



The effect of anxiety and spiritual well-being on the care burden of caregivers of cancer patients during the COVID-19 pandemic

Yeliz Akkuş¹ · Yasemin Karacan² · Kübra Ünlü³ · Muhammed Deniz¹ · Ayşegül Parlak⁴

Received: 12 May 2021 / Accepted: 27 September 2021 / Published online: 6 October 2021
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Objectives The COVID-19 pandemic has adversely affected the caregivers of people with all chronic diseases, including people with cancer (PWC). This study was conducted to determine the impact of anxiety and spiritual well-being on the care burden of caregivers of PWC during the COVID-19 pandemic.

Design This cross-sectional descriptive study included 250 caregivers of hematology and oncology patients registered with a cancer support association. All participants completed the following self-report questionnaires: the Spiritual Well-Being Scale (SWBS), Generalized Anxiety Disorder 7-item scale (GAD-7), and the Zarit Caregiver Burden Interview (ZBI).

Results Most (82.4%) of the caregivers expressed fear that their patient may contract COVID-19, and 42.0% stated that they had difficulty getting to the hospital. The caregivers' mean ZBI score was 21.06 ± 14.64 , their mean GAD-7 score was 14.51 ± 6.02 , and their mean SWBS score was 111.50 ± 16.84 . According to the results of regression analysis, SWBS and GAD-7 scores had a significant effect on the ZBI score ($p < 0.05$).

Conclusion In this study, anxiety explained most of the care burden during COVID-19. Therefore, during the COVID-19 pandemic, it may be beneficial to implement practices to promote spirituality and reduce anxiety in caregivers of PWC.

Keywords Cancer patients' caregivers · Caregiver burden · Spiritual well-being · Generalized anxiety disorder

Introduction

COVID-19 infection poses a greater risk of morbidity and mortality for patients with advanced age, male sex, and comorbidities such as chronic lung disease, hypertension, diabetes, and cancer [1]. Of all these groups, people with cancer (PWC) and immunocompromised patients, are at higher risk of serious complications or COVID-19 infection [2]. In a study conducted in China, 18 of a total of 1590 COVID-19 patients in 575 hospitals had a history of cancer, with lung cancer being the most common [3]. Although the sample was small, patients undergoing chemotherapy or surgical treatment were found to have a higher risk of COVID-19 infection than those who were not [3]. It is known that advanced age and hematological malignancy are associated with more severe COVID-19 symptoms in PWC, while the risk of mortality is higher among patients undergoing chemotherapy [4]. The need for intensive care and ventilation was reported to be 3.5 times higher in PWC infected with COVID-19 compared to non-cancer patients [5]. Lee et al. reported that 349 of 1044 PWC who were followed up during the pandemic

✉ Yeliz Akkuş
yelizakkus@gmail.com

Yasemin Karacan
ykaracan@uludag.edu.tr

Kübra Ünlü
kubraunlu171@gmail.com

Muhammed Deniz
m.deniz476474@gmail.com

Ayşegül Parlak
aysegulozyildizparlak@hotmail.com

¹ Nursing Department, Health Science Faculty, Kafkas University, 36100 Kars, Turkey

² Health Science Faculty, Nursing Department, Medical Nursing, Uludağ University, Bursa, Turkey

³ Pathology Department, Celal Bayar University, Manisa, Turkey

⁴ Atatürk Vocational Health School, Kafkas University, 36100 Kars, Turkey

died and that 295 (92.5%) of those deaths were not related to treatment toxicity or cancer progression but occurred due to COVID-19 [4].

In addition to somatic problems, the COVID-19 pandemic has also caused many psychosocial and economic problems for PWC. The greatest risk for PWC during the pandemic is not receiving the necessary medical services, both in terms of hospital admissions and regular medical care [6]. In addition, the isolation of PWC due to fear of COVID-19 transmission has caused increased stress levels and had a negative impact on all social support systems of both PWC and their caregivers [7, 8].

Caregiver burden is multidimensional in nature and encompasses difficulties in assuming and functioning in the caregiver role. Caregiving is also associated with effects on the caregiver's emotional and physical health that can occur when care demands exceed resources [9]. Caregivers, who are often in a caregiving position out of obligation and not choice, also have to cope with unlimited responsibility in the care and treatment of PWC [10, 11]. Caregivers of PWC face many problems during care, and the difficulties they experience can often be overlooked [12]. Caregivers must coordinate care between the patient and healthcare professionals, as well as manage the patients' diet, treatment-related symptoms, and side effects, and other issues such as stress and anxiety [13, 14].

Considering all the responsibilities that caregivers undertake under ordinary circumstances, it is inevitable that they will be adversely affected during the COVID-19 pandemic [15]. Yao et al. [8] compared informal caregivers and healthcare personnel caring for PWC and found that informal caregivers experienced the most anxiety. In a recent meta-analysis study, the prevalence of depression and anxiety in caregivers of PWC was reported to be 42.30% and 46.55%, respectively [16]. A study conducted in Turkey also showed that care burden increased with anxiety in caregivers of PWC [17]. In a study of caregivers of PWC during the COVID-19 pandemic, 22.5% of the caregivers were reported to have a GAD-7 score of 10 or higher [18]. Kent et al. [19] stated that caregivers primarily experienced social isolation, loneliness, and health issues due to these problems; secondly, they experienced economic problems due to COVID-19; and thirdly, they experienced stress about making the right decisions pertaining to the PWC due to their role as the decision-maker. Sannes et al. [20] reported that COVID-19 had a double-hit effect due to the risk of infection in PWC and the risk of social isolation for caregivers. In addition, caregivers may experience feelings of acute anxiety, frustration, guilt, and anger for reasons such as transmission of the disease to their loved ones, inability to access health services when needed, fear of cancer relapse/progression, social stigma, and lack of social support for transportation [13, 14].

