The First Decade
# Center for Ethics in Health Care

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The leaders of the Center had a vision back in the late 1980s: create a center without walls that would bring people with diverse talents and interests into a cohesive force to solve ethical dilemmas through teaching, research, and clinical collaboration, and influence health policy. Together they would be greater than the sum of their parts.

Their timing was perfect. Many hospitals had created ethics committees to arbitrate conflicts arising from the use of life-prolonging technology against patient wishes. “A lot of people in the region were doing good work but they were doing it in isolation,” says Susan Tolle, M.D., the Center's director from its inception. “We thought that if we could link arms, we could create a powerful force for sharing and collaborating, and have better vision than if we each worked alone.”

The four leaders exemplify this notion perfectly. Tolle was an internal medicine physician on the medical school faculty who had just finished up an ethics training program at the University of Chicago. Michael Garland, D.Sc.Rel., was a philosopher on the medical school faculty devoted to social ethics. Virginia Tilden, D.N.Sc., was a researcher at the nursing school with a particular interest in family and end-of-life issues. And Gary Chiodo, D.M.D., a public health dentist on the faculty of the dental school, worried about such troubling ethical issues as HIV-positive patients having difficulty accessing dental care and patient autonomy in managed care systems.

All four were teachers at OHSU but each brought a unique perspective to the Center — giving it a true multidisciplinary footing. This group now serves as the center’s executive committee.

That interdisciplinary approach, which was extended to include community leaders, social workers, allied health professionals, chaplains, lawyers and social scientists, proved highly effective over the years. With initial support from the Meyer Memorial Trust, the Center flourished, growing from a small cadre of academicians to a statewide network with a $2 million endowment and a national reputation for reform, especially in end-of-life care.

Not only did the Center evolve into a powerful voice for compassion in health care, but it earned itself a national reputation for compassionate care of the dying. “When we started out in ’89,” says Tolle, “we had no idea our work would attract national attention so soon.”

The Center’s work in the arenas of ethics education, research, policy, and practical issues has ensured that its “products” are of practical significance for all in health care. Its interdisciplinary approach to doing this work is unique. In fact, during the Center’s first year, a number of national ethics experts from impressive ethics centers around the United States warned that such an interdisci-
“Many of the challenges in the future, relating to issues such as genetic testing, managed care and electronic medical records, will require greater skill in effecting systems reform.”

— Susan Tolle, M.D.
As an ethicist, Virginia Tilden, D.N.Sc., R.N., will say that she is lucky to be doing end-of-life research in Oregon. “Oregon is different.” It has the lowest rate of in-hospital deaths in the United States (and also fewer hospital beds per person than most states), expansive advance directive legislation, thriving hospice and home health services, a high level of respect from practitioners for patient preferences regarding death, and aggressive pain management.

Oregon has presented Tilden, her colleagues and some 15 to 20 graduate students with a rich environment for study. They’ve used this advantage of place and time to tell the world about improving care of the dying.

During the 1990s, a multidisciplinary team of researchers in the Program of Research on Ethics and End-of-Life Care built a body of work, published in major scientific journals, on family decision-making and ethical dilemmas.

In one of their first studies they learned that advance directives reduce family conflict and that clinician behavior can affect the stress level of families having to make decisions about treatment, such as withdrawing life support. A later study examined how people of different ethnic, age, and cultural make-up might approach the same decisions. Christine Nelson, R.N., MS, project director for both those studies, notes … “that families play a key role in helping patients (or their loved ones) receive the level of care or aggressive treatment wanted at the end of life.”

In 1996, the program published a widely reported study on physician attitudes on assisted suicide, finding back then that while a majority of physicians favored the practice, many were morally opposed.

Another study points to a disturbing fact about pain control in dying patients. “Although practitioners in our study had a high respect for patient preferences, 34 percent of patients reported moderate to severe pain in their last week of life,” said Anne Rosenfeld, R.N., Ph.D., project director of the study. According to
“We’re taking all that we’ve learned to this point in time and will use that data to facilitate or trigger systems changes.”

— Virginia Tilden, D.N.Sc., R.N.
“Although we’ve made huge strides in improving care of the dying, we still have work to do.”

— Susan Tolle, M.D.

as hospital, hospice and nursing home administrators, nursing and medical staffs, and patient advocacy groups.

“Everyone agrees that it’s time to change what they’re doing for dying patients,” says Tolle, principal investigator of current foundation-funded research. “People want a better way of doing things. A recent grant will bring together key decision-makers in townhall-style meetings where we can present data. They can then use this information to effect change within their organizations.”

Despite Improvements, We Face Future Challenges and Barriers to End-of-Life Care

Although we’ve made huge strides in improving care of the dying, we still have work to do,” Tolle says. She cites three focus areas: advance directives for people with chronic lung disease and heart failure, enhanced communication and logistics for patients who receive care in multiple settings at the end of life, and better end-of-life pain management. She adds that it’s difficult for practitioners to give a six-month-until-death prediction, which Medicare requires for patients to qualify for hospice care. Therefore, many patients don’t get into hospice care or have it only for a short while. And, because they don’t recognize the gravity of their illness, some people don’t make an advance directive. “We need to do a better job of reaching these patients.”

Another area for work includes logistics and communication for dying patients. A common scenario is this: an elderly patient who is living alone at home suffers a stroke and goes to the hospital for emergency treatment. She survives the stroke but has devastating impairment. When it becomes obvious that she’s dying, the hospital transfers her to a long-term care facility, where she later dies. Meanwhile, her family physician doesn’t know that she was transferred and may not even know when she dies. Because her health spiraled downward so fast, her medical records didn’t accompany her from the hospital to the nursing home, and there are gaps in communication among her various health care providers. On top of everything, the family has to tell her story over and over again, and receives different bills from different health systems, leaving them confused and discouraged.

In addition, there’s the worrisome news that one-third of patients who die in Oregon hospitals suffer moderate to severe pain in their final days. “Although this rate of pain is lower than that reported by other studies, we have to do better,” says Tolle. “We need to get past the simplistic notion that if we teach physicians and nurses about pain management, patients will suffer less.”

Tilden says that more research is needed to understand what factors contribute to patient reports of pain. “Pain is complex and many factors can affect the reports of pain … for example, a family’s worry for the patient tends to increase the family’s perception of the patient’s pain. Careful research is needed to sort out these factors,” says Tilden.

Finally, a vital part of the research program is to train tomorrow’s investigators. The program has employed many research assistants — mostly graduate students working toward their master’s or doctoral degrees. They’ve come from nursing, social work, public health, psychology, medicine and the basic sciences. “This opportunity mentors them in a research team,” says Tilden. Training the researchers of the future meets another of the Center’s goals to serve as an agent of change.
Imagine having to write the world’s first guidebook on physician-assisted suicide. And imagine that you had to do this with people on both sides of the debate and still maintain absolute neutrality throughout the guidebook. The Task Force to Improve the Care of Terminally-Ill Oregonians took on this formidable task just months after Oregonians passed the Death with Dignity Act in 1994.

“Our intent in developing the guidebook has been to carefully think through scenarios in detail and to recommend actions that will optimize care and minimize harm, no matter where the provider sets the limit of involvement along the spectrum of possible scenarios.”

