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Who gets what in critical care? Task force tackles care rationing

Initiative to yield ethical guidelines for limiting treatment launched

Two severely ill patients in the emergency department of your hospital need admission to the intensive care unit (ICU), but only one bed is available. Who gets admitted first?

Another critical care patient is severely ill, with several coexisting conditions. A costly new medication is available to treat one problem, but her treatment may be complicated due to the other comorbidities. The new treatment also is in short supply. If she gets the medication, it might be unavailable for other patients who could benefit more. Should the physician take a chance and prescribe the medication, anyway?

These are some of the dilemmas that critical care specialists face nearly every day in the United States — limited resources and overwhelming demand.

The end result, say experts, is that most now are engaging in bedside rationing — deciding on a case-by-case basis which treatments to restrict or offer based on their assessment of the potential benefit to the patient vs. the costs to the system and to others.

In a 2002 survey of more than 5,000 members of the Society of Critical Care Medicine (SCCM), two-thirds of the respondents stated they would withhold from one patient a medication, test, or service that is in limited supply in order to give it to a patient who might benefit more.¹

In addition, more than half of those providers reported routinely withholding medications, tests, or services from patients when they felt that costs outweighed the potential benefit. Yet most also indicated they wanted more guidance on how to make such decisions.

“The survey basically showed that a high percentage of physicians ration and, at the same time, feel badly that they do,” says **Mitchell Levy, MD, FCCM, FCCP**, a critical care specialist at Brown Medical School/Rhode Island Hospital in Providence and chair of Brown University’s Values, Ethics, and Rationing in Critical Care (VERICC) Task Force. “You have people making decisions at the bedside on resource allocation in a relatively haphazard way, not a measured

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way. We all struggle to deliver the highest quality of care possible for our patients, and we are successful to varying degrees. But some of the decisions that we make are not made from the broad overview perspective but from a more focused, bedside perspective."

In June, the VERICC Task Force announced a new, 18-month research and education initiative aimed at developing a national consensus on rationing in critical care — to include guidelines to help hospitals and critical care specialists

determine how to make treatment decisions when resources are in short supply.

The task force plans to conduct a larger nationwide attitudinal survey of critical care physicians, nurses, hospital administrators and the public to determine what rationing practices take place and the attitude the various groups of people have toward them.

Then, the VERICC group will conduct focus groups, summit meetings, and conferences for clinicians, hospital CEOs, and administrators that will lead to the development of resource allocation practice guidelines for critical care clinicians.

The task force also wants to develop a comprehensive database and sophisticated software capable of assisting ICU personnel in making resource allocation decisions, no matter where in the country they are located.

"What you'd really like to do [as a physician] is to take into account your patient's perspectives — what they want — and then a more global perspective of what works and what doesn't work and be able to make a more measured decision about the most effective way to apply resources at the bedside," Levy explains. "Unfortunately, there are no guidelines and no clear ways to go about it."

Bringing it out in the open

The first step for the task force will be to initiate discussions that encourage physicians to begin talking about their rationing decisions, to educate the public about how and why rationing is necessary and to foster public dialogue about the moral and ethical values that need to be addressed, says **Dan W. Brock**, PhD, senior scientist in the Department of Clinical Bioethics at the National Institutes of Health in Bethesda, MD, and a member of the VERICC Task Force.

"There is a denial that it happens on the part of both the health care system and the public," Brock says. "On the part of the public, there is always a concern about getting the care they need, and this sort of belief that rationing does not occur — and if it occurs, it is wrong."

The truth is that rationing of health care services does occur and has always occurred, in some form, and that it is necessary, he adds. "We need to acknowledge that: a) it does happen and has always happened; and b) it is necessary because if we didn't there would be enormous costs. There is an assumption, by many, that all care is beneficial. But few people would say that we should provide all possible care to everyone

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Editorial Questions

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ICU rationing linked to shortage of resources

Older patients, fewer beds strain system

Although all health care institutions and specialties are challenged by simultaneously rising costs and lack of financial resources, the problem is particularly acute in critical care, say experts.

