# RESEARCH

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# Spiritual needs of family caregivers in palliative care



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# Abstract

**Objective** The primary aim of this study is to elucidate the spiritual needs encountered by family members who intricately engage in the progression of illness within the palliative care framework, thus assuming the paramount responsibility of caregiving.

**Methods** This study was approved by the Institutional Review Board and Ethics Committee of the University of Health Sciences İzmir Tepecik Training and Research Hospital (17/01/2022–2022/01–16). The research was designed as a prospective study. It was conducted through face-to-face, interactive interviews with family caregivers of patients admitted to the palliative care unit at Tepecik Training and Research Hospital between April 2022 and December 2022. The interviews were performed using a phenomenological approach and structured in a question-and-answer format. Data from twenty family caregivers were analyzed using thematic analysis. The questions were specifically designed to explore the psychological processes, spirituality, conceptions of God, meaning-making, and coping strategies of the family caregivers.

**Results** Caregivers experienced various psychological and emotional states progressing through stages of denial, anger, and acceptance. Spirituality emerged as a critical coping mechanism providing strength and meaning amidst caregiving challenges. Caregivers' perceptions of God varied from loving to punitive, influencing their interpretations of suffering and caregiving roles.

**Conclusion** This study underscores the importance of integrating spiritual support into palliative care practices. Recognizing and addressing caregivers' spiritual needs is crucial for enhancing their well-being and improving the quality of palliative care delivery. Training healthcare professionals in spiritual care and implementing targeted interventions can effectively support family caregivers in their caregiving journey.

Keywords Palliative care, Family caregivers, Spiritual need, Conception of God

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We have confirmed that neither the manuscript nor any part of it has been published nor being considered for publication elsewhere in any language.

All authors approved the manuscript and this submission.

# Introduction

When considering an individual's well-being holistically, it is essential to acknowledge spiritual well-being alongside biological, psychological and social aspects [1] Especially when confronted with challenging life circumstances, such as illness, it becomes crucial for both the patient and their family members to maintain strength and resilience. Understanding and meeting an individual's spiritual needs can significantly contribute to achieving overall spiritual well-being [2]. The growing availability of novel and effective treatments has enabled patients with life-threatening illnesses to live longer. In many cases, these patients are primarily cared for by family members, which is driven by socio-cultural and economic factors. Family caregivers take on the responsibility of attending to the patient's daily care needs, often prioritizing the patient's needs over their own. However, as the patient's needs increase over time and because other family members may not share the caregiving burden equally, caregivers experience heightened stress and psychological burden [3, 4]. This burden can take a toll on their physical, mental, social and emotional wellbeing. Therefore, individuals often turn to spiritual and religious practices in order to improve their quality of life and reduce the risk of disease during difficult times such as illness. These practices serve as a source of comfort and strength, aiding individuals in coping with the challenges they face [5–7]. Although spiritual and religious practices are widely used as coping mechanisms in difficult times, there are large gaps in how individuals should be supported in this regard [5, 8].

Our study aims to provide a structured approach to understanding the mechanisms through which spirituality influences caregivers' coping strategies. Insights from this research may lead to the implementation of targeted interventions and policy changes aimed at better supporting family caregivers in their vital role.

### **Material and method**

This study was prospectively planned with the approval of the Ethics Committee of Izmir Tepecik Training and Research Hospital, University of Health Sciences (17/01/2022-2022/01-16) and conducted in the Palliative Care Unit between April 2022 and December 2022. A descriptive phenomenological research design, based on Husserl's philosophy, was employed in this study. Participants were selected from 20 family members (family caregivers) who provided care to individuals who had entered the intensive care unit following an acute event (e.g., trauma or cerebrovascular disease) and subsequently became palliative care patients. The main criterion for participant selection was that the caregivers had experienced the entire disease process of their patients from beginning to end. This allowed participants to deeply share the challenges they faced and enabled a detailed analysis of the psychosocial issues they encountered.To collect the data, open-ended, semi-structured questions were developed with the contributions of palliative care physicians, psychologists, spiritual support specialists, and religious figures (Table 1). These questions were framed based on literature reviews focusing on psychosocial issues, meaning-making, perceptions of God, and spirituality. To allow participants to express their experiences without external influence, the number of questions was limited to 10. The interviews were conducted in a private room to respect the privacy of the participants, and written informed consent was obtained after explaining the study's objectives. The interviews were planned to last 1.5 h to allow participants to share their experiences in depth and were recorded. Participants' responses were recorded verbatim without any intervention or guidance, and the recordings were fully transcribed. The written transcripts were then verified by the participants, and all were signed together. Colaizzi's phenomenological analysis process was followed for data analysis. After reading the transcripts several times, meaningful statements were extracted and analyzed. These statements were then categorized into five main themes: psychological and social problems, spirituality, perceptions of God, meaning and meaning-making, and coping strategies. These themes were integrated, and a descriptive analysis was conducted. The analysis aimed to delve deeply into the participants' experiences

