; n=10) were illiterate.

In this study, 85.7% of the subjects (n=90) had health insurance. With regard to income status, only 15.3% (n=16) had a monthly income of 8,000,000 Rials (1$=34,000 Rials), while the other participants reported their monthly income to be less than 8,000,000 Rials (Table 1). According to the collected data, 33.3% of the participants (n=35) had irregular sleep patterns.

With respect to the subscales of quality of life, the highest mean score was observed in the subscale of "lifestyle disruption" (66.14±17.31), while the lowest mean score belonged to the subscale of "emotional/mental burden" (49.43±18.49), which almost equaled half the maximum possible score (50 out of 100). Mean scores of the other subscales of quality of life were calculated to be more than 50 (Table 2).

Analysis of variance was performed for the scores of quality of life subscales (emotional/mental burden, financial concerns, overall quality of life) in terms of the education level of the participants, and the highest scores were observed in subjects with academic education with a significant difference in this regard (P<0.02). In the subscale of "positive adaptation", the lowest score of quality of life was observed in participants with high education.

Table 1. Demographic characteristics of female family caregivers of breast cancer patients (n=105)

Quality of life subscales	Minimum	Maximum	Mean±SD
Emotional/mental burden	7.25	90.50	49.43±18.49
Lifestyle disruption	14.00	94.50	66.14±17.31
Positive adaptation	12.50	87.50	52.57±16.25
Financial concerns	0	100	53.10±23.72
Total	28.75	77.25	55.48±10.87

Table 2. Minimum, maximum and mean scores of overall quality of life and its subscales (score range: 0-100)

Subgroup	Frequency (%)
Age (year)	
17-20	7(6.7)
20-30	25(23.8)
30-40	33(31.4)
40-50	25(23.8)
>50	15(14.3)
Education level	
Illiterate	10(9.5)
Primary	27(25.7)
Secondary	13(12.4)
High school	29(27.6)
Academic	26(24.8)
Occupational status	
Housewife	81(77.1)
Worker	10(9.5)
Employee	5(4.8)
Others	9(8.6)
Marital status	
Married	80(76.2)
Single	18(17.1)
Widowed	6(5.7)
Divorced	1(1)
Income status	
Very poor	48(45.7)
Poor	41(39)
Average	9(8.6)
Favorable	7(6.7)
Insurance status	
Yes	90(85.7)
No	15(14.3)

Table 3. Correlations between mean scores of quality of life subscales and demographic variables of participants

Quality of life subscale / Variable	Emotional/mental burden	Lifestyle disruption	Positive adaptation	Financial concerns	Total
Education level					
Illiterate	48.58±18.03	64.95±20.94	51.35±11.71	46.68±23.96	54.08±13.25
Primary (1-8 years)	52.19±18.93	68.13±19.18	53.28±17.24	53.34±21.41	57.29±10.70
High school	40.77±17.46	60.46±16.53	55.78±15.50	45.71±28.14	50.64±11.36
Academic	55.18±16.47	69.88±12.24	48.39±16.88	63.47±18.43	58.63±7.83
P-value	0.018	0.179	0.400	0.034	0.024
Occupational status					
Housewife	48.16±18.81	64.95±18.75	54.35±15.91	50.63±23.78	54.83±11.51
Employed	53.73±17.04	70.14±10.53	46.57±16.26	61.46±21.96	57.66±8.20
P-value	0.196	0.199	0.039	0.049	0.266
Insurance status					
Yes	50.34±18.56	67.44±16.93	52.05±16.13	55.01±22.05	56.22±10.71
No	44.02±17.71	58.33±18.13	55.70±17.20	41.68±30.38	51.02±11.08
P-value	0.222	0.059	0.424	0.043	0.086
Income status (Rials)					
4,000,000<	48.79±20.09	64.35±17.85	52.81±17.41	44.45±25.27	54.02±11.43
4,000,000-8,000,000	47.58±16.47	66.86±15.10	53.20±13.01	55.71±19.50	55.32±10.31
8,000,000>	56.11±17.99	69.66±21.13	50.25±20.54	72.41±15.13	60.27±9.73
P-value	0.281	0.541	0.822	0.000	0.137
Family relation with patient					
Daughter	49.45±19.20	65.79±18.10	50.25±16.71	53.15±23.69	54.76±10.99
Sister	49.41±17.30	66.81±15.91	57.02±14.53	53.01±24.10	56.86±10.64
P-value	0.993	0.775	0.042	0.978	0.349

levels; however, it was not statistically significant (Table 3).

Analysis of quality of life in the subscale of "positive adaptation" indicated that housewives achieved higher scores in this subscale compared to employed women. With reference to family relations, no statistically significant difference was observed between this variable

and mean scores of "lifestyle disruption" and overall quality of life (Table3).

