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EDITORIAL

Directions in research on spiritual and religious issues for improving palliative care

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Spiritual and religious issues are often important to people with serious illnesses. Spiritual beliefs and religious ceremonies may help patients near the end of life find meaning and comfort. Comprehensive palliative care ought to address patients' spiritual and religious needs and concerns as well as their physical distress. Puchalski et al. (2003) document the paucity of studies that collect empirical data on spiritual and religious issues in palliative care. They argue convincingly that more studies are essential in order to develop evidence-based standards for appropriate ways to address patients' spiritual and religious needs at the end of life. Such research would help us better understand how spiritual and religious concerns, beliefs, practices, and interventions might impact outcomes of end-of-life care. For instance, routine inquiry by physicians about patients' spiritual and religious concerns might lead to such outcomes as better relief of physical symptoms or improved quality of life. Puchalski et al. (2003) call for more empirical research on these important topics and also the development of better measures. For example, they point out the need for measurements of religiousness that account for more than a patient's denomination. They also found that very few of the available scales had undergone evaluation for internal consistency or test–retest reliability. Moreover, many existing instruments concerning spirituality are not validated for patients near the end of life.

A number of researchers are developing such measures and validating them with these patients. Joan Teno and her team are working on "TIME: Toolkit of Instruments to Measure End-of-Life Care." They treat spirituality as a separate domain and have compiled a list of quality of life instruments that address spirituality (Teno, 2001). They are developing an instrument that will measure spirituality in end-of-life care. Randall Curtis and colleagues measure quality of death and dying with an instrument directed at the relatives of patients (Curtis et al., 2001, Patrick et al., 2001). This instrument has a number of questions addressing meaning and purpose, as well as overt religious activity, such as meetings with spiritual advisors or participation in ceremonies. Steinhauser et al. (in press) measure a patient's feelings about meaning in life and peacefulness in approaching death. All of these instruments are well designed and are being carefully studied to assure internal and external validity. When possible, future research on end-of-life spiritual and religious concerns should take advantage of these instruments.

Puchalski et al. (2003) offer four reasonable and timely recommendations for improving empirical research on spiritual and religious issues at the end of life. In addition, several other types of empirical research would be desirable.

First, we need to understand in more detail patients' perspectives and preferences regarding religious and spiritual aspects of palliative care. This will require skilled qualitative, in-depth studies in addition to the quantitative, closed-ended studies that Puchalski and Larson (1998) urge. Studies have found that as many as 77% of patients would like their physicians to discuss religion with them (King & Bushwick, 1994). On the other hand, this means that almost one in four patients does not prefer that physicians discuss religion or spiritual-

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ity. Ehman et al. (1999) found that 7% of respondents "strongly disagreed" that "They would like their physicians to ask whether they have spiritual or religious beliefs that would influence their decisions if they become gravely ill." We need a better understanding of what patients near the end of life might find problematic about physicians raising spiritual or religious issues. Some have argued that patients may be concerned about their privacy, the appropriate boundaries of the doctor–patient relationship, or about their dependence on physicians. It would be important to gather careful empirical data regarding patients' perspectives on this important topic.

Second, empirical studies need to take into account the possibility that patients and physicians may belong to different faith traditions. Studies have shown that physicians tend to be less religious and to belong to different faith traditions than patients (Koenig et al., 1991; Maugans & Wadland, 1991; Oyama & Koenig, 1998). For example, a study done at Duke University in North Carolina found that while 38% of patients were Baptist, only 2% of physicians were (Oyama & Koenig, 1998). While 1% of patients were Catholic, 26% of physicians were. Another study found that 13% of patients surveyed "thought that a physician should not inquire [about spiritual or religious beliefs] if the physician might not agree with their beliefs" (Ehman et al., 1999). It would be useful to conduct a qualitative study asking patients whether they would want to be asked about spiritual and religious issues by a physician belonging to a different faith tradition and what their concerns might be about such discussions.

Third, researchers should analyze actual conversations of discussions between physicians and seriously ill patients regarding spiritual and religious concerns and needs. Even well-intentioned physicians may feel uncomfortable or unprepared for such interactions. A survey of physicians in 1999 found that one of the most frequently cited barriers to discussions of spiritual issues was lack of training (Ellis et al., 1999). Medical schools have increasingly been including religion in their curricula (Puchalski & Larson, 1998), and recommendations for carrying out such discussions have been presented (Lo et al., 2002). Empirical studies of actual discussions could point out problems in such discussions and suggest specific ways in which physicians could improve them. Precedents exist concerning other physician-patient discussions near end of life. In other aspects of palliative care, analyses of conversations between doctors and patients regarding DNR orders and advance directives have led to specific suggestions for improving such discussions (Tulsky et al., 1995; Fischer et al., 1998; Roter et al., 2000). Similar studies might help raise the quality of discussions of religious or spiritual issues with patients.

Aside from empirical research, difficult policy issues regarding the spiritual and religious aspects of palliative care need to be addressed. Standards of care for spiritual and religious concerns and needs must respect patient autonomy and privacy and the appropriate boundaries of the doctor–patient relationship, as well as be consistent with empirical information on effectiveness of interventions. Spiritual and religious beliefs are matters of personal belief and conscience, not scientific proof. Beliefs and practices that are followed by one person may be rejected by another. Practices and beliefs in a faith tradition may be accepted by believers, independent of any empirical evidence of effectiveness. Conversely, some practices, even if proven effective, may be inappropriate for the physician role. For example, even if prayer were proven efficacious in palliative care, physicians should not prescribe it as they do prescription medications. As Sloan et al. (2000) note, we would consider it unacceptable for a physician to advise an unmarried patient to marry because the data show that marriage is associated with lower mortality.

The United States has a diversity of spiritual and religious beliefs and is committed to religious freedom and respect for the beliefs of others. Physicians are trained in clinical medicine. Few doctors have completed chaplaincy training or other formal religious training. Their expertise as physicians merits a respect distinct from that which is granted by patients to their religious leaders.

Thus, the practicing physician wanting to take an active role in the spiritual and religious care of patients with serious illness should be responsive to several potential problems. As noted, physicians and patients may have different beliefs. Because sick patients are dependent on physicians, they may find it difficult to decline physicians' invitations to discuss spiritual and religious issues or to carry out religious practices such as prayer. Chaplaincy training stresses a nondenominational, patient-centered approach to counseling on spiritual and religious issues. However, some physicians may reject these approaches because their personal religious beliefs include active attempts to convert others to their faith (Elder, 1999). Such attempts by physicians to persuade patients to change their religious beliefs are deeply troubling. Patients usually do not consider a physician's or nurse's religious beliefs in choosing where to seek care, and patients admitted to a hospital may not have a choice of physicians, but be assigned to the hospitalist on call.

Respect for minority beliefs is another important consideration. Most studies promoting physician–patient religious involvement focus on the majority of patients who desire religious discussions with their medical care providers. However, a sizable minority of patients do not want to discuss spiritual and religious issues with their physicians. Existing studies may even underestimate this percentage because they have not explicitly asked patients about discussions with physicians who belong to a different faith tradition. The challenge is to design guidelines for spiritual and religious care that respect minority views and do not subject patients to pressure to accept offered interventions.

Guidelines for caring for spiritual and religious concerns at the end of life must be carefully developed. Discussions that provide comfort to patients and families need to be encouraged. The article of Puchalski et al. (2003) suggests how sound empirical studies can contribute to the development of appropriate guidelines. As researchers and physicians proceed, however, they should be mindful of the religious diversity of the United States and approach this arena with sensitivity and respect.

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