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ORIGINAL PAPER

Spiritual Well-Being and Care Burden in Caregivers of Patients with Breast Cancer in Turkey

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Abstract

This research was carried out to identify the relationship between the spiritual well-being and caregiver burden in caregivers of patients with breast cancer. The study was conducted with family caregivers of patients with breast cancer who presented to the oncology clinic of a university hospital for treatment. The study sample included a total of 138 family caregivers who met the criteria for participation and agreed to participate in the study. The data were collected using a participant information form, caregiver burden scale and three-dimensional spiritual well-being scale. The caregivers have a moderate level of caregiver burden and their spiritual well-being was quite high. The caregiver burden of female caregivers was found to be significantly higher than that of male caregivers ($p=0.040$). There is a negatively significant relationship between caregiver burden and spiritual well-being ($p=0.000$, $r=-0.357$). The caregiver burden is significantly higher among the 24-h caregivers compared to that among the 3-h and 4–6-h caregivers ($p=0.003$). The spiritual well-being of the caregivers who provide care between 3 h and 4–6 h a day was significantly higher than that of those who provide 24-h care ($p=0.001$). Increasing spiritual well-being may help to reduce caregiver burden in caregivers of those with breast cancer.

Keywords Breast cancer · Spiritual well-being · Caregiver burden · Family caregiver

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Introduction

Breast cancer in women is one of the most common cancers all over the world. With 2,261,419 new cases in 2020, the incidence rate of breast cancer is 11.7% (World Health Organization, 2020). Breast cancer can be treated using methods such as surgery, chemotherapy, radiotherapy and immunotherapy. The side effects of these treatments increase the care needs of patients (Baider, 2014). Caring for a patient with breast cancer can often strain family caregivers psychologically, socially and financially, leading to negative consequences called caregiver burden (CB). CB is defined as ''a multidimensional response to the physical, psychological, social and financial stress factors associated with the caregiving experience'' (Zarit et al., 1980).

Breast cancer patients are now treated on an outpatient basis without the need for hospitalisation. Care needs are often provided by voluntary family caregivers (Schulz et al, 2020). Caregivers help patients with their daily work, provide medication and manage symptoms (Sun et al, 2019). In this process, caregivers' CB and needs are often unnoticed, and the treatment process is often shaped by the needs of the patient (care recipient) (Jite et al., 2021). Caregivers often receive neither adequate education nor social support (Adelman et al., 2014). Studies on CB have reported a moderate CB (Jite et al, 2021; Lee et al., 2018; Vahidi et al., 2016; Yusuf et al., 2011; Zuo et al., 2020). However, some studies report advanced CB (Garcia et al., 2020). The CB of those who provide care for patients with cancer is affected by many factors. One of them is spiritual well-being (SWB). SWB is an expression of spirituality and a measure of a person's spiritual health (Spatuzzi et al., 2019).

Spiritual well-being is a feeling of one's contentment defined as "the affirmation of life in a relationship with God, self, community and environment that nurtures and celebrates wholeness." (National Interfaith Coalition on Aging, 1975). Various studies show that people who are spiritually strong feel more positive about their roles and communicate better when caring for their patients (Newberry et al., 2013; Sankhe et al., 2017; Spazutti et al., 2019; Tan et al., 2015; Vigna et al., 2020). The International Council of Nurses has included spirituality in nursing codes. 'Spiritual distress' and 'risk for spiritual distress' diagnoses are included in the nursing diagnosis list of the North American Nursing Diagnosis Association (Wilkinson & Barcus, 2016). Nurses are responsible for identifying CBs that may affect the health of caregivers and SWBs that are known to be associated with CBs as well as for providing care. SWB can be used as a cost-effective and effective intervention to reduce the CB of caregivers of patients with breast cancer. In line with this information, our research was carried out to define the relationship between the SWB of caregivers of patients with breast cancer and their CB.

Study Questions

- What is the level of CB of caregivers of patients with breast cancer?
- What is the level of SWB of caregivers of patients with breast cancer?

- Is there a relationship between the SWB of caregivers of patients with breast cancer and their CB?

