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Gaps in the provision of spiritual care for terminally ill patients in Islamic societies — a systematic review

Abstract

Background. Islam has a profound concept about death and aftermath. Believing in living after death and resurrection is one of the three main principles of Islam. Since the increasing incidence of people in need of palliative care in developing countries and the fact that Muslims, who dominantly live in developing world, are very dependent on spirituality, describing the ways that spiritual care is described and provided in the Islamic context is highly demanded. This paper aims at delineating original research in this subject in a systematic manner.

Method. Several medical databases were reviewed in a systematic manner to investigate original quantitative or qualitative researches about providing spiritual care in Muslim societies.

Results. Searching main databases lead to identifying 84 articles alongside with 18 papers from hand searching, which all were reviewed by two investigators. Of this collection, only five papers met the criteria as being original research either quantitative or qualitative, published during the last 10 years. Cultural background plays an important role. Our findings conceded that very few papers are available in Islamic context about spiritual care at the end of life, where only three were quantitative. Research in this field, however, is rapidly growing compared with the previous year.

Conclusion. While cancer is rapidly increasing specially in developing world, the need of terminally ill patients with other conditions should be equally considered. Spirituality in Islamic societies does exist profoundly, which needs more research especially in terminal life and even bereavement.

Key words: spiritual care, terminally ill patients

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Introduction

In Islam, death is a right that no one can escape from it. It transfers to the isthmus life and resurrection occurs before the judgement day. It is mentioned that death is a difficult frightening process that is made easier to the good and more difficult to the wicked. The aftermath is also dependent on how

good the person was. Islam has a profound concept about death and aftermath. Believing in living 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 describes the after death world. The Quran emphasizes that death is only a transition from this existence to a future life. The Quran always

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affirms the unlimited mercy and forgiveness of God, but links future life to performance in the present life (from birth to death) [1].

Death for the Muslim is a passage between two segments 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 did not believe in an afterlife, the only life they knew is ending, and it was 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). In Islam there is no place for euthanasia and it is regarded as a suicide by the patient part and a crime by the individual who allowed it. However, there may be no objection on sedation and analgesia.

Of the 58 million people dying each year [3], approximately 60% die with a chronic condition of whom 6 million deaths are from cancer and 3 million from HIV/AIDS with the majority occurring in developing countries [4–6]. According to the statistics from Ministry of Health and Medical Education, over 30,000 deaths occur annually in Iran due to cancer with an incidence of over 70,000 new cases. The incidence of cancer in many developing countries is increasing [7]. 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 and also impose a huge burden on patients, families and the healthcare system

Definition of spiritual care

Terminally ill patients experience fear and loneliness during serious illness most of the time, which generate spiritual crisis that requires special care. Spiritual care can play an important role when cure is not possible. Terminally ill patients usually question the meaning of life; approaching death may stimulate serious spiritual questions that contribute to psychological symptoms such as anxiety, depression, hopelessness and despair. Amongst different definitions for spiritual care, the Scottish spiritual care services is one of the most available, which has defined it as follow: "Religious care is given in the context of the shared religious beliefs, values, liturgies and life-

style of a faith community. Spiritual Care is usually given in a one to one relationship, is completely person centered and makes no assumptions about personal conviction or life orientation. Spiritual care is not necessarily religious. Religious care, at its best should always be spiritual" [8].

Nolan and Mock (2004) developed the Conceptual Framework for End of Life Care which corroborates the importance of spirituality to overall care. In this framework the spiritual domain is at the centre of the 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. [9] 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 include physical, psychological, cognitive symptoms, social relationships and support, economic demands, caregiver needs, hope and expectations, and spiritual and existential beliefs [10].

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 involved, 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 [11].

The role of family

In Islam there is a lot of mention about visiting the ill and about supporting the in-need carers. It is a culture in Islam to provide the spiritual support of reading certain verses from Quran to the ill. The cultural background of most Islamic countries stresses about the family ties. Therefore it is more the responsibility of the family and close relatives and friends to provide the care in dedicated way. There is inadequate professional power in the health systems in Islamic countries to provide superior care than to

what the family can provide. The carer feels responsible particularly in the terminal stages and not being able to provide this care is a stigma or a sin.

