

American Journal of Hospice and Palliative Medicine®

<http://ajh.sagepub.com>

Pastoral care, spirituality, and religion in palliative care journals

Maaïke A. Hermsen and Henk A.M.J. ten Have

Am J Hosp Palliat Care 2004; 21; 353

DOI: 10.1177/104990910402100509

The online version of this article can be found at:
<http://ajh.sagepub.com/cgi/content/abstract/21/5/353>

Published by:

 SAGE Publications

<http://www.sagepublications.com>

Additional services and information for *American Journal of Hospice and Palliative Medicine*® can be found at:

Email Alerts: <http://ajh.sagepub.com/cgi/alerts>

Subscriptions: <http://ajh.sagepub.com/subscriptions>

Reprints: <http://www.sagepub.com/journalsReprints.nav>

Permissions: <http://www.sagepub.com/journalsPermissions.nav>

Citations (this article cites 25 articles hosted on the
SAGE Journals Online and HighWire Press platforms):
<http://ajh.sagepub.com/cgi/content/refs/21/5/353>

Pastoral care, spirituality, and religion in palliative care journals

Maaïke A. Hermsen, MA
Henk A.M.J. ten Have, MD, PhD

Abstract

With the growth and development of palliative care, interest in pastoral care, spirituality, and religion also seems to be growing. The aim of this article is to review the topic of pastoral care, spirituality, and religion appearing in the journals of palliative care, between January 1984 and January 2002.

Key words: Pastoral care, spirituality, religion, qualitative analysis, journals of palliative care

Introduction

With the growth and development of palliative care, interest in pastoral care, spirituality, and religion also seems to be growing. This finding is supported by two studies that examined the content of the scholarly journals, in both a quantitative and, in the area of palliative care, a qualitative way.^{1,2} These studies indicate that there are significant issues related to the

topic of pastoral care, spirituality, and religion.

The aim of this article is to review the topic of pastoral care, spirituality, and religion appearing in the journals of palliative care, between January 1984 and January 2002. Although deliberation about this topic in palliative care takes place in a much wider context (for example, in the psychological literature), the 12 identified journals are the only professional journals that specifically focused on palliative care in the review period. The journals reflect their own views of caregivers and practices in palliative care.

Our article attempts to identify the central issues related to pastoral care, spirituality, and religion and to determine if practitioners in palliative care need a literature review. Furthermore, we seek to find the reason for the growing attention to pastoral care, spirituality, and religion.

Methods

We followed four methodological steps to identify which issues about pastoral care, spirituality, and religion have been addressed in the journals of palliative care:

1. First, we identified the relevant

journals using several databases and the mission statement of each journal, focusing on English language publications only. Beginning with the first journal in 1984, 12 professional journals were identified: *American Journal of Hospice & Palliative Care*; *Journal of Palliative Care*; *The Hospice Journal*; *Journal of Pain and Symptom Management*; *Palliative Medicine*; *European Journal of Cancer Care*; *Progress in Palliative Care*; *European Journal of Palliative Care*; *International Journal of Palliative Nursing*; *European Journal of Pain*; *Topics in Palliative Care*; and *Journal of Palliative Medicine*.

2. Second, we selected articles about pastoral care, spirituality, and religion from these journals. Articles were selected if they paid explicit attention to spiritual, existential, and religious issues or to questions about pastoral care and meaning; these broader issues should be either the subject of the publication or the topic of substantial sections of the publication. Although abstracts, guest editorials, and correspondence were not counted as articles, and therefore not

Maaïke A. Hermsen, MA, Researcher in Palliative Care Ethics, University Medical Centre Nijmegen, Department of Ethics, Philosophy and History of Medicine, Nijmegen, The Netherlands.
Henk A.M.J. ten Have, MD, PhD, Professor of Medical Ethics, University Medical Centre Nijmegen, The Netherlands.

Table 1. Proportional distribution of the issues about pastoral care, spirituality, and religion that have been addressed per year in the palliative care literature

Year	Number of articles	Year	Number of articles
1984	1	1993	2
1985	1	1994	8
1986	–	1995	2
1987	–	1996	3
1988	7	1997	17
1989	1	1998	6
1990	2	1999	6
1991	1	2000	10
1992	1	2001	12

included in our study, case presentations were included. There were 80 total published articles about this subject in the period January 1984–January 2002 (almost 2 percent of all published articles in the same period). A full list of literature can be obtained from the authors.

