Spiritual Care at the End of Life:
What Is It and Who Does It?

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The inclusion of "spirituality" in medical practice and research has become increasingly commonplace in recent years. Although clarity as to exactly what is meant by this term continues to be elusive, acceptance of its significance in the care of patients has increased as we continue to gain a better understanding of its role and develop related standards of practice. End-of-life care has incorporated some consideration of spiritual care since the advent of the modern hospice movement within the vision of Dame Cicely Saunders in England approximately 40 years ago.[1] Her vision of a community of caring that would attend to the spiritual needs of dying patients, along with addressing their pain management and other medical needs in a more humane fashion, was the foundation for the modern hospice movement. Although much of current end-of-life care has evolved from the challenge extended by Saunders regarding appropriate care of the dying, her commitment to meeting the spiritual needs of dying patients continues to be a challenge for healthcare providers.

These challenges grow out of a number of exacerbating factors concerning the diverse understandings of spirituality in a culturally pluralistic society, as well as the complexities of contemporary healthcare delivery systems. While recent evidence[2] indicates that both patients and their families consider spiritual care to be important in end-of-life care, the understanding of what this means varies considerably. The breadth of expectations expressed by this desire for spiritual care is expansive. It can include the spectrum from some sense of an emotionally sensitive care of the "human spirit" to a highly ritualized religious care incorporating very specific rites for the dying and a multitude of possibilities in between. Even those healthcare providers most sensitive to the inclusion of spiritual care at the end of life may be daunted by the thought of engaging such a fluid and somewhat nebulous expression of need.

Dr. Hanson's description of palliative care and its significance as a practice of medicine in the lead article of this issue[3] lays the groundwork for our considering the role of spiritual care at the end of life. Two primary aspects of palliative care are (1) an understanding of the virtue of caring (in contradistinction to curing) as a practice of medicine and (2) an appreciation of the art of listening well in the care of patients. Both of these resonate with the provision of spiritual care to the dying, and their central roles in palliative care speak to the potential for palliative medicine to remind all of us of the importance of listening and caring as essential aspects of practice throughout all of medicine, not just with the dying. The resolution of who can best provide intentional listening, as well as interpret the stories and struggle faced by those considering their mortality while reviewing their lives for a sense of purpose and closure, is not the same for every person. Those who render such care must examine themselves regarding their capacities and willingness to engage the rich and textured complexities of those for whom there are no illusions of cure, but who none the less need their undivided attention at the junction of life and death. The development of the skills and capacity to do such work has not been a standard part of medical education in the past and we, as well as our patients, have suffered for this inadequacy. Arthur Frank comments in *The Wounded Storyteller* that, "One of our most difficult duties as human beings is to listen to the voices of those who suffer."[4] I fear that we do not adequately equip ourselves as physicians and other healthcare providers to fulfill this "duty" and all that it entails.

Voices of suffering—especially the voices of those who know they are dying and their families—become poignantly focused. Along with asking challenging questions regarding prognosis and other "medical" inquiries, they become seekers and purveyors of "spiritual" understanding and wisdom. The language used for such communication will frequently be very specific to a particular cultural or religious tradition. While considerable strides are being made in improving communication skills for physicians in the care of the dying, lack of familiarity with such tradition—specific language and metaphors through which a dying person expresses her "soul"—can limit the capacity of the physician or other provider to listen well. This lack of familiarity is not a fault in the provider, but acknowledgement of this lack and seeking the assistance of someone more versed in the tradition of the dying patient can be crucial for providing

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meaningful spiritual care. Awareness of one's lack of familiarity with the religious or cultural tradition and language of a patient may not be readily evident, and patients may be hesitant to point out such gaps of understanding. Only through our attentiveness to the patient's story and the humility to discern our own inadequacies will we best serve the communication needs central to providing optimal spiritual care for dying patients.

The best spiritual care for the dying patient is most likely to be delivered in the same way other types of care are best provided, through partnerships within the team of persons caring for the patient. Although much of medicine is best practiced within a context of teamwork, palliative care particularly denotes a team approach,[5] and vital to a palliative care team is the clergy member of the team or the chaplain. While many physicians, nurses, and social workers have substantial gifts to offer to the spiritual care of patients, the role of a clergy member on the team to give leadership in providing spiritual care cannot be overstated. The other providers on the team may have a greater appreciation of the particular faith tradition of a patient and may serve as the more trusted spiritual confidant and care provider, but the clergy member of the team brings an interpretive, liturgical, and communal sense of spiritual care from her or his pastoral formation unique to that vocational formation. The optimally-trained and wise chaplain provides pastoral services within the entire community surrounding the dying patient and fosters a sense of care for one another that acknowledges the interdependency of the providers, the family, and the dying person in this work of living and dying.