Considering research on this topic in Turkey, Gereklioğlu et al. [21] determined that quality of life was affected in 46% of caregivers of PWC. Furthermore, Akpınar and Yurtsever [22] reported that caregivers who were spouses of PWC had lower quality-of-life scores. In other studies, it was determined that the burden of care for caregivers of PWC was between 39.02 and 50.7 points, indicating moderate care burden [23–25]. Although the caregivers of disabled people and others requiring care in Turkey receive an amount equivalent to approximately US \$200 per month, this amount is quite low considering the economic circumstances [26].

Informal caregivers are important partners in healthcare services, and spirituality plays an important role in caregivers' ability to cope with care-related challenges during the COVID-19 pandemic [27]. Spirituality provides an interpretive framework for finding meaning and facilitates access to sources of social support through participation in religious/spiritual activities [28, 29]. La et al. [30] reported that low spirituality was a predictor of depression in caregivers of PWC. In recent years, the concept of spiritual well-being has emerged along with the concept of spirituality. Spiritual well-being is conceptualized as an expression of spirituality, and serves as a measure of a person's spiritual health [31]. It is a multifaceted concept that encompasses both religion and spirituality.

The dominant religion in Turkey is Islam. Turkey is a religious country, and religious beliefs are important for 82% of Turkish people [32]. In Turkish culture, the terms spirituality and religion are sometimes used interchangeably. Although spirituality is a significant coping mechanism in disease states, spiritual well-being has been neglected in both clinical practice and research. There are very few studies on the relationship between spiritual well-being and care burden in caregivers of PWC [31, 33].

Interventional studies have shown that the spiritual well-being of caregivers of PWC can be increased, thereby reducing care burden, anxiety, and depression. Lapid et al. [34] determined that there was an improvement in the spiritual well-being in caregivers of PWC after a structured multidisciplinary intervention session (physical therapy, health behavior changes, self care and symptom management, relaxation training) that started with physical therapy for 4 weeks and ended with relaxation exercise. In a study of the effects of web-based meaning-centered psychotherapy on care burden, anxiety, depression, finding benefit, and spiritual well-being in caregivers of PWC, a longitudinal mixed-effects model revealed significant differential increases in finding benefit in favor of the intervention group [35]. Uğurluoğlu and Erdem [36] stated that spiritual well-being had a positive effect on posttraumatic growth. Therefore, we believe that evaluating the care burden as well as the anxiety and spiritual well-being of caregivers of PWC during the COVID-19 pandemic will contribute to the literature.

Research questions

1. How have PWC caregivers been affected by the COVID-19 pandemic?
2. What are factors affecting PWC caregivers' scores in the Zarit Caregiver Burden Interview?
3. Do anxiety and spiritual well-being have an effect on the care burden of caregivers of PWC during the COVID-19 pandemic?

Methods

Study design

This was a cross-sectional descriptive study.

Objective

This study was conducted to determine the effects of anxiety and spiritual well-being on the care burden of caregivers of PWC during the COVID-19 pandemic.

Participants

Due to the risk of COVID-19 transmission, we decided to recruit participants and conduct the study through online platforms. A questionnaire created using Google Forms was shared electronically in Facebook and Instagram for completion between May 10 and July 16, 2020. Caregivers of PWC were recruited from among the members of the Cancer Fighters Association, a cancer patient and caregiver association in Turkey. Before starting to complete the questionnaire, the caregivers of PWC had to read a fact sheet including information about the study and its objectives. They were only able to continue to the questionnaire after providing consent by ticking a box accompanying the statement "I agree to participate in the study." PWC caregivers who were able to access the online questionnaire and voluntarily participated were included in the study. The forms were created in such a way as to allow each person to complete the survey only once.

The study sample included 250 first-degree relative caregivers who were over 18 years of age, were caring for a patient with a primary hematological/oncological cancer diagnosis for at least 1 year, had no disorder/disease affecting their decision-making ability (dementia, mental illness, etc.), and volunteered to participate in the study. Non-probability (convenience) sampling was used.

Data collection

Data were collected using a sociodemographic information form, a COVID-19 questionnaire, the Generalized Anxiety Disorder 7-item scale (GAD-7), the Zarit Caregiver Burden Interview (ZBI), and the Spiritual Well-Being Scale (SWBS).

Sociodemographic information form.

This form included questions about both the caregiver and the PWC. Caregiver-related questions included age, gender, marital status and marriage duration if applicable, socioeconomic and employment status, relationship to the patient, whether they lived with the patient, change in work life, duration of care (years) and daily care time (hours), whether anyone else assisted with care, whether they had previous care experience, chronic illnesses, and whether they had difficulty fulfilling their responsibilities. Patient-related questions included age, gender, marital status, socioeconomic status, diagnosis, health status, and whether they had undergone a psychiatric evaluation.

COVID-19 questionnaire.

A questionnaire was developed by the researchers to identify caregivers' concerns related to COVID-19. It consisted of yes/no questions regarding the caregiver's concern that they or the PWC would contract COVID-19, the PWC's COVID-19 risk status, whether they thought there is a relationship between cancer and COVID-19, increase in cancer symptoms, whether the PWC had any hospital follow-up visits or admissions during the pandemic, and the difficulties and emotions they experienced.

General Anxiety Disorder-7 Scale (GAD-7).

The GAD-7 is a self-assessment scale that measures generalized anxiety disorder according to the DSM-IV criteria [37]. It consists of 7 items scored on a 4-point Likert-type scale (0 = none, 1 = some days, 2 = more than half of the days, 3 = almost every day). Scores range from 0 to 21, with scores of 0–4 interpreted as mild, 5–9 as moderate, 10–14 as high, and 15–21 as severe anxiety. A GAD-7 total score of 8 was determined as the diagnostic threshold for probable GAD. In the validity and reliability study, the Cronbach's alpha reliability coefficient was 0.85.

