

Quantity and Quality of Life Duties of Care in Life-Limiting Illness

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Everyone dies. Dying today typically involves a period of protracted illness, disability, and intense involvement of medical professionals. Although the experience is woefully understudied, a significant body of evidence is emerging to guide clinicians, health systems, and society toward better practices for people facing serious, life-threatening conditions.

That evidence has shown, importantly, that the amount of suffering that people endure in their last year of life is considerable. Singer et al¹ recently reported on the experience of 7204 adults older than 50 years who died while being followed up as part of a longitudinal study of US health and retirement. The researchers found that, during their last year, 51% of study participants were often troubled by moderate to severe pain, and 46% to 53% also experienced at least a month of depression, periodic confusion, dyspnea, and incontinence during that time.¹ Furthermore, among those who died between 1998 and 2010, none of these symptoms decreased in occurrence during their last year of life, but rather occurrence of pain, depression, and periodic confusion actually increased. Medical care for the symptoms people experience at the end of life does not seem to have gotten better; it may have gotten worse.

It could be argued that the findings simply reflect people following their wishes to trade the quality of their lives for therapies that extend their lives. But this is not the case. In 2014, the Institute of Medicine (IOM) published *Dying in America*, which included an extensive review of the medical literature on the end of life, including the efficacy of expert palliative care.² Palliative care is a field dedicated to assisting seriously ill people with setting and achieving goals aside from just survival, which may include control of symptoms, attending to life projects, connecting with loved ones, or other vital objectives. The literature has established that when care is provided with a narrow focus on disease control, without palliative care expertise directed at eliciting these broader goals and tailoring care to include them, patients experience more pain, more anxiety, and more family exhaustion; they receive more nonbeneficial care and more hospitalization; and they do not live longer. Indeed, studies suggest that earlier involvement of palliative care specialists, either through consultation or enrollment in hospice, can produce increased survival.^{3,4}

Another cause of physical suffering and family distress identified in the IOM report is that the majority of people reach the end of life cognitively impaired by illness, treatment, or frailty, and they are unable to make their own decisions about their care. They must rely on a proxy to make their medical choices. Only with advance planning conversations can they ensure alignment between the treatment they receive and their

goals and values. But most people do not have these conversations with their clinicians or family members. Treatment therefore often violates their preferences, usually in the direction of undervaluing measures to support the quality of their remaining life.

The picture of care at the end of life that emerges is therefore disturbing. A widespread perception among both the medical profession and the public at large has been that seeking palliative care consultation or hospice services, or even just having advance planning discussions, amounts to “giving up” and is only relevant when people no longer have options for disease-based therapy. This view is incorrect and harmful.

It is also sometimes regarded as uniquely American. However, in this issue of *JAMA*, dedicated to the topic of death, dying, and the end of life, Bekelman et al⁵ report findings that suggest otherwise. The authors analyzed data from patients older than 65 years who died with cancer in 7 countries: Belgium, Canada, England, Germany, the Netherlands, Norway, and the United States.⁵ Among these countries, the United States actually had the lowest proportion of patients whose site of death was the hospital (22% vs up to 51% elsewhere). To be sure, the United States registered the highest rate of intensive care unit admission and chemotherapy administration in the last 180 days of life, indicating a mixed and still complex picture of care at the end of life. High use of intensive care and other technologies is a general characteristic of US health care,⁶ and the study found that use of chemotherapy in the last 30 days of life declined in the United States, just as in the other countries, to approximately 10%. All of these countries appeared to be making a radical transition away from nearly universal reliance on hospitalization at death for cancer patients, with the United States, perhaps surprisingly, having moved the farthest and fastest away from institutionalization at death. Other research shows the United States now has perhaps the highest level of hospice capacity and use, and the highest likelihood of death at home, in the developed world.⁷

Data from another study in this issue of *JAMA*, by Wright et al,⁸ indicate that this shift has likely been beneficial. The authors report survey data from family members of 1146 elderly patients who died with advanced lung or colorectal cancer. Patients who died in the hospital proved the least likely to be reported to have excellent quality of care near death (just 41% did) or to die where they had wished to (only 18% preferred to die in the hospital and did so). By contrast, patients who had been enrolled in hospice for at least 3 days had the best reported quality of life near death and best alignment of care with their wishes.

However, only half of the patients in this multiregional study received 3 or more days of hospice. The authors' conclusion was therefore, reasonably, that efforts should promote earlier hospice enrollment and avoid hospital death. However, this interpretation is incomplete. The results also suggest that palliative care for hospitalized patients must improve. There is no intrinsic reason that the quality of care for the dying should be poorer in hospitals than elsewhere. Indeed, as Angus and Truog point out in their Viewpoint in this issue of *JAMA*, even intensive care units can provide critical resources for improvement in the quality of life of dying patients.⁶

Furthermore, care in out-of-hospital settings can still be inadequate. As Wright et al noted, more than 40% of bereaved family members reported less-than-excellent quality of care near death for patients who received more than 3 days of hospice care.⁸ The common missing element, whether patients die in the hospital or at home in hospice, likely remains a lack of early discussion and planning of care around their goals and priorities for the quality of the life they are leading as they experience serious illness.

