Spiritual well-being levels of formal and informal cancer caregivers in Turkish society and influencing factors: A comparative study

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ABSTRACT

Purpose: This study aimed to compare the spiritual well-being levels of formal and informal caregivers of cancer patients.
Materials and Methods: This study using a cross-sectional survey was conducted with formal (*n*=52) and informal caregivers (*n*=52), who met the inclusion criteria, were included in the sample. The data of the study were collected using web-based and self-reported questionnaires.
Results: The scores of spiritual well-being in all dimensions of formal and informal caregivers are at a moderate level. There was a difference between informal and formal caregivers in the belief and peace sub-dimension scores. Moreover, there was no difference in total score averages of the spiritual well-being scale. It was found that there was no statistically significant difference between them according to age groups, gender, marital status, having a child, and income status.
Conclusions: This study provides that the care process of cancer patients may affect the spiritual well-being of formal and informal caregivers.
Keywords: cancer, formal caregivers, informal caregivers, spiritual well-being, oncology nursing

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INTRODUCTION

Cancer affects patients and caregivers in physical, psychosocial, and spiritual areas, starting from the diagnosis stage during and after treatment [1, 2]. The care process for cancer is carried out by formal caregivers that provide health care services such as nurses, social workers, physiotherapists, and informal caregivers, including family members/ relatives of the individual, without a fee. Informal and formal caregivers meet the basic needs of cancer patients and provide support on issues such as access to medical care and health services. The care process of cancer patients, which is a long and tiring process, can lead to many negativities such as helplessness, hopelessness, depression, fatigue, insomnia, and burnout for caregivers and patients [3].

In the literature, spirituality is associated with religion, belief, and spirituality. Spiritual well-being includes a sense of meaning in life, inner peace, harmony, strength, and an experienced understanding of comfort associated with faith [4, 5].

The World Health Organization emphasizes that spiritual well-being is essential to health. With the recent studies covering the clinical care of cancer patients, the literature stressing the importance of spiritual well-being has been enriched. Many clinical guidelines have identified spiritual care as important in quality cancer care from diagnosis to end-of-life. At the same time, spiritual care is one of the core components of palliative care in increasing the quality of life of caregivers of cancer patients [4, 6, 7].

In the National Comprehensive Cancer Network (NCCN) clinical guidelines, it is suggested that spiritual well-being should be examined with a comprehensive assessment to be made in the management of distress [7].

As in cancer patients, it is reported that individuals who care for these patients also have spiritual needs, such as the need to love/be loved, the need to find meaning, and the need for hope. It is stated that not meeting these needs is associated with an increased risk of depression and a decrease in the level of the spiritual well-being of caregivers [8-10]. During the cancer process, caregivers experience limitations in their lifestyle, socialize less, face economic problems, perceive reduced family and community support, report care-related stress and burden, and decrease their self-esteem related to their caregiver role. In this direction, it is emphasized that the level of spiritual well-being is vital in coping with the adverse situations experienced by the caregivers and in maintaining the quality of life [9, 11]. Spiritual activities such as religious practices and relaxation methods provide an interpretative framework for individuals to find meaning and increase their participation in social support activities. Recent studies have shown that spiritual well-being improves health, protects against stress due to negative situations in life, and supports the immune status [4, 5, 12]. Although there are studies examining the spiritual well-being of cancer patients in the literature, it has been observed that studies examining the spiritual well-being of caregivers are limited [9, 11, 13]. However, despite the positive effects of spiritual well-being and spiritual practices on the biopsychosocial health and quality of life of individuals in many studies, it is understood that the spiritual well-being of caregivers is not given the necessary importance. There is no study in the literature in which formal and informal caregivers of cancer patients evaluate spiritual well-being together. It is thought that there is a need to define the spiritual well-being levels of the caregivers of cancer patients, examine their needs, and take initiatives to meet these needs. This study aimed to compare the spiritual well-being levels of formal and informal caregivers, who have an important place in the care of cancer patients.

METHODS

Study design

This comparative study uses a cross-sectional survey conducted in Turkey between May and December 2021.

Participants and setting

Purposive sampling was utilized to include the participants in the sample. Participants were grouped into two groups: formal and informal caregivers. In the first group, 840 nurses actively registered with the Oncology Nurses Association, the only association in Türkiye to which oncology nurses are members were defined as formal caregivers. In the second group, the relatives of the patients who cared for cancer patients were defined as informal caregivers.

For the study sample, an online invitation to participate was sent to cancer patients' nurses and relatives. They were reached via social media groups through the Oncology Nurses Association. A total of 104 individuals, 52 nurses, and 52 patient relatives who met the inclusion criteria answered the questionnaire and responded to the invitation to participate.

