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

Issue 8, April 2000 Focus: Long-Term Care—Part IV

Developing Quality Indicators for End-of-Life Care in Nursing Homes

One in five Americans died in a nursing home in 1993, and recent data indicate that, in some states, as many as one-third of citizens die in nursing homes. These figures highlight the importance of assessing and managing the quality of care dying nursing-home residents receive. Many experts believe that better measurements, stronger consumer education, and regulation that uses measures sensitively are needed. Several states—including Maryland, Rhode Island, Texas, and Utah—have shown leadership in legislating the production of report cards on quality of care in nursing homes. There are many opportunities for other policymakers to learn from these early efforts at the state level, and to that end, this brief will focus on Rhode Island's groundbreaking work.

INSIDE

In some states, one-third of citizens die in nursing homes, and it has been estimated that, within the next 40 years, 40 percent of all Americans will die in nursing homes. These figures highlight the importance of assessing and measuring the quality of end-of-life care provided in these facilities. This nursing home resident was served by Hospicare of Thompkins County.

Currently, nursing homes assess their quality of care using nursing facility quality indicators (QIs) developed by the Center for Health Systems Research and Analysis (CHSRA) at the University of Wisconsin–Madison and mandated by the Health Care Financing Administration (HCFA) in July 1999. The QIs are a set of 24 outcome measures in 12 domains—accidents/injuries, behavioral/emotional patterns, clinical management, cognitive patterns, elimination, infection control, nutrition, physical functioning, psychotropic drug use, quality of life, sensory functioning, and skin care (for more detailed examples, see p. 2). These measures are taken at regular intervals to determine how many residents are and are not affected.

How the QIs Work

The QIs are derived directly from the Minimum Data Set (MDS) 2.0, a tool that nursing homes must use to gather data about each resident to develop their care plans.

For each QI, the numerator is the number of residents for whom the measurement applies; for most QIs, the denominator is the entire facility population. For example, for QI 7.3 on nutrition (see box, p. 2), the numerator is all residents with a feeding tube on the last MDS assessment; the denominator is all residents. The ratio, if high enough, results in a "flag" on the facility's Quality

Indicator Profile (see chart, p.5), a document used by state surveyors to identify potential problems in a facility's quality of care. The QIs on fecal impaction, dehydration, and pressure ulcers in low-risk residents—conditions which have special relevance to end-of-life care—flag "sentinel health events," meaning that if even one resident flags on these QIs, surveyors must investigate.

The QI flags are not meant to be proof of substandard care. Surveyors are instructed to refer to residents' care plans in investigating flags, but that doesn't always happen, says Judy Peres, M.S.W., Director of Health Policy at the American Association of Homes and Services for the Aging (AAHSA). About 700 of AAHSA's 3,600 member facilities helped pilot the QIs for two years before their debut last summer. "It's important to make sure that surveyors go back to the care plans to contextualize the data that the QIs generate. Surveyors are supposed to do this. But sometimes it's easier to just look at the flags and cite the facility," Peres says.

Limitations for End-of-Life Care

Ironically, some clinicians working in end-of-life care believe the QIs actually can *impede* good end-of-life care. They point out that the QIs contain no specific language pertaining to dying residents, or risk-adjustment to factor them out: many dying individuals, for example, stop drinking and eating as a natural part of the dying process and therefore are not being mistreated when food and water are not given. The QIs also do not delve into important end-of-life areas such as advance care planning or pain management, though many studies show pain is a major, unaddressed problem among nursing home residents.

"Where the QIs fall down is around dehydration," says Joan Teno, M.D., M.S., Associate Professor of Community Health and Medicine at Brown University's Center for Gerontology and Health Care Research. Teno posits that the QIs ought to factor out actively dying residents whose advance care plans include a preference for no hydration. Teno, associate medical director of Hospice Care of Rhode Island, who cares for dying patients in nursing homes, says, "Artificial hydration may cause severe suffering in that fluids can collect in the lungs and dying residents can't breathe. They suffocate and die in their own fluids."

Teno and other researchers have suggested not only that new QIs be developed specifically for dying residents, but also that the MDS be revised to collect data more efficiently to explore other areas in more detail when needed—such as advance care planning, spirituality, and patient satisfaction.