"It is both a combination of money shrinking and possibilities getting bigger, so that we both have less money — yet every day there are new things you can do with patients in the ICU [intensive care unit]," says **Mitchell Levy**, MD, FCCM, FCCP, medical director of the intensive care unit at Rhode Island Hospital in Providence and the chair and principal investigator of the Values, Ethics, and Rationing in Critical Care (VERICC) Task Force.

"We are getting into more sophisticated technologies allowing for more diagnosis, but not necessarily better diagnosis; new sophisticated therapeutic interventions and drugs, not necessarily with better outcomes, but they are becoming more available. Families are uncertain about how to make decisions and how aggressive to be. We have both inadequate conversations with families and no guidelines on how to apply limits reasonably at the bedside. You add all of that up and, unfortunately, you get a bad combination," he explains.

Below are just some of the factors influencing the critical care crisis:^{1,2,3}

- Overall, total health care spending grew seven times faster than the overall economy in 2001, with hospital costs accounting for more than half the total. Expenditures for health care represent nearly one-seventh of the nation's gross domestic product, with intensive care usage alone accounting for \$142 billion, or approximately 1% of the gross domestic product.

- Compounding the problem, in the year 2000, the percentage of the U.S. population older than 65

grew to nearly 12.5%. Among that group, the fastest accelerating segment were those ages 80 and older — the same segment of the population that requires the most expensive medical care.

- Though there is a growing demand for hospital services, particularly critical care, there is a shrinking supply of critical care beds. Between 1995 and 2001, the number of beds per ICU dropped by some 20%. And 62% of all hospital emergency departments are full or overflowing.

- One-third of U.S. hospitals are losing money every day. Another one-third is barely solvent.

- ICU services account for 20% of all hospital costs incurred in the United States and approximately 50% of the total is the cost of staffing ICUs.

- Each year, 4.4 million patients are admitted to intensive care units. The cost of one ICU day is four times that of a regular hospital bed day.

- Improved technology has increased the number of surgeries performed on previously untreatable patients by 28%. Increasing demand for critical care is exceeding the current availability of ICU beds.

- During the period of 1995-2001, the average number of beds per ICU decreased by 20%, from 15.6 to 12.5 beds per unit — often due to cost constraints, staff shortages, and other administrative complications.

- ICUs are often marginal or money-losing operations, primarily due to outlier cases — those patients that stay in the ICU for six days or more. Up to 67% of ICU costs are spent on outlier cases, though they make up only 10% of ICU patients.

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3. The Lewin Group. *Emergency Department Overload: A Growing Crisis*. The Lewin Group Analysis of AHA ED and Hospital Capacity Survey; 2002. ■

no matter what the cost."

The initial mission of the task force will be to educate the public about how rationing in critical care occurs, by what criteria resources might be allocated and the processes by which they might be rationed.

Health care providers also must be more willing to discuss rationing in an open way, adds Levy. "We don't want to admit that or talk about these decisions: 'Who should get the bed if I have one left? How much time do I spend with the patient? Who is going to get the more acute nursing care? Which

patient should I send down [for a test] if I have to send down one first? Who do I want to insist get the test today and who can wait until tomorrow?' Rationing happens at a very subtle level, and making those decisions is part of medical judgment. But we could provide better help for physicians if we were willing to talk a little more in public."

The bioethicists on the VERICC panel will help the task force explore the different criteria that might be used to allocate scarce resources, Brock adds.

For example, many may feel that scarce resources

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should be reserved for those who will most benefit.

"But there are also concerns about justice in medicine — about preserving care for those worst off," Brock adds.

Patients who have not had adequate access to primary care or care early in a disease process may end up sicker than patients who have had the benefit of better health care overall. Restricting critical care based on the potential for a good outcome may leave out those patients, he notes.

"There are also questions about what weight should be given to patient age," Brock continues. "Should priority be given to younger patients rather than to the old?"

Discussions guide rationing model

The task force is made up of ICU physicians, nurses, bioethicists, hospital CEOs, chairs of hospital departments of medicine, and other policy-makers.