Inclusion criteria defined for formal caregivers in the study were (i) working in the oncology service, (ii) being an oncology nurse, and (iii) volunteering to participate in the study. The inclusion criteria defined for informal, formal caregivers were (i) being 18 years of age or older, (ii) being a family member or relative providing care without any contract or payment for care, (iii) caring for a cancer patient for at least three months,
and (iv) volunteering to participate in the study.

Instruments

Data were collected using the "Formal Caregiver Descriptive Information Form," "Informal

Caregiver Descriptive Information Form," and the "Functional Assessment of Chronic Illness Therapy-Spiritual Well-Being- Non-Illness Version-FACIT-Sp-NI".

Formal Caregiver Descriptive Information Form: This form was prepared for formal caregivers by reviewing the literature by the researchers [1-6]. The form consists of 15 questions describing the personal information of oncology nurses and the characteristics of the care of cancer patients (socio-demographic characteristics: age, gender, education status, etc., and professional information: professional experience, time to care for a cancer patient/day, etc.).

Informal Caregiver Descriptive Information Form: This form was prepared for informal caregivers by reviewing the literature by the researchers [1-6].

For informal caregivers, the form included 19 questions about the introduction and the experience of caring for cancer patients (socio-demographic characteristics: age, gender, education status, Receiving education about caring for cancer patients, etc.)

Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being- Non-Illness Version-FACIT-Sp-NI: This scale is designed to detect the level of the spiritual well-being of individuals who do not have the disease. The permission to use the scale was obtained from "FACIT.org." The scale consists of 12 items evaluated on the 5-point Likert type and consists of the following criteria:

- '4: "too much,"
- 3: "quite,"
- 2: "somewhat,"
- 1: "very little,"
- 0: "not at all."

The scale has three sub-dimensions: meaning (2,3,5,8), peace (1,4,6,7), and belief (9,10,11,12) [14].

A score between 0-48 is taken from the scale. As the total score obtained from the scale increases, the level of spiritual well-being increases. Each of the sub-dimensions of the scale is calculated between 0 and 16 points. The total Cronbach's alpha coefficient of the scale was 0.89 [14].

In this study, the Cronbach's alpha coefficient was 0.85 [14].

Data collection

The online questionnaire form created via Google Forms to obtain the research data was shared on the website of the Oncology Nurses Association and social media accounts where the relatives of cancer patients are registered. Due to pandemic restrictions, data could not be collected face-to-face. The questionnaire was filled out online by individuals who read and approved the informed consent, explaining the purpose and rationale of the study.

Data analysis

Statistical data analysis was reported using the Statistical Package for the Social Science (SPSS), version 26.0 statistical software program (Armonk, New York, USA).

An independent sample t-test was used in paired groups, and One-way ANOVA was used in groups of more than two for comparisons between the descriptive characteristics of caregivers and the FACIT-Sp-NI scale total score moderate.

Two-tailed p-values ≤ 0.05 were considered statistically significant.

Ethical considerations

Permission was obtained from the non-interventional research ethics committee of Izmir Bakırçay University in Türkiye (decision no: 2021/267). Additional permission was obtained from the Oncology Nurses Association to share the questionnaires with oncology nurses. This study was carried out in accordance with the Helsinki Declaration.

RESULTS

96.1% of the formal caregivers included in the study were women, 42.3% were 41 years and older, 84.6% were married, and 71.2% had children. According to the nurses' professional characteristics of the nurses, 82.7% of them had vocational education at the undergraduate level, and 42.3% had 6-10 years of professional experience (Table 1).

According to the descriptive characteristics of informal caregivers, 88.5% were women, 42.3% were between 30 and 40, 92.3% were married, and 92.3% had children. 63.5% did not work in any job, and 46.2% were in the role of mother/father as relatives of the patients. When caregivers were asked how they felt generally, 38.5% of formal caregivers indicated they felt peaceful, and 50% said they felt tired. 71.2% of formal caregivers and 72.3% of informal caregivers reported needing psychological support. When the supportive methods they use in the process of caring for cancer patients are examined, music was used by 67.3% of formal caregivers, relaxation exercises by 40.4%, prayer/worship by 38.5%, and prayer/worship by 90.4% by informal caregivers and by 25.0% music and 17.3% preferred phytotherapy methods (Table 1).