HCFA is in fact developing new data-set modules for different nursing-home populations—short-stay, palliative care, and pediatric—which may address some of these concerns. Each module will have its own tailored set of QIs, according to Sue Nonemaker, R.N., M.S., technical advisor in HCFA's Office of Clinical Standards and Quality. These modules and QIs are at least three years from being ready.

InterRAI, an international group working for standardized assessment of quality of care for the elderly, both to improve care and to guide policy developments, is also working on a palliative care assessment module to gather data across all care settings.

InterRAI's module is currently being field-tested, says John N. Morris, Ph.D., an interRAI fellow and prime MDS researcher who is also working on HCFA's new modules.

While these projects are being finalized, consumer groups continue to push for release of information about quality of care. Public reporting of quality, Nonemaker says, is a policy issue that is "very hot and politically sensitive. HCFA is committed to getting more information to consumers. But you have to be sure you have appropriate scientific research to undergird your measures, and then make sure the information is understandable and is in the appropriate context for consumers." ■

Examples of Quality Indicators

Examples of QIs Derived from MDS 2.0 that Bear Particularly upon End-of-Life Care

- QI 5.4 Prevalence of Fecal Impaction: Residents who have been noted with a fecal impaction on their most recent assessment.This QI is considered to be a sentinel health event.This QI is not risk adjusted and the denominator is all residents on the most recent assessment.
- QI 7.3 Prevalence of Dehydration: Residents who have been either coded with the condition of dehydration or with a diagnosis of dehydration. This QI is not risk adjusted and the denominator is all residents on most recent assessment.

Source: Center for Health Systems Research and Analysis (CHSRA), University of Wisconsin–Madison

Possible Patient-Centered QIs on End-of-Life Pain Control

- Did patient have access to as much pain relief as patient wanted?
- To what extent could patient control amount of pain medication?

Source: Fowler FJ et al. "Methological Challenges for Measuring Quality of Care at the End of Life." *J Pain & Symptom Management* 17:2, 118

Breaking Ground in Quality Measurement and Reporting: Rhode Island

Legislating the Public Reporting of Quality

In order to provide more information about quality of care to its citizens, Rhode Island—38 percent of whose residents die in nursing homes—instituted the Health Quality Performance Measurement and Reporting Program. A 1998 law requires the state department of health (RIDOH) to assess and begin to report publicly the quality of care in its 13 acute-care facilities and in its 107 nursing homes. Other states, including Maryland, Texas, and Utah, have passed quality-reporting legislation, but Rhode Island is the first to call for comprehensive statewide assessment and public reporting of patient satisfaction, core clinical measures (quality of care), and administrative data for all licensed health care facilities, says RIDOH Deputy Director William Waters, Ph.D.

Reports will be formulated for use by consumers, providers, payers, purchasers, and health plans, Waters says. "The first market that might come to mind is consumers, but the reports will really go beyond consumers. The main impact . . . is to establish a feedback loop to the industry itself. We believe that bringing quality information into the public arena will itself result in quality improvement."

Data on individual facilities will be published, though RIDOH is still considering how to do this, according to Waters. The law requires reports to be designed for both internal quality improvement and external accountability. One hoped-for by-product of the law could be to defuse the wariness that exists between nursing facilities and state surveyors, by creating an additional incentive separate from the survey process.

"Our goal is to get information out about quality in a responsible way, in order to help consumers make better decisions. Ultimately, as a result of this law, we hope that every piece of the long-term-continuum—from visiting nurses to nursing facilities—will provide higher quality care," says Lt. Gov. Charles J. Fogarty, who heads up the state's Long-Term-Care Coordinating Council.

If this law represents a policy bellwether, Waters says, it is that "it's no longer satisfactory for state health departments to regulate providers behind the scenes…. The whole psychology of information about quality is changing with the Internet. People will want to have access to that information, and the technology makes it possible. The challenge for health departments is to collect and analyze these data in a responsible way, then make the information accessible and understandable to the public."

