

State Initiatives *in* End-of-Life Care

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Focus: Long-Term Care—Part II

How Regional Long-Term Care Ethics Committees Improve End-of-Life Care

“For six years my mother lay in a fetal position, unable to recognize us; she’d always said she didn’t want that to happen to her, yet when I asked about removing the feeding tube, all I got was resistance from staff,” says Anita Greenspan who supervised her mother’s care in a New Jersey nursing home. “Every day of my life during those six years was agony—a little private hell.”

The situation faced by Greenspan and her brother, David Cohen, is not uncommon, particularly among families in which dying loved ones cannot make their own decisions and lack written advance directives. As Greenspan and Cohen ultimately learned, “clear and convincing evidence” of their mother’s desires established a valid (oral) directive under New Jersey law (for more on this case, see page 2).

Many barriers needlessly impede the resolution of such painful ethical dilemmas, say experts in the field. Nursing homes can be penalized by regulators if patients lose weight, and may therefore mistakenly regard weight gain achieved with feeding tubes as a triumph, even when residents are actively dying. Like other providers of health care, they often see death in their facilities as a “failure” to be avoided at all costs. The religious values of family members and staff may also be in conflict. Many doctors



and nurses don’t know relevant case law and lack ways of communicating effectively with families about end-of-life decisions and ethical dilemmas. Most nursing homes, in fact, do not have ethics committees.

“Real in-house ethics committees haven’t gotten off the ground in long-term care, generally speaking,” says Don Reynolds, J.D., director of special projects at Midwest Bioethics Center, Kansas City, Missouri. “Most nursing homes are thinly staffed and rely heavily on unlicensed personnel, so they often don’t have people inside who can bring ethics to the table. Also, nursing homes typically draw personnel who are hands-on doers, not reflective types. And nursing homes are always responding to the market. So to stimulate ethical reflec-

tion, they need to connect to an entity outside them that is grounded in ethics.”

Well-trained regional and municipal long-term care (LTC) ethics committees and consortia appear to be one promising way to infuse ethical perspectives into facility decision making, improve communication with families, and advance the cause of good palliative care. They may also help to prevent litigation crises such as those plaguing court systems in California and Florida. The following pages illustrate how several different regional groups are making positive contributions through ethics education, professional networking and support, sophisticated bedside ethics consultation, institutional policy development and consultation, and policy research.

Although nursing homes and other long-term care facilities are regularly confronted with wrenching bioethical dilemmas, few have the resources to establish real, in-house ethics committees. Regional long-term care ethics committees are one way to fill this gap.

New Jersey's Regional Long-Term Care Ethics Committees

While many regulatory bodies have adversarial relationships with the LTC industry, the New Jersey Office of the Ombudsman for the Institutionalized Elderly has charted a different course with the state's more than 400 nursing homes and assisted living residences.

Between 1998 and 2001, the Office of the Ombudsman, in collaboration with Cooper Hospital University Medical Center, will complete the development of 12 LTC regional ethics committees, as part of the New Jersey Stein Ethics Education & Development project (NJ SEED). Once all the committees are up and running, every facility in the state will have access to sophisticated bedside ethics consultation and policy development. Two \$250,000 grants, from the Robert Wood Johnson Foundation and the Louis & Bessie Stein Foundation, fund the project.

Eleven committees have been formed; eight are doing consultations on a regular basis. Committees, made up primarily of facility administrators, social workers, nurses, physicians (a few), and clergy are consulting on the full range of issues from roommate disputes to end-of-life matters. The Office of the Ombudsman handles approximately 2,500 cases a year. Just over half of the state's facilities now have personnel on a committee.

There are several incentives to join: the Office of the Ombudsman's authority and support, low-cost ethics training, continuing education units, and a chance to become a regional representative on the New Jersey Long-Term Care Ethics Consortium, which provides on-going education and peer support.

"I was so relieved when I saw the way the committee reacted. They were very deliberative and compassionate. They felt the way I felt and understood what I was saying."

