

# State Initiatives *in* End-of-Life Care

Issue 1, June 1998

Focus: Oregon

## Using Qualitative and Quantitative Data to Shape Policy Change



Carole Archer/The Oregonian

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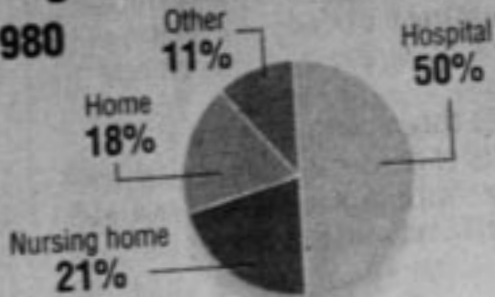
CAROLE ARCHER/The Oregonian

Frances Reinauer, 74, says when she has needed a more comfortable bed or medications better tailored to her cancer symptoms, her Mt. Hood Hospice caregivers, including nurse Joyce Taylor, are there to help.

## Where Oregonians die

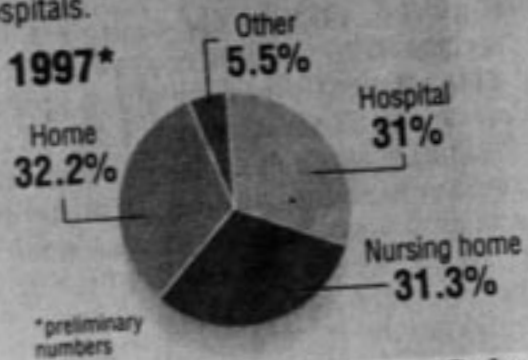
The popularity of hospice and in-home care and the state's advancements in end-of-life care planning contribute to fewer deaths in hospitals.

1980



Source: Oregon Health Division

1997\*



\*preliminary numbers

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## Using Qualitative and Quantitative Data to Shape Policy Change

When Oregon newspaper readers opened *The Oregonian* on April 1, 1998, they saw a familiar story: “Oregon has comfortable lead in nation’s end-of-life care.”



Since 1994, when a vote to legalize physician-assisted suicide shocked the medical community into reforming end-of-life care, articles like this have regularly reported evidence of Oregon’s progress in taking better care of the dying:

- expansive advanced directive legislation
- the lowest rates of in-hospital death in the U.S.
- exceptional and growing hospice utilization rates
- pioneering comfort care teams and pain management practices
- comprehensive end-of-life care for many poor citizens through the Oregon Health Plan.

While advocates readily acknowledge that their work is far from complete and that final conclusions about the effectiveness of their efforts must await more comprehensive analysis, Oregon’s status as a leader in end-of-life care is now also being acknowledged outside the state’s borders.

The April article’s graphic elements (facing page) also suggest a basic truth about reform’s education-driven successes: policy changes in end-of-life care have been significantly influenced by the savvy use of qualitative and quantitative data to engage a variety of audiences, identify problems, celebrate victories, and monitor progress.

The following pages attempt to suggest the richness and diversity of these data, as well as the variety of environments where policy—defined broadly to include legislation, curriculum, and standards of practice—has clearly been advanced.

# Simple Data and Stories Help Create a Climate for Change

## Effective Media Relations

Policy change has been possible in part because *The Oregonian*, the state's leading newspaper, is giving end-of-life care ongoing front-page coverage. In addition to providing hard news about problems and progress, the paper aims to engage readers personally by offering extensive feature treatment of how terminally-ill Oregonians and their caregivers are dealing differently with the end of life.

This exceptional coverage is also a function of leading reformers who have understood the importance of developing sophisticated media strategies and educating reporters. "Our use of data with the news media often precedes efforts to bring about change in other settings," says Susan Tolle, M.D., director of the Center for Ethics in Health Care, an institutional pillar of reform. "If data have not been presented effectively to a wider audience, we are unlikely to be of tremendous influence to legislative bodies. And don't forget that physicians read newspapers. There is no doubt that *The Oregonian* has made a huge difference. You can help change the culture of medicine through the popular press. Now the question is, how can we make the climate receptive to the next wave of changes?"

"If data have not been presented effectively to a wider audience, we are unlikely to be of tremendous influence to legislative bodies."