Zarit Caregiver Burden Interview (ZBI).

The ZBI was developed by Zarit, Reever, and Bach-Peterson in 1980 and the Turkish adaptation, validity, and reliability study was conducted by İnci and Erdem [38]. This tool is used to evaluate the stress experienced by caregivers of older adults or other people who require care and can be completed by the caregivers themselves or the researcher. It consists of 22 items that determine the effect of caring on the caregiver's life, generally regarding the social and emotional domains. The items are rated on a Likert-type scale ranging from 0 to 4 (never, occasionally, sometimes, frequently, or almost always). The total score ranges from 0

to 88 points, with higher scores indicating greater difficulty related to caregiving [39]. Scores of 0–20 are interpreted as no care burden, 21–40 as light care burden, 41–60 as moderate care burden, and 61–88 as heavy care burden. In the validity and reliability study, the Cronbach's alpha reliability coefficient was 0.95.

Spiritual Well-Being Scale (SWBS).

This scale was developed by Eksi and Kardas [40] in order to understand how people live and understand life in personal, social, environmental, and faith terms. In the Turkish validity and reliability study of the scale, the Cronbach's alpha coefficient was determined as 0.88. The scale consists of 29 items in three dimensions: faith, harmony with nature, and anomie. The items are rated on a 5-point Likert-type scale, resulting in a score range of 29 to 145. Higher scores indicate a higher level of spiritual well-being.

Statistical methods

Nominal and ordinal data were presented as frequency and percentage and measured data as mean and standard deviation values. The Kolmogorov–Smirnov test was used to test the normality of the data distributions. Spearman's correlation and partial correlation analysis were used to examine the relationships between variables. For multivariate analysis, logarithmic transformation was done, and the logit model was used. The logit model is a statistical method that provides a classification according to the rules of probability by calculating the values of the dependent variable [41]. All analyses were performed with 95% confidence intervals using the SPSS 22.0 program.

Ethics

This study was conducted in accordance with the principles of the Declaration of Helsinki. Before the study, ethical approval was obtained from the ethics committee of the health sciences faculty of a university (approval date: 06.05.2020, number: 81829502.903/30). All participants were informed about the study's purpose and type, and the confidentiality of the research data was guaranteed. Individuals who provided informed consent were included in the study.

Results

In terms of demographic profile, 56.0% of the participants in our study were female, 70.4% were married, 60.4% had children, 51.2% lived in urban centers, 31.6% had a chronic disease, 91.6% had health insurance, 28.8% were not working, and 55.2% stated that their income was sufficient to cover their expenses. Nearly all (92.8%) of the caregivers lived

with family members, 67.2% lived in the same household with the PWC, and 28.8% were the PWC's parent and 26.8% were the PWC's spouse. In terms of caregiving, 25.2% of the participants provided care around the clock, 44.8% were obligated to care for the PWC (e.g., spouse, child, parent), 44.8% were also caring for other patients, 46.8% had someone to help with caregiving, and 3.2% received a wage for caregiving. Most of the caregivers (80.4%) stated they had a good relationship with the PWC, while 18.8% described their relationship as not good. The mean age of the caregivers was 40.21 ± 12.49 years, they had been caring for the PWC for a mean of 7.37 ± 7.5 months, and the mean daily care time was 10.43 ± 9.7 h per day. The mean ZBI score was 21.06 ± 14.64 , the mean GAD-7 score was 14.51 ± 6.02 , and the mean SWBS score was 111.50 ± 16.84 . These results indicate that caregivers of PWC have a light care burden, severe anxiety, and high spirituality. Most of the caregivers (83.2%) had a mean GAD-7 score above 8.

Of the PWC, 50.8% were female, 43.6% had a primary school education, and 94.6% had social insurance. Clinically, 48.4% had oncological malignancy, 93.6% received chemotherapy, 22.8% had radiation therapy, 5.2% were receiving immunotherapy, 30.8% had undergone surgery, 10.8% had autologous stem cell transplantation (SCT), 2.4% had allogeneic SCT, 0.4% had unrelated SCT, and 21.6% had undergone a psychiatric evaluation. The mean age was 56.12 ± 14.42 years (Table 1).

When asked their views related to COVID-19, 75.6% of the caregivers were afraid of contracting COVID-19 themselves, while 82.4% were afraid for the PWC. Most caregivers (89.2%) thought that the PWC was at increased risk for COVID-19, 44.0% thought there was a relationship between the PWC's cancer type and COVID-19, 9.6% reported an increase in cancer-related symptoms, 36.0% stated that the pandemic had affected the PWC's treatment, and 15.6% of the PWC had been hospitalized during the pandemic. The most common problems cited by the caregivers were difficulty getting to the hospital (42.0%), followed by difficulty seeing/contacting the doctor (40.4%), difficulty acquiring protective equipment such as masks (38.0%), and difficulty continuing treatment (33.2%). Fear was the most common emotion expressed in relation to COVID-19 (Table 2).

