Original Article

Spıritual needs and practıces among famıly caregıvers of patıents wıth cancer

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Abstract

Objective: The purpose of this study was to assess the spiritual needs and practices among family caregivers of patients with cancer.
Methods: This study which is descriptive and cross sectional was conducted with 230 family caregivers at the hematology-oncology clinic hospitalize and outpatients in a university hospital in Manisa, Turkey (West Anatolian). The data were collected by means of sociodemographic and Spiritual Needs Assessment Scale. Arithmetic averages, standart deviation (SD), pergentage were used in statistical analysis. The mean age of family caregivers were 44.9±14.7 (19-84) years, 61.7% were female, and 74.8% were married.
Results: Family caregivers described as spiritual practices that 33.3% saying prayers (Namaz), 28.2% prayer, 16.9% saying prayers and prayer, 14.7% saying prayers (Namaz) and reciting the Holy Quran (Koran), 6.9% Holy Quran (Koran). When family care givers were asked common spiritual needs, the participations stated that "For companionship" (59.6%), "To experience or appreciate beauty" (58.6%), and "To be accepted as a person" (58.0%).
Conclusion: The results of this study indicated that care process should be planned to provide with spiritual needs and practices among family caregivers of patients with cancer.

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Introduction

Cancer that is as a chronic disease, affects physical and psychological health.[1] Also, cancer patients have several kinds of problems and needs including symptom management, disease and treatment monitoring, medication administration, psycho-emotional support, assistance with activities of daily living, and assistance with instrument care. The patient's symptom managements and needs can cause care burdens for family members because they are often unprepared to provide care for the patients at home. Although family caregivers are a vulnerable and at-risk population, they also receive only minimal attention from most health care providers. Health care providers tend to be focused primarily on the patients' needs, however, family members were neglected by the health care system.[2,3] Several studies have stated that spirituality is one of the unmet needs among family caregivers of patients with cancer.[1,4-6]

Spirituality is also patients and family caregivers' common experience related to illness, such as cancer. Numerous studies have demonstrated that spirituality and spiritual practices significant effect on physical and psycho-social well-being, quality of life and coping with illness among cancer patients.[2,7-9] Moreover, there are a few studies have investigated on spiritual needs and spiritual practices among family caregivers of patients with cancer.[4,6,10] As far as we know, there are no studies in Turkish family caregivers of patients with cancer on spiritual needs and spiritual practices. The purpose of this study was to assess the spiritual needs and practices among family caregivers of patients with cancer.

Methods

This study was conducted as a descriptive and cross-sectional study. A total of 230 family caregivers of patients with cancer were enrolled from a university hospital in Manisa, Turkey (West Anatolia), between September 2014 and September 2015. The eligibility criteria included age between 18 and above years, to be primary caregiver and family member of patient, able to speak and read Turkish, to be willing participant. The study purpose, procedural details, the participant's rights and potential benefits and risks of the study were explained and written consent forms were obtained from them. A socio-demographic questionnare and Turkish version of the Spiritual Needs Assessment Scale (SNAS) were used the data gathering. In face-to-face interviews, the socio-demographic questionnare and SNAS were filled by the first researcher. Each interview took approximately 40 minutes.

The socio-demographic questionnaire was developed by the authors to capture personal information on age, gender, marital status, education, and spiritual practices.

Psychometric properties of SNAS were assessed by Flannelly et al.[11] which was conducted on the 23 items and the 6 dimensions. The 6 dimensions were appreciation of art and beauty, meaning and purpose, love and belonging, death/resolution, positivity/gratitude/ hope/peace, and the divine. The response categories were "never," "rarely," "fairly often," and "very often." The Turkish version of the SNAS were tested by Dedeli et al.[9] Cronbach' alpha for the Turkish version of the SNAS was 0.89.The scale are well-documented, and norm values for a Turkish population are available.(9) In the present study, alpha coefficient was found 0.87 for the SNAS.

