SPECIAL  SECTION

LEARNING TO PAY ATTENTION

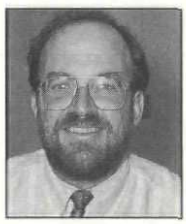
An Ethics Study Group Refocuses on Issues Affecting Long-Term Care Residents' Daily Lives

BY CORNELIUS KELLY, PhD, JD, & ALAN LAZAROFF, MD

The average nursing home resident is 80-plus years of age, functionally and memory impaired, passing her final days in a place not of her own choosing. Nursing home residents are real persons. Their lives are continuous with their past, distinguished now, as then, by rights demanding respect and needs worthy of attention. Regrettably, institutions dedicated to care of these residents tend to disregard those rights and to be distracted from those needs.

In 1991 the Sisters of Charity Health Care Systems (SCHCS), Cincinnati, established an ethics study group for its long-term care facilities. The group's charge was to develop ways of ensuring systematic reflection on ethical issues peculiar to that setting.

The group originally was organized to address end-of-life treatment decisions in long-term care facilities. In the course of its deliberations, however, members became aware that the daily lives of people by and for whom such decisions will be made were worthy of attention in their own right. Although this was hardly a dramatic insight, it served as a healthy corrective to a professional mind-set that directs attention away from the issues and concerns that affect the daily lives of elderly residents of long-term care facilities.



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INSTITUTIONAL INATTENTION

The inability to notice important issues because they are concealed by their ordinary, everyday quality has been described by one writer as "institutional inattention." In their recent work, *The Good Society*, Robert Bellah and colleagues identify a good society as one that fosters attention

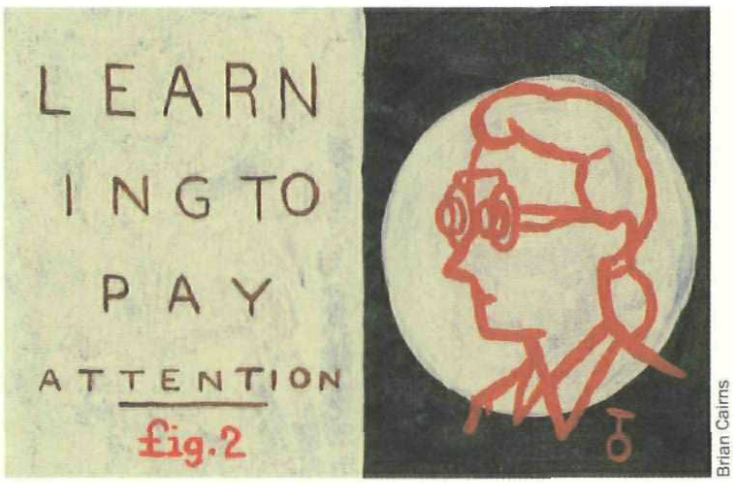
Summary In 1991 the Sisters of Charity Healthcare Systems (SCHCS), Cincinnati, established an ethics study group for its long-term care facilities. The group was originally organized to address end-of-life treatment decisions, but it soon found that the daily lives of people by and for whom such decisions would be made were worthy of attention in their own right.

Autonomy had been a topic of group discussions early on. Once reinterpreted in the context of long-term care, it became the pivotal value for the group.

One key to the group's progress was identifying intrinsic and extrinsic factors that distract care givers' attention from issues of concern to residents. Members found that state and federal regulations, as well as constraints on medical treatment by payers such as Medicare and Medicaid, often ignore the human dimension in terms of which the elderly's needs and preferences can be framed. Rigidly defined roles and routines also blunt care givers' sensitivity to residents' concerns.

The group is currently developing a program of in-service ethics education and training. Designed in four modules, the program will focus on the following topics: protecting and enhancing resident rights, staff issues and professionalism, talking about death and dying, and staff-physician issues.

rather than distraction (Alfred A. Knopf, New York City, 1991, p. 273). They describe attention as openness to experience. More than conscious awareness, attention is the productive use of our resources of intelligence, feelings, and moral sensitivity. How we use our psychic energy determines the kind of person we are learning to be and the kind of relationships we cultivate. When fully attentive, we are absorbed in what we are doing. We seek such moments not so much for enjoyment, but because they help us relate to things we really value in the large context of our lives. By attending to the world around us and to meanings discovered as we interact with that world, we make sense of our lives by seeing their interconnection with other lives.



Brian Cairns

Distraction, by contrast, is the destruction of attention. When we do the many things we "have to do," our minds and feelings tend to be elsewhere, leaving us fragmented and exhausted. This eventually creates anxiety or "stress" and a strong desire for distraction when there is time. Unfortunately, preferred forms of distraction tend to be counterproductive: the shallow escapism of alcohol, restless television watching, or defensive attempts to control anxiety through power or money.

