

## The Caring-related Problems Experienced by Family Caregivers of Patients With Breast Cancer: A Descriptive Study

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**Introduction:** The diagnosis of cancer involves the patients, their caregivers, and families. Caregivers should obtain guidance from health care professionals to promote care facilities. The current study aimed at investigating the economic, socio-individual, informational, and psycho-spiritual problems of caregivers in post-treatment phase of breast cancer.

**Methods:** The present descriptive study was conducted on 251 subjects using a questionnaire consisted of demographic part and the caregivers' difficulties. Answers were estimated based on a Likert scale. Data were analyzed using SPSS software.

**Results:** Totally, 42% and 37% of participants were spouses and close relatives, respectively; 97%, 89%, and 74% of caregivers had psychological, economic, and spiritual problems, respectively. All of the caregivers had individual, emotional, physical, economic, and informational problems with care giving ( $P < 0.0001$ ). Significant relationships were observed between the employee group and individual, emotional, informational, and economic problems ( $P < 0.0001$ ). There were significant negative relationships between either of the occupational, educational, relationship, caregiving duration, and marital status with spiritual problems ( $P < 0.0001$ ). Significant correlation was observed between the duration of caring and the socio-individual, physical, informational and economic problems ( $P < 0.0001$ ).

**Conclusions:** Although the current study reported insignificant relationships between the socio-individual, informational, and psycho-spiritual problems of caregivers and some demographic variables, related positive trends were observed. Future studies with powerful strategies are needed to alleviate the observed concerns.

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## INTRODUCTION

The diagnosis of cancer is a devastating condition that involves the patients, their family members, and friends [1]. Family caregivers are mostly the patients' untrained spouses, parents or even

children, and provide uncompensated care to the patient [2]. The provided cares usually consist of physical, social, emotional, and medical assistants as well as interacting with professional caregivers

[3]. Patients often enter a shock phase after the diagnosis of cancer and need effective support and attention [4]. Thus, it is necessary for family caregivers to obtain special guidance from health care professionals and related systems in order not to face any unsolvable problems [1]. Studies show that if caregivers are not well-informed about the details of the disease, its diagnosis, the treatment procedures and their side effects as well as the particular supports in every stage of the disease, they cannot help patients properly and may even put themselves at serious risks [5]. On the other hand, family caregivers are susceptible to have economic, physical, psychological and spiritual difficulties [5, 6]. Previous studies show that caregivers of patients with cancer are exposed to psychological symptoms including depression, anxiety, anger or phobia, and social concerns such as role limitations, constraints on life activities, changes in the status of marital life or endangering their individual health [1, 2, 7]. As there are many patients with cancer or other chronic diseases, there are growing claims for non-hospital or outpatient care, and thus, patients are more in favor of being discharged from hospitals. Therefore, it is essential to promote care facilities to a higher and more professional level [8].

Meanwhile, there are prevalent problems in terms of care giving related to the lack of personal information and professional knowledge of caregivers about the disease [9, 10]. In a study by Shin et al., conducted in south Korea among patients with different types of cancers in 2018, it was reported that cancer caregivers had 49.6%, 47.6%, and 43% of physical, emotional and financial problems, respectively [11]. Recent studies believe that such problems of caregivers are common in different societies, yet with various incidences due to the cultural aspects and overall situation of every country [8, 12]. A similar recent study conducted in Sari, Iran, among patients with breast cancer revealed that 60% of breast cancer caregivers had depression [13]. Other similar articles conducted by Soleimani et al., and Khanjari et al., in Iran showed that caregivers of patients with cancer had moderate levels of well-being, spirituality, death anxiety, and decrements in quality of life. Female caregivers who were daughters had higher death anxiety, whereas male caregivers who were sons reported higher quality of life [6, 8]. Generally, domestic care certainly decreases the hospital treatments and increases the

outpatient health care services, and thus, expands the chance of survival of every patient [14]. Family members are more responsible to take better care of patients for a longer time at home, since they have more access to basic information and facilities and on the other hand, patients also have more tendency for home care [15, 16].

Hence, it is vital to dissolve the existing problems of caregivers in order to increase their morale and improve care conditions in different societies to better understand the related complications and thus find preferable solutions. The current study mainly aimed at investigating the economic, socio-individual, informational, and psycho-spiritual problems of caregivers in post-treatment phase.

