

State Initiatives *in* End-of-Life Care

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Focus: Long-Term Care—Part I

Promising Educational Initiatives for Staff, Regulators, and Families

As medical technology lengthens the lifespan, nursing homes have become a long-term care solution for elderly Americans who need time-consuming skilled attention usually not available at home.

About one-third of Americans now pass through a nursing home before they die, and the average stay is four years (hospital stays, by comparison, average just three days). About one-fifth of Americans die in a nursing home. This figure is increasing as nursing homes attempt to lower their rates of hospital transfer for residents at the end of life, to allow for peaceful deaths “at home” rather than in an acute-care facility. The number of Americans who spend their final days or years in a nursing home is only expected to increase as the baby-boom generation ages.

Because nursing homes and other long-term care facilities are growing in their importance as end-of-life care providers, they have become a focus for reforms seeking to improve palliative care and general quality of life for dying Americans.

This issue of *State Initiatives in End-of-Life Care* is the first of four briefs examining different approaches to long-term care reform:

- educational interventions for nursing home staff, regulators, and families of residents



At Chapel Hill Rehabilitation and Health Care Center in North Carolina, a certified nurse assistant uses pillows to reposition a resident. Repositioning is an important skill that CNAs can use to give comfort to residents at the end of life.

- municipal and regional long-term care ethics committees and consortia
- finance and reimbursement issues
- advances in developing quality indicators for palliative care and treatment in the long-term care setting.
- breaking down nursing homes’ isolation and sharing best practices
- educating nursing home staff, especially nurses and certified nursing assistants (CNAs), about the ethics and practices of palliative care
- involving state regulators in training nursing home personnel about the ethics of end-of-life decision-making
- helping physicians communicate better with residents and their families about death and dying.

Since good end-of-life care is so dependent upon the skills and attitudes of all those who treat and support residents at the end of life, continuing education is a necessary—if not solely sufficient—reform intervention. This brief looks at a range of educational initiatives either now under way or planned to begin in 2000. Each shares one or more of the following goals:

Educating Nursing Home Staff: Challenges and Opportunities

The recent shift toward permitting residents to die within nursing homes has been difficult for some nursing home staff. Nursing homes have long

Promising Educational Initiatives
for Staff, Regulators, and Families
Continued



“The number-one factor for [a nursing-home educational initiative’s] success is faculty commitment....It’s a very labor-intensive process, but I’m convinced that anything short of that doesn’t work.”

David E. Weissman, M.D., Professor, Medical College of Wisconsin (Milwaukee) Palliative Care Program

attempted to keep the numbers of nursing home deaths low, and many nursing homes lack clarity about whether and how to care for the end-of-life resident, for whom dementia is a common and difficult complication. Many physicians, including medical directors, lack palliative care training, or even interest in talking to their patients about the dying process. These tasks are often left to social workers, chaplains, nurses, and CNAs, all of whom are often equally undertrained in this area. Tension and turnover in nursing homes are high as a result.

Add to these limitations the lack of financial resources, and the question is bound to surface whether educational initiatives can offer any promise of better care within nursing homes. Yet nursing homes possess other resources that uniquely position them to become expert providers of end-of-life care: nursing home staff usually have years to get to know residents, and nursing homes are required by law to use multi-disciplinary teams, an approach to palliative care that works best.

“Meeting the minimum rules and regulations required to be accredited is virtually the only system-wide incentive behind any behavior change in the long-term care system,” says Knight Steel, M.D., President of the American

Federation for Aging Research. “If you’re going to train nursing home staff, you need to recognize, create, and implement other incentives.”

Ira Byock, M.D., Research Professor of Philosophy, University of Montana (Missoula), suggests that attempts to change staff behavior ideally should offer personal incentives. “The issues of staff retention and compensation and staff-to-resident ratios ought to be part of any long-term care educational initiative. . . . The turnover of personnel is a severely limiting factor for any educational initiative in the long-term care setting. Even if staff do obtain

skills, they may not be able to apply them because they are caring for far too many people with far too few resources.”

But Byock stresses nursing home staffs’ desperate need for the knowledge and practical experience, as well as the morale boost, that training programs can give. “Educational initiatives still can do a great deal to contribute to a sense of stature for a long-term-care staff—especially for nurse assistants. CNAs are the real heroes of long-term care. They are the Rosie-the-Riveters of this age’s greatest social challenge.”