Method

Study Design

It is a descriptive and correlational study.

Study Setting and Sample

The study was conducted in the inpatient unit of a university hospital oncology clinic and in the outpatient chemotherapy unit. The study conducted with family caregivers of patients with breast cancer who applied to a university hospital oncology clinic for treatment. A total of 138 family caregivers who met the criteria for participation in the study and agreed to participate in the study constituted the study sample.

Study Power

Gpower 3.1.9.2 was used in calculating the sample size (Faul et al., 2009). The mean care load score of caregivers of cancer patients in the study by Bahrami et al. (2014) was used for calculating the sample size. With a 95% confidence $(1-\alpha)$, 95% test power $(1-\beta)$, $d=0.333$ effect size and two-way t-test, the sample size for this study was determined as 133 people. The study was completed with 138 people. The post-hoc power of the research is 0.957.

Inclusion Criteria for Participants in the Study

Being ≥ 18 years of age, being a family member responsible for the care of a patient diagnosed with breast cancer, being referred to by the caregivers themselves or the patient as a primary care provider, not having any health problems, not having a cancer diagnosis or neurological cognitive disorder, being able to communicate in Turkish, and being a caregiver for ≥ 3 months.

Exclusion Criteria for Participants

Wanting to withdraw from the research for any reason while the research is in progress and being < 18 years of age.

Data Collection Technique and Tools

Data were collected using the participant information form, caregiver burden scale and spiritual well-being scale.

Participant Information Form

It is a form prepared by the researchers, consisting of a total of 16 questions related to the age, socio-demographic status and employment status of the participants (Spatuzzi et al., 2019; Vigna et al., 2020).

Caregiver Burden Scale (CBS)

It is a scale used to evaluate the CB of those who care for a person or elderly in need of care (Zarit et al., 1980). ‘‘The Turkish validity and reliability of the scale was assessed by İnci and Erdem. The reliability coefficient of the scale is between 0.87 and 0.99. The scale consists of 22 statements. It is a 5-point Likert type scale (never, rarely, sometimes, frequently, and nearly always). A minimum score of 0 and a maximum score of 88 points can be obtained on the scale. In this study, scale scores were evaluated as no/little burden (0–20 points), moderate burden (21–40 points), severe burden (41–60 points) and very severe burden (61–88 points)’’ (İnci & Erdem, 2010). The Cronbach's α value of this study is 0.92.

Three-Factor Spiritual Well-Being Scale (SWBS)

The validity and reliability of this scale was assessed by Ekşi and Kardaş (Ekşi & Kardaş, 2017; Kardaş, 2019). Three-factor Spiritual Well-being Scale in Turkish was given in Table 1 (Ekşi and Kardaş 2017; Kardaş 2019), spiritual and social dimensions of a person's life and to determine the quality of this process. It is a 5-point Likert type scale. The transcendency subscale consists of items 1, 4, 5, 8, 9, 12, 13, 16, 17, 20, 21, 24, 25, 27 and 29; the harmony with nature subscale consists of items 2, 6, 10, 14, 18, 22 and 28 and the anomie subscale consists of items 3, 7, 11, 15, 19, 23 and 26. When a total score is desired, reverse scoring is applied for the items in the anomie subscale. The Cronbach's α value of the scale was determined as 0.763’’ (Ekşi & Kardaş, 2017; Kardaş, 2019). The Cronbach' alpha value of this study is 0.81.

Data Collection

The data of the study were collected between August 2021 and October 2021. The data were collected through face-to-face interviews with caregivers of patients with breast cancer. The data collection took approximately 10–15 min. Due to the ongoing coronavirus disease-19 pandemic, the interviewers and interviewees wore masks and maintained social distance during the interview.