Table 1         Psychological and Mental proc
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Table T r sychological and Mental processes	
Shock-Denial	"We haven't been able to accept the disease, we didn't want to. We said maybe they changed names, maybe they mispronounced it, but it wasn't the case…"B7.
Feeling of Anger-Guilt	"When something happens to him, we think "Are we responsible for it? Does it hurt? Is it because of us, we feel afraid"B3.
Bargaining	"I said to myself 'there is nothing to do, what happens will be endured, Allah has given this to us, and I will cope with it""B10.
Depression	"I'm emotionally shattered, my mental health has deteriorated. I wasn't able to sleep, I wasn't able to eat for a while"B2.
Acceptance	"We used to spend a great time with my spouse, we have deleted all of it from our life and have accepted the situation. In fact, we learnt to accept very quickly"B11.

and, ultimately, to compare the findings with existing literature.

Although participants are female in the study, "s/he" subject was used in the quotations of the participants to avoid confusion and ensure participants' confidentiality. Additionally, participants' identities were protected by coding their records as "B1", "B2"... "B20" in the manuscript.

# Results

Upon examining the demographic characteristics of the 20 family caregivers participating in the study, 15 were female and 5 were male. Of the family caregivers, the age range was 30–40 for 10%, 41–60 for 70% and 61–80 for 20%. Of the family caregivers, 30% were the patient's spouse, 25% were parents and 45% were siblings. In terms of the family caregivers educational background, 50% had a primary education, 45% completed high school and 5% were university graduates. Their occupational profiles showed that 65% were homemakers, 30% were retired and 5% were unemployed. Of the family caregivers, 75% had a monthly domestic income below the minimum wage, 15% received between the minimum wage and twice the minimum wage.

# **Psychological and Mental processes**

The psychological and mental processes of family caregivers were examined using the following question (Table 2): What are the negative changes in your life that started after the treatment process due to your relative's illness?

Similar to patients, patients' relatives experienced various emotions and thoughts while trying to confront the upheavals disrupting their lives. These emotions and thoughts include the stages of shock-denial, anger, bargaining, depression and acceptance. The stages do not always follow the same order and may sometimes overlap, shift and change place. Denial, the first of these stages, acts as a psychological defense mechanism. Despite the overwhelming evidence that supports denial, Sigmund Freud defined it as one's refusal of a truth when faced with a disturbing and unacceptable one [1, 9]. Some participants chose denial as the first stage, saying, "We couldn't accept the disease, we didn't want to. We thought they could have changed the name, mispronounced it, but it wasn't the case...(B7)". Anger predominantly occurred in the form of a feeling of guilt among family caregivers. Participants expressed this in the following statements: "We think as if there was something to do, but we weren't able to do that...(B2)". Bargaining is an attempt to delay bad things through good manners. This was expressed by the participants as follows: "That day, the doctor took us into the room and explained our son's disease, what is going on and what will happen. I was totally devastated when I heard it...I told to myself, 'There is nothing to do, we have to endure that, it is given by God, I'll fight against it'... (B10)".

Stress brought about by the caregiving process is seen to result in the fear of losing a loved one, emotional exhaustion, a life in isolation, deteriorated sleep quality, extension of the process, depression and psychological problems. B18, B19 and B20 expressed that they experienced depression, confusion and exhaustion and that they no longer expected anything from life. B3 remained hopeful by comparing the process s/he was going through to a "stormy sea" and saying, "This is an ongoing process... one hopes for the good, but it is a long way, hope comes to an end at some point. It's like being in a stormy sea... one wave comes, we come to the surface to breathe at those moments...when that wave recedes, we are drowned in the dark waters, though ... ". B11 expressed that acceptance started where hope ended, saying, "We would spend a great time with my spouse, we've deleted all of these from our life and have accepted it. We actually learnt how to accept very quickly...".

