

The Spiritual Needs of the Dying Patient

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“... The American people want to reclaim and reassert the spiritual dimension in dying.”¹

This was the major conclusion of a recent survey of 1,200 adults, 18 years or older, conducted in the United States during May 1997 (and completed before the June 1997 Supreme Court decision on physician-assisted suicide). Spirituality has been defined as “. . . that which allows a person to experience transcendent meaning in life. This is often expressed as a relationship with God, but it can also be about nature, art, music, family, or community—whatever beliefs and values give a person a sense of meaning and purpose in life.”² So, every person, regardless of any commitment to a particular religious faith, has a real spirituality inasmuch as one experiences meaning and purpose in life. It is the real and immediate threat to this sense of meaning in the face of terminal illness that creates the spiritual distress of the dying. This article will expand on previous material presented in this series.³ It will explore the nature of suffering and its relationship to spiritual distress, identify ways that caregivers can address the spiritual distress of their patients, and examine the potential for healing in the terminally ill. The intent of this article is to help establish common ground in the midst of great diversity of faith and culture to facilitate dialogue and understanding between patient and caregiver as spiritual issues are addressed at the end of life.

An inherent conflict exists between the technique (including technology) of medicine, which is problem-focused and reductionist by nature, and the spiritual needs of the dying, which are rooted in mystery. “Death is the edge of a mystery, and turning our faces toward the problematic, through the persistent use of technology, at the hour of death keeps us from having to face mystery. Death is no problem to be solved; it resists any such formulation . . . By keeping our attention on end-of-life *problems*, we ignore the *mystery* of the end of life.”⁴ Ad-

ressing the problems of the dying without caring for the person who is dying can cause suffering.

At the heart of the spiritual distress of the dying is suffering. Eric Cassel has defined suffering as “. . . the state of severe distress associated with events that threaten the intactness of the person.”⁵ By its very nature, “suffering is experienced by persons. Suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner.”⁵ Indeed, the challenge at the end of life is to restore and maintain the integrity of the dying person in the face of a clear and ever present threat of disintegration. Suffering affects persons in all their complexity. “. . . Suffering can occur in relation to any aspect of the person, whether it is in the realm of social roles, group identification, the relation with self, body, or family, or the relation with a transpersonal, transcendent source of meaning.”⁵ Another way to express the all encompassing nature of suffering is the concept of “total pain” articulated by Dame Cicely Saunders, the founder of the modern hospice movement.⁶ The four domains of pain that in their totality constitute “total pain” or suffering are: physical pain (and other distressing physical symptoms); psychologic or emotional pain (eg, symptoms of anxiety and depression); social pain (eg, fear of separation from loved ones, broken relationships); and spiritual pain.

Many of the major spiritual concerns that Americans have about death were identified in the May 1997 Gallup survey.¹ These include: fears of not being forgiven by God (56%), not being reconciled with others (56%), dying while being cut off or removed from God or a higher power (51%), not being forgiven by someone for a past offense (49%), not having a blessing from a family member or clergy member (39%), and concerns about the nature of the experience after death (39%).

Dr Cassel has also observed that if the caregiver doesn't recognize or diagnose suffering, he cannot relieve it.⁷ Because suffering affects persons, the standard objective measures used to diagnose diseases will not be helpful. Typically, suffering involves symptoms that threaten the integrity of the patient as a person. The meaning that

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the symptoms have for the individual patient defines the nature of the suffering experienced (eg, if cancer-related pain is progressing, the fear of impending death can cause intense suffering). So, apparently simple symptoms may, in their symbolic value, epitomize the deepest existential anguish of the patient with a terminal illness. A unidimensional approach to managing the symptoms (eg, narcotic analgesics alone for the pain of cancer progression) may not relieve the total pain of such a patient. Failure to recognize and treat suffering is often a reflection of the inability of the caregiver to focus on the person rather than the disease. Simply put—to make a diagnosis of suffering, one must be looking for it. Ask, “Are you suffering?”⁷