LTC Peer Workgroup Set to Convene in 2000

A new Long-Term Care Peer Workgroup will be jointly headed by two Robert Wood Johnson National Program Offices—the Community-State Partnerships to Improve End-of-Life Care (C-SP) office, directed by Myra Christopher, who is also director of Midwest Bioethics Center; and the Promoting Excellence in End-of-Life Care office, headed by Ira Byock, M.D. Chaired by Knight Steel, M.D., the workgroup will gather a diverse membership of innovators and emerging leaders in the end-of-life care

field, with the goal of jump-starting change. “We want to bring people already working in the field into focused conversation about how to improve the quality of long-term care and the quality of life of people living in long-term care facilities,” Byock says of the workgroup, slated to begin by 2000. “The culmination will be a set of recommendations for policy-makers and private and government funders of health care research—recommendations for a research agenda that will rapidly advance the field.”

Indeed, training programs are being designed and implemented for nursing home staff, using incentives other than financial rewards. Some have hard data to prove their effectiveness. For example, a Wisconsin program has found that, in lieu of financial or other incentives, intensive training can help nursing home staff retain and apply new knowledge. The program, led by David Weissman, M.D., a professor in the Palliative Care Program at the Medical College of Wisconsin (Milwaukee), helped staff in 87 nursing homes learn to implement standardized pain assessment and management tools, and to sustain that learning over time. Before the intervention, only 14 percent of facilities had more than half the indicators in place; two years later, after the intervention, 76 percent had institutionalized more than half the indicators. The project achieved this success despite “a financial *disincentive*” to participate, Weissman says. “The main incentive was an extremely strong feeling among facilities that they were not doing a good job with regard to pain management. Also, the state regulators were beginning to look at pain management in nursing homes.”

The project depended upon “a stable facility management,” specifically directors of nursing who intended to remain at their posts, Weissman says. The project targeted staff “in senior level management areas who could make change happen.” Most of the facilities have asked for a continuation of the project past its original two years because of the instructors’ dedication. “The number-one factor for [a nursing home educational initiative’s] success is faculty commitment,” Weissman says. Sustaining knowledge among nursing homes requires “a very intense involvement. There was a lot of coaching by faculty nurses” at each and every one of the 87 facilities. Because facilities have vastly different populations and staffs,



he says, “it’s a very labor-intensive process, but I’m convinced that anything short of that doesn’t work.”

A North Carolina-based coalition funded by the Soros Foundation’s Project on Death in America and the Robert Wood Johnson Foundation’s Community-State Partnerships to Improve End-of-Life Care (C-SP) is also finding ways to motivate nursing home staff without financial incentives. The coalition is in the middle of a pilot series of on-site classes for nursing home nurses, CNAs, and social workers that seeks to get them thinking consciously about specific ways to improve residents’ end-of-life care. Laura Hanson, M.D., who co-directs the project with geriatric nurse practitioner Martha Henderson, and who trains staff in two nursing homes as part of the project, says outcomes include measuring staff and family satisfaction with symptom management and implementing advance care planning during the dying experience. Nursing administrators are being trained to facilitate hospice referrals and improve documentation of advance directives.

Hanson said financial incentives and the opportunity for job promotion should be part of an ideal nursing home educational program, but the coalition could not afford these. “The money simply isn’t there for pay raises,” Hanson says. “For now, our

A Good Nursing-Home Training Initiative

- helps facilities craft and institutionalize processes that eliminate organizational, social, and cultural barriers to better care
- has an interdisciplinary approach
- is on-site and hands-on
- employs user-friendly assessment and charting tools
- teaches pain assessment on an emotional and spiritual—not just a physical—level.

incentives include making it easier for employees to do their job, helping them do better teamwork, and offering a lot of praise and support.”

Breaking Down Nursing Homes’ Institutional Isolation

From 1980 to 1987 the Teaching Nursing Homes program attempted to improve long-term care and nursing instruction by placing academic nurses within nursing homes and appointing nursing home nurses as lecturers at nursing schools. A dozen years after its funding ran out, the program has sustained links in nearly 50 percent—five of 11—of its sites. This figure pleases its former director, Mathy Mezey, R.N., FAAN, who now directs the Hartford Institute of Geriatric Nursing at the New York University Division of Nursing.

Out of that project came the idea for the Practice Improvement Clusters (PICs), Mezey’s current project. A component of a two-year program funded by C-SP, the PIC model is fostering opportunities for nursing homes to share knowledge and practices and to collaborate on clinical improvements. One of PIC’s incentives for staff is the chance it offers to break the institutional isolation within which nursing homes operate. “Nursing homes very much work within their own walls,” Mezey says. “We want to give staff the sense that they’re part of a movement.”