The quotes and themes illustrate the complex psychological and emotional journey experienced by family caregivers. This journey encompasses denial, anger, bargaining, and ultimately acceptance, profoundly impacting their mental well-being.

### Spirituality

To explore family caregivers' existential, sense-making, belonging and personal beliefs and practices as well as their relationships with the sacred the following questions were asked: "How do you see yourself spiritually? How do you meet your spiritual needs? Have there been any changes in your spiritual values during this process?" (Table 3).

# Table 2 Spirituality

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Existence	"I have always felt happy as long as my son and spouse are happy" B1. "If someone comes over and wishes us patience, wishes well and says it'll be fine, my heart opens up" B2.	
Belonging	"I'm afraid. I always hope to get well, that hope keeps me standing. On the other hand, I live for my son, I can't leave him with anyone. I can't leave him with his father, either. If something bad (death) will happen, I pray for it to happen to all three of us " B1.	
Sense-making	"I'm strong but what's life after all, isn't everything temporary?" B20.	
Self-understanding	"My life purposeFor my daughterI was born once. It is good to breathe, to live in this life" B5.	

Table 3         Conceptions of God	
Loving	"God gives challenges to the servants He loves…Allah is examining us, we're taking a test…my son says "why did He give this to us?", I tell him "don't talk like this". He says "OK". My son says "Mom, you'll go to heaven by taking care of me, I'll be waiting for you in the other side, I'll take you to heaven"…Well, we don't rebel…".B10.
Punishing	"From my point of view, I see it as a punishmentMom displayed favouritism towards her children. She did all kinds of discrimination. She was so connected to my older brother, but now I am taking care of her" B12.

#### Table 4 Meaning and sense-making

"My life purpose is my two kids... There have been many changes in the meaning and purpose of my life in this process. What upset me in the past was very unnecessary. The real problem is what we have now. Those were things that could be corrected. I've realized that health upsets a person more ..." B3. "... My life is less valuable. We used to be happier, but now our biggest disappointment is that we can't see the future. We used to have dreams. My daughter had dreams of her own. Now they have all vanished ..." B4.

.... I've learnt patience. I've learnt gratitude. I started to believe in the real power of Allah. Life is more beautiful and I'm living it ...". B5.

Generally, spirituality is defined in the literature as an individual's personal beliefs and practices in life, sense of connection with the sacred and the universe, development of the self and realization of personal potentials, search for meaning, and life satisfaction [10–12]. In his book titled "On Death and Dying", Kübler Ross highlights that patients need "help, understanding and support" more than ever based on the data obtained from the interviews held by cancer patients [13].

These needs are not only material but also spiritual. This is not different for family caregivers who care for patients. The spiritual needs of an individual are defined as existence, belonging, sense-making and transcendence [14, 15]. The quality of life increases if individuals can meet these needs positively, but if they fail to fulfill these needs, they may be exposed to physical, psychosocial and mental problems.

Spirituality allows family caregivers to cope with the demands of caregiving, providing them with the power to manage the difficulties of caregiving, overcome fears about caregiving, and develop decision-making skills [5]. Those who perceive themselves as spiritually strong, as well as those who do not, seek support from similar religious rituals. B8 and B9 said that they felt strong, as they knew Allah (Islamic God) was always with them, they performed Namaz (Islamic prayer), and they read the Quran and found power and peace by so doing. B5 expressed that s/he could stand thanks to her/his belief in Allah, and B7 said s/he prayed and implored Allah and expected nothing from people but only from Allah. Spirituality is closely related to patient care [16, 17]. B11 expressed that s/he found peace, felt lighter and tasks became easier as s/he read the Quran. B14 and B15 said that when they recited prayers, they felt stronger, and thus they were able to cope with difficulties without depending on anyone. Spirituality also enables family caregivers to search for meaning [18]. B16 said that s/he felt strong, always read the Quran, and performed Namaz for spiritual strength, that people always called them, which made them feel better, and that s/he questioned the value of life. According to (B6), s/he had no other way to survive than to take refuge in her/his Lord.

