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Role of the doctor in relieving spiritual distress at the end of life

Karen Pronk, MB, ChB, FRACGP, PGDipPM

Abstract

Relief of spiritual distress is a part of good palliative care. This literature review examines journal articles and texts dealing with patient spiritual issues at the end of life to see what constitutes spiritual care, why such issues are felt to be part of healthcare, and how, when, and by whom they should be explored. It also looks at the anticipated outcomes of addressing spiritual distress. This review also notes recommendations in the literature regarding prerequisite skills and attributes of those providing spiritual care and some tools for spiritual assessment and guidance.

Key words: end of life, spirituality, palliative, existential

Introduction

The World Health Organization, in defining palliative care, emphasizes that the control of pain, of other symptoms, and of psychological, social, and spiritual problems is paramount.¹ In other words, a basic principle of palliative medicine is the relief of suffering. The term “total suffering” has been used to describe the physical,

psychological, social, cultural, and spiritual components contributing to a patient’s distress,² and the implication is that good palliative care addresses all of these aspects. Unrelieved pain may cause or aggravate suffering and conversely, unresolved problems relating to any other aspects of suffering may cause or aggravate pain.^{3,4}

The Canadian Palliative Care Association⁵ notes that care is delivered through the collaborative efforts of an interdisciplinary team, including the individual, family, and others involved in the provision of care. To be able to intervene in each of the physical, psychosocial, and spiritual domains requires a range of skills, and the availability of different team members provides opportunity for support from a number of sources. An interdisciplinary team works interdependently to develop goals, with leadership being shared depending on the task at hand.⁶ Spiritual care requires awareness of the patient as a person, in the sense that the person is defined by his past, roles and relationships, hopes and dreams, and a creative inner self,⁷ as well as a body in need of repair. Patients differ in how they relate to any one person, and spiritual care requires an understanding of how or where the patient finds meaning in life. Some patients will not, or cannot, talk about this aspect of their lives, but

can nevertheless receive benefit from a longstanding supportive relationship. The doctor may be ideally placed to assist in this regard.

The task of medicine is to preserve and restore health and to relieve suffering.⁸ The doctor, without minimizing the role of others in the interdisciplinary team, may have a role in relieving spiritual as well as other forms of suffering. This review focuses on how the doctor can approach the problem of relief of spiritual suffering.

What constitutes spiritual care?

Descriptions of spirituality vary widely, ranging from those that do not include any concept of God to those that identify God as the source of life, peace, and inspiration. Some descriptions are listed below:

- the human concern for things that matter⁹;
- the need for meaning, purpose, and fulfillment in life;
- hope/will to live;
- belief and faith at any given time¹⁰;
- the transcendental, inspirational,

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and existential way to live one's life¹¹;

- a way of being and experiencing life that is based on an awareness of a transcendent dimension^{12,13};
- the affirmation of life in relationship with God, self, community, and environment, which nurtures and celebrates wholeness¹⁴;
- the breath that gives life to the physical organism¹⁵;
- the attempt to be in harmony with an unseen order of things¹⁶;
- the ability to find meaning in life, surrender to the transcendent, and feel at peace¹⁷; and
- ineffable (incorporating ideas about the "soul" or "spirit" of persons, much of which is indefinable).¹⁸

Most authors agree that the word escapes clear definition ("to the scientifically trained mind, 'spirituality' is a bit like jelly—good if you can grasp it, but notoriously difficult to pin down").⁹ However, most attempts at definition incorporate the need for meaning and the quality of transcendence—the sense that one's spirituality is something beyond one's physical self, relationships, and environment, a sense of connection that will endure beyond the life of the individual.¹⁹

If spirituality is the search for meaning, then spiritual distress is the inability to find meaning. For those whose spirituality incorporates the concept of God, suffering can be a means of being closer to God,¹⁹ and spiritual distress is experienced as a sense that one is disconnected from God.²⁰ For others, the ability to find meaning is centered on their sense of

self-worth, relationships, and achievements, all of which may be perceived as being lost at the end of life. To quote Frankl, "Man is not destroyed by suffering; he is destroyed by meaningless suffering."²¹ Even in dying, meaning may be found through the realization that one matters, in that one's life has changed others, particularly if there is the perception that one's existence has left the world a better place.

