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Joy Daugherty Dickinson, (Executive Editor)
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Can ethics and economics of healthcare share common ground?

Palliative care is one example of overlap

Hospital ethics committees sometimes find they are drawn into local cases that reflect national debates over healthcare costs and policies. These debates might surface when there are conflicts between family and hospital providers over continuing life-sustaining treatment, including nutritional support and ventilator care. But adding healthcare costs to the mix can make the situation more complicated.

The high expense of most life-sustaining treatment also contributes to healthcare inequities and disparities, experts say.

“We have vast healthcare disparity domestically as well as globally,” says **Norman Daniels**, PhD, Mary B. Saltonstall professor of population ethics and professor of ethics and population health at the Harvard School of Public Health in Boston.

“The main barrier has been in financing services,” Daniels adds. “So if people do not have insurance coverage, then some kinds of services in hospitals that are not emergency-based are not available to them.”

For instance, one type of life-sustaining treatment that typically is not available to some patients, including undocumented workers, is dialysis for end stage renal disease (ESRD). However, some hospitals will provide this care to all patients, regardless of their ability to pay.

The consequences of providing a treatment irrespective of cost can be wrenching from an ethical perspective when that cost no longer becomes sustainable, an expert notes.

“Hospitals have difficult questions about what to do when an undocumented alien comes in and is on dialysis or needs to be on dialysis,” says **Haavi Morreim**, JD, PhD, a professor in the Department of Internal Medicine, College of Medicine, University of Tennessee Health Science Center in Memphis.

This situation happened at Grady Memorial Hospital in Atlanta, when the hospital announced it was forced to shut down its dialysis clinic that offered treatment to all patients who were ineligible for treatment through any other payer. It mainly served undocumented

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workers. After court challenges and national publicity, the hospital agreed to continue to provide treatment for existing dialysis patients through Sept. 1, 2011, according to Advocates for Responsible Care of Atlanta.

Most U.S. citizens have access to clinic-based dialysis treatment through Medicare's End Stage Renal Disease (ESRD) Program, implemented in 1973 as a way to pay for treatment for people with chronic kidney failure.

"It's one thing for Medicare to cover dialysis, but it's another for no one but the hospital to cover dialysis expenses because the person is

undocumented," Morreim says.

Unfortunately, there have been some unintended consequences of the Medicare ESRD program. One is that it costs Medicare more than \$20 billion a year because dialysis treatment is expensive and more people are using the program than initially anticipated. Secondly, its outcomes are poor when compared with other countries, according to DialysisEthics of Timnath, CO. The U.S. death rate is higher than many other countries.

"What originally was supposed to be a program to save the lives of relatively young and active people tends to be used quite unthinkingly, no matter how many complications or comorbidities a person has," Morreim says. "A person could be dying of end-stage cancer, and they could be put on dialysis."

The Medicare payment has reinforced a one-size fits all type of dialysis treatment, whereas some patients would have better health outcomes from at-home dialysis, which is being used in other high-resource nations, according to DialysisEthics.

Healthcare providers and researchers usually are aware of medical costs even when cost savings is not a priority in patient care. It might not be enough in a costly healthcare environment to think only about outcomes and quality of care, experts say.

For this reason, palliative care researchers at Mount Sinai School of Medicine in New York City, have conducted studies about the cost of palliative care medicine, says **Diane E. Meier, MD**, director of the Center to Advance Palliative Care (CAPC) at Mount Sinai School of Medicine in New York City. "We studied the costs because from a pragmatic standpoint in this kind of fiscal environment in healthcare, there was no way we could make the argument that palliative care should be a core component of every hospital and nursing home and every doctor's and nurse's training unless we could make a business case for it," Meier says.

Hospital ethics committees need to focus on whether a palliative care program is promoting ethically good care, and not on the program's cost savings, says **Robert M. Arnold, MD**, Leo H. Kreep chair in patient care and chief of the Section of Palliative Care and Medical Ethics at the University of Pittsburgh (PA). "The fact that palliative care programs can save money may be a reason why it's easier for them to get funded in this tough economic time, but from an ethics point of view, this shouldn't fall into the equation," Arnold adds.

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Executive Editor: **Joy Daugherty Dickinson** (229) 551-9195 (joy.dickinson@ahcmmedia.com).

