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Spirituality and End-of-Life Care: A Time for Listening and Caring

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INTRODUCTION

DYING IS A NORMAL PART of life. In today's society, however, dying is still treated as an illness. All too often people die in hospitals or nursing homes, alone and burdened with unnecessary treatment; the same treatment they would have refused if they had the chance to talk about their choices with their physicians long before the deathbed scene. Dying people are not listened to—their wishes, their dreams, their fears go unheeded. They want to share those with us.

At the turn of the century, Americans' life expectancy was 50 years. Now 73% of deaths are among people at least 65 years old, and 24% of deaths are among those at least 85 years old according to an end-of-life committee of the Institute of Medicine.[1] The causes of death in 1900 were influenza, tuberculosis, diphtheria, heart disease, cancer, and stroke. Today, heart disease is the number one cause of death followed by cancer and stroke. Modern medicine has granted more people an old age but it also slows the process of dying. The end of life can last several years.

As baby boomers and their parents age, problems in end-of-life care are increasingly documented from inadequately treated pain to unwanted or futile therapies. The Institute of Medicine committee reported on a study that showed that 40% of family members of people who died reported their loved ones being in severe pain. 10%–50% of various patient populations receive care that violates their preferences, often in the form of costly emergency department visits or intensive care unit (ICU) stays.[1]

People often die alone and in pain in hospitals or ICUs. However, 90% of people surveyed said they would prefer to be cared for at home if they were terminally ill with 6 months or less to live. In the early 1900s most people died at home. But in 1992, 57% of deaths were in hospitals and 37% of deaths were in nursing homes and other residencies. Hospices have provided excellent care, but hospice referrals have not been the perfect solution. To receive Medicare benefits a patient must be expected to die within 6 months, and the patient must forego curative therapies. Patients and insurance companies want physicians to make prognosis about time of death. Patients often want the physicians to tell them when they will die, and often, the physicians also want the prognostic certainty before giving up on therapies. Yet, numerous studies have shown that such estimates are often wrong.[1]

How can we meet the patients' needs, so that they can die at home and avoid treatments that violate their preferences? How can we, as health care providers and as a society, guarantee people a peaceful, meaningful death? There are no easy answers, but it is clear that spirituality is a very important part of the solution.

SPIRITUALITY: MEANING AND COPING

Dying should be as natural an experience as birth. It should be a meaningful experience for dying persons, a time when they find meaning in their suffering and have various dimensions of their experience addressed by their caregiver. These dimensions are:

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- The physical (pain and symptom control);
- The psychological (anxiety and depression);
- The social (feeling of isolation from friends and family, feeling too fatigued to engage in social activities); and
- The spiritual.

It is our responsibility to listen to people as they struggle with their dying. We need to be willing to listen to their anxieties, their fears, their unresolved conflicts, their hopes, and their despairs. If people are stuck in despair, they will suffer deeply. It is through their spirituality that people become liberated from despair. As people are faced with serious illness or the prospect of dying, questions often arise:

- Why did this happen to me?
- What will happen to me after I die?
- Why would God allow me to suffer this way?
- Will I be remembered?
- Will I be missed?

Victor Frankl wrote that "man is not destroyed by suffering; he is destroyed by suffering without meaning."[2] Spirituality helps give meaning to people's suffering. Rabbi Cohen wrote:

> When my mother died, I inherited her needlepoint tapestries. When I was a little boy, I used to sit at her feet as she worked on them. Have you ever seen needlepoint from underneath? All I could see was chaos; strands of thread all over with no seeming purpose. As I grew, I was able to see her work from above. I came to appreciate the patterns, the need for the dark threads as well as the light and gaily colored ones. Life is like that. From our human perspective, we cannot see the whole picture, but we should not despair or feel that there is no purpose. There is meaning and purpose even for the dark threads, but we cannot see that right away.[3]

Spirituality helps people find hope in the midst of despair. We as care givers need to engage with our patients on the same spiritual level.[4]

