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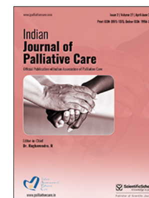

Original Article

Unmet Spiritual Needs: A Study among Patients with Chronic Illness

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ABSTRACT

Objectives: The conventional healthcare system operates on the 'physiological man' and overlooks the 'spiritual man'. Many studies reported on the unmet spiritual needs of terminally ill patients. Despite spiritual care being a predictor of a positive mindset (meaning making) among patients with terminal illnesses, assessing spiritual needs and providing adequate spiritual care is still a distant phenomenon in the healthcare setting.

Materials and Methods: With the help of a spiritual needs questionnaire, we analysed the unmet spiritual needs and preferences of 30 terminally ill patients. Specific attention was given to psychosocial, emotional, existential, religious and acceptance of death.

Results: The results show that 72% of terminally ill patients reported a strong desire to have their spiritual needs met. Psychosocial needs scored the highest, while acceptance of dying scored the least. The need to be connected with the family was one of the strongest wishes expressed in the study. Religious needs ranked as the second category of needs. Findings show that the highest needs are intertwined with the patients' culture.

Conclusion: In India, religion and family connections are essential; terminally ill patients expressed the desire that meeting these two aspects makes their lives meaningful even at the end stage. The results warrant a spiritual needs assessment as a deathbed test to make the end–of–life more meaningful.

Keywords: Spiritual needs, Chronic/terminal illness, End of life, Meaning in life, Family support

INTRODUCTION

'*Patients, when confronted with a fatal disease, ask a question to themselves, if at all their life has a meaning*', wrote Kalanidhi.[1] He contends that a severe illness affects a patient's physical, psychological and spiritual well-being and is life-shattering rather than life-altering. Patients suffering from life-threatening diseases are often deprived of human experiences. A mechanistic pattern of physiological care repudiates emotional needs. The intricacies of physical care crumble the self. Several types of research provide evidence for the unmet spiritual needs of terminally ill patients. Patients require a genuine carer to turn their fragmented self into an integrated whole. The emotional transaction between a care provider and patient, interwoven with communication, care, empathy and acceptance, is influential in bringing meaning and hope to people with terminal illnesses.

Patients with chronic illness suffer from feelings of guilt, loneliness, sadness, anxiety, despair, loss of hope, communication problems with family and friends, questions about meaning in life, religious struggle, loss of meaning and fear of dying.[2-5] Studies show that spiritual care is essential for a patient's well-being, supporting their need for meaning, purpose and connectedness.[6] While meeting spiritual needs fosters a positive attitude even amid critical illness, the distress agonisingly disintegrates the self. There needs to be opportunities for patients to express and experience the meaning of their lives. This meaning-making helps patients embrace life and death meaningfully, even at a chronic stage of illness. This article focuses on spiritual care and contends that unmet spiritual needs impede meaningful living and death.

Spiritual needs

The exponents of need theory in psychology have categorised the fundamental human needs as primary and secondary. While primary needs are physiological needs such as hunger, thirst, sex and shelter, secondary needs are more psychological, social and transcendental. Murray's 'Need-Press' theory discusses 24 human needs, which may be

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categorised as primary and secondary. Later, Abraham Maslow positioned human needs at five levels in a hierarchy where primary needs are physiological and secondary needs are psychosocial. McClelland's need classification goes beyond the primary needs to more psychosocial needs: achievement, power and affiliation. The recent developments of positive psychology emphasise the connection between well-being and meeting one's spiritual needs.

The spiritual need has been condensed as humans' needs and expectations to find meaning, purpose and value in their lives. Secondary needs, such as love, compassion, affiliation, care, proximity and acceptance, are essential humanistic experiences and are the keystone of spiritual needs. Several attempts have been made to list out the spiritual needs of chronically ill patients. Connection; self-worth; community feeling; reinterpretation of life; vital energy; peace; meaning/purpose; communication including talking, listening and touching; values such as health, faith and hope; transcendence; need for positivity, hope and gratitude; the need for religiosity such as prayer; the need to review beliefs; the need to give and receive love and the need to prepare for death are various spiritual needs identified in the research literature.[4,5,7-10]