Initially, they will sponsor conferences and meetings designed to establish a common taxonomy, Levy says. "We need a unified terminology — when I say the word 'rationing,' does it mean what others think it means?" he says. "Then, we need to develop some examples of what we mean, some models of rationing."

At that point, they will initiate the national survey of critical care providers and other stakeholders to find out what methods of rationing and resource allocation currently are used.

The final phase will be a large consensus conference that will work on developing guidelines on critical care resource allocation, he notes.

The guidelines will not be a blueprint for how each treatment, medication, or service should be allocated in each setting, but an effort to guide facilities in determining how they will make their decisions.

Hospitals may end up choosing different criteria on which to base their decisions, depending on the values of their community and the patients that they see and treat, Brock notes.

"It may be that there is not widespread

consensus on any one issue," he notes.

The task force also intends to examine a number of factors related to critical care outcomes, however, and it may be that many of the guidelines will cover general issues not related to individual patient care at the bedside, say Levy and Brock.

For example, the role of nursing ratios and patient outcomes will be examined, as will allocation of hospital funding for critical care services.

"The third phase of our project will be to actually build a computerized modeling program that would allow us to figure out in a more careful way what is the impact of allocating different resources," says Levy. "If I am trying to decide between hiring new nurses or buying a new X-ray machine vs. getting expensive new drugs, where am I likely to see the most benefit? So, some of the rationing that is going to occur is going to occur up front and not have to trickle down to the bedside level."

More information on the VERICC project can be found on the group's web site at www.vericc.org. And information on rationing in critical care medicine at the national survey of critical care providers can be found on the web site of the Society for Critical Care Medicine at: www.sccm.org.

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Name-only ethics committees abound

Most ineffective due to lack of training

Hospital ethics committees are meant to be both a key resource and watchdog at their institutions, helping clinicians work through difficult cases and helping ensure the facility provides medical care in an ethical and equitable manner.

But many hospital ethics committees do little more than exist on paper, established to fulfill the requirement by the Joint Commission, then largely forgotten as the hospital leadership moved on to more pressing matters, say experts.

Though expected to provide ethics consultations to clinicians struggling to resolve conflicts with

families or to make difficult decisions, they often lack the appropriate training and background.

"You got to the hospital and find that [the committee] exists on paper. It met once, three years ago, or it meets quarterly, or it may even meet all the time. But you ask what they have read, what they've done to get themselves in a position to believe they are capable of addressing these serious issues, and they hem and haw, or say nothing," says **Matt Weinberg, MB**, a consultant with Clinical Consultation Services in Philadelphia. "That's why they aren't getting requests for consults. Why would anyone call them?"

Hospitals have to do more than just recruit willing volunteers to serve on the ethics committee, adds **David M. Price**, director of the Center for Healthcare Ethics at the University of Medicine and Dentistry of New Jersey-New Jersey Medical School in Newark. They must give careful consideration to the people who will serve on the committee and what will be expected of them.

"Ethics committees differ so widely, it's not funny," he explains. "Most of them have very little sense of themselves — they don't read the ethics literature, their leadership doesn't read the literature. They don't think a lot about what their ultimate role is and then creatively work from there to deciding how often to meet and how they should be constituted."

Hospital administrators and/or the medical staff leadership also often don't have a clear idea of what they want from the ethics committee, Price adds.

"If we don't expect anything from them, then they don't do anything," Price continues. "We don't hold them accountable for what they ought to be contributing because we don't know and then we are busy with other things that are more urgent."

As a result, many committees stagnate and drift year to year without having a true impact on the functioning of their institution.

Support from hospital leadership

For a hospital to have an ethics committee that functions meaningfully, it must be a high priority of both the hospital administrative and clinical leadership, Price says.

"If it is established as a medical staff committee, then it needs to be to the chief physician, or the top administrator, if it is an administrative committee," he notes. "If that person is not a member of the committee, then he or she should at least have a strong expectation of the committee's function and

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Source: Matt Weinberg, MB, Clinical Consultation Services, Newtown Square, PA.

the willingness to make inquiries if that doesn't happen."

