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ORIGINAL ARTICLES

A systematic review of spiritual and religious variables in *Palliative Medicine*, *American Journal of Hospice and Palliative Care*, *Hospice Journal*, *Journal of Palliative Care*, and *Journal of Pain and Symptom Management*

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ABSTRACT

Objective: There has been increasing recognition and acceptance of the importance of addressing existential and spiritual suffering as an important and necessary component of palliative medicine and end-of-life care in the United States. This paper seeks to empirically and systematically examine the extent to which there is an adequate scientific research base on spirituality and its role in palliative care, in the palliative care and hospice literature.

Methods: We sought to locate all empirical studies published in five palliative medicine/hospice journals from 1994 to 1998. The journals included: *American Journal of Hospice and Palliative Care*, *Journal of Palliative Care*, *Hospice Journal*, *Palliative Medicine*, and *The Journal of Pain and Symptom Management*. Journal contents were searched to identify studies that included spiritual or religious measures or results. Case studies, editorials, and theoretical or descriptive articles were not included in the search.

Results: During the years 1994–1998, 1,117 original empirical articles were published in the five journals reviewed. Only 6.3% (70 articles) included spiritual or religious variables. This percentage, while low, was better that the 1% previously reported in an examination of studies published in *Journal of the American Medical Association*, *The Lancet*, and *New England Journal of Medicine*.

Significance of results: While researchers in the field of palliative care have studied spiritual/religious variables more than other areas of medicine, the total percentage for studies is still a low 6.3%. To move the field of palliative medicine forward so appropriate guidelines for spiritual care can be developed, it is critical that good research be conducted upon which to base spiritual care in an evidence-based model. Recommendations are made for future studies on spiritual care in palliative medicine.

KEYWORDS: Spirituality, Palliative medicine, Research, Literature, Journals

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INTRODUCTION

End-of-life care in the United States has been an increasing focus of healthcare professionals in recent years. Since the Support Study (Support Principal Investigators, 1995) it has become clear that many patients receive inadequate care at the end of life. Pain and suffering often are unrelieved (Field & Cassell, 1997). Much of the suffering patients experience is spiritual (Puchalski, 1999). Yet, attention to spiritual issues is still not part of routine medical care. Although it is the ethical obligation of physicians to address patients' suffering, including the spiritual suffering (Puchalski & Larson, 1998) many physicians do not know how to address spiritual issues in the clinical setting (Ellis et al., 1999). Lo and his colleagues in 1999 consensus report write that "In addition to addressing physical suffering, physicians can extend their caring by acknowledging and exploring psychosocial, existential or spiritual suffering" (Lo et al., 1999).

Medical training has focused in large part on the technical aspects of patient care, often with a curative focus. Most medical schools offer little or no training on palliative care; even major medical texts have a lack of helpful information on caring for dying patients (Rabow et al., 2000). Surveys reveal that while the majority of patients who are dying would like their spiritual issues addressed by their doctors, very few actually received attention to spiritual issues from their physicians (Gallup, 1997).

Since its inception, hospice has had a tradition of caring for the patients holistically; the patient is seen as a whole person with both biopsychosocial and spiritual dimensions of health (Franco, 1983). From its beginning, hospice has recognized and included the spiritual aspect in care (O'Connor, 1986). Many authors have written about the importance of spirituality and the need for members of all palliative care disciplines to meet the spiritual needs of dying and chronically ill patients and families (O'Connor, 1986; Ley & Corless, 1988; Millison & Dudley, 1990, 1992; Puchalski, 1998). Most of the spiritual work is often done by clergy (Reese & Brown, 1997), but Babler (1997) suggests that spirituality is "too critical an area of practice to be left to clergy alone."