## **METHODS**

The present descriptive-analytic study with a cross sectional design was conducted in Breast Cancer Research Center (BCRC), Motamed Cancer Institute (MCI), Tehran, Iran, in 2016. Sampling was performed based on the sample size formula of descriptive studies [17]. The current study was approved by Ethics Committee of Academic Center for Education of Motamed Cancer Institute (NO. 1865). Participants were assured that their names and personal information would not be disclosed at any time and their identity would remain confidential. Sample size was calculated based on a previous study; 251 caregivers helping breast cancer survivors with the disease stages of one to three were recruited for the present study; recruitment of participants was performed among individuals referred to the Breast Cancer Clinic and Research Center with their patients for one year. The history of every participant was asked individually to make sure that there were no physical or mental traumatic symptoms. The participants completed the questionnaire two steps before and after treatment. The research tools included a validated questionnaire designed based on previous studies. Some items were selected from studies such as overall mental health, emotional distress, physical stress, social functioning, physical health, social support, social adjustment, and overall spiritual health. [12, 18, 19]. The questionnaire was verified to have construct and content validity and was reviewed and modified by several health professionals including epidemiologists, psychiatrists, surgeons, lymphologists, and other healthcare specialists. All the caregivers completed the final

version of questionnaire (face validity). To test the reliability of the questionnaire, Cronbach's alpha coefficient method was applied; the Cronbach's alpha was 0.768 and was pre-tested before the initiation of the research. All of the caregivers approved to participate in the study voluntarily and then were interviewed by a trained interviewer at the clinic in a safe condition. Informed consent was obtained from all participants. The study was conducted in accordance with principles of the Declaration of Helsinki. This questionnaire included two sections; demographic part and the caregivers' difficulties. The features of questions were as follows: Nine questions were on informational problems and were scaled from 9 to 45 points, six questions were on physical problems and were scaled from 6 to 30 points, eight questions were on psychological problems and were scored from 8 to 40 points, three questions were designed for spiritual problems ranging from 3 to 15 points, nine questions were on the social and individual problems ranging from 9 to 45 points and four questions were designed for economic issues and were scored from 4 to 20. Every participant was asked about psychological problems by a trained psychologist via eight main questions on anxiety, tiredness, and nervousness; further questions regarded the physical problems including the patient translocation and house chores. Questions of spiritual problems were also those related to the belief in God or religious affairs. The examples of the information and psychological questions were as follows: did you have any problems with getting information (diagnosis, treatment, and post-treatment)? What kind of problems did you have about the care and nutrition of the patient and yourself? Do you have anxiety and depression problems such as feeling anxious or sadness? The answers were then scored based on a Likert scale as strongly disagree, disagree, no idea, agree and strongly agree [20].

The data analysis was performed using SPSS. Descriptive statistics (frequency and percentage) and chi-squared test (considering the fact that the assumption of normality was not observed in the current study) were applied to determine the association of independent variables including age, caregiving duration, the relationship of family member, marital status, academic status or occupations of caregiver with the problems and difficulty status of caregivers.

**Table 1:** Demographic Characteristics of Participants

| Patients Characteristics          | Number(%) |
|-----------------------------------|-----------|
| <b>Age, y</b>                     |           |
| 14-25                             | 28(11)    |
| 26-40                             | 84(33)    |
| 41-55                             | 102(40)   |
| 56-78                             | 37(14)    |
| <b>Relationship</b>               |           |
| Husband                           | 105(42)   |
| Close Relatives <sup>a</sup>      | 94(37)    |
| Other Relatives                   | 52(21)    |
| <b>Occupation</b>                 |           |
| Student                           | 28(11)    |
| Employee                          | 53(21)    |
| Retired/ Housewife                | 96(38)    |
| Others                            | 74(29)    |
| <b>Marital Status</b>             |           |
| Married                           | 194(77)   |
| Single                            | 57(22)    |
| <b>Educational Level</b>          |           |
| Illiterate                        | 9(3)      |
| High School Diploma               | 135(53)   |
| University Degree, PhD            | 107(42)   |
| <b>Duration of Caregiving, mo</b> |           |
| <6                                | 53(21)    |
| 6-12                              | 99(39)    |
| 13-24                             | 36(14)    |
| 25-36                             | 30(11)    |
| 37-48                             | 9(3)      |
| 49-60                             | 11(4)     |
| 61-180                            | 13(5)     |
| <b>Stage of Disease</b>           |           |
| 1                                 | 14(6)     |
| 2                                 | 96(38)    |
| 3                                 | 131(52)   |
| 4                                 | 10(4)     |
| <b>Total Problems With Caring</b> |           |
| Never                             | 5(1)      |
| A Little                          | 211(84)   |
| Severe                            | 35(13)    |