Tolle regularly discusses possible story ideas with reporters, often suggesting, for example, that news coverage be tied to the release of significant articles in national medical journals. The April news article in fact announced the release of a publication in the *Annals of Internal Medicine*. Tolle recommended and got an article that summarized progress but clearly identified unfinished business on the reform agenda. "Our more recent goal with *The Oregonian*," she acknowledges, "is to highlight Oregon's successes and contrast them with our continuing lack of universal access to hospice care."

Tolle and other reformers typically advance descriptive data as the framework for stories and offer plenty of support to reporters developing statistical interpretations: "You need to plan to educate reporters so that they can grasp data," says Tolle. "You've got to sit down with them person-to-person to walk them through charts and welcome questions back."



## Using Simple Descriptive Statistics

More often than not, these data have been drawn from readily available sources like *Oregon Vital Statistics*, or taken from small representative samples gathered by the Oregon Hospice Association, for example. Often data are coupled with illustrative patient stories

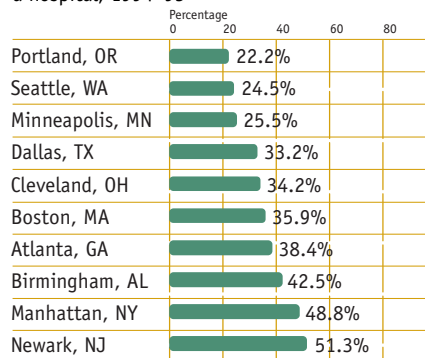
Invariably, such data are used to dramatize four central themes of reform:

### Low and Declining Rates of In-Hospital Death

Reformers consistently remind audiences that Oregon has the lowest in-hospital death rate in the nation; this distinction is typically attributed to high levels of advanced care planning and respect for patient wishes. Research-in-progress at Oregon Health Science University's Program of Research on Ethics and End-of-Life Care is also exploring potential problems associated with deaths outside hospital settings (More on this in the sidebar titled "Listening to the Voices of Bereaved Families," page 9). The positive and negative effects of managed care on place and circumstances of death are clearly in need of further study.

### Hospital Deaths in Selected U.S. Cities

Percentage of Medicare patients who died in a hospital, 1994-95

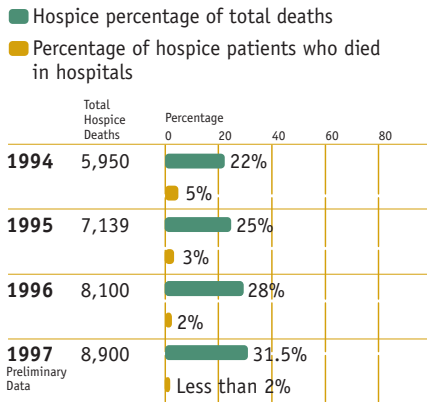


Source: Dartmouth Atlas of Health Care 1998

## Focus: Oregon

Using Quantitative and Qualitative Data to Shape Policy Change

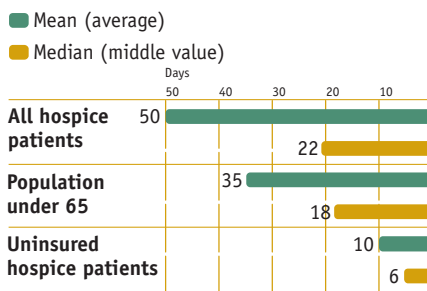
### Hospice Deaths in Oregon, 1994–1997



Of Oregonians who die, a growing percentage die in hospice care. Only a small percentage of hospice patients die in hospitals.