In spite of these assertions, the field of palliative care lacks adequate knowledge regarding the spiritual needs of chronically ill and dying patients, about who should provide spiritual care, and what constitutes adequate or even good spiritual care. The organizations that provide regulation or governing principles for hospice outline general requirements for spiritual care without specifics. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO, 1996) wrote that "Hospitals respects and provide for each patient's right to pastoral care. Pastoral counseling and other spiritual services are often an integral part of the patient's daily life." The Standards and Accreditation Committee of the National Hospice Organization (NHO, 1988) has developed guidelines for setting up hospice programs. According to these standards, spiritual concerns are to be addressed during the patient assessment and clergy are to be part of, or at least available to, the interdisciplinary teams. Medicare regulations for hospice programs require a pastoral or other counselor on the interdisciplinary team (U.S. Department of Health and Human Services, 1983). In a recent report by Cassell and Foley (1999) one of the core principles for end-of-life care is to "assess and manage psychological, social, and spiritual/religious problems."

Although all of these general standards advocate for spiritual provisions to address the spiritual needs of patients and family, there are no specific standards of what is spiritual care and what constitutes essential or good spiritual care. In fact, some authors suggest that hospice overemphasizes medical care (Reese & Brown, 1997). Research in palliative care reflects the emphasis on medical care. For example, most commonly used quality-of-life instruments do not include spirituality as a core domain (Techekmedyian & Cella, 1991). Cella and his colleagues have recently developed a measure of spirituality (FACIT-Sp) to include quality of life measures (Brady et al., 1999). We would argue that in order to have standards of care regarding spiritual care, one needs to have the following: (1) a body of scientific evidence that demonstrates what are the spiritual needs of the dying, (2) research on the associations of spirituality and quality of life among dying persons, (3) clinical outcomes of spiritual interventions, and (4) guidelines for spiritual interventions based on clinical data.

Most fields of medicine have neglected to address the spiritual dimensions of health and well-being in their published research (Larson & Larson, 1994). In an earlier study, we searched leading journals in medicine, *Journal of the American Medical Association*, *New England Journal of Medicine*, and *Lancet*, and found that only 1% of the studies utilized spiritual or religious measures when studying a variety of clinical outcomes. Others have found similar results in family practice, psychiatry, and geriatrics (Sherrill et al., 1993). To what extent does an adequate research base on spirituality already exist in the fields of palliative and hospice care? To date, no systematic review of the literature has been reported in the field of palliative and hospice care. In this study, we surveyed the leading

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palliative care journals to address this question systematically and empirically.

METHOD

Identification of Studies

We sought to locate all empirical studies published in five journals including: (1) *American Journal of Hospice and Palliative Care*, (2) *Journal of Palliative Care*, (3) *Hospice Journal*, (4) *Palliative Medicine*, and (5) *The Journal of Pain and Symptom Management* from January 1994 through December 1998. Journals were searched manually to identify studies that included spiritual and religious measures or results. Search terms related to religion included, but were not limited to, religiosity, religiousness, religious, religion, faith, church, and particular religious groups (Jewish, Muslim, Christian, etc.). Search terms related to spirituality included, but were not limited to, transcendence, existential, "meaning of life," prayer, and meditation. Case studies, editorials, and theoretical or descriptive articles were not searched.

Characteristics of Studies

For each selected article the following characteristics were recorded: (1) the main palliative care issue addressed, (2) characteristics of the participant population, (3) number of hypotheses concerning religion and spirituality, and (4) number of citations concerning religion and spirituality.

Characteristics of Spiritual/ Religious Variables

Characteristics of spiritual or religious variables were recorded. Each variable was categorized as belonging to 1 of 11 mutually exclusive categories: (a) religious affiliation (e.g., Catholic, Protestant, Jewish, Muslim), (b) public religious involvement (e.g., church attendance, social support from membership in a religious group), (c) private religious involvement (e.g., prayer/meditation, scripture reading, religious coping), (d) spiritual well-being, meaning, or transcendence, (e) subjective spiritual/ religious importance, (f) specific spiritual or religious beliefs (e.g., belief in life after death), (g) suffering, hope, or despair, (h) spiritual/religious staffing (e.g., inclusion of chaplain on palliative care team), (i) services provided (e.g., screening patients for spiritual distress), (j) multi-item measures of spirituality or religiousness (i.e., measures which contain items representing two or more categories a–h), or (k) other.