Correlation analysis revealed negative correlations between ZBI and caregiver education and income level, living with the PWC, an increase in the PWC's cancer-related symptoms, and COVID-19 affecting treatment ($p < 0.05$). There were positive correlations between ZBI and the quality of the caregiver's relationship with the PWC (good/not good) and daily care time ($p < 0.05$). Correlations were detected between SWBS score and caregiver gender (male, female), and between working status and daily care time ($p < 0.05$). GAD-7 score was correlated with caregiver gender and fear of COVID-19 infection for self and the PWC,

Table 1 Selected demographic characteristics of the caregivers and patients ($n = 250$)

	<i>n</i>	%
Caregiver characteristics		
Female	140	56.0
Married	176	70.4
Has health insurance	229	91.6
Lives in urban center	128	51.2
Parent of patient	72	28.8
Income equal to expenses	138	55.2
Not working	127	50.8
Has a child/children	160	64.0
Lives with family	232	92.8
Care obligation (spouse, child, parent)	131	44.8
Cares for another patient	112	44.8
Has someone to assist with care	117	46.8
Provides 24-h care	63	25.2
Receives payment for care	8	3.2
Has care experience	49	19.6
Has a chronic disease	79	31.6
Relationship with patient		
Good	201	80.4
Bad	47	18.8
Lives with the patient	168	67.2
	Mean \pm SD	
Age (years)	40.21 \pm 12.49	
Duration of care (months)	7.37 \pm 7.5	
Daily care time (h/day)	10.43 \pm 9.7	
Patient characteristics		
Female	127	50.8
Primary school graduate	109	43.6
Has social insurance	235	94.6
Diagnosis		
Oncological malignancy	121	48.4
Hematological malignancy	79	31.6
Gynecological malignancy	13	5.2
Neuroendocrine malignancy	12	4.8
Urological malignancy	9	3.6
Head and neck malignancy	9	3.6
Bone and soft tissue malignancy	6	2.4
Other malignancy	1	0.4
Treatment		
Chemotherapy	234	93.6
Radiotherapy	57	22.8
Immunotherapy	13	5.2
Surgery	77	30.8
Autologous SCT	27	10.8
Allogeneic SCT	6	2.4
Unrelated donor SCT	1	0.4
Psychiatric evaluation	54	21.6
	Mean \pm SD	
Age (years)	56.12 \pm 14.42	

SCT stem cell transplantation

belief that cancer increased the PWC's risk of COVID-19, cancer-related symptoms, and COVID-19 affecting treatment ($p < 0.05$) (Table 3). GAD-7 score was correlated with caregiver marital status, the quality of the caregiver's relationship with the PWC (good/not good), and daily care time ($p < 0.05$). The only factor associated with all three variables (ZBI, SWBS, GAD-7) was daily care time. The moderate negative correlation between COVID-19 affecting treatment and GAD-7 score was the strongest relationship observed (Table 3).

Both Spearman's correlation analysis and the partial correlation analysis controlled for daily care time revealed statistically significant positive correlations between ZBI and SWBS ($p < 0.01$), between ZBI and GAD-7 ($p < 0.01$), and between SWBS and GAD-7 ($p < 0.05$). The results of correlation analysis between ZBI, SWBS, and GAD-7 are shown in Table 4.

According to the results of the regression analysis, SWBS and GAD-7 scores had significant effects on the ZBI score ($p < 0.05$). However, the effect of daily care time on ZBI was not statistically significant ($p > 0.05$). Therefore, although daily care time alone was significantly associated with the ZBI score in univariate analysis, this effect was not statistically significant when evaluated together with GAD-7 and SWBS scores in multivariate analysis. When the regression coefficients were examined, GAD-7 had a much larger effect on ZBI than SWBS. The results of the logit analysis for the effect of SWBS and GAD-7 on ZBI are given in Table 5. According to this model, 56.8% of the ZBI score was explained by GAD-7 and SWBS scores. As daily care time affected all three variables (GAD-7, SWBS, ZBI), it was used as an effective factor in the analysis.

Discussion

To our knowledge, this is the first study to investigate the effects of anxiety and spiritual well-being on care burden among caregivers of PWC during the COVID-19 pandemic. Therefore, we believe this study makes an important contribution to the literature.

In this study, 56.8% of the care burden of caregivers of PWC during the COVID-19 pandemic was explained by GAD-7 and SWBS scores, especially anxiety, while other variables are needed to explain the remaining 43.2%. These findings indicate that anxiety significantly increased the care burden of caregivers during the COVID-19 pandemic. In our review of the literature, we found some studies on the effect of COVID-19 on the care burden of PWC caregivers [18, 42]. There is also a report stating that most caregivers of dementia patients perceived COVID-19 as a threat to themselves (75%) and the person with dementia (82.1%) [43]. This is very similar to our findings that 75.6% of caregivers feared contracting COVID-19

Table 2 Caregiver's opinions about the relationship between COVID-19 and the patient's cancer treatment during the COVID-19 pandemic

	<i>n</i>	%
Opinions about the COVID-19 pandemic		
I'm afraid that I might contract COVID-19	189	75.6
I'm afraid that my patient might contract COVID-19	206	82.4
My patient is at high risk for COVID-19 infection	223	89.2
I investigated the relationship between my patient's cancer diagnosis and COVID-19	110	44.0
My patient's cancer-related symptoms increased during the COVID-19 pandemic	24	9.6
My patient's treatment has been affected by the COVID-19 pandemic	90	36.0
Hospitalized for cancer-related reasons during pandemic	39	15.6
Difficulties experienced during the COVID-19 pandemic		
Problem seeing/contacting doctor	101	40.4
Shortage of protective equipment	95	38.0
Difficulty continuing treatment	83	33.2
Difficulty getting to the hospital	105	42.0
Patient is over 65 years old and subject to curfews	2	0.8
Longer wait in the outpatient clinic	4	1.6
Economic problems	3	1.2
None	23	9.2
Emotional problems		
Fear	148	59.2
Sadness	83	33.2
Poor concentration	72	28.8
Unhappiness	67	26.8
Burnout	66	26.4
Anger	57	22.8
Insomnia	57	22.8
Guilt	26	10.4
Obsession	7	2.8
None	16	6.4

Table 3 Results of Spearman's correlation analysis of the relationship between selected demographic characteristics and ZBI, SWBS, and GAD-7 scores