For many people, ritual plays an important part in formalizing what is meaningful to them. Walter notes that spiritual care of the dying entails affirming or eliciting faith in the dying person by means of a dialogue that draws on belief systems that may be in play.²² Religion has been defined as a particular system of faith and worship that expresses an underlying spirituality.²³ However, different cultures view the concept in entirely different ways. As Markham²⁴ states, "An individual's spirituality might not include any of the more commonly understood concepts of God, and the majority of recent literature on spirituality assumes a secularized Christian understanding, with spirituality in healthcare being primarily an Anglo-American debate." He further says that "the four other major religions give distinct accounts of their own. In Islam, spirituality involves the extinction of the self [and] the transcendent element is everything; in Judaism, it is the perception of the spiritual through the mundane [and] the transcendent is not central; in Hinduism, spirituality is found within you, [and] searching for God outside oneself is wrong; and in Buddhism, spirituality is found within the ethical, [and] beliefs are being misused if they become the 'meaning to life'."²⁴

Rumbold nevertheless suggests that there is some continuity between religion and spirituality, with spirituality continuing to draw upon religious concepts and resources. He says further that common elements to religions and

"new spiritualities" that do not align themselves with religious groups both "provide meaning and develop practices that create and nurture transformative experiences, forming communities of experience."²⁵

It is widely agreed that everyone possesses spirituality, though for many it may not be expressed in a religious way. Spiritual care begins with attempting to understand another's spirituality and search for meaning, aims to support the patient in this search, and can involve attending to relevant rituals, which may or may not be within an established religious framework.

Should spiritual care be part of palliative care?

It has been persuasively argued that spiritual care should be part of palliative care. In a large North American study that elucidated factors considered to be important to patients at the end of life, 89 percent of patients and 65 percent of physicians rated being at peace with God as very important.²⁶ Another study found that 79 percent of 250 unselected patients at a large teaching hospital professed some form of spiritual belief, whether or not they engaged in religious activities.²⁷ This study examined spiritual belief and outcome from illness and found that a shaken spiritual belief was predictive of poorer outcome, and that spiritual support early in the illness could improve outcomes. These findings imply that spiritual distress has measurable physical effects. Pain, noncompliance with the care plan, guilt, and hopelessness have also been suggested as indicators of spiritual suffering,²⁸ again showing that spiritual distress can be expressed in physical and psychological terms.

The "end of life" loosely describes the time leading up to a person's death. Spiritual distress is readily recognized in the dying and wherever life

is seriously threatened.⁹ While confrontation with death may eventually lead to appreciation of life, it can also engender death anxiety.²⁹ Spirituality at the end of life has been said to be associated with a need for forgiveness, reconciliation, and affirmation.³⁰ Byock describes the end of life as a time of opportunity, citing the frequent observation of healthcare professionals that some people emerge from the depths of suffering to report a sense of wellness as they are dying.¹⁹

Palliative care can thus only claim to provide total care, addressing all aspects of the patient's distress by being constantly aware of their spirituality and attending to spiritual needs as part of the preparation for a good death. Why spiritual care assumes such prominence at the end of life is described succinctly by Small when he says "It is the encounter with the deity that allows one to put oneself in the hands of something greater than oneself, without which there is a danger that reliance on oneself can fall short of what one needs at the end of life."³¹

Who should provide spiritual care?

Current training for healthcare workers is felt to be lacking in both the language and the permission to talk about spiritual care issues, and Neuberger says that we have become impoverished in the vocabulary of what we would describe as spiritual care.³² It has been suggested that a diagnostic spiritual language is needed to link that of religion and psychology.³³ Several authors have commented on the use of the language³⁴ and techniques of psychology.^{20,35,36} However, for some, speaking the language of psychology is seen as adopting a language that leaves out God so as not to distance the secular group.³¹ Others recognize spiritual care as a development of psychology, commenting that

spiritual matters encompass existentialism and mysticism as well as the challenges of psychoanalysis.³¹ Some recommend that listening skills, coupled with insight, are necessary for psychological/emotional care to approach spiritual care.³⁶ Saunders asserts that a good deal of spiritual suffering has to be lived through, and that the important thing is being there, perhaps silently, to share the pain of spiritual growth in the awareness that one can do nothing, with the patient gaining support by simply being understood.³⁷ Millard adds that ignoring such pastoral skills involves the risk of pastoral care becoming psychological care.³⁶ Walter further notes that the difference with psychotherapy is in the language of love, forgiveness, and hope.²²