<sup>a</sup> mother, daughter, sister, brother, and son

**Table 2: Frequency of Caregivers' Problems**

|                      | Participants Without Problems, No.(%) | Participants With Problems, No.(%) |
|----------------------|---------------------------------------|------------------------------------|
| <b>Informational</b> | 7(3)                                  | 244(97)                            |
| <b>Physical</b>      | 58(23)                                | 193(76)                            |
| <b>Psychological</b> | 7(3)                                  | 247(97)                            |
| <b>Spiritual</b>     | 184(74)                               | 67(26)                             |
| <b>Individual</b>    | 59(23)                                | 192(77)                            |
| <b>Economic</b>      | 30(12)                                | 221(88)                            |

**Table 3: Patient-Caregiver Relationship Correlation With the Existing Problems<sup>a</sup>**

|                      | Care Duration (6-12 mo) |         | Relationship (Patient-Husband) |         | Job (Self-employee, or Other) |         | Education (Educated) |         | Marital Status (Married) |         |
|----------------------|-------------------------|---------|--------------------------------|---------|-------------------------------|---------|----------------------|---------|--------------------------|---------|
|                      | No.(%)                  | P Value | No.(%)                         | P Value | No.(%)                        | P Value | No.(%)               | P Value | No.(%)                   | P Value |
| <b>Informational</b> | 91(62)                  | <0.001  | 64(44)                         | <0.001  | 79(55)                        | <0.001  | 117(75)              | <0.001  | 111(77)                  | <0.001  |
| <b>Physical</b>      | 56(64)                  | <0.001  | 47(54)                         | 0.0140  | 52(60)                        | <0.080  | 78(77)               | <0.001  | 76(39)                   | <0.002  |
| <b>Economical</b>    | 48(60)                  | <0.001  | 37(46)                         | <0.001  | 38(47)                        | <0.001  | 64(80)               | <0.001  | 64(81)                   | <0.001  |
| <b>Emotional</b>     | 104(58)                 | <0.001  | 68(38)                         | <0.066  | 89(49)                        | <0.001  | 146(89)              | <0.001  | 134(69)                  | <0.001  |
| <b>Spiritual</b>     | 165(58)                 | <0.001  | 97(42)                         | <0.001  | 115(50)                       | <0.001  | 190(82)              | <0.001  | 177(77)                  | <0.001  |
| <b>Individual</b>    | 34(63)                  | <0.001  | 34(64)                         | <0.002  | 40(75)                        | <0.001  | 46(79)               | <0.001  | 43(81)                   | <0.001  |

<sup>a</sup>P<0.005 was considered as significant.

## RESULTS

The current study was conducted on 251 caregivers taking care of patients with breast cancer. Mean age of participants was  $41 \pm 13$ . Concerning the relationship between caregivers and patients, the obtained results indicated that 105 of the subjects (42%) were their spouses, 94 (37%) were close relatives such as mother, daughter, sister or brother and 52 care givers (21%) were other relatives. 96 subjects (39%) were housewives, 21% employees, and 29% self-employed. Concerning the marital status, 194 subjects (77%) were married; 135 individuals (53%) had high school diploma and (42%) were mentor. The total duration of caregiving was from six months to 17 years. The stages of disease ranged from 1 to 3, in which 131 patients (52%) had stage 3 of the disease. The basic characteristics of caregivers are shown in Table 1.

The frequency of caregivers' problems is also shown in Table 2, 97% of the caregivers had psychological problems and 89% of them had economic difficulties, while 74% of them had no spiritual problems.

Table 3 illustrates the correlation between the patient-caregiver relationship and the existing problems. Data indicated that all of the caregivers had individual, emotional, physical, economic, and informational problems with care giving ( $P < 0.0001$ ). Significant relationships were observed between the employee group and individual, emotional, informational, and economic problems ( $P < 0.0001$ ). However, there were significant negative relationships between either of the occupational, educational, relativeness, care-giving duration, and marital status with spiritual problems ( $P < 0.0001$ ). On the other hand, significant correlation was observed between the duration of caring and the socio-individual, physical, informational and economic problems ( $P < 0.0001$ ). Table 3 also illustrates a significant relationship between married caregivers and every caregiving problem ( $P < 0.0001$ ).

## DISCUSSION

The current study aimed at investigating the economic, socio-individual, informational and psycho-spiritual problems of caregivers in post-treatment phase; the results indicated that more than 79% of the caregivers were among spouses and close relatives reporting informational, individual, and economic problems. However, their main complaints were physical difficulties. The self-

employed subjects were more dissatisfied with socio-individual problems compared to the other caregivers. Furthermore, in the Iranian caregivers, sexual problems, caregivers' lack of information, and the religious context was important [21]; physical, mental, spiritual and emotional dimensions of quality of life were also important [6, 8, 13].