— The Task Force to Improve the Care of Terminally-Ill Oregonians

Convened by the OHSU Center for Ethics in Health Care and not mandated by the law, the voluntary task force (with support from the Greenwall Foundation) stepped forward to provide the state with solid, credible leadership and expertise on this thorny, emotional issue. That it accomplished anything, given the wide diversity of strongly held beliefs, is just short of miraculous. In the big picture, it not only developed a thoughtful and thorough guidebook for health providers on physician-assisted suicide, but the group’s work in this and other areas, it might be argued, has led to many improvements and reforms in end-of-life care.

“This was a very interesting time,” says Pat Dunn, M.D., chair of the task force and a master of the understatement. “The representatives worked very hard. We came to trust each other and knew what to do. Each could go to his or her organization and advocate for the group’s progress.”

Task force members represent state health care professional organizations, state agencies involved in health care, and health systems in the Portland metro area — 25 altogether. Task force members were quick to point out in the preface of “The Oregon Death with Dignity Act: A Guidebook for Health Care Provider” that chapter authorship does not represent endorsement by the author’s organizations and the appendix contains disclaimers from task force member groups such as the Catholic Health Systems, Oregon State Bar Association, and others.

The publication devotes an entire chapter to conscientious practice — which means allowing practitioners and health systems to be true to their own moral and ethical beliefs and not having to act contrary to those. The project took three years to complete. A quick read of the guidebook shows that it’s anything but a step-by-step guide on how to help a patient commit suicide. Instead, it offers a thorough and studied review of the law and its practical applications. The message one gets after reading it is that these often-disparate groups have one
“The representatives worked very hard. We came to trust each other and knew what to do. Each could go to his or her organization and advocate for the group’s progress.”

— Pat Dunn, M.D.

common goal: to promote excellent and compassionate care of the dying. The sub-message might be this: if we can accomplish our first goal through statewide education and systems reform, far fewer patients will seek to use this law.

The book states it this way: “Underlying this work is the assumption that regardless of the health care provider’s personal view on physician-assisted suicide or the act itself, open communication, consideration of comfort needs, and respect for divergent views are necessary components of care.”

The book further states, “Our intent in developing the guidebook has been to carefully think through scenarios in detail and to recommend actions that will optimize care and minimize harm, no matter where the provider sets the limit of involvement along the spectrum of possible scenarios.”

The ethics center has membership on the task force; the Center also provides staff support and distributes publications of the group. It sold copies at cost to organizations and health systems to help them formulate policy regarding physician-assisted suicide. The Center also sells the guide to physicians who request it. Says Dunn, “It usually comes up when a physician is asked and who then says, ‘What am I going to do?’” He points out that complying with requests for a lethal prescription from dying patients has been an uncommon event since the law went into effect in late 1997.

The group, which continues to meet, also published “The Final Months of Life: A Guide to Oregon Resources.” This booklet lists resources for all aspects of the care of terminally-ill Oregonians, county-by-county. First published in 1997 and revised in 1998, the book can be used by physicians, other health care professionals and families to counter the pain, isolation and loneliness that dying patients face by listing resources for a broad range of needs. These resources have been widely used and now are available on the Center’s Web site, www.ohsu.edu/ethics.

Dunn says that publishing these books is not enough — the group continues to meet to facilitate education and to offer input on public policy. Although the group does no lobbying, it offers its considerable expertise to Oregon’s state and federal lawmakers on compassionate care of the dying. “Our major push right now,” says Dunn, “is advocating for improving access to hospice care in Oregon. In a state with assisted suicide as policy, it seems like hospice care should be available to all citizens.”
Pink “POLST” Works in Oregon: Use Spreading Across U.S.

The bright pink form called “POLST” (Physician Orders for Life-Sustaining Treatment) is perhaps the ethics center’s most visible, literally, of its many first decade accomplishments. This simple, two-sided form gives dying patients, especially those in nursing homes, a venue to express their wishes regarding life support and comfort care. It also may be contributing to Oregon’s small number of deaths inside hospitals — the lowest rate in the United States (in 1996, 33 percent compared to 56 percent nationally).

POLST is not an advance directive, like a living will, but rather a form that sets limits now, not in the future, for medical treatment. It spells out the exact types of treatment a terminally-ill person would want if, for example, he or she stops breathing or has no pulse.

It was the desire to give dying patients a voice — in urgent medical situations and when they are incapable of expressing their wishes — which led to the creation of POLST. In 1991, the ethics center, with leadership from Patrick Dunn, M.D., brought together all the entities which had a stake in caring for patients across settings — hospice, legal authorities, acute care hospitals, emergency medical services, nursing homes and others. This group of about 40 disparate individuals first tackled the problem of do-not-resuscitate orders that go unheeded when patients are transferred from a nursing home to a hospital.

Says Susan Tolle, M.D., ethics center director, “This was a formidable task. We’re talking about people who traditionally didn’t talk with one another. As soon as you got a patient into an ambulance, any doctor’s orders before then didn’t matter. The ambulance service had to follow EMS protocols. Once the patient reached the emergency room, only the hospital’s protocols mattered.”

Under Dunn’s expert facilitation, the group came up with the idea of a portable set of physician’s orders that would accompany patients during a transfer between settings. The group devised a form, and the ethics center’s researchers, with support from The Greenwall Foundation, went to work testing and refining it. The first POLST forms went into practice in 1995, but the group today continues to make improvements. “With each revision, we better meet the needs of additional groups of people,” says Tolle.

Center personnel played other key roles in getting the POLST into practice. Terri Schmidt, M.D., senior scholar with the Center, physician-supervisor for a number of EMS agencies in Clackamas County, and vice-chair, Department of Emergency Medicine, led the way in educating emergency medical personnel statewide in using POLST.

“POLST has promoted advance care planning for Oregonians with serious illness,” says Dunn. “It honors patient wishes for life-sustaining treatments and preferences about hospital transfer.” He added that, “POLST allows making it possible for people to stay in their care setting, ensuring good symptom management.”

Tolle, Dunn, Virginia Tilden, D.N.Sc., and Christine Nelson, M.S., proved that things are better in Oregon in a study published in the September 1998 Journal of the American Geriatrics Society. The other...
“The form ... takes patient wishes and converts them to a medical order. The physician signature means that everyone from nursing home staff to emergency medical personnel have legal authority to honor a patient’s desires.”

— Susan Tolle, M.D.

Researchers prospectively studied 180 nursing home residents who had POLST forms designating “do not resuscitate” and stipulating a desire for transfer only if comfort care measures failed. Results showed that no study subject received CPR, ICU care or ventilator support, and only four patients (2 percent) were hospitalized to extend life.

“The form directs attention to palliative versus life-extending care,” says Tolle. “It takes patient wishes and converts them to a medical order. The physician signature means that everyone from nursing home staff to emergency medical personnel have legal authority to honor a patient’s desires.”

The authors concluded that POLST orders regarding CPR in nursing home residents were universally respected. Furthermore, study subjects received remarkably high levels of comfort care and low rates of transfer for aggressive life-extending treatments.

“For those who wish to give the message, ‘I want the primary focus of my care to be on my comfort, rather than on extending my life,’ the most powerful thing about POLST is that their wishes will not be ignored, as often occurs in other parts of the country,” says Tolle.

