# Spiritual care at the end of life in the Islamic context, a systematic review

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#### **Abstract**

According to the statistics over 30000 deaths occur annually in Iran due to cancer with an incidence of over 70000 new cases; this growing rate is similar to the developing world. These figures do not take into account other chronic illnesses like diabetes, heart failure, gastro-intestinal disorders, chronic neurological disorders and lung disease, which all warrant palliative care.

A systematic review was conducted until the end of 2007, to find out the ways that palliative care services are provided for Muslim patients suffering from cancer. Only three papers met the criteria as being original research either quantitative or qualitative, published during the last 10 years. Our findings conceded that very few papers are available in Islamic context about spiritual care at the end of life, where only one was quantitative. While cancer is rapidly increasing specially in developing world, the need of terminally ill patients with other conditions should be equally considered. Despite the fact that spirituality in Islamic societies exists profoundly, spiritual care must be institutionalised for patients who are in most need at their end of life, which needs more evidence.

Keywords: palliative care, spiritual care, islamic societies

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# Introduction

Islam has a profound concept about death and aftermath. Believing in life after death and resurrection is one of the three main principles of Islam, besides believing in Allah (Unity of God) and his last messenger (Prophecy). Many verses of the Holy Quran describe the world after death. The Quran emphasizes that death is only a transition from this existence to another form of life. The Quran always affirms the unlimited mercy and forgiveness of God, but links the life after death to one's performance in the present life (from birth to death).

Death from a Muslim's point of view is a passage between two parts of a continuous life. Furthermore, this transition is portrayed by the Quran as a smooth and satisfying passage for faithful people and a difficult experience for the wicked because they do not believe in an afterlife, the only life they know is ending, and it is spent carelessly and unwisely. [2] "But how -will it be- when the angels take their souls

at death, and smite their faces and their backs? This is because they followed that which called forth the wrath of God, and they hated God's good pleasure, so he made their deeds of no effect (47:27- 28)." On the other hand, the righteous souls will return to Allah in a well-pleased (with him) and well-pleasing (Him) manner, entering His garden (89:27-30).

Of 58 million people dying each year [3], approximately 60% die with a chronic condition of whom 6 million die of cancer and 3 million of HIV/AIDS with the majority occurring in developing countries. [4-6] According to the statistics from the Ministry of Health and Medical Education, over 30000 deaths occur annually in Iran due to cancer with an incidence of about 70000 new cases. The incidence of cancer in many developing countries is increasing. [7] These figures do not take into account other chronic illnesses such as diabetes, heart failure, gastro-intestinal disorders, chronic neurological disorders and lung diseases, which all warrant palliative care and also impose a huge burden on patients, families and the healthcare system.

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#### Models for spiritual strain

and Mock (2004) Nolan developed the Conceptual Framework for End of Life Care which corroborates the importance of spirituality in overall care. In this framework, the spiritual domain is in the centre of physical, functional and physiological domains. Outcomes in this framework encompass quality of life, patient decision making methods, and achievement of life goals, indicating the potential influence of spirituality on cognitive and functional outcomes in the end of life population [8]. Saunders et al developed the Conceptual Framework for a Good Death, emphasising the multifaceted nature of death. In this framework, different dimensions including fixed (socio-demographics, clinical status) and modifiable characteristics and also service provision and outcome of dying were considered. Modifiable dimensions included physical, psychological, cognitive social symptoms, relationships and support, economic demands, caregiver needs, hope and expectations, and spiritual and existential beliefs [9].

Cultural background may also play an important role in shaping responses to difficult situations. Wikan discusses the experimental dimension of bereavement and grief in two Muslim societies (Egypt and Bali-Indonesia), and argues that culture more than religion shapes and organizes responses to loss. The risks to health, clearly conceptualized in both societies, require entirely different preventive measures at the popular health care level to accommodate to different, culturally constructed notions of self, body and interpersonal obligation. In-depth studies that focus more on emotional experience in loss than on ritualized mourning are required. [10]

#### The role of Mosques in care provision

Mosques had a central role in the beginning of Islam. They were places to treat those who were wounded in battles, to pray, to teach, to gather or to learn Islamic rules. Muslim scholars also play an important and pivotal role in the daily life of Muslims particularly in difficult conditions such as death. Moreover, mosques are frequently used for health promotion in Islamic and even non-Muslim countries. [11] Historically, mosques have always had an important and sacred position in Iran and Islamic revolution, particularly after the performance of these holy places in health and vaccination programs has been outstanding [12]. This is noticeable at least from two aspects: family members and friends who look after a patient are in more need to seek religious support and to pray for their beloved ones. On the other hand, the dying patient may be in despair to search for spiritual care, repentance and mental preparedness for death.

Referring to clergymen is also usual in other religions such as in Christians and Jews. Several studies have found that bereavement; death and death-related problems are the most common problems congregants bring to clerics. Americans who lose a close person are almost five times more likely to seek help from a clergyman than in any other mental condition. [13]

Due to the increasing incidence of people in need of palliative care in developing countries and the fact that Muslims, who dominantly live in developing countries, are very dependent on spirituality, describing the ways that spiritual care is provided in the Islamic context is highly demanded. The aim of this paper was to perform an original research in spirituality at the end of life in Islamic context in a systematic manner.

#### Method

The following databases were searched for specific keywords from January 1997 until January 2008 Medline, Cinahl, PsychlNFO, Embase, and Ovid. Keywords incorporated: spiritual, spirituality, palliative, terminal, end of life, Muslim and related phrases. This approach was supplemented by hand searching of key journals (J Palliative Medicine, Palliative Medicine, Supportive Care in Cancer, J Symptom management, Palliative & Supportive Care, Int'l J Palliative Nursing, Indian J of Palliative Care, and BMC Palliative Care) and a systematic review of the reference lists of all identified papers. Included papers were peer reviewed journal articles written in English within the specific search period focusing specifically on spiritual care in the Islamic context (cancer and nonpalliative care. Review commentaries, editorials, letters, books, reports and theses were excluded from the study.