Family caregivers provided varying answers to the question, have there been any changes in your spiritual values during the caregiving process. B5 said that her/his spirituality improved, s/he learned gratitude and patience, her/his belief in the power of the Creator increased, and s/he started leading a better life than before. B6, B9, B18 and B19 expressed praying more and feeling closer to Allah. B11 said her/his patience improved and added that s/he felt as if s/he was living in hell and prayed for living with what is good and dying with faith. B13 stated that s/he experienced better development than before and read the Quran more often than s/he did before. B14 mentioned that her/his spirituality improved, and s/he performed prayers (Namaz) more. B16 mentioned finding an opportunity to memorize the surahs (sections of the Quran) that s/he did not know and performing more prayers without missing any of them.

These responses clearly show that family caregivers draw on religious practices and beliefs from the deep roles of spirituality in providing strength, peace, and help to escape the impossibility of caregiving.

#### **Conceptions of God**

To explore family caregivers' conceptions of God, they were asked the following questions: How do you define your connection with the Creator? Do you perceive Him as a punisher or a lover? (Table 4).

Among spiritual needs, seeking refuge and direction from a superior power is a manifestation of the need for "self-transcendence". B1, B2 and B3 believed that Allah has a purpose and said that He would not have created us if He did not love us. B1, B2, B4, B6 and B10 stated that they believed Allah had the servants He loves suffer, that this was not a punishment and that the reward was going to heaven. Family caregivers generally believe that God will not burden them with more than they can bear [6]. B3, B6 and B13 thought that this difficult situation was a test, that they should be grateful that it was not worse, and that Allah is loving. B5 stated that what happened should be accepted as a predetermined fate, thinking that good servants will not suffer in this world and evil will be punished. B7, B8, B15, B16, B17, B18, B19 and B20 said that Allah was loving and that they connected to Him further with the strength they got from His love. In the interviews held with those who held a conception of a punishing God, the findings showed a belief that "suffering is the result of wrongdoing". B12 and B20 stated that this could be a punishment for her/him. Another perspective specific to caregivers was the opinion that they were called as a caregiver [6]. B14 stated that s/he was given an opportunity, saying "Allah. He has given me the opportunity to help...".

In exploring family caregivers' understandings of God, it is clear that their perceptions vary from seeing God as a loving and compassionate figure to viewing Him as a punisher. Those who perceive God as loving often find solace and strength in His love, while those who see Him as punitive interpret suffering as the result of wrong behavior. However, the common thread among caregivers is a belief in a purpose behind their caregiving role, whether the situation is a test or an opportunity bestowed by a higher power.

# Meaning and making sense

The following questions were asked to reveal what is important in the lives of family caregivers, whether their past priorities are still valid, how they live now, and what they expect from the future. Do you find your life meaningful (valuable)? What is your life purpose? Has there been any change in the meaning and purpose of your life during this process? (Table 5).

Family caregivers' responses highlight the diverse perspectives on life's meaning and purpose, reflecting the importance of finding personal fulfillment and meaning amidst the challenges of caregiving.

B1 said that her/his life purpose was her/his patient who was her/his son, while it was her/his children for B7.

B5 stated that s/he found her/his life meaningful, but s/he did not relate this to one single thing, emphasizing that life is good despite it all. B8 found her/his life significant but did not think about her/his life purpose very much and often chose to seize the moment. B12 expressed that s/he found her/his life meaningful and adopted leading a good life as her/his life purpose. B13 defined her/his life purpose as her/his spouse getting a little better and said that s/he had learned not to worry about anything and that her/his life perspective had changed a lot. It is observed that each day becomes meaningful in the lives of family caregivers as they find a reason to live [19]. B17 said that s/he was satisfied with his current situation, acknowledging that there were others in worse situations. B17 also stated that her/his life purpose was her/his children, but now her/his spouse's recovery had taken precedence over everything. B18 and B19 defined their life purpose as their patients' recovery and expressing this purpose was above everything else. While some family caregivers appeared to find deep meaning and purpose in life through their caring roles and personal goals, others had difficulty finding value and fulfillment amid the challenges they faced. B4 did not find life valuable, had lost her/his future expectations and that her/his daughter who was her/his patient used to have dreams that had now vanished. B9 found her/his life valueless, as s/ he felt s/he could not live if something happened to her/ his sick spouse. B15 expressed s/he did not find her/his life meaningful anymore as her/his control of her/his life was no longer in her/his hands; thus, s/he had no expectations from life.