3. Third, we identified the professional background of the authors. Since in many cases the profession of the author(s) was not provided in the publication, we focused on the professional background, i.e. the professional setting where the author was working (as provided in the address of the authors).

4. Finally, the primary theme of each article was identified. Only one topic was assigned to each article, even if multiple topics were discussed. The topic of pastoral care, spirituality, and religion is multidimensional, covering at least four central issues: 1) concepts of spirituality,

pastoral care, religion, and patients' search for meaning; 2) coping with terminal disease and the experience of hope; 3) the nature of suffering; and 4) education and training. These items were identified by the title, keywords, and the main theme running through the publication.

Results

Table 1 shows the proportional distribution of the issues surrounding pastoral care, spirituality, and religion that have been addressed each year in the palliative care literature.

This section discusses the four items making up the subject of our study: 1) concepts of pastoral care, spirituality, religion, and patients' search for meaning; 2) coping with terminal disease and the experience of hope; 3) the nature of suffering; and 4) education and training.

Concepts of pastoral care, spirituality, religion, and search for meaning

Approximately one-third of all

publications in this category raise questions about concepts such as spirituality, pastoral care, religion, and patients' search for meaning. However, the majority of publications do not make any clear distinctions. There is a "lack of clarity about the nature of spirituality and spiritual care. The requirement of healthcare professionals to consider the whole person, including spirituality, is hampered by a lack of clarity."³ The result is that "we are often led to believe that spiritual care and pastoral care are somehow the same. This view has even brought some to state that as long as one is 'spiritual,' one can give pastoral care."⁴ However, some publications do provide an extended analysis. Although no unanimity or common understanding exists, certain trends can be distinguished.

Spirituality is quite often related to the search for meaning. Several authors state that the search for meaning is universal, especially in the face of death.⁵⁻⁷ Examples of spiritual questions are: "What is the meaning of life? What is Man? Is there a God? Is there life after death?"⁸ Spiritual questions raise the issue of meaning and, in particular, the question of "Why is this happening to me?" A sensitive problem is the relation between "spiritual" and "religious." Some argue that spiritual equals religious,⁶ while others have a different view. For example, Eaton⁹ claims that "religious concerns give expression to some spiritual needs." Smyth and Bellemare⁴ assert that pastoral care overlaps both spirituality and religion.

Religion is closely connected with the profession of a faith. According to Doyle, "By religious, we mean practices carried out by those who profess a faith. By practices, I am thinking of prayer, Bible reading, the receiving of sacraments, the discipline of times of devotions, and so forth."⁸ Religion usually expresses spirituality, but spirituality does not necessarily relate to

religion. Some of the terminology Doyle uses in his definition is language more limited to the Judeo-Christian tradition.

Pastoral care is the expertise to help patients find answers to complex philosophical and theological questions. The term "pastoral care" is a professional term with specific standards: "the need is not so much for someone to provide answers, but for someone who can help patients find their own answers. . . . Such expertise is known as pastoral care."⁴ This expertise has its roots in Judeo-Christian tradition as well. According to Smyth and Bellemare, pastoral care has four functions: healing, sustaining, guiding, and reconciling.

Coping and the experience of hope

Two frequently referenced works are Frankl's *Man's Search for Meaning* and Cassell's *The Nature of Suffering and the Goals of Medicine*. It is argued that an important aspect of coping with the prospect of death is the ability to make meaning of such an experience.¹⁰ Several authors deal with the question of whether being religious offers help or hinders coping with chronic illness.¹¹⁻¹³ On one hand, being religious can have positive effects on managing a terminal illness: ". . . belief in God or a supreme being is at the centre of their lives, providing a source of inner strength and peace. The fear of dying, physical aspects excepted, is absent because of a belief in an afterlife and a reunion with loved ones who have died before them."¹⁴