Table 1. Descriptive characteristics of formal and informal caregivers *(n=104)*

Variables	**Formal caregivers (n=52)**	**Informal caregivers (n=52)**
	n (%)	**n (%)**
Age groups		
23-30 years	10 (19.2)	9 (17.3)
31-40 years	20 (38.5)	22 (42.3)
41 years and older	22 (42.3)	21 (40.4)
Gender		
Woman	50 (96.1)	46 (88.5)
Man	2 (3.9)	6 (11.5)
Marital status		
The married	44 (84.6)	48 (92.3)
Single	8 (15.4)	4 (7.7)
Having children		
Yes	37 (71.2)	48 (92.3)
No	15 (28.8)	4 (7.7)
Income status		
Income less than expenses	9 (17.3)	13 (25.0)
Income equal to expenses	36 (69.2)	29 (55.8)
Income more than expenses	7 (13.4)	10 (19.2)
General mood*		
Exhausted	10 (19.2)	8 (15.4)
Tired	19 (36.5)	26 (50.0)
Peaceful	20 (38.5)	6 (11.5)
Disconcerting	14 (26.9)	16 (30.8)
Stressful	14 (26.9)	14 (26.9)
Happy	4 (7.7)	1 (1.9)
Need for psychological support		
Yes	37 (71.2)	38 (73.1)
No	15 (28.8)	14 (26.9)
Supportive methods used in the patient's care process*		
Prayer/worship	20 (38.5)	47 (90.4)
Music	35 (67.3)	13 (25.0)
Relaxation exercises	21 (40.4)	6 (11.5)
Phytotherapy	2 (3.9)	9 (17.3)
Massage	6 (11.5)	1 (1.9)
Energy therapies	3 (5.8)	-

* Multiple options answered

According to the frequency of diagnosis of cancer patients cared for by informal caregivers included in the study, 28.8% had lung cancer, 26.9% had breast cancer, and 23.1% had colon cancer. 65.4% of cancer patients were in the chemotherapy process, and 30.8% were in the radiotherapy process at the time of the study. When the patients' performance status was examined to evaluate their general well-being, 51.9% had an ECOG score of 0.

When the characteristics of the participants regarding the care of cancer patients were examined, 94.2% of formal caregivers and 46.2% of informal caregivers had experience caring for cancer patients. 84.6% of the formal caregivers received training to care for cancer patients, and 82.7% of the informal caregivers did not receive training. While caring for cancer patients, 88.5% of formal caregivers and 59.6% of informal caregivers stated that they were competent to provide care. While 62.5% of the formal caregivers of cancer patients care for 7-12 hours a day and 42.3% for 4-7 years, 62.5% of the informal caregivers provide 13 hours and more a day, and 75%, He stated that 0 of them gave care between 1-3 years (Table 2).

Comparisons between the descriptive characteristics of the participants and the FACIT-Sp-NI scale total score moderates are given in Table 3. When the descriptive characteristics of formal and informal caregivers were compared with the FACIT-Sp-NI scale total score moderates, it was found that there was no statistically significant difference between them according to age groups, gender, marital status, having a child and income status ($p>0.05$).

Table 2. Characteristics of formal and informal caregivers for caring for cancer patients *(n=104)*

Variables	Formal caregivers (n=52)	Informal caregivers (n=52)
	n (%)	n (%)
Experience of caring for a cancer patient		
Yes	49 (94.2)	24 (46.2)
No	3 (5.8)	28 (53.8)
Receiving education about caring for cancer patients		
Yes	44 (84.6)	9 (17.3)
No	8 (15.4)	43 (82.7)
Competence in caring for a cancer patient		
Yes	46 (88.5)	31 (59.6)
No	6 (11.5)	21 (40.4)
Time to care for a cancer patient/day		
3 hours	1 (1.9)	5 (9.6)
4-6 hours	6 (11.5)	8 (15.7)
7-12 hours	32 (61.5)	7 (13.5)
13 hours or more	13 (25.0)	32 (61.5)
Time to care for a cancer patient/year		
1-3 years	13 (25.0)	39 (75.0)
4-7 years	22 (42.3)	13 (25.0)
8 years and above	17 (32.7)	-

Table 3. Comparison of the descriptive characteristics of formal and informal caregivers and FACIT-Sp-NI scale total score moderates *(n=104)*

