

State Initiatives in End-of-Life Care

Issue 18, February 2003

Focus: Data-Driven Policymaking (An Update)

Using Statistics to Shape Agendas and Measure Progress

Over the past five years, the movement to reform end-of-life care policy has gained significant momentum. Today, scores of initiatives are underway at the community, state, and national level to improve care for the dying. While reformers continue to draw inspiration from their own personal and professional experiences, the use of statistics to shape agendas and measure progress is becoming more widespread.

Leading the way are health care professionals, academicians, legislators, administrators, and community activists who rely heavily on data to identify needs, establish priorities, engender support, and launch effective campaigns for change. Advocates have benefited from an increase in the availability of policy-relevant data concerning end-of-life care in recent years.

Much work remains to be done, however. Where serious data gaps persist, speculation and myth continue to prevail. And even where data are available, they are not being used in every possible arena to inform decisionmaking around end-of-life care. What are the barriers? It is possible that potential change agents lack proficiency with statistics. Or maybe they just assume that human experiences such as death and dying are best conveyed through stories rather than through tables and graphs.

While anecdotes can be very compelling, the power of statistics to describe populations, convey the scale and scope of problems, reveal trends, and document the impact of interventions should not be underestimated,

says Alvin Moss, MD, project director of the West Virginia Center on End-of-Life Care. Quantitative analysis represents a powerful tool for improving the quality of our lives—and our deaths. “If you are not using data,” says Moss, “you are missing the boat.”

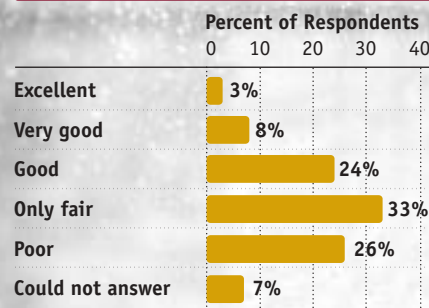
This publication provides examples of data-driven reform, lists good sources of data on end-of-life care, identifies some of the data gaps that remain, and shares practical advice from data experts across the country. ■

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Quantitative analysis represents a powerful tool for improving the quality of our lives—and our deaths. Survey data like these, for example, offer a compelling case for reform by revealing that a majority of Americans are not satisfied with the care available to dying people.

How Does the Current Health Care System Do in Caring for Dying People?



Source: National survey of 1,002 adults conducted by Lake Snell Perry and Associates for Last Acts, 2002

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Using Data to Drive Reform— Spotlight on West Virginia

Under the leadership of Moss, the West Virginia Center on End-of-Life Care (formerly the West Virginia Initiative to Improve End-of-Life Care) has had considerable success using data to drive legislative and regulatory reform in the areas of advance directives, professional training, hospice utilization, and pain management. In addition to relying on existing data sources, his team has collected new data through surveys and focus groups. According to Moss, these data have made all the difference. “Our legislature wants the data. They want to be convinced these are issues they should spend money on.”

Reducing Barriers to Continuity of Care

According to site of death statistics, only 15.5 percent of West Virginia residents died in a nursing home in 1997, well below the national average. To find out why, Moss and his team conducted interviews with health care providers and administrators who revealed that it was standard practice to transfer gravely ill nursing home residents to the hospital. The underlying assumption was that individuals

approaching death would fare better in hospitals, whether they needed curative or palliative care.

Moss was concerned about vulnerable residents being uprooted unnecessarily, separated from familiar caregivers, and subjected to invasive procedures. To make it easier for individual preferences concerning end-of-life care to be communicated and respected, his team developed the Physician Orders for Scope of Treatment (POST) form, a standardized form that incorporates a patient's advance directive. This form was adapted from Oregon's Physician Orders for Life-Sustaining Treatment (POLST) form.

The POST form was subsequently incorporated into the West Virginia Code through legislation sponsored by Vicki V. Douglas, a member of the House of Delegates with a strong interest in issues related to death and dying. State law now prescribes a protocol for the use of POST forms by all providers during inter-institutional transfers. Questions have been added to the state nursing home survey, meanwhile, to reveal how many resi-

dents are being transferred to a hospital at the end of their lives.