RIDOH will get some help in this task from Aging 2000, a media-savvy, non-profit, consumer-education organization that recently joined with the Long-Term-Care Council and the state's Department of Elderly Affairs (DEA) to publish a 1999 consumer guide on long-term care. The guide collects information about community and in-home services, residential facilities, financial and legal planning, and Medicare fraud into a single booklet. It was inserted into the Sunday Providence *Journal*—circulation 225,000—and covered by the NBC affiliate's news programs every day for an entire week after release.

Aging 2000 plans to use RIDOH's data and similar media saturation to reach a mass audience with a new publication on Performance Measures in Nursing Homes scheduled for 2002, says Ed Zesk, the group's Executive Director. The group wants a clear, unambiguous consumer guide to how quality is measured and the state of the quality of services in Rhode Island nursing homes, Zesk says. Though the law stipulates that the report should "show how individual facilities compare," Zesk says, "Our purpose is not to rank nursing homes, but to look at their performance alongside national data and facility-specific trends over time."

Educating future nursing-home residents and relatives is another of Aging 2000's priorities. Educating residents and families to negotiate and advocate for top-quality end-of-life care in nursing homes, says Zesk, is "one catalyst to get the system to act like a system. The care a patient receives may, for example, be a result of how the facility is reimbursed for the costs of care. We want to change that and make sure the care a patient receives is the care the patient actually needs."

Aging 2000 will raise public awareness by helping to develop an end-of-life care consumer guide, to be issued concurrently with a PBS television series ("On Our Own Terms: Bill Moyers on Dying in America," Sept. 10–13). The guide will be launched with the same local media campaign that made previous guides so popular that they were in demand in adjacent states, says Zesk. The guide's audiences will include not only the elderly—prospective nursing home residents—but also adult children of the elderly.

The guide also will be used in workshops about end-of-life care and nursing-home issues targeted to senior citizens and future family decision-makers. The agency is recruiting volunteer retirees—former physicians, nurses, social workers, educators, and other professionals well-known on

"Ultimately, as a result of this law, we hope that every piece of the long-term care continuum—from visiting nurses to nursing facilities—will provide higher quality care, will have appropriate clientele, and will not necessarily be competing with other segments."

Lt. Gov. Charles Fogarty, D-Rhode Island

their home turfs—to conduct these workshops. A spring 2000 series will focus on Advance Care Planning for Consumers; fall 2000 workshops will address Advance Care Planning for Surrogates.

Coalition Seeks to Develop End-of-Life QIs

Aging 2000 is just one member of a multi-disciplinary Rhode Island coaltion working under the new law to help nursing homes with internal quality improvement in end-of-life care.

Funded by The Robert Wood Johnson's Community-State Partnerships to Improve End-of-Life Care Program (C–SP), the coalition also includes representatives from the following groups: the state executive branch, RIDOH, state surveyors, consumer groups, clinicians, the University of Rhode Island, Rhode Island Quality Partners (RIQP)—the state's peer review organization, contracted by HCFA to do quality assurance review regarding Medicare patients—as well as nearly one-third of the state's nursing homes. Teno, who played a major part in gathering such a diverse group of stakeholders, is particularly gratified that both for-profit and non-profit nursing homes are involved. "The good news is that every segment is willing to work together on the initiative," Teno says. David Gifford, M.D., Assistant Professor of Medicine and Community Health at Brown and RIQP's Clinical Coordinator, agrees: "The level of cooperation has been tremendous." He adds adds that the coalition has created synergistic working relationships that benefit all parties—and, as a result, nursing home residents.

HCFA, too, recognizes the importance of working in coalitions. "We have a long history of coalition-building with all our MDS development, and we intend that to continue in our QI work," says HCFA's Nonemaker. "To make this kind of initiative work, you have to bring in all the relevant players." Nonemaker adds that raising awareness of good palliative-care practices is necessary for both facility clinical staff and surveyors, and HCFA hopes to work in this area over the next few years.

The coalition hopes to formulate three or four new indicators on pain management and advance care planning for dying residents, and to test whether and how much the QIs improve quality of end-of-life care, says Teno. The Rhode Island legislation calls for measurement of patient satisfaction; likewise, the coalition wants QIs to focus more on patient satisfaction than do the current QIs (see box, p. 2), to help facility staff "tailor" care plans to each resident. Elma Holder, M.S.Ph., founder of the National Coalition for Nursing Home Reform, a 25-year-old consumer advocacy group, notes that this is consistent with consumers' preferences: "We need to tailor care to individuals. Everything has to be resident-centered and related to a real person, and not just to information on paper."