Variables	Formal caregivers FACIT-Sp-NI (n=52)	Informal caregivers FACIT-Sp-NI (n=52)	Test	
	$\bar{X} \pm SD$	$\bar{X} \pm SD$	test	p value
Age groups[a]				
23-30 years	27.80±6.54	31.77±8.37	1.345	0.262
31-40 years	25.90±6.34	29.22±6.43	2.840	0.100
41 years and older	23.72±4.04	21.71±7.67	1.172	0.285
Gender[b]				
Woman	25.22±5.63	27.17±7.98	-1.393	0.167
Man	28.50±6.36	22.50±10.15	.763	0.474
Marital status[b]				
The married	25.04±5.57	26.47±7.99	-.989	0.325
Single	27.00±6.04	28.50±12.66	-.285	0.781
Having children				
Yes	24.45±4.71	27.14±8.38	-1.745	0.085
No	27.53±7.15	20.50±3.31	1.883	0.077
Income status[a]				
Income less than expenses	25.22±4.38	27.76±6.45	1.055	0.317
Income equal to expenses	25.69±6.24	26.31±9.54	.098	0.755
Income more than expenses	23.71±3.54	26.10±6.90	.697	0.417
General mental state[b*]				
Exhausted	26.40±4.47	23.00±8.01	1.142	0.270
Tired	24.10±4.33	24.30±7.49	-.105	0.917
Peaceful	26.90±5.88	26.66±6.74	.083	0.935
Disconcerting	23.85±5.33	29.25±8.22	-2.095	**0.045**
Stressful	21.42±4.12	28.50±9.13	-2.639	**0.014**
Happy	33.75±2.98	35.00	-.374	0.733
Need for psychological support[b]				
Yes	24.48±5.25	25.81±8.41	-.818	0.416
No	27.46±6.13	28.85±7.78	.536	0.596

* Multiple options answered; p-value <0.05; [a] F=One-Way ANOVA; [b] t=Independent Samples *t*- test

The spiritual well-being levels of informal caregivers aged 41 and over were lower than those of formal caregivers. The spiritual well-being levels of the formal caregivers in the other age group were lower than those of the informal caregivers. Among female caregivers, informal caregivers' spiritual well-being levels were higher than those of formal caregivers. In contrast, among male caregivers, the spiritual well-being levels of formal caregivers were higher than those of informal caregivers.

When the caregivers were compared according to their marital status, the spiritual well-being levels of the informal caregivers were higher than those of the formal caregivers. The spiritual well-being levels of formal caregivers with children were lower than those of informal caregivers. When the caregivers were compared according to their income, the spiritual well-being levels of the informal caregivers were higher than those of the formal caregivers. When the caregivers who needed and did not need psychological support were compared, it was determined that the level of spiritual well-being of the formal caregivers was lower than that of the informal caregivers.

When the spiritual well-being levels of the caregivers were compared according to their general mental states, the difference between formal and informal caregivers who stated that they were exhausted, tired, peaceful, and happy was not significant (p>0.05). A statistically significant difference was found between the levels of spiritual well-being of the caregivers who indicated that they were anxious and those who stated that they were stressed (p=0.045 and p=0.014, respectively) (Table 3).

The formal (25.34±5.63) and informal (26.63±8.28) caregivers had a moderate (24 points and above) level of spiritual well-being. The formal and informal caregivers had a moderate level of meaning sub-dimension scores. The peace sub-dimension average score of the formal caregivers was moderate, while the informal caregivers were below moderate.

While the belief sub-dimension mean scores of the formal caregivers were below the moderate level, the informal caregivers were at a moderate level. There was no difference between the FACIT-Sp-NI scale total score averages and meaning sub-dimension mean scores of the formal caregivers and the mean scores of the informal caregivers (p>0.05). The difference between caregivers' peace and belief sub-dimension mean scores was significant (p=0.003 and p=0.017) (Table 4).

Table 4. Comparison of formal and informal caregivers' FACIT-Sp-NI scale total score and sub-dimension mean score *(n=104)*

FACIT-Sp-NI	Caregivers	$\bar{X} \pm SD$	min-max	test*	p value
Meaning sub-dimension score	Formal	8.92±2.48	5.00-16.00	-1.941	0.055
	İnformal	10.03±3.31	2.00-16.00		
Peace sub-dimension score	Formal	8.65±2.01	4.00-14.00	3.046	**0.003**
	İnformal	7.26±2.58	1.00-14.00		
Belief sub-dimension score	Formal	7.76±2.28	2.00-13.00	-2.416	**0.017**
	İnformal	9.32±4.04	2.00-16.00		
FACIT-Sp-NI total score	Formal	25.34±5.63	16.00-40.00	-.927	0.356
	İnformal	26.63±8.28	7.00-43.00		

p value <0.05; *Independent samples *t*- test

DISCUSSION

Spiritual well-being is an essential quality of life for patients and caregivers coping with a cancer diagnosis. The number of studies in literature examining the spiritual well-being of cancer caregivers is limited [9,11,13]. This study provides an opinion on the spiritual well-being of formal and informal caregivers of cancer patients.