Source: Oregon Hospice Association

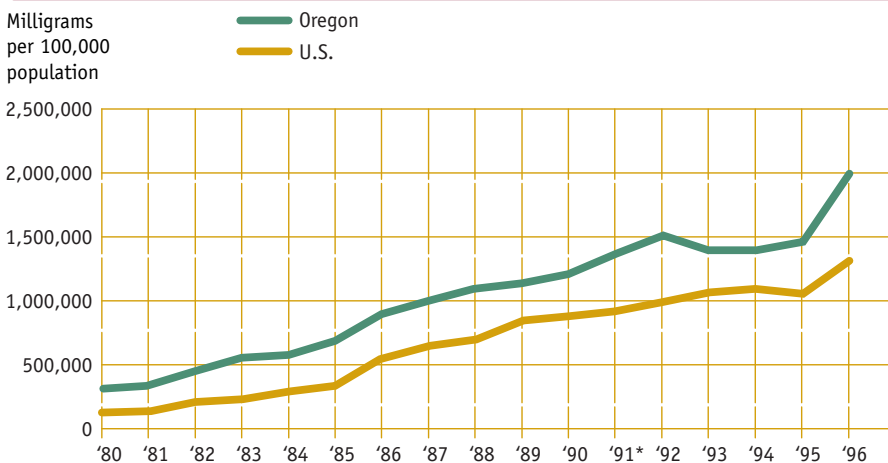
### Estimated Hospice Lengths of Stay, 1995



In Oregon, uninsured patients are being referred to hospice care much later and often in crisis. Data for 1996–1998 suggest that hospice stays are dropping for all populations.

Source: Oregon Hospice Association

### Morphine Prescriptions: Oregon vs. United States



Source: Office of Diversion Control, DADS Quarterly Reports, U.S. Dept. of Justice

\*1991 Data being reworked

### High and Growing Rates of Hospice Utilization

Another standard measure of success is Oregon’s growing hospice utilization rate. As the April article concludes, “Preliminary data for 1997 suggest that the rate has increased to 31.5 percent, which could put Oregon in the top three states in the nation for hospice penetration.” How Oregon is meeting the workforce demands of this dramatic change is a significant issue for analysis.

### Different Lengths of Stay In Hospice For Uninsured Oregonians and Other Populations

To press for universal access to hospice care, reformers offer data comparing the hospice stays of uninsured Oregonians to two other hospice populations: all hospice patients and those under 65. Uninsured Oregonians who do get referred to hospice have much shorter stays because they are referred later and often in crisis when their symptoms are out of control, according to advocates, who point out that lack of hospice coverage and referral problems have the effect of limiting access to comfort care measures, even though many hospices provide care without regard to patients’ ability to pay.

An emerging issue is the apparent local and national trend toward reduced lengths of hospice stay for all populations. “The downward trend in length of hospice stay since 1995 is truly alarming,” says Ann Jackson, director of the Oregon Hospice Association. “In one of our hospices, for example, the average length of stay has dropped from 52 days in 1996, to 45 in 1997, to 28 days in the first quarter of 1998. I wish I could say this is unusual, but it isn’t.”

Jackson attributes this trend to a wide variety of factors including adverse managed care treatment incentives, federal regulatory threats to penalize physicians who wrongfully certify patients as terminally ill, an increasing percentage of non-cancer patients with ambiguous prognoses, and physician inexperience with hospice referral.

### Aggressive Pain Treatment

The undertreatment of pain experienced by terminally-ill Americans is well documented in the SUPPORT study and elsewhere. To suggest the magnitude of Oregon’s progress in pain treatment for the dying, reformers offer statistics comparing Oregon’s prescriptions for morphine to those for the whole country. According to the U.S. Drug Enforcement Administration, Oregon ranks first among states.

## Survey Data Support Change in Curriculum and Clinical Practice

While much of Oregon end-of-life care reform has been played out publicly in task force meetings, citizen focus groups, and the media, significant advances have also been made quietly in clinical settings by doctors and nurses who saw problems, armed themselves with simple survey data, and used that data to argue successfully for internal policy change.

### Changing Medical School Curriculum

When Paul Bascom, M.D., came to Oregon Health Sciences University (OHSU) in 1995 from his community practice in internal medicine and hospice, his mission was to spend half his time providing direct care to patients and half making the principles of hospice care available to his colleagues and patients.

While Bascom was helping to establish a new interdisciplinary Comfort Care Team in the University's hospital, he was also beginning to notice that as more terminally-ill patients died with hospice support, outside of acute-care settings like OHSU, fewer medical students appeared to be getting experience caring for patients in the later stages of dying.

Rather than merely acting on his hunch, however, Bascom decided to administer a nine-item survey to graduating medical students. "When change has occurred," says Bascom, "gathering data has been the pivotal first step. You've got to get the evidence to provide the motivation for change. Patient stories are memorable and provide emotional weight. But anecdotes alone are ineffective, because they can be viewed as exceptions."