Managing Editor: **Felicia Willis** (404) 262-5446 (felicia.willis@ahcmmedia.com)

Production Editor: **Kristen Ramsey**.

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EDITORIAL QUESTIONS

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R. Sean Morrison, MD, director of the National Palliative Care Research Center and a Hermann Merkin professor of palliative care, a professor of geriatrics and medicine, and vice-chair for research, all at Mount Sinai School of Medicine, says, “Palliative care teams take on care of patients with serious or life-threatening illness in their families, and our approach is to improve their quality of life while they live with a serious illness.” Morrison and Meier were authors of a recent study on palliative care and cost savings.¹

“We address distressing symptoms such as pain and communicate about difficult topics while matching treatment to goals,” Morrison says.

However, in the current economic environment, it is also important to find out if palliative care treatment costs hospitals and the healthcare system more than standard treatment, or if there is a cost savings, he adds. (*See article on palliative care and biomedical ethics, p. 52.*)

“We looked at those patients who received palliative care and compared those to patients who received usual care, and the findings were fairly dramatic,” Morrison says. “The cost was less for patients treated by palliative care teams.”

The study found that Medicaid patients facing serious or life-threatening illnesses who received palliative care had \$6,900 less in hospital costs during a given admission than a similar group of patients who received usual care.¹

The Medicaid study builds on Morrison’s previous research, including a 2008 study that showed that patients seen by palliative care teams had a net savings of \$1,696 in direct costs per admission.²

The 2008 study looked at eight hospitals across the United States. The patients’ healthcare costs were paid by all different payers, Meier says. “For this latest study we concentrated on New York state because the state has a terrible Medicaid crisis due to reduced income tax revenues, increasing numbers of people in poverty, increasing Medicaid needs, and the continually rising costs of healthcare,” he explains.

“We hoped to contribute to that dialogue involving finding the least restrictive, least harmful alternative ways of improving quality while avoiding unnecessary spending,” she says. “Part of the reason Medicaid patients end up in the hospital is because there is no safety net for them.”

These patients often lack family members who can stay home from work to care for them, and they cannot afford private pay assistance. “Their problems are a direct result of poverty and social

inequity, and it’s related to poverty, not the fault of the healthcare system,” Meier says. “This is why I was not optimistic that we would show the same kind of cost savings impact with a Medicaid population.”

Yet, that’s precisely what happened. The cost savings were remarkable, she says. The reduced costs of patients seen by palliative care teams included \$4,098 less in hospital costs per admission for patients discharged alive and \$7,563 less for patients who died in the hospital. Investigators estimated the reductions in Medicaid hospital spending could range from \$84 million to \$252 million annually if every hospital with 150 or more beds had a palliative care team.²

“The question people ask is ‘Why?’” Morrison says. “The answer is that the patients that palliative care teams take care of are the sickest patients in hospitals.”

They consist of 5% of the general population, and they utilize 50% of healthcare costs, he adds. “These patients are very complex, so palliative care teams focus on those with special needs,” he says. “They sit down with patients and families and talk about what their values and goals are and what they hope to accomplish.”

For that reason, palliative care patients are less likely to die in intensive care units (ICUs), spend less time in ICUs, and are more likely to receive hospice referrals.

Once members of the palliative care team understand what their patient wants, they can match treatment to the patient’s goals. It’s a patient-centered model that improves efficiency and reduces unwanted and non-beneficial treatments, all of which helps streamline costs, Morrison explains. “One of the things palliative care teams do is sit down with patients and help them go through the benefits and burdens of particular treatments, depending on their goals,” he adds.

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• **Robert M. Arnold, MD**, Leo H. Kreep Chair in Patient Care, Chief of the Section of Palliative Care and Medical

Ethics, University of Pittsburgh, Section of Palliative Care and Medical Ethics, Pittsburgh, PA. E-mail: arnoldrm@upmc.edu.

• **Norman Daniels**, PhD, Mary B. Saltonstall Professor of Population Ethics, Harvard School of Public Health, 665 Huntington Ave., Boston, MA 02115. E-mail: ndaniels@hsph.harvard.edu.

• **Diane E. Meier**, MD, Director of the Center to Advance Palliative Care, Mount Sinai School of Medicine, New York, NY. Email: diane.meier@mssm.edu.