Table 1 Three-factor spiritual well-being scale

		Bana hiç uygun değil	Bana uygun değil	Bana biraz uygun	Bana oldukça uygun	Bana tamamen uygun
1	İlahi bir güce bağlı olmak bana güven verir	(1)	(2)	(3)	(4)	(5)
2	Doğaya saygı duyulması gerektiğini düşünürüm	(1)	(2)	(3)	(4)	(5)
3	Hayata dair bir hoşnutsuzluk duygusu hissederim	(1)	(2)	(3)	(4)	(5)
4	Bir problemle karşılaştığımda Allah'ın yardımını hissederim	(1)	(2)	(3)	(4)	(5)
5	Allah'ın gizli ve açık tüm duygu ve düşüncelerimi bildiğine inanırım	(1)	(2)	(3)	(4)	(5)
6	Bütün canlıların saygıyı hak ettiğini düşünürüm	(1)	(2)	(3)	(4)	(5)
7	Hayatımda büyük bir boşluk var	(1)	(2)	(3)	(4)	(5)
8	Günlük hayatta Allah'ın kudretine şahit olurum	(1)	(2)	(3)	(4)	(5)
9	Allah'ın beni sevdiğine ve önemsediğine inanırım	(1)	(2)	(3)	(4)	(5)
10	Yeryüzündeki tüm canlılara iyi davranırım	(1)	(2)	(3)	(4)	(5)
11	Hayattan zevk almam	(1)	(2)	(3)	(4)	(5)
12	Hayatımın her anında Allah'ın varlığını hissederim	(1)	(2)	(3)	(4)	(5)
13	Daha güçlü bir varlığa sığınma duygusu beni rahatlatır	(1)	(2)	(3)	(4)	(5)
14	Kendimi doğanın bir parçası olarak görürüm	(1)	(2)	(3)	(4)	(5)
15	Hayatımın amacını halen bulabilmiş değilim	(1)	(2)	(3)	(4)	(5)
16	Yaşadığım her olayda bir hayır olduğuna inanırım	(1)	(2)	(3)	(4)	(5)

Table 1 (Continued)

		Bana hiç uygun değil	Bana uygun değil	Bana biraz uygun	Bana oldukça uygun	Bana tamamen uygun
17	İnancım, nasıl bir hayat süreceğime dair bana yol gösterir	(1)	(2)	(3)	(4)	(5)
18	Yeryüzündeki bütün canlıların hakları benim için önemlidir	(1)	(2)	(3)	(4)	(5)
19	Sorunlarımı çözm-eye nereden başlayacağımı bilemem	(1)	(2)	(3)	(4)	(5)
20	Yalnız kaldığımda Allah'ı ve yarattıklarını düşünürüm (tefekkür ederim)	(1)	(2)	(3)	(4)	(5)
21	İnanç ve değerlerim, zorluklar karşısında dayanabilme gücümü arttırır	(1)	(2)	(3)	(4)	(5)
22	Doğayla uyum içinde yaşarım	(1)	(2)	(3)	(4)	(5)
23	Zorluklar yaşadığımda bunalmış hissederim	(1)	(2)	(3)	(4)	(5)
24	İnancım, yaşadığım sıkıntılarda dahi olumlu tarafların olabileceğini görmemi sağlar	(1)	(2)	(3)	(4)	(5)
25	Hayatta hiçbir şey sebepsiz değildir	(1)	(2)	(3)	(4)	(5)
26	Hayatın beni mutsuz eden olaylardan ibaret olduğunu düşünürüm	(1)	(2)	(3)	(4)	(5)
27	Her şeyin elimde olmadığını bilmek üzüldüğüm olaylar karşısında bir teselli kaynağıdır	(1)	(2)	(3)	(4)	(5)
28	Yeryüzündeki her doğal varlığın eşsiz olduğuna inanırım	(1)	(2)	(3)	(4)	(5)
29	Dünya hayatının geçici olduğuna inanmak beni hırslarımdan arındırır	(1)	(2)	(3)	(4)	(5)

Table 2 The descriptive characteristics of the patients ($N = 138$)

	N	%
Marital status		
Married	125	90.6
Single	13	9.4
Education		
İlliterate	15	10.9
Literate	7	5.1
Primary school	82	59.4
High school	17	12.3
University	17	12.3
Disease stage		
1	13	9.4
2	16	11.6
3	39	28.3
4	70	50.7

	$\overline{X} \pm$ SD	Min	Max
The average age/year	53.75 ± 11.91	28	87
Disease duration/month	28.49 ± 36.15	3	220

Ethical Principles

Ethics committee approval was obtained before starting the research (App. Date/No: 07.07.2021/ 2021–12-63). Institutional permission was obtained from the hospital (E-14567952–900-71,409). Oral and written consents of the participants were obtained. The research was carried out according to the principles of the Declaration of Helsinki.