Because of its success in Oregon, use of the form is spreading across the United States. So far, the ethics center has distributed 220,000 of them.

For the ethics center, POLST is more than a form, it’s a program of education, scientific research and support for families. POLST Task Force leaders feel that the POLST program has done well in Oregon because of the state’s strong interest in enhancing end-of-life care. Dunn says, “POLST encourages health care providers to understand and communicate the wishes of their patients — a worthy and essential goal.”

POLST Task Force members, front row (left to right): Susan Tolle, Trudy Schiddleman, Pat Dunn, Terri Schmidt. Back row (left to right): Mark Bonanno, Ann Jackson, Dan McFarling, Tim Hennigan, Jerry Andrews, Chris Nelson (standing behind Pat Dunn), Dan Field, Holly Robinson and Anne-Marie Jones.
Ethics Center’s Chiodo and Tolle Offer American Dentists Leadership and Thought-Provoking Column

Case 1 — A general dentist is examining a new patient with a toothache. The tooth is badly infected so the dentist explains the diagnosis and the patient consents to extraction. He quickly realizes that he has pulled the wrong tooth. Fearing a lawsuit and damage to his reputation, the dentist covers his mistake by telling the patient that an adjacent tooth (the one that should have been extracted) also needs to be removed. The patient agrees and actually feels grateful that the dentist has identified the “additional problem.”

Case 2 — A woman shows up at her dentist’s office with a damaged tooth, swollen lip and bruises on her face and neck. He asks her how she was injured; she says that she fell against a corner of the wall as she chased one of her children. The dentist notes from her chart that she has sought emergency treatment three times in the past two years. His growing suspicion is that her attorney-husband may be beating her; this bothers him but he wants to respect her privacy. He wants to say something to her but doesn’t know how. He can’t believe that a woman being beaten to this degree would stay in the situation.

Every other month, two Oregon ethicists present patient scenarios like these and provocative ethical issues, such as a dentist’s duty to treat HIV-infected patients, to 66,000 American dentists. Gary T. Chiodo, D.M.D., and Susan W. Tolle, M.D., write a dental ethics column that appears six times a year in General Dentistry, the peer-reviewed, scientific journal of the Academy of General Dentistry, which is oriented to practicing dentists.

The two OHSU doctors, one a dentist and the other a physician, serve up such thorny issues as the pitfalls of treating family members, what to do about chemically dependent practitioners, getting consent for treatment among non-English-speaking immigrants, dealing with sexual advances of patients and the wisdom of accepting gifts from drug companies or wealthy widows.

Managing Editor Ellen Paul Odehnal says that the ethics column is “the most letter-generating feature” at the journal. “It stirs up a number
widespread bereavement support was among general dentists. He took as his example a 1984 groundbreaking study by his colleague Susan Tolle, who surveyed 100 family members one year after the death of a spouse to find out how physicians expressed condolences and support. Chiodo teamed up with Tolle to do a similar study among Oregon dentists, who lose an average of five patients a year to death.

They asked whether the dentist had attended the patient's funeral, sent the family a card or telephoned. They found that dentists had a remarkably high level of contact with families after a death. They also learned that bereavement support from the family dentist is very appreciated by surviving loved ones.

"Surviving family members need some reassurance that the patient was important to all his or her health care providers," Chiodo states.

As a public health dentist and a faculty member of the dental school since 1978, Chiodo used the results of the survey to press for national-level curriculum changes that would teach students about bereavement support.

The two colleagues continued their collaborations. In 1989, based on many mutual interests, and the shared belief that an interdisciplinary approach to ethics could be a powerful force, Chiodo and Tolle, along with many others across campus, formed the Center for Ethics in Health Care. The column seemed to arise naturally from this collaboration.

Tolle says that their two disciplines — medicine and dentistry — complement one another. She says that dentistry has been ahead of medicine in defining ethical business practices. Conversely, she says, medicine has led dentistry in probing the ethics of the doctor/patient relationship. “We are learning from each other,” says Tolle.

Journal Editor Odehnal says that it’s the authors’ unique perspective, not only as academics, but also as involved members of the national ethics community, that makes the column so compelling. "It elicits from readers a bond of trust and belief. They look to them (Chiodo and Tolle) for leadership. This doesn't happen with other features. It is consistently one of our top-rated features in readership surveys.”
Melissa Buchan, M.D., 1934–1998: Brought Soul to the Ethics Center

When Melissa Buchan, M.D., left this world, exactly 64 years from the day she entered it, the Center for Ethics in Health Care lost a piece of its soul.

Says her longtime colleague and friend Susan Tolle, M.D., director of the center, “Melissa had a deep interest in the spirituality of medicine, where you treat the patient as a whole person.” As a family physician who practiced at the OHSU student health service, Buchan worried that the medical profession was becoming too enamored with techniques and procedures, resulting in less time spent talking with patients. “She was concerned that medicine was losing the art as it became better at the science.”

— Susan Tolle, M.D.

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About 14 years ago, to provide a counterbalance, Buchan and a couple of other colleagues came up with an idea for giving new physicians actual training in the humanistic side of medicine. They devised role-playing sessions in which resident physicians could learn compassionate and sensitive ways to deal with families at the time of a loved one’s death.

Buchan recruited community volunteers — many of whom had some experience with death, either in their own families or as professional counselors — to role-play with the residents. Faculty members trained in ethics observe the role-playing and later offer the residents a constructive critique of how well they managed the situation. Tolle says the method helps young physicians get over being nervous and gives them language that makes families comfortable.

The role-play program became so successful that the departments of internal medicine, family practice and emergency medicine incorporated it as a required part of residency orientation. The first afternoon of orientation, residents receive training in how to notify relatives of a death.
The next afternoon they get information about talking with their future healthy clinic patients about advance directives.

Says Tolle, “It’s a very powerful, real experience for house staff. After two days of role-playing, they go home drained but better prepared.”

The first of its kind in the United States, the training method has now spread to other residency programs across the country.

Buchan, of course, left more than a training program as her legacy. Her fighting spirit and unflagging enthusiasm touched everyone she met. While fighting colon cancer, she earned a black belt in karate. “It (karate) has taught me a lot about myself,” Buchan said in an Oregonian newspaper article about her. “It’s given me patience, courage and focus. It’s taught me the Eastern philosophy of what’s important is right now.”

In the summer of ’97, a year before her death and on chemotherapy, Buchan competed in the Nike World Masters Games in Eugene. She won a silver medal in the discus and a bronze in the shot put. “Her participation in those games symbolized that even as the odds get difficult, you can still mount an incredible fight,” says Tolle.

Hanging in Tolle’s office is the first track medal Buchan won after her diagnosis of colon cancer in 1997.

It was her way of thanking the ethics center for giving her a venue to express her spirituality and compassion for dying patients.

Buchan spent many hours comforting patients at the end of their lives.

“When Melissa entered the room, you could feel her caring, that everything would be OK because she was there,” says Tolle. “She had a presence, and she was not afraid of people’s feelings. She didn’t pull back because someone was dying.”

Her spirituality also led her to the Unitarian Universalist Church, which ordained her as a lay minister in February 1998.