• **Haavi Morreim**, JD, PhD, Professor, Department of Internal Medicine, College of Medicine, University of Tennessee Health Science Center, 956 Court, Suite G212, Memphis, TN 38163. E-mail: hmorreim@uthsc.edu.

• **R. Sean Morrison**, MD, Director, National Palliative Care Research Center, Hermann Merkin Professor of Palliative Care, Professor of Geriatrics and Medicine, Vice-Chair for Research, Brookdale Department of Geriatrics and Palliative Medicine, Mount Sinai School of Medicine, One Gustave L. Levy Place, New York, NY 10029. E-mail: sean.morrison@mssm.edu. ■

Palliative care model fits biomed ethics principles

Side benefit: It brings cost savings

Some of the core principles of medical ethics are patient determination, doing good for patients, and doing justice. These also are some of the chief attributes of palliative care, experts say.

“I view palliative care as applied medical ethics,” says **Diane E. Meier**, MD, director of the Center to Advance Palliative Care (CAPC) at Mount Sinai School of Medicine in New York City. “Palliative care is medical ethics operationalized at the bedside. My interest in palliative care grew out of my interest and work in medical ethics.”

The modern U.S. healthcare system has become so fragmented that patients are viewed in the system as a series of organs and diseases with a different specialist for each one, Meier says. “The patient as a person is no longer the focus of the healthcare system, so it’s very difficult to honor the core principles of medical ethics when healthcare is approached in this very narrow, organ-disease-driven manner,” she says.

The best way to influence this culture might be to show healthcare providers a different way of approaching the care of patients by beginning with trying to understand who the patient is and what they hope the medical profession can accomplish for them, Meier suggests.

“We can help patients and families develop a

care plan and set of goals that are achievable with reasonable expectation of benefits and that are matched to what is most important to this patient and family,” she adds. “This is what palliative care embodies, an approach in which patient self-determination is at the core.”

The fact that palliative care saves hospitals and healthcare systems money is incidental to its goals. Meier says that palliative care advocates do not design or try to advance access to palliative care because of any concern about saving money. The drive behind palliative care is a desire to rekindle the originating impulses of the medical profession and making patient care center stage. “Cost savings was an unexpected consequence,” Meier says.

Hospital systems do care about the cost savings. This unplanned benefit has been an important reason why there has been a recent and rapid growth of palliative care programs nationwide, experts say.

R. Sean Morrison, MD, director of the National Palliative Care Research Center and a Hermann Merkin professor of palliative care, a professor of geriatrics and medicine, and vice-chair for research, all at Mount Sinai School of Medicine, says, “There is a reluctance in healthcare right now to embark on any new program that is going to cost the system a lot more money, even if it’s the right thing to do. Hospital budgets and healthcare budgets are stretched so tight there’s no room in the system for something new, even if it improves quality. That’s an unfortunate statement of where we are now.”

Between 2000 and 2008, the number of palliative care programs in U.S. hospitals increased from 658 to 1,486, a 125.8% increase. This increase means 58.5% of hospitals with 50 or more beds now have a palliative care program, according to CAPC.

Prior to the 21st century, palliative care had very limited availability in the United States. It was an option delivered primarily through hospice care and was available to patients living at home.

With palliative care programs, there’s a win-win on all counts because investigations including a study Meier and Morrison recently published show that palliative care can accomplish both quality and cost-savings.¹

From a biomedical ethics perspective, the cost savings is immaterial, but from a pragmatic viewpoint, it matters. “Palliative care teams effectively improve quality of life, reduce symptoms, and improve satisfaction with the healthcare system,” Morrison says. “They can do this and at the same

time be fiscally responsible.”

From an ethical perspective it's important to draw distinctions between what palliative care accomplishes and what it is intended to do, says **Haavi Morreim, JD, PhD**, a professor in the Department of Internal Medicine, College of Medicine, University of Tennessee Health Science Center in Memphis.

“The focus of good quality palliative care is to enhance the quality of life of the patient,” Morreim says. “And if the patient is mortally ill, then its purpose is to enhance the quality of the dying process.”