Hospital ethics committees should have a definite, stated mission and one that aims high, as well, he adds.

"It ought to be, and think of itself, as an engine of progressive thinking about the mission of the institution, whether it is an acute care hospital or nursing home or hospice," he says. "And it therefore wants to have nothing less than an impact on the culture of the institution. If you want a statement of an ultimate goal — not just a functional description — it should try to impact the culture of the caregiving institution. This is where ideas ought to percolate that will try to make that kind of impact and will keep thinking outside the conventional modes of doing things."

When procedural habits get separated from the mission of the institution, they get in the way of the institution's success, he emphasizes. It is the role of the ethics committee to keep this divorce from happening.

"When people just do what they always do and don't keep asking, 'How does this play out relative to our purpose?' that has serious consequences. It is the job of the ethics committee to keep asking those questions," he adds.

Who should serve?

The committee must also comprise representatives from a variety of disciplines who will be committed, interested participants, adds Weinberg.

Too many times, different personnel simply do time on the committee, rotating on and off at specific times during the course of a year.

"Every July, or a particular month, committees switch membership and many people typically just get assigned," he explains. "They might happen to have an interest in the assignment, but typically it is random."

In some cases, busy physicians are assigned to the committee when they don't have the time to serve or give thoughtful input, he notes.

"And if the physician members aren't showing up at the meeting, everyone else on the committee will not take it seriously," he notes.

The hospital leadership need to recruit people from all of the different disciplines at the hospital (physical therapists, respiratory therapists, social workers, pastoral care, paramedics, ICU and surgical nurses, obstetric nurses, and patient care coordinators, as well as physicians in different specialties).

And the committee should include some representation from the community where the facility is located.

"My personal bias for community reps is that I try to call the local high schools and find the person that has the biology class or teaches the pre-health profession courses," he notes. "They tend to be the best community members. They are very outspoken and ask the wild-card questions, which is why you need them there."

It is also important to select representatives from all of these areas who are known to be thoughtful and who will be willing to show up at the meetings, he adds.

"You especially have to get good physicians who will find it interesting and spend time reading the material and have time to show up at meetings," he emphasizes. "And figure out a good time when everyone else can be there consistently. Then, I usually make them almost stand up and raise their right hand and swear that, notwithstanding emergencies, they commit to being there."

Choice of leadership is key

Committees must be particularly careful in their choice of a chairperson, say both Weinberg and Price.

The ideal chair needs to be someone with a strong personality, but not someone who is very authoritarian and will dominate the rest of the membership, says Price.

"You have to have somebody who can administer a committee — who sets an agenda and can discipline a meeting," he advises. "I've seen committees where good people come and we have a good discussion because these are very smart folks who would not otherwise be sitting around a table talking — these committees by definition are broadly constituted. It is stimulating and we may have stimulating bull sessions — But it doesn't go anywhere."

Education before consults begin

Once a committee has been formed and has a clear definition of their mission in front of them, they still require an intensive period of education before they are ready to perform ethics consults and truly serve as a resource to the hospital staff, Price and Weinberg state.

"There is a huge body of literature in medical ethics," Price says. "There are more books and journals published every year, and there is a huge

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body of knowledge. If you are going to do this seriously, then you have to be prepared to learn some things and to read.”

When Weinberg consults with hospitals, he often helps establish the institution’s ethics committee or works with a new committee as it begins to meet. As part of that process, he institutes a formal yearlong education program for committee members.

“You have to start with basic education,” Weinberg emphasizes. “In many institutions, we think nothing of putting people on the committee who may have no background in medical ethics or health care delivery whatsoever, and then saying, ‘Go out and do consults.’ Then, they just have to walk around and make it up as they go along.”

You wouldn’t allow a surgeon to operate without ever taking anatomy and physiology, nor hire a nurse who had never been to nursing school, and you shouldn’t ask untrained people to perform ethics consults, he continues.

While his committees-in-training are going through the educational process, Weinberg functions as the hospital ethics consultant and performs ethics consults as needed. At the same time, he is taking the committee through an organized educational program as part of their monthly meeting.