Such frequent reference to psychology implies that spiritual care requires psychiatric training. Peck, however, comments that "the traditional lack of training in the realm of spirituality assures that most well-trained, astute practitioners [of psychiatry] will often flounder destructively in these matters."³⁸ Other ingredients for provision of good spiritual care include the awareness of a spiritual dimension in one's own life,^{28,39,40} the use of discernment (knowing when to talk and when not to talk),²² establishing a trusting relationship^{28,41} usually of some duration,⁴² using common sense,³² and drawing on one's own life experience and maturity.³⁹

Who provides spiritual care? Any doctor who has more than a passing involvement in the care of a patient with a terminal illness may be involved in spiritual care. Patients may choose to derive spiritual support from other relationships, but the closeness and confidentiality implicit in the doctor-patient relationship puts the doctor in a privileged position, and the patient may welcome openness to discussions of a spiritual nature. Cleaning staff, having a nonthreatening and nondenominational

presence, have also been advocated for the role of spiritual caregiver,³² as have nurses with sensitivity, perceptivity, and life experience.³⁹ In secular institutions where spirituality is felt to be equated with religion, the nonreligious may be assumed to be ill-equipped for the job. In these cases, chaplains are seen as spiritual caregivers.²² Others believe that the key role of the chaplain is to promote spiritual direction³⁴ as leader and trainer.³² A number of authors advocate that all hospice professionals provide spiritual care,^{22,33,37,41} though this assumes that all dying patients have access to hospice professionals. Rumbold cautions that spiritual caregivers are often part of the patient's own community, including family, friends, and long-standing caregivers, and that hospice professionals need to avoid relegating these people to second place.²⁵

How can spiritual distress be relieved?

Acknowledgment to the patient by the doctor that the illness is incurable is possibly the first step to providing spiritual care. Diagnosis of an incurable illness is a time when a person is confronted with his mortality, and this is often observed to be a period of accelerated spiritual growth.^{43,44} For example, cancer patients are said to report a heightened sense of spirituality and an increase in existential concerns.⁴⁵ However, both patient and doctor may feel the need to do "all that is possible" to effect a cure, and the search for cure, involving complex treatment and a variety of specialists, may become the patient's source of meaning.²⁵ Therefore, it is important that the doctor is aware of, and addresses, spiritual needs so that the patient is not left with a sense of failure and desertion when treatment fails.

Addressing spiritual needs requires a change in pace in the relationship

between caregiver and patient, a different language, and the ability to be mutually vulnerable. Much depends on the unhurried approach of the doctor and may require a change in mindset from that of result-oriented scientific thought and need for control.²² In contrast, in providing spiritual care, it is necessary to focus on the need for the patient to dictate the pace and nature of care. This is distinct from the need to feel in control seen in those patients who genuinely desire euthanasia, where fear results in a lost opportunity for emotional growth.²⁹ It is suggested that the doctor allow the patient to set the agenda, giving time for the patient to develop a sense of wholeness⁹ hopefully resulting in a relationship that should be characterized by openness, availability, and sensitivity.⁴⁶ Several authors note that listening to questions is more valuable than having the answers,^{22,23,31,35,36} with participants being mutually vulnerable, thereby encouraging development of spiritual insight.^{22,25} However, it is cautioned that overinvolvement and overidentification with the patient may compromise the ability to give spiritual care.⁴⁶ It should also be recognized that, while spiritual care can include religion, it must not be used to exclude religion.²² Although there seems to be an increasing tendency for people to embark on spiritual journeys that do not involve rituals and institutions, many still have what has been termed a religious spirituality.⁴⁷ This spirituality may be patterned around an organized system of beliefs, and these people are more likely to be open to contact with a designated chaplain. One group of chaplains who were interviewed observed that being a sign of God's presence or revealing God's presence was seen by patients to be more important than any verbal expression of conversion or faith.⁴⁶

