

Research Article

Spiritual Needs of Patients with End-stage Cancer; An Exploratory Description through Nurses' Lens

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Abstract

Background: Cancer diagnosis can lead to an emotional state of distress, hopelessness, and fear which can cause uncertainty. Subsequently, both self-esteem and spiritual belief may be threatened and personal relations are lessened leading to spiritual needs. In oncology, evaluating spiritual needs is essential for fostering a value of life throughout severe illness. For some patients, the most dependable way to manage their illness is through their spirituality.

Objective: To explore the lived experiences of oncology nurses regarding the need for spirituality among patients with end-stage cancer.

Method: This was a qualitative descriptive exploratory study. This includes the Pakistan Institute of Medical Sciences, Rawalpindi's Combined Military Hospital (CMH), and Shifa International Hospital. The time frame for the study was April 2021–September 2021. The data was collected through structured questionnaire in-depth interviews. The study's rigor was assessed using trustworthy standards and qualitative thematic analysis approach was employed for data analysis.

Results: A total of 15 nurses participated in the study through purposive sampling from three different oncology facilities. Four themes and 11 categories emerged from the data itself namely; need to address spiritual suffering, need for spiritual coping, and religious path to spirituality, and need for holistic care.

Conclusion: This study deliberates spiritual care needs of patients hospitalized in the oncology department and their experiences of nursing care practices. Oncology patients require a holistic care plan to meet their spiritual needs. Spiritual training of nurse is recommended for their spiritual well-being and spiritual care competencies.

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Introduction

Global Cancer Statistics, 2024, showed that 9.7 million individuals globally passed away from

cancer in 2022, while an anticipated 20 million new cases were diagnosed with the disease. An estimated 35 million instances of cancer are expected by 2050.¹ significant public health problems in South Asia are the danger of cancer and its prevalence. Cancer is one of the non-communicable diseases (NCDs). In South Asia, non-communicable diseases (NCDs) account for over 69% of all fatalities, with cancer playing a significant role.² Pakistan is experiencing an increase in



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the number of cancer diagnoses; 19 million new cases were reported in 2020.³ Dealing with end stage cancer patients develop distinctive needs, the utmost essential spiritual needs. The spiritual aspect becomes the most reliable method for these patients to deal with their disease.⁴ Spiritual need assessment is vital in oncology to develop value of life throughout severe disease.⁵ Patients undergoing terminal illness may have the following spiritual needs: (a) Making a connection with their religion's beliefs and customs (b) Realizing the purpose of their lives (c) investigating their desired memory (d) pleading with oneself for forgiveness Granting pardon to others (e) relating their life narrative.⁶ Patients who are experiencing increasing ending of life, and psychological suffering can benefit from spirituality as it can help them find purpose and meaning in life. Humans have inner wants, or spiritual needs, which are the goals and desires that a person has in order to find meaning and purpose in life. But defining spiritual requirements is difficult since they are inextricably linked to a person's bodily, emotional, social, and cognitive demands.⁷

A significant number of people, including end stage cancer patients, turn to religion and spirituality to help them cope with life's challenges. In order to cope with life's hardships, patients frequently turn to religion and spirituality, receiving solace and motivation from these kinds of activities.⁸ Religious concerns and sources, such as faith, beliefs, and practices, as well as spiritual problems, all included in the broad category of spiritual caring.⁹ Nurses should be alert for spiritual issues in a curative setting, and should be given attention due to its significance in providing person-centered nursing care and its beneficial effects on patients' health.¹⁰ Spiritual care of dying patients is within the scope of nursing practice if nurses are to enhance the quality of life of dying patients, spiritual needs must be addressed. There has been very few studies on spiritual needs of cancer patients and no study is available on the need assessment by oncology nurses for cancer patients for their spiritual needs in Pakistani context. This study will significantly impact global health and education policy, specifically SDG 3 and 4, by promoting inclusive and comprehensive care. By stressing the significance of spiritual care in nursing profession.

This study aim was to explore the experiences of onco-

logy nurses with the consideration to research question that what are the lived experiences of oncology nurses regarding patients' spirituality in terminal disease in order to have perspective of their feelings about spiritual needs of the individual suffering with end stage cancer.