The role-playing program may be Melissa Buchan’s greatest legacy to the university, but her friends and colleagues will remember that she brought heart and soul to the ethics center.

Husband Colin Buchan, M.D., two daughters and two sons-in-law, three sisters and two grandchildren survive her.

“When Melissa entered the room, you could feel her caring, that everything would be OK because she was there … She had a presence, and she was not afraid of people’s feelings. She didn’t pull back because someone was dying.”

— Susan Tolle, M.D.
The old adage that the more things change, the more they stay the same seems apt at this moment in Miles Edwards’ life. The 70-year-old former chief of pulmonary medicine in the medical school is back in the exact space where he saw patients 43 years ago as an intern.

“At night and on weekends, people would wander into the old hospital,” says Edwards. He means Multnomah (County) Hospital, one of OHSU’s oldest buildings and the new home for the Center for Ethics in Health Care. “There wasn’t an emergency room on Marquam Hill in those days, but the county hospital served that function,” he says. “It was low-tech, low-volume care. Everyone we saw was poor.”

After 27 years as a lung and critical care specialist, Edwards will once again be spending time in that space — now as a clinical consultant for the ethics center.

Edwards’ interest in ethics actually evolved from the high-tech side of medicine when he took care of sick and dying patients in the hospital’s critical care unit. “We had to make frequent decisions regarding continuation or discontinuation of life support,” he says. “This led to many complicated issues of ‘How do you make that judgment?’ and ‘Is there a systematic way to do so?’ We had to face problems without any formal ethics training; we did it intuitively. But it would have been nice to have had some ethical training,” he says. As he got closer to giving up direct intensive care responsibilities, he thought about turning his focus toward ethics. He spoke with Susan Tolle who suggested he take formal training. He took her advice and, in 1991, completed the Oregon arm of the University of Washington certificate program in medical ethics.

For the past several years, he has been part of a group of physicians, nurses, social workers and lawyers who arbitrate differences between the hospital and its patients or among groups of employees. Many of the consult team’s cases involve clashing ethical values between people, such as continuing or discontinuing kidney dialysis, mechanical ventilation or other life support.

“The service is provided free of charge by the ethics center. With most of his clinical and teaching duties behind him, Edwards, now professor emeritus, devotes his professional efforts to medical ethics. He researches and writes articles on various topics for publication in medical journals. “My favorite subject is how managed care affects relationships between patients and doctors … When I see my colleagues, under intense economic pressure, continuing to put the legitimate needs of the patient first in their motivations and first in their hearts, I feel pride in being a physician,” he said in a recent interview. “That’s continued on page 18.
What does a retired doctor do with all his wonderful experience — maybe 40 or even 50 years of it?” Daniel Labby, M.D., asked himself. “I’ve always thought that the retired physician was one of society’s greatest losses of manpower.”

Approaching his own retirement — an odd term for a man of 84 who still spends two days a week seeing patients, teaching psychiatry residents and putting on a popular seminar series — Labby sought the advice of retired colleagues. They realized that they’d all been forced to make difficult judgments during their many years in practice. Perhaps they could share their hard-earned wisdom with each other and a younger generation of practitioners.

Labby put a handful of these retired practitioners in a room for a couple of hours in 1989, and in doing so, tapped into a great brain trust. Group members dedicated themselves to open discussions about vexing ethical problem cases they’d encountered in practice. At the first seminar, Labby, now professor emeritus of medicine and psychiatry in the OHSU School of Medicine, presented two cases of his own. Both concerned the dilemma of what to do with unsolicited, secret information that someone gives you about a patient.

Ten years later, the twice-annual seminar series is thriving. The series, now called the Daniel Labby Senior Clinicians’ Seminars, averages 50 participants, but has drawn as many as 90 in a single session.

What’s the secret to his success? It may be, in part, due to maintaining confidentiality during the closed-door seminar discussions. He allows no reporters and discourages note taking. He asks participants to keep the discussions to themselves or among professional colleagues. This way, he says, members of the audience have the freedom to speak openly.

The audience is there by invitation only, and the energetic founder writes a personal note to each invited guest. The ethics center, which sponsors the series, sometimes sends as many as 150 invitations for a seminar. “We never refuse anyone in a caring profession who wants to come,” says Labby. The audience is usually a mix of senior and younger psychiatrists, internists, surgeons, family practitioners, anesthesiologists, and even lawyers, principally from the community and faculty. Some attend for only one seminar because the topic is of special interest to them, but there’s also a core group that attends regularly.

The semiretired internist-turned-psychiatrist serves as moderator during discussions. Usually a speaker...
“I’ve always thought that the retired physician was one of society’s greatest losses of manpower.”

— Daniel Labby, M.D.

with a special interest and skills in a topic presents a case; and often a panel of experts offers insights on a subject. With all the rapid advances in technology and medical science, there’s never a shortage of topics. The most recent seminar covered threats to privacy, and access to patient records by insurance companies and others with access to electronic records. Other subjects over the years have included issues of confidentiality and secrets, the futility of treatment for seriously ill newborns, care of patients who refuse treatment, the privacy and rights of patients, ethical issues during end-of-life care, and even doctors’ errors — confess or keep secret? “Our basic tenents are how to preserve the patients’ autonomy and their sense of self-determination as a partner in their health care decision, and to respect privileged information and confidentiality, while maintaining a sense of fairness to the community in public health matters,” he says.

As far as anyone can tell, the senior clinicians’ seminars are unique. Labby and Susan Tolle, M.D., director of the ethics center, searched medical literature for mention of a similar format devoted to medical ethics and found nothing. They later published an article in the spring 1997 issue of Pharos, a journal of Alpha Omega Alpha (the medical honor society), explaining the series’ purpose to a national audience of physicians who graduated at the top of their medical school class. “(Our goal has been) to produce information, attitudes and viewpoints that can be channeled into teaching, policy guidance, and research … ,” they wrote.

They also said, “the discussions could be used to enrich and expand contemporary teaching and training needs in our institution if they were designed in such a way that the mature experience and good judgment of the seasoned clinician could be salvaged and channeled.”

That is indeed what has happened at OHSU. Seminar participants have become a valuable source of volunteer teachers and consultants for the medical school. Some are helping to teach the Principles of Clinical Medicine course for first- and second-year medical students and the Transition to Residency course for fourth-year students, and some have helped with curriculum design.

The seminars also are a way for alumni to stay in touch with the schools, and some have become contributors to the ethics center.

What’s next for Labby, who has already received a lifetime achievement award from Reed College (he was graduated in the class of ’35) and a Preuss Award for Outstanding Alumni from the OHSU School of Medicine (class of ’39), and whose seminar series now bears his name?

He says longevity runs in his family and he’ll probably just keep going — “as long as I’m doing something useful.”

Miles Edwards, M.D., continued from page 16 what we’re here for; that’s the core of our profession.”

In recognition of his many accomplishments, the School of Medicine in 1998 honored him (class of ’56) with the Charles Preuss, M.D., Distinguished Alumni Award.

Says Tolle, who nominated Edwards for the Preuss award, “Miles personifies humanism and compassion. The Center’s whole thrust is health care with compassion; Miles embodies that.”
Kinsman Investment in The Center for Ethics One of His Best; Kinsman Conferences a Big Success

The Center for Ethics and one of its chief sponsors have at least one thing in common: they’re both self-made.