Peck³⁸ identified five categories of defective spiritual care. These are failure to listen, failure to encourage

healthy spirituality, failure to combat unhealthy spirituality, failure to comprehend what is important to the patient, and denigration of the patient's humanity.²⁹ Hamilton also comments on inadequate exploration of this area when he stresses the need to be aware of the distinction between extrinsic (observance of religious customs) and intrinsic (religious spirituality) religion; it is important to go beyond superficial enquiry to find out what patients mean when they say that they consider themselves religious.⁴⁸

Several instruments have been devised to identify a person's spiritual needs, using scales that measure quality of life, attitudes, religiousness, and spirituality.^{33,49} However, the validity of scales that measure well-being has been questioned.²³ The use of spiritual assessment methods intended for use by members of the care team may limit their sensitivity and inadvertently fail to elicit the needs they seek to discern.²⁸ Also, there is a risk that asking relatively intrusive questions may invade a person's privacy.³² Spiritual needs should be assessed in a personal way to avoid assessment becoming routinized and losing its meaning.²⁸

The language of need, with its implications for resource allocations, could help gauge spirituality, particularly in the context of planning of services.²⁸ Spiritual needs can be divided into categories, the commonest of these being:

1. worship, beliefs, rituals, and customs^{34,41,50-52};
2. human relationships and life review^{25,34,42,50}; and
3. need for transcendence and to find meaning in suffering.^{34,50,51}

These authors do not mention assessment tools, which are seen to contribute to patient disempowerment, and imply that the spiritual caregiver

needs to be alert to the possibility of such needs in all patients. Familiarity with Fowler's stages of religious development⁵³ has been advocated, and Hamilton⁴⁸ suggests that questions about spiritual beliefs should be part of the initial medical interview, with Peck further describing a process of spiritual history-taking as follows:

"What religion were you raised in? What denomination? Are you still in that same religion? The same denomination? If not, what religion do you adhere to, and how did the change come about? Are you an atheist? An agnostic? If you are a believer, what is your notion of God? Does God seem abstract and distant, or does God seem close to you and personal? Has this changed recently? Do you pray? Have you had any spiritual experiences? What were they? What effect did they have on you?"⁴³

He goes on to note that while some doctors felt this might be too threatening to patients, his own experience as a psychiatrist was that patients appreciated being asked and liked to answer such questions.³⁸

Another aspect of spiritual care is that of life review. Patients are felt to gain enormous support in telling, writing, or painting their stories and should be encouraged in this.²⁵ The relationship of trust and respect that emerges may lead on to disclosure of their spirituality.²⁸ Life review leads to a desire for reconciliation, reunion, forgiveness, and closure³⁴ and is one of the tasks of spiritual care,⁴² which may include making sense of the patient's terminal illness. Three forms of illness narrative have been recognized⁵⁴:

1. restitution narratives, where suffering is a problem to be solved and the aim is for recovery;

2. chaos narratives, where patients are unable to find meaning in their suffering, but the suffering needs to be acknowledged before change occurs; and

3. quest narratives, where the illness is a journey leading to new possibilities for the human spirit.

A similar framework is suggested by Speck⁵⁵:

1. the past: dying people have a story to tell and may express feelings of guilt and shame, including shame associated with breaking a religious practice;

2. the present: entailing spiritual searching, including suffering and a growing sense of hopelessness; and

3. the future: the importance of hope and finding meaning in the mystery of death.

Naming the patient's narrative in this way may help the doctor see his role as mainly supportive rather than as reliever of suffering. For example, biographical pain (the distress from a sense that one's life has not added up the way one wished it to)⁵⁶ could be seen in the context of a chaos narrative, requiring acknowledgment but not necessarily intervention.

In addition to taking a spiritual history and encouraging life review, other suggestions include asking the patient about specific wishes regarding worship, death customs, and beliefs that may conflict with treatment²⁸; assistance in practices and rituals, with encouragement of prayer²⁰; journal writing; meditation; dream recording and reflection⁴²; the use of touch, which may have a healing effect³²; relaxation and therapeutic touch²⁰; understanding how the

patient sees his illness in relation to God²⁰—whether he feels at peace with God²⁶ or abandoned by God; or simply asking the patient, “How do you feel within yourself?”⁴⁴

Anticipated outcomes of providing spiritual care

As mentioned above, several authors feel that assessment tools may have the unwanted effect of rendering the patient less communicative of spiritual matters. Patients may feel disempowered when they should be setting the agenda for their care. Spiritual distress need not necessarily be controlled, but the caregiver should strive to be a supportive companion. But how does the doctor know if his care is effective?