Methods

A qualitative exploratory study methodology allowed for a deeper comprehension of the oncology nurses' lived experiences. An in-depth investigation of the topic was made possible by this exploratory approach, which also revealed the details, new perspectives, and unresolved problems that quantitative approaches would have missed. It made it easier to examine how nurses felt about spirituality in the context of providing end-of-life care, as well as their perceptions, beliefs, attitudes, and emotions.¹¹

A total of 15 oncology nurses were recruited based on the voluntary participation through informed consent form, from the three different oncology set-ups in the capital city of Pakistan. Which includes Shifa International hospital, Pakistan Institute of Medical Sciences, Combined Military Hospital (CMH), Rawalpindi "Shifa International Hospital is a 550-bed tertiary care facility in Islamabad that provides inpatient care in over 35 medical and surgical disciplines. Pakistan Institute of Medical Sciences is an Islamabad, Pakistan-based health sciences institution with a focus on research. It is one of the top tertiary level hospitals in the area, with 22 centers for medical and surgical specialists. The Pakistan Army's main tertiary care facility is the Combined Military Hospital (CMH), located in Rawalpindi. The 1000-bed hospital in Rawalpindi offers outstanding healthcare as well as rehabilitation. The hospitals feature a cutting-edge cancer treatment center supported by the newest technology and a multidisciplinary team with extensive international expertise and board certification." There were oncology nurses who have worked in an oncology ward for at least six months and for a maximum of twenty-five years. All participants gave their informed consent form, and those who refused to take part were not allowed to take part in the study. Focus group discussions (FGDs), which were guided by a semi-structured interview guide, were used to gather data in order to get insight into the participants. "Oncology nurse" was defined as the professional caregiver possessed

the active nurse practice license, work full time with oncology patient in the specialized unit/set-up.

Purposive sampling technique was used to invite study participants for data collection. Purposive sampling technique allows the research to select the study participants based on the assumption that they are best suited to provide the information relevant to phenomenon of interest. Sample of the oncology nurse was subject upon data saturation achieved through in-depth interviews.¹²

Data was collected by investigator triangulation method where primary researcher took one on one interviews and data saturation was reached when there was no new information available with the participants. Data saturation was achieved at 13th participant, two more interviews were conducted to ensure data saturation, and total 15 interviews were conducted. A semi-structured guide of face-to-face interview was established constructed on the purpose of the research study; this was pilot tested with two nurses to confirm the questions were comprehensible and understandable. Participants were provided with the opportunity to describe their experiences in detail and to fill a demographic form, prior to the one-to-one interviews, with awareness aim of the study. The interviews, time duration was from 30 to 60 min, were carried out in free consulting rooms as to maintain privacy in the provided setting of each hospital. Each participant was requested to narrate their feelings and personal experiences concerning spiritual needs of cancer patients. The interviews were captured on audio. The participants' identities were coded as alphabets, and the contents were transcribed verbatim. The accuracy of the transcribed version was verified. Notable claims were highlighted, formal meanings were organized into theme groups (coding), and in-depth explanations were provided. For the purposes of the study, conformability meant keeping research neutral in order to make the findings reliable, transferability meant the extent to which the results were generalizable, dependability meant the stability of the study data, which is similar to reliability, and credibility which is refer as validity; meant confidence and trust in the study findings. All participants received the data for post-transcription feedback. It was also forwarded to specialists for an outside review. Ultimately, themes, and categories were formed as a result of thematic analysis of the data.

Interviews were alphanumerically documented and

transcribed verbatim. The questions were included; what do you think about cancer and patients' spiritual need in suffering cancer? What was your experience in caring for patient with cancer and his/her family? What did you feel while nursing cancer patients? What were the challenges while nursing the cancer patients? Has the experience of nursing cancer patients with their spiritual needs affected your own nursing behavior?