Furthermore, we determined whether each variable was used for each of the following purposes: (a) describing the spirituality or religiousness of the sample, (b) describing the religious/spiritual services (e.g., chaplain visits, meditation, etc.) that are provided in a particular health care setting, and (c) examining the association of religious/spiritual involvement with a measure of physical health, mental health, attitudes, healthcare practices, coping/adjustment, or quality of life. Any reported data regarding the psychometric qualities of the items of spirituality or religiousness (e.g., number of items, internal consistency reliability, test–retest reliability) were recorded. We also noted whether the variable was a dependent or outcome variable instead of a descriptive or independent variable.

RESULTS

Identification of Studies

During the years 1994–1998, 1,117 original empirical articles were published in *Palliative Medicine* (198), *American Journal of Hospice and Palliative Care* (206), *Hospice Journal* (99), *Journal of Palliative Care* (193), and *Journal of Pain and Symptom Management* (421). Of those articles, 70 (6.3%) included spiritual or religious variables. This percentage is considerably better than the 1% found in studies cited in *Journal of the American Medical Association*, *Lancet*, and *New England Journal of Medicine* (McCullough et al., 2000). The 70 retrieved articles were spread relatively evenly over the selected journals. *Palliative Medicine* published a slightly higher proportion of articles containing measures of spirituality or religion than did the other journals (*Palliative Medicine*, 21 or 30%; *American Journal of Hospice and Palliative Care*, 13 or 19%; *Hospice Journal*, 10 or 14%; *Journal of Palliative Care*, 14 or 20%; *Journal of Pain and Symptom Management*, 12 or 17%).

Characteristics of Studies

Thirty-eight (54%) of the 70 relevant articles cited other articles related to spirituality or religion. There was an average of six references per article citing other studies addressing spirituality or religion. Only five (7%) of the articles stated explicit hypotheses relating to spirituality or religion.

The most frequently occurring medical issues in the 70 studies were: (1) general palliative care (nature of hospice or palliative care and methods: 19 studies or 27%, (2) pain (11 studies or 16%), (3) quality of life (11 studies or 16%), (4) palliative care staff (7 studies or 10%), and (5) bereavement

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and grief (6 studies or 9%). All other issues were addressed in 3 or fewer articles.

The sample populations of the studies included: (1) patients with illness (34 or 49%), (2) nurses (20 or 28%), (3) palliative care staff (15 or 21%), (4) family/caregivers (14 or 19.7%), (5) physicians/medical students (11 or 16%), (6) social workers (9 or 13%), (7) volunteers (4 or 6%), (8) clergy/chaplains (5 or 7%), (9) palliative care institutions (5 or 7%), (10) the general population (5 or 7%), and (11) pharmacists (1 or 1%). While the majority of the studies involved adults (49 or 70%) and people aged 65 and over (41 or 57%), a substantial portion also studied adolescents of 12 to 20 years old (13 or 19%). A single article included children in the study population (1%).

Characteristics of Spiritual/Religious Variables

Surprisingly, there were 141 spiritual or religious variables in the 70 studies. The majority of studies (38 or 54%) contained only a single spiritual or religious variable, though a large portion of the studies (31 or 44%) contained two or more spiritual or religious variables. One exceptional study contained 22 spirituality or religion variables. This study is omitted from further analyses because that study's large number of religious variables would distort the percentages. Only 13 internal consistency reliabilities and 7 test–retest reliabilities were reported for the 141 variables. Several different types of variables were used in the studies (Table 1). Spiritual well-being, meaning, and transcendence variables were the most common (32 studies, 46%), followed closely by religious affiliation (29 studies, 41%). Of the 141 variables, 48 were used as outcome measures. Some of these outcome measures included: effect of illness on religious beliefs and practices; change of religious affiliation after a child's death; and change in attitude, including meaning and purpose, as result of a life event. Most variables were used primarily to describe the spirituality or religiousness of the sample (45 studies, 64%) or to describe provision of spiritual/religious services provided (43 studies, 61%). See Table 2 for other uses of the variables.