Saving money is not the goal, but it is a noticed side effect of good quality palliative care, she adds. “Another side effect is there have been some studies that show people live longer on palliative care,” Morreim says.

Palliative care help to put ethics committee education and goals into action in the areas of conversations of inappropriate treatments and end of life issues, notes **Robert M. Arnold, MD**, Leo H. Kreep chair in patient care and chief of the section of palliative care and medical ethics at the University of Pittsburgh (PA). The palliative care model is very helpful to ethics committees because they provide clinicians who can focus on patients, elicit patients' goals and values, and then provide the best possible care to people who have life-threatening illnesses, he adds. “As mediators, palliative care teams have good communications skills and can operationalize many ethical concepts in helping patients,” Arnold says. “You have to have basic competencies in medical ethics to do a good job in palliative care.”

The goal of palliative care is to elucidate the patient's goals and make sure the treatment a patient receives matches those goals. These goals also overlap with what ethics committees want to see happen in the clinical arena, he says. “Many palliative care committees have multidisciplinary teams, and the ethics committee can say, ‘Can we get involved to help you work together, provide education, communication, informal consults?’” Arnold suggests. “Many palliative care teams have multidisciplinary teams meeting once a month, and ethics committee members can go to these meetings.”

Hospital ethics committees could view their health systems' palliative care programs as a role model for how healthcare providers can adhere to biomedical ethics principles, Meier says. “Pontificating on those values is not a good way of teaching,” she adds. “You need to show people

how to implement and apply those values at the bedside, and that's what palliative care teams do; these are their central principles of work.”

Palliative care teams might seek out members of hospital ethics committees to work with them and coordinate educational efforts. In certain types of cases, palliative care teams and ethics committees might collaborate. “A lot of what hospital ethics teams have done overlaps with palliative care,” Morrison says. “They are consulted when there are unclear goals of care and conflicts arise; they are called in to mediate that conflict.”

Ethics committees and palliative care teams can work well together because there is much less reason for conflict when providers help patients and families articulate their goals of care, he adds.

Morreim notes that one idea palliative care advocates and ethics committees have been working on involves encouraging providers involved in the care of long-term intensive care unit patients to have standard team and family meetings.

“As soon as it looks like the patient will be in intensive care for more than a few days, this person will encourage early communication and a sit-down meeting with the family and main people providing the care,” Morreim says. “This is not for the purposes of making drastic decisions, but is to make sure everybody is on the same page.”

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Responding to medical errors ethically

Use a 'just culture' framework

Hospital ethics committees need to review their hospitals' policies and approach to medical error reporting to determine whether or not the approach is a principled one, an expert says.

“The key principles that ought to be part of the medical error reporting and response system are that staff and providers have a way to report errors that occur and near misses,” says **Daniel Hyman, MD, MMM**, an assistant professor of pediatrics at the University of Colorado in Aurora. Hyman also is the chief quality officer at the

Children's Hospital in Aurora.

Ethics boards might consider reviewing their organizations' approach to medical error reporting and their responses to problems that are discovered, Hyman says. "Adverse events that impact patients should be disclosed appropriately to those patients and their families, and the staff that made the error should be responded to in a principled way," he says.

A good model for this approach is the "just culture" framework devised by David Marx, JD, in a 2001 primer about patient safety. (*See resources, p. 55.*) "David Marx is a risk management systems analyst who has developed this framework for thinking about an institution's response to error," Hyman says. "The idea is that people make mistakes, and we need to understand that, as in any fundamentally human endeavor, people are going to make mistakes in the course of providing healthcare. The way we respond to those errors should recognize that fact."

Following the just culture model, there are three basic responses to medical errors:

- **Intentional bad acts.**

In these rare cases, a staff person intentionally, recklessly, or illegally does something wrong that leads to a medical adverse event. Taken to the extreme, this category would apply to those headliner cases of nurses who intentionally kill nursing home patients. This category also could apply to medical staff that abuse drugs in the workplace and endanger patients by their habit and subterfuge, Hyman says.

When healthcare administrators discover an instance of someone behaving badly on purpose, they should initiate a thorough investigation and take the appropriate legal actions.

- **Simple human error.**

Most medical errors involve simple human mistakes in which the healthcare provider did not do anything wrong other than make the mistake, Hyman says. "They are a victim of that situation," he says.

