



# Spirituality and End-of-Life Care

by Scott E. Shannon, MD and Paul Tatum, MD

Patients in the United States consider religion and spirituality to be important in their lives and a part of how they deal with their medical experiences.



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## Abstract

As dying patients adjust to the irreversible nature of their illness, their needs and focus of care changes. Spiritual issues may become a central concern for them, and addressing these issues can be key to relieving suffering. Physicians, unfortunately, have little training in this area and are often uncomfortable discussing spirituality. In this article, we address the role of spirituality in end-of-life care, and discuss a format for spiritual assessment. We hope this will encourage more comprehensive patient-centered, end-of-life care.

## Background

Prior to the modern medical era, spiritual issues were central to care of the dying. During the Fourth Century AD, hospices founded by religious orders for pilgrims and travelers became centers to care for the sick. The core values of these hospices are often attributed to the Gospel of Matthew, Chapter 25: “I was hungry and you gave me food, I was thirsty and you gave me drink. I was a stranger and you welcomed me.... I was sick and you visited me.” And, “As you did it to one of the least of these my brethren, you did it to me.”

With the rise of modern medicine, focus shifted from treating symptoms to cure, and secularization separated the care of spiritual issues from medical care.

In reaction to the suffering of the dying that was perceived from the de-emphasis on symptom care, the modern hospice movement arose. A key aspect in the early modern hospices was the spiritual care of the dying. At St. Christopher’s, the landmark hospice founded in South London by Cicely Saunders, the “religious foundation” of the hospice is still emphasized in its Aim and Basis Statement.

The very purpose of palliative medicine is to ease suffering. Easing suffering means more than easing the physical pain of disease. Palliation of the dying is easing of what Cicely Saunders called “Total Pain,” – the combination of physical, psychological, social, and spiritual pain. Thanks to the hospice movement, attending to a patient’s spirituality has become increasingly recognized as a component of good, holistic, end-of-life care.

## Spirituality Defined

Both caregivers and the medical literature differ on how to define spirituality. Much of the difficulty

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stems from trying to define spirituality in non-religious terms in order to be all-inclusive. Spirituality and religiosity have long been viewed as distinct concepts even within religious circles; spirituality has historically been defined in religious terms that involve an immaterial component of human nature and its relationship to a deity. In efforts to be more broadly inclusive, most discussion of spirituality in the medical literature has viewed spirituality simply as one's search for meaning. This definition may not be fully true to the origin of the word and its past use. It has been, however, a pragmatic definition for medicine in that it captures much of the practical essence of traditional spirituality while not excluding the non-religious or philosophical naturalist.

In their comprehensive work, *Religion and Health*, Koenig, McCullough and Larson have proposed a more nuanced definition of spirituality as distinct from religion, yet acknowledging its common relationship to spirituality. They define spirituality as "the personal quest for understanding answers to ultimate questions about life, about meaning, and about relationship to the sacred or transcendent which may (or may not) lead to or arise from the development

of religious rituals and the formation of community."<sup>1</sup>

In concert with the medical literature, this paper will use the simple definition of spirituality as "one's personal search for meaning," recognizing as suggested by Koenig, McCullough and Larson that this commonly occurs within a religious context.

### Importance of Spirituality in Medical and End-of-Life Care

There is a rapidly growing body of medical literature relating to religion, spirituality and medicine. The International Center for the Integration of Health and Spirituality (ICIHS) formerly National Institute for Healthcare Research (NIHR) reports that the medical literature doubled in size between 1991 and 2001.<sup>2</sup>

One clear message from that body of literature is that patients in the United States consider religion and spirituality to be important in their lives and a part of how they deal with their medical experiences. Examples can be drawn from a wide array of medical disciplines. In a 1994 study of family practice inpatients in North Carolina and Pennsylvania, 94 percent agreed that spiritual health was as important as physical health.<sup>3</sup> In 1997, a study of gynecological cancer patients stated that 91 percent reported religion

helped sustain their hopes with 49 percent becoming more religious following their diagnosis.<sup>4</sup> In a 1999 survey of pulmonary clinic patients, 45 percent felt that their religious beliefs would influence their medical decisions when gravely ill, and of that group nearly all felt that the physician should ask about their beliefs.<sup>5</sup>

In a national survey of dying veterans, their family or friends, along with physicians and supporting health care workers, patients appeared to value spiritual concerns more highly than physicians.<sup>6</sup> The patients specifically ranked "coming to peace with God" as second only to pain control in importance at the end of life. This was significantly different than the ranking given by physicians ( $p < 0.001$ ). Based on these and many other research findings, physicians seeking to practice patient-centered care would do well to pay attention to this spiritual component of their patients' experiences, especially in end-of-life care.