Among the goals of spiritual care, Rumbold⁴² suggests that patients acknowledge their spirituality and achieve some spiritual maturity, whereby they are able to face suffering, transcend their immediate situation, and affirm the value of life. Such goals, while intangible, are appropriate. However, there is a perceived need in many institutions to measure outcome as part of quality control, leading to research aimed at measuring the effect of spiritual and religious practices. In a series of studies researching spirituality, Reed²⁰ notes the relationship between spiritual perspective and well-being in terminally ill patients, ranging from those still ambulatory to those actively dying. He also summarizes several research findings that indicate spiritual or religious involvement by patients showed measurable benefit, such as:

- belief in and relationship with God and involvement in religiously oriented activities were therapeutic for patients under treatment for cancer;
- religiously oriented expressions

of transcendence were more important than existential or psychological expressions of transcendence in African-American adults with cancer and women with breast cancer;

- Reflection on the meaning of life and belief in a higher power were clinically important healing effects in AIDS patients.
- A positive effect on survival in elderly disabled occurred when there was spiritual and religious involvement.
- A positive correlation between prayer and emotional coping and physiological outcomes was noted in surgical patients.
- Men treated in a Veterans' Affairs hospital who reported the use of prayer, faith, and drawing strength from belief in God were less likely to be depressed and better able to cope with their life situation.²⁰

Some facets of effective spiritual care cannot, or should not, be measured. Spiritual care is seen as reciprocal ministry, where the person offering care also becomes the recipient of care,⁴⁶ echoing Carl Jung's observation that effective treatment results in change in both doctor and patient.⁵⁷ Hockey also notes that people who are facing death in some contexts offer spiritual care to staff.⁵⁸ Both patients and spiritual caregivers face issues of fear of incompleteness and loss of control,⁴⁶ with the implication that spiritual care promotes a diminishing fear of death, a sense of completeness, and the timely relinquishment of control.

Conclusion

To be a human being is to possess

spirituality or a desire, however consciously recognized, to understand one's place in the universe and the purpose of one's existence. This spiritual awareness has been widely recognized as heightened in people who are faced with their mortality, and it occurs frequently at diagnosis of an incurable illness.

As no two patients will ever be at the same stage of their spiritual journey, and no two spiritual journeys are alike, there can be no set formula for provision of spiritual care. However, it is important for the doctor to be aware of, and, if able, to respond to the need for spiritual care as an integral part of whole patient care. The relationship in spiritual care should be mutually vulnerable and mutually beneficial and, unlike other care the doctor provides, the pace and pattern of that relationship is ideally determined by the patient.

To quote Byock, "We may not have the answers for the existential questions of life and death any more than the person dying . . . but it is not our solutions that matter. The role of the clinical team is to stand by the patient, steadfastly providing meticulous care and psychosocial support, while people strive to discover their own answers"; and "... beyond symptom management, hospice and palliative care intervention can be directed at helping patients attain a sense of completion within the social and interpersonal dimensions, to develop or deepen a sense of worthiness, and to find their own unique sense of meaning of life."¹⁹

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References

1. World Health Organization: Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee. Technical report series 804. Geneva: World Health Organization, 1990.

2. Woodruff R: *Palliative Medicine: Symptomatic and Supportive Care for Patients with Advanced Cancer and AIDS* (3rd ed.). Melbourne: Oxford University Press, 1999.

3. Chern NI, Coyle N, Foley KM: Suffering in the advanced cancer patient: A definition and taxonomy. *J Palliat Care*. 1994; 10(2): 57-70.

4. Saunders C: The philosophy of terminal care. In Saunders C (ed.): *The Management of Terminal Malignant Disease* (2nd ed.). Baltimore: Arnold, 1984, pp. 232-241.