Improving Pain Management

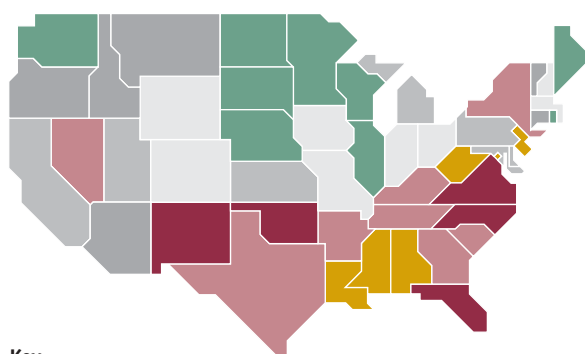
In 2000, the West Virginia Initiative to Improve End-of-Life Care convened focus groups, town meetings, and community dialogues to examine public attitudes about care for the dying. Content analysis revealed that pain was the biggest concern.

In response, the Initiative invited the state boards of medicine, nursing, pharmacy, and osteopathy to develop a joint policy statement with the goal of promoting better pain management. The outcome was so compelling that the West Virginia Legislature amended its Management of Intractable Pain Act to incorporate the new joint policy statement. The amended legislation educates health care professionals about the management of pain and gives them legal protection when they follow the guidelines outlined in the joint policy statement.

The joint policy statement is a great achievement, according to David Joranson, director of the Pain and Policy Studies Group at the University of Wisconsin Medical School, and a pain policy expert. He says it is unique in that it represents a broad consensus among multiple health regulatory boards, summarizes relevant laws and professional standards, encourages patient-centered communication and cooperation among the health care team, and promotes a “balanced” approach. This means concerns about drug addiction and diversion do not interfere with legitimate, medically-supervised pain management. “A number of states have policies aimed at encouraging pain management and end-of-life care...West Virginia has gone a big step further,” says Joranson.

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Proportion of Deaths Occurring in a Nursing Home, 1997



Data compiled by Brown University's Center for Gerontology and Health Care Research revealed that West Virginia had one of the lowest rates of nursing home deaths in the nation. This finding triggered legislative and regulatory reform aimed at honoring the wishes of dying patients.

Key		
12.6–16.5%	16.5–19.9%	20.9–22.8%
23.9–27.7%	27.9–30.6%	30.7–32.4%
33–57.7%		

The Importance of Legislative Champions



“End-of-life care is fraught with taboos and myths.... I used compelling, verifiable data to educate my colleagues and convince them that there was a mandate to act.”

Vicki V. Douglas

Vicki V. Douglas (D-Berkeley), a member of the West Virginia House of Delegates from 1990-2002, was instrumental in passing state legislation to improve care for the dying. Having witnessed more than one “bad death,” in which personal preferences were not honored, she entered the legislature determined to make it easier for dying individuals and their families. End-of-life care became her “legislative passion,” she says, and she distinguished herself by championing efforts in the areas of advance care planning, palliative care training, and pain management.

She credits the West Virginia Initiative to Improve End-of-Life Care with providing credible data that helped her prioritize goals and garner the support of her colleagues. “I am very information driven,” she says. “I knew it would be futile to appeal to the legislature on the basis of what I thought or what one doctor said. I wanted to be able to speak with some certainty.”

According to Douglas, state legislatures can leverage resources by empowering coalitions, associations, and other groups to gather information, analyze it, and then get policy recommendations back to the legislature. “Data collection need not be extraordinarily expensive,” she says. “By asking some simple questions, you can learn a great deal.”

Increasing Hospice Utilization

A review of West Virginia Medicaid program data in 1999 revealed that only ten nursing home residents across the state were enrolled in hospice each month. Alarmed by this low rate of utilization, the West Virginia Initiative to Improve End-of-Life Care convened a task force with representatives from the state nursing home association, the state hospice council, and the state office of health facility licensure and certification.

The task force concluded that Medicaid had created a financial disincentive for nursing homes to enroll residents in hospice. Specifically, hospice enrollees—who tend to be sicker than other nursing home residents—were excluded from the case mix used to calculate daily reimbursement rates, resulting in a lower base payment for all residents. To eliminate this disincentive, the task force convinced the state Medicaid office to change its regulations, allowing hospice enrollees to be included in the case mix. In just two years, the number of hospice enrollees in nursing homes is up 400 percent statewide.