“At the meeting, the first 45 minutes will be an educational seminar on a particular topic, and the last 45 minutes will be new business and old business,” he explains. “I start off with ethical theory and give them a general overview of the different ways to think about ethical issues.”

Weinberg then expands the sessions into specific ethical issues that the committees will likely face — end-of-life decision making, withdrawal or termination of treatments, and specific ethical issues related to different medical specialties — then onto some of the more controversial topics like euthanasia and assisted suicide, he notes.

It’s important that the educational programs be

weighted more toward practical application than abstract theory, Price and Weinberg add.

“Most of the members learned what they do as health care professionals by an apprenticeship-type training program — learning by doing,” Price says. “They are not philosophy majors. If it doesn’t apply at the bedside, it doesn’t make any difference to them.”

Weinberg agrees. “My sessions are not a philosophy class,” he notes. “The readings tend to be practical and have to be digestible. They need to have some ethical theory to understand practice, but if it is too deep into the theory then they will never read them.”

It’s also important, Weinberg believes, to let the rest of the hospital staff know about the educational process that the committee is undertaking and how this can be of benefit to them.

“When I go out and do consultation inservices with the nurses and medical staff, I am sure to mention that this is also what I am working with the ethics committee on,” he notes. “That builds confidence that the committee members are really learning something and can be called upon when the time comes.”

Consults should be the focus

Although most committees feel that they have a trifold purpose of providing ethics consultations on individual cases, developing hospital policy, and serving as an educational resource to the rest of the staff, Price says the committee should keep consults as the main focus of what they do.

“Successful committees are almost always committees that have case consultation as their central priority,” he states. “Physicians and nurses and other providers are patient-care folks. That is what gets them. That is what is important and that is the ultimate activity that justifies the institution in the first place — patient care.”

The cases the committee has as consults should drive the educational and policy initiatives it takes on.

“The educational agenda flows out of the case consults,” he explains. “We discover what we don’t know because we run up against some pattern of ignorance when we do our case consultations. Then, we know what we ought to be trying to do. The same thing is true of policy formation. That agenda inevitably arises out of discussions of cases because we find out our current policies don’t work or are inadequate.” ■

Conduct concerns raise issue of ethics training

But little academic education exists

For many years, institutions involved in training the nation's bioscience researchers have spent a great deal of time and money ensuring that their graduates function at the cutting edge of science and technology. But they've placed far less emphasis on ensuring that the same graduates are aware of the accompanying ethical, legal, and social implications of the work they do.

The high-profile cases of questionable research conduct occurring in recent years at some of these same institutions have led to questions about the need for formal ethics instruction for graduate students in the biosciences, say some instructors.

"We must teach our students the professional ethical rules that have been worked out by institutions and professional societies. They cannot hope to abide by rules they've never learned," advises **Roberta M. Berry**, JD, associate professor of public policy and director of the Law, Science, and Technology Program at the Georgia Institute of Technology in Atlanta.

"We must equip our students with ethical reasoning skills — just as we equip them with scientific reasoning skills — so they know how to apply the rules competently to the situations they will encounter in their professional lives. Students need to appreciate the implications of their work for others if they are to be ethically mature adults who take responsibility for their conduct and its consequences in their professional lives as they do in their personal lives."

Writing in a recent issue of the *American Journal of Bioethics*, Berry and colleague **Arri Eisen** from Atlanta-based Emory University examine the lack of formal ethics education for researchers in the biosciences and provide recommendations for future development of curricula.¹

The vast majority of principal investigators in bioscience have received little or no formal training in responsible research conduct, Berry and Eisen point out.

Recent surveys of both professors and students reveal that although nearly 90% of graduate students from major research institutions reported having supportive faculty members, fewer than half said these faculty provided a lot of help with regard to the details of good research practice. A

fifth of the graduate students reported they got no help at all in this area.

As for the faculty, 99% of the 2,000 faculty members surveyed believed they and others in their positions should have collective responsibility for the professional conduct of their graduate students, yet only 27% felt that they followed through with this responsibility.