Data Analysis

Data analysis was performed using Statistical Package for Social Science 22.0 package program. Descriptive data were evaluated using percentile, mean, standard deviation, minimum and maximum values. The conformity of the data to the normal distribution according to the groups was determined by the Kolmogorov–Smirnov/Shapiro–Wilk test. The one-way analysis of variance, independent samples t-test and post-hoc Tukey's test were used for the analysis of the data. The relationship between the total scale scores was determined using Pearson's correlation analysis. $P < 0.05$ was accepted as the level of statistical significance.

Table 3 The total SWBS and CBS scores based on the descriptive characteristics of the caregivers

			CBS		SWBS	
	n	%	$\overline{X} \pm SD$	Test and p value	$\overline{X} \pm SD$	Test and *p* value
Sex						
Female	50	36.2	36.12 ± 16.83	$t = -2.075$	119.33 ± 9.37	$t = 1.194$
Male	88	63.8	29.93 ± 16.85	**$p = 0.040$**	121.39 ± 9.99	$p = 0.234$
Marital status						
Married	117	84.8	32.17 ± 16.69	$t = -0.005$	121.11 ± 9.18	$t = 1.323$
Single	21	15.2	32.19 ± 19.36	$p = 0.996$	118.05 ± 12.62	$p = 0.188$
Education						
Primary school	60	43.5	32.70 ± 16.29	$F = 0.259$	120.82 ± 9.12	$F = 0.584$
High school	37	26.8	33.09 ± 21.57	$p = 0.772$	119.26 ± 11.16	$p = 0.559$
University	41	29.7	30.58 ± 13.45		121.64 ± 9.53	
Income						
Good	22	15.9	28.74 ± 14.95	$F = 0.618$	123.52 ± 11.33	$F = 1.48$
Middle	100	72.5	32.56 ± 16.70	$p = 0.541$	120.40 ± 9.38	$p = 0.231$
Bad	16	11.6	34.51 ± 21.79		118.21 ± 9.79	
Duration of care hour/a day						
24 hour[a]	81	58.7	36.38 ± 17.92	$F = 4.89$	117.90 ± 9.58	$F = 6.18$
3 hour[b]	18	13.0	25.09 ± 15.63	**$p = 0.003$**	125.32 ± 6.82	**$p = 0.001$**
4–6 hour[c]	18	13.0	23.10 ± 10.87	$a > b, c$	125.99 ± 10.30	$b, c > a$
7–12 hour[d]	21	15.2	29.81 ± 14.14		122.64 ± 8.93	
Relationship						
Spouse	72	52.2	31.40 ± 16.88	$F = 0.256$	121.20 ± 9.69	$F = 0.265$
Children	50	36.2	33.56 ± 17.03	$p = 0.775$	120.20 ± 10.43	$p = 0.768$
Other Relatives	16	11.6	31.32 ± 18.59		119.53 ± 8.52	
Education about the disease						
Yes	65	47.1	33.65 ± 17.23	$t = 0.961$	118.29 ± 9.87	$t = -2.726$
No	73	52.9	30.86 ± 16.88	$p = 0.338$	122.74 ± 9.30	**$p = 0.007$**

Average age of caregiver	$\overline{X} \pm SD$	Min	Max
	46.09 ± 13.00	18	72

Abbreviation: *CB* Caregiver burden, *SWB* Spiritual well-being *F* one-way analysis of variance

t: independent samples *t*-test, Statistically significant values ($p < .05$) are shown in bold

Results

The descriptive characteristics of the patients are given in Table 2.