Statistical evaluation of the data was performed via Statistical Package for Social Sciences (SPSS 16.0) soft-ware on computers. Descriptive statistics were shown in numbers and percentages (%) for the variables obtained by counting and in mean±standard deviation (SD) for variables obtained by measurement.

This study protocol was approved by the Research Ethics Committee of the Manisa Celal Bayar University Faculty of Medicine at Manisa, Turkey, number 27/08/2014-20478486/298. Participants were informed about the aim and nature of the study. The study was initiated upon receiving the approval and consent form of the planned participants.

Results

The mean age of family caregivers was 44.9±14.7 (19-84) years. Of the participants, 142 were female subjects. The majority of the participants reported themselves as married 74.8%. Table 1 shows the sociodemographic characteristics among family caregivers of patients with cancer. Table 2 shows the care characteristics among family caregivers of patients with cancer. The female was primary caregivers, and the majority of cases provided care spouses 37.8% and mothers 25.2%. Most of them (40.4%) provided care the patients 1 year and below.

Table 1. Sociodemographic characteristics of family caregivers (n=230)

Characteristics	n(%)
Gender	
Female	142(61.7)
Male	88(38.3)
Marital status	
Married	172(74.8)
Single	58(25.2)
Educational status	
Literate	18(7.8)
Primary school	105(45.6)
High school	42(18.3)
University and Post graduate education (MSc,PhD)	65(28.3)
Working status	
Yes	119(51.7)
No	111(48.3)
Income	
Low	81(35.2)
Moderate	132(57.4)
High	17(7.4)
Insurance	
Yes	228(99.1)
No	2(0.9)

Table 2. Care characteristics of family caregivers (n=230)

Characteristics	n(%)
Being know diagnosis	
Yes	223(97.0)
No	7(3.0)
Diagnosis years	
1 year and below	93(40.4)
1-5 years	89(38.6)
6-10 years	26(11.3)
11 and above	22(9.5)
Relationship between caregiver and patient	
Mother	58(25.2)
Father	40(17.3)
Child	11(4.7)
Spouse	87(37.8)
Sister/brother	4(1.7)
Grandmother/grandfather	30 (13.0)
Care years	
1 year and below	52(22.6)
1-5 years	103 (44.7)
6-10 years	64 (27.8)
11 and above	11(4.7)

To understand the participants' perception of the meaning of spirituality, they were asked to define spirituality in their own words and describe spiritual activities. As a result, it was found that all of them believe in the religious aspect of spirituality and, to define spirituality, they used such terms as "relationship with God (Allah)" and "trust in God (Allah)." All participants were Muslim.

When defining spirituality, the majority of the participants mentioned "relationship with God (Allah)" and "religious activities" including "saying prayers (Namaz) (33.3%)", "prayer (28.2%)", "saying prayers (Namaz) and prayer (16.9%)", "saying prayers (Namaz) and reciting the Holy Quran (Koran)" (6.9%) as important parts of spiritual practices, in their opinion. Most of them (47.1%) have believed in these spiritual practices that help them to relieve and cope with their stress. Also, spiritual practices was a quite important in their life (68.2%).

When they were asked about their meaning of life, their responses included health (36.0%), live (33.0%), peace (13.4%), family (12.1%), and children (5.2%). Their family (46.5%), spouse (37.8%), spouse and children (15.6%) were described as the most important people in their life.

We also asked the question to the participants that how were their spiritual practices affected after diagnosis. Approximately 35.0 % of the participants replied that they spent more time to practices, 30.0% of the participants stated that they spend less time, 35.6% of the participants said that nothing changed, and 2.7% of the participants said that they did not spend time any more. When they were asked do you any spiritual practices in order to heal of your patient. They defined cheer up (42.6%), prayer (27.8%), reciting the Holy Quran (Koran) (15.6%), and saying prayers (Namaz) (13.9%) as spiritual practices.