According to a review article by Haley et al., conducted on the main issues of family caregivers, the related problems that occurred in the workplace of caregivers including distress and disruption might result in psychological and socio-individual problems [22]. In line with similar studies performed on cancer caregivers [22-25], the current study demonstrated that most of the caregivers were from the close relatives, mostly the patients' spouses. Moreover, the present study reported that the first-degree relatives often had physical problems and did not complain over psychological issues, while other studies achieved contrary results [23, 26]. On the other hand, Kim et al., proved that stress level was higher in first-degree relatives compared to other groups [23]. According to the studies by Lopez et al., and Duggle by et al., the spouses of patients with breast cancer were considered the major caregivers mostly exposed to excessive physical, cognitive, and psychological pressure [24, 25]. However, there was an increasing hope that care services developed in near future in which the caregivers attended enthusiastically in such supportive programs [27]. As a matter of fact, hope has direct effects on increasing the willingness of spouses of patients with breast cancer [28]. Precisely, after the diagnosis of cancer, both patients and caregivers need more hope to keep the balance between care-providing and performing their own affairs [24, 25].

The present study also showed that the employee subjects had from socio-individual problems. Groganfeld et al., in a study on 89 patients with breast cancer and their caregivers evaluated the public health criteria, social factors, anxiety, and depression and reported that the level of caregivers' anxiety and depression was significantly higher than that of the patients. They also indicated that 69% of the caregivers had self-care problems and 77% of them lost their jobs during the chronic stages of the spouse disease, because they felt excessive responsibility for taking care of their patients [29]. Another study by Wadhwa et al., investigating the quality of life of caregivers in terms of protecting

non-hospitalized patients with cancer, showed that half of the caregivers were clerks and 25% of them were forced to change their career as they had more individual and social problems [30]. Investigations on adaptability of caregivers showed that caregivers were more capable of accommodating themselves to the present conditions, after a longer period of caregiving [31].

Studies reported a great need for comprehensive and reliable educational programs in order to promote caregiving of all patients [32]. Such programs that were mostly based on personal experiences helped caregivers better perform their own responsibilities via augmenting their consciousness as well as decreasing their stress and worries [23]. Caregivers are assumed as the major providers of supports and primary health care decision makers in long-term care; hence, if they face any stressful conditions, patients have irreversible problems including little information about the illness, high concerns on the disease occurrence, and less withstanding with the burden of disease [26, 27]; therefore, having more information about the details of caregiving and the disease alleviates such consequences. Studies indicated that a well-designed theoretical program is needed in order to have a better care of patients; such programs might help caregivers to promote their self-management and independence via augmenting their knowledge in terms of caring [33]. In fact, the more the disease-related knowledge and information that caregivers have, the better compatibility with the disease and the less stress and tension they face. In general, the current study indicated that in order to have an accurate care of patients with breast cancer, it is vital to improve the care conditions and abilities of caregivers. It was observed that the most common problems among caregivers were the absence of complete information about the disease and the caregiving process. Although the current study reported insignificant relationships between the socio-individual, informational, and psycho-spiritual problems of caregivers and some demographic variables, positive trends were observed. In the current study, there were very strong emotional relationships between Iranian family members, some of the caregivers did not mention their actual and the real intensity of their problems or many of them refrained from participating in the study. The patients with stage four of breast cancer who had metastasis were not included in the study, since they

needed to be assessed separately from other patients. Hence, it is highly suggested that larger sample sizes from different social and economic levels be selected in future studies in order to consider every possible aspect of such unpredictable problems and further, to better perform future trials.

As long as the healthcare systems solve the social, personal, and psychological issues of caregivers via complete educational programs, it has beneficial outcomes for both patients and the caregivers; thus, future studies with new powerful strategies are needed to alleviate the observed concerns in patients with breast cancer and their caregivers who face huge condemning problems.

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### **CONFLICT OF INTEREST**

The authors declared no conflict of interest.

### **ETHICS APPROVAL**

The project was approved by Motamed Cancer Institute ethics committee. The original version of this article has been published in Farsi and due to the high request, it has been translated into English with some modifications, after obtaining reprint permission from the IJBD Editor. "Sajadian A, Hydary L, Mokhtari Hesari P. Common Breast Cancer Family Care Giving Problems. *IJBD*. 2015;8(2):7-14."

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