Another clear message from the literature is that religion and spirituality commonly provide mechanisms for coping with medical illness. In their systematic review, Koenig et al report on at least 60 studies detailing that religion is used to cope with a variety of illnesses. They state that "in certain parts of the United States, between one-third



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**Physicians should ask this question  
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and one-half of patients report that religion is the most important strategy used to cope with the stress of medical illness and health problems.”<sup>1</sup>

One of the groups for which these religious beliefs and practices are particularly important is the elderly. It has also been noted that the amount of religious coping appears to increase as the severity of illness or distress increases. A patient-centered approach to medical care would suggest that these coping mechanisms warrant physician attention and respectful consideration regardless of their medical effects. As more and more studies reveal a beneficial health effect associated with religiosity and spirituality,<sup>7</sup> many physicians feel justified in encouraging patients’ spiritual coping strategies if care is taken not to impose or prescribe their own beliefs.<sup>8,9</sup>

Despite the overwhelmingly positive assessment of spirituality and religion on health in general, the response to spiritual issues may vary for individuals including negative effects for some. Many studies have shown that more frequent church attendance (even when controlled for other confounding effects) is predictive of lower mortality; there is now also evidence that religious struggle during illness (feeling deserted by one’s church or believing that God is punishing, abandoning,

not loving them or powerless to help) is predictive of higher mortality.<sup>10</sup> For this reason, Dr. Koenig suggests the following question as part of a spiritual history: “Do your religious or spiritual beliefs provide comfort and support or do they cause stress?”<sup>11</sup>

For end-of-life care in particular, the belief in an afterlife may serve as a source of peace to some patients; whereas to others, the belief in a final judgment where one may face “hellfire and brimstone” can be a source of angst. Some may view death as a finality, and struggle with a sense of personal meaning, while other patients may view death as a step in the process of rebirth or reincarnation. A review of studies of the relationship between religious involvement and death anxiety show that on the whole, the more religiously active have lower levels of death anxiety, but the relationship is complex and poorly understood.<sup>1</sup> The important issue is that each individual may react to his or her beliefs in a unique way, and the physician must address each case individually.

In clinical practice, these spiritual issues may surface in a number of different ways. Pain symptoms that do not respond to appropriate therapy may suggest a co-existing spiritual crisis. Depression symptoms suddenly occurring for the first time in a patient may be related to spiritual

issues rather than a chemical imbalance. Sudden refusal of medication or care may also be related to unresolved spiritual issues. An awareness of this possibility and the willingness to address such issues will prepare a physician to provide better patient care.

### **Spiritual Assessment**

It is paramount that physicians develop a method of spiritual assessment in end-of-life care where questions about ultimate meaning and individual hopes most often affect a patient’s approach to care. A spiritual history goes far beyond the hospital intake question about religious affiliation. It is also more than what is usually covered in psychosocial histories. The purpose of the spiritual history is to help identify how a person pursues meaning in his/her life and what underlying hopes he/she has for life. As hope for a cure is relinquished near the end of life, a patient may turn to other equally important hopes. These might include achieving a sense of completion in relationships with family, friends or community; achieving a sense of meaning about life in general; or “coming to peace with God” as reported in the VA study.

Without some understanding of these different hopes and meaningful



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pursuits at the end-of life, it is almost impossible to provide patient-centered care. Not having this information requires a physician to make many value assumptions about their patient's life. These can lead to serious misunderstandings in the doctor-patient relationship.

The spiritual assessment may be done by a nurse, social worker, chaplain or physician. In fact, it may often be done by all members of the health care team, and at repeated intervals. Some initial spiritual assessment should be done at the time of diagnosis of terminal illness or transition into palliative care, but it is also important to reevaluate as health status changes.

There are a number of tools available that can assist a caregiver in making a spiritual assessment.<sup>9,12,13</sup> The acronym, FICA, is a popular tool that takes 2-5 minutes to administer (Table 1).<sup>13</sup> A non-judgmental opening question like "Do you consider yourself spiritual or religious?" shows that the physician does not have an agenda. Religious patients may respond with a number of issues that they might not have otherwise discussed. For patients who consider themselves neither religious nor spiritual, this gives the opportunity to then ask if there are some other aspects of life that are particularly meaningful to them or

for which they entertain some future hopes. Though it may not be understood as spirituality, many people do have open or secretly meaningful aspects to their lives that they hope their illness will not overly interfere with, or at least that medical care will be sensitive to.

In order to accomplish any spiritual assessment well, one needs to maintain a respect for any patient's beliefs. Since many answers to questions about meaning and ultimate hopes in life are related to people's religious expressions, a physician or other caregiver should be comfortable listening to such a discussion. This should be the case regardless of the difference between a physician's and patient's beliefs.

The process of maintaining respect for another's beliefs is facilitated by a physician's awareness of his/her own spiritual beliefs or biases. Cultivating an attitude of "spiritual humility" regardless of how "enlightened, good, right or wrong" one believes their own or another's beliefs are also helps maintain this respect. A patient who feels safe from receiving physician judgment is more likely to share their deepest hopes. This provides caregivers the best opportunity to tailor their care in a patient-centered manner and to avoid tensions that may result from unrealized or differing goals.

