

Virtual Mentor

American Medical Association Journal of Ethics
December 2013, Volume 15, Number 12: 1069-1080.

MEDICINE AND SOCIETY

Whole-Person, Whole-Community Care at the End of Life

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Dying is a Human and Communal Experience, Not a Medical Event

As human beings, we are programmed from birth to grow and develop in all our dimensions—biological, social, psychological, spiritual—to change, and to die. A small percent of us die suddenly and unexpectedly without previous warning, but the vast majority of us today experience dying as a process characterized by progressive illness or gradual frailty. Making the now all-but-universal experience of deteriorating and eventually dying as comfortable and as rich as possible for each person and those closest to her is an ethical responsibility of caregivers and the community, as well as an opportunity for all involved to advance in knowledge and compassion.

To live as well as possible until the end requires more than attention to our bodies. One's whole being participates in the process of living and ending life. The totality of who we are needs care. Physicians have always had a role at the end of life, but during the last half century medical care has so overtaken all aspects of the dying process that we mistakenly have come to assume that death is a disease and dying a medical condition [1].

We are social animals who live and die in social settings with particular histories and traditions. With changes in the stages of life, our roles in our families, our social circles, and community life evolve. Old bonds may be broken and new ones forged; our vision of what is meaningful often changes; and we are likely to grow increasingly aware of the looming end. We may seek transcendence, focus on personal relationships, become concerned about leaving legacies, or try to ignore what is happening to us. We may feel anxious at the prospect of dying or we may look forward and backward with a sense of fulfillment. These feelings and ruminations may be common among people of advanced ages or those facing serious illness, but they may also be present in someone who is still young and active.

Who Is Dying?

Before we consider what care is appropriate for “the dying,” we need to identify who they are. Individuals who are in their last days or hours and exhibit common signs of “actively dying” are comparatively easy to recognize [2], but this description only fits those in the ultimate stage of the dying process. How would we have characterized these people a week earlier, or a month, or a year? When is it warranted to start thinking of a person as “at the end of life” and decide that it is time for “end-of-life care”?

Reflecting on this, it becomes clear there is no “trigger point”—in years lived or disease progression—when the process of “dying” can be said to begin. Since birth, all of us are on a trajectory to death with the potential of the process speeding up or slowing down. Healthy people have a straight downward sloping trajectory to the date set by actuarial tables until illness strikes (or creeps up) and the curve changes [3]. Hence, “end-of-life care” should not be separated from a continuum of care that begins at birth and varies over time according to individual need. A continuum of care is ongoing across time, across diagnoses, across medical, custodial, and supplementary care providers, and across family units and community support groups. Good end-of-life care manifests as the intensification of care that is, ideally, already and always ongoing.

The Needs of the Dying

Those who have the end in sight are still living [4]. As human beings, albeit in the last stage of life, their needs are not so different from the needs of the rest of us. They have ordinary needs that require special, sometimes extraordinary, support. All of us, presumably, like to live in a dignified manner, in a safe environment, free of pain and troubling symptoms, with clean bodies and clothing, appropriately hydrated and nourished, in nurturing and loving relationships, with the right amount of mental stimulation, and at peace with ourselves and the world. Although these needs may not be exceptional, the hurdles to achieve them may increase as illness and frailty set in, and the urgency with which they must be satisfied may be magnified as life constricts toward its end.

To learn how we can provide the necessary enhanced support, we have to look beyond medical care to a multidimensional solution. People at the end of life—and those close to them—need assistance with the activities of daily living—dressing, bathing, getting on and off the toilet, cooking and cleaning, managing bill payments, and completing insurance forms. Access to transportation and a wheelchair-friendly residence outfitted with handrails and a hospital bed become critical. Friendly companions safeguard against depression. Pain and symptom management are essential, but existential suffering can be as burdensome as physical discomfort. A chaplain or someone else to talk to about meaning, value, and connectedness can be indispensable.

