
Educational Initiatives in Long-Term Care — Midwest Bioethics Center's Kansas Nursing Home Project

by Jeremy Kenner

Most Americans would doubtless agree that positive change is a critical need in facilities providing long-term care. This article describes a project currently underway in which Midwest Bioethics Center (MBC) staff and Kansas City area experts in long-term care are doing their part to create meaningful change in the way residents of nursing homes are cared for in the last chapter of their lives.

Improving end-of-life care in long-term care facilities is a goal widely shared by industry experts, foundation task forces, health care educators, government surveyors, and consumers. Approximately one-fifth of the Americans who die each year die in a nursing home; and an additional 10 to 15 percent pass through a nursing home sometime before their death (*State Initiatives in End-of-Life Care* 1999). Thus, when we speak of the need to improve care in nursing homes, we are talking about meeting the needs of tens of millions of people, many of whom are our own family members. As a community-based ethics center, Midwest Bioethics Center is compelled to respond to this need.

To set the context for this project, I begin with some comments on the genesis of the project and conclude with a brief review of initiatives in other states intended to produce similar results.

Background

Nursing home care has long been on Midwest Bioethics Center's agenda. In 1989, the Center organized its Long-Term Care Ethics Consortium. This resource and advocacy group, made up of professionals and lay persons providing care for older adults, provides guidance and resources for long-term care facilities, consumers, government agencies, senior advocates, and others. Its central

mission is to advocate for ethical decision making in long-term care. Among its many projects, the Consortium collaborated with the Missouri Division of Aging in 1992 to produce the document: *Considerations Regarding Life-Prolonging Treatment Decisions for Residents of Missouri Long-Term Care Facilities*, a document still recognized as a standard resource by Missouri regulators. More recently, the Consortium completed a comprehensive resource book that addresses the care of seriously ill and dying residents of long-term care facilities, including guidelines regarding advance directives, resuscitation status, treatment redirection, symptom management, and psychological and spiritual care.

In parallel fashion, the Center's Palliative Care Task Force developed a training manual and curriculum that was the basis for educational programming targeted to both health care professionals and Kansas Department of Health and Environment surveyors. This task force is comprised of local specialists from multiple disciplines and care settings, including representatives from both federal and state regulatory agencies. Together, the Long-Term Care Ethics Consortium and the Palliative Care Task Force formed the basis of what would become the plan for a program of educational intervention in selected Kansas nursing homes.

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meaningful and lasting change in any institution, particularly one beset by the problems endemic to nursing homes. We recognized that designing and implementing strategies that would be effective in reaching the staff and influencing the culture of a nursing home would be a major challenge. What follows is a descriptive outline of one effort to meet this challenge.

Kansas Nursing Home Project

In January 1999, Midwest Bioethics Center began work on a pilot project funded by the Project on Death in America designed to improve the quality of care at the end of life for residents of long-term care facilities. The most recent of the Center's educational initiatives in the area of long-term care, this project was designed as an intensive and time-limited intervention among a small group of nursing homes. The project consists of the following components:

- collection of data on measurable outcomes,
- a one-day educational seminar provided to a cross-section of facility staff,
- a pre- and post-seminar survey of facility staff assessing knowledge, attitudes, and current practice,

- follow-up videotaped in-service programs and resource materials,
- case consultation and technical assistance, and
- access to the MBC on-line discussion group and MBC mediation services.

After consultation with the state agency that regulates and surveys nursing homes, we identified two dozen nursing homes in northeastern Kansas as candidate sites. From this group, we then created pairs of facilities, matching them according to similar characteristics. The pertinent characteristics included geography (urban vs. suburban vs. rural settings), percentage of residents on Medicaid, and whether the facilities were for profit or not for profit. Ultimately, we asked eight nursing homes to participate, of which seven responded affirmatively. An eighth site was then added from the candidate pool. With attention to matching characteristics, the eight facilities were divided into two groups: four intervention sites and four sites to serve as a control group.

MBC staff worked with individuals from the Center on Aging at the University of Kansas Medical Center (KUMC) to develop the survey instruments and data collection tools. The project design specified that we would collect data from the facilities on transfers to hospitals in anticipation of death, referrals to hospice, use of advance directives, and pain assessment and management. Facilities would track transfers and referrals for a twelve month period. Before the seminars and again at the end of the project, data on advance directives and pain assessment and management would be compiled from chart reviews.