That spirituality is central to the dying person is well recognized by many experts, the most important of whom are our patients. A recent survey by George Gallup[5] showed that people overwhelmingly want to reclaim and reassert the spiritual dimensions in dying. In the study, survey respondents said they wanted warm relationships with their providers, to be listened to, to have someone to share their fears and concerns with, to have someone with them when they are dying, to be able to pray and have others pray for them, and to have a chance to say goodbye to loved ones. When asked what would worry them, they said not being forgiven by God or by others, or having continued emotional and spiritual suffering. When asked about what would bring them comfort, they said they wanted to believe that death is a normal part of the life cycle and that they would live on, either through their relationships, their accomplishments, or their good works. They also wanted to believe that they had done their best in their life and that they will be in the presence of a loving God or Higher Power. It is as important for health care providers and other caretakers to talk with patients about these issues as it is to address the medical-practical side of care. As numerous other surveys have shown, patients want their physicians to talk with them about their spiritual needs. In these surveys 65%–95% of respondents say they want their physicians to address their spiritual issues with them, yet only about 10% of their physicians actually do.[6,7]

There are also data that suggest that spirituality may be helpful to people as they cope with dying or with loss. For example, patients with advanced cancer who found comfort from their religious and spiritual beliefs were more satisfied with their lives. They were happier and also had diminished pain.[8] Women with breast cancer felt that their spiritual beliefs helped them cope with their illness and with facing death.[9]

How does spirituality work to help people cope with their dying? One mechanism might be through hope. Spirituality and religion offer people hope. It helps people find hope in the midst of despair that often occurs in the course of serious illness and dying. Hope can change during a course of an illness. At early stage, the patient may hope for a cure. Later when a cure becomes unlikely, the patient may hope for time to finish important projects or goals, travel, make peace with loved ones or with God, and experience a peaceful death. This can result in a healing, which can be manifested as a restoration of one's relationships or a sense of self. Often our society thinks in terms of cures. While cure may not always be possible, healing—restoration of wholeness—may be possible to the very end of life.

Beyond the data are personal stories from physicians and their patients. In my own experience as a physician who cares for patients with chronic and terminal illness, I feel privileged and honored to care for people who are facing death. Their strength and courage in the midst of suffering is inspiring. My patients are greater teachers to me and to my students on life than any philosophical text. The stories they share are ones of personal transcendence, courage, and dignity. My patients continually live with dying, in the midst of which they are often able to face their losses, fears, and pains. They transcend to a place where they see their lives as rich and fulfilling. They reprioritize life and find a place of deep meaning and purpose in their lives. It is often humbling to me to recognize that things in life on which I place importance now may have little or no importance in the end, when facing my own mortality. My annoyance at rush hour traffic or emphasis on academic success pale in comparison to my patients' descriptions of a glowing sunrise or the deep love they feel for another. We need systems of care where people are able to find their deep sense of meaning and purpose in the midst of suffering, where they can find peace.

SPIRITUALITY: CURRENT TREND IN MEDICINE

We have survey data showing that our patients think spiritual issues are central in life, particularly in death and dying. We have some data suggesting that people use their spiritual beliefs in coping with chronic illness and loss. And we have patients' stories of personal transformation. Yet we have systems of care that do not incorporate spirituality into the care of patients.

Medical professionals are recognizing these inadequacies in the health care system in terms of care of the dying. The American College of Physicians convened an end-of-life consensus panel where they concluded that physicians should extend their care for those with serious medical illness by attention to psychosocial, existential, or spiritual suffering.[10] Other national organizations have also supported the inclusion of spirituality in the clinical setting. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has a policy that states that: "Pastoral counseling and other spiritual services are often an integral part of the patient's daily life. When requested the hospital provides or provides for pastoral counseling services."[11]

The interest in spirituality in medicine among medical educators has been growing exponentially. Medical schools are now teaching courses in end-of-life care and in spirituality and medicine.[12,13] Only one school had a formal course in spirituality in medicine in 1992. Now more than 70 medical schools are teaching such courses. The key elements of these courses involve listening to what is important to the patient, respecting their spiritual beliefs, and being able to communicate effectively with patients about their spiritual beliefs and their preferences at the end of life.