According to the results of stepwise multiple regression analysis, score of overall quality of life in the female caregivers who were the sisters of breast cancer patients was 4.678 units higher

Table 4. Associations between quality of life and some variables based on stepwise multiple regression analysis

	B	Std. Error	β	t	P-value
Constancy	36.707	8.188		4.483	0.000
Income status	3.390	1.393	0.225	2.434	0.017
Insurance status*	-5.457	2.836	-0.177	-1.924	0.057
Regular sleep patterns	-4.068	2.091	-0.177	-1.945	0.055
Family relation of caregiver with patient**	4.677	2.133	0.205	2.193	0.031

*Base (having insurance); **base of family relations (sister)

compared to the caregivers who were the daughter of the patients. Furthermore, mean score of quality of life in breast cancer patients without health insurance was 5.457 units lower compared to patients with insurance (Table 4).

Discussion

According to the results of the present study, score of quality of life in the female caregivers of breast cancer patients was slightly higher than half the maximum possible score; this could be attributed to the score of the subscale of "emotional/mental burden", which was significantly lower compared to other subscales of quality of life.

In a study by Turkoglu and Klic performed in Turkey (21), minimum score of quality of life achieved by the caregivers of cancer patients undergoing chemotherapy was reported to be 43 out of the maximum score of 123 (score range: 0-140), with the mean score estimated at 80.3. Since this score was slightly lower than half the maximum possible score, quality of life of the caregivers was reported to be at an average level, which is in congruence with our findings.

In a similar research conducted in Iran, Khanjari et al. (2012) reported the score of quality of life to be 92.7 (score range: 0-140) (20), which equals 66.2% of the total score. As such, mean score of quality of life in the mentioned study is higher compared to the results of the current research. This difference could be because in the study by Khanjari et al., sample population

consisted of newly diagnosed cases of breast cancer, while in the present study, one of the inclusion criteria for the participants was breast cancer diagnosis within the past two years and receiving treatment for a minimum of one year.

In the present study, the lowest score of quality of life was observed in the subscale of "emotional/mental burden", while in the research by Turkoglu and Klic (2012), the lowest score was reported in the subscales of "positive adaptation" and "lifestyle disruption", which were slightly lower than half the maximum possible score (21).

Several studies have denoted the occurrence of psychological disorders (e.g., stress and anxiety) in the family caregivers of cancer patients, claiming that mental and emotional issues adversely affect the quality of life of these individuals leading to the decreased scores of this index. This has been supported by the National Cancer Institute, confirming the psychological damage caused by cancer as a major challenge faced by the caregivers of these patients (22).

Undoubtedly, cancer diagnosis substantially influences the immediate family members of the patients, imposing a significant emotional and mental burden on the caregivers in particular. In explanation, it could be stated that in Iran, informal caregivers (i.e., family members) rarely receive training in this regard and perform care giving out of duty, compassion or even obligation. As such, numerous studies have emphasized on the importance of the targeted training of caregivers for the proper care of chronic patients,

as well as self-care behaviors of these individuals in order to maintain their emotional and mental health (12, 23).

Findings of the current study indicated that kin relationships between the caregivers and breast cancer patients and having health insurance areamong significant influential factors of the quality of life of caregivers. In the study by Turkoglu and Klic (2012), these factors were determined as age, gender and income status (21). On the other hand, Meyers and Gray (2001) proposed that demographic characteristics, such as age and gender, as the most significant predictive factors for the quality of life of patient caregivers, which accounted for 44% of the variance (24).

With respect to the subscale of "financial concerns" in the evaluation of quality of life, insurance status of the participants was investigated in the present study. Since the majority of our subjects claimed to have poor or average income status, lack of health insurance might have been involved in achieving low scores in this subscale, leading to the reduced score of overall quality of life.

Moreover, in the present study, scores of quality of life were lower in the caregivers who were the daughter of breast cancer patients compared to those who were the sister of the patients. This could be attributed to the stronger bond between the mother and daughter compared to that of sisters; however, further investigation is required in this regard. Similar studies have focused on both male and female caregivers, proposing that women tend to experience higher stress and lower quality of life compared to men (25), while the current research was performed on female caregivers only.

Findings of the present study were indicative of a statistically significant association between education level and quality of life. In another research, Tang (2009) assessed education level and other factors (e.g., quality and quantity of social support) as the indicators of quality of life in the caregivers of cancer patients, which explained 42% of the variance (19).

In a study by Karimzadeh Shirazi (2008) conducted in Iran, a significant association was reported between quality of life and education level. Furthermore, the results of the mentioned study indicated that quality of life of caregivers increased with higher education level (26). This is in line with the results of the present study, as the family caregivers with academic education had higher quality of life compared to those with lower education levels (17). In explanation, it could be stated that education may positively affect the awareness and knowledge of caregivers regarding proper patient care and the complications associated with the treatment process, which helps them adjust better with disease outcomes and complications.

One of the limitations of the present study was that our participants were only selected from the female caregivers of breast cancer patients due to easier access to these individuals, as well as their higher willingness to participate in the study than male caregivers.

Women constitute half the population of the community. Considering the higher dominance of emotions and sensitivity compared to men, women account for a major proportion of family caregivers of chronic patients. Therefore, respecting the mental and emotional needs of these individuals should be considered in educational programs for health professionals. Moreover, nursing interventions should be tailored to the needs of these caregivers.

Conclusion

Special attention must be paid to the emotional and psychological needs of the family caregivers of patients diagnosed with breast cancer in order to promote their quality of life.

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Conflicts of interest

There are no conflicts of interest.

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