In addition, several articles explain that hope (as a dynamic experience) can help people cope with coming death.¹⁵ "Hope is a dynamic experience, important to both a meaningful life and a dignified death, for those patients suffering from incurable cancer. Although the hope of being cured is judged impossible, hope can still be

maintained."¹⁶ Several articles address the idea of fostering hope within palliative care. Through their attitude and behavior, these articles suggest that nurses are in a powerful position to generate hope: "asking patients what they are hoping for demonstrates a willingness to listen, conveys acceptance of them as they are, and facilitates a trusting relationship. Attending to climate, communication, comfort, and change are key aspects of care."^{17,18}

On the other hand, faith can have a negative impact on the ability to handle approaching death: "a spiritual crisis may occur when a patient is first faced with terminal cancer. He may cry out in despair, disbelief, or rage: 'How can there possibly be a God when there is so much suffering?' Occasionally, patients harbor the misconception that the illness has been sent as a punishment from God, especially if guilt is present over past sins."¹⁴

The nature of suffering

Some articles focus on the nature of persistent suffering.^{19,20} Generally, they convey the idea that although great effort is made to control human suffering, we cannot eliminate all suffering. Suffering is an inevitable dimension of human life. Therefore, it is not possible to end suffering: "rather than imposing control over another's suffering or avoiding that which is not acknowledged, caregivers in the palliative setting stand by patients—affirming and validating their plight and gently waiting for an invitation to accompany patients in their suffering."²¹

Education and training

An important topic considers how to respond to the spiritual needs of dying patients with different cultural backgrounds, specifically providing education about the beliefs of different

ethnic minorities, while respecting their cultural and religious background.²²⁻²⁵ The multicultural nature of society makes it necessary to understand other cultures. This understanding can be developed by being aware and sensitive as a caregiver.²⁶ On this topic, Orchard and Clark²⁷ investigate perceptions and the practice of spiritual care in nursing and residential homes for older people.

Another central question addresses how to teach caregivers to deal with spiritual issues. Several authors claim that it is very important that caregivers themselves are given the opportunity to reflect on their own attitudes and expectations towards the spiritual dimension of care. Moreover, it is important that we reflect on our own attitude towards life and death.^{28,29}

Conclusion

In this article, we reviewed the issues surrounding pastoral care, spirituality, and religion appearing in the scholarly journals of palliative care between January 1984 and January 2002. This review reflects current practices and the views of clinical leaders and caregivers in the field of palliative care in 12 journals. Four central issues related to the subject of our study were identified: 1) concepts of spirituality, pastoral care, religion, and patients' search for meaning; 2) coping with terminal disease and the experience of hope; 3) the nature of suffering; and 4) education and training.

A review like this can contribute to the quality of care provided to terminally ill patients. Caregivers working in palliative care should pay attention to the whole person, as defined by the World Health Organization (WHO). To do so, caregivers must be equipped to deal with the various needs of patients, including spiritual needs. The lack of clarity about those needs is an obstacle to the ability to adequately respond to them. Therefore,

those needs should be constantly reinforced in a multidisciplinary team. Furthermore, caregivers should know that hope and the ability to make meaning of the prospect of death are important aspects of coping. By knowing this, practitioners might be better able to foster hope and to accompany patients in their suffering.

The growing number of different ethnic minorities in our society and the need to provide care to terminally ill people from other cultures may explain why an increasing amount of attention has been paid to pastoral care, spirituality, and religion through the years. As shown in Table 1, there is a growing interest in this topic in the context of palliative care. Also, there is a growing tendency to reflect on the quality of palliative care; the strong development that palliative care is going through leads to consideration of issues surrounding pastoral care, spirituality, religion, and moral issues in general. This is not surprising because "toward the end of life, existential issues tend to relate to autonomy and a dignified death, meaning and goals, communication, relationships, and guilt. These are, therefore, important dimensions in the care of the very ill."³⁰

Acknowledgments

We would like to thank the Dutch Ministry of Health, Welfare, and Sport for funding the Centre for Development of Palliative Care (COPZ) project, which sponsored the research project "Practical Ethics of Palliative Care" of which this paper forms a part. The authors are grateful to Valesca Hulsman for her constructive comments in editing this article.