Whether we remain in our private homes or move into residential facilities, being part of a caring community fosters satisfaction [5]. We seek dignity and respect, and the best quality of life possible, according to how we as individuals and members of our cultural groups perceive those concepts, based on our traditions and values. Conveying *I see you, I hear you, I value you* goes a long way when caring for someone who is losing functionality. This is when the full humanity of the individual is often ignored and the medical diagnosis dominates all interaction. As caregivers we need to be receptive to the whole person, her story, and her wishes and hopes for the time that remains. We show that we value her by supporting her according to her wishes and our professional or personal roles—mitigating pain, explaining insurance forms, treating pressure sores, ensuring hygiene, preparing meals and feeding,

reading a book, performing a ritual, sitting quietly and holding a hand—but also by fully “being with” as much as “doing.” “Being with suffering” is the root meaning of “compassion,” and, regardless of our relationships to the dying person, the underlying nature of our response needs to be one of compassion and love.

Meeting the Needs in an Integrated Service System

To effectuate appropriate care, the receptive and responsive caregiver needs to be part of a coordinated network of services that takes into account the families and communities that are affected by the approaching death. Joanne Lynn argues that we should start by looking at *need*, rather than a system of care to which the individual is made to conform [6]. To accomplish this goal, the current health care system would need to be reformed in multiple ways. Fees for services, a general lack of advance directives, and the default practice of “full code” regardless of the age or health status of the patient are among the most problematic practices [7, 8].

In meeting the needs of those with progressive serious illness and frailty, the most promising health care models are currently hospice care and palliative care. The Medicare hospice benefit mandates a coordinated care team: physicians and nurses manage pain and symptoms; social workers navigate the social service system, answer insurance questions, and offer counseling; aides assist with activities of daily living; chaplains address spiritual needs; and trained volunteers provide social interactions and perform nonprofessional chores. Speech, occupational, and physical therapists and necessary pharmaceuticals to keep the patient comfortable are also included in the benefit. In addition, many hospices provide massage, Reiki, pet, and music therapy, among other complementary services that enhance the patient’s well-being [9]. Palliative care is defined as a philosophy and a system of care, an interdisciplinary care system that embraces the whole person as well as the surrounding family, and potentially the whole community [10, 11]. Palliative medicine is the medical component of palliative care.

Almost half of the people who die in the United States receive hospice services in their dying hours [12]. Because the hospice benefit requires that the patient forgo curative treatment and that a physician certify that life expectancy is less than 6 months, many who could benefit from the support by enrolling early hesitate; more than a third of hospice patients enroll only for the last several days of life [13]. One reason for the late referrals to hospice is many physicians’ reluctance to recognize that their task has changed from seeking disease improvement and cure to offering comfort care. Palliative care services are designed to meet this challenge by creating an additional layer of care that can be provided without the patient’s forgoing curative treatments. Palliative care services can be as comprehensive as hospice services but are often circumscribed due to current restrictions in the reimbursement system.

An expansion of insurance payments for palliative care services and reforms to better align hospice care with a continuum of care appear to offer the best short-term prospects for meeting the health care needs of the dying under our current insurance

system. Regardless of when such reforms may occur, other changes can be initiated among caregivers and among the general public on a broad societal level. All social services and all communal life across the life span potentially intersect with good end-of-life care.

Expanding Roles of Care Providers

Medical and other professional caregivers share the responsibility of all citizens to work for a whole-person, whole-community approach to care. This means being open to integrating our own care system with other support systems and allowing the breaking down of traditional separations among domains that designate and circumscribe who is responsible for what aspect of the care. When disease-modifying measures are no longer possible, the roles among the medical team members shift as the palliative medicine experts enter or become more dominant in the care. Controlling pain and alleviating symptoms are the most important services that medicine can offer at the end of life [14]. However, many patients worry about insulting their primary or disease-specific physicians if they suggest that their pain is not well managed and that they want to consult a pain specialist. This can be avoided if the attending physician suggests a referral to a palliative medicine specialist him- or herself.