	ZBI	SWBS	GAD-7
Gender	−0.086	−0.196**	−0.170**
Education level	−0.217**	−0.107	0.000
Marital status	0.042	−0.052	0.168**
Income level	−0.193**	−0.118	−0.049
Working status	0.067	0.139*	0.039
Having a child	−0.054	−0.033	0.123
Having health insurance	0.039	0.054	0.103
Caregiver's relationship to patient (well/not well)	0.221**	−0.008	0.214**
Caregiving obligation	−0.051	−0.107	−0.046
Living with the patient	−0.159*	−0.057	−0.060
Daily care time	0.199**	0.250**	0.160*
Fear of COVID-19, self	−0.121	−0.038	−0.183**
Fear of COVID-19, patient	−0.028	−0.029	−0.131*
Higher risk of COVID-19 due to cancer	−0.008	−0.015	−0.132*
Cancer-related symptoms	−0.268**	−0.088	−0.188**
Effect of COVID-19 on cancer treatment	−0.249**	0.011	−0.387**

* $p < 0.05$; ** $p < 0.01$

Table 4 Results of correlation analysis between ZBI, SWBS, and GAD-7 scores

		ZBI	SWBS
SWBS	Spearman's rho	0.222**	
	Controlled for daily care duration	0.216**	
GAD-7	Spearman's rho	0.517**	0.152*
	Controlled for daily care duration	0.179**	0.199*

* $p < 0.05$; ** $p < 0.01$ **Table 5** Results of logit analysis for the effect of SWBS, GAD-7, and daily caregiving duration on ZBI

	Non-standardized coefficients		Standardized coefficients Beta	<i>t</i>	<i>p</i>
	<i>B</i>	Standard error			
(Constant)	−14.214	5.933		−2.396	.017
Log_SWBS	.144	.052	.164	2.776	.006
Log_GAD-7	1.246	.148	.496	8.414	.000
Daily care time	.146	.092	.095	1.591	.113

 R^2 : 0.568; F : 32.221; $p < 0.01$

themselves and 82.4% were afraid the PWC would contract COVID-19. Karacin et al. [44] determined that 14.2% of PWC receiving chemotherapy postponed their chemotherapy appointments due to COVID-19. In the same study, 70% of the patients stated that they believed COVID-19 would affect them more because they had cancer [44]. Sigorski et al. [45] reported in their study that PWC were more afraid of cancer than of COVID-19. In the present study, 36% of the caregivers stated that the pandemic had affected the PWC's treatment and 33.2% stated they had difficulty continuing treatment. Wimberly et al. [42] determined in their study that 50% of caregivers of childhood cancer survivors reported delayed/canceled appointments and 19% reported delayed/canceled imaging. Ng et al. determined in their study that 72.8% of caregivers of PWC were afraid of COVID-19 [18]. Wu et al. [46] reported in their study that 64% of PWC experienced changes in their cancer management plan, with a median treatment delay of 21 days. In another study, it was determined that 45.5% of caregivers of older adults received less social support than before the pandemic [47]. In this study, the most common problem experienced by caregivers during the COVID-19 pandemic was access to hospitals and doctors. These problems may have been related to the fact that oncology centers in Turkey are located in large urban centers, and during the pandemic, there were intercity transport restrictions and rotating/remote working arrangements.

In a study conducted with PWC during the COVID-19 outbreak in China, the prevalence rates of depression, anxiety, and posttraumatic stress syndrome were 23.4%, 17.7%, and 9.3%, respectively [48]. Ng et al. [18] determined that the prevalence of anxiety among PWC, their caregivers, and healthcare workers was 19.1%, 22.5%, and 14.0%, respectively. Wimberly et al. [42] reported in their study that 77% of caregivers of childhood cancer survivors had increased feelings of anxiety due to the outbreak. Nearly half (46.8%) of caregivers of older people with neurocognitive disorders were found to have anxiety during the COVID-19 pandemic [49, 50]. Some studies have evaluated fear in caregivers of PWC during the pandemic, and one group reported detecting psychological distress in 46.5% of long-term caregivers [51]. When the literature data regarding fear among PWC are examined, it can be seen that the caregivers in the present study experienced more fear than the PWC. Caregivers may experience more fear due to the possibility of losing the PWC, the uncertainty felt at the start of the pandemic, and the lack of sufficient social support. For this reason, the Memorial Sloan Kettering Cancer Center has created alternative options for the treatment of PWC due to COVID-19, such as extending the treatment intervals and switching to oral chemotherapeutic agents [7].

Park [51] reported that caregivers experienced somatic symptoms such as headache, fatigue, body pain, and abdominal discomfort. In addition to fear, the caregivers in our study also described having psychosomatic symptoms such as sadness, poor concentration, unhappiness, anger, insomnia, and guilt. The prevalence of sleep problems among caregivers of older adults with neurocognitive disorders during the COVID-19 period was found to be 9.4–10.8%, which is lower than in the present study [49, 50].

In studies conducted before the COVID-19 pandemic, the mean ZBI score of caregivers of PWC was higher compared to our study [23, 52, 53]. This may be related to the decrease in the rate of hospital admissions due to lockdowns during the pandemic. According to Ng et al. [18], PWC caregivers stated that the caregiver burden is higher in those with high anxiety. In two studies evaluating the care burden of caregivers of older adults and dementia patients during the COVID-19 pandemic, care burden was found to be higher than in the pre-pandemic period and was associated with a degree of dependency [43, 47]. In the present study, we detected a significant relationship between ZBI and education level. Similarly, studies conducted in Turkey have shown that the ZBI score increases with a lower education level [23, 52, 54].

Parry et al. [55] reported that the Patient Health Questionnaire and GAD-7 are frequently used to evaluate anxiety and that 14 to 82% of caregivers had anxiety. Ng et al. [18] found that GAD-7 scores were higher in caregivers compared to those in PWC and healthcare personnel. Alexopoulos et al.