Adding Professional Education Requirements

When the West Virginia Initiative to Improve End-of-Life Care surveyed residents about the quality of care available for the dying, fewer than 20 percent rated the care as “excellent.” A survey of doctors, nurses, pharmacists, and social workers throughout the state revealed similar perceptions.

The Initiative used these data to advocate for improvements in professional education. In 2001, the state legislature passed a bill, sponsored by Delegate Douglas, that requires doctors, nurses, physician assistants, and pharmacists to complete two hours of continuing education in end-of-life care to get their licenses renewed.

Benchmarking

West Virginia Healthy People 2010, a project based on the national Healthy People 2010 initiative, serves as the state’s plan for improving the health of its residents. “Measurement is the key to the development of West Virginia Healthy People 2010, and measurement is what sets this initiative apart from other efforts to improve the health of West Virginians,” writes Henry G. Taylor, MD, MPH, commissioner of the West Virginia Bureau for Public Health, in his introduction to the Healthy People 2010 report.

More than 300 target objectives have been established, including four related to end-of-life care:

- **Objective 29.1:** Increase the percentage of dying persons receiving hospice care to 25 percent (baseline: 13 percent in 1997).
- **Objective 29.2:** Increase the percentage of persons dying in their homes to 35 percent (baseline: 24 percent in 1997).
- **Objective 29.3:** Increase the percentage of persons receiving hospice care while dying in a nursing home to 10 percent (baseline: 2 percent in 1997).
- **Objective 29.4:** Increase the percentage of persons who have talked with their families and doctors about their preference for end-of-life care to 75 percent and increase the percentage of persons who have completed written advance directives to 50 percent (baseline: in 1999–2000, 60 percent reported talking with their family or close friend about the medical treatment they would or would not want at life’s end, and 34 percent had completed written advance directives). ■

Good Sources of Data on End-of-Life Care

Primary Sources

The **National Repository of the Minimum Data Set (MDS)**, maintained by the Centers for Medicare & Medicaid Services, consists of information collected by long-term care facilities to assess Medicare and Medicaid residents. The MDS is a useful tool for establishing baseline data on the frequency and severity of pain, use of feeding tubes, and prevalence of advance directives.
www.cms.gov/researchers/

Death certificates, on file in state vital records offices, provide information concerning the cause and location of death. The National Center for Health Statistics' **National Death Index**, a central computerized index of death record information, makes it easier for epidemiologists and others to conduct statistical research.
www.cdc.gov/nchs/r&d/ndi/ndi.htm

The **National Home and Hospice Care Survey**, administered by the National Center for Health Statistics, includes diagnostic and health status information on patients as well as data on types of services provided and costs of care.
www.cdc.gov/nchs/about/major/nhhcsd/nhhcsd.htm

Public opinion surveys about attitudes and preferences concerning end-of-life care are conducted periodically. In fall 2002, for example, Last Acts commissioned a survey of more than 1000 Americans, asking them to rate the overall quality of care for those who are dying as well as specific components of the care related to managing pain, providing emotional support, honoring patients' preferences and beliefs, and paying for care.
www.lastacts.org/files/publications/pollingdata.pdf

The **Healthcare Cost and Utilization Project**, a set of databases managed by the Agency for Healthcare Research and Quality, includes hospital discharge data that reveal the rate of dying during the hospital stay.
www.ahrq.gov/data/hcup

Health care insurance claims show utilization of services as well as costs of care. Large databases are maintained by the Centers for Medicare & Medicaid Services, state Medicaid offices, Blue Cross organizations, and other insurance providers.

Licensing boards, accreditation agencies, and professional associations compile data concerning **professional training and certification** in palliative care.

Brown University is in the process of conducting a **mortality follow-back survey** and capturing **end-of-life narratives** that together comprise "the largest study of dying that's ever been done," according to Joan M. Teno, MD, MS, principal investigator. Findings will be published later this year.