The data was analyzed by using Colaizzi's thematic approach.¹³ Data analysis was done self-sufficiently by the first author. The second author, who monitored the standard approaches for qualitative thematic analysis. Data analysis initiated with the first interview and was done in combination with data collection. The method used for analyzing qualitative data was Colaizzi's approach based on Husserl theory¹⁴ consists of the following: (a) reading the transcripts often; each transcript was read through at least three times; and (b) extracting important statements from the transcripts; these were indicated by underlining the spoken word transcripts. (c) To code the same statements; important statements were underlined and given codes. (d) Grouping the clusters into themes; categories, and themes were created by grouping the codes. (e) To provide in-depth explanations for each extracted theme; study participants' spoken words were used to describe each theme in detail. To show the data arranged into categories and uttered phrases, a table was created. (f) To read the themes and the details once more. In order to improve the analysis of the material, the constructed tabular data was read at least three times. (g) To make the transcripts available to the members once again in order to confirm and gather their opinions. To verify the information, the transcripts were given to the oncology nurses. In order to guarantee data accuracy through member checking (respondent validation), researchers work in collaboration with study participants. Data collection continued until redundancy of data was experienced, which designates data saturation has been achieved.

The four criteria of Lincoln and Guba as cited in McCaffrey et al 2016 were followed to ensure trustworthiness. These four criteria include credibility, dependability, conformability and transferability. Long-term involvement with data was necessary to establish credibility, and the researchers took the time to guarantee that rich data was collected substantially up until

data saturation was reached. Additionally, the analyzed data was merged with the body of existing literature. Dependability and conformability was achieved by way of crystallization to reveal the perception of the participants. The findings and significance were successfully transferred into study contexts, complemented by a thorough explanation of the research process.¹⁵

The research protocol was approval from Institutional Review Board and Research Ethics Committee of Rawal Institute of Health Sciences was taken (Reference No: RIHS-REC/067/21). Participant's information sheet and informed consent form was provided to study participants. Informed consent form briefly described the phenomenon of interest and purpose for the voluntary participation in the study. Interviews were conducted following their voluntary informed consent form. Participants could leave the study giving a reason so that other participant can be recruited. Interviews were conducted at a feasible time suited to study participants.

Results

As shown in Table-1, four themes and eleven categories emerged from the data analysis namely spiritual suffering, need for spiritual coping, religious path to spirituality, need for holistic care. The need to address spiritual suffering is described in categories encompassing hopelessness, powerlessness and agonizing feelings for family members. The need for spiritual coping is described for performing spiritual rituals while suffering through end stage cancer conditions. The sources of hope and strength was abstracted from three categories namely trans-religion spirituality, offering to religious as a gateway to spirituality, facilitating patient to perform religious activities to experience and exercise spirituality. Lastly, patient's needs holistic care was collated from patient's need for sympathetic care, empathetic care, compassionate care and comfort care.

1. *Spiritual suffering:*

Spiritual suffering, according to nurses, is a very subjective and individualized feeling that defies religious convictions. It may entail looking for experiences that give people a sense of wholeness and individuality, as well as experiences that provide significance. Patients who struggle with spiritual concerns, anxiety, guilt, or thoughts of being abandoned by a higher power may experience spiritual discomfort. The theme was catego-

rized as hopelessness, powerlessness and feeling of agony.

1.1 *Hopelessness:*

Participants described that in many cancer patients; hopelessness is a serious problem that negatively affects both their mental and bodily health. This emotion is frequently caused by fear of the disease getting worse,

Table 1: Themes and Categories:

S.No	Theme	Category
1.	Spiritual suffering	<ul style="list-style-type: none"> • Hopelessness • Powerlessness • Feeling of Agony
2.	Need for spiritual coping	<ul style="list-style-type: none"> • Performing rituals for coping
3.	Religious Path to Spirituality	<ul style="list-style-type: none"> • Trans-religion spirituality • Offering spirituality through religiosity • Promoting spirituality through religiosity
4.	Need for holistic Care	<ul style="list-style-type: none"> • Sympathetic care • Empathetic care • Compassionate care • Comfort care measures

of treatment side effects, and of dying. It may show up as hopelessness, a loss of direction and a weakened will to fight the sickness.