Table 3. Spiritual needs of family caregivers

How often do you experience each of these needs during in hospital? Dimension	Never n(%)	Rarely n(%)	Fairly often n(%)	Very often n(%)
Divine				
To participate in religious or spiritual services	32(13.9)	65(18.9)	106(57.3)	27(14.6)
To read spiritual or religious material	29(12.6)	55(23.9)	114(57.9)	32(16.2)
To have someone pray with or for you	85(36.9)	54(23.4)	53(23.0)	38(16.5)
For guidance from a higher power	28(12.1)	42(19.5)	122(53.0)	38(16.5)
Appreciation of beuty				
To experience or appreciate beauty	15(6.5)	24(10.4)	135(58.6)	56(24.3)
To experience or appreciate nature	84(36.5)	36(15.6)	67(29.1)	43(18.6)
To experience or appreciate music	104(45.2)	46(20.0)	67(29.1)	13(5.6)
Meaning and purpose				
To find meaning and purpose in life	22(9.5)	66(28.6)	98(42.6)	44(19.1)
To find meaning in the suffering	51(22.1)	54(23.4)	84(36.5)	41(17.8)
To make sense of why this happened to you	41(17.8)	45(19.5)	84(36.5)	60(26.0)
Love and belonging				
To give or receive love	11(4.7)	17(7.3)	133(57.8)	69(30.0)
To be accepted as a person	3(1.3)	46(20.0)	134(58.2)	47(20.4)
For companionship	5(2.1)	3(1.3)	137(59.5)	85(36.9)
For compassion and kindness	6(2.6)	17(7.3)	132(57.3)	75(32.6)
To feel a sense of connection with the world	15(6.5)	41(17.8)	97(42.1)	77(33.4)
Death and resolution				
To address issues before death and dying	61(26.5)	56(24.5)	72(31.3)	41(17.8)
To address concerns about life after death	41(17.8)	45(19.5)	101(43.9)	43(18.6)
To review your life	14(6.0)	26(11.3)	98(42.6)	92(40.0)
To forgive yourself and others	28(12.1)	87(37.8)	83(36.0)	32(13.9)
Positivity/gratitude/hope/peace				
To be thankful or grateful	28(12.1)	41(17.8)	102(44.3)	59(25.6)
To feel hopeful	21(9.1)	51(22.1)	102(44.3)	56(24.3)
To keep a positive outlook	9(3.9)	39(16.9)	97(42.1)	85(36.9)
To feel a sense of peace and contentment	15(6.5)	83(36.0)	43(18.6)	89(38.6)

We asked a question that do you think about your health care specialists to support your spiritual practices? 70.8% of the participants responded "yes" to that question. We also asked a question that your health care specialists how should be support your spiritual practices? Participants (44.7%) demanded the specialists should show respect their practices, 33.0% said that specialist should cheer up, had sympathy to their practices, 20.0% said that they should be gracious, and 31.7% said that they should provide with psychological support.

As shown in table 3, the most common spiritual needs of family caregivers were "for companionship" (59.5%), "to experience or appricate beauty" (58.2%), "to be accepted as a person" (58.2%), "to give or receive love" (57.8%), and "for compassion and kindness" (57.3%).

Discussion

Cancer is considered by many to be a financially devastating burden because of the expenses for diagnosis and treatment process. In this situation patient support is completely or partially paid by the family or herself.[12] The majority of the participants provided care family members (spouse, mother, father, etc). We expected that families provide adequate informal care at home as well as at the hospital for their family members with life-threatening chronic disease such as cancer. Therefore, the family, thespouses and children of the participants were the most important people in their life. Possibly, they responded, their meaning of life included health, live, peace, family, and children, because these concepts make sense feel well and contentment.