[56] determined that caregivers of people with neurocognitive diseases had a GAD-7 score of 5.18 (4.90) and stated that the GAD-7 score was not associated with caregiver distress. In the present study, we found that caregivers of PWC experienced severe anxiety, with 83.2% having a GAD-7 score above 8. This may be attributable to the chronic nature of cancer, the caregivers being relatively young, and the uncertainty at the start of the COVID-19 pandemic.

There are no studies in the literature that evaluated spiritual well-being among caregivers of PWC during the COVID-19 pandemic. Studies on caregivers of PWC in the pre-COVID-19 period are also limited. Of these, two studies showed that PWC caregivers with high spiritual well-being had better quality of life and lower care burden scores [31, 57]. Vigna et al. [58] reported that low spirituality increased the emotional burden of caregivers of palliative care patients. Kasapoğlu [59] also reported a negative correlation between spiritual well-being and fear of COVID-19 in the normal population. In the present study, it was observed that spiritual well-being explained the care burden to a certain extent and that caregivers had high spirituality. These findings suggest that spiritual well-being was effective in reducing the burden of care and coping with anxiety during the COVID-19 pandemic.

Limitations

There are several limitations of this study. Our sample included patients registered with a single cancer support association. Therefore, it cannot be generalized to the whole of Turkey. Secondly, the study was not prospective but cross-sectional and was conducted early in the pandemic. The participants were not questioned about the pre-pandemic period, so their situation in that period is unknown. In the literature, depression is generally evaluated together with anxiety, whereas only anxiety was assessed in the present study. In addition, the sample was limited to those who were able to respond to the online questionnaire. Another limitation is that the COVID-19 questionnaire developed by the researchers is not a standardized measurement tool.

Conclusion

The needs of caregivers of PWC have changed due to the pandemic. These needs include support in terms of physically caring for the PWC, receiving social support, and protecting themselves from psychological effects and infection. This is the first study to evaluate the care burden, anxiety, and spiritual well-being of caregivers of PWC during the COVID-19 pandemic. Our results suggest that anxiety explained most of the care burden during COVID-19.

Therefore, it may be beneficial to implement practices to promote spirituality and reduce anxiety in the caregivers of PWC. This study provides important implications for clinical practice; by determining the spiritual needs of caregivers of PWC, it can reduce anxiety and care burden in the clinical environment, and it is important in terms of guiding the studies to be conducted on the spiritual needs of the caregivers of PWC. Online applications can also be implemented to support caregivers in areas of need during the pandemic.

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s00520-021-06611-0>.

Acknowledgements We would like to thank all the caregivers of PWC for their participation and cooperation.

Author contribution Concept—Y.A., Y.K.; design—Y.A., Y.K.; supervision—Y.A.; funding—Y.A., Y.K., K.Ü., M.D., A.P.; data collection and/or processing—Y.A., Y.K.; analysis and/or interpretation—by a statistician/Y.A., Y.K.; literature search—Y.A., Y.K., K.Ü., M.D., A.P.; writing—Y.A., Y.K., K.Ü., M.D., A.P.; critical review—Y.A., Y.K., A.P.

Availability of data and material The data that support the findings of this study are available from the corresponding author upon reasonable request. The data are not publicly available due to privacy or ethical restrictions.

Code availability Not applicable

Declarations

Ethics approval This study was conducted in accordance with the principles of the Declaration of Helsinki. Before the study, ethical approval was obtained from the ethics committee of the health sciences faculty of a university (approval date: 06.05.2020, number: 81829502.903/30).

Consent to participate All participants were informed about the study's purpose and type, and the confidentiality of the research data was guaranteed. The individuals who provided informed consent were included in the study.

Consent for publication N/A

Conflict of interest The authors declare no competing interests.

References

1. WHO, Aylward, Bruce (WHO); Liang W (PRC). Report of the WHO-China Joint Mission on Coronavirus Disease 2019 (COVID-19). WHO-China Jt Mission Coronavirus Dis 2019. 2020;2019(February):16–24
2. CDC. Coronavirus disease (COVID-19): people who are at higher risk for severe illness. Centers for Disease Control and Prevention. 2019 [Internet]. 2021 [cited 2021 Jan 8]. Available from: <https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precaution>
3. Landman A, Feetham L, Stuckey D (2020) Cancer patients in SARS-CoV-2 infection: a nationwide analysis in China. *Lancet Oncol* 2045(20):335–337