One of the participants articulated that "While performing my duty in oncology private ward when I ask patients how are you today, I used to get dialogue of negative thoughts that my life is going to end soon; I won't be able to survive" (Participant A).

Anxiety and depression are common symptoms that patients encounter, especially during cancer treatment. Breathing with terminal disease did not mean alive without hope. The nurses naturally expressed, although in different terms, where hope was merely decreased. Another participant articulated that "Cancer patient requires our attention because they feel dis-hearted due to the disease. Cancer patient family also involve in the care of their patients. We experience that cancer patients suffer a lot due to affordability, patients even sold their houses for the sake of treatment but they don't recovered completely. Ultimately they suffer from hopeless condition which demoralizes them." (Participant C)

1.2 *Powerlessness*

Participants stated that the emotional impacts of cancer can be severe. Fear, worry, powerlessness, and anger are common emotions experienced by patients as a result of perceived loss of control over their lives and uncertainty. One of the participants said that “Cancer patients suffer a lot due to emotional, financial, social isolation and low self-esteem crises which results in powerlessness” (Participant G)

Another participant uttered that “Cancer patients suffer a lot due to emotional, financial, social isolation and low self-esteem crises which results in powerlessness and negativity overall.” (Participant G)

1.3 Feeling of Agony:

Participants described that cancer sufferers' agony can take many forms and drastically lower their quality of life. This pain frequently has multiple facets, including psychological, emotional, and physical aspects. One of the participants said that “Cancer is a disease with poor prognosis, which is most of the time known to patients and family members. Cancer patients feel anxiety that what will happen to their family after death”. (Participant B)

2. Need for spiritual coping:

Participants defined that for many cancer patients, spiritual coping strategies are crucial to overcoming the emotional and psychological difficulties brought on by the illness. These processes frequently entail by participants as performing rituals for coping, trans-religion spirituality, promoting spirituality through religiosity and offering spirituality through religiosity.

Performing rituals for coping:

Emotional support and a sense of hope can be obtained through spirituality. Many cancer patients find solace in their faith, which enables them to face the anxiety and uncertainty that come with the disease. During treatment, it can promote calm, lessen depressive symptoms, and improve general wellbeing. One of the participant said that “I remember it was my morning duty in ward when I went to administer medication to the patient, the patient and family both asked me to hold medication for a while and give permission to leave hospital for one hour to perform some rituals on Mazar (temple) because of their faith on Allah that he will do a miracle for them” (Participant C)

The attendants have very strong beliefs along with patients regarding performing spiritual rituals. One of the participant discussed that “While writing nursing notes patient's family came to me and ask me to take the goat in ward to have their patients hand on the heal of the he goat as to give Sadka (animal sacrifice) to fulfill the religious requirement” (Participant B)

3. Religious Path to Spirituality

Participants described that using beliefs and religious rituals to gain strength, consolation, and purpose during their sickness is a common way for cancer patients to go from a religious path to a spiritual one. Many patients find that having strong spiritual beliefs helps them deal with the psychological and emotional difficulties that come with having cancer.

3.1 Trans-Religion Spirituality

Participants described that a big part of some cancer sufferers' coping strategies is trans-religious spirituality. This method makes it possible for a spiritual practice to be more adaptable and inclusive, which can offer thorough emotional and psychological support throughout the cancer experience.

One of the participants stated that “There are religious committees available from different religion like Muslims, Christians, and Hindus with provision of different language translators of Holy books in our hospital. When observe patients' beliefs it somehow stimulates my internal intuition too which also provides me to learn different values and norms of spirituality.” (Participant G)

3.2 Offering spirituality through religiosity:

Participants discussed that praying, meditating, or partaking in other religious practices can bring comfort and a sense of being connected to a higher force. These techniques can promote a sense of calm and acceptance and frequently assist patients in feeling less alone in their pain. One of the participant uttered that “When patients diagnosed with cancer they developed a thought of life threatening disease, which will end as a result loss of life. Because of our cultural beliefs I suggest patients to do recitation of Holy Quran and offer prayer regularly.” (Participant E)