These mistakes can be the result of circumstances outside of the individual's control.

In these circumstances, an institution's ethical obligation is to align its response to these types of errors to the root cause and not to the outcome, Hyman says. "Making decisions about how to discipline a staff person on the basis of the outcome of the error is not ethical," he says. "No harm, no foul has no place in this." For example, a staff member could walk into an MRI suite with metallic content in his pocket and forget that this is in

the MRI area, despite signage being in place and having completed training, Hyman says.

"The staff member made an honest mistake in this instant," he adds. "This is an opportunity to think about how we educate people in this situation. The ethical response is think about the root causes of the mistake to reduce the likelihood in the future of a recurrence of the error."

In another example involving an honest mistake, the response is inappropriately outcome-based. In this actual case in Cleveland, OH, a pharmacist named Eric Cropp approved a pharmacy technician's mix of chemotherapy solution for a 2-year-old child who was treated at a local children's hospital. The pharmacist had been under pressure to quickly fill the prescription, and he mistakenly thought the experienced technician had drawn the sodium chloride from an empty 250 mL bag of 0.9% sodium chloride located near the bag of chemotherapy, according to a first-hand account obtained by the Institute for Safe Medication Practices of Horsham, PA.

Instead, the technician had drawn from a different bag, and the mixture contained more than 20 times the correct amount of sodium chloride. The child was given the mixture and died within days of receiving the incorrect mixture. The response to this mistake was outcome-based. Because the simple mistake resulted in a death, the pharmacist was stripped of his license, prosecuted in a criminal trial, and spent time in jail, Hyman says.

"Errors in the medication dispensing process are a frequent problem, which are often caught prior to reaching the patient, or they result in no or minimal harm in most cases," he says. "But a child died, so the pharmacist was put in jail. That doesn't make us safer as a society; it's unethical decision-making that doesn't make us safer."

The fact that this particular case resulted in severe harm should not be the determinant of the punishment, he adds.

- **Policy and procedural breakdown.**

In these cases, a staff member makes a choice that involves not following the institution's policies and/or procedures, and this choice can result in a medical error and possibly patient harm, Hyman explains.

"That staff person should be counseled and educated," he adds. "This should be a compact between staff and the hospital leadership where people know how this type of situation will be handled."

Policy and procedural breakdowns include cases in which a nurse gives medication to the wrong

patient because the nurse didn't check the patient's ID wristband before administering the medication, Hyman says. "This type of mistake should result in a conversation between the staff person's manager and the staff person about what was going on that resulted in the person making this error and not checking the wristband," he says. "Maybe there were staffing problems, or the lighting was dark, or the staff member forgot the policy."

The response would be to reinforce the policy, highlighting reasons why the policy is in place, providing additional training if necessary, and reiterating the need for employees to follow policies that are in place to protect patients' safety, he adds. "It also should result in correcting any system factors that created the context within which the policy was not appropriately followed," Hyman says.

Hospital ethics committees should review the medical error reporting policies and culture at their own institutions to see whether these create disincentives for medical error self-reports, Hyman suggests. "We don't want to punish people for making mistakes because that only discourages other people from reporting errors," he adds. "We have to understand all of the risks in our systems, and we'll only understand those risks if people tell us about them."

When reviewing an institution's culture regarding medical errors, an ethics committee might collaborate with the hospital's patient safety and risk management staff to learn how they handle these situations and what kind of framework is their guiding principle, Hyman says. "In our department, we use just culture principles in all event reviews we do," he adds. "But it also involves educating staff and managers about these principles so that they respond to errors using this framework. We've done this education for staff and managers in a few departments in our hospital, and we've seen increases in reporting these errors following this work."

SOURCE/RESOURCES

- **Daniel Hyman, MD, MMM**, Assistant Professor of Pediatrics, University of Colorado, Aurora, Chief Quality Officer, The Children's Hospital, Aurora. E-mail: hyman.daniel@tchden.org.

- For more information about "just culture," visit the just culture web site at <http://www.justculture.org> or see an April 17, 2001, paper published by Columbia University, titled *Patient Safety and the "Just Culture": A Primer for Health Care Executives*. The paper is available for a free

download at the web site:

http://www.mers-tm.org/support/Marx_Primer.pdf.