Spiritual practices vary according to the culture. In Islam, it can be punitive or Allah's will.[13] Being Muslims, they often believed that illness and injury are caused by a higher power (Allah) and they offered their illness, injury, pain, and suffering to Allah in thanks for the good fortune of being allowed the special medical or/and surgical treatments.[14] The sample in this study of spiritual practices consists of persons who were predominantly Muslim and had come from an Islamic background. Thus, the participants explained spirituality related religion. Most of participants reported that praying, saying prayers (Namaz), reciting the Holy Quran (Koran) were frequently a spiritual practice. Pray is a universal spiritual practice; it may take the form of intercessory prayer, confession, gratitude, or silent communion. Muslims are expected to saying prayers (Namaz) 5 times a day starting with the age of 10 years. Family members would stay by the bedside reciting the Holy Quran (Koran) hoping to imbue peace and serenity into the heart of the loved one.[9,13,15]

Spirituality is a distinctive, potentially creative and universal dimension, rising both within the inner subjective awareness of individuals and within communities. Several studies demonstrated that many individuals rely on their spirituality and faith when coping with stres in most cultures.[16-20] Dedeli & Kaptan[13] indicated that people apply cognitive and behavioral strategies including religion/spirituality to cope with pain. Another study showed religious-spiritual coping can be very helpful when dealing with chronic disease.[21] We found that the participants have believed in their spiritual practices that help them to relieve and cope with their stress. Also, spiritual practices were a quite important in their life.

Spiritual needs are defined[22] as "the needs and expectations which humans have to find meaning, purpose and value in their life. Such needs can be specifically religious, but even people who have no religious faith or are not members of an organized religion have belief systems that give their lives meaning and purpose". Other researchers[20,23,24] defined as spiritual needs "need for peace of mind", the "need of overcoming despair and guilt", and "to find meaning and purpose in life" as existential needs. Taylor stated[4,25] that the most important spiritual needs included being positive, loving others, finding meaning, and relating to God among patients with cancer and family caregivers. The current study demonstrated that the most common spiritual needs of family caregivers were "for companionship" (59.5%), "to experience or appricate beauty" (58.2%), "to be accepted as a person" (58.2%), "to give or receive love" (57.8%), and "for compassion and kindness" (57.3%). Although the participants defined spiritual practices as religious activity, there was their spiritual needs differences between their spiritual practices. Of course, spirituality is a multidimensional construct which is connected to religion, existentialism, and also humanism. The participants described spirituality as an individual and open approach in the search for meaning and purpose in life, as a search for `transcendental truth´, which may include a sense of connectedness with others, nature, and/or the divine. Some family caregivers may interpret their existential and spiritual needs in religious terms, while other family caregivers would interpret the same needs as existential and humanistic. Maslow stated that the fundamental needs of humans can be categorized as primary (*i.e.*,food and drink, warmth and sleep, shelter, sexuality) and secondary needs (*i.e.*, security, friendship, belonging and acceptance, and finally self-realization). While it is adequate from a theoretical point of view to differentiate psychosocial, existential and spiritual needs, it is obvious that these `secondary needs´ are interconnected.[26]

Spirituality is one of the most indispensable dimension of the holistic care philosophy which is often defined as the experience of transcendence, connectedness, meaning, and purpose in life, integrating aspects of the self or a search for the sacret. Therefore, spirituality reveals itself as a necessity to be fulfilled in unfavourable conditions as life-threatening disease. Having cancer could makes the patients negative effects on their beliefs which add meaning and worth to their lives leading to the development of loneliness.[9]

Spiritual needs should be met together with all the physical and psychological necessities in patients with cancer, because spiritual care is a part of the holistic care. However, nurses frequently disregard the spiritual dimension of the family caregivers and

become inapt to integrate the spiritual dimension to cancer care. Moreover, spiritual care is indivisible part of not only holistic care and family focused care. Although, many studies conducted on investigating positive effects of religion and spirituality on various aspects of health in patients with chronic diseases, few studies conducted on spiritual practices and almost no studies are carried out spiritual needs on family caregivers of patients with cancer.[9,15]