Abstracts of papers which met the inclusion criteria were obtained and reviewed by 2 independent reviewers. Full papers were subsequently obtained and reviewed by the team. Details were entered in a

table summarising the focus, design, main outcomes, weaknesses and generalisability of each study.

Comparison of study details, particularly their focus, design and weaknesses, which was facilitated via the use of common tables as outlined in Table 2, formed the basis of the analysis. Analytical process focused in particular upon the identification of similarities and differences in setting, sample, measurement, and generalisability. outcome Subsequent realisation of the heterogeneity of these factors including the predominant nature of design prevented meta-analysis.

# Table 1: General characteristics of selected papers

# **Results**

Searching main databases led to identifying 74 articles alongside with 18 papers from hand searching which were all reviewed by two investigators. Of this collection, 5 papers met the criteria as being original either quantitatively or qualitatively which were published during the last 10 years on spiritual care in the Islamic context. However after careful review of the full papers; only three papers eventually entered the study. (Table-1)

Year of publication	Authors	Title	Journal	Type of study
1998	Almuzaini AS, Salek MS, Nicholls PJ, Alomar BA.[14]	The attitude of health care professionals toward the availability of hospice services for cancer patients and their careers in Saudi Arabia.	Palliat Med; 12(5):365-73.	Quantitative
2004	Musgrave CF, McFarlane EA.[15]	Israeli oncology nurses' religiosity, spiritual well-being, and attitudes toward spiritual care: a path analysis.	Oncol Nurs Forum. 31(2):321-7.	Qualitative
2007	Bray YM. Goodyear-Smith FA [16]	A migrant family's experience of palliative care.	J.Hospice & Palliat Nursing; 9(2): 92-9.	Qualitative

#### **Discussion**

Several studies argue that cancer patients with strong spiritual beliefs and practice can cope better with their illness. [17, 18] According to a research by Williams [19], there are basically few qualitative research in the literature about spirituality at the end of life, this is underpinned in the Islamic context concerning the fact that the number of research about spirituality in life-threatening conditions in Muslim patients is exceptionally low. Themes which are mostly emphasised in the limited number of studies encircle around spiritual despair (alienation, loss of self, dissonance), spiritual work (forgiveness, self-exploration, search for balance), and spiritual well-being (connection, self-actualization, consonance).

Public hospitals usually offer less comprehensive and low-quality care for cancer patients compared with specialised medical centres. [14] There are much more examples in Iran that overall patients' satisfaction is not responded in public services. [20] On the other hand, healthcare professionals stress

their lack of knowledge towards meeting spiritual care of terminally ill patients. In a study on Specialist Registrars from different disciplines in Iran, nearly three quarters were not able to either talk about death or refer to a scholar for spiritual support. [21] Cultural background has a significant role in coping with the difficult situations at the end of life, where health professionals, specially nursing staff and social workers, may be very helpful.[16] A rigorous search in Medline indicated that research on death and dying in Islamic context is under-represented. [22]

Our findings indicate that very few papers are available in Islamic context about spiritual care at the end of life, while only one was quantitative. Patients at the end of life are more vulnerable and sensitive to care provision; they desire holistic care including controlling pain and physical symptoms and paying attention to social, psychological and spiritual components. Lack of robust research in this field underscores the importance and urgency of more studies to find out what kind of spiritual support is required for dying patients and their families. While cancer is rapidly growing especially in developing

Table 2: Comparison of studies

Author	Main focus	Aim	Study design	Study population	Major findings	Strength and weaknesses	Implications
Almuzaini AS, et al	Cancer patients and their informal carers	To assess the cancer care and need for palliative services in Saudi Arabia	Cross- sectional survey	136 cancer patients, 161 informal carers, and 398 health care professionals (physicians and nursing staff)	Public hospitals provided poorer services than other hospitals; shortage of cancer drugs, severe restriction on analgesics and lack of knowledge	Strength: A diffuse sample size from different regions and hospitals; Weakness: vague inclusion criteria	The need of improving cancer care in public hospitals, and the implementation of hospice and palliative care in all regions in Saudi Arabia, is indicated.
Musgrave CF, et al	Nursing staff	To investigate the relationship among the antecedent factors of age, ethnicity, and education and the mediating variables of intrinsic religiosity, extrinsic religiosity, and spiritual well-being on Israeli oncology nurses' attitudes toward spiritual care.	Cross- sectional survey	155 oncology nurses	Nurses' attitudes toward spiritual care are influenced by their education, intrinsic and extrinsic religiosity, and spiritual well-being	Strength: A wide sample size from different disciplines; Weakness: Vague inclusion criteria; the influence of spiritual care on patients is not recognised	Nurses' spiritual well- being should be supported to provide better services for terminally ill patients
Bray YM. et al	Careers' of a cancer patient	To explore the experience of palliative care for of a migrant family in New Zealand	Case study	4 members of a migrant family	Family's region and their immigration experience influenced their ways of coping in the four domains of family relationships, the community support, their ability to communicate, and their relationship with palliative care services. This shows the importance of cultural background in palliative nursing care.	Strength: in depth analysis of the case. Weakness: lack of generalisability	Underpinning of culturally safe palliative nursing care

world, the need of terminally ill patients should be equally considered. Table 2 displays the studies' main focus, sample size, major findings, strength and weaknesses and implications of the research.

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