Secondary Sources

Compilations of data from a variety of sources

Means to a Better End: A Report on Dying in America Today, published by Last Acts in 2002, assesses the quality of end-of-life care in every state using eight measures: effectiveness of state policies in promoting advance care planning; proportion of deaths occurring at home; utilization of hospice care; availability of pain and palliative care services; utilization of intensive care for dying patients; extent to which pain is adequately managed in nursing homes; effectiveness of state policies in encouraging good pain control; and availability of physicians and nurses who are trained and certified in palliative care. Letter grades assigned to each state have caught the attention of legislators and health care leaders in communities across the nation. North Carolina's low rating ("D") in the area of advance directives, for example, convinced an elder law task force to survey attorneys, health care providers, and advocates to identify weaknesses in the state laws and obstacles to widespread use by consumers.
www.lastacts.org

The **1999 Dartmouth Atlas of Health Care** examined health care utilization by Medicare enrollees at the end of life by focusing on the following questions:

- When death occurs, is it in a hospital?
 - When death occurs, is it associated with admission to intensive care?
 - How many days do patients spend in the hospital during the last six months of life?
 - How many patients spend a week or more in ICUs during the last six months of life?
 - How does end-of-life care affect Medicare spending?
- www.dartmouthatlas.org

The **Facts on Dying website**, a project of the Brown University Center for Gerontology and Health Care Research, looks at twelve indicators of end-of-life care for each state and the nation as a whole. The site incorporates information from a variety of sources including the Brown Atlas of Dying which examines the trends in location of death for Americans with chronic illness from 1989 to 1997.
www.chcr.brown.edu/dying/factsondying.htm

Congress has charged the Agency for Healthcare Research and Quality in the U.S. Department of Health and Human Services with producing an annual report on the quality of the nation's health care. The first edition of the **National Healthcare Quality Report**, due this year, will include four measures related to palliative care for cancer patients and nursing home residents.
www.ahrq.gov/qual/nhqrfact.htm

Data Gaps Continue to Hinder Informed Decisionmaking

While statistics are being used effectively in West Virginia and other states to effect change through legislation and other avenues of reform, some serious data gaps remain. Addressing these gaps is key to promoting more informed policymaking at the local, state, and national levels.

End-of-Life Preferences

Surveys have revealed Americans' general preferences about end-of-life care such as the desire to be free from pain and to die in the company of family and friends. Extrapolating from general preferences to specific clinical situations, however, can be very tricky. Research is needed to determine which methods are most effective for communicating wishes to health care proxies so they can make informed decisions on behalf of their loved ones. The extent to which preferences expressed in advance directives are actually honored deserves attention, too, says Judith R. Peres, LCSW, deputy director of Last Acts. This would entail longitudinal research involving labor-intensive medical record reviews, or interviews with next of kin.

Continuity of Care

Site of death data are widely available; however, data related to continuity of care are more elusive. Dying individuals often receive care in a variety of settings—including intensive care units, long-term care facilities, and their own homes. The impact of transfers on quality and outcomes should be examined.

Dying at Home

It is easy to calculate rates of death in the home; determining the level of service utilized by individuals who die outside of institutions is more problematic, says Edward Ratner, MD, principal investigator for the Minnesota Partnership to Improve End-of-Life Care. Are they in hospice or benefiting from other home-based services? Or are they relying on friends and family to attend to their physical, emotional, and spiritual needs? Are caregivers—especially those who make major financial sacrifices to care for their loved ones—aware of and able to access adequate support services?

Professional Training

Palliative care certification for physicians and nurses is one metric for evaluating professional preparedness. The majority of health care professionals who care for the dying, however, are not certified. Without specialized education and training, do these professionals have the skills, knowledge, and experience to respond appropriately to the needs of patients who are gravely ill? Data are not widely available.

Cultural Competency

Information about the dying experience of minorities, including Hispanics and other non-English-speaking patients, is very limited. As noted in a recent Last Acts report, a few studies have been conducted at the national level but state and regional data do not exist. (Issues related to cultural diversity and discrimination are examined in a new *State Initiatives in End-of-Life Care* audio program. For more information, visit www.partnershipforcaring.org/statepolicy/audio-series/ or call 1-800-989-9455.)