The survey, titled "Medical Student Experience In Caring For Dying Patients," sought to uncover both useful quantitative and qualitative information. To get directly at how much experience students had at caring for dying patients, the survey asked, for example, "How many times did a patient die while on your service and under your care?" and, "Have you observed or participated in...informing family of patient death?"

Additional open-ended questions gave students a chance to identify "distressing experiences" encountered while caring for the dying.

Survey results bore out Bascom's hunches. While 67 percent of those responding had had some experience caring for terminally-ill patients, their experience was typically limited to tertiary care settings during the early stages of terminal illnesses. Fully half of those responding had never witnessed a patient death, and 60 percent had never participated in notifying families of a patient's death.

Many students also reported distress in situations where "good deaths" were not being supported because of conflict within patient care teams, disjointed care, and physicians who were having difficulty honoring patient wishes.



*Paul Bascom (right) discussing the new hospice curriculum with third-year medical student Glen Patrizio.*

**"When change has occurred, gathering data**

**has been the pivotal first step.**

**You've got to get the evidence to provide motivation for change."**

Paul Bascom, M.D.

*“The whole goal, no matter how you go about it, is to create a passion, to make pain management a priority.”*

Lori Andreas, R.N., pictured far right

Bascom took these results directly to OHSU’s medical school curriculum committee, which responded with genuine interest and support. “Like so many others,” Bascom says, “They hadn’t yet grasped the magnitude of Oregon’s changing end-of-life care landscape and its implications for medical education.” Bascom argued for integrating a hospice option into the required rotation in community medicine so that the change would be seen as a mainstream educational opportunity rather than a narrow, isolated specialty.

In April 1998, OHSU launched a small pilot hospice option for medical students completing the required community medicine rotation. Participating students spend a half-day each week with a hospice care worker caring for a dying patient. Each student also follows a terminally-ill patient throughout the final weeks of life. Students will keep a journal of their experiences and will write a patient-centered narrative of the assigned patient’s life and death. Telling the “story of dying” allows students to record and integrate both the emotional and medical aspects of the dying process. Students in the pilot program share their journals with each other through a cyberspace link-up and receive feedback from Bascom.

New self-guided curriculum materials have been developed to augment the hospice experience. The materials cover four key areas of comfort care: communicating effectively with dying patients, managing pain, controlling common symptoms, and understanding the nature of suffering.

Bascom is continuing to administer the original survey instrument to monitor the impact of the pilot. Readers interested in more information about the curriculum changes may write Bascom at OHSU, 3181 S. W. Sam Jackson Park Road, Portland, Oregon 97201.

### **Reforming Hospital Pain Management Policy and Practices**

Survey data were also crucial to the success of the “5A/C Cancer Pain Initiative,” spearheaded by Lori Andreas, R.N., another member of OHSU’s Comfort Care Team.

Since the 37-bed “5A/C” adult oncology unit had a shared governance model, Andreas and other members of the unit’s quality improvement group decided to survey its medical personnel in order to identify projects to work on. The one-page survey they developed simply asked respondents to prioritize a list of possible issues. Two-thirds picked pain management as the first priority. “This was the beginning of a lot of interest and concern about symptom management—an attempt to heighten awareness about care of patients at the end of life and in active treatment,” says Andreas.

Two surveys were administered repeatedly in 1993. One, a ten-item questionnaire administered to cancer patients with significant pain, probed both for levels of pain and medical attention to pain treatment, posing questions like:

- What was your worst pain?
- What is your pain now?
- How long did you wait for medication?
- Did your doctor and nurse discuss pain treatment with you?
- Were you satisfied with your treatment?



The survey was administered four times and included approximately 50 patients in each sample.

Another 23-item survey aimed to identify the knowledge and beliefs of medical personnel regarding pain control, asking, for example, whether respondents believed patients had a right to have their pain fully relieved.

The initial administrations of both surveys demonstrated that levels of pain relief were not optimal, that patients needed education about their rights to receive adequate pain control, and that many medical professionals needed education to dispel pain treatment myths and improve technical skills. As change efforts proceeded, the surveys were re-administered to monitor results—which indicated significant improvements.