John Kinsman, who sponsors conferences including the annual statewide ethics conference that carries his name, didn’t always have money to give away. He says he was born “in a house or a grain elevator” in Darmody Saskatchewan, Canada, and as a young man did farm chores for room and board.

His strong work ethic, along with a bit of luck and an evident knack for spotting a good investment eventually led to Kinsman Enterprises, a private company that has been involved in a variety of interests. His early business success came from buying property in an area that eventually grew to be Wilsonville. He also invested in bank stocks, and as his portfolio grew, he became a director of First State Bank, Pacific Western and most recently Key Bank from which he retired. He was also a member of the board of Columbia Funds for twenty-five years after having played a part in the formation of the Funds.

When he met Susan Tolle, he saw another good investment — of the personal variety. “I was so impressed with Susan’s dedication for bereavement care that I put my money on her. No one else would do so at the time. Of course, she has shown all those non-believers how important a good investment can be.”

“John Kinsman has given generously to the Center in several ways, including funding an endowment to support the Kinsman Conference Series,” says Tolle. “This has enabled the Center to permanently co-sponsor regional ethics conferences.”

The conferences are held around the state and always are jointly sponsored by local health systems or other entities. Topics, which can vary widely, are unified by an ethical theme. For the 20-some conferences held in the past, topics have included ethical concerns in managed care, poverty and access to care, emergency room decision-making, special concerns in pediatrics and much more.

“The wonderful thing about the conferences is the sharing that happens,” says Tolle. “Something is brought from every part of the state.” She uses the example of St. Charles Hospital in Bend. The hospital’s catchment area has the country’s lowest in-hospital death rate among Medicare patients and the highest rate of hospice care in Oregon. She says everyone is learning from this example. She adds that, “So much more is possible when we build networks.”

Due to John Kinsman’s foresight and willingness to take a risk, health care ethicists are getting together and working out solutions to many vexing problems. As he has said before, “The Center for Ethics has been one of my most worthwhile investments.”
The Coalition of Oregon Ethics Resources Highlights Ethics Center Role as Convener

Perhaps nothing illustrates the Center for Ethics in Health Care’s role as facilitator better than “COER” — the Coalition of Oregon Ethics Resources. Think of it as the statewide umbrella for several highly productive task forces and a communication link for four regional networks — all separate from the ethics center but sharing common ethical concerns.

“The ethics center has been wonderfully supportive as the convener,” says Patrick M. Dunn, M.D., senior scholar and founder of COER.

As a loosely structured, voluntary organization without walls, COER has succeeded in building trusting relationships among diverse individuals and entities. With ideas from COER, the ethics center spawned the Task Force to Improve Care of Terminally-Ill Oregonians, the POLST Task Force and the Kinsman Conferences. COER’s main thrust is to share information and resources, improve the knowledge and skills of health care providers, propose public policy and provide opportunities for ethicists to share common experiences.

The coalition has its roots in the Health Ethics Network of Oregon (HENO), which began in the mid-1980s as a way to share experiences across care settings. Says Dunn, “I started talking with Mike Garland, D.Sc.Rel., about whether he thought it would be helpful to have a group of professional ethicists in Portland get together on a regular basis. We both thought it would, and so we came up with a list of people from diverse clinical care settings. We met and asked, ‘Is there an interest?’”

— Patrick M. Dunn, M.D.

Regional Representatives

Central Oregon Network
Dorothy Gowdy

Health Ethics Network of Northern Oregon and Southwest Washington
Mary Ann Dickey

Southern Oregon Coalition of Ethics Resources
Patrick Gillette

Willamette Region Ethics Network
Barry Heath

“I started talking with Mike Garland, D.Sc.Rel., about whether he thought it would be helpful to have a group of professional ethicists in Portland get together on a regular basis. We both thought it would, and so we came up with a list of people from diverse clinical care settings. We met and asked, ‘Is there an interest?’”

Garland, associate director of the Center, and Dunn got an enthusiastic response from the early participants. At the time, many of them were struggling with the issue of patients who had been resuscitated against their wishes. The group began to meet quarterly, and membership increased.
“The beauty of COER is that it’s not ‘owned’ by a single institution nor is it dominated by the Portland area or by any particular group”

— Patrick M. Dunn, M.D.

In early 1991, with assistance from the two-year-old Center for Ethics in Health Care at OHSU and Legacy Good Samaritan Hospital and Medical Center, HENO sponsored a statewide meeting. “There was a lot of energy and excitement at that first convention,” says Dunn. “We did a needs assessment and from that initial prototype of ethics networking built the foundation for COER. It was among the first such networks in the United States.” This meeting led to a statewide consensus on the need for a system to better communicate patient wishes about life-sustaining treatment when transferred across settings. With this strong mandate from COER, the ethics center convened the Physician Orders for Life-Sustaining Treatment Task Force.

In addition to the statewide coalition, COER members divided themselves into four geographic networks (HENNO for the Health Ethics Network of Northern Oregon, CONET for Central Oregon Network, SOCOER for Southern Oregon Coalition of Ethics Resources and WREN for Willamette Region Ethics Network). These networks collaborate on local issues and also take turns hosting the annual Kinsman Conferences. The result is that once a year, anyone with an interest or stake in health care ethics comes together at one place and time.

“The beauty of COER is that it’s not ‘owned’ by a single institution nor is it dominated by the Portland area or by any particular group,” says Dunn.

After a decade of shepherding COER, Dunn stepped aside last year. His successor, Robert H. Richardson, M.D., assistant director and community liaison for the Center, says their next major task includes developing a comprehensive program, which guarantees a decent level of health care for all Oregonians. “We’re looking at disadvantaged groups of people with limited access to health care, such as immigrants, women, children, and the working poor.”

Richardson says COER will continue to be active in end-of-life care, the ethics of managed care and they will be looking at how to achieve better mental health care. “When multiple disciplines from around the state strive for a common goal, real change is possible.”
Talk is cheap,” the saying goes.

But the talk that lives at the heart of ethics education is anything but cheap. This talk is a difficult art that connects people in trust, compassion, justice, solidarity, and even in profound disagreement. Ethics teaching at OHSU challenges professional students to open themselves to others’ values and to trust others enough to speak of their own deeply held values. One student recently shared these reflections on finding herself alone in her conviction among a group of colleagues:

“Suddenly I felt a need to defend myself, a need to say significant things. But of course, my mind went almost blank at this point and I was only left with an emotional response that I had not even known was within me.”

Ethics talk takes colleagues to places where fundamental moral disagreement requires them to find words that honor the others’ convictions without betraying their own. A student gave this description of the power of ethics talk to transform his thinking about moral disagreement with colleagues: “I think that in the future I will have a resolve to first think, ‘how can I work TOGETHER with this person whom I really disagree with to resolve this issue as much as possible,’ rather than ‘I need to keep silent and avoid this topic because it is uncomfortable,’ or ‘I need to make sure that my agenda wins at all costs.’”