The culture of bereavement is also usually well supported by the close family and friends circle. There is usually some financial and social support included in those difficult times. Home based support usually provided by these people. The bereaved family is usually supported for the first forty days to recover and restore.

What mosques do in care provision?

Mosques at the beginning had central role varying from treating the battle wounded, praying, teaching, and gathering to where the Islamic rules were announced. Muslim scholars have significant position and are supposed to be central in daily life of Muslim people particularly in difficult conditions like end of life. Moreover, mosques are frequently used for health promotion in Islamic and even non-Muslim countries [12]. Mosques have important position in Iran during the history in particular after the Islamic revolution these holy places operated outstanding tasks in health and vaccination campaigns [13]. This is noticeable at least from two aspects; family and friends looking after the patients are in more need to seek religious support and pray for their beloved ones, and on the other hand the dying patient may be in despair to search for spiritual care, repent and mentally preparedness for death.

Referring to clergymen is also frequent in other religions such as Christians and Jewish; several studies have found that bereavement, death and dying issues are the most common problems congregants bring to clergy. Americans who lost a close person are almost five times more likely to seek help from a clergyman than any other mental conditions [14].

Since the increasing incidence of people in need of palliative care in developing countries and the fact that Muslims, who dominantly live in developing world, are very dependent on spirituality, describing the ways that spiritual care is provided in the Islamic context is highly demanded. This paper aims at delineating original research in this subject in a systematic manner.

Method

In September 2007 the following databases were searched for specific keywords for the period of January 1997 until June 2008: Medline, Cinahl, PsychINFO, Embase, and Ovid. Keyword searches

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 Pain & 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, English language, journal articles within the specific search period focusing specifically upon spiritual care in the Islamic context (cancer and non-cancer) in palliative care. Review papers, commentaries, editorials, letters, books, reports and theses were excluded from the study.

Abstracts of papers meeting these inclusion criteria were obtained and reviewed by 2 independent reviewers. Full papers were subsequently obtained and reviewed by the team. Details were entered into a table summarising the focus, design, main outcomes, weaknesses and generalisability of each study.

The review was undertaken using an established, validated scoring system [15] which assesses different sections of the papers (introduction, method, sampling, bias, and results) in addition to the transferability and implications of all included papers. This standard guidance has been devised to apply a judgment of good (4), fair (3), poor (2) or very poor (1) across 8 different components which are combined to generate an overall score for the paper (maximum 32). During the review process, with regards to decisions regarding inclusion and scoring, where agreement could not be achieved, consensus was obtained via reference to a third team member.

Comparison of study details, in particular focus, design and weaknesses, facilitated via the use of common tables, as outlined in Table 1, formed the basis of the analysis. Analytical process focused in particular upon the identification of similarities and differences in setting, sample, measurement, outcome and generalisability. Subsequent realisation of the heterogeneity of these factors including the predominantly nature of design, prevented the undertaking of a meta-analysis.

Results

Searching main databases lead to identifying 84 articles alongside with 18 papers from hand searching, which all were reviewed by two investigators. Of this collection, 5 papers met the criteria as being

Table 1. Citation details for selected papers

Year of publication	Authors	Title	Journal	Type of study
1998	Almuzaini A.S., Salek M.S., Nicholls P.J., Alomar B.A. [16]	The attitude of health care professionals toward the availability of hospice services for cancer patients and their carers in Saudi Arabia	Palliat. Med.; 12 (5): 365–373	Quantitative
2004	Musgrave C.F., McFarlane E.A. [17]	Israeli oncology nurses' religiosity, spiritual well-being, and attitudes toward spiritual care: a path analysis	Oncol. Nurs. Forum. 31 (2): 321–327	Qualitative
2007	Bray Y.M., Goodyear-Smith F.A. [18]	A migrant family's experience of palliative care	J. Hospice & Palliat. Nursing; 9 (2): 92–99	Qualitative
2008	Rohani C., Langius-Eklöf A., Abedi H. [19]	Spirituality in Iranian women with breast cancer	Proceeding; 1 st congress on supportive and palliative care in cancer	Quantitative
2008	Rezaei M. et al. [20]	Prayer in Iranian cancer patients undergoing chemotherapy	Complementary Therapies in Clinical Practice	Quantitative