According to our study findings, there was no difference between the FACIT-Sp-NI scale total score averages, and spiritual well-being levels were to be moderate of formal and informal caregivers. The literature results are similar to our study findings

on the spiritual well-being of informal caregivers of cancer patients. In a study evaluating the effect of spiritual therapy on the quality of life of cancer patients and their caregivers, the level of the spiritual well-being of informal caregivers before therapy was moderate [15]. Unlike the results of this study, in a study conducted with informal caregivers of advanced cancer patients, it was reported that the level of spiritual well-being of caregivers was low [16]. In addition, it is seen that the care process of advanced cancer patients negatively affects the spiritual well-being of informal caregivers. In this context, the healthcare team involved in the care of cancer patients must evaluate the spiritual well-being levels of informal caregivers, especially advanced cancer patients. The family-centered approach in the nursing care process for cancer will help reduce the distress of patients and caregivers, positively affect their spiritual well-being levels in coping with the disease, and plan appropriate interventions to increase the quality of care.

In our study, the spiritual well-being levels of oncology nurses, who are formal caregivers of cancer patients, were found to be moderate, similar to informal caregivers. No research has been found in the literature examining the spiritual well-being levels of formal caregivers of cancer patients. In this context, it is thought that our study findings will contribute to an optimal cancer care process by determining the spiritual well-being levels of oncology nurses. In addition, it is envisaged to lead the development of institutional strategies such as training programs and counseling/guidance services to meet the spiritual needs of oncology nurses. A cross-sectional study conducted in three European countries determined that oncology nurses with low levels of spiritual well-being did not provide adequate spiritual care to cancer patients [17]. In a study conducted in Taiwan, it was reported that nurses with high levels of spiritual well-being approached their patients with more love and compassion during the care process and focused more on their patients' spiritual needs [18]. In a qualitative study, it was emphasized that the spiritual well-being levels of oncology nurses should be taken into account in determining and meeting the spiritual needs of cancer patients [19].

As in the literature, it is seen in our study that the care process of cancer patients affects the spiritual well-being levels of informal and formal caregivers [20, 21]. During the care process of cancer patients, both patient relatives and oncology nurses are constantly exposed to critical and stressful situations [21]. For this reason, implementing initiatives to increase the spiritual well-being of both groups will be beneficial in reducing and coping with spiritual distress. In studies examining the effects of training programs conducted with different models for spiritual care on the level of the spiritual well-being of nurses, it has been detected that these programs improve the spiritual levels of nurses. It has also been shown to contribute positively to the spiritual care processes of patients [22-24]. In this direction, it is recommended to implement training programs on spiritual care for formal and informal caregivers to increase the quality of life of cancer patients.

It is reported in the literature that spiritual distress can be seen in situations where religious beliefs and practices do not make sense under challenging conditions [25, 26]. Studies have reported that individual spiritual practices such as reading holy books, meditation, and prayer/worship affect spiritual well-being, peace, and faith sub-dimension scores [20, 21, 27, 28]. In our study, the peace sub-dimension score of the formal caregivers was higher than that of the informal caregivers. A remarkable finding is that although formal caregivers use spiritual practices less than informal caregivers, their peace sub-dimension scores are higher. That may be related to nurses constantly encountering a patient group struggling with a life-threatening illness and working in a stressful environment. The fact that the spiritual well-being of the anxious and stressed formal caregivers was significantly lower in our study also supports this situation. In this direction, it is predicted that reducing the stress levels of oncology nurses will contribute to their spiritual well-being.

In our research, we observed that the belief sub-dimension scores of informal caregivers were significantly higher than those of formal caregivers. When the supportive methods used by the caregivers in the cancer care process were examined, almost all of the informal caregivers (90.4%) performed religious practices such as prayer/worship. The fact that the formal caregivers in our study group used spiritual practices less in the patient care process may have caused the belief sub-dimension scores of spiritual well-being to be lower. The evidence on spiritual well-being shows that religion is used to cope with current circumstances and find comfort. Its primary benefit is to facilitate the creation of meaning, purpose, and coherence. Fulfilling spiritual practices allows one to make sense of life [26].

CONCLUSION

As a result, the spiritual well-being levels were moderate, and there was no difference between the FACIT-Sp-NI scale total score averages of formal and informal caregivers. Informal caregivers use spiritual practices more than formal caregivers in patient care. Our study results suggest that religion/religious practices positively affect the spiritual well-being of informal caregivers. In addition, the patient's relatives possibly turned to more supportive methods for recovering the patients they care for and relieving the symptoms they experienced. It is recommended to plan interventions

to meet the spiritual needs of caregivers of cancer patients.

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Conflicts of Interest

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