There are many explanations for the discrepancy between the perceived need for ethics training and the actual lack of it in the formal education process, Berry says.

"From the public perspective, bioscience research has been overshadowed over the last couple of years. On the one hand, by the larger research projects of physics and associated technologies — for example, nuclear weapons and nuclear power — and, on the other hand, by the more immediate and compelling ethical issues presented by the practice of medicine and by human subjects research," she explains. "Public scrutiny has grown only recently and in tandem with the enormous increase in public and private funding of bioscience research; its great successes — as for example, in mapping and sequencing the human genome — has increased worries about the ethical, legal, and social implications of bioscience, in particular, worries associated with genetic information and technologies and scandals about the conduct of bioscientific research."

Ethics by osmosis

From the researchers' perspective, there has been little prior public scrutiny of their work and many of them believed that ethical norms of their particular area or profession were being honored and passed down from veteran scientists to novice students without the need for explicit instruction, Berry notes.

"From the perspective of the bioscientist, the inside perspective, there has not been the sense of professional self-interest in developing and enforcing an explicit code of conduct to be used in instructing the next generation and in reassuring private clients as well as regulators that the profession's ethical house was in order," she continues.

"Bioscience researchers are a diverse group of scientists without a singular professional identity, without individual clients, and, until fairly recently, without an immediate sense of public regulatory interest in their conduct. But the same pressures that have led to increased scrutiny from the outside — plus the globalization and expansion of research

across diverse cultures — seem to be leading to increased interest from the inside in developing explicit instruction in research ethics.”

But developing a formalized model of ethics instruction will not be simple. Few experts in both bioethics and the basic sciences agree on just what exactly should be taught, how it should be taught — and how successful instruction can be evaluated, say Berry and others.

Different fields of science may have different perspectives on the same issues. And it’s unclear whether traditional ethics faculty members or veteran scientists themselves are the appropriate instructors of ethics for bioscience graduate students.

“The crux of the matter is that not all disciplines deal with the same set of ethical issues. An animal researcher does not have to be concerned with whether the financial compensation for participation in research is coercive, for example,” explains **Elisa Gordon**, PhD, assistant professor at the Neiswanger Institute for Bioethics and Health Policy at Loyola University of Chicago. Gordon and colleague Kayhan Parsi, PhD, wrote a commentary on ethics education in the same journal issue.²

“But what is less obvious,” says Gordon, “is that even when disciplines share ethical issues, such as informed consent for human subjects, different disciplines have different approaches or even standards for obtaining consent.”

For example, she notes, the Federal Policy for the Protection of Human Subjects or Common Rule has been undergoing revision under the supervision of the National Bioethics Advisory Commission (NBAC) and the Department of Health and Human Services. In 2001, NBAC proposed various efforts to strengthen the protection of humans participating in research, such as the requirement to obtain written consent. Many of these efforts, however, do not necessarily apply to all kinds of research, particularly ethnographic research, she argues.

In ethnographic research, written consent can undermine the rapport between an investigator and respondent that is essential to the research enterprise.

“Written consent and even oral consent can transform a trusting relationship into a hierarchical one. In addition, obtaining consent may not even be feasible when ethnographers conduct participant observation, that is, observing human events without disturbing their temporal processes and outcome,” Gordon says.

“Many scholars in the social sciences and

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humanities have responded to NBAC’s suggested revisions about this problem. One of their suggestions is to include more social scientists on institutional IRBs in order to better address the variety of research methods and the ethical issues they generate.”

Going beyond the basics

There are basic ethical concepts common to all areas of research, and pursuing a basic curriculum may be a worthwhile goal as long as efforts don’t end there, she adds.

“A core curriculum that governs biological, chemical, and social science may be partly feasible if it addresses some of the broad issues relating to research ethics,” Gordon says. “For instance, such a course may include a discussion of authoring publications, conflicts of interest, and plagiarism, among other topics. However, the course would be inherently limited by its attempt to be applicable to such a broad audience. It may be worthwhile to first identify what the general topics are, like the ones listed above, and then for individual disciplines to develop and adapt the topics for their own specific needs.”