The challenge of ethics talk arises every day in OHSU classrooms, resident lounges, staff and conference rooms — just about anywhere people congregate on campus. Faculty of the Center for Ethics in Health Care regularly share resources, ideas, and methods for nurturing this talk across a wide array of topics. Catherine Salveson, Ph.D., challenges undergraduate and graduate level nurses to explore gray zones of patient care, community health issues, access to care, and patient rights. Gary Chiodo, D.M.D., and Susan Tolle, M.D., challenge dental students with cases like the following: Should a dentist treat a patient who needs immediate care for extensive dental disease then post-date the insurance claim to get beyond her required waiting period for dental coverage at her new job?

Virginia Tilden, D.N.Sc., and Michael Garland, D.Sc.Rel., bring research ethics questions to graduate students in the Schools of Nursing and Medicine. Leslie Ray, Ph.D., introduces nursing students to organizational ethics to aid their capacity to engage in ethics talk in the committees, unit meetings and work teams of modern health care institutions. Molly Osborne, M.D., Ph.D., helps resident physicians to explore the ethical significance of comfort care, hospice, advanced care planning, and the psychosocial and spiritual needs of seriously ill patients. Martin Donohoe, M.D., uses literature, history and philosophy to draw resident physicians into deeper explorations of humanistic values in health care.

Faculty in the School of Medicine invite students to engage in ethics talk right from the beginning of their studies, helping them explore a continuous stream of questions from privacy to pain management, cost control to experimental procedures, abortion to physician-assisted suicide. Who owns genetic information? Should the diagnosis of depression go in the medical record? Are we keeping our commitments to patients when we limit tests or eliminate return visits or discourage bedside counseling in the name of efficiency? Are we doing our fair share of caring for uninsured patients?

When the Center for Ethics was initiated, its founding members understood that moral responsibility is shared and that ethics talk has to occur among a wide array of health care professionals. The future of ethics education at OHSU will go beyond merely sharing methods among faculty from different disciplines, who then return to their separate schools and work with their students. Ethics talk in interdisciplinary groups of students at all levels is the path that OHSU educators need to pursue. For example, nurses, physicians, social workers, chaplains...
“Mike Garland has been a guiding force in student education. From the time I was a student in the 1970s until the present, I have valued Mike’s skill in inspiring each of us to become a better physician, nurse or dentist.”

— Susan Tolle, M.D.

all have to explore together what to do when they encounter a patient who refuses to undergo life-saving surgery.

The challenge of ethics education continues to be the same. Faculty must find ways to create occasions where ethics talk can produce insight like the one described by this OHSU student: “I had tried to borrow the thoughts and ideas of authors before even trying to find an answer within myself. And it became a ‘defeat’ because when I saw my values being tested, I ran for cover under published arguments rather than going first to establish my own values … Slowly, as I became more firm on knowing why I believed what I believed, the defensive attitude was taken away; and in its place was a new desire to help others understand me — to see my heart not my arguments.”

Michael Garland, D.Sc.Rel., (center left) leads a seminar discussion on ethics with OHSU students.
Weeks before Joe DiMaggio died and while he was critically ill and comatose, journalists fed the public hourly updates from the hospital on his impending death. DiMaggio defied his doctors’ prognosis and lived long enough to complain about his loss of privacy. Of course, it’s not just baseball Hall of Famers who suffer public intrusion into their lives. Public voyeurism at the most private moments of our lives has been going on for years. This is the most private information about our lives and bodies may be posted to a lifetime electronic medical record by a large health care system.

At a recent Daniel Labby Senior Clinicians’ Seminar sponsored by the ethics center, John Benson, M.D., assistant director of the ethics center and dean emeritus of the School of Medicine, raised this question: Is medical privacy an illusion or a sacred trust?

Patient confidentiality used to be of managed care, providers had to manage both patient care and the costs of care, making the medical record also a financial record. OHSU Hospital, for example, must show medical records to government insurers to prove that the services billed for were actually rendered. And because managed care and large health care systems are inherently about providing cost effective, quality care, it means they must often use patient data for outcomes research.

The issue of who has access to medical records worries patients and practitioners alike. In decades past, a solo practitioner could simply store the records behind a locked door. Today, providers who post information to electronic records must institute a new set of procedures and protocols to prevent unauthorized access.

The sharing of information across settings is not necessarily bad. As Roy Magnuson, M.D., medical director of OHSU Hospital, points out, hospitals and their systems need aggregate data to determine whether they’re doing a good job and whether they have the right patient mix to maintain the viability of teaching and research programs. The sharing of information can also help patients through better coordination of care.
“We need to remember that the database is someone’s personal medical record story. With Web-based electronic records, the challenge is to make them secure but also make them available to the 1,400 physicians in the system.”

— Roy Magnuson, M.D.

avoidance of dangerous drug interactions and duplication of services.

Magnuson, however, offers this caution: “We need to remember that the database is someone’s personal medical record story. With Web-based electronic records, the challenge is to make them secure but also make them available to the 1,400 physicians in the system.”

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Today, providers who post information to electronic records must institute a new set of procedures and protocols to prevent unauthorized access.

Patient confidentiality is challenged by not only who has access, but by limits on the information providers incorporate into the record. Providers may be reluctant to add such sensitive information as drug addiction, sexual history or orientation, or mental health problems. Yet all these matters may affect a person’s on-going treatment for other ailments.

The loss of privacy and confidentiality are big issues that ethicists and the public must face in the coming decade. The OHSU Center for Ethics hopes to find ways to balance non-practitioners’ need to know what’s in a medical record with a patient’s right to privacy. Large health systems will need guidance in setting standards for granting access to persons not directly involved in the patient’s health care and in deciding what, if anything, is transferred to large databases. The tradeoffs are challenging.

Future challenges for the Center include protecting the dignity and privacy of individuals.
Ethics Center Helps Find Balance in Biomedical Research

Biomedical research on humans is essential if society is to alleviate suffering from today’s ills. Yet, in early to mid-20th century, some governments and institutions took advantage of people who couldn’t give their consent because they lived in mental institutions and prisons. When these abuses came to light, the U.S. Congress passed strict laws protecting vulnerable populations from further exploitation. In fact, federal guidelines governing research at most universities and research centers provided so many safeguards that many groups, such as those with severe dementia, children and others who could not consent were excluded from clinical trials.

During this time, medical science made little headway in treating disorders that affected these populations, especially the chronically mentally ill. However, in the past 20 years, and especially since the advent of AIDS, patient advocates have lobbied for guidelines that are more flexible in allowing those who may be vulnerable to participate in research studies while ensuring increased protections for them. The question they raise is, how do you test a drug to treat Alzheimer’s or schizophrenia, for example, if you can’t give it to the patients it’s designed to treat?

Where the pendulum stops now is a matter for public debate. To help find the balance, President Bill Clinton created a National Bioethics Advisory Commission in 1996 and appointed Patricia Backlar, Center for Ethics assistant director, to the prestigious panel. Vulnerable populations, particularly those with mental illness, have found a strong voice nationally through Backlar, whose son has schizophrenia. She is the author of the book, The Family Face of Schizophrenia (G. P. Putnam’s Sons, 1994), and many published articles on mental illness and ethics.