- For detailed information about the Eric Cropp pharmacy mistake and outcome, visit the Institute for Safe Medication Practices (ISMP) at the web site: <http://www.ismp.org/Newsletters/acutecare/articles/20091203.asp>. ■

Be aware of the culture of ethics consultations

Start with asking critical questions

Hospital ethics committees and consultants can improve their own understanding of cultural clashes between the institution and patients/families by first considering the culture inherent in an ethics consult.

"The literature is filled with an important discussion of ethics consultation and a clash of cultures," says **Jacqueline J. Glover, PhD**, an associate professor of pediatrics at the Center for Bioethics and Humanities at the University of Colorado in Aurora.

Far less has been written about the actual culture of the ethics consult itself, she adds. "We're always aware of the work we do with other people's cultures, but we need to shed more light on this process of ethics consultation and its factors," Glover says. "It's like asking a fish to take a look at its own water – you're the fish, and you need an outsider perspective."

The ethics consult's culture is related to expectations and how listener's and speakers perceive what is being said, she explains. "When a family hears there is going to be an ethics consult, do they say, 'What did I do wrong?'" she adds.

Researchers who have studied ethics consults have used participant observers to watch actual consultations and to provide a thoughtful framework for what occurs during these consults, Glover notes. "They observe what people are expecting and what they think is happening," she says.

Hospital ethics committees and consultants who would like to learn more about their own and their institution's ethics culture might follow Glover's advice:

- **Ask critical questions.**

"Turn yourself into an anthropologist, asking critical questions about how you do ethics consults," Glover says. "What is your understanding of what the goal of an ethics consult is? What is

“We’re always aware of the work we do with other people’s cultures, but we need to shed more light on this process of ethics consultation and its factors.”

your understanding of what goal is for an ethics consult, and what is the patient and family’s understanding?”

The chief objectives of an ethics consultation include these:

- Identify the goal of ethics consultation.
- Describe the gap in expectations among interested parties.
- Describe different perspectives in the process of ethics consultation.
- Critically analyze barriers to full participation in ethics consultation.

“How do you describe what an ethics consult is to someone else?” Glover says. “How do ethics team members describe an ethics consult to the rest of the team?”

Examine the words used to ask for and describe an ethics consult, she adds.

• **Practice your “script” for speaking with families and patients.**

“I say, ‘Hi, I’m Jackie Glover, and I’m a member of the ethics committee,’” Glover says.

Lay people might hear something in the news about government ethics boards and have misconceptions about hospital ethics committees. So the key is to put their worries at ease and prevent cultural misconceptions about the consult. “I say, ‘We’re part of a team that helps patients and families and providers with difficult decisions,’” Glover says. “I might say, ‘We don’t make decisions for you, but we can help, and how we help is by making sure all voices are heard and everyone has the same information.’”

Ethics consultants could inform patients and families about what will happen when there is a conflict or disagreement. “If there’s a conflict, we look for points of agreement with an overlap of values,” Glover says. “We make sure — when it’s an adult case — that the patient’s voice is heard.”

The “script” can change depending on why the ethics consult was called. For instance, if the family calls for a consult, then Glover might say, “I’m here from the ethics committee. Please tell me why

you called us.”

This is a great way to start the dialogue, she says.

By practicing communication strategies, ethics consultants can reduce the cultural divide in understanding and perceptions. “I have this image of being in a meeting and hearing the language used as bubbles of thoughts appear above each person’s head,” Glover says. “One person says, ‘The expectation is that your baby will have severe developmental issues.’ The doctor’s bubble says, ‘This baby will not walk, talk, eat.’”

The bubble over the head of the parents says, “Maybe our baby won’t go to college.”

There are big differences in expectations, and different cultural understandings of the language used contributes to these differences, she adds.

• **Examine ethics consultation processes.**

“Look at your processes and behind your processes for who can call an ethics consult and how this ethics problem is described or understood at intake,” Glover suggests. (*See story on ethics consult meetings, below.*)

“There are complex contextual features,” she adds. “Most ethics committees have a screening and intake process, then an answer or description of the case, and detail who is on the consult service and how they answer the call.”