Armed with survey results, Andreas and others went to key internal OHSU policy committees to seek hospital-wide policy changes. Perhaps the most impressive outcome was the establishment of pain as the fifth vital sign, along with respiration, heart rate, blood pressure, and temperature. Patient charting practices were amended to make pain assessment routine. All patients now receive ongoing pain rating (on a scale of 1 to 10). A new analgesic flow chart to help

## Survey Data Support Change in Curriculum and Clinical Practice

*Continued*

medical personnel adjust dosages of intravenous and epidural medication based on pain assessments was also instituted. A database has also been developed for use in establishing pain diagnoses at the time of hospital admission, and a written policy on how to write pain medication titration orders for dying patients was put in place.

On the educational front, a new in-service training program for all medical disciplines was instituted, and a bill of rights for cancer patients was posted along with other educational material to encourage patients to request adequate pain control.

All these efforts brought about significant improvements in pain management, according to both Andreas and Bascom. Yet Andreas warns that training and education must be continuous because medical rotation in the academic setting creates a constant change of personnel and because “educating doctors is an ongoing struggle. What we found is if you get nurses invested, they help patients advocate, and patients then push doctors.” Technical changes, no matter how innovative and widespread cannot alone bring change, says Andreas. “The whole goal, no matter how you go about it, is to create a passion, to make pain management a priority.” ■

## Putting Academic Research Into Practice

The Program of Research on Ethics and End-of-Life Care, an arm of the Center for Ethics in Health Care, is another institutional pillar of Oregon’s end-of-life care reform. Situated in OHSU’s School of Nursing, the Program’s highly respected scientific studies have informed changes already in place and are working to identify remaining problems and solutions.

The Program is distinctive for its capacity to respond quickly and effectively to the rapidly changing local and national health care policy environment. When citizens unexpectedly passed the first U.S. law authorizing physician-assisted suicide, through a ballot measure, the Program quickly mounted an ambitious study of Oregon physicians’ attitudes and prac-

tices regarding physician-assisted suicide. Completed in little more than a year, the study’s findings were reported in *The New England Journal of Medicine* (February 1, 1996) and picked up by the national media while debate on the issue was still raging.

Yet, if the program is flexible and politically astute, it is also centered by a set of core values and themes. “We want to understand the families’ perspective in end-of-life care,” says Virginia Tilden, D.N.Sc., director of the Program: “what they need, what they actually got, and how much it costs them in all ways. The Program also seeks to honor patient values—helping people have the death they want. Finally, our research is concerned with making a difference in policy. Early research was descriptive. Now we are on the cusp of a policy push that will allow us to see and act on research implications for system change.”

The first major study in this “policy push,” titled “Barriers To Improving Care of the Dying,” will link consumer perceptions of problems and solutions to reform planning and action. For more on “Barriers,” see “Listening to the Voices of Bereaved Families,” on the next page. ■

*“Our research is concerned with making a difference in policy.... Now we are on the cusp of a policy push that will allow us to see and act on research implications for system change.”*

Virginia Tilden, D.N.Sc., R.N.

*“I want nurses and doctors to have training in school so that they realize the emotional impact of what they do.”*



# Listening to the Voices of Bereaved Families

## “Barriers” Study to Link Research and System Change

Much end-of-life care research is strictly quantitative, looking at dying through the dispassionate lens of morbidity and mortality statistics. Qualitative studies of end-of-life care often focus on the views and behaviors of medical personnel. Though useful, these approaches fail to capture the experiences of those on the receiving end of care: the dying and their family members. And, too often, research never reaches policy makers and practitioners working in health care settings.

A new two-year study nearing completion at the Oregon Health Sciences University’s Program of Research on Ethics and End-of-Life Care promises to overcome these limitations. Combining both quantitative and qualitative methods, the study, titled “Barriers to Improving Care of the Dying,” is capturing the wisdom of health care consumers. Investigators are also developing mechanisms to link study results with changes in policy and practice.

“We are listening to the voices of families,” says Virginia Tilden, D.N.Sc., one of the study’s principal investigators and director of OHSU’s Program of Research. “These are the people

who have actual experience with health care systems. They then become our partners in describing reality. We are not merely listening to voices of health care providers and statistical data.”