3.3 Promoting spirituality through religiosity:

Participants deliberated that utilizing patient' religious practices and beliefs to improve their overall quality of

life and spiritual well-being. The spiritual well-being offers a framework for discovering purpose during the cancer journey as well as emotional support. One of the participant said that “Cancer patients follow different spiritual practices and we also provide the religious material to them so that they enhance their spirituality. Cancer patients follow the spiritual practices like NAMAZ, reading Quran, different WAZAIF and we provide them whatever is required.” (Participant F)

4. Need for holistic Care

Spirituality and religion were believed to be significant phases of holistic care that enhanced handling with the disease and signs as well as support quality of life. The nurses highlighted that their compassion to dying patients’ spiritual background was vital, and they were predictable to come across their patients’ divine needs.

The participants articulated their experiences of spiritual needs into subcategories of Sympathetic care, comfort care measures, compassionate care and empathetic care. While participants expressed above mentioned sub-categories from their lived experiences.

4.1 Sympathetic care:

Participants discussed that sympathetic care for cancer patients entails a patient-centered, compassionate approach that attends to their emotional, psychological, and spiritual needs in addition to their physical ones. During a difficult period, this kind of care is essential for enhancing the general quality of life for patients and their families. One of the participants expressed that “Cancer patient requires our attention because they feel dishearted due to the disease. Cancer patient family also involve in the care of their patients. We experience that cancer patients suffer a lot due to affordability; patients even sold their houses for the sake of treatment but they don’t recover completely. Ultimately, they suffer from hopeless condition which demoralizes them.” (Participant C)

4.2 Empathetic care

Participants expressed empathy that by acknowledging the patients’ feelings and showing genuine concern can make a significant difference in their emotional well-being. One of the participant communicated that “It seems very challenging in following infection control practices, reaction of chemo drugs, side effects of chemo-

therapy, extravasation and inflammation of intravenous line. I remember because of chemotherapy a patient developed cellulitis and it was really hard to maintain the IV line and the patient was also in pain which was making a very difficult condition”. (Participant G)

4.3 Compassionate care:

Participants discussed that compassionate care is an essential component of comprehensive patient management. It includes the emotional, psychological, and practical support that patients and their families require while facing a cancer diagnosis in addition to medical therapy. The following are some essential elements of compassionate cancer care. One of the participants uttered that “I feel very much good to care cancer patients. We encourage our patients to sit and spend time with family members in their daily routine work. We feel love and affection with our patients and try to tolerate the patient aggressiveness. I used to provide a friendly therapeutic touch with positivity as I can understand the misery which patient is suffering.” (Participant J)

4.4 Comfort care measures:

Participants stated that patients with cancer experience emotional and psychological effects. Access to counseling, support groups, and other psychosocial treatments is made possible by compassionate care, assisting patients in managing their stress, anxiety, and depression. One of the participants said defined that “I have a lot of experience in dealing with cancer patients. In initial visit of cancer patients we assess their needs and then we educate them about the infection control practices, diet, self-care, side effects of chemotherapy and overall comforting care plan”. (Participant F)

Discussion

The patient’s need to address spiritual suffering emerged as a one of the core theme in current study. Spiritual suffering is also denoted as spiritual distress and used interchangeably. A synthesis of qualitative study reported spiritual suffering amongst common issue with patients suffering from cancer(s).¹⁶ The findings of this study suggest that addressing spiritual needs is crucial in the comprehensive care of cancer patients. The essential need of the human is to have connection with others. Relationship is measured the social aspect of spiritual needs, which is uttered in the part of love, be in the hands of family, and interaction with others.¹⁷ Cancer patients

expend enormous amounts of meticulous energy in dealing with diagnosis of cancer, management of disease, and sentiment of uncertainties, and often touch a point where they sense they are in an indeterminate and extremely distressed position.¹⁸ Cancer causes hopeless life and disturbs not just the physically but the spiritually¹⁹ and leads to such sicknesses as negative thoughts, life threatening condition, poor prognosis and spiritual instability. Hopelessness develops predominantly due to conflict between desire to live and acceptance to death.²⁰