Directions Forward

How is it possible to do better? It appears that the fundamental error has been to split the primary responsibilities for treatment of serious illness from providing care enabling the best possible quality of life in the face of such illness. Palliative care clinicians, geriatricians, and others have been doing essential work to develop, articulate, and deploy the skills required to serve the well-being of the sick and the frail. These patients have fears and worries about what is to come; they have goals and priorities for how they wish to live their lives; they have aspects of their lives they are willing to sacrifice, and aspects they are not willing to sacrifice, for the sake of more time; they have certain functions they consider essential for life to be worth preserving; and they want and need their caregivers and families to understand and support these concerns as a central part of their care.⁹

Such support is not a responsibility to be outsourced to a specialized few, however. For one, the supply is lacking—there are not nearly enough skilled palliative and geriatric specialists for the more than 2 million people per year in the United States who die from heart disease, cancer, chronic respiratory illness, cerebrovascular disease, Alzheimer disease, or end-stage renal disease, let alone around the world.² Moreover, providing this support effectively requires integrating it into the care that everyone provides. There are reasonably well-established best practices for communicating prognosis, planning goals of care, and managing symptoms.^{9,10} However, training in using them has been absent from medical education in most specialties.

One view, often more implicit than explicit, is that the skills involved are not really that challenging—that clinicians are already perfectly capable of providing high-quality end-of-life care when they want to. Hence the popular claim that physicians receive different care when facing limited life expectancy—that physicians “die differently,” with more holistic, less heroic, and less institutional care than their patients receive. The implication is that physicians already know how to provide high-quality end-of-life care when they want to. Two

Research Letters in this issue of *JAMA* indicate that physicians do not die so differently, however.^{11,12} Both found that physicians were only a few percentage points less likely to die in the hospital than others, and Weissman et al¹² found no difference in hospice use or total expenditures at the end of life. The hurdles are larger than mere motivation. Although the recently announced change in Medicare rules to provide payment for advance care planning conversations is welcome, necessary, and long overdue, evidence suggests it alone will not produce substantial improvement in patient care.

Physicians and other health professionals—even those with substantial experience caring for the seriously ill—commonly lack skills in eliciting the goals, preferences, and values of their patients and in effectively tuning their care to align with those aims. Incorporating these skills into practice will require dedicated education and coaching for trainees and practicing clinicians. It will also require their participation in research and innovation on how to best deploy their specialized capabilities at the end of life. Research in radiation oncology, for example, has established that single-fraction radiation therapy should be favored over multiple fraction therapy for palliation of bone metastasis.¹³ Likewise, Prigerson et al recently evaluated chemotherapy use in a prospective cohort of 384 patients with end-stage cancer (ie, progressive metastasis refractory to at least 1 line of chemotherapy) followed up until death.¹⁴ Half received palliative chemotherapy, but its use was not associated with improvement in either survival or quality of life in the last week of life, even when controlling for performance status. Indeed, patients with good baseline performance status—the group expected to achieve the most benefit—experienced a significantly worsened quality of life with chemotherapy use compared with none. This type of research, however, has been uncommon, particularly for non-oncologic conditions. Society has encouraged research talent and funding to focus narrowly on extending the quantity of life and not quality—another harmful consequence of pitting these 2 aims against one another.

Perhaps the most harmful splitting, however, has occurred in national policy concerning eligibility for hospice services. As Odejide¹⁵ notes in this issue of *JAMA*, Medicare and private insurers have codified benefit limits that require patients to give up on curative therapy in order to receive the intensive palliative services and management that hospice care provides. This has been a major contributor to the underuse of hospice, the underrecognition of the value of palliative care, and therefore the poor quality of life experienced by patients with advanced disease and limited life expectancy. This needs to change.

The recent Medicare demonstration project testing the lifting of those limits with 141 hospice organizations across the country is a welcome initiative.¹⁶ However, the evaluation runs the danger of continuing to treat support of quality of life differently from support of extension of life. Adoption as national policy should not depend merely on whether the change reduces overall health care costs. It may well do so, based on the experience of private insurers who have tested the idea. Nonetheless, just as with any other medical intervention, the key measure of effectiveness is how much it improves patients' health and well-being.

Aims of Care

A bitter debate is continuing (including in this issue of *JAMA*^{17,18}) about the role of clinicians in enabling a good death for the small number of people who wish for assistance in dying. That discussion—about how best to balance respect for the sanctity of human life with the principle of autonomy—has drawn substantial public attention. However, the vital goal almost all people want from medicine is not having a good death but having as good a life as possible all the way to the very end.

The evidence indicates that the medical profession is harming vast numbers of patients by neglecting this goal—and that this is not just a US phenomenon but a global one. People everywhere have essential needs aside from just living longer. Medical practices, research, and policies must ensure that clinicians have the skills to understand those needs and have the capabilities to serve them for patients with life-limiting illness.

Everyone dies. Death is not an inherent failure. Neglect, however, is.

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