The two-year study is expected to advance knowledge about these key concerns of reform:

- whether patient and family wishes about where death occurs are being honored
- medical personnel’s knowledge and respect for patient desires about the use of life-sustaining treatment
- the effectiveness of pain and other symptom management
- the adequacy of resources and support available to all families in settings where death is likely to occur
- whether patient and family needs are being met in the rapid transitions from acute-care hospital to home now typical of managed care climate

*Continues*



*Members of the “Barriers” research team confer. From left: Chris Nelson, Virginia Tilden, Anne Rosenfeld, and Yon Park.*

## Family Members Speak Their Minds to “Barriers” Researchers

*“That he was at home. That was the best. When he was in the hospital I couldn’t really see him and I certainly couldn’t touch or hold him.”*

*“There was the insecurity of not knowing if my mom’s care would bankrupt us if she lingered.”*

*“I struggled over feeding [my mother] and did not realize she was dying and that the food would not help. Early education about the signs and start of death would have helped.”*

*“Because there were so many persons involved in her care, they didn’t pay attention to my comments, and there was a lack of communication between members of the health care team.”*

Listening to the Voices of Bereaved Families  
*Continued*

Using death certificates to locate a random sample of decedents' next of kin, researchers have already completed telephone interviews with 475 recently bereaved family members throughout the state to explore their perceptions about the care they experienced. Families whose loved ones had been hospitalized within 10 days of death and discharged to home without plans for re-hospitalization or hospice support were engaged in face-to-face interviews.

Although the study posed a number of forced-choice questions to identify predictable problem areas, it also employed open-ended questions prompting family members to recount their experiences and offer suggestions for improvement.

Several responses to these questions appear on the preceding pages.

When findings have been analyzed, investigators plan to produce a practitioner-friendly monograph of key findings and provide it to selected decision making personnel in a variety of health care settings. During focus groups convened by investigators, these key change agents will be asked to consider the relevance of top "Barriers" findings for their particular organizations, to plan change, and to implement solutions. Investigators will monitor and report on outcomes.

The "Barriers" study is funded by grants from The Robert Wood Johnson Foundation, The Meyer Memorial Trust, and the Open Society Institute *Project on Death in America*. ■

## Values Research Shapes Legislative Policy

Since the mid-1980s, Oregon health care has been heavily influenced by qualitative research into citizen values conducted by Oregon Health Decisions (OHD), a small, nonprofit, grassroots organization. The kind of values data that OHD brings to the change process is considered so essential that Tolle and Tilden, for example, call OHD another "pillar of reform."

Using focus groups and other forms of organized community discourse to help citizens give voice to their health care values, OHD identifies and then translates these values into policy-relevant language credible to consumers, health care providers, and decision makers in state government.

altogether. The Plan's backbone is a list of some 740 disease and treatment pairs ranked according to importance. Required by statute to build a consensus on the values to guide list development, the Oregon Health Services Commission asked OHD to conduct a community meeting process to identify the values. Ultimately, a total of 1,048 Oregonians gathered in 47



meetings throughout the state to reflect on the question, "Why are certain health care services important to us?"

Perhaps the clearest example of this translation is OHD's 1990 role in the development of the Oregon Health Plan. The Plan combines Medicaid reform and private insurance programs to reduce the number of uninsured citizens in Oregon. As part of its Medicaid reform, Oregon established a prioritized list of health services that legislators use when deciding how much to budget for Medicaid. The Plan is based on the assumption that all health systems ration in one way or another, and that fair rationing systems will be explicit in their choices and eliminate coverage for less effective and less critical services, rather than eliminating people from coverage

"Community compassion," including strong support for adequate pain relief and hospice care funding—comfort care—emerged as one of 13 values that would guide development of the Plan's prioritized list of diseases and treatments. (Readers interested in the full report may request *Health Care In Common*, by writing OHD at 812 SW Tenth Avenue, Suite 203, Portland, Oregon 97205).

Using a data-based formula including the values, treatment effectiveness measures, quality of life indicators, and cost figures, the Commission constructed a Plan list that made comfort care the seventh of 17 ranked

## Triggering Hopes, Fears, and Stories

categories. When the federal government disallowed all but the cost and values data—a result of misguided fears and election year politics, say state officials—the values data became even more instrumental in accomplishing Plan reconfiguration. As of 1998, comfort care is the 263rd of 574 funded items—well up in the permanently untouchable range, says Commission Director Darren Coffinan. The Plan and values discussions preceding it created a public recognition that comfort care was as crucial as health care at other times in life.