The state will be divided into seven regions, with seven to 10 model nursing homes per region. Each region will have a community-based expert to lead its PIC team, and each regional team will work with its expert to identify issues for educational sessions. Likely issues include pain assessment and management in dying residents with dementia; developing methods to assess the necessity of hospital transfers for dying residents; and creating tools to assess facilities' resources to maintain dying residents. Under the PIC model, staff will also visit each facility covered by their team, creating what Mezey hopes will be a clinical cross-pollination. "Nursing homes see themselves as isolated institutions. We're trying to say to the facilities, 'You're not as different from each other as you think you are,'" Mezey says.

Outcomes and evaluation tools have yet to be created, but Mezey would like to see PICs measure nursing homes' rates of hospital transfer and whether making pain a fifth vital sign helps nursing homes manage pain better. The PICs will use public relations to create another incentive for practice improvement in non-team nursing homes: teams will work to raise public awareness and expectations of nursing homes by placing stories about PIC activities in local media.

Training the Trainers—and the Whole Staff

While PICs focuses on inter-facility information-sharing, Rhode Island's "Training the Trainers" program will operate on an intra-facility level by educating the staff development nurses who train each facility's CNAs, so they can provide ongoing orientation for current staff and new staff. This C-SP initiative will gather experts in thanatology from the University of Rhode Island; members of the Rhode

Island Geriatric Education Center (RIGEC), a consortium of academic nurses and pharmacists from the University of Rhode Island, social workers from Rhode Island College; and physicians from Brown University medical school. These academic experts will conduct on-site, hands-on training sessions focusing on pain assessment and management, charting methods, evaluation methods, and the use of teamwork to develop and enact care plans.

The project hopes to develop user-friendly pain-assessment tools and quality indicators on a pain-free and peaceful death, says Jean Miller, R.N., who holds URI's Weyker endowed chair in thanatology. As one of the program's directors, Miller hopes to bring her expertise to bear in broadening nursing home staffs' attitudes toward pain treatment. "Nursing home residents have pain on emotional and spiritual levels as well as physical levels. And pain can be managed not only with drugs but with many other methods, too," Miller says.

Kentucky also plans to address the spiritual dimensions of pain in its C-SP-sponsored "Journey's End" program. The 56 members of Kentuckians for Compassionate Care (KCC) include a Roman Catholic priest and several sisters, a Jewish rabbi, a Methodist minister, and a Zen Buddhist monk. This diverse group hopes to educate nursing home staff into awareness of spiritual components of pain and death. "Sometimes people can be in pain and they just want somebody to listen. They want to have their back massaged or their feet rubbed. They need human contact, not just pharmacological intervention," says Cindy Keeney, RN, project director for KCC. "Journey's

"We want to create a public standard around palliative care in nursing homes.

We want all the nursing homes in each region to know that if they're not on board with the PIC model, they're not in compliance with that standard."

Mathy Mezey, Ed.D., RN, FAAN, Director, Hartford Institute for Geriatric Nursing, NYU Division of Nursing



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End-of-Life Care Educational Initiatives Needed for Nursing Homes

- State agencies and organizations that license and recertify nursing home staff should require staff instruction in palliative care. Special attention should be given to the needs of certified nurse assistants (CNAs).
- Nursing home administrators should be educated about good end-of-life care.
- State surveyors should be educated about good end-of-life care.
- States should ask for consultation or education to determine where regulations may present ethical problems: mandatory requirements for intake of food and hydration and other such requirements, for example, may have unintended consequences for the dying. Regulations may then be revised to provide special accommodations.
- Funders of nursing-home educational programs should provide budget lines for program evaluation, and funded educational programs in the long-term care setting should define and evaluate specific outcomes.
- The American Medical Directors Association should be encouraged to include palliative care as a module in its certification program.
- Educational projects should include families of nursing-home residents, in order to empower them to ask for better end-of-life care.

Promising Educational Initiatives for Staff, Regulators, and Families *Continued*

End” proposes training sessions for all staff—from CNAs to medical directors—on assessing pain as the fifth vital sign and identifying and utilizing three different tools to assess pain in residents with dementia. The coalition plans to draft guidelines for nursing home-to-hospital transfers. It also hopes to educate staff, residents, and families about end-of-life care planning, in order to help families ask for better care for relatives at the end of their lives in nursing homes.