Powerlessness emerged another category under spiritual suffering theme. A study participant shared that “cancer patients suffer a lot due to emotional, financial, social isolation and low self-esteem crises which results in powerlessness”. Physical ailments associated with end stage cancer reduce the mobility of the patient which compromise independence and cause emotional and social isolation. A systematic review reported significant positive association between financial burdens termed as financial toxicity and spiritual suffering.²¹ Unmanageable cost of treatment possibly develops the feelings of burden on family, low self-esteem and powerlessness. The multitude effects of financial toxicity compromise disease prognosis. A study participant shared “cancer is a disease with poor prognosis. Cancer patients feel anxiety that what will happen to their family after death”. Cancer patients expressed feeling of agony due to poor prognosis and impact of financial disasters on family members. Patient and family may interfere with cancer treatment. Evidently, a study participant shared that “the patient and family both asked me to hold medication” Therefore, role of nurse to address the spiritual suffering by assessment and appropriate interventions is imperative for coping with cancer. Spiritual coping emerged as a second main theme and one of the means to address the spiritual suffering. A study participant shared that “the patient and family both asked me to give permission to leave hospital for one hour to perform some rituals on Mazar (temple) because of their faith on Allah that he will do a miracle for them”. This finding is consistent with a qualitative study from Turkey whose study participants used the similar coping strategy.²²

Third theme namely sources of hope and strength was construed from data. Religion and religious practices

predominantly emerged as to practice spirituality and sources of hope and strength. Study participant shared that “cancer patients follow the spiritual practices like NAMAZ [prayers], reading Quran, different WAZAIF [recitation of Holy Scripture] and we provide them the holy essentials which is required.” Most of the participants reported that patients turn into nearer to God after serious sickness and they worship more. Reports from meta-analyses indicate healthier physical²³ and social health outcomes among patient who experience spiritual wellbeing through religious practices. Therefore, oncology nurse should facilitate patients for religious practices. This study highlighted the role of religious services to patients without discrimination. A study participant shared “there are religious committees available from different religion like Muslims, Christians, and Hindus with provision of different language translators of holy books in our hospital”. Nurse competence for trans-religion spirituality services is considerably vital. Nurses could assess the patients’ needs to offer and facilitate the performance of religious practices. The patients’ need for holistic care emerged as a result of fourth main theme in current study. The need for holistic care was deduced from patients’ need for sympathetic care, empathetic care, compassionate care and comfort care requiring from oncology nurses. Sympathy, empathy and compassion are often used interchangeably but patients distinguish and experience them uniquely.²⁴ Study participants shared that “we experience that cancer patients suffer a lot due to affordability; patients even sold their houses for the sake of treatment but they don’t recovered completely”. Studies have shown that nurses possessed low to moderate levels of empathy; therefore nurses need to improve empathy competence.²⁵ Lastly, patient with end stage cancer require the comfort care. A study participant expressed that “I have a lot of experience in dealing with cancer patients. In initial visit of cancer patients we assess their needs and then we educate them about the infection control practices, diet, self-care, side effects of chemotherapy and overall comforting care plan”. A study has shown significant correlation between comfort and spirituality.²⁶ Study findings indicate the nurse competence to educate patient for self-care comforting measures.

The present study has certain limitations. Firstly, the study's population was limited to Federal Hospitals only, which may limit the generalizability of the results

to other settings. Second, just three hospitals' worth of data was collected due to scheduling constraints.

Conclusion

The study findings revealed that improving patient-nurse communication in the healthcare setting can be achieved by addressing cultural stigmas. Encourage family members to participate in the spiritual care process, acknowledging the significant influence they have on the patient's spiritual health. Promote a comprehensive understanding of spirituality that is adapted to each patient's unique requirements and incorporates vital, psychological, and emotional elements.

Ethical Approval: The Research & Ethics committee of Rawal Institute of Health Sciences, Islamabad approved this study vide Reference No. RIHS-REC/067/21,

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Authors' Contribution:

DJ: Conception and design, acquisition of data, drafting and revising article, final approval of the version

SA: Data analysis and interpretation

FA: Acquisition of data

GV: Data, analysis, drafting and revising article

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