If the Oregon Health Plan development gave the state its first health care rationing system and a clearer sense of the value of comfort care, it also gave discourse on health care reform something equally important, if less tangible, says Mark Gibson, a leading health policy analyst in the Governor's Office: "It helped insurers, providers, and practitioners push aside taboos and break through the facade that somehow you can avoid difficult choices. Then blunt discussions became possible. After all, rationing explicitly is a choice, and once we had gotten over that hurdle, we had a new presumption for policy discussions: explicit is better."

Clearly part of this Oregon political ethic of openness and explicitness is a demand for policy choices based on a rich mix of factual information drawn from simple descriptive statistics, scientific research, patient and family stories, as well as citizen values. ■

The second issue of *State Initiatives in End-of-Life Care*, forthcoming in the summer of 1998, will provide more extensive coverage of OHD.

### How Oregon Health Decisions Uncovers Citizen Values

Michael Garland and Ralph Crawshaw, M.D., two of the founding fathers of Oregon Health Decisions, take great pains to make clear what OHD doesn't do: not citizen education, not priority setting, not opinion research, not satisfaction surveys. Instead, OHD searches for something deeper and more general: the basic values that should animate health policy choices. It also helps citizens define those values in ways that build community and inform policy.

want to leave something behind in a society that's cynical and alienated. Traditional surveys don't leave anything behind."

Garland, an ethicist at Oregon Health Sciences University, says OHD carefully designs community meetings to help citizens identify values. "Asking the public to set priorities among health services," he says, "assumes everyone knows more facts than is usually the case. For example, most citizens can't address a question like, 'What are the rates of success in

"Both patients and doctors suffer around end-of-life issues, and when we allow them to talk about why they are suffering we have a constituency. We must find ways of sustaining that discourse."

Ralph Crawshaw, M.D.

"Look for suffering," says Crawshaw, who is a psychiatrist. "People are reticent to talk about suffering. Both patients and doctors suffer around end-of-life issues, and when we allow them to talk about why they are suffering, we have a constituency. We must find ways of sustaining that discourse."

Before initiating discourse, OHD gets ironclad agreements with policy makers to honor the values uncovered in the dialogue process.

Then, rather than "calling a party," OHD tries to stimulate local democracy by seeking out local leaders and tapping into existing networks with ready-made constituencies like Oregon's Hospice Association or the local Rotary Club. "Anywhere where there are enclaves with a feeling of community," says Crawshaw. "We

intensive care for premature infants compared to success rates for treating skin cancer?" Instead, we should ask the public what they value; we should go to experts to ask about facts and probabilities. New policy should arise from this partnership."

Garland says the question that OHD most often asks citizens is a simple one: "What stories come to mind about health care? Then you get a man telling the group about Uncle George who had terrible cancer, but got such good care from a hospice, how the nurse understood what was going through his mind. You want to help people describe their hopes and fears about what's important, what they value. The abstracted value will be embedded in the story. That value becomes the goal and the specification for policy change." ■

# State Initiatives in End-of-Life Care

## Information About the Series

"Using Qualitative and Quantitative Data To Shape Policy Change" is the first in a series of briefs profiling promising new policies and practices in end-of-life care. Series issues 1-4 will focus on reforms in Oregon. Profiles of reforms in other states are now being planned.

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State Initiatives In End-of-Life Care is a publication of the National Program Office for Community-State Partnerships to Improve End-of-Life Care (C-SP), in cooperation with the Last Acts Campaign. C-SP is a national program supported by The Robert Wood Johnson Foundation with direction and technical assistance provided by Midwest Bioethics Center. The program promotes broad-based change in public policies and practices to improve care for dying Americans. Midwest Bioethics Center provides resources and education about ethical issues in health care to policy makers, professionals, and consumers.



We urge readers to send comments and suggestions regarding this and subsequent briefs via letter or e-mail to:

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## Acknowledgments

The National Program Office of Community-State Partnerships to Improve End-of-Life Care and its partners thank *The Oregonian* and Tom Reinauer for permission to use Frances Reinauer's picture on the cover and page 2, and gratefully acknowledge the many Oregonians who have offered their assistance in creating this brief:

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