Bellah et al. acknowledge that "attention" is a topic normally discussed in individual psychology. But institutions, they claim, are socially organized forms of paying attention. Unfortunately, they can also be socially organized forms of distraction, making it difficult for persons associated with them to notice what is right in front of their eyes.

Ethics Study Group

Although SCHCS acute care hospitals have had ethics committees in place for about 10 years, nothing comparable existed within the systems' long-term care facilities. SCHCS's slowness in developing ethics structures for long-term care is in keeping with a nationwide pattern. Certain characteristics of long-term care facilities and their residents have contributed to this pattern. Compared with acute care hospitals, long-term care facilities are administratively "thin" and have limited access to outside resources and expertise. Many operate within severe financial constraints. Staff shortages and turnover are common. Physicians' presence is limited, as is their involvement in facility activities other than direct patient care.

Regulation is more pervasive and resource consuming in long-term care. The presenting condition of residents poses additional limiting factors. Many are permanently impaired, mentally and physically. Some, suffering from conditions that are disabling but not necessarily terminal, have compromised decision-making capacity. A significant proportion lack a family member or other person to act as a surrogate decision maker. Thus the demands on care givers and administrators often leave them little time to focus on ethical issues.

Part of the challenge to the study group, made up of representatives from each of SCHCS's nine eldercare facilities, was to accommodate their different needs. For example, the seven facilities in Colorado—which include a congregate living center, nursing homes, and a stand-alone Alzheimer's facility—represent the continuum of elder care. Included among the study group's representatives were administrators, nursing service providers, and a physician.

Once convened, the group set the following objectives:

- To become knowledgeable about ethics and ethical issues relevant to long-term care
- To draft model policies and guidelines for end-of-life decision making
- To develop processes and structures appropriate to individual facilities that would address ethical issues on an ongoing basis

Beginnings

The group undertook its first task, self-education, about two years ago. Following introductory instruction in general ethics (theory, principles, and values), members began a directed reading program covering a variety of topics. During meetings, which were scheduled for a half day in alternate months, group members took turns as presenters. A guest lecturer was with the group for a half day. A variety of videos were circulated.

Serious interest in ethical issues relevant to long-term care, together with almost daily experi-

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ences with related on-the-job issues, helped the group learn quickly. Within a year the members decided they were ready to address the second objective—development of guidelines for medical treatment decisions.

The group developed this first work product over a nine-month period from late 1991 to mid-1992. Titled *Guidelines for Limiting Medical Treatment in Long-Term Care Facilities*, the final document is currently under review by governing bodies of the participating facilities. Developing the guidelines was a good experience in collaboration. Each member claimed ownership of the end result because of the give-and-take that characterized the process.

Written from the perspective of the patient or resident, the guidelines reflect the shift in authority for treatment decisions that has occurred in acute care, according to which care recipients work together with care givers to decide on a course of action. The rise of patient autonomy is also reflected in the guidelines, which place individual residents and their rights at the center of statements of policy, lists of principles, and articulation of procedures. Autonomy—its meanings and implications—had been a topic of group discussion early on. Once reinterpreted in the context of long-term care, it became the pivotal value for the group.

Key to this reinterpretation was the recognition that the "exchange rate" for autonomy is different in long-term care facilities than it is in a hospital. Residents have a different worldview from that of patients. Patients will generally accept severe constraints on their autonomy for a limited time in exchange for the prospect of substantial improvement in health. Long-term care residents, however, should not be expected to accept similar constraints for an indefinite period in exchange for an ill-defined benefit.

Residents obviously do not use words like "constraint" or "autonomy." Even lawyers and ethicists have not been able to agree on a uniform, operational definition of autonomy. But they all agree that autonomy is a critical component of quality of life that includes features like liberty, personal choice, and options.

Liberty, choice, and options are issues residents talk about and think about—whether they experience them or not. Had group members consciously taken time to listen, they would have heard residents saying, in different ways, that they wanted more control of their daily lives and care. They knew how important, in theory, the exercise of self-determination is for elderly residents. But they had not yet acknowledged that residents generally have little control or opportunity for personal choice.

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Paying Attention

As it happened, the group gradually began to listen, but even then, more by chance than by design. After completion of model guidelines, the schedule called for development of procedures and structures for use in individual facilities to address ethical issues. Fortunately, some within the group recognized that an intermediate step was necessary to determine more clearly the sorts of problems and issues these procedures and structures would address.