## The Difficulty Discussing Spirituality

Despite patients' desire to discuss spirituality with their physicians, many physicians feel uncomfortable discussing patients spiritual concerns, and often may avoid such conversation.<sup>14</sup> In a study of Missouri physicians, doctors acknowledge the importance of spiritual issues, but seldom engaged patients in conversations about such issues.<sup>15</sup> Nationwide, less than 10 percent of physicians routinely take a spiritual history.<sup>16</sup>

In the Missouri study, barriers to spiritual discussions included lack of time, inadequate training for taking spiritual histories, and difficulty in identifying patients who want to discuss spiritual issues.<sup>15</sup> Some physicians have cited ethical concerns about integrating spiritual discussions into practice and fear of being accused of evangelizing by discussing spiritual issues. Patient factors that may prevent a discussion of spirituality include: the patient's perception of lack of time of the doctor, lack of continuity or established relationship with the physician, and the patient's fear that it is improper to discuss spirituality with the physician.<sup>15</sup>

Despite the difficulties in having a discussion about spirituality, physicians may facilitate these discussions in a number of ways. Expressing interest over time in the



Table 1

## FICA- A Two-Minute Spiritual History

### FAITH

*What is your faith or belief?*

*Do you consider yourself spiritual or religious?*

*What things do you believe in that give meaning to your life?*

### IMPORTANCE or INFLUENCE

*Is your faith important in your life?*

*How do your beliefs affect or influence your behavior or health?*

### COMMUNITY

*Are you part of a religious or spiritual community?*

*How is it important?*

*Who do you love or who is important to you?*

### ADDRESS

*How would you like me to address these issues in your care?*

*From Puchalski C. A spiritual history. Supportive Voice. Summer 1999;5(3):12-13*

person's life may help develop rapport. Reinforcing the importance of spiritual coping mechanisms shows that it is safe to discuss these issues with the physician. A home visit or hospital bedside visit may be a particularly useful time to discuss spiritual themes.<sup>8</sup> Approaching these conversations in a sensitive manner as one would any other personal issue in the medical interview should alleviate most of the possible difficulties or pitfalls.

### Intervention

Once a spiritual issue is identified, the physician may act in a number of ways. In some cases, the physician may effectively intervene simply by listening, conversing and caring. For more formal or extended interventions, a pastoral care referral may be important. The authors of the study that noted a higher mortality in patients undergoing

religious struggle,<sup>10</sup> speculate that physicians may have a salutary effect by referring people with such struggles to the services of chaplains. When such patients refuse a chaplain's involvement, it may be possible for physicians to contribute to their healing simply by listening to such struggles without necessarily trying to fix them.<sup>17</sup> In the case of the imminently dying where there may not be time for a pastoral care consult, the physician can still play an important role merely by listening to spiritual concerns.

A physician can also enlist resources that are identified in the spiritual history. To many, a local church community is an important resource. Involving the local community in visitations, provision of communion, or other ritual may be important. Care should be taken to honor the patient's needs. For example, in the case of a lifelong

agnostic who identifies herself as a naturalist, providing a hospice room with a view to a garden may be an effective intervention.

Prayer with patients, though controversial, is an area that is clearly welcomed by some patients. In a family practice inpatient study,<sup>3</sup> 48 percent of patients responded that they would like their physicians to pray with them; 28 percent were disagreeable with the praying together. Because of these varying desires, even most enthusiasts for incorporating spirituality with medicine generally agree that physicians should not prescribe prayer for patients, as that may be coercive.

Koenig suggests that physicians may pray with patients when the following conditions are met: a spiritual history has been taken; the patient is



religious; the patient requests prayer; the physician's religious background is similar to patients; and the situation calls for prayer.<sup>9,18</sup> An individual approach is necessary not only depending on patient's desires, but on physician's comfort as well. Some physicians may be uncomfortable or reluctant to participate, and their position should be carefully respected as well.

Finally, a physician can play an important interventional role by tailoring their care to facilitate a patient's effort to accomplish some of their final meaningful tasks. As stated previously these might include achieving a sense of completion in relationships with family, friends or community; achieving a sense of meaning about life in general; or "coming to peace with God." Ira Byock, in a paper on the nature of suffering in the context of dying well, discusses these and other potential developmental landmarks and tasks for the end of life.<sup>19</sup> If no such hopes have been identified - because a patient is still focused on cure - a physician might also play an important role by helping a patient turn from an unrealistic hope for ultimate cure and towards setting hopes on some of these potentially meaningful tasks at the end of life.

## Conclusion

Spirituality and spiritual suffering are of great importance in end-of-life care. The specter of one's mortality almost universally causes one to raise questions and concerns about the

significance and meaning of one's life. In our culture, where the reality of death has commonly been avoided, removed or sanitized from our regular flow of life, questions about meaning and a transcendent power in the face of death are apt to come with particular force as they may not have been considered previously. While the physician may not be able to adequately resolve all these issues, proper identification of spiritual issues, respectful listening and appropriate referral is essential to good care at the end of life.

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