References

1. Hermsen MA, ten Have HAMJ: Moral problems in palliative care journals. *Palliat Med.* 2001; 15(5): 425-431.
2. Hermsen MA, ten Have HAMJ: Euthanasia in palliative care journals. *J Pain Symptom Manage.* 2002; 23(6): 517-525.
3. White G: An inquiry into the concepts of spirituality and spiritual care. *Int J Palliat Nurs.* 2000; 6(10): 479-484.
4. Smyth P, Bellemare D: Spirituality, pastoral care, and religion: The need for clear distinctions. *J Palliat Care.* 1988; 4: 86-88.
5. Weisman AD: Ultimate questions and existential vulnerability. *J Palliat Care.* 1988; 4: 89-90.
6. Walter T: The ideology and organization of spiritual care: Three approaches. *Palliat Med.* 1997; 11: 21-30.
7. Kellehear A: Spirituality and palliative care: A model of needs. *Palliat Med.* 2000; 14: 149-155.
8. Doyle D: Have we looked beyond the physical and psychosocial? *J Pain Symptom Manage.* 1992; 7: 302-311.
9. Eaton S: Spiritual care: the software of life. *J Palliat Care.* 1988; 4: 91-93.
10. Ersek M, Ferrell BR: Providing relief from cancer pain by assisting in the search for meaning. *J Palliat Care.* 1994; 10: 15-22.
11. Morton GM: 'Captive and free?': Pastoral care of patients with chronic renal failure. *Palliat Med.* 1988; 2: 122-130.
12. Coates S: Spiritual components in palliative care. *Europ J Palliat Care.* 1995; 2: 37-39.
13. Dein S, Stygall J: Does being religious help or hinder coping with chronic illness? A critical literature review. *Palliat Med.* 1997; 11: 291-298.
14. Clark B: Spirituality in the hospice setting. *Palliat Med.* 1991; 5: 151-154.
15. Hegarty M: The dynamics of hope: Hoping in the face of death. *Progress Palliat Care.* 2001; 9: x.
16. Benzein E, Norberg A, Saveman BI: The meaning of the lived experience of hope in patients with cancer in palliative home care. *Palliat Med.* 2001; 15: 117-126.
17. Kennett CE: Participation in a creative arts project can foster hope in a hospice day centre. *Palliat Med.* 2000; 14: 419-425.
18. Penson J: A hope is not a promise: Fostering hope within palliative care. *Int J Palliat Nurs.* 2000; 6: 94-98.
19. Byock IR: When suffering persists. *J Palliat Care.* 1994; 10: 8-13.
20. Klagsbrun SC: Patient, family and staff suffering. *J Palliat Care.* 1994; 10: 14-17.
21. Gregory D, English JCB: The myth of control: suffering in palliative care. *J Palliat Care.* 1994; 10: 18-22.
22. Katz JS: Caring for dying Jewish people in a multicultural/religious society. *Int J Palliat Nurs.* 1996; 2: 43-47.
23. Sarhill N, LeGrand S, Islambouli R, et al.: The terminally ill Muslim: Death and dying from the Muslim perspective. *Am J Hosp Palliat Care.* 2001; 18: 251-255.
24. Gelfand DE, Balcazar DE, Parzuchowski J, et al.: Mexicans and care for the terminally ill: Family, hospice and the church. *Am J Hosp Palliat Care.* 2001; 18: 391-396.
25. Sharma K: A question of faith for the Hindu patient. *Europ J Palliat Care.* 2000; 7: 99-101.
26. Lister AN: Other faith perspectives. Multi-faith hospices. *Int J Palliat Nurs.* 1997; 3: 23-25.
27. Orchard H, Clark D: Tending the soul as well as the body: Spiritual care in nursing and residential homes. *Int J Palliat Nurs.* 2001; 7: 541-546.
28. Bradshaw A: Teaching spiritual care to nurses: An alternative approach. *Int J Palliat Nurs.* 1997; 3: 51-57.
29. Husebo S: Is there hope, doctor? *J Palliat Care.* 1998; 14: 43-48.
30. Bolmsjö I: Existential issues in palliative care—interviews with cancer patients. *J Palliat Care.* 2000; 16: 20-24.