Table 2. Key details and scores of selected papers

Author	Main focus	Aim	Study design	Study population	Major findings	Strength and weaknesses	Quality score	Implications
Almuzaini A.S. 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 (physicians and nursing staff)	Public hospitals provided poorer services than other hospitals; shortage	Strength: A diffuse sample size from different regions and hospitals Weakness: professionals of cancer drugs, criteria palliative	23	The need of improving cancer care in public hospitals, and the implementation of hospice and vague inclusion on analgesics sever restrictions and lack of knowledge care in all regions in Saudi Arabia is indicated
Musgrave C.F. 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,	Cross-sectional survey	155 oncology nurses	Nurses' attitude 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 and spiritual patients is well-being on not recognised Israel oncology nurses' attitudes toward spiritual care	19	Nurses' spiritual well-being should be supported to provide better services for terminally ill patients



Table 2. Continuation

Author	Main focus	Aim	Study design	Study population	Major findings	Strength and weaknesses	Quality score	Implications
Bray Y.M. et al.	Carers' of a cancer patient	To explore the experience of palliative care for a migrant family in New Zealand	Case study	4 members of a migrant family 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	Family's region and their migration experience influenced their ways of coping lack of generalisability	Strength: in depth analysis of the case Weakness: care	12	Underpinning of culturally safe palliative nursing care
Rohani C. et al.	Women with breast cancer	To test coping strategies consist of spiritual perspective, positive and negative religious coping, and to investigate correlation between these factors in Iranian women before and after the diagnosis of breast cancer	Before-after study	100 patients with breast cancer	Results indicated that these patients with breast cancer used spirituality and religious coping to overcome the disease. No change was found before and after the breast cancer diagnosis in Iranian patients	Before and after design may not show the causal effect; therefore this study could be conducted with a better design	18	Religiosity and spirituality can help patients cope better with their serious illness
Rezaei M. et al	Cancer patients undergoing chemotherapy	To assess the impact of prayer in Iranian cancer patients undergoing chemotherapy	Descriptive cross-sectional	360 cancer patients	Individual characteristics had an important effect on prayer. Patients with age of more than 60 years female, widowed and divorced, and patients with primary education had higher scores for prayer activity than the others	No control groups were selected. No clinical data was provided to compare between different conditions	17	Prayer may have a role in coping with cancer

original research either quantitative or qualitative, published during the last 10 years about spiritual care in the Islamic context, however after scrutinised review of the full papers, only six papers were selected eventually (Table 1). Table 2 displays the studies main focus, sample size, major findings, strength and weaknesses and implications of the research.

Discussion

Several studies designate that cancer patients with strong spiritual beliefs and practice can cope better with their illness [21, 22]. According to a research by Williams [23], 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 are 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 [16]. There are much more examples in Iran that overall patients' satisfaction is not responded in public services [24]. 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 [25].

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 have important position [18]. A rigorous search in Medline indicated that death and dying research in Islamic context is under-represented [26]. Our findings conceded this, indicate that very few papers are available in Islamic context about spiritual care at the end of life, where only one achieved an acceptable score (more than 20 out of 32 scoring system).

Apart from the voluntary role of mosque attendants, and despite recommendations of religious leaders, the spiritual care is not institutionalised in Muslim societies. There is the assumption that the

family/friends circle will provide all the support needed. There is usually no communication between the government health institutes (public) and the religious clergy in the context of the care for the dying. However, probably private Islamic sponsored health institutes and palliative and supportive care non-government organisations (NGOs) may have this link and may be able to engage in palliative care if the government support the use of analgesia more liberally.

Patients at the end of life are more vulnerable and sensitive to care provision; they desire holistic care constitute of controlling pain and physical symptoms, 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 specially in developing world, the need of terminally ill patients with other conditions should be equally considered.

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