The Association of American Medical Colleges (AAMC) in 1998, responding to concerns by the medical professional community that young doctors lacked these humanitarian skills, has undertaken a major initiative, The Medical School Objectives Project (MSOP), to assist medical schools in their efforts to respond to the concerns. The report notes that, "Physicians must be compassionate and empathetic in caring for patients . . . they must act with integrity, honesty, respect for patients' privacy and respect for the dignity of patients as persons. In all of their interactions with patients they must seek to understand the meaning of the patients' stories in the context of the patients, and family and cultural values."[14] In recognition of the importance of teaching students how to respect patients' beliefs, AAMC has supported the development of courses in spirituality and medicine. In 1999, a consensus conference with AAMC was convened to determine learning objectives and methods of teaching courses on spirituality, cultural issues and end-of-life care. The findings of our conference are published as Report III of the Medical School Objectives Project (MSOP). As a part of this report, we developed a definition of spirituality as relevant in the clinical setting:

> Spirituality is recognized as a factor that contributes to health in many persons. The concept of spirituality is found in all cultures and societies. It is expressed in an individual's search for ultimate meaning through participation in religion and/or belief in God, family, naturalism, rationalism, humanism, and the arts. All of these factors can influence how patients and health care professionals perceive health and illness and how they interact with one another.[15]

Spirituality, and that which gives us meaning, can be expressed in many ways. The outcome goals are:

> Students will be aware that spirituality and cultural beliefs and practices are important elements of the health and well-being of many patients. They will be aware of the need to incorporate awareness of spirituality and culture beliefs and practices into the care of patients in a variety of clinical contexts. They will recognize that their own spirituality and cultural beliefs and practices might affect the ways they relate and provide care to patients. Students will be aware of the range of end-of-life care issues and when such issues have or should become a focus for the patient, the patient's family, and members of the health care team involved in the care of the patient. They will be aware of the need to respond not only to the physical needs that occur at the end of life, but also the emotional, sociocultural, and spiritual needs that occur.[15]

Currently, more than half of U.S. medical schools have courses in spirituality and medicine, many of which are required and integrated into the curriculum. The response to these courses has been positive. Students and practicing physicians find their relationships with their patients to be warmer, more meaningful and deeper once they talk with their patients about their spiritual beliefs. Medical students and residents are finding it easier to address end-of-life issues in the context of a spiritual history (C.M. Puchalski, personal observations).

Doctors who felt burned out by the hectic schedules of managed care now feel that spiritual discussions give them a way to reconnect with their patients and bring compassionate care back into the practice of medicine. Most importantly, the patients are more satisfied because their whole person (body, mind, and spirit) is treated, and not just their illness.

SPIRITUAL HISTORY IN FUTURE PATIENT INTERVIEW

Medical students must learn how to communicate with patients about the patients' spiritual beliefs. A spiritual history is really nothing more than listening to the patient, i.e., their fears, hopes, and beliefs.[16] In the course of talking with someone about their spiritual beliefs, it is natural to bring up issues of advance directives. Advance directives are usually obtained through forms or brief questions in a history, often sterile and out of context conversations. Discussions about the way people want to die should be done in the context of a person's values and beliefs. A spiritual history is an ideal place for centering discussions around advance directives.

A spiritual history that has been developed for physicians and other health care providers is FICA.[13,16] The goal of this acronym is to provide physicians and health care providers with a tool by which to remember key elements of a spiritual history.

F—Faith and Belief

"Do you consider yourself spiritual or religious?" or "Do you have spiritual beliefs that help you cope with stress?" If the patient responds "no," the physician might ask, "What gives your life meaning?" Sometimes patients respond with answers such as family, career, or nature.

I—Importance

"What importance does your faith or belief have in your life? Have your beliefs influenced how you take care of yourself in this illness? What role do your beliefs play in regaining your health?"

C—Community

"Are you a part of a spiritual or religious community? Is this of support to you and how? Is there a group of people you really love or who are important to you?" Communities such as churches, temples, and mosques or a group of like-minded friends can serve as strong support systems for some patients.

A—Address in Care

"How would you like me, your health care provider, to address these issues in your health care?"