A case example may serve to illustrate the concept of total pain. “A” was a woman in her mid 50s with advanced metastatic pancreatic cancer. Just before developing cancer, she was married quite happily for a second time after having been in an abusive relationship with her first husband. She was receiving very high doses of narcotic analgesics with very little relief for her intense abdominal and back pain. She could not understand why this was happening to her at a time when she had finally found a loving relationship. Her physical, psychologic, and spiritual distress were further aggravated by the social pain she experienced in the presence of her grieving husband, who could not bear to let her go. Total pain (suffering) affects the whole person. “. . . No man can be rendered pain free whilst he still wrestles with his faith. No man can come to terms with his God when every waking moment is taken up with pain or vomiting.”⁸

To better identify the spiritual needs of patients, Christina Puchalski has developed a tool for taking a spiritual history.² By taking a spiritual history, the caregiver endorses the importance of spirituality and gives the terminally ill patient permission to discuss spiritual issues. Dr Puchalski uses an acronym, FICA, to summarize key elements of the spiritual history. “F” represents *faith*—Do you consider yourself religious or spiritual? Do you have a faith? (If there is a negative response to these questions—What gives meaning to your life?) “I” represents *importance*—Is it important (or how important is it) in your life? “C” represents *community*—Are you part of a spiritual (or faith) community? “A” represents *address*—How can your healthcare providers address (and respect) these issues in your care?²

When addressing the spiritual needs and concerns of

terminally ill patients, there are several important principles to keep in mind. Spirituality is an important, if not essential, component of each patient’s overall well being. Spirituality is an ongoing issue; readdress it over time. Caregivers should not impose their beliefs on others. There should be consistent respect for a patient’s values, autonomy, and vulnerability. Make referrals to chaplains or spiritual directors when appropriate (with the consent and desire of the patient). Perhaps the most important principle for the caregiver is to know oneself. “. . . You can’t address a patient’s spirituality until you address your own.”²

The following case example illustrates the role of a patient’s spirituality in the relief of suffering. “C” was a woman in her early 70s who presented with a locally advanced unresectable colon cancer that had replaced the lower half of her abdominal wall with a large, stinking, fungating mass. The nursing staff had noted that she rarely required pain medications and was often found in deep, meditative prayer. When asked about how she was coping with her affliction, her response without hesitation was to quote the tenth verse of Psalm 46: “Be still, and know that I am God!”

“In my end is my beginning.”⁹ With this last sentence of the second of his *Four Quartets* (*East Coker*), TS Eliot expresses all the potential for renewal of hope and discovery of meaning that the terminally ill seek as they face death. The word *end* has two meanings that are expressed in ancient Greek with two different words directly relevant to the spiritual struggle of the dying; end as a “*state of completion or maturity*” (Greek—telos) and end as “*last*” (in time, eg, end of life) (Greek—eschatos).¹⁰ It is the discovery and experience of these two qualities of the end, balancing a full awareness of having arrived at the last stage of one’s life with a sense of the opportunity for completion and full maturation that can transform one’s end into a beginning. For example, one patient dying slowly after struggling for several years with metastatic breast cancer was able to observe that she hadn’t really begun to live until she faced her own mortality. Morrie Schwartz was the subject of a best-selling book, entitled *Tuesdays with Morrie*, about his dying from amyotrophic lateral sclerosis, and he stated this principle very succinctly, “When you learn how to die, you learn how to live.”¹¹

Real potential for healing in death exists not only for the dying person, but also for the family and loved ones who will remain, and even for the caregivers. The poten-

tial for healing begins with a redefinition of hope. Hope has been defined in the context of terminal illness as the “positive expectation for meaning attached to life events.”¹² “Hope lies in *meaning* that is attached to life, not in events themselves.” Ultimately, “. . . as long as there is meaning, there is hope.” It is a loss of meaning and a loss of hope that often underlie requests for physician-assisted suicide.

Several factors are crucial to helping dying patients as they redefine hope.¹² Patients need to know that they are dying. This understanding is critical before a successful transition from the role of being sick to that of dying can occur. Hospice can facilitate this transition by creating a new identity and point of reference for the dying patient. Hope can then be redefined in terms appropriate to the new circumstances. The clear and unambiguous commitment of caregivers to the dying patient generates hope. This commitment should include strong reassurance that the dying person will not be abandoned, pain and other distressing symptoms will be controlled, the dying person will be remembered, and reconciliation and forgiveness can occur.