The coalition wants to stress to facilities that QIs can be used not just for external accountability, but also for internal quality improvement. Participating Rhode Island homes will use the new QIs to conduct a 15-month continuous quality improvement (CQI) process, repeatedly charting residents' outcomes on pain management and advance care planning; through multiple cycles of evaluations done in real-time, the coalition hopes that nursing homes will sustain performance improvements in these domains.

If the coalition can show that their QIs help facilities achieve better outcomes for dying residents, the next step would be to advance Rhode Island's QIs as candidates for use in HCFA's mandated set. HCFA has contracted with a team at Brown to develop pain QIs, so national influence is a possibility. ■

Using QIs Constructively for Nursing-Home Regulation

Fostering Sensitive Use of QIs in the Survey Process

Some clinicians believe the QIs themselves can lead to substandard end-of-life care and to tension between facilities and surveyors responsible for investigating QI flags. Others suggest the federal nursing-home regulations and interpretive guidelines for the QIs create additional barriers to good end-of-life care in nursing homes.

One example is the federal regulation on weight-loss, says Peres. "If the regs are calling for residents to be weighed every day, and the staff is not weighing a patient who's dying, then they can get cited," she says. Peres suggests that, to preclude such misunderstandings, specific palliative care standards, as well as a requirement that surveyors always to refer to residents' care plans, could be built into HCFA's regulations and interpretive guidelines.

HCFA's new MDS modules may alleviate at least some of this tension. Till then, "[Surveyors] have to go behind the flags," Peres says, "and look at whether the resident is in selective hospice or has a living will or an advance care plan—otherwise we'll have facilities doing poor palliative care because they're scared of the $10,000 fine." Peres notes the case of one member facility, fined for inadequate nutrition and hydration in a dying resident. "They had all the documentation and they were still not able to get it overturned on appeal. So they had to pay the fine," Peres says. Facility staff and administrators need only one story of this sort to be convinced to meet QIs "by the book"—even if a resident is dying and the rules don't make sense.

The QIs as a "Work-in-Progress"

David Zimmerman, Ph.D., Director of CHSRA, which developed the QIs, acknowledges

What "Flags" Might Say—and Not Say—About Quality of Care

Sample Facility Quality Indicator Profile

Run Date: 9/20/1999 3:16:13 pm
Facility: CHSRA SAMPLE 01, MADISON
Comparison Group Used: All State Facilities: Apr–Jun, 1999

Report Period: 1/1/1998 to 6/30/1998
Data Submitted By: 9/19/1999
Facility Login ID: T1

Domain/Quality Indicator	# in Num	# in Denom	Facility Percent	Comparison Group Percent	Percentile Rank
Nutrition/Eating					
Prevalence of weight loss	15	105	14.3	12.4	67
Prevalence of tube feeding	7	105	6.7	4.9	75
Prevalence of dehydration	3	105	2.9	1.6	83

Source: Center for Health Systems Research and Analysis (CHSRA), University of Wisconsin–Madison

Facility Quality Indicator Profiles are designed to show each nursing home how its quality of care rates according to the QIs. The excerpt above shows one nursing home's performance in the Nutrition/Eating category—a domain that those working for better end-of-life care say the QIs could measure more selectively, in particular for residents who are actively dying. The "flag" in the bottom right-hand corner is a sign to state surveyors that this nursing home's treatment practices should be investigated. The presence of dehydration qualifies as a "sentinel health event": if even one resident flags as dehydrated, surveyors must investigate. Those working in end-of-life care point out that actively dying residents normally stop drinking, and nothing should suggest that it is substandard treatment not to administer fluids. However, the goal of most nursing homes is, reasonably, to minimize the number of flags on their profiles—so, end-of-life-care experts posit, their staffs may engage in treatments that work at cross-purposes with good care for dying residents.

that they "have some but limited value for patients at the very end of life. But that doesn't constitute a very high percentage of all nursing home residents, so that population's significance, while clearly important, shouldn't be overestimated," he says. "Issues about quality of care at the very end of life are an excellent reason why the QIs should be used in combination with subsequent review. Before the quality of care at the very end of life can be adequately assessed, the instruments that produce the measures will have to be more sensitive to resident status."