Table 1. *Type of religious/spiritual variables*

Type of variable	Number of variables (%)
Spiritual well-being, meaning, transcendence	32 (23%)
Religious affiliation	29 (21%)
Spiritual/religious services provided	19 (13%)
Staffing	10 (7%)
Private religious involvement	8 (6%)
Public religious involvement	8 (6%)
Suffering, hope, despair	8 (6%)
Importance of religious/spiritual belief	7 (5%)
Specific spiritual or religious belief	4 (2%)
Multi-item measures of spirituality or religion	1 (1%)
Other	15 (10%)
Total	141 (100%)

DISCUSSION

In the flagship journals of most fields of medicine (1% of medicine, 1% of psychiatry, 2.5% of family medicine, and 3.5% of geriatrics) only 1–3% of the studies include quantitative measures of spirituality or religion (Larson, 1993). In the area of palliative care the percentage of studies including measures is much higher. In this review, 6.3% of the articles surveyed in the leading medical journals in palliative care use some spirituality and/or religion variables. Thus, it appears that in the field of palliative medicine there is a greater recognition of the importance of spirituality than in many other areas of medical care.

Only 13 internal consistency reliabilities and 7 test–retest reliabilities, that is, 20 psychometric properties, were reported for the 141 variables. This exceeds the other areas of medicine where spiritual or religious variables were rarely reported and statistically verified. Only one study in 5 years of the journals reported psychometric properties for

Table 2. *Use of religious/spiritual variables*

Use of variable	Number of variables (%)
Description of spirituality or religiousness of the sample	45 (31%)
Description of religious/spiritual services provided	43 (29%)
Associations with coping/adjustment	17 (12%)
Associations with quality of life	17 (12%)
Associations with healthcare practices	12 (8%)
Associations with attitudes	9 (6%)
Associations with mental health	7 (4%)
Associations with physical health	5 (5%)
Total	155 (107%)*

*Greater than 100% because some variables appear more than one time.

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a measure of spirituality or religion (McCullough et al., 2000). In addition to the 141 spiritual/religious variables, 35 variables were used as outcome measures. For example, Dudley et al. (1995) looked at the effect of patients' illness on their religious beliefs and practices. Talbot (1996) investigated the effect that the death of a child had on mothers' changing their religious affiliations. In other medical fields, spirituality and religion have not been used as outcome measures. Studies of this nature in the palliative care field suggest that researchers in this field are looking at spirituality or religion as an important variable. The fact that the percent of total spiritual or religious variables is higher (6.3% vs. 1–3.5%) than the other medical fields and that spirituality and religion are used as outcome measures may be the result of a greater awareness of the importance of spirituality in the hospice and palliative care field. The precepts of good palliative care include attention to all dimensions of patient care: physical, emotional, social, and spiritual. The long involvement of clergy and religious volunteers in hospice may have sensitized researchers to the importance of spiritual variables as important factors and outcomes in their own right.

Of the 70 articles included in this study, only 5 (7%) had hypothesis related to spirituality or religion. This is indicative of spirituality and religion not having central themes in the studies; the majority of studies used spiritual or religious variables in studies exploring broader issues such as pain management, quality of life, or general palliative care.