A comprehensive support plan for the final journey, which goes beyond the traditional care plan, needs to be drawn up by a professional caregiver who looks at the whole person and those closest to her. In addition to medical directives, the values and wishes of the patient should be included, as well as custodial arrangements and other matters of importance to the patient. The plan should note favorite activities (and substitutes if they are no longer possible), preferences about dress and skin care products, when visitors are welcome, and what gifts are well received. Such details may strike the clinician who is grappling with a complex disease situation as incidental, but to the patient whose functionality is deteriorating they can be sources of comfort and pleasure [15, 16].

Home care medicine is gaining inroads in certain states and showing positive results [17]. Increased volumes of home visits by palliative care-trained physicians, nurse practitioners, and nurses are a positive development for end-of life care. Along with a return to the physician house call may come a return to a personal and empathic relationship between the physician and his or her patients. Medical schools increasingly recognize the need for physicians to communicate more effectively and empathically with their patients [18]. Good bedside manners include taking time with patients [19], being generous about consulting colleagues, and being careful not to medicalize all suffering. Forgiveness, gratitude, sorrow, and love belong in the room of the dying individual, and these sentiments need to be acknowledged—when appropriate—by the visiting physician as well as by the chaplain and grief counselor.

Possibly the most important action that physicians—including disease specialists—can take to show their empathy, especially after treatments have ceased to have disease-improving effect, is to remain in contact, *not* to abandon the patient and her

family. The physician's training and experience endow her with authority. We need our trusted doctors to be with us in shared—even wordless—humanity when we struggle with leaving this life. It matters who the doctor is and how she acts [20].

Outside the field of medicine, other professional institutions and community organizations are initiating and expanding care models, which serve the whole person at the end of life. Education of health care advocates and case managers increasingly includes tools to help families navigate the final journey and locate helpful resources [21]. Training of doulas for the dying—people who offer practical, emotional, and spiritual support but whose primary role is being available as experienced, reassuring presences when someone is “actively dying”—is in its infancy but a growing field [22]. Not-for-profit organizations and faith groups have stepped up their training of “friendly visitor” programs and volunteer drivers [23-27]. Community and professional associations are promoting and creating appropriate educational programs and certification so that these new vocations can become part of a formalized system, similar to the aides with specialized end-of-life training who are now available through licensed or certified home health agencies [28, 29]. The advocacy work is in its early stage but is gaining momentum in large part through caregiver associations and other lay entities [30].

Beyond Integrated Service Models

As discussed, comprehensive, integrated end-of-life care involves adding a layer of palliative care to current medical practices and expanding traditional caregiver roles. Additionally it requires breaking down the “silos” of care to better manage patient transfers among the different care settings of home, hospital, and nursing home [31, 32]. Further, it entreats us to embrace innovative ideas and, ultimately, rethink traditional service systems.

A fundamental hurdle to comprehensive care is the existing strict separation on the managerial and financial level between health care and whole-person (social) care systems. Separate funding sources and a lack of coordination among providers lead to deficiencies, inefficiencies, and, often, high overall costs. Currently in the United States, the expense for repairing a broken leg—a medical necessity—is covered by Medicare (and most insurance companies), but preventive measures, such as reviews of a private residence and removal of slippery rugs and other hazards are rarely covered or subsidized [33]. A hip replacement is paid for but, in general, reimbursement is not available for custodial care such as assistance with bathing and dressing, shopping and cooking when the patient gets home, making the recovery period difficult [34]. Comprehensive, coordinated care has proven to be both cost-effective and beneficial to patients in foreign countries as well as in selected projects and entities within the United States [35-41].

Whole-community care also entails many social services that respond to a variety of needs (e.g., transportation, daycare) and extend seamlessly into the end of life. If good, communal childcare services and after-school programs are available, they provide a measure of ongoing stability for the family as a parent struggles with

treatments and worries about the prognosis and the prospect of arranging care for her children after her death. If good public and subsidized transportation and housing are in place for the disabled, elderly, and poor, these services can be made accessible to those newly diagnosed with a terminal illness without creating new systems of care. Such structural reforms may be difficult to achieve in the current political climate. We can nevertheless envision—and work for—a network of care that spreads on the grassroots level and reaches into the life of the community [42].

