

In Summary...

from the **INSTITUTE OF MEDICINE**

Shaping the Future for Health

DESCRIBING DEATH IN AMERICA: WHAT WE NEED TO KNOW

About 2.4 million Americans die each year, most in old age, and most from—or accompanied by—chronic diseases. It is now well known that more and more dollars are spent on medical care the nearer one is to death. What we do not know—but what we need to know—is much about the quality of the care provided and the quality of life achieved by the dying in relation to that care during the final period of life.

Describing Death in America, a new Institute of Medicine (IOM) report, examines the data available to track and evaluate the quality of life and quality of care experienced by Americans in the months immediately preceding death. It explains why better information about that care is needed if Americans are to attain what we all wish for: a decent and dignified death, free from avoidable distress and suffering for our families, our caregivers and ourselves. Anecdotes and a variety of studies provide convincing evidence that for a significant proportion of Americans, that ideal is not met. But we have few benchmarks to say how close we are to achieving it as a nation, nor do we have the means to monitor our progress toward it. We need to know more about the quality of life and the effectiveness of health care for people close to death in order to:

1. hold providers accountable for the quality of care they provide to patients and their families at such a difficult and vulnerable time,
2. allow caregivers to evaluate and continually improve their approaches to the care of dying patients and their families,
3. project future needs for health care resources for our aging population, and
4. advance research on the effects of standard and innovative clinical, organizational and financing options for end-of-life care.

In the course of examining the national-level information available to describe the quality of care and quality of life in America in the days and months before death, IOM uncovered wide gaps between what we should know and what we actually do know. Some of the gaps could be filled by fuller exploration and analysis of already-collected data, which would require only modest investments in research support. Other gaps in our knowledge could be filled by training researchers to use existing data systems to address questions about care of the dying, by making incremental changes in the content of existing surveys, and by improving the quality of the data recorded in those surveys.

One major new initiative recommended in the report is the establishment of an ongoing National Mortality Followback Survey program. National Mortality Followback Surveys (NMFS) can provide some of the most focused and relevant information about the dying process. They work by taking a sample of people who die each year and then interviewing the next-of-kin, who are named on the death certificate. Since the 1960s, six NMFS have been conducted in the United States, but no more have been planned. The previous surveys focused more on finding out about risk factors for the fatal illness (e.g., did the person smoke cigarettes?)—under the assumption that any death could be postponed. A new initiative—a program of regular, periodic, and comparable surveys—should focus on the period of dying. The design should include “oversampling” of children, to yield information on this understudied group. Minority populations also should be oversampled, to improve understanding of the ethnic and racial differences in the experience of death and dying in America.

The report also recommends that agencies promote research that uses existing data resources to describe aspects of the quality of life and quality of care at the end of life, by publicizing their availability and providing funding for analysis. A great deal of information is recorded for other purposes that could add to the knowledge base around care at the end of life. For example, Medicare records can be used to describe the types, amounts, providers and sites of medical care provided to beneficiaries in the period before death. These records have also been linked to

various health surveys and other datasets to enrich the information (with appropriate measures to assure confidentiality and privacy). While some work of this nature is done, it is limited by extremely low levels of funding.

Additionally, government and private organizations should institute training initiatives and make incremental changes to surveys to improve the usefulness of currently collected data in describing aspects of quality of life and quality of care at the end of life.



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Describing Death in America: What We Need to Know is available for sale from the National Academies Press, 500 Fifth St. NW, Washington, DC 20001; call (800) 624-6242 or (202) 334-3313 (in the Washington metropolitan area), or visit the NAP's on-line bookstore at www.nap.edu. For more information about the Institute of Medicine, visit the IOM home page at www.iom.edu.

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