Berry agrees that it would be best for individual disciplines, with possible input from public policy scholars, sociologists, philosophers, and legal experts, to examine the ethical issues most relevant to their work. Then, in the future, representatives from the different basic science disciplines and different institutions may want to work together on a more uniform approach to ethics education.

“I think there will come a time when quality of research ethics education is associated with significant uniformity across institutions, with variation reflecting the distinctive character of different institutions as well as some pluralism with respect to the proper goals and means of ethics education,” she says. “But, in the next several years, I think we’ll learn best by proceeding as experimentalists,

developing diverse hypotheses, testing them, and studying and comparing the results. This may well include multi-institutional collaboration in large-scale experiments aimed at developing models, and it certainly will involve drawing on the fine programs and supporting materials that have already been developed by a number of institutions and centers."

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End-of-life caregivers often don't get support

Grief counseling should be available

In teaching health care providers how to care for patients at the end of life, many institutions forget to teach the providers that they need to care for themselves as well.

Physicians, nurses, and other personnel who care for dying patients on a daily basis — who must also frequently cope with the death of a patient — need special support if they are going to continue to provide optimal care.

Nursing homes, hospices, and hospitals are just beginning to provide the sorts of programs and education that these caregivers need, say advocates.

"Caregivers and staff often become like family," says **Donalyn Gross**, PhD, LCSW, a clinical social worker who works with nursing homes to improve the care of and response to dying residents. "Sometimes, residents will tell the caregivers something that they would not tell their immediate family. And they also hear things from family members that they don't want the resident to hear. They develop a relationship."

When Gross began working in nursing homes as a teenager, she noticed that residents' deaths were met with little ceremony.

Often after a resident died following a long illness, the staff members would simply do what was necessary to take care of the body, then simply close the door and wait for representatives from the family or funeral home to arrive and do the rest.

Aside from the negative impact on residents' families, this also had a detrimental effect on the caregivers, Gross believes.

"The tended to shut down and feel as if they had to distance themselves from the people they cared for," she says. "They were also very uncomfortable with death, and the process of dying, yet they saw it all the time."

In Gross' current practice, she encourages nursing homes and hospitals to establish support groups for people who care for dying patients and encourage open discussion and sharing of feelings of grief and uncertainty after a patient's death.

"It doesn't have to be mandatory that people attend the groups, but it should be available," she notes. "More people are recognizing that this is a need that caregivers have. I had a call recently from a nursing home director who said, 'We've had a lot of deaths here recently. Can you come in here and help get people to talk?' They need to know that their feelings are normal, and it is OK to feel bad, and it is OK for them to cry."

Gross also encourages facilities to hold some sort of ceremony for people who have died. At the nursing home where she currently works, a memorial service is held annually to honor the residents who have died over the past year.

"We invite the residents, family, staff . . . everybody," she explains. "Everybody pitches in with the planning and it is a wonderful thing. We play music and we allow people to share their memories of the people who died."

The services give the staff a chance to honor the residents they have come to know, and the residents' family members are comforted by realizing their loved ones were cared for, really known by the people at the facility, she adds.

Spiritual, psychological support are essential

Although hospices are often an exception, many health care facilities fail to recognize that clinicians may grieve the loss of a patient or have difficulty dealing with patients' deaths over time, agrees the Rev. **Martha Jacobs**, former chaplain with the New York United Hospital Medical Center, now the associate director of pastoral education and community based programs with The Healthcare Chaplaincy, a nonprofit, multifaith center dedicated to advancing pastoral care at health care sites throughout the New York City metro area.

"Hospices do a better job with this, and they often offer support groups for their staff," she notes. "But in hospitals, a lot of times the prevailing

attitude seems to be that you shouldn't have feelings, and if you do, you need to deal with them on your own time."

Hospital staff often have problems coping with their feelings of grief over dying patients, particularly when a patient's case has been very difficult, or when the patient is close to the caregiver's own age, Jacobs says.