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We healthcare providers rarely fully attend to the role of this interdependency in forming the health of the community, which ultimately determines how we care for the suffering and dying among us. Wendell Berry provides insight into the shared communal underpinnings of spiritual and palliative care when he says, "Health is not just the sense of completeness in ourselves but also is the sense of belonging to others and to our place; it is an unconscious awareness of community, of having in common."[6] Mindfulness of our interdependence allows us to be less captive to consumerist expectations and their distortion of caring relationships, while nurturing a greater sense of gratitude within an awareness of the limitations and finitude of healthcare. Palliative care informed by spiritual attentiveness allows both the patient and the provider to give up illusions of therapeutic entitlement to cure and at the same time honor the privilege of intentional and reverent caring for the dying.

Good spiritual care is not just calling the chaplain for last rites or prayer with the bereaved family near the time of death. Although these are both valued and legitimate aspects of spiritual care, they fall short of the vision for spiritual care indicated by a comprehensive strategy for palliative care. Spiritual care should inform the practice of palliative care throughout the course of treatment.

There is no substitute for time to do the work of a "good death." While the interpretation of a good death may vary by tradition and culture, most consider the opportunity for a good death to include adequate pain management and the time to make peace with one's neighbor and with God while supported emotionally by family or friends. Adequate spiritual care helps provide the context for such a death for the dying person with an attentiveness to that individual's particular needs. Spiritual care as part of a comprehensive strategy for palliative care provides the opportunity and support to narrate one's story in such a way as to provide a legacy and memory of a "good death" for the family and broader community. The spiritual legacy of such a narrative can be a gift for generations to come and reframes the inevitable experience of loss within death as a reminder of the gift of the life that has been lived.

The importance and value of well-trained clergy as partners in providing the hope of a "good death" and its legacy is evident, but the lack of availability of such persons is all too common. Recent collaborative efforts between the Pastoral Services Department at Duke University Medical Center and the Duke Institute on Care at the End of Life to train specialist chaplains in end-of-life care are an attempt to address this issue. While the equipping of more specialized chaplains for tertiary care centers is helpful, the large numbers of persons dying in smaller hospitals without staff chaplains require our consideration. If we are convinced of the value of spiritual care as a part of palliative care and believe clergy to be important in the rendering of that care, we are challenged to consider how to best address this void of spiritual care providers in smaller hospitals and communities. The Caring Communities Program of Duke Divinity School and The Duke Endowment provides one response to this need in the Pastoral Care in Community program, which offers a curriculum certifying local clergy as Pastoral Care Specialists and equipping them to serve as volunteer chaplains in local hospitals. Although most of these clergy have visited regularly in the hospitals in the past, they are now receiving education in order to more ably partner with healthcare providers as part of palliative care teams in the provision of spiritual care to suffering and dying patients.

Spiritual care is still finding its place as a practice in healthcare.

Standards of practice for spiritual care have not been developed and we are still unsure as to just who should be engaging in its practice. Spiritual care has been part of end-of-life care since the start of the modern hospice movement, but it continues to evolve in content and form in response to increasingly pluralistic societies in the United States and western Europe. Providing spiritual care with integrity to the faith tradition of the dying patient can be challenging, but such care cannot be viewed as an optional luxury within the developing discipline of palliative care. The substantive shared commitments of good spiritual care and palliative care bear witness to spiritual care being inherently constitutive of palliative medicine rightly construed. Support for intentional spiritual care as an integral part of quality end-of-life care should come from many quarters, but support and commitment to spiritual care's place in palliative care at the end of life *must* come from physicians and administrative leaders in palliative care. The health of us all depends on it. **NCMJ**

REFERENCES

1 Bradshaw, A. The Spiritual Dimension of Hospice: secularization of an ideal. Soc Sci Med, Vol 43, No. 3, 409-418.
2 Steinhauser 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, 284:2476-82.
3 Hanson, LC. Palliative Care: Innovation in Care at the End of Life. North Carolina Medical Journal 65(4) 2004.
4 Frank AW. The Wounded Storyteller: Body, Illness, and Ethics. University of Chicago Press 1995; 25.
5 Morrison RS, Meier D, Palliative Care. N Engl J Med 2004;350:2582-2590.
6 Berry W. The Art of the Commonplace: agrarian essays of Wendell Berry;144.