Family caregivers' responses reveal diverse perspectives on the meaning and purpose of life. While some derive deep satisfaction from caregiving roles, personal goals, and relationships, others strive to find value and fulfillment amidst these conditions. Additionally, it is observed that some adapt their life goals to current circumstances, prioritizing family, personal development, and finding

Table 5	Coping	methods
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1.Fate	"This is predestined, so we'll endure it" B7.
2.Good and Evil	"He says there may be evil in good and good in evil. Whatever Allah does, He does it for the good" .B11.
3.Test	"Everyone goes through certain tests in this world. Mine is a little bit more. Belief sometimes tests me. Sometimes I feel constricted I can't bear it anymore, but my faith prevents me from doing harm to myself. I get emotional, but I don't resort to rebellionB8.
4.Gratitude	"Religiously and in other aspects, I believe that they have done everything they can, they're now facing a very difficult situation, but still, I think one should be grateful for every circumstance" B2.
5.Patience	"Because I'm devout, I can show patience to Allah's destiny and testAllah gives me patience in return" B17.
6.Religious rituals 7.Non-religious	"I pray the mostI perform namaz, and read the Quran, give my alms and seek help from Allah by sacrificing an animal." B16.
5	"I became a member to mediation groups, I gain power with this method, I resort to positive thinking, I try to something good behind the worst thing" B1.
	"When my spouse opens his eyes and makes a reaction, I feel like the whole world is minewhen he says "I love you" through gestures, the sparkle in his eyes makes me more than happyNow I love him like a baby".B6. "I am simply living the day right now, If I think in too much detail, my reliance on God decreases and I would be rebelling"B8.

meaning in daily life. Conversely, others express feelings of hopelessness, loss of control, and a lack of purpose, often attributing these emotions to the challenges of caregiving.

#### **Coping methods**

It is important to reveal the coping methods that are utilized by family caregivers in dealing with the challenges encountered during the caregiving process. Coping methods can include religious approaches as well as nonreligious ones. To determine how caregivers cope with the challenges they face during the caregiving process, we asked family caregivers, "Did you make any religious or non-religious effort to overcome the problems you encountered?" (Table 6).

Although religion and spirituality are defined in different terms, in health research, the concept of religion replaces spirituality, as it is more reliable [18, 20, 21]. In a study conducted by Steinhauser et al., patients considered that the most significant aspects of quality of life in a deadly disease were "being in peace with God" and "pain relief" [22]. The study carried out by Alcorn et al. with advanced cancer patients reported that patients shared their experiences, saying "If God had wanted me yesterday, I would not be here today" [23]. The negative events in life are perceived as tests bestowed by God. B6, B10, B12, B15 and B17 said that they were living a predestined fate. B2, B16 and B20 expressed that s/he believed good and evil came from Allah and everything happened by His will. B9 believed that Allah would give them the best outcome in everything.

B1, B2, B4, B5, B8, B10, B15, B17 and B19 said what they were living was an examination, and B7 compared this process to the tests taken at school. B12 expressed that life in this world was a world of tests, and B13 thought Allah sent these tests to evaluate faith and see whether it was denied at times of hardship. B19 said s/ he sometimes asks, "My God, what is this test for?" but could find no answer. B2, B6, B7 and B14 said that they expressed gratitude as it could be worse and thought they should be thankful for what comes from Allah. B4 mentioned that s/he derived strength from the possibility of their daughter opening her/his eyes, and B5 and B8 expressed that seeing her/his mother breathe gave her/ him the strength to endure.

In many holy books, it is emphasized that the concept that individuals are tested in this world is an inherent aspect of human existence. This is seen as an opportunity to distinguish between believers and non-believers, and for spiritual development and strengthening of faith. These religious teachings intersect with contemporary psychiatric literature, where there is a growing debate about the perception that life's difficulties are tests from a higher power, often conceptualized as a test from God. While some individuals may perceive adverse events as a challenge to their faith and resilience, others find solace and meaning in the belief that trials are part of a divine plan, highlighting the complex interplay between religious beliefs and psychological health [24, 25].