The surveys were administered just prior to the seminars and again at the close of the seminar day. Staff of the four control sites were surveyed separately. The surveys will be readministered to staff of all eight facilities at the end of the project. KUMC Center on Aging experts and MBC staff will analyze the data and surveys to determine evidence of change in staff attitudes or facility practice and factors that might account for the changes identified.

The curricular materials for the educational seminars were based on the curriculum developed by the Palliative Care Task Force and were adapted for use with nursing home staff. Issues included in the program were health care ethics, health care decision making, legal considerations, advance care planning, communication and family issues, palliative care, and pain management. We paid particular attention to making the information concise, easily accessible, and accommodating of time for further discussion.

The administrators of the four "intervention site" nursing homes were required to commit to maximizing their staff's attendance at the seminars. We were particularly concerned with having clinical staff and nurse's aides (CNAs) present. We also encouraged the presence of clerical and housekeeping staff not ordinarily invited to continuing education programs.

The faculty for the seminars included hospital-based nurse experts, hospice nurses, a regional administrator from the state agency charged with the responsibility of surveying Kansas nursing homes, and MBC staff. The seminars took place in July and early August, and were attended by administrators, nurses, social service staff, CNAs, and clerical and housekeeping staff. Forty people were in attendance at two of the seminars; twenty-five attended a third seminar; and ten attended the fourth. In each case, the administrator and director of social services were present along with a representative group of other staff. Noticeably absent were the medical directors and, at three of the four facilities, charge nurses responsible for decision making with respect to pain medication.

Anecdotal responses indicate that the seminars were very well received and were considered particularly valuable in validating the perspectives of the CNAs regarding end-of-life care and for providing facility staff with the opportunity to engage with the state agency representative responsible for regulating and surveying the facility. It also seemed apparent that many attendees appreciated the interdisciplinary nature of the gathering.

Each of the four facilities that are participating in the intervention phase of the project has been provided with a videotape of the original seminar for use with staff who were unable to attend the scheduled event. As planned, we are distributing follow-up videos of five to fifteen minute presentations on a variety of topics including the dying process, advance directives, pain assessment, pain management, and hospice and other models of palliative care. The facilities have also been supplied with multiple copies of the resource book developed by the Kansas City Long-Term Care Ethics Consortium.

Monthly meetings are occurring, during which administrators, directors of nursing, social service directors, and Center staff discuss initiatives taken and planned, as well as resident care issues. Staff training, teamwork, and improved processes for pain assessment and management are prevalent themes at these meetings. Other support activities include an email discussion group and access to materials and discussion originating from relevant sites on the internet, the development of pain assessment and management tools for use by facility nurses and CNAs, short programs on advance directives presented by Center staff, and case-specific consultation with nurse experts.

While it is not possible at this stage to make any predictions regarding the measurable success of the project, it is fair to say that our involvement in the nursing homes has stimulated activity in the facilities that had not existed previously. Facility staff, while overwhelmed by the considerable operational problems that they face daily, are cooperating in the development and use of pain assessment tools, new approaches to staff training, better processes for tracking resident care preferences, and other pragmatic efforts to improve care for their residents.

Additionally, lines of communication may have been opened within and among facilities which will have an impact on the care that residents of those facilities receive. Many of those who work in nursing homes feel isolated from the larger world of long-term care and are encouraged by the opportunity to be linked with their colleagues.

Within facilities, the value of opportunities to collaborate seems to be self-evident.

In particular, our anecdotal findings reveal that the relationship between CNAs, "med nurses" (CMAs), and charge nurses may indeed be the

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critical pathway for assuring the best and most appropriate care for residents, particularly as it concerns pain assessment and pain management. If this is the case, then further work will need to be done to understand this relationship and to support its optimal expression.

Other Educational Initiatives

Midwest Bioethics Center's Kansas Nursing Home Project is founded on the belief that, although promoting change in the culture of a long-term care facility is a complex task requiring sustained effort and commitment on the part of both educators and facility leadership, educational intervention and support are necessary components of the process of cultural change. Implementing the project has, thus far, taught us that the nursing home is a uniquely difficult and promising context for educational programs intended to promote such change.