5. Ferris FD, Cummings I (eds.): *Canadian Palliative Care Association Standards Committee: Palliative care—towards a consensus in standardized principles of practice* (first phase working document). Ottawa: Canadian Palliative Care Association, 1995, p. 12.

6. Cummings I: The interdisciplinary team. In Doyle D, Hanks G, McDonald N (eds.) *Oxford Text of Palliative Medicine* (2nd ed.) Oxford: Oxford University Press, 1999, pp. 19-30.

7. Cassell EJ: The nature of suffering and the goals of medicine. *N Engl J Med*. 1982; 306(11): 639-645.

8. Fields H, Martin J: Pain: pathophysiology and management. In Braunwald E, Fauci AS, Kasper DL, et al. (eds.): *Harrison's Principles of Internal Medicine* (15th ed.). New York: McGraw-Hill, 2000, p. 55.

9. Whipp M: Spirituality and the scientific mind: A dilemma for doctors. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, 137-150.

10. Ross L: The spiritual dimension: Its importance to patients' health, well-being and quality of life and its implications for nursing practice. *Int J Nurs Stud*. 1995; 32: 457-468.

11. International Work Group on Death, Dying and Bereavement: Assumptions and principles of spiritual care. In Corr CA, Morgan JD, Wass H. *Statements on Death, Dying and Bereavement*. Toronto: International Work Group on Death, Dying and Bereavement at King's College, 1994.

12. Elkins DN, Hedstrom LJ, Hughes LL, et al.: Toward a humanistic-phenomenological spirituality: Definition, description, measurement. *J Humanist Psychol*. 1988; 35: 78-98.

13. Ellison CW: Spiritual well-being: Conceptualisation and measurement. *J Psychol Theol*. 1983; 11: 330-340.

14. Moberg DO: Religion and aging. In Ferraro KF (ed.): *Gerontology: Perspectives*

and Issues (2nd ed.). New York: Springer, 1997, pp. 193-220.

15. Onions CT: Spirituality. In *The Shorter Oxford English Dictionary on Historical Principles* 3rd ed.). Oxford: Clarendon Press, 1973.

16. James W: *The Varieties of Religious Experience: A Study in Human Nature*. London: Longmans, Green, 1902.

17. Kellehear A: Spirituality and palliative care: a model of needs. *Palliat Med*. 2000; 14: 149-155.

18. Cohen SR, Mount BM: Quality of life in terminal illness: Defining and measuring subjective well-being in the dying. *J Palliat Care*. 1992; 8: 40-45.

19. Byock IR: The nature of suffering and the nature of opportunity at the end of life. *Clin Geriatr Med*. 1996; 12(2): 237-252.

20. Reed P: The re-enchantment of health care: a paradigm of spirituality. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 35-55. 21. Frankl VE: *Man's Search for Meaning*. London: Hodder and Stoughton, 1987.

22. Walter T: The ideology and organisation of spiritual care: Three approaches. *Palliat Med*. 1997; 11: 21-30.

23. Speck P: The meaning of spirituality in illness. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 21-33.

24. Markham I: Spirituality and the world faiths. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 73-87.

25. Rumbold B: *Spirituality and Palliative Care: Social and Pastoral Perspectives*. South Melbourne: Oxford University Press, 2002, p. 15.

26. Steinhauer KE, Christakis NA, Clipp EC, et al.: Factors considered important at the end of life by patients, family, physicians and other care providers. *JAMA*. 2000; 284(19): 2476-2482.

27. King M, Speck P, Thomas A: The effect of spiritual beliefs on outcome from illness. *Soc Sci Med*. 1997; 48(9): 1291-1299.

28. Cobb M: Assessing spiritual needs: an examination of practice. In Cobb M, Robshaw V, (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 105-118.