4. Lee LYW, Cazier J-B, Starkey T, Briggs SEW, Arnold R et al (2020) COVID-19 prevalence and mortality in patients with cancer and the effect of primary tumour subtype and patient demographics: a prospective cohort study. *Lancet Oncol* 20(20):1–8
5. Motlagh A, Yamrali M, Azghandi S, Azadeh P, Vaezi M, Ashrafi F (2020) Iranian COVID-19 prevention & care; a cancer specific guideline. *Acad Med Sci IR Iran* 23(4):255–264
6. Wang H, Zhang L (2020) Risk of COVID-19 for patients with cancer. *Lancet Oncol* 21(4):e181. [https://doi.org/10.1016/S1470-2045\(20\)30149-2](https://doi.org/10.1016/S1470-2045(20)30149-2)
7. Mohile S, Dumontier C, Mian H, Loh KP, Williams GR, Wildes TM et al (2020) Perspectives from the Cancer and Aging Research Group: caring for the vulnerable older patient with cancer and their caregivers during the COVID-19 crisis in the United States. *J Geriatr Oncol* 11(5):753–760
8. Ng KYY, Zhou S, Tan SH, Ishak NDB, Goh ZZS, Chua ZY, Chia JMX, Chew EL, Shwe T, Mok JKY et al (2020) Understanding the psychological impact of COVID-19 pandemic on patients with cancer, their caregivers, and health care workers in Singapore. *JCO Glob Oncol* 6:1494–1509. <https://doi.org/10.1200/GO.20.00374>
9. Jadalla A, Page M, Ginex P, Coleman M, Vrabell M, Bevans M (2020) Family caregiver strain and burden. *Clin J Oncol Nurs* [Internet] 24(1):31–50. Available from: <https://search.proquest.com/scholarly-journals/family-caregiver-strain-burden/docview/2408853734/se-2?accountid=17242>. Accessed 01.03.2021
10. Rha SY, Park Y, Song SK, Lee CE, Lee J (2015) Caregiving burden and the quality of life of family caregivers of cancer patients: the relationship and correlates. *Eur J Oncol Nurs* 19(4):376–382
11. Coolbrandt A, Sterckx W, Clement P, Borgenon S, de Mees MDS, VAM, Casterle BD de, (2015) Family caregivers of patients with a high-grade glioma: a qualitative study of their lived experience and needs related to professional care. *Cancer Nurs* 38(5):406–413
12. Girgis BA, Lambert S, Johnson C, Waller A (2013) Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. *J Oncol Pract* 9(4):197–202
13. Kent EE, Ornstein KA (2020) The family caregiving crisis meets an actual pandemic. *JPSM* 60(1):66–69
14. Mishra S, Biswas S, More S, Gupta R, Bharti J, Nandi R (2020) Caring the cancer caregivers in the era of COVID-19 outbreak. *Asian Pacific J Cancer Care* 5(S1):203–208
15. Harbegue K, Mejri N, El BH, Berrazega Y, Rachdi H, Labidi S et al (2020) COVID-19: An additional burden on caregivers of cancer patients in Tunisia. *Ann Oncol* 31(4):1017
16. Geng H, mei, Chuang D mei, Yang F, Yang Y, Liu W min, Liu L hui et al (2018) Prevalence and determinants of depression in caregivers of cancer patients: a systematic review and meta-analysis. *Med (United States)* 97(39):11863
17. Unsar S, Erol Ö, Özdemir Ö (2021) Caregiving burden, depression, and anxiety in family caregivers of patients with cancer. *Eur J Oncol Nurs* 50(101882)
18. Ng KYY, Zhou S, Tan SH, Ishak NDB, Goh ZZS, Chua ZY et al (2020) Understanding the psychological impact of COVID-19 pandemic on patients with cancer, their caregivers, and health care workers in Singapore. *JCO Glob Oncol* 6:1494–1509
19. Kent EE, Ornstein KA, Dionne-Odom JN (2020) The family caregiving crisis meets an actual pandemic. *J Pain Symptom Manage*. 60(1):e66-9. <https://doi.org/10.1016/j.jpainsymman.2020.04.006>
20. Sannes TS, Yeh IM, Gray TF (2020) Caring for loved ones with cancer during the COVID-19 pandemic: a double hit risk for social isolation and need for action. *Psycho-Oncology* 29:1418–1420
21. Gereklioğlu Ç, Korur A, Asma S, Büyükkurt N, Solmaz S, Boğa C et al (2019) Assessment of quality of life in caregivers of the patients with hematologic neoplasms. *TJFMPC* 13(3):265–273
22. Akpınar NB, Yurtsever S (2018) Care burden and quality of life of family members caring for cancer outpatients. *Int J Caring Sci* 11(3):1516–1525
23. Orak OS, Sezgin S (2015) Caregiver burden in family members of cancer patients. *J Psychiatr Nurs* 6(1):33–39
24. Danacı E, Koç Z (2018) Caregiving burden and life satisfaction among caregivers of cancer patients admitted to the emergency department. *Clin Nurs Res* 27(7):800–825
25. Timur Ö, Gündüz N, Altaş H, Turan H, Kardeşin Ö, Taşar PT et al (2021) Burden, quality of life and coping strategies of palliative care patients' caregivers. *Ege J Med* 60:1–9
26. Turkish Republic The Ministry of Labor and Social Security (Türkiye Cumhuriyeti Çalışma ve Sosyal Güvenlik Bakanlığı) [Internet]. 2021. Available from: <https://www.csgb.gov.tr/>. Accessed 01.03.2021
27. Azman A, Jamir Singh PS, Sulaiman J (2017) Caregiver coping with the mentally ill: a qualitative study. *J Ment Heal* 26(2):98–103
28. Gürsu O, Ay Y (2018) Religion, spiritual well-being and aging. *J Int Soc Res* 11(61):1176–1190
29. Holt CL, Roth DL, Huang J, Clark EM (2018) Role of religious social support in longitudinal relationships between religiosity and health-related outcomes in African Americans. *J Behav Med* 41(1):62–73
30. La IS, Ross A, Johantgen M, Storr CL, Cagle JG, Zhu S (2020) Spirituality among family caregivers of cancer patients: the spiritual perspective scale. *Res Nurs Heal* 43(May):407–418
31. Spatuzzi R, Giulietti MV, Ricciuti M, Merico F, Fabbietti P, Raucci L et al (2019) Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients. *Palliat Support Care* 17(3):294–299
32. Importance of religion by country [Internet]. 2009. Available from: https://en.wikipedia.org/wiki/Importance_of_religion_by_country. Accessed 01.03.2021
33. Rezaei H, Maryam M (2020) Correlation between spiritual well-being and family caregiver burden in patients with cancer. *Iran J Rehabil Res Nurs* 6(2):115–124
34. Lapid MI, Atherton PJ, Kung S, Sloan JA, Shahi V, Clark MM et al (2016) Cancer caregiver quality of life: need for targeted intervention. *Psychooncology* 25(12):1400–1407
35. Applebaum AJ, Buda KL, Schofield E, Farberov M, Teitelbaum ND, Evans K et al (2018) Exploring the cancer caregiver's journey through web-based meaning-centered psychotherapy. *Psychooncology* 27(3):847–856
36. Uğurluoğlu D, Erdem R (2019) The impact of individuals' spiritual well-being who go through a trauma on posttraumatic growth. *Dokuz Eylül Üniversitesi Sos Bilim Enstitüsü Derg* 21(3):833–858
37. Konkan R, Şenormancı Ö, Güçlü O, Aydın E, Sungur MZ (2013) Validity and reliability study for the Turkish adaptation of the generalized anxiety disorder-7 (GAD-7) scale. *Noropsikiyatri Ars* 50(1):53–58
38. İnci FH, Erdem M (2008) Validity and reliability of the burden interview and its adaptation to Turkish. *J Anatolia Nurs Heal Sci* 11(4):85–95
39. Zarit SH ZJ (1990) The memory and behavior problems checklist and the burden interview. In: University Park, PA: Pennsylvania State University, Gerontology Center
40. Ekşi H, Kardaş S (2017) Spiritual well-being: scale development and validation. *Spirit Psychol Couns* 2(1):73–88
41. Özdamar K (2017) Statistical data analysis with package programs (10 ed.). Eskişehir: Kaan Kitabevi
42. Wimberly CE, Towry L, Caudill C, Johnston EE, Walsh KM. Impacts of COVID-19 on caregivers of childhood cancer survivors. *Pediatr Blood & Cancer*. 2021;68(e28943)