FICA is not meant to be used as a checklist but rather as a guide on how to start the spiritual history and what to listen for as the patient talks about his or her beliefs. Mostly FICA is a tool to help physicians and other health care providers know how to open a conversation to spiritual issues and issues of meaning and value. In the context of the spiritual history, patients may relate fears, dreams, and hopes to their care provider. The spiritual history can be done in the context

of a routine history or at any time in the patient interview. The spiritual history is patient-centered, therefore one should always respect patient's wishes and understand appropriate boundaries. Physicians and other health care providers need to respect patients' privacy regarding matters of spirituality and religion and should avoid imposing their own beliefs onto the patient.[17]

The following case is an example of how FICA can be used. It is based on an encounter with one of my patients who eventually died of metastatic malignant melanoma. An Episcopalian, her religious beliefs were central to her life and the way she became peaceful with dying. During her last hospitalization, the residents caring for her were apprehensive about discussing advance directives and dying. However, during the spiritual history, the patient told the residents how her religious beliefs helped her come to terms with dying and how she was ready to die naturally. She handed them her living will. She also asked that her church members be allowed to visit her often. She later told me that being asked about her beliefs helped her feel respected and valued by the residents. She felt that she could trust them even more. The residents told me that once they asked a spiritual history, the nature of the interaction between themselves and this patient was changed. One resident said that it felt "more natural, more comfortable, warmer and more honest." The lessons learned from this story is supported by a research survey at the University of Pennsylvania: 65% of patients in a pulmonary outpatient clinic noted that a physician's inquiry about spiritual beliefs would strengthen their trust in their physician.[18]

SUMMARY

It should be the obligation of all physicians to respond to, as well as attempt to relieve, all suffering if possible. Therefore, physicians and other caregivers should communicate with their patients about their patients' spirituality and the way their patients cope with suffering. We should have systems of care that allow people to die in peace, to die the way they want to, to be able to engage in those activities that bring peace to them: prayer, meditation, listening to music, art, writing a journal, sacred ritual, and relationships with others. Our systems of care should be interdisciplinary: physicians, nurses, social workers, chaplains, and other spiritual care providers all working together to provide spiritual and holistic care for our patients.

Our culture, as a whole, needs to look at dying differently from the way it currently does. We need to see dying not as a medical problem but as a natural part of life that can be meaningful and peaceful. We can broaden and perhaps even enhance our lives now by knowing that one day we will die. By thinking about our mortality early in life, we will not be caught off guard and pressured by the dilemmas of choices at the end of life. We will have had a chance to think about some of those choices sooner and to come to peace with our mortality. This is where religious organizations can be particularly helpful. They can facilitate our discussions of dying and what death means to us. They can educate their members about the importance of preparing themselves for the choices, both spiritual and medical, that need to be made near the end of life. We, the interdisciplinary care team, can jointly assist the dying person come to peace in life's last moments.

All of us, whether actively dying or helping care for the dying, have one thing in common: we all will die. The personal transformation that is often seen in patients as they face death can also occur in all of our lives. By facing our inevitable death we can ask ourselves the same questions that dying patients face: what gives meaning and purpose to our lives, who am I at my deepest core, and what are the important things I want to do in my life.

Wayne Muller has written:

> There are times in all our lives when we are forced to reach deep into ourselves to feel the truth of our real nature. For each of us there comes a moment when we can no longer live our lives by accident. Life throws us into questions that some of us refuse to ask until we are confronted by death or some tragedy in our lives. What do I know to be most deeply true? What do I love, and have I loved well? Who do I believe myself to be and what have I placed on the center of the altar of my life? Where do I belong? What will people find in the ashes of my incarnation when it is over? How shall I live my life knowing that I will die? And what is my gift to the family of earth?[19]

Of all life's difficult yet important experiences, dying may be the most difficult one we will ever have. The moment of death, and the dying that precedes it, brings to a close our life-long journey. We are the privileged persons who attend people while they are dying, be they our patients or our loved ones and friends. We are the persons who can bring hope and comfort to dying patients as they complete their lives. We need to ensure that our society and our systems of care preserve and enhance the dignity of all people, especially when they are made vulnerable by illness and suffering. We need to listen to the dying and to all our patients and be with them, for them. The process of dying can be a meaningful one—one that we can all embrace and celebrate rather than fear and dread.

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