Anita Greenspan

Participants in NJ SEED credit former Ombudsman Bonnie Kelly for the initiative's bold vision (Kelly stepped down in the fall of 1999 but remains active in committee work). Linda O'Brien, R.N., M.A., who represents Cooper Hospital University Medical Center on the project, says the Office of the Ombudsman's new approach grew out of Kelly's "commitment to empowering providers to resolve ethics conflicts at the bedside without always calling in regulatory bodies. While providers haven't typically had good self-esteem, Bonnie believes in their ability to handle complex ethical issues."

Kelly has used leadership development as a way to build self-esteem and committee skills: "You've got to foster leadership among long-term care professionals out there. It's an opportunity to push people into key leadership positions in their communities. We've had to convince them that they could do this."

William Isele, J.D., formerly general counsel to the Ombudsman and now acting Ombudsman, says the Office has looked to acute-care ethics committee models for guidance but has adapted them freely: "In bringing in the regional ethics committees, we're providing the kind of interdisciplinary input that hospitals have had since the Karen Quinlan case, but our focus and

Anita Greenspan (pictured at right) and her brother, David Cohen, received support from the New Jersey Office of the Ombudsman for the Institutionalized Elderly and one of its regional ethics committees.



approach are a little different: we're looking to educate and bring consensus around good palliative care."

The foundation for committee empowerment is "Stein Ethics Training," 5.5 days of sessions that teach committees ethical theory and principles as well as dispute resolution methodologies. O'Brien, who has spearheaded the development and implementation of the training and who originally proposed the NJ SEED collaboration, says the sessions provide the tools for an effective, cohesive committee network: "systematic education, a common statewide ethics language, and a standardized consultation process."

The process begins with fact-finding to answer key questions: who is this patient—how has she lived her life, and what are her values? What are the values of all the parties? Subsequent consultation conferences typically involve two or three members of the nearest regional committee, a representative from the Office of the Ombudsman, family, and facility staff, including those often overlooked—certified nursing assistants and dietitians. Great care is taken to ensure that all parties, regardless of rank, have equal standing in answering a set of challenging questions: What are the

Don Reynold, staff, and Jamie Floyd, chair, of the Kansas City Regional Long-Term Care Ethics Consortium, getting set to convene a monthly meeting.

patient's expressed preferences? What is the ideal outcome? How realistic is this outcome? What are the burdens and benefits of each option according to the *patient's* values? What ethical principle does each benefit and burden exemplify?

Ombudsman staff say that most cases involve poor communication—unspoken fears and unclarified conflicts that the process ferrets out and resolves—and that the vast majority of consultations result in consensus recommendations.

Post-consultation support is a priority, says Kathryn Hirschfield, R.N., B.S.N., who represents the Ombudsman at consultations, as NJ SEED's director of outreach. "I spend a lot of time after decisions are made reviewing the plan of care to see if pain and comfort have been addressed, assisting the families in dealing with decisions, and supporting the facility."

How do facilities feel about NJ SEED? "There was initial concern among administrators," says Isele, "about hanging out dirty laundry for competitors to see, but because of the quality of the people involved and because the Office of the Ombudsman backed the effort, the concern didn't bloom."

Administrators on the committees are enthusiastic. "It's making us grow up," says Mike Rauseo, Nursing Home Administrator for The Gospel Home for the Aged, Inc., Longport, N.J. "We've felt so threatened by state and federal officials that we weren't willing to stick our necks out and call the ethical question. Now we can. It was a brilliant move for the Office of the Ombudsman and the Cooper Hospital University Medical Center."

The Kansas City Regional Long-Term Care Ethics Consortium

A pioneer in the new world of LTC ethics groups, the Kansas City Regional Long-Term Care Ethics Consortium has been meeting continuously since 1989, with administrative and staff support from Midwest Bioethics Center (MBC) and funding through modest membership dues and occasional grants, ranging from \$5,000–\$20,000.

The Consortium's chief mission "is to provide a forum for the discussion of ethical issues and offer a network of support for people who serve LTC residents directly or indirectly," says current chair Jamie Floyd, admissions and marketing coordinator for Liberty Care Center.

Drawing from counties within a 60-mile radius of Kansas City, the Consortium has approximately 50 paying members and attracts some 150 people per year to its monthly meetings, quarterly bioethical case reviews, and educational programs. Professionals from mid-sized LTC facilities, government agencies, hospices, and ombudsman offices form the group's core.