### Discussion

Family caregivers experience stress, depression, hopelessness, loss of control, anger, guilt, resentment, and sorrow due to the increased responsibility of the caregiving process and seeing their loved ones sick and bedridden [3, 26]. This leads to existential and spiritual problems [27, 28]. Spirituality refers to a dynamic power that exists in human nature and helps individuals find meaning in their personal lives, past experiences, and realities. This force refers to a transcendent search for meaning in life, which can happen through religion, art, music, nature, sports and solidarity [29]. It helps individuals discover their potential, have self-confidence, develop feelings of loving and forgiving, and overcome pain [30]. Spirituality enables people to find a meaning in themselves, creates hope to keep on living, relieve pain and cope with it [31]. The spiritual needs of family caregivers include love, positivity, meaning and aim, hope, gratitude, relationship with God, transcendence, religious rituals, interpersonal relationships, support, communication, processing the feeling of guilt, and guidance and preparation for death [32, 33]. It is important to recognize and meet these needs. Fulfillment of individuals' spiritual needs helps them progress through the stages of denial, angerfrustration, bargaining, depression and the healthy state of acceptance. Healthy acceptance improves their quality of life [27]. Meeting spiritual needs provides family caregivers with satisfaction, power and peace, transforming the act of caregiving into a rewarding and meaningful experience. In contrast, unmet spiritual needs lead to spiritual pain or distress in the individual. As found in our study, the religious aspects of spirituality are more predominant than many other aspects. Religiousness is seen to enhance family caregivers' relationships with the supreme being and others, increase life satisfaction, and help caregivers tolerate their situation [34, 35]. Prayers are known to create a sense of devotion to God, and being at peace with God increases quality of life [22, 36, 37].

İzmir is located in the western part of Turkey and is one of the most developed and cosmopolitan provinces in the country, in terms of its socio-economic structure [38]. As a training and research hospital, our institution serves patients from various socio-economic backgrounds within our province. Therefore, we believe that the results we have obtained can be representative of the national population and provide applicable conclusions.

#### Limitations

This study has certain limitations that should be considered and addressed in future research. First, the sample size used in this study was limited, and using a larger sample size could help obtain more comprehensive results. Second, while the phenomenological design used in the study is suitable for understanding participants' experiences in depth, the findings could be compared with those obtained using different research methods. Third, the random selection of participants in the study may be limited in reflecting the diversity in the sample. Future studies could employ methods that encompass a broader participant pool. Fourth, the results of this study were based on the characteristics and experiences of the participants; hence, their generalizability is limited. Further research is needed to determine whether similar findings hold true for different populations or cultural contexts. Considering these limitations is important for the design and execution of future research. The findings of this study should be interpreted considering these limitations, and they may guide further research in relevant areas.

## **Conclusion and recommendations**

Family caregivers struggle with various psychological, emotional, and spiritual challenges during the palliative care process. Factors such as stress, depression, hopelessness, and loss of control play a significant role among these challenges. Particularly, spiritual support plays a critical role in helping many family caregivers cope with the difficulties they encounter. Within the integral approach that is an inseparable part of palliative care, the importance of spiritual support should not be overlooked. In this context, integrating spiritual support practices into routine palliative care processes, encouraging family caregivers' participation in religious or spiritual activities, and collaborating with clergy or spiritual support specialists when necessary are important. Additionally, healthcare professionals need to be trained to recognize family caregivers' spiritual needs and respond to them appropriately. It is important for healthcare institutions to research the effectiveness of spiritual interventions in enhancing the well-being of family caregivers and develop appropriate strategies to meet the spiritual needs of different cultural and religious groups.

#### Supplementary Information

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Supplementary Material 1

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#### Author contributions

U.U. made substantial contributions to the conception and design of the work, and the acquisition, analysis, and interpretation of data. U.U. also drafted the manuscript and contributed to the revision process.S.B. made substantial contributions to the analysis and interpretation of data, and was actively involved in drafting and revising the manuscript. S.B. also contributed to the design of the study and approved the final version of the manuscript.A.S. made substantial contributions to the conception and design of the work, as well as the acquisition and interpretation of data. A.S. also drafted and substantively revised the manuscript, and approved the submitted version.All authors agreed to be personally accountable for their own contributions and to ensure that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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#### Data availability

The data and other relevant materials used for the study are available from the first author on reasonable request.