Despite growing recognition of spiritual needs in chronically ill patients, many times, spiritual needs remain unmet. Several studies observed chronically ill patients reporting unmet spiritual needs.[3,10-14] Unmet emotional/spiritual needs result in unwarranted conditions. Inadequate emotional support can create new or at least aggravate pre-existing psychological distress, resulting in depression, anxiety, adjustment disorders and diminished self-perceptions.[2] Spiritual constraints and unmet spiritual needs were associated with poorer spiritual, psychological and physical well-being among chronically ill patients.[13-15] Patients' struggle with chronic symptoms can bring about feelings of guilt, loss, sadness, anxiety, diminished self-esteem, loss of role function, communication problems with family and friends, questions about meaning in life and religious struggle.[2] A conscious effort to meet their spiritual needs can reduce this distress.

The above discussion calls for the dire need to assess and meet the spiritual needs of terminally ill patients. Given this contention, the present study assessed the spiritual needs of chronically/terminally ill patients.

MATERIALS AND METHODS

The method employed was mixed, incorporating a spiritual needs questionnaire (SNQ) and an interview.

The participants for this study consisted of 30 chronically ill in-patients. The inclusion criteria comprised (i) terminal illness or long-term chronic illness, (ii) a 2-week stay in the hospital, and (iii) receiving pastoral care for a week in the respective hospital. The characteristics of the participants are given in Table 1.

A SNQ was developed to assess the spiritual needs of chronically ill patients. The questionnaire consists of 14 items spread over five dimensions of spiritual needs: psychosocial, religious, existential, emotional, and acceptance of dying [Table 2]. This 14 item scale was developed by referring previous SNQs [Appendix 1].[16,17]

The participants were met in their respective hospital rooms and were explained about the questionnaire. Although the questionnaire was self-administered, except for a few participants, the researcher stayed along until the questionnaire was filled.

The questionnaire data were subjected to descriptive analysis. Each item was scored to determine the requirement of meeting spiritual needs among the participants under study. A higher score on each item corroborated the spiritual needs of the patients.

A semi-structured interview was undertaken with three participants to collect in-depth information on their spiritual needs during an advanced stage of a terminal illness. The criteria for selection were the duration of stay in the hospital care and the advanced stage of their illness. The participants interviewed are PA1 – A 52-year-old man with liver cancer who underwent liver surgery and remained as an inpatient for about 3 months; PA2 – A 58-year-old woman with bone cancer. She stayed in the hospital for 4 weeks, and PA3 – A 78-year-old woman with heart failure who was in the hospital intensive care unit for 4 days and later shifted to the ward where she spent almost 3 weeks.

The interview was conducted after a preliminary analysis of the questionnaire data was performed. The questions were asked based on the topics covered in the questionnaire: religious, psychosocial, existential, emotional and acceptance of dying. The questions were asked so that the respondents came up with their desire to meet the abovementioned needs. The interview data were noted down and later transcribed. The themes are described under each category.

Ethical consideration

The participants were well-informed about the study's purpose, and written consent was obtained from each before data collection.

Limitations

Studying people with terminal illnesses poses a moral dilemma. Should they be studied at this crucial stage of their life? Access to in-patient wards and palliative care was difficult in the present study. Pairing with a healthcare professional in the concerned setting may be an option to reduce this difficulty.

RESULTS

Each item in the questionnaire was subjected to percentage analysis. The following Table 3 provides the percentage of

Table 1: Characteristics of participants.

Medical condition	Ave age in years	Sex		Religion			Average weeks in hospital
		Male	Female	Christian	Hindu	Muslim	
Diabetes (*n*=7)	63	3	4	4	1	2	2
Cancer (*n*=6)	62	2	4	4	2	0	4
Heart issues (*n*=5)	62	1	4	3	2	0	2.4
Hypertension (*n*=4)	47.5	4	0	2	2	0	2
Kidney issues (*n*=3)	69	1	2	0	3	0	2
Asthma (*n*=3)	58	1	2	2	1	0	2
Arthritis (*n*=2)	61	0	2	1	1	0	2.5

Table 2: Description of the categories of the tool.