29. Yalom ID: *Existential Psychotherapy*. New York: Basic Books, 1980.

30. Twycross R, Barton J, Clench P, et al.: *Mud and Stars: The Impact of Hospice Experience on the Church's Ministry of*

- Healing*. Oxford: Sobell Publications, 1991.
31. Small N: Spirituality and hospice care. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 167-182.
 32. Neuberger J: Spiritual care, health care, what's the difference? In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, 7-20.
 33. Hay MW: Principles in building spiritual assessment tools. *Am J Hosp Care*. 1989; 6(5): 25-31.
 34. Kellehear A: Spiritual care in palliative care: Whose job is it? In Rumbold B (ed.): *Spirituality and Palliative Care: Social and Pastoral Perspectives*. South Melbourne: Oxford University Press, 2002, pp. 166-178.
 35. Jacobs M: Faith as 'the space between.' In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 57-71.
 36. Millard R: Facing the situation. In Rumbold B (ed.): *Spirituality and Palliative Care: Social and Pastoral Perspectives*. South Melbourne: Oxford University Press, 2002, pp. 97-115.
 37. Saunders C: Spiritual pain. *J Palliat Care*. 1988; 4(3): 29-32.
 38. Peck MS: Psychiatry's predicament. In *Further Along the Road Less Travelled. The Unending Journey towards Spiritual Growth*. Riverside, NJ: Simon and Schuster, 1993, p. 38.
 39. Ross L: The nurse's role in spiritual care. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, 121-135.
 40. Wright MC: The essence of spiritual care: A phenomenological enquiry. *Palliat Med*. 2002; 16: 125-132.
 41. Johnson A: The notion of spiritual care in professional practice. In Cobb M, Robshaw V (eds.): *The Spiritual Challenge of Health Care*. Edinburgh: Churchill Livingstone, 1998, pp. 151-166.
 42. Rumbold B: Spiritual dimensions in palliative care. In Hodder P, Turley A (eds.): *The Creative Options of Palliative Care*. Brunswick, Victoria: Melbourne City Mission, 1989, pp. 110-127.
 43. Peck MS: *Denial of the Soul: Spiritual and Medical Perspectives on Euthanasia and Mortality*. New York: Harmony Books, 1997, pp. 160-189.
 44. Byock IR: *Dying Well: Peace and Possibilities at the End of Life*. New York: Riverhead Books, 1997.
 45. Taylor EJ, Amanta M, Highfield M: Spiritual care practices of oncology. *Oncol Nurs Forum*. 1995; 22(1): 31-39.
 46. Jenkins B: Offering spiritual care. In Rumbold B (ed.): *Spirituality and Palliative Care: Social and Pastoral Perspectives*. South Melbourne: Oxford University Press, 2002, 116-149.
 47. Cobb M: *The Dying Soul*. Buckingham: Open University Press, 2001.
 48. Hamilton DG: Believing in patients' beliefs: Physician attunement to the spiritual dimension as a positive factor in patient healing and health. *Am J Hosp Palliat Care*. 1998; 15(5): 276-279.
 49. Puchalski C: Toolkit of instruments to measure end of life care. The George Washington Institute for Spirituality and Health. Available online at www.gwu.edu/~cid/toolkit/toolkit.htm. Accessed October 12, 2005.
 50. Emblem JD, Halstead L: Spiritual needs and interventions: Comparing the views of patients, nurses and chaplains. *Clin Nurse Spec*. 1993; 7(4): 175-182.
 51. Stoll RI: Guidelines for spiritual assessment. *Am J Nurs*. 1979; 79(9): 1574-1577.
 52. NHS Executive Northern and Yorkshire Chaplains and Pastoral Care Committee 1995: Framework for spiritual, faith and related pastoral care. Leeds, UK: University of Leeds Institute of Nursing, 1998.
 53. Fowler J: *Stages of Faith*. San Francisco: Harper and Row, 1981.
 54. Frank A: *The Wounded Storyteller: Body, Illness, and Ethics*. Chicago: University of Chicago Press, 1995.
 55. Speck P: Spiritual issues in palliative care. In Doyle D, Hanks GWC, McDonald N (eds.): *Oxford Textbook of Palliative Medicine*. Oxford: Oxford University Press, 1993, pp. 517-525.
 56. Walter T: Spirituality in palliative care: Opportunity or burden? *Palliat Med*. 2002; 16(2): 133-139.
 57. Jung C: *Memories, Dreams, Reflections*. London: Routledge & Kegan Paul, 1961.
 58. Hockey J: Dying the way we live. In Rumbold B (ed.): *Spirituality and Palliative Care: Social and Pastoral Perspectives*. South Melbourne: Oxford University Press, 2002, pp. 51-63.