43. Altieri M, Santangelo G (2021) The Psychological Impact of COVID-19 Pandemic and lockdown on caregivers of people with dementia. *Am J Geriatr Psychiatry* 29(1):27–34
44. Karacin C, Bilgetekin I, Basal FB, Oksuzoglu OB (2020) How does COVID-19 fear and anxiety affect chemotherapy adherence in patients with cancer. *Futur Oncol* 16(29):2283–93
45. Sigorski D, Sobczuk P, Osmola M, Kuć K, Walerzak A, Wilk M et al (2020) Impact of COVID-19 on anxiety levels among patients with cancer actively treated with systemic therapy. *ESMO Open* 5(5):1–8
46. Wu JT-Y, Kwon DH, Glover MJ, Henry S, Wood D, Rubin DL et al (2020) Changes in cancer management due to COVID-19 illness in patients with cancer in Northern California. *JCO Oncol Pract* 17(3):377–385
47. Archer J, Reiboldt W, Claver M, Fay J (2021) Caregiving in quarantine : evaluating the impact of the Covid-19 pandemic on adult child informal caregivers of a parent. *Gerontol Geriatr Med* 7:1–7
48. Wang Y, Duan Z, Ma Z, Mao Y, Li X, Wilson A, et al (2020) Epidemiology of mental health problems among patients with cancer during COVID-19 pandemic. *Transl Psychiatry* [Internet]. 10(1). Available from: <https://doi.org/10.1038/s41398-020-00950-y>
49. Li Q, Zhang H, Zhang M, Li T, Ma W, An C, et al (2021) Mental health multimorbidity among caregivers of older adults during the COVID-19 epidemic. *Am J Geriatr Psychiatry* 29(7): 687–697.
50. Li Q, Zhang H, Zhang M, Li T, Ma W, An C et al (2021) Prevalence and risk factors of anxiety, depression, and sleep problems among caregivers of people living with neurocognitive disorders during the COVID-19 pandemic. *Front Psychiatry* 11(January):1–9
51. Park SS (2020) Caregivers' mental health and somatic symptoms during COVID-19. *Journals Gerontol Ser B* 76(4):235–240
52. Eskin SG, Yuksel R, Bulut H (2021) Investigation of the relationship between care giving burden and quality of life of caregivers of cancer patients. *JEMDS* 10(09):567–572
53. García-Torres F, Jabłoński MJ, Solís ÁG, Jaén-Moreno MJ, Gálvez-Lara M, Moriana JA et al (2020) Caregiver burden domains and their relationship with anxiety and depression in the first six months of cancer diagnosis. *Int J Environ Res Public Health* 17(11):1–10
54. Karakurt P, Tuncer SK, Çihtaş NY, Doğan M (2020) Determination of caregiver burden and social support levels among caregivers providing care for patients hospitalized in palliative care clinics. *Galician Med J* 27(4):E2020414
55. Parry M, Ak B, Nickerson N, Warkentin K, Burnside H, Hemani S et al (2020) Family caregivers and COVID-19: a rapid integrated mixed methods systematic review. Available from: <https://covid19mentalhealthresearch.ca/wp-content/uploads/2021/01/Parry-CIHR-Knowledge-Synthesis-Report-Family-Caregivers-and-COVID-19-2020-11-24.pdf>. Accessed 01.03.2021
56. Alexopoulos P, Soldatos R, Kontogianni E, Frouda M, Loanna Aligianni S, Skondra M et al (2021) COVID-19 crisis effects on caregiver distress in neurocognitive disorder. *J Alzheimer's Dis* 79(1):459–466
57. Vespa A, Spatuzzi R, Merico F, Ottaviani M, Fabbietti P, Meloni C et al (2018) Spiritual well-being associated with personality traits and quality of life in family caregivers of cancer patients. *Support Care Cancer* 26(8):2633–2640
58. Vigna PM, De Castro I, Fumis RRL (2020) Spirituality alleviates the burden on family members caring for patients receiving palliative care exclusively. *BMC Palliat Care* 19(1):1–8
59. Kasapoğlu F (2020) Examining the relationship between fear of COVID-19 and spiritual well-being. *Spirit Psychol Couns* 5(3):341–354

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.