Categories	Item numbers	Total
Religious	3, 5, 14	3
Psychosocial	1, 8, 9, 11	4
Existential	2, 4, 6, 7	4
Emotional	12, 13	2
Acceptance of dying	10	1
Total	1–14	14

Table 3: Spiritual needs of patients with chronic illness.

Categories	Sub-categories	Percentage of Responses
Psychosocial needs		84
	Accepted as a person	87
	Give and receive love	80
	Connected with family	90
	Respectful care of bodily needs	80
Religious needs		72
	Participate in religious services	75
	Have someone pray with or for you	71
	Turn to a higher presence	70
Existential		68
	Review life	67
	Meaning in suffering	71
	Meaning and purpose in life	65
	Concerns on life after death	70
Emotional		68
	Forgiveness	70
	Give away	66
Acceptance of dying		30
	Conversations on death and dying	30

each major category and sub-categories. Psychosocial needs top the categories, and religious needs follow. Connecting with family, being accepted as a person, giving and receiving love and respectful care of bodily needs are the sub-categories of psychosocial needs. About 90% of the participants expressed a desire to connect with the family, followed by the desire to be accepted as a person (87%). The second highest need expressed was religious needs [Table 3]. The items included in this category were to participate in religious or spiritual services, to have someone pray with or for you and to turn to a higher presence. Existential and emotional needs share the third position in the category. The least preferred one in the category is the 'acceptance of dying'.

DISCUSSION

This study attempts to determine the grading of spiritual needs among chronically ill patients. The overarching goal behind this study is to promote a better understanding of the spiritual and emotional needs of chronically ill patients among healthcare professionals and the public. Chronic illnesses are more prone to be in the population aged over 65. People above a certain age are considered vulnerable and, hence, restrained. Often, physical needs are taken care of, though it does not work wonders in terminal illness. In the long run, the emotional and spiritual side of the patients is ignored, resulting in conflicts and stress that are not appropriately addressed. In this study, patients with chronic illnesses desired to attend to their spiritual needs.

The second leading needs are religious needs, at 72%. Participating in religious services, having someone pray with you or for you and turning to a higher presence are the religious activities identified under religious needs. Participants expressed an equal intensity on existential and emotional needs. Finally, acceptance of dying is the least essential in the need's dimensions.

Psychosocial needs: Connecting with family

Psychosocial needs are the dominant needs expressed in the survey, with 84%. Accepting as a person, giving and receiving love, connecting with family and respectfully caring for bodily needs are the sub-categories under the psychosocial dimension. Many studies reported that chronically ill patients felt the necessity to meet spiritual needs.[4] Research evidence shows that for many patients with chronic diseases, psychosocial needs rank the highest spiritual needs.[12] The need for love, belonging, respect, the need to be accepted as

a person, to feel a sense of connection to the world, to give and receive love, to experience the committed presence of others, the need for compassion and kindness and respectful care of bodily needs are some of the needs identified under psychosocial needs in the literature.[5,18-20]

The most vital psychosocial need reported in the present study is connecting with family. About 90% of the participants felt that proximity to family members is essential for a chronically ill patient who is hospitalised. '*When my children are with me, my heart does not pound so extensively*', was a loud cry from PA3 during the interview. The hope and optimism linked with family members are evident in her voicing out her actual physical experience. Old age, coupled with terminal illness, is a time of emotional insecurity for many; parting with children is an additional stressor. Several studies have reported that connecting with family at times of physical distress may be a potential healing agent for many terminally ill patients.[5] A general understanding is that a strong family creates an atmosphere for the spiritual needs of its members. Research has shown evidence for this high need for familial connection.[21]

India is a very relationship-oriented country, where individual preferences and choices are subordinated to a collective solidarity. The developing ego of a new member is nurtured in the shadow of the older members. In contrast to an individual self, 'we-self' is being developed in family-oriented societies.[20] This we-self is a distinctive feature of family-oriented cultures,[21] where familial interdependence becomes dominant compared to hospital medical care. It is natural for people from such a robust and interdependent culture to continue seeking security from their loved ones. Therefore, one of the reasons for a strong need to connect with family members may be that in a hospital setting, people feel more isolated and rather individualistic with intense insecurity. In the interview, PA1 said, '*I feel much more secure when I know that my elder brother and my wife are around*'. This indicates that a strong bond with family members may be the most potent security source, even amid critical illness. The presence and interaction with the family members during critical illness is the most effective medicine to solace a soul.