Financial Implications

The relationships among cost, access, and quality of end-of-life care are not well understood. Preliminary data from the Promoting Excellence in End-of-Life Care program indicate it is possible to improve access to end-of-life care without increasing costs. The data also suggest that palliative care can actually extend the length of people's lives and significantly reduce costs associated with caregiver burden. Ira Byock, MD, program director, says further research is needed to confirm the validity of these preliminary findings.

Impact of Reform

It can be difficult to measure the impact of major end-of-life care policy changes, especially if the intervention is implemented statewide. "To find out whether Oregon's POLST program is influencing advance care planning," says Susan Tolle, MD, "we really need two to three states at various levels of roll-out."

Actions for Policymakers

In its recent report, *Means to a Better End: A Report on Dying in America Today*, Last Acts offers public policymakers some concrete actions for improving the quality of end-of-life care, including three related to data: "support large-scale demonstrations of promising models of coordinated end-of-life care that are likely to show both better quality of life for patients and families, and cost savings; collect data to assess quality, cost, and access to end-of-life care in a variety of settings; [and] develop evidence-based palliative care clinical protocols." ■

Practical Advice from Data Experts

Advocates for the dying should take advantage of the data resources available to help them advance their causes, says Joan M. Teno, MD, MS, associate director of the Brown University Center for Gerontology and Health Care Research. Tips from practitioners who have successfully launched data-driven reform efforts follow.

Choose Projects Carefully

“No one can afford to collect data for the sake of collecting data,” says Kandyce Powell, executive director of the Maine Hospice Council. “We focus on projects that yield useful information for an identified need.” The Maine Hospice Council conducts an annual census survey of volunteer and Medicare certified hospice programs. Findings from this survey appear in the Council’s annual report to the Maine Legislature, along with data from other sources.

Select Appropriate Sampling Strategies

Population-based research can be very expensive as well as administratively burdensome to carry out. Fortunately, it is almost never necessary. Using statistically representative samples will allow you to generalize your findings to a broader population. When working with small samples, however, keep in mind that anonymity should not be compromised. Tolle says she relies on statewide random sampling when collecting information about institutions or communities, and uses a sample size of at least ten to prevent specific constituents from being singled out.

Make Sure Your Data Are Credible

As Mark Twain observed, “There are three kinds of lies: lies, damn lies, and statistics.” When you use data, make sure they come from reputable sources. When you undertake your own data collection efforts, follow established protocols to avoid inadvertently introducing bias or error. “Our legislature comes back to us again and again because we focus on the truth,” says Powell. “They know they can trust us because we never manipulate our data [to advance a hidden agenda].”

Use Stories to Bring the Data to Life

“Appeal to the head and the heart by presenting statistics in conjunction with anecdotes,” says Victoria Weisfeld, senior communications officer at The Robert Wood Johnson Foundation. This is the approach Teno has adopted with her mortality follow-back survey. “I intend to show the rate of unmet need in the African American community and then provide a story about what that unmet need really means to someone whose loved one is approaching death,” she says.

Be Prepared for Setbacks

“Collecting data is risky,” says Tolle. “You might find out your intervention has failed, either across the board or in certain areas, with certain populations, etc. This is why it is so important to keep the end goal in mind. Our intent is always to improve patient care.” ■

Final Heart-to-Heart Audio Program Available

State Initiatives’ newest audio release, *Heart-to-Heart: Improving Care for the Dying through Public Policy: Part IV—Cultural Diversity and Discrimination*, is now available. This segment features initiatives that are promoting good end-of-life care for seriously ill individuals from different racial, ethnic, and cultural backgrounds.

For detailed information, sound clips, or to order tapes online, visit www.partnershipforcaring.org/statepolicy/audioseries/.

Call 1 (800) 989-9455 to order by phone.

Information about the Series

“Data-Driven Policymaking (An Update): Using Statistics to Shape Agendas and Measure Progress” is the eighteenth in a series of briefs profiling promising new policies and practices in end-of-life care.

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Last acts.
A national coalition to improve care and caring at the end of life

Last Acts is a coalition of more than 1,075 national and local organizations dedicated to improving end-of-life care. For more information about the Last Acts campaign, contact

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