The total SWBS scores and CBS scores are given in Table 3 based on the descriptive characteristics of the caregivers. The CBS of female caregivers were

significantly higher than those of male caregivers ($p=0.040$). A statistically significant difference was observed between the duration of care and SWB ($p=0.001$) and CB ($p=0.003$) scales mean scores. According to the post-hoc Tukey's test, caregivers who provide 24-h care had a significantly higher CBS score than the score of those who provide care for 3 h ($p=0.044$) and 4–6 h ($p=0.012$). According to the post-hoc Tukey's test results, the total SWB scores of caregivers who provide care between 3 hours ($p=0.014$) and 4–6 hours ($p=0.006$) a day were significantly higher than those who provide care for 24 hours a day. A statistically significant difference was observed between the SWBS scores of those who received education about the disease and those who did not ($p=0.007$). The SWBS scores of those who did not receive education were significantly higher (Table 3).

Caregivers' total CB scale, total SWB and subscale scores are given in Table 4. The caregivers had a moderate CB, whereas their SWB was quite high.

Table 5 demonstrates the negatively significant relationship between CB and SWB ($p=0.000$, $r=-0.357$). There was no significant relationship of disease duration, disease stage, caregiver's age and SWB with CB (Table 5).

Participants reported no/little burden (27%), moderate burden (36%), severe burden (30%) and very severe burden (7%).

Discussion

This research aimed to identify the CB and SWB of family caregivers of patients with breast cancer and the relationship between them. As breast cancer is the most common cancer, the research was conducted with the caregivers of these patients.

A total of 50.7% of the patients of the caregivers participating in this study had stage 4 breast cancer. Due to the increased care needs of advanced cancer patients as a result of treatments such as chemotherapy and radiotherapy, many family caregivers have a high CB (Roij et al., 2021). In this study, the CB of female caregivers was significantly higher than that of male caregivers. According to the literature, women are at a higher risk of having a high CB than men (Han et al., 2013; Jansen et al., 2018). This may be due to the fact that women, whose responsibilities are already excessive in daily life, are also the caregivers of an individual with cancer. As the responsibilities of a caregiver increase, the care process becomes tiring, dependent and long. According to our research results, the CB of those who provide 24-h care is significantly higher than those who care for 3 h and 4–6 h. Similarly, caregivers who provide care for more than 6 h a day have the highest CB (Zuo et al., 2020). Providing intensive and uninterrupted care leads to an increase in the CB (Vigna et al., 2020). For this reason, caregivers should be supported socially, psychologically and economically as the duration of care increases. Caregivers should be supported with practical support, better case management and greater recognition of the role of caregivers (Heath et al., 2018).

In this study, the SWB of those who did not receive education about the disease was significantly higher than that of those who received education. In Turkey, patients diagnosed with cancer and their caregiver family members are informed about the stage of the disease, its treatment, side-effects of the treatment and

Table 4 Caregivers' total CBS, total SWB and subscale scores

	$\overline{X} \pm SD$	Min–Max
SWBS total	120.64 ± 9.79	89.07–142.03
Transcendence	67.20 ± 4.19	41.13–70.33
Harmony with nature	28.71 ± 2.49	13.71–30.71
Anomie	17.41 ± 6.10	6.43–32.71
CBS	32.17 ± 17.04	0–70.18

Abbreviation: *CBS* Caregiver burden scale, *SWB* Spiritual well-being scale

emergency situations. The educational contents are prepared in a standard manner by the healthcare professionals of the hospital education unit. However, each individual's educational needs are different. The education should be tailored to the educational needs of the patients and caregivers.

The caregivers who participated in this study had a moderate CB. Studies on CB reported moderate CB (Jite et al., 2021; Zuo et al., 2020) as well as severe CB (Garcia et al., 2020). Excessive CB may cause the care receiver to receive inappropriate and unsafe care (Lafferty et al., 2016). Increased CB is associated with depression and anxiety in patients (Dionne et al., 2016). At the same time, CB negatively affects the patient's quality of life (An et al., 2019). The needs of caregivers may change at different times during the care process (Treanor, 2020). Basically, caregivers with a high level of CB are at risk for a continued increase in CB in the following years (Jansen et al., 2021). In the present study, 36% of the participants had moderate care burden. Similarly Asadi et al. reported 39.5% moderate burden (Asadi et al., 2019).