At first, such a step seemed like a diversion from the group's purpose, since it would turn attention from "medical" decision issues to the ordinary, everyday events of resident life. Changing focus, however, opened up myriad issues across the spectrum of activities of daily living—issues that were at once ethically challenging and professionally compelling. The switch forced the group to attend to matters usually deemed too mundane to consider seriously or outside the purview of ethics. It also compelled the group to get closer to the issues and concerns that drew them to a career (ministry) in eldercare in the first place.

Discussing assigned readings, the group could detect a change in philosophy in the regulation of long-term care, signaling a shift from assigning residents a passive, dependent role to one focusing on resident rights and responsibilities. The requirements of informed consent, the development of advance directives formalized in the Patient Self-Determination Act, and the protections incorporated into processes such as do-not-resuscitate (DNR) orders were all signs of this shift. Noteworthy among the readings that galvanized the group's thinking was the work edited by Rosalie Kane and Arthur Caplan titled *Everyday Ethics: Resolving Dilemmas in Nursing Home Care* (Springer, New York City, 1990). The group devoted two entire sessions to discussion of everyday issues in the lives of residents and staff.

For group members, none of these everyday issues was actually new or startling. Selecting roommates and tablemates, resolving disputes (interresident, interfamily, and interfacility), handling residents' money, and determining acceptable risks were simply part of the workaday world of eldercare. Determining whether to separate or to mainstream persons with dementia and when, if ever, to use restraints were issues administrators settled by creating policies and procedures.

Whether to increase or decrease a medication, to write a DNR order, or to hospitalize a resident was a routine medical decision.

In a renewed environment, however, old issues can be reframed to take on new urgency—which is what happened once group members took off their providers' hats and began to look at residents' needs and preferences. Much of what had been viewed as "the way things are" was now recognized as inimical to residents' best interests. The group had come to appreciate how pervasive institutional inattention (distraction) is throughout the eldercare landscape.

Sources of Distraction

Mapping this new moral landscape was now the group's task. Forms of institutional distraction that derived from forces outside the facility, such as regulation and financing, were obvious. But forms endemic to eldercare, such as facility design and staff roles and attitudes, were detectable only when the parameters of attention were expanded.

Regulation The most prominent source of distraction outside the eldercare environment is probably regulation. In a system as complex as the U.S. healthcare system, bureaucracy is inevitable. It provides special skills and resolves otherwise overwhelming complexities by reducing problems to their lowest common denominator. Unfortunately, the lowest common denominator normally ignores the human dimension, in terms of which the needs and preferences of the elderly can be framed.

Finances Nearly half of nursing home residents are, by definition, poor. Even cognitively intact residents frequently have limited or no access to their own funds. Residents requiring medical care may experience additional constraints. Private insurance coverage is severely limited, and payment rates by Medicare and Medicaid are low.

As a result, physician interest and commitment are also low, and the choice of available physicians may thus be narrow. Nursing homes often fail to provide adequate facilities for examining residents and have difficulty diverting staff from their other activities to assist physicians. Ambulatory residents of long-term care facilities, if on Medicaid, are not permitted to receive their routine care in the physician's office like everyone else, even if this requires that they change to a physician willing to visit the facility.

Institutional Efficiency Life within a long-term care facility is driven by routine. The normal pace of a person's life is gradually altered in the name of institutional efficiency. For example, a resident who wishes to stay up late or to sleep late risks being classified as inappropriately demanding. As prerogatives such as freedom to leave the facility and access to telephones and mail disappear, barriers arise between the world inside and that outside the residence. The more frail and dependent a person is, the greater the regimentation. And as a resident's health declines, medicalization begins. For a resident who requires 24-hour-a-day care, a care plan will turn many ordinary decisions into healthcare decisions.

Routines Roles inevitably influence attention. In the normal course of operations within an eldercare facility, administrators' concerns differ from those of dieticians. But whether one prepares budgets or meals, there are also common patterns of thought, affect, and conversation that color institutional attention. The routine of providing care in this setting, especially for people needing assistance with activities of daily living, blunts care givers' ability to identify with residents and to be aware of their needs and preferences.

Fear of Aging On a personal level, fear and a self-protective attitude can deflect attention from deeper issues affecting residents—in particular, aging and dying. To the degree that providers fail to look into the faces of elderly residents, they are spared the need to deal with their own aging. Only by coming to terms with their own finitude can care givers recognize themselves in the frailties of their geriatric patients.

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SENIOR CARE ETHICS COMMITTEE

Provenant Senior Life Center, Denver, was the first system facility to create a senior care ethics committee. With leadership from charter members of the system study group and impetus from staff involved in developing the first of the four educational modules (on resident rights), the committee has completed an orientation session and held its organizational meeting.