One tool that has been used in hospice to help patients find meaning at the end of life is the preparation of a patient’s biography.¹³ Volunteer “biographers” first record the dying person’s autobiography on tape and then prepare a written transcript, which is bound, for the patient to pass on to loved ones. “Life review enables a person to identify what has been accomplished or created, and what will be left behind as a result . . . a sense of meaning may be captured in the recognition of the uniqueness of the individual.”¹³

Reconciliation is central to the work of the dying. It extends the healing they can experience beyond themselves to others. “Reconciliation is the most crucial thing for the dying irrespective of whether or not the person is religious or secular. Even as their bodies are disintegrating they are becoming whole.”¹⁴ Ira Byock has been quoted as describing the work of reconciliation for the dying and those they love as occurring in five steps: “Forgive me; I forgive you; Thank you; I love you; and Good-bye.”¹² A case example may help illustrate how family healing and reconciliation can occur in the midst of intense suffering. “S” was a woman in her late 50s with widely metastatic lung cancer with multiple, extremely painful cutaneous and soft tissue metastases. She had a deep religious faith and was able to say that her affliction had been a blessing by bringing her children

back to faith and confirming a religious vocation for her husband.

How can caregivers experience healing through the death of their patients? Several critical opportunities for personal growth are presented to those who witness, attempt to alleviate, and experience the suffering of the dying. Observing and really seeing the death of a terminally ill patient can break down one’s own denial of death. The grace that so many patients exhibit as they die can overcome the fear of death and sense of failure in the face of death that so many caregivers experience. Finally, and perhaps most important, is the opportunity to find and fully experience empathy—empathy for the dying patient, empathy for the family and loved ones, and empathy for the other members of the team of caregivers who have also suffered with the patient and family. But there are barriers to empathy. To have pain is “to have certainty.” The patient has this certainty; the caregiver does not. Caregivers, in developing empathy, must overcome their tendency to doubt the patient. They should listen to their patient’s complaints of pain (their suffering) “not to explain but to understand, not to diagnose but to witness and help.”¹⁵ Sometimes patients are not particularly likeable, indeed they may be abusive and threatening to the caregiver. Finding a common history or shared experience can serve as a bridge in developing a relationship of caring for the “difficult” patient.¹⁶

Jerome, the late 4th-century scholar and translator of the Scriptures into Latin, may have best described the common bond in our humanity that draws forth empathy in the face of suffering. “He whom we look down upon, whom we cannot bear to see, the very sight of whom causes us to vomit, is the same as we, formed with us from the selfsame clay, compacted of the same elements. Wherever he suffers we also can suffer.”¹⁷ Empathy can and should be the end and the beginning for all those who care for the dying.

APPENDIX

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Invited Commentary

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“The earliest healers were usually the ‘priests’ of their societies—not by chance, but because of a communal recognition that matters of health, disease, and healing were intertwined with concepts of life, death, and afterlife.”¹

In his thoughtful manuscript, Dr Hinshaw urges us to remember that the human experience incorporates multiple domains: the physical, psychological, social, and spiritual. Suffering or pain surface when any of these dimensions are disturbed. As the end of life approaches, the spiritual needs of our patients become increasingly intense. “Modern” medicine too often diminishes or fails to recognize the importance of spiritual needs as distinct from other dimensions. So the source of the suffering might remain obscure, and appropriate management might not be initiated. The pain might persist.

Our culture of surgical education produces efficient problem solvers with emphasis on the physical needs of patients. Surgeons justifiably take pride in their diagnostic and technical skills. When surgical expertise is not sufficient to resolve the medical problem, surgeons might promptly shift the care of their patients to physicians in other disciplines. An opportunity to address the spiritual needs of a patient, especially a patient who has come face-to-face with his own mortality, might be missed.

Undergoing a major operation most often generates a special, although usually unspoken, bond between surgeon and patient. Inherent in that bond are a trust in the surgeon's skills, a focus of the patient's hopes for the future, and the expectation that the surgeon would be a confidant and a source of advice and emotional support. So the surgeon is positioned well to assume a supportive role, especially when caring for a dying patient, that includes more than addressing the patient's physical ills.

The role of the surgeon in caring for spiritual con-