SWB is a protective factor against psychological and physiological diseases. (Delgado-Guay et al., 2014). SWB is an important factor in coping with the difficulties that caregivers experience during the care of patients with cancer. SWB is a concept that includes both religion and spirituality (Akkuş et al., 2022). More religion or spirituality was associated with lower depressive symptoms and less personality disorder (Power & McKinney, 2014), less post-traumatic stress and perceived stress (Arévalo et al., 2008) also this may affect caregiver burden. In this study, the SWB of the caregivers was found to be quite high. SWB is an important factor that can affect CB and the physical health of caregivers (Spatuzzi et al., 2019). Individuals with high spirituality feel less CB (Vigna et al., 2020). Some studies show that spirituality and religious beliefs reduce distress in caregivers (Hosseini et al., 2016; Koenig, 2015) and also this may be used as coping strategies for stressful situations (Torabi Chafjiri et al., 2017).

The most important result of this research is that as the SWB of caregivers increases, their CB decreases. Similarly, there are studies reporting that SWB is negatively related to CB, and that spirituality can be used as an effective and low-cost intervention to reduce the CB (Rafati et al., 2020). Caregivers with low levels of spirituality are at higher risk of CB, anxiety and stress (Newberry et al., 2013). In this study, the total SWB scores of the caregivers who provide care between 3 h and

Table 5 The relationship between SWBS and CBS total scores and some variables

	SWBS		CBS	
	r	*p*	*R*	*p*
CBS	−0.357	**0.000**	–	–
Disease duration	0.034	0.688	0.044	0.606
Disease stage	−0.158	0.065	0.160	0.060
Caregiver age	0.007	0.936	−0.032	0.709

Statistically significant values ($p < .05$) are shown in bold

Abbreviation: *CBS* Caregiver burden scale, *SWBS* Spiritual well-being scale, *r*: Pearson's correlation

4–6 h a day are significantly higher than the scores of those who care for 24 h a day. This finding also supports the negative relationship between SWB and CB.

Due to the increase in the elderly population and in the number of chronic and fatal diseases, the number of individuals who need care and the number of caregivers increase every year. The CB of caregivers of women with breast cancer, one of the most common types of cancer, also increases in this process. Caregivers should be supported in terms of treatment, care and financial issues to eliminate the negative effects of CB on both the caregiver and the patient.

Limitations

The first limitation of the study is that the data were collected only from a single hospital. Therefore, the results of this study should be cautiously generalized to other settings. It is recommended to conduct longitudinal design studies. Many factors affecting the concept of spiritual well-being, such as psychosocial characteristics of caregivers, perceptions of social support, and attachment patterns, were not considered.

Conclusion and Recommendations

According to our results, caregivers have a moderate level of CB and their SWB is quite high. There is a negative relationship between CB and SWB. Nurses, whose main role is to provide care, have important duties in reducing the CB of family caregivers. Follow-up of patients with breast cancer who are cared for at home should be provided by primary health care services. Family physicians and nurses should be in frequent contact with caregivers to reduce the CB and develop coping strategies. Caregivers of patients with breast cancer should be provided effective health counselling, psychosocial care and moral support following the diagnosis of cancer. Since female caregivers have a high care burden, they should be supported more and protected from burnout. Caregivers with longer daily care periods have a higher CB and lower SWB. It is recommended that caregivers with long daily caregiving periods

are supported by social services in their care activities. Spirituality can be an important factor influencing the role of a caregiver. As spirituality has different meanings and roles in different cultures and religious beliefs, its relationship with CB may vary. Therefore, conducting more studies in different countries is recommended.

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Data Availability The data that support the findings of this study are available on request from the corresponding author.

Declarations

Conflict of interest The author declares they have no potential conflict of interest. The authors report no actual or potential conflicts of interest.

Ethical Approval All procedures in the study performed in accordance with the ethical standards of the 1964 Helsinki Declaration and its later amendments.

Informed Consent Was obtained from all participants who were included in the study. This study was verbal presented in 10th International Medicine and Health Sciences Researchers Congress, 27–28 August 2022 Ankara /Turkey.

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