We asked a question that do you think about your health care specialists to support your spiritual practices? 70.8% of the participants responded "yes" to that question. We also asked a question that your health care specialists how should be support your spiritual practices? Participants (44.7%) demanded that the specialists should show respect their practices, 33.0% said that specialist should cheer up, had sympathy to their practices, 20.0% said that they should be gracious, and 31.7% said that they should provide with psychological support. Similar results were obtained in a dated study of 90 hospitalized adults completed by Martin et al.[27] When asked how they thought nurses could help to address spiritual needs, participants most frequently identified listening or allowing them to talk, calling clergy, and being kind and polite. Approximately every informant (97%) agreed that "nurses give spiritual care by being concerned, cheerful, and kind" Another study conducted by Sellers[28] 18 midwestern adults requested "Nurses can enhance spirituality by understanding the unique human experience of each person through the establishment of a caring human relationship characterized by the art of being present, listening, respecting, and giving of self" Taylor[4,10] observed patients and family caregivers were all humans with spiritual needs that many not significantly differ from each other. Patients and family caregivers demanded that nurses provide kindness, connectedness, prayerfulness, physical support, and so forth. Some participants eagered for nurses to provide overt forms of religious support. Also, patients with cancer and caregivers perceive that oncology nurses can influence their spiritual health.When 19 surgical patients were asked, "How do you think a nurse might provide for spiritual as opposed to physical comfort?," their responses included providing prayer, scripture, compassion, and presence; talking, touching, or smiling with patients; offering referrals; providing physical care; assessing needs; and being accommodating to treatment needs.[29]

Conclusıon

Concepts such as spirituality, religiosity, hope and social support end up overlapping each other and despite daily use, religiosity and spirituality are not synonymous, thus religion is a form of expression of spirituality. Spirituality can be used as a coping strategy for patients with life-threatening chronic disease and their family caregivers since it can increase the sense of purpose and meaning of life, which are associated with greater resistance to stress, which is related to diseases. Of course, there are limitation in the current study. A limitation of the study is that only the family caregivers of the oncology unit of a university hospital in Manisa (West Anatolia) were included in study. Because culture is a hybrid of Eastern and Western lifestyles, more interventional research will be needed in this area as more is learned about the importance of spiritual needs in Turkey. Nevertheless, the results of this study can be highlighted that further researches have been conducted on our country and cannot be generalized for the family caregivers of other religions or country. In addition, the results of this study suggest that the Turkish version of the PSNAS is required to measure for assessing spiritual needs of family caregivers who provided with care other chronic diseases. Overall, for patients with cancer, spirituality can be defined in a religious context. The highest needs "for companionship", "to experience or appricate beauty", "to be accepted as a person" , "to give or receive love" and "for compassion and kindness". Spiritual needs should be met together with all the physical and psychological necessities in patients with cancer, because spiritual care is a part of the holistic care. However, nurses frequently disregard the spiritual dimension of the family caregivers and become inapt to integrate the spiritual dimension to cancer care. Moreover, spiritual care is indivisible part of not only holistic care and family focused

care. Patients and family caregivers were all humans with spiritual needs that many may be significantly differ from each other. Nurses should be aware these differences and could provide with care regard to spiritual needs of family caregivers. These findings can help nurses to begin this process of providing spiritual care. There are implications for both nursing practice and nursing research. Perhaps the most notable is the significance of implementing spiritual nursing practice as a part of holistic care for family caregivers of patients with cancer.

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Collaborations

CAYDAM OD was responsible for the study design. KİYANCİCEK Z performed the data collection. CAYDAM OD planned and carried out the analysis and interpretation of the results. CAYDAM OD and KİYANCİCEK Z drafted the manuscript, and CAYDAM OD revised it critically. All authors checked the manuscript for accuracy and completeness.

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