Zimmerman also believes the QIs should be viewed as a work-in-progress; it is clear they are widely considered to be in their infancy. Future revisions to the QIs, he says, will help eliminate misunderstandings between facilities and regulators. "You're going to see refinements in the risk-factors, more precise risk-adjustments, and in the threshhold levels at which [a treatment] becomes problematic"—in other words, the sensitivity with which the QIs raise flags about a nursing-home's practices.

Other experts suggest that QI development, to function at its best, must be informed by more data about the end-of-life experience—data that currently is sorely lacking. "We don't have enough national data on what people experience at the end of life," says interRAI's Morris, who co-directs the Hebrew Rehabilitation Center for the Aged in Boston, affiliated with Harvard University Medical School and, with 720 beds, one of the largest nursing homes in the country. "There is no ability today to do the kind of quality assessment in nursing homes that we ought to be doing because we don't have a requirement of a discharge assessment." When an HRCA resident dies, the staff reviews the resident's chart and MDS assessments to glean data about the last seven days of the resident's life. "This data has been very helpful to us in our work on new assessment modules," Morris says. Morris advocates for a required end-of-life assessment with the implementation of new MDS modules and QIs.

Using QIs to Encourage Internal Quality Improvement

Both the Rhode Island coalition and AAHSA are encouraging their participating nursing homes to approach the QIs proactively—as a toolbox that can free them to provide the best care possible. Rhode Island hopes to do this with its 15-month CQI process, while AAHSA is developing a technical assistance guide to help facility staff use the QIs to implement CQI programs. AAHSA expects to issue it to member facilities later in 2000.

"The QIs can really provide a snapshot of where you are," says Peres. "Some of our excellent facilities are making bar charts for different floors or teams, and tracking them weekly or even daily." Mary Jane Koren, M.D., M.Ph., Vice-President of the Fan Fox and Leslie R. Samuels Foundation and former director of the New York State Health Department's Bureau of Long-Term Care Services, agrees: "QIs can be useful not only for facilities to look at their own performance, but also to compare themselves to their peers—since often facilities operate in relative isolation. They can have a development of benchmarks against which they can try to perform."

Ultimately, using the QIs in this way redirects facilities away from fear of citation toward patient-oriented and family-centered care. It can work hand-in-hand with coalition-building to get facilities and regulators working not at cross-purposes but for the same thing—top-quality care. ■

Information About the Series

"Long-Term Care—Part IV: Developing Quality Indicators for End-of-Life Care in Nursing Homes" is the eighth in a series and fourth in a mini-series of briefs profiling promising policies and practices in end-of-life care, and the third in a mini-series about improving end-of-life care in nursing homes.

Executive Editor:
Myra Christopher
Director, Community-State Partnerships to Improve End-of-Life Care;
CEO, Midwest Bioethics Center

Researcher and Writer:
Jennifer Matesa
Associate, Spann Publications Consulting, L.L.C.
Pittsburgh, PA

Designer:
Rob Henning
Rob Henning Design
for Spann Publications Consulting, L.L.C.

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 policymakers, professionals, and consumers.

To Order Publications

To order additional copies of this publication, phone, write, or fax Community-State Partnerships (C-SP) at the following address and reference **Issue #8** in your request.

Previous issues of this series are available. C-SP will provide a list of available back issues upon request. They are also available online at www.lastacts.org.

Community-State Partnerships to Improve End-of-Life Care
Midwest Bioethics Center
1021–1025 Jefferson Street
Kansas City, MO 64105-1329

Telephone (816) 842-7110
Fax (816) 842-3440
E-mail partners@midbio.org
Web site www.midbio.org

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

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

Last Acts is a coalition of 449 national and local organizations dedicated to improving end-of-life care. For more information about the Last Acts campaign, contact

The Robert Wood Johnson Foundation
Route 1 and College Road East, P. O. Box 2316,
Princeton, NJ 08543-2316

Telephone (609) 243-5926
Fax (609) 452-1865
E-mail lastacts@aol.com
Web site http://www.lastacts.org