
A Good Death: Improving Care Inch-by-Inch

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A good death can *be* and *mean* many things. It can be testimony to a life fully lived; invoke spiritual meaning; and can inspire beautiful art and poetry. It can be resolution and renewal. Many visions of a good death do, however, share basic characteristics. People often hope for a death that is free from pain and other troubling symptoms. They want to maintain personal function and autonomy, which are critical to the preservation of self-respect and dignity. Even in declining health, people want to have a good quality of life during the final stages of their lives. Families want to be able to provide care without becoming overwhelmed by the challenges of being a caregiver or burdened by financial constraints.

Because people are living longer, often into their eighties and nineties, the concept of a good death has become more important. Today, fewer of us die suddenly or quickly. The population aged sixty-five and older has exceeded the rate of growth of the United States population as a whole during this century (Hobbs and Damon 1996). Into the next century, those aged eighty-five and older are expected to be the fastest growing segment of the population (Hobbs and Damon 1996). We are dying less from acute, infectious disease and accidents, and more from chronic illnesses such as dementia, stroke, heart disease, and obstructive lung disease. Furthermore, dying of chronic illness often is a slow process accompanied by frequent, acute hospitalizations and increased use of long-term care. Approximately eighty percent of all deaths now occur in hospitals or nursing homes (Sager 1989; Vital Statistics of the United States 1996). The risks of dehumanization and

isolation during institutionalization are substantial.

To ensure a good death, we must provide adequate, appropriate, and effective care to the person dying. Our current health care delivery system often does not ensure such care. *The Study to Understand Prognoses and Preferences for Outcomes and Treatments (SUPPORT)*, a ten-year, multicenter study, provided descriptive information and insight into the experiences of dying patients and their families. It showed that about one-third of those patients studied died in pain, and frequently they are not involved in planning their own care. Additionally, family members reported that half of the hospitalized, conscious patients were in moderate or severe pain most or all of the time during their last few days (The SUPPORT Principal Investigators 1995). Devastating economic and social burdens were experienced often by family members caring for loved ones (Covinsky et al. 1994).

The SUPPORT study also provided descriptive information about physician-patient relationships. Aggressive care was provided even for

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many patients whose prognosis was grim and patients who desired only comfort care (Lynn et al. 1997). Other studies have shown that providers frequently lack the skills needed to provide good pain management (The American Board of Internal Medicine 1996). In SUPPORT, providers often failed to communicate with patients and families about treatment preferences and failed to integrate patients' belief systems into the care provided.

We must realign our social support and care systems to meet these challenges associated with dying over a long period of time. When treatment will no longer produce desirable results, comprehensive care that emphasizes relief of symptoms, provisions for comfort, dignity, and control must be in place. Quality end-of-life care must be an integral part of our health care system.

To ensure someone has a good death, we must begin measuring the quality of care provided during the end of his or her life.

To accomplish this, we need to develop objective outcome criteria to measure how well health systems deliver care. Although it will be difficult for some independent health care systems to make needed changes, the growing managed care industry can provide a framework to improve quality in service delivery for those who are dying. Managed care systems have the resources needed to conduct studies about end-of-life care, integrate caregivers into multidisciplinary teams, provide nonmedical services, evaluate care planning and treatment, and organize to improve outcomes.

To ensure someone has a good death, we must begin measuring the quality of care provided during the end of his or her life. Moreover, a commitment needs to be made not just to measure end-of-life quality, but also to report how health care systems are doing and to make necessary changes. Other aspects of health care quality have

long been measured. Minimum levels of performance have been required in order to allow organizations to compete for patients and to be reimbursed for the care provided. Health care organizations similarly must be accountable for producing acceptable, quality outcomes for end-of-life-care.

Ten measurable domains of quality have been identified (as summarized below), and initiatives to develop tools to measure these domains have begun. Over forty organizations, including the American Medical Association, the American College of Physicians, the American Nurses Association, the American Association of Retired Persons, and Choice in Dying have endorsed measurement of these domains — a first step toward improving care of the dying. Ultimate success, however, will depend upon whether provider organizations actually make changes needed to improve the care they provide to allow for a good death.

Domains for the Measurement of Quality Care:

1. *Physical and emotional symptoms.* Pain, shortness of breath, fatigue, depression, fear, anxiety, nausea, skin breakdown, and other physical and emotional problems often destroy the quality of life at its end. Symptom management often is deficient. Care systems should focus upon these needs to ensure people a comfortable and meaningful end of their lives.
2. *Support of function and autonomy.* Even during the inevitable and progressive decline of a fatal illness, much can be done to maintain personal dignity and self-respect. Achieving better functional outcomes and greater autonomy should be valued.
3. *Advance care planning.* Often, the experience of patient and family can be improved just by planning ahead for likely problems, so that crisis decisions reflect the patient's preferences and circumstances.
4. *Aggressive care near death — site of death, CPR, and hospitalization.* Although aggressive care

often is justified, most patients prefer to avoid it when the short-term outcome of such care is death. High rates of medical intervention near death should prompt examination of provider judgment and care system design.

5. *Patient and family satisfaction.* A dying patient's peace of mind and the family's perception of the patient's care and comfort are extremely important. The time at the end of life should be precious to both, not merely tolerable. We must measure both patient and family satisfaction with the decision-making process, care given, outcomes achieved, and the extent to which opportunities were provided to complete life in a meaningful way.
6. *Global Quality of Life.* Often, a patient's assessment of his or her overall well being illuminates successes and shortcomings in care that are not apparent in more specific measures. Quality of life can be quite good despite declining physical health, and care systems that achieve this should be valued.
7. *Family burden.* How health care is provided affects whether families have serious financial and emotional effects from the costs of care and the challenges of direct caregiving. Current and future financial pressures on providers are likely to displace more responsibility for services and payment onto families.
8. *Survival time.* With pressures upon health care resources likely to increase, there is new reason to worry that death will be too readily accepted. Purchasers and patients need to know how survival times vary across plans and provider systems. In conjunction with information about symptoms, satisfaction, and the other domains listed here, such measures will allow insights into the priorities and tradeoffs within each care system.
9. *Provider continuity and skill.* Only through enduring relationships with professional caregivers can patient and family develop trust, communicate effectively, and develop reliable plans. Providers also must have rele-

vant skills, including rehabilitation, symptom control, and psychological support. Care systems must demonstrate continuity and provider skill.

10. *Bereavement.* Health care stops with the patient's death, but the suffering of the family goes on. Survivors may benefit from relatively modest interventions.

Central to the notion of a good death is knowing how to assess the quality of end-of-life care. We are making progress in knowing what to measure, and how. Now, we need to use these measures and the information they generate to bring about improvements that will give us, and our loved ones, more to look forward to.

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