She says that "an overly protectionist stance that shields certain groups from research participation may deny such populations the benefits garnered from scientific research that are available to other disease populations." Backlar, adds, "the concept of protection for research subjects need no longer mean that vulnerable subjects must be excluded from research participation. Rather it should signify a constellation of safeguards provided to guarantee the rights and welfare of all subjects enrolled in studies."

Through her seat on the presidential commission, Backlar is able to bring her concerns to a national forum and influence national policy. She says that being on the commission has put her in a position to do more for the population she cares about. "This is a precious opportunity to improve the lives of people who may be unable to look after their own interests.“ She credits the ethics centers’ leaders for successfully lobbying the White House for her appointment.

Gary Chiodo, D.M.D, associate director of the Center, chairs the OHSU Institutional Review Board, which oversees human research at the university. His training as an ethicist
makes him ideal to head this key board, which he has been a member of since 1992. In addition to ensuring the university's compliance with federal regulations on human research, the group must wrestle with such topics as obtaining consent from subjects with reduced or fluctuating capacity to consent; research with children; genetic research; use of placebo controls in studies where the subjects have existing disease; deferred consent in emergency protocol research; under-representation of minorities in research; and many others. All of these issues form the calculus for a current national atmosphere in research reform. Dr. Chiodo adds, “Clearly it is ‘high-noon’ for the ethical reform of human subjects research.”

Dr. Chiodo raises the issue of women in research — a hot topic in Oregon and nationally. “Some pharmaceutical companies prefer to exclude women of childbearing potential from studies of new drugs because of the possibility of these drugs causing birth defects. On the other hand, women are able to understand and appreciate these risks and utilize effective contraception. “The principle of respect for autonomy would seem to require that women not be excluded from the potential benefits of such trials, and the principle of justice would require that men not bear the entire burden of such trials.

A particularly thorny area for research ethics relates to genetic privacy. Can researchers test stored tissue and blood samples and, if they find something interesting, can they find out who you are and read your medical record or contact you? Probably one of the stickiest issues now facing physicians is how to handle the results of genetic testing. While drug companies and patient rights advocates battle in court and in the legislative arena over ownership of genes, health care providers and genetic counselors face these practical concerns every day. For example, if a person learns that he or she has a devastating genetic condition, is the counselor bound by traditional providers doctor/patient relationships to withhold this information from blood relatives who also may be at risk? Or, does the counselor have a moral obligation to warn other family members, especially if treatment for the disorder is available?

Brad Popovich, Ph.D., medical geneticist, asks this: Should clinicians treat genetic information differently from other medical information in a patient’s record? Should genetic information go into the medical record where insurers or even employers may gain access to it? Will this exclude people from insurance and jobs? And if one person’s inherited condition becomes known, do we need laws to protect untested family members from discrimination? It really boils down to this: If a person is genetically predisposed to illness and you can therefore predict his or her future health, how do you protect this individual’s privacy?

In August 2000, OHSU and the Center for Ethics will co-host with the federal Office for the Protection from Research Risks a conference on "Ethical Research in the New Millennium: What the Belmont Report did not Anticipate." It will deal with contemporary ethical dilemmas in human subjects research.

As co-chairs of the Center for Ethics’ Research Task Force, Backlar and Chiodo work together in assisting OHSU to deal with the most difficult ethical issues impacting human subjects research. As we cross into the next millennium, Backlar, Chiodo and others at the center will be among those defining biomedical research practices that give vulnerable populations and women more freedom to participate and yet provide adequate safeguards. They anticipate many new challenges – human stem cell research, embryonic and fetal tissue research, cloning and many new directions in genetics. The key is to ensure that all human subjects, and especially those who may be disadvantaged or vulnerable, can participate safely.
A big message coming from community advisors to the ethics center is this: pay more attention to access to health care.

The community advisory council includes representatives from the Oregon Health Plan, Oregon Health Decisions, migrant health clinics, the Ecumenical Ministries, the Jewish community and community health activists. This group believes the Center should urgently press the argument that all citizens should have access to health care.

The Center’s leaders agreed to take a clear stand in favor of universal coverage and, with assistance from the advisory council, wrote a commentary published in The Oregonian on December 26, 1998, pushing for health insurance coverage for every Oregonian. The authors note that 40 million Americans lack coverage for health care and 150 million have no insurance for dental care. They call that “an ethical shortcoming in the richest nation on Earth.”

The strongly worded piece, written by John Benson, M.D., Gary Chiodo, D.M.D., Michael Garland, D.Sc.Rel, Virginia Tilden, R.N., D.N.Sc., Susan Tolle, M.D., and Gloria Tuma, M.S.W., calls for health insurance coverage for all Oregonians by 2003. “We call on colleagues and fellow Oregonians to join in acknowledging our social responsibility to identify and take the steps necessary to finish the task. Let us value the social solidarity of universal health coverage. What is beneficial to individuals can benefit society.”

They state that managed care, practice guidelines, utilization review take a clear stand in favor of universal coverage and, with assistance from the advisory council, wrote a commentary published in The Oregonian on December 26, 1998, pushing for health insurance coverage for every Oregonian. The authors note that 40 million Americans lack coverage for health care and 150 million have no insurance for dental care. They call that “an ethical shortcoming in the richest nation on Earth.”

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— Michael Garland, D.Sc.Rel

and other part-way measures have failed to stem the steadily increasing costs of health care or the unacceptably high number of uninsured individuals. The authors cite the Oregon Health Plan as a good beginning but note that it has failed to achieve universal coverage.

“In our first decade, we tended to focus on ethical issues of individual patients, such as improving care at the end of life,” says Center associate director Garland. “Now we need to increase our focus on systems issues where social policy and organizational ethics affect whole populations of people. The Center for Ethics in Health Care should be a voice for universal access to health care as a matter of justice and the common good. We need to pay attention to ethics as a social process, not merely an intellectual puzzle.”

Garland says the Center’s efforts should keep connecting abstractions like access to care with visible human realities. Fixing a single person’s problem leaves the source of the problem intact. “When we see a young boy die because his family can’t afford an organ transplant, we need to see that the cause is society’s failure to guarantee universal coverage. He says the Oregon Health Plan has improved access to care for Oregon’s poorest citizens, but that too many other people are still without coverage.

In addition to taking a stand on universal coverage and making it public, the Center’s most recent Kinsman Conference was devoted to managed care and access. Participants looked at such issues as access in underserved regions, serving the uninsured working poor, low-income, mentally ill and elderly populations.

The authors conclude in the Oregonian piece that “achieving the goal (of universal access) will require widespread community support, business commitment and political will. Because of the fundamental fairness of this goal, we Oregonians must demand of ourselves its early fulfillment.”
Managed health care came riding into the 1990s full of the promise to reign in the ever-increasing costs of health care. It also gave policymakers hope that they could minimize the new costs of providing coverage to 40 million uninsured citizens. Managed care could also reward wellness and discourage overuse of expensive and sometimes futile high-tech care. “Gatekeepers” would coordinate care, and providers would reap financial benefits if they could keep their patients healthy and out of the hospital.

Care ethicists is whether the financial incentives of managed care have benefited or harmed patients. Has it been good for society?