Researchers in palliative care most frequently assessed spirituality and religiousness in terms of spiritual well-being, meaning, or transcendence (32%) followed by religious affiliation (29%) and spiritual/religious services provided (chaplains visits, meditation, formal church/temple services; 19%). Researchers in other fields have typically measured spirituality and religiousness in terms of religious affiliation. Religious affiliation, while an important variable, does not adequately describe the spiritual/religious characteristics of the study population. As has been shown by others, (Larson et al., 1997) more thorough assessment of religiousness should at least examine the importance of religion in a person's life. In palliative care, researchers assessed spirituality using more informative variables such as spiritual well-being, meaning, and transcendence. Thirty-two of the 141 variables were on spiritual well-being, meaning, and transcendence, more than any other category (see Table 1). In addition, spiritual well-being, meaning, transcendence, suffering, and hope variables were more likely to be discussed in relation to a study question such as quality of life or pain and were more likely to be used as an outcome measure than religious variables. This may be because of the importance of quality-of-life studies in palliative care research. Patients' quality of life is valued as an important clinical indicator. Transcendence and meaning variables are found in the larger quality of life measures. However, with regards to religiousness, the predominant variable was religious affiliation, not importance of religion in a person's life. Twenty-nine of the studies used religious affiliation whereas seven used importance of (Table 1). Thus, in palliative care research, while spirituality may be recognized as important and measured in more functional terms (well-being, transcendence), religiousness is measured in only the most superficial way, (i.e., denomination). In this regard, palliative care medicine is similar to other areas of medicine, which also measure religion in a unidimensional way. This may reflect an opinion that spirituality is more relevant to the clinical care of dying patients than religiousness or that it is simply what researchers are measuring more often.

While researchers in the field of palliative care appear to have studied spiritual/religious variables more than other areas of medicine, the total percent of studies addressing spirituality or religion is still a low 6.3%. Compared to other variables such as race, economic status, or severity of illness, spirituality or religiousness are not measured as frequently. In a recent study, Steinhauser et al. (2000) investigated what physicians, nurses, social workers, chaplains, and patients defined as a good death. Control of pain and attention to spiritual issues ranked first with patients, nurses, social workers, and chaplains while physicians ranked spiritual issues as third. That the majority of other healthcare providers and patients rate spiritual issues as a top concern indicates that it is an important clinical variable. In recent years medical schools have started teaching courses on spirituality and medicine (Puchalski & Larson, 1998). Therefore, more physicians are addressing spiritual issues with their dying patients. Physicians in the future may appreciate the importance of spirituality and begin to do scholarly research in the area. However, good research on spirituality in palliative care will also be needed to enhance the existing courses.

This review is encouraging because it demonstrates that, in the field of palliative care, spiritual and religious variables are being measured with a significantly higher frequency than in other medical fields. We would recommend that in future studies:

1. More precise and comprehensive measures of religiousness be used that describe the full dimension of the person's religious life (i.e., denomination, service attendance, community aspects, importance of religion). Furthermore, we would suggest that studies correlate those dimensions with health variables and outcomes (e.g., pain, coping with death anxiety, acceptance of death, etc.).
2. Spirituality to be measured using items that score for spiritual dimensions such as meaning, transcendence, hope, and spiritual well-being and that these measures be correlated with health variables and outcomes.
3. Spirituality and religion need to be viewed as a separate category from psychosocial and cultural variables. However, correlations between spirituality or religion and such variables can be studied.
4. Studies address the role of spirituality and religion in palliative care using well-developed hypotheses on how spirituality or religion might affect quality of life, pain control, coping with grief, and other palliative care issues.

Many scholars now argue that spiritual care is thought to be important in end-of-life care. In fact, medical schools are teaching courses on spirituality and medicine. The fact that organizations that provide regulation or governing principles for hospice outline requirements for spiritual care reflects the field's recognition of the importance of spiritual care. Yet few standards are available to determine what spiritual care is and what the criteria should be for evaluating and delivering of good spiritual care. To move the field of palliative medicine forward so appropriate guidelines for spiritual care can be developed, it is critical that good research be conducted upon which to base spiritual care in an evidence-based model. It will be only then that palliative medicine will be truly holistic, providing evidence-based care in all dimensions of the patient: biological, psychological, social, and spiritual.

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