Unmet religious needs of chronically ill patients

Religion and religious practices such as prayer, religious rituals and connecting with the divine are significant among chronically ill patients.[4,12,22] Nevertheless, this phenomenon varies across cultures. Some cultures find religious practices as a non-drug method of controlling physical illness,[22] while some other cultures consider certain spiritual practices as necessary to step toward death.[23] Interestingly, studies also show that religious needs are the least preferred in some cultures.[24] The overarching idea is how efficiently chronically ill patients' religious needs are met.

Religion is central to Indian daily life, intertwined with various religious practices. Several cultural, religious and moral factors in India determine people's perception of religious needs during a long-term, chronically ill phase. The faith and beliefs of people in India are connected with the performance of particular cultural and religious practices for the terminally ill.[4] As per the tradition, religious practices and prayers strongly connect with one's salvation and rebirth. In India, there are several religious and cultural factors embedded when one thinks of the religious needs of terminally ill patients.

Religious needs are the second top needs of the participants under study. The items looked at the need to participate in religious or spiritual services, have someone pray with or for them and turn to a higher presence. The findings show that chronically ill patients considered this an essential need to be met in their current health-care setting. A significant complaint reported was that from PA2, a pious woman, '*I don't get enough space to do prayers and other religious practices in the hospital*'. Several studies have shown that in India, especially in Hinduism, terminally ill patients prefer to be at home to do the necessary religious practices.[4]

Hence, it may be ideal to think that religious needs may be highly connected with the particular culture of the patients. Religion and its practices play a crucial role in a country like India. Most of its masses consider the fulfilment of spirituality through religious practices. Therefore, the needs expressed by the patients have a specific link with their upbringing in a particular culture. In India, religious needs are given priority due to the cultural aspects. Religious practices and salvation are intricately connected. Therefore, performing and participating in religious activities make their life more meaningful, even with a critical illness. For Indians, irrespective of health and age, striding toward death cannot be split from their religious beliefs and practices. Studies have also shown that religiosity gives people solace at the time of terminal illness.

Acceptance of dying

Supporting patients spiritually at the end of life is essential[15] to help them move forward. Acceptance of dying was the least felt need of the participants under study. There may be various reasons for this phenomenon. One possible reason could be the patients' belief that they recover from their illness and can have a normal life for some more time. PA3 reported, '*I pray every day that my illness gets cured, and I go back home and live the life I was leading*'. For another question on her illness, she added, '*These doctors do not test me properly, and they do not give enough medicines either. If they give me proper medicines, things will be better*. This bargaining is a form of resistance to a near-death.[25] The lowest score on the death dimension is a manifestation of patients' difficulty in embracing death, even on a deathbed. Maybe the thought of death can produce insecurity in a person who is never prepared for the same. Hence, from the findings, it may be

assumed that patients experience conflict when confronted with the very thought of death. This also implies that spirituality needs to be strengthened among chronically ill patients.

CONCLUSION

The study found that the spiritual needs of patients are very high. Among the categories of spiritual needs, psychosocial needs ranked the highest, whereas acceptance of dying ranked the least. Although all the participants are undergoing pastoral care, this was insufficient for them to find meaning in their present state. The study suggests that there should be more avenues in the healthcare system to meet the spiritual needs of terminally ill patients. The needs of the patients are connected with the kind of life that they have been living. Hence, the study suggests two critical propositions for further research as well as implementation: (i) There is a pressing need for assessing the spiritual needs of chronically ill patients, and (ii) healthcare settings must have the flexibility to accommodate the spiritual needs of chronically ill patients so that they can embrace death meaningfully.

Ethical approval

The Institutional Review Board approval is not required.

Declaration of patient consent

The research/study complied with the Helsinki Declaration of 1964.

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Conflicts of interest

There are no conflicts of interest.

Use of artificial intelligence (AI)-assisted technology for manuscript preparation

The authors confirm that there was no use of artificial intelligence (AI)-assisted technology for assisting in the writing or editing of the manuscript and no images were manipulated using AI.

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