Advocating for Political and Social Change

As members of a political system and a civil society that empower us by law and tradition, we can all act to effect positive change in the end-of-life experience. If we believe in reforming our care system so it responds to the needs of the individual—and not vice versa—then we have to advocate and work for improvements. We have constitutional ways to promote favorable legislation and appropriation on the federal, state, and county government level, and we can join groups that educate and advocate around these issues [43]. We can, for example, urge our political representatives to support legislation that reimburses end-of-life conversations between physicians and their patients [44] and we can lobby for a more flexible reimbursement system that breaks down the boundaries between medical and social support services. We have access to faith congregations, social media, and cultural entities to share our experiences and knowledge, and to encourage our families, friends, and colleagues to engage in a whole-person, whole-community approach to end-of-life care. All of us have a stake in the outcome and we also have an ethical responsibility to engage in improving the care of others.

Experience and the literature have shown that successful integration and coordination among entities occur when projects are initiated from the ground level, rather than imposed from the top; when collaborations are undertaken among service providers at the local level; and when all stakeholders are included [45]. These basic tenets indicate that the healthy general public must be roused in the quest for an optimal care system.

Preparing Ourselves

We will all one day die and we will want to receive appropriate care. Thus all of us age 18 and older should complete an advance directive assigning health care agents to represent us in case we lose capacity. We teach teenagers about the perils of drugs and unprotected sex; we also need to make sure that our 18-year-olds have conversations with their parents, siblings, and doctors about whom they would want to speak for them if they lost capacity to make health care decisions for themselves.

Widespread conversations about our wishes at the end may be the most effective ways to promote improved end-of-life care on a personal and communal level. Designating an agent provides a natural opportunity for a conversation about care preferences with the agent and family members and to share thoughts about the kind of care that would be desired at the end. The advance directives we give to our health care agents may change as time goes by, so conversations need to be repeated when

our circumstances alter or our physical conditions deteriorate [46, 47]. If we get serious progressive illnesses and when we become frail and elderly, in-depth conversations about life-sustaining measures become critical. At that point, a physician needs to document our wishes and, if appropriate, prepare portable documents with medical orders stating them [48].

Beyond these basics, we can help ourselves and our families by creating a personal “goals-of-life” plan. Such a plan covers what we would want for ourselves if we were given a limited time to live, say, a final year, final month, or final few days. It includes where we would want to be and with whom, doing what [49]. If all adults became accustomed to considering such things, responding when a similar situation occurred would be easier. The majority of us will have to face how we want to live when we are elderly and frail and—not unlikely—have multiple medical conditions. Many of us will lose capacity and need to rely on others to make decisions for us.

The “goals-of-life” plan differs from a traditional care plan in that it is the patient, in conversation with his or her intimates, who initiates and develops the plan. Creating the plan is almost akin to a parlor game [50], but the product serves well as the foundation of a future personalized “support plan.” The “goals-of-life” exercise is like a fire drill. The real-life situation will never compare exactly to the training sessions but stark panic might be replaced by a sense of knowing some of the necessary action steps. The plan may be revised with our evolving circumstances and health status but, with ongoing conversations, we and our loved ones will have an idea of our wishes and can advocate for them with enhanced confidence.

In Conclusion

As members of the general public and as lay and professional caregivers, we need to acquire “end-of-life competence.” We need to become comfortable around those who are living in their last days and show them compassion. We need to allow them to enter into our individual and communal lives by working for major systemic change and by performing small, daily acts of kindness—and by being available and present when the need arises.

The cultivation of compassion may be our most powerful tool in the quest to improve the end-of-life experience for the person who is dying and those closest to her [51]. The possibility of creating a more compassionate society may sound farfetched, but attitudes and values change over time, sometimes remarkably quickly [52]. Witness broadly accepted changes in attitudes towards civil rights and corporeal punishments in schools during the last half-century. Acts of compassion can be fostered on a personal level and have a communal effect [53]. The ability to listen and respond with sensitivity, to be caring and empathic, is not the exclusive domain of any particular profession. It is a skill set that everyone can acquire.

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