Most nursing homes, including those involved in this project, are faced with significant limitations including a lack of financial resources and oppressive regulation. Further, their employees, particularly the CNAs, are, more often than not, overworked, underpaid, poorly trained, and underappreciated. As a consequence, the turnover of nursing home personnel is extremely

high. These limitations present a significant impediment for education-oriented reforms, such as this Midwest Bioethics Center project. Nevertheless, working with facility staff, who often have many months or years to get to know their "charges" and are less crisis-oriented than other health care providers, may provide an unparalleled opportunity to instigate long-term change in the way we care for each other at the end of our lives.

This sentiment is shared by forward thinking educators and advocates in other parts of the country. Initiatives are currently in place or are ready for implementation in a number of other states. These initiatives range from train-the-trainer programs to sharing inter-facility information in the form of practice clusters (*State Initiatives in End-of-Life Care* 1999).

Rhode Island is directing its efforts toward educating the staff development nurses who train CNAs. The trainers plan to provide ongoing orientation for current staff and new employees. The project relies on academic experts and focuses on practical aspects of improved pain treatment.

On the other side of the country, California's Coalition for Compassionate Care has developed a curriculum and training manual for use in in-service education, policy development, and organizational change. The curriculum is one piece of a broader initiative to improve end-of-life care funded by the Robert Wood Johnson Foundation. Unique to the California initiative is intensive training for physicians in physician-patient communication, particularly with respect to discussions about the dying process with residents and families.

While North Carolina is piloting a series of on-site classes for nurses, CNAs and social workers on basic care and improving teamwork, Kentucky is addressing the spiritual dimension of pain and death. Kentucky's *Journey's End* program promotes heightened awareness on the part of staff, residents, and families to the experience of pain. It also advocates the use of a variety of methods for assessing pain as the fifth vital sign.

This focus on pain assessment and management is shared by Wisconsin long-term care educators, who provided extensive training to staff in eighty-seven nursing homes directed specifically toward implementing standardized pain assessment and management tools. That project remains active beyond its original term as a result of a continuing demand from facilities.

Perhaps the most innovative program is New York's PIC (*Practice Improvement Clusters*) program, an attempt to break through the feeling of isolation that is pervasive among long-term care facilities. An outgrowth of a program begun in 1980, New York's initiative promotes regional collaboration between nursing home staffs on educational programming and clinical improvements.

All of these projects share certain common commitments. Each project is

- interdisciplinary in nature and directed toward improvements in communication, decision making, and clinical care;
- premised on the idea that educating nursing home staff about ethical issues and palliative care is a worthy goal; and
- grounded in an understanding that educational initiatives, however well conceived, are most effective when based on multiple approaches and regular contact between educators and staff.

Future Prospects

Ideally, educational initiatives such as the Kansas Nursing Home Project would complement instruction provided by licensing and recertification agencies and professional associations. Nursing home staff training would be matched by similar programs targeted to surveyors and other regulatory agency personnel. Educational initiatives would be accompanied by financial incentives and opportunities for job promotion (*State Initiatives in End-of-Life Care* 1999). Perhaps most importantly, education and support would not be directed solely to nursing home employees, but also to families of residents and even to the residents themselves.

Even if all these objectives were met, educational initiatives will continue to be necessary to pilot research projects aimed at changing the culture of nursing homes. One cannot overstate the message that decision making is an ethical activity; every person deserves appropriate and compassionate care, and this care can be delivered effectively

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despite resource limitations and logistical impediments. This message will always need to reach new ears and stimulate new consciousness.

To that end, Midwest Bioethics Center is committed to further initiatives in long-term care education. We hope to secure funding for a follow-up study to see if any demonstrated change in staff attitudes or facility practice has become integrated into the culture of the participating facilities or, alternatively, whether changes not immediately evident at the end of the current project are percolating and will be manifest at a later date.

We are also hopeful that some of the facilities in the Kansas Nursing Home Project will become our partners as we seek to broaden and deepen our work so as to reach a larger group of long-term care facilities.

Stay tuned!

Reference

State Initiatives in End-of-Life Care. 1999. (5) November: 1, 3, 5.