"That challenges the chaplains a lot as well, when someone close to your own age dies," she notes. "And if the providers have gone through a death in the family recently, that can be difficult as well. For example, a nurse whose mother has died may have a difficult time coping when faced with the children of a dying patient."

At her former hospital, Jacobs frequently tried to organize debriefing sessions for staff after the death of a patient — particularly if the patient's care had been difficult or the patient had been in the hospital for a long period of time.

"It's essential that staff have that opportunity to vent their feelings and talk about them," she notes. "If they are forced to keep bottling it up inside, they start lose the ability to be sympathetic with the patients, and start to distance themselves. At that point, they will burn out very quickly."

It may be necessary for the support group meetings or debriefing sessions to be held at an out-of-the-way place, Jacobs adds, because there still is sometimes a stigma associated with health care providers who need help.

"I found this to be true during 9/11," she relates. "The fire and police departments had support groups and sessions available for the people working at Ground Zero, but many people did not want to be seen leaving the site or be taken away from their duties."

Health care providers are very accustomed to being the people that others turn to for help, and it may be difficult to accept the idea that they need help from others.

"There is sometimes the idea that if you seek help to deal with these negative feelings of grief, then others will think you are burned out or you aren't capable of doing that job any more," she says. "In reality, I think the day you don't have a

SOURCES

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problem with patients who die, is the day that you need to stop."

Facilities also need to provide education about the stages of dying, and what might happen with patients when they are dying, says Gross. This information is particularly necessary for staff who may help care for patients, but have little medical training themselves.

Gross does training workshops for nursing home staff on understanding death and dying. She covers both common clinical stages of dying and some of the physical manifestations that might occur. She also covers how to relate to and speak to patients who are dying and to their families.

"Especially in a nursing home, the housekeepers and even the dietary staff will get to know a patient, and it is important — and they are so relieved to learn these things," she notes. "It helps them become more comfortable with the idea of death and dying and in knowing the things that will happen."

As the staff become more comfortable with death and mortality, they are better able to bond with the residents and care for them, both before and when they die, she adds.

"I've seen such a change in people," she notes. "Where once they may have been very remote — when someone died, they just did their job and cleaned the body and shut the door and that was that," she says. "Now, some people will actually sit with someone who has died, they wait until the family comes in or the funeral director comes in. You can really see the change and that they are more comfortable with things. They talk about things more freely and are more comfortable with the family and talking about that person than they were before." ■

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CME Questions

5. A 2002 survey by the Society of Critical Care Medicine found that:
 - A. Two-thirds of respondents would not withhold a beneficial treatment or service under any condition.
 - B. Two-thirds of respondents would withhold a treatment, service, or medication that was in limited supply in order to give it to a patient who would benefit more.
 - C. Two-thirds of respondents had withheld a treatment, service, or medication that was needed because of concerns about the cost.
 - D. Half of the respondents felt they had rationed care inappropriately in the last 12 months.
6. Expenditures for health care now represent what percentage of the nation's gross domestic product?
 - A. One-tenth
 - B. One-fourth
 - C. One-seventh
 - D. None of the above
7. According to sources in our article, what key, primary function should ethics committees provide to their facilities?
 - A. Ethics consults
 - B. Ethics education
 - C. Policy development
 - D. None of the above
8. What methods of support have some hospices, nursing homes, and hospices implemented to help caregivers cope with feelings of grief about patients who have died?
 - A. Support groups
 - B. Memorial services
 - C. Debriefing sessions
 - D. All of the above

Answers: 5-B; 6-C; 7-A; 8-D

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Physicians participate in this continuing medical education program by reading the issue, using the provided references for further research, and studying the questions at the end of the issue. Participants should select what they believe to be the correct answers, then refer to the list of correct answers to test their knowledge. To clarify confusion surrounding any questions answered incorrectly, please consult the source material. After completing this activity, you must complete the evaluation form provided at the end of each semester and return it in the reply envelope provided to receive a certificate of completion. When your evaluation is received, a certificate will be mailed to you. ■

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