Even before the era of managed care, Michael Garland, D.Sc. Rel, ethics center associate director, taught medical students about cost-conscious health care. Garland believes that managed care has the potential, if well designed, to promote prevention. “When people complain about managed care, they are really complaining about badly managed care. The solution isn’t unmanaged reimbursement as it affects decision-making as well as access to health services by such groups as the uninsured working poor, the mentally ill and the elderly. Smith cites the problem of the chronically mentally ill getting access to care. “It takes many resources to assist these individuals to live in communities and not require re-hospitalization — community support systems, costly drugs, time-consuming interventions by providers, on-going crisis management.”

Gary Chiodo, D.M.D., associate director for the Center cites another, “It’s easy to demonize managed care … But managed care can be used for good. It has made us better stewards of our resources — it forces us to look at our practices differently and come up with new solutions.”

— Mary Denise Smith, R.N., M.S.

In 10 short years, managed care restructured the health care industry. Anywhere from 50 to 70 percent of the population is now in some type of managed care system — an astonishing feat. In Oregon, 85 percent of those who have insurance are in managed care. Whether managed care has achieved its goals is a matter of debate for policymakers and the public. What concerns health care. Finding a solution requires us to think ethically about management.”

Mary Denise Smith, R.N., M.S., assistant director of the ethics center, concedes that “we’re making the initial steps in looking at the ethics issues in managed care,” and that like any reimbursement system with a profit margin associated with it, the risk for abuse exists.

She and other ethicists have begun to focus more on the matter of often overlooked problem in health care access — a problem that managed care also holds potential to address. Chiodo explains that “the often quoted number of 40 million Americans without medical insurance pales by comparison to the 150 million Americans without dental insurance. Most of these individuals do not seek oral health care until small problems that are inexpensive to prevent or cure have escalated to
major infections with pain and poor prognosis. For some reason, we have a tradition in this country of separating medical insurance from oral health insurance. It’s as though your mouth is not part of your body and your oral health has no effect on your systemic health. People are just not put together that way.” Clearly, the health care dollars that could be conserved by well-managed care could be used, in part, to expand the availability of oral health services. Similarly, the delivery of oral health care through a well-managed plan can be an effective method for reducing the number of Americans with no oral health insurance.

Ethicists everywhere are asking these questions: Do some managed care strategies maintain or erode quality by cutting too many corners?

Do some plans “skim” off the healthy patients, leaving the sick without access? Because managed care makes it harder for hospitals to “cost shift,” are they downsizing to the point of endangering patients? Do providers have a moral obligation to reveal their own self-interest in a plan that rewards them for not ordering tests or not referring patients to more expensive specialty care? Do limits on hospital stays compromise quality patient care?

Susan Tolle, M.D., director of the OHSU Center for Ethics in Health Care believes that managed care will be the center’s greatest area of future growth. “Economic incentives are not new in health care. In the fee-for-service model, the more treatments and procedures we did, the more money we made. Sometimes procedures were done that were of little benefit. The tide has changed. In some managed care plans, the more treatments and referrals a doctor provides, the less he or she makes,” says Tolle. “At times, these new incentives encourage doctors to provide less treatment than patients need. The key is finding the right balance of incentives. This leaves a vital role for ethics in exploring the details of each incentive.”

“It’s easy to demonize managed care,” Smith says. “But managed care can be used for good. It has made us better stewards of our resources — it forces us to look at our practices differently and come up with new solutions.”

Smith and others agree that the ethics center has the wisdom and experience to tease out solutions and help design the future.

“Economic incentives are not new in health care. In the fee-for-service model, the more treatments and procedures we did, the more money we made. Sometimes procedures were done that were of little benefit. The tide has changed. In some managed care plans, the more treatments and referrals a doctor provides, the less he or she makes.”

— Susan Tolle, M.D.
Compassion in health care, especially at the end of life, touches everyone. As the Center for Ethics enters its second decade, it is still evocative and rewarding for me to support the Center’s commitment to practical or applied ethics. The Center does more than just debate today’s moral dilemmas; it is offering real solutions that impact individual patients. The Center’s work affects people not just in Oregon but throughout the entire country. There is much work remaining to be done.

We can all feel proud of the Center’s accomplishments. Please think of the challenges ahead of us as you read this report of our first decade.

Cornelia (“Cornie”) Hayes Stevens

Over a cup of tea at Vista Springs Cafe in Portland’s West Hills, Cornelia (“Cornie”) Hayes Stevens explains her involvement with the ethics center this way: “Compassion in health care, especially at the end of life, touches everyone.”

This universal truth and a family history of advocating for compassionate health care gave the Portland philanthropist a natural interest in helping fund an ethics center at OHSU. (Her father, the late Edmund Hayes, provided funding to the OHSU medical school to support the Gold Headed Cane Award. The graduating senior class selects a classmate to receive the prestigious award for compassion in health care.)

It was at an OHSU commencement ceremony where Stevens was presenting that year’s Gold Headed Cane Award that she met Susan Tolle, M.D. “We hit it off right away,” she recalls. Tolle and Stevens realized that they could each help the other: Tolle by putting together a stellar panel of ethicists from disciplines across diverse fields of health care, law, social work, and religion, and Stevens by raising money to bring these people together into a cohesive, formal unit.

The two women combined forces and within three years had raised $2 million for an endowment to support the center’s core operations. “While we had a few very generous donors, there were more than 300 people who gave to the center — many in the $25 to $50 bracket,” says Stevens. “Our methods were not the usual glitzy fund-raisers; some small luncheons and letters raised most of the funds.” She relied on the fact that everyone has a medical problem in his or her background. She adds that, “People responded most generously and for that I am most grateful.”

She adds: “When we started, Susan was always saying that she couldn’t get national foundation funding until we could show very strong support locally. We did that and now national foundations have taken an interest in the center’s work.” Impressive national organizations, such as the Robert Wood Johnson Foundation, have provided substantial grants for the center’s work in end-of-life care.

“When I first met Susan Tolle, the Center was just taking off,” says Stevens. “It has grown faster than anyone anticipated.” As the Center’s chief fundraiser and to keep donors and others informed on the center’s progress, she writes a quarterly “Cornie” letter, — a pithy, “insiders’ account of the center.

She’s particularly proud of the fact that the Center is “unbesmirched with any political overtones.” She says the center’s leadership carefully screens prospective large donors to...
ensure that they don’t have a political agenda. “We’re not compromised in any way by our funding sources — no HMOs, no pharmaceutical companies, for example,” she says. The advantage of this approach confers on the Center freedom from political influence and hence, greater credibility. “We are believed,” she says.

Another reason for her unqualified support is the ethics center’s commitment to practical or applied ethics. “They do more than debate today’s moral dilemmas; they are committed to doing something concrete for patients. I’ve never seen people spend so much of their professional time carefully working with individuals to see that they are well represented and cared for.” And, she adds, “They figure out how to make change happen so patients can benefit.” She says that the Center’s work affects people not just in Oregon but throughout the entire country. “People in Oregon don’t realize how well known the Center is outside the state, especially for its advocacy of more compassionate care at the end of life.”

As she finishes her cup of tea, Stevens acknowledges that the ethics center has much work remaining. There’s managed care, genetic screening, privacy and electronic medical records, and a host of other issues. And it’s clear that as the Center starts its second decade, Cornie Stevens will be there, raising money, writing letters, and doing what she can to ensure the Center’s continued success.
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