In Kansas City, Midwest Bioethics Center (MBC)—the national field office for C-SP—is piloting a project funded by the Project on Death in America with eight Kansas facilities. Central to the project is an intensive seminar available to entire nursing home staffs that provides an overview of ethical decision making. A regional director of state surveyors is serving as a presenter, who MBC believes will legitimize the seminars in the eyes of staff. The seminar is augmented with additional self-education materials, telephone consultation and mediation provided by MBC. Jeremy Kenner, M.T.S., J.D., and project director, says four outcomes will be measured: pain management, transfers to hospitals for death, hospice referrals, and advance care planning. His colleague at MBC, Sr. Rosemary Flanigan, Ph.D., is conducting a series of on-site seminars in the ethics of end-of-life care for CNAs and staff nurses. Flanigan says about seminar participants, “I want them to be able to ask themselves, ‘What would the patient want?’ and ‘How can I help the family to ask themselves that question?’”

Enlightened Regulation

Training provided by state regulatory personnel can play a critical role in protecting patient legal rights and in advancing the cause of good palliative care in nursing homes. In addition to

its more traditional monitoring functions, the California State Department of Health Services (DHS), which oversees 1,439 nursing home facilities, trains its surveyors and nursing home staff on ethical and legal standards, and teaches ways to communicate tactfully and effectively with patients and families about sensitive issues. “We all come to the table with certain personal beliefs about proper end-of-life care,” says Marlys Huez, J.D., DHS Senior Counsel, “but it’s important that we do not impose these beliefs on others. In California, the legal standard requires that you follow the patient’s desires. We’re here to make sure the patient’s rights and values get effectuated and that the conversation about end-of-life desires is open, with full consideration of medical alternatives. That’s the bottom line for us as a state agency.”

In 1998 Huez worked with the California Coalition for Compassionate Care on a pilot project that trained administrators, physicians, and nursing leadership from six nursing homes in how to have effective end-of-life discussions with patients and families and how to incorporate these discussions into the care planning process. A series of four collaborative training programs for facility leaders and ombudsmen is planned for the next two years. State surveyors will receive more formal training at an all-surveyor conference in 2000. Huez also provides short training modules on end-of-life issues to district administrators and managers and will soon train supervisors, in collaboration with the resident rights coordinator. She routinely provides informal training through phone consultations with investigators working in the field and through postmortem reviews of regulatory actions.

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Seeing Death as a "Story": Educating Physicians

Nursing home medical directors, many of whom oversee several facilities, can be an elusive audience for those trying to educate nursing home staff. "We have to reach physicians in other ways," says Terry Hill, M.D., a geriatrician and nursing home medical director who is active in the American Medical Directors Association (AMDA) and Co-Principal Investigator of the California Coalition for Compassionate Care. Through professional associations like AMDA and the California Medical Directors Association, Hill offers physicians intensive training on physician-patient communication. "If a physician can establish trust with a patient at one single point," he says, "that can be built on forever."

Hill teaches physicians to look at the dying process not as a series of discrete crises and interventions but rather as

the last part of a life story told by the patient (or family). The story helps the interdisciplinary team know how to care for that person. "Rather than focusing on each individual intervention," Hill says, "we want them to ask, 'What do you want the rest of your life to look like?'"—then match the interventions to that goal." A lengthy section in Hill's curriculum teaches physicians how to facilitate discussions about the dying process with residents and families. It includes role-play exercises in "active listening," "receptive silence," and asking probing questions.

Hill thinks time—or a lack thereof—isn't the only problem or solution for better physician-patient communication. "You can give doctors all the time in the world, but if they don't have the necessary communications skills, they're not going to help patients determine how they want to die and help patients get there," he says. ■

NAGNA: Nurse Assistants Unite to Improve Care at the End of Life

The National Association for Geriatric Nurse Assistants (NAGNA) is a growing professional organization of CNAs dedicated to improving long-term-care by elevating the professional standing, training, and performance of the 1 million CNAs working across the country. According to Cindy Frakes, R.N., Administrator of Medicalodge Post-Acute Care Center in Kansas City and a NAGNA board member, this five-year-old organization will soon testify

before Congress as part of the Clinton Administration's investigation into the state of long-term care. NAGNA also operates on the institutional level, too. "Our facility has a NAGNA group that promotes leadership, quality of services, development of the nurse assistant job, and enhancement of their role in long-term care."

For more information:
www.nagna.org.

Information About the Series

"Long-Term Care—Part I: Promising Educational Initiatives for Staff, Regulators, and Families" is the fifth in a series of briefs profiling promising policies and practices in end-of-life care, and the first 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

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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



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Last Acts is a coalition of more than 420 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, New Jersey, 08543-2316

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