#### Declarations

#### Ethics approval and consent to participate

This study was conducted in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board and Ethics Committee of the Health Sciences University İzmir Tepecik Training and Research Hospital (approval number 17/01/2022–2022/01–16).

## **Consent for publication**

Not applicable.

#### **Competing interests**

The authors declare no competing interests.

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#### References

- Barman A, Roy Choudhury D. Holistic Model of Subjective Well-Being-A proposed model and Exploration of contents. Zenith Int J Multidisciplinary Res. 2014;4(3):259–78.
- Puchalski C, Blatt B, Koagan M, Butler A. Spirituality and health: the Development of Field. Acad Med. 2014;89(1):10–6. https://doi.org/10.1097/ACM.0000 00000000083.
- Plank A, Mazzoni V, Cavada L. Becoming a caregiver: New family carers' experience during the transition from hospital to home. J Clin Nurs. 2012;21(13– 14):2072–82. https://doi.org/10.1111/j.1365-2702.2011.04025.x.
- Ransmayr G. Challenges of caregiving to neurogical patients. Herausforderungen in Der Betreuung Und Pflege Neurogischer Patientinnen Und Patienten. Wien Med Wochenschr. 2021;171(11–12):282–8. https://doi.org/10. 1007/s10354-021-00844-8.
- Lalani N, Duggleby W, Olson J. Spirituality among family caregivers in palliative care: an integrative literature review. Int J Palliat Nurs. 2018;24(2):80–91. https://doi.org/10.12968/ijpn.2018.24.2.80.
- Sterba KR, Burris JL, Heiney SP, Ruppel MB, Ford ME, Zapka J. We both just trusted and leaned on the Lord: a qualitative study of religiousness and spirituality among African American breast cancer survivors and their caregivers. Qual Life Res. 2014;23(7):1909–20. https://doi.org/10.1007/s11136-014-065 4-3.
- Rego F, Nunes R. The interface between psychology and spirituality in palliative care. J Health Psychol. 2019;24:279–87.

- Applebaum AJ, Kryza-Lacombe M, Buthorn J, DeRosa A, Corner G, Diamond EL. Existential distress among caregivers of patients with brain tumors: a review of the literature. Neurooncology Pract. 2016;3:232–44.
- 9. Freud A. The Ego and the mechanisms of Defence. 1st ed. The Institute of Psychoanalysis; 1966.
- 10. Quinn B, Connolly M. Spirituality in palliative care. BMC Palliat Care. 2023;22(1):1. https://doi.org/10.1186/s12904-022-01116-x.
- Asgeirsdottir GH, Sigurbjörnsson E, Traustadottir R, Sigurdardottir V, Gunnarsdottir S, Kelly E. To cherish each day as it comes: a qualitative study of spirituality among persons receiving palliative care. Support Care Cancer. 2013;21(5):1445–51. https://doi.org/10.1007/s00520-012-1690-6.
- Sánchez CT. Abordaje Aconfesional de la espiritualidad en cuidados paliativos. FMC. 2012;19(6):331–8.
- Kübler-Ross E. Ölüm ve Ölmek Üzerine. Çeviren: Büyükkal, B. April Yayınevi; 2010.
- 14. Kömürcü Ş. İleri Evre Kanserde Bakım El Kitabı. Türkiye Klinikleri; 2009.
- Özdoğan Ö. Değer Odaklı Manevî Güçlenme ve Bakım Programının Geliştirilmesi ve Uygulanması. 5. Uluslararası Sosyal Bilimler Kongresi Bildiriler Kitabı; 2019. pp. 913–8.
- Kidholm ML, Hvidt NC, Dieperink KB. Supportive care for elderly patients with cancer. Ugeskr Laeger. 2024;186(4):V06230429. https://doi.org/10.61409/V062 30429.
- Ross L, Austin J. Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers. J Nurs Adm Manag. 2015;23(1):87–95. https://doi.org/10.1111/jonm.12087.
- Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. J Palliat Med. 2009;12(10):885–904. https://doi.org/10.1089/jpm.2009.0142.
- 19. Peteet JR, Balboni MJ. Spirituality and religion in oncology. Cancer J Clin. 2013;63(4):280–9. https://doi.org/10.3322/caac.21187.
- Puchalski CM, Lunsford B, Harris MH, Miller RT. Interdisciplinary spiritual care for seriously ill and dying patients: a collaborative model. Cancer J. 2006;12(5):398–416. https://doi.org/10.1097/00130404-200609000-00009.
- 21. Koenig HG. Medicine, Religion, and Health: where Science and Spirituality Meet. Templeton Foundation; 2008.
- Steinhauser KE, Christakis NA, Clipp EC, McNeilly M, McIntyre L, Tulsky JA. Factors considered important at the end of life by patients, family, physicians, and other care providers. JAMA. 2000;284(19):2476–82. https://doi.org/10.100 1/jama.284.19.2476.
- Alcorn SR, Balboni MJ, Prigerson HG, et al. If God wanted me yesterday, I wouldn't be here today: Religious and spiritual themes in patients' experiences of advanced cancer. J Palliat Med. 2010;13(5):581–8. https://doi.org/10. 1089/jpm.2009.0343.
- Klitzman R. Why me? Qualitative research on why patients ask, what they mean, how they answer and what factors and processes are involved. SSM Ment Health. 2023;3:100218. https://doi.org/10.1016/j.ssmmh.2023.100218.
- Harmon-Jones E, editor. Cognitive dissonance: reexamining a pivotal theory in psychology. Washington, D.C.: American Psychological Association; 2019. pp. 3–23.

