

Virtual Mentor

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Medicine and society

Dying well in America: What is required of physicians?

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A commonly heard joke in hospitals and clinics is that “death is optional.” Our popular culture reflects an obsession with perpetual youth and vigor and seems to devalue aging, particularly the frailty that often accompanies illness and aging. Our medical culture reflects these attitudes. The emphasis on problem-oriented medicine and the focus on subspecialty practice have reinforced fragmented and less-than-holistic models of care that sometimes isolate patients from their families and communities. This shortcoming of contemporary medical practice has particular consequences for individuals who are most vulnerable and in need of coordinated comprehensive care—those with advanced chronic and life-limiting illness, especially the elderly.

Although medical progress in the past century has nearly doubled life expectancy for Americans, and we now have the lowest annual death rate on record, it is still true that everyone must die. A review of Medicare records indicates that the average person experiences two years of disability prior to death [1], and recent studies have documented many deficiencies in our care of these seriously ill and dying patients beyond just fragmented systems of care. Poor symptom assessment and management skills, perceived low prioritization for documenting and respecting patient preferences for care, late referrals to hospice programs and general training deficiencies in palliative medicine have all been identified as contributors to less-than-optimal end-of-life care [2, 3]. Given the probability that most of us will experience chronic illness and progressive frailty before dying, what should physicians and our health care system do to maximize our likelihood of dying well?

Dying well

The term “dying well” is much preferred to the often-used phrase “a good death” since many believe there is nothing “good” about death itself. In psychological and emotional terms death is not “good” because it represents the disintegration of personal identity and separates us from family and loved ones. The physical realities of chronic illness leading to death—e.g., cachexia, bed sores and mucosal ulcerations—can even alienate patients from their own bodies. This threat of separation from personhood, family and community engenders fear that can lead to suffering. As physicians we can attend to this anxiety and suffering through models of caring that integrate the medical, psychosocial and spiritual needs of patients and families. This approach to healing is best exemplified by palliative medicine, defined

as an approach to care that attends to suffering associated with chronic advanced illness and emphasizes the physical, emotional and spiritual well-being of patients and their family [4]. Hospice care is the best-developed system for delivery of palliative care and is designed to maintain the highest quality of life for patients diagnosed with a terminal illness who choose comfort care over curative medicine. It is important to note that hospice programs invite primary care physicians to continue their relationships with their patients after referral to the program.

A public opinion survey of all North Carolina AARP members by the Carolinas Center for Hospice and End of Life Care asked respondents to list their most important end-of-life needs [5]. Although they listed medical needs such as freedom from pain, physical comfort, knowing what medications are available, honest answers from doctors and understanding treatment options as important, it is useful to review the nonmedical concerns of the respondents. Some of the most striking of these were: being at peace spiritually, not being a burden, having things settled with family and knowing how to say goodbye [5]. The message from this survey is that when we view care for the seriously ill and dying *only* in medical terms we risk neglecting equally critical psychosocial and spiritual needs.

Beyond medicine

What is our role as physicians with respect to the nonmedical needs of our seriously ill and dying patients? We can begin by adapting the philosophy of palliative medicine. Palliative and hospice medicine offer powerful options for doctoring, especially for patients who have incurable or terminal illness. A truly comprehensive palliative care approach avoids overly medicalizing care. Competency in palliative medicine provides physicians with the knowledge and skills necessary to continue caring for patients when we can no longer provide curative treatment and also provides a means for maintaining a legitimate presence so that we will not abandon our patients at the time of their greatest need.

Palliative medicine calls upon the physician's knowledge of the natural history of disease and requires her to lead an interdisciplinary team of health care workers who are truly practicing patient-centered care. Proficiency in palliative medicine also includes expertise in pain and symptom management. This is much needed; far too many patients still experience avoidable pain and distress [2]. We must effectively manage pain and other unpleasant symptoms such as nausea so that patients have the physical and mental strength to attend to their spiritual and existential concerns. Expertise in palliative medicine also requires excellent communication skills, including the ability to listen and connect to patients in a sincere and empathic manner. We must attend to suffering caused by the assault on the integrity of personhood if we wish to assist families as they struggle with the toll taken by advanced illness on the physical, emotional, spiritual and social aspects of their lives [6, 7]. Above all, competency in palliative medicine requires the ability to solicit and comprehend each patient's unique narrative [8].

As indicated in the Carolinas Center AARP study, spiritual concerns are high on the list of patient needs at life's end [5]. Although patients do not expect physicians to be their spiritual care providers, they do want their doctor's respect for their spiritual concerns which include fear of abandonment, guilt, anger with God and the fear of not being remembered [9]. Ira Byock, MD, director of palliative medicine at Dartmouth Medical Center has said to me, "Confrontation with death lays bare our spiritual concerns about life's end." We must learn to do routine assessments of the spiritual needs of our patients and include their pastors, hospital chaplains and faith leaders as part of the health care team.

As physicians we can provide the foundation and the space for our patients to "die well." We have a role in creating the conditions patients and families need in order to reach closure on important life issues—they need to say "goodbye," "I love you," "forgive me" and "I forgive you" [10]. Contemporary medical practice still has need for the physician to play this role as a true healer.

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