Members are enthusiastic about the support and education they receive. "Long-term care professionals feel they live in a little world nobody understands," says past chair, Jacqueline Talman, manager of development group services at Health Midwest. "When they come together and hear others, it normalizes their situation and lets them learn from each other and from guest speakers. The Consortium is a place to see problems in different ways, to go beyond law and crisis to remember residents' rights and family situations."



The Consortium has also been a place where the message of good palliative care in LTC is being reclaimed, says Don Reynolds of MBC, who staffs the group. Determined to carry this message to the community and have a more systematic impact at the facility level, the Consortium has recently developed a comprehensive set of policy guidelines entitled "Improving Care for Seriously Ill and Dying Residents of Long-Term Care Facilities" (1998). The guidelines advance palliative care as "the primary goal of institutional long-term care" and provide a program of work to help facilities change practices in five areas: advance care planning, resuscitation status, orientation of care, spiritual support, and pain and symptom management.

While a limited distribution of the guidelines has occurred already, full-scale dissemination has been hampered by lack of funds. "Every hospital has an ethics committee we can pour our work into, but there's no comparable mechanism in most LTC facilities," says Reynolds, "so you have to design comprehensive training interventions. This requires resources that are hard to get. Given what our Consortium has been able to do with no money, I can see so much potential with additional funding."

Long-Term Care Bioethics Consortium of the East Bay

“Our hook is assisting nursing homes with policy research and development,” says Theresa Drought, R.N., Ph.D., director of the Long-Term Care Bioethics Consortium of the East Bay and associate director of ethics, Northern California Kaiser Permanente (Oakland, Calif.). “There is no point in doing ethics without policy work; you need to learn from cases but keep moving things back upstream so you can avoid the problem next time.” The group also shares a passionate interest in improving end-of-life care through better doctor-patient communication.

The East Bay Consortium draws its members from nursing homes, hospitals, advocacy organizations, and government agencies in the Oakland metropolitan area. While the group holds regular monthly meetings and quarterly educational events, its current focus is a research project measuring how successful the Consortium’s interventions have been in getting Oakland area hospitals and nursing homes to use an advance care planning tool called the Preferred Intensity of Treatment (PIT) form. The California Medical Association developed the form with significant input from Consortium leaders. PIT has already attracted support from key statewide organizations. The project is funded by a \$132,000 innovations grant from Kaiser Permanente.

“PIT is a structured progress note that can capture the communication that takes place between doctor and patient about end-of-life care goals and

values,” says Consortium member Terry Hill, M.D. The next hurdle is to make sure that this information is transferred when the patient goes from one health care setting to another. On a different policy front, the Consortium has worked successfully with other groups to get the local Office of the Public Guardian to change its no-DNR/no-palliative care policy.

Consortium members are also engaged in discussions about the group’s future. Hill believes that the Consortium must ultimately position itself to do bedside ethics consultation if it is to survive long-term, but funds are lacking for the requisite training.

Implications for Other Localities

The experiences of all three LTC groups profiled here suggest that they are low-tech, effective, and relatively inexpensive mechanisms to empower LTC professionals and fill a critical “ethics gap” in end-of-life care. Yet committees need some support from larger entities and modest infusions of funds at strategic points in their life cycles.

The social costs of this gap argue for such support, says Hill. “Trying to build ethics committees in nursing homes that don’t have the necessary elements seems like a recipe for failure. A little expertise available from a regional ethics committee could have a tremendous impact on reducing unnecessary suffering, grief, guilt, and litigation by families. We have a great opportunity as we close this century to start a model that will be abiding.” ■

For more information on featured regional committees, call:

New Jersey Office of the Ombudsman at (609) 588-3614
Cooper Hospital University Medical Center at (856) 963-3714
Midwest Bioethics Center at (816) 842-7110
Long-Term Care Bioethics Consortium of the East Bay at (510) 596-7151

Information About the Series

“Long-Term Care—Part II: How Regional Long-Term Care Ethics Committees Improve End-of-Life Care” is the sixth in a series of briefs profiling promising policies and practices in end-of-life care, and the second in a mini-series about improving end-of-life care in nursing homes.

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