- Flaskerud JH, Carter PA, Lee P. Distressing emotions in female caregivers of people with AIDS, age-related dementias, and advanced-stage cancers. Perspect Psychiatr Care. 2000;36(4):121–30. https://doi.org/10.1111/j.1744-61 63.2000.tb00600.x.
- Hocker A, Krull A, Koch U, Mehnert A. Exploring spiritual needs and their associated factors in an urban sample of early and advanced cancer patients. Eur J Cancer Care. 2014;23:786–94. https://doi.org/10.1111/ecc.12200).
- Ross L, Austin J. Spiritual needs and spiritual support preferences of people with end-stage heart failure and their carers: implications for nurse managers. J Nurs Manag. 2015;23:87–95. https://doi.org/10.1111/jonm.12087).
- Evangelista CB, Lopes ME, Costa SF, Batista PS, Batista JB, Oliveira AM. Palliative care and spirituality: an integrative literature review. Revista Brasileira De Enfermagem. 2016;69(3):591–601. https://doi.org/10.1590/0034-7167.201669 0324i.
- T Sánchez C. Abordaje Aconfesional de la espiritualidad en cuidados paliativos. FMC - Formación Médica Continuada en Atención Primaria. 2012;19(6):331–8.
- Gomes R. Espiritualidade E cuidados paliativos: Alguns Pontos para reflexão. Espaços. 2019;18(2):187–96.
- Taylor EJ. Prevalence and associated factors of spiritual needs among patients with cancer and family caregivers. Oncol Nurs Forum. 2006;33(4):729–35. https://doi.org/10.1188/06.ONF.729-735.
- 33. Kang KA, Kim DB, Korean Society for Hospice and Palliative Care. *Textbook of hospice & palliative care*. Koonja; Paju: 2018. Spiritual care; pp. 449–67.
- Nolan MT, Hodgin MB, Olsen SJ, et al. Spiritual issues of family members in a pancreatic cancer chat room. Oncol Nurs Forum. 2006;33(2):239–44. https://d oi.org/10.1188/06.ONF.239-244.
- 35. Paiva BS, Carvalho AL, Lucchetti G, Barroso EM, Paiva CE. Oh, yeah, I'm getting closer to god: spirituality and religiousness of family caregivers of cancer patients undergoing palliative care. Support Care Cancer. 2015;23(8):2383–9. https://doi.org/10.1007/s00520-015-2604-1.
- Johnston EE, Rosenberg AR. Palliative care in adolescents and young adults with cancer. J Clin Oncol. 2024;42(6):755–63. https://doi.org/10.1200/JCO.23.0 0709.
- Delgado-Guay MO, Parsons HA, Hui D, De la Cruz MG, Thorney S, Bruera E. Spirituality, religiosity, and spiritual pain among caregivers of patients with advanced cancer. Am J Hospice Palliat Med. 2013;30(5):455–61. https://doi.or g/10.1177/1049909112458030.
- Alptekin E. (2022). İzmir İlçelerinin Sosyo-Ekonomik Gelişmişlik Düzeylerinin Tahlili, İzmir Ticaret Odas&#305.

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