Drawing on resources from diverse segments of Provenant's Senior Care Division, the committee is composed of representatives from all departments of the senior life center, a separate retirement facility and site of the center's home care division. Three physicians are on the committee, as well as two staff members who recently completed an intensive ethics program sponsored by Provenant's acute care facilities.

Taking direction from the study group, the Senior Care Ethics Committee will focus on everyday issues in the eldercare setting, with primary emphasis on resident needs and preferences. A process for identifying issues is under development.

As the remaining modules are completed, it is expected that other facilities participating in the study group will establish permanent means of addressing ethical issues.

LEARNING TO PAY ATTENTION

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Good Institutions

Institutions are socially organized forms of paying attention. If a good institution is one that encourages attention rather than distraction, SCHCS eldercare facilities are moving in that direction. A group of people have come to appreciate the importance—and the challenge—of paying attention. Having become conscious of new ethical horizons, they are emboldened by the words of anthropologist Margaret Meade: "Never doubt that a small group of thoughtful citizens can change the world. Indeed, it is the only thing that ever has."

Changing a small corner of the world would satisfy this group. They have taken steps to bring their experiences back to their respective facilities and share them with staff. With approval from senior management, the group is currently developing an in-service program on ethics education and training. Designed in four modules, the program will focus on protecting and enhancing resident rights, staff issues and professionalism, talking about death and dying, and staff-physician issues.

The program's goal is to sensitize staff to what it is like to be a resident. A number of staff from SCHCS facilities are actively involved in both the design and development of these modules, two of which are near completion (see **Box**, p. 43). Each includes a video, a leader's guide, participant materials, and relevant resource materials. All indications are that the process of developing these modules has been as educative for those involved as the finished products will be for target audiences.

The project is scheduled for completion in December. At that point, the four modules will be exchanged between facilities involved in their development and, eventually, with other SCHCS eldercare facilities. The ultimate objective of the group—development of ethics structures—will be addressed in concert with implementation of this education program. □

VARIED ISSUES

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require that these individuals return their copy. Seventy-two percent of hospitals allow their committee members to retain a copy of their own minutes from the meetings, whereas 28 percent do not. Whether minutes are retained or broadly distributed, 95 percent of the respondents are satisfied that their patients' confidentiality is sufficiently protected.

Future Directions

Although respondents on average rated their ethics committees as effective, in open-ended comments respondents indicated services and programs provided by CHA that might enhance their committees' effectiveness.

The 52 comments related to medical-ethical issues indicated the need for further education on end-of-life decisions (19 percent), technology-versus-cost decisions (14 percent), and euthanasia/physician-assisted suicide (14 percent). Issues related to obstetrics and reproduction were mentioned in 12 percent of the comments. Also, 25 percent of the comments indicated a desire for advice on how to deal with these issues.

Respondents expressed interest in attending seminars, conferences, and workshops. They were also interested in short videos and printed resources. They requested information about newsletters that provided a Catholic perspective on issues, and they also need books to help ethics committee members understand various medical-moral issues and strengthen their programs for medical staff and the community (see **Box**, p. 39). CHA's Division of Theology, Mission, and Ethics will incorporate member needs and interests, as expressed in the survey, in planning its future activities. □

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GROWTH

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wellness focus, and science versus humanism, the authors suggested.

They said that the ethical foundation embodied in the SMHS vision and mission can provide a framework to ensure that the system's philosophy and values inform its actions. SMHS and its members are committed to developing a worldview that enables them to see patterns of organizational and system behavior; to grasp the root causes of illness, disease, and other health-related problems; and to understand why the poor and other disadvantaged groups suffer disproportionately. A mature CEC will become an advocate for a more just healthcare system by carrying that analysis outside the system and into communities, Congress, courtrooms, and corporate boardrooms.

Continue to Grow According to the report, comments from members indicate that confronting contemporary ethical issues will require the committee to:

- Perform in-depth analyses of current healthcare issues
- Continue work on defined goals
- Assist in policy formation
- Help realize the SMHS Vision 2000, strategic plan, and articulated core values
- Educate current and new members
- Network, internally and externally

Current CEC Activities

The CEC has already reflected on its growth, renewed its commitment, and formed a task force to develop an ethical framework that can be used systemwide to translate the SMHS mission and values into just action. Although the evaluation of the system's CEC has some limitations, the results clearly demonstrate that the committee has achieved real growth. Committee members also believe that the process used to evaluate the CEC can be easily adapted for evaluating other ethics committees. □