Examine the processes of who is on the ethics team and how they initiate an ethics consult process and then work together. “We usually want the clinician to call the physician, but why are we doing it this way?” Glover asks. “There are hierarchical considerations about who gets heard, and there usually is a complex contextual feature in how the case is described.”

SOURCE

• **Jacqueline Glover**, PhD, Associate Professor of Pediatrics, Center for Bioethics and Humanities, University of Colorado, Aurora. E-mail: jackie.glover@ucdenver.edu. ■

Improve dynamics of ethics consult meetings

Consider who called for the meeting

Take a critical look at the dynamics of the ethics consult meeting in a debriefing, as a way to improve the process, an expert suggests.

“If the meetings goal is to have all voices heard, then who felt heard and who didn’t feel heard?” says **Jacqueline J. Glover**, PhD, an associate pro-

fessor of pediatrics at the Center for Bioethics and Humanities at the University of Colorado in Aurora. Glover was member of the core competencies committee/revision committee and task force that developed an education guide for the American Society of Bioethics + Humanities (ASBH) in Glenview, IL.

Ask these questions:

- Whose voice was shut down?
- How did the process work?
- Where are the glitches in the road?
- Did the family feel supported?

How an ethics consult meeting is called makes a difference in how the actual meeting is perceived. “It’s not enough to say that anyone can call an ethics consult,” Glover says. “You need to consider how that will play out in response.”

For example, if a nurse asked for an ethics consult without first letting the attending physician know about the issue or request, then it can create conflict, Glover notes. “If an attending physician receives a call from the ethics committing saying an ethics consult has been called, then it’s hard to have that conversation with the physician,” she explains.

This type of situation can cause some triangulation in which the physician is defensive about the meeting, she adds. “It’s better if the nurse goes to the attending and explains why she thinks an ethics consult would be helpful,” Glover says. “If she needs back-up support, then she should go to the charge nurse and work through the channels.”

This team approach is less likely to create a confrontational environment in which the attending physician is blindsided by an unexpected call from an ethics consultant, she adds.

Another way to improve the dynamics of an ethics consultation meeting is to structure the meeting around answering the question the ethics consult caller actually asked, rather than answering any perceived expectations. For example, if an ethics consult meeting is called to discuss a specific do-not-resuscitate (DNR) resolution, then the expectations between meeting attendees might be widely divergent, Glover says.

One person might discuss the issue of medical futility when all the person who called the meeting wants is a specific resolution to the case at hand, saying they wanted an answer, not a conversation, she adds. “That’s why it’s important in the process to somehow clarify why they wanted to call for the consult and to think about what you’re doing with the meeting,” Glover says. “You can walk into a hornet’s nest if you’re not attuned to these

dynamics.”

Also, be aware of the goals of an ethics consult. Each organization can develop its own goals, but a good starting point might be the goals outlined by ASBH in its publication titled “Improving Competencies in Clinical Ethics Consultation: An Education Guide.” (See resources, below.) The education guide includes these goals:

- Help the different parties understand the ethical problem, relevant concepts and facts, alternative courses of action, and likely consequences.
- Help the different parties communicate more effectively.
- Help the different parties evaluate moral reasons for different alternatives.
- Help the parties achieve agreement on a course of action.

What was private between a family and doctor or nurse is now public discourse, and what was once private is now more open, transparent, and public, Glover says. “This has great potential to advance our conversation to be more patient-centered and family-centered in the way that we care for patients every day,” she says.

Thus, the ethics consultation meeting should reflect this patient-centered and family-centered approach through a reflective process that improves the meeting dynamics, she adds. “Shine a light on your processes, looking at gaps in expectations about why you do what you do,” Glover says. “Look at the culture of your institution because the culture of the ethics consult will reflect the culture of your institution, and look at the power dynamics.”

RESOURCE

- “Improving Competencies in Clinical Ethics Consultation: An Education Guide” is available for ordering on the web site of the American Society of Bioethics + Humanities at <http://www.asbh.org/uploads/files/pubs/EdGuideOrder.pdf>. It costs \$15 plus \$8.75 for shipping and handling. ■

Group to study protection of humans

Panel probes human subject protection

President Barack Obama has called for an investigation of U.S. human subjects research protections in response to last fall’s disclosure that in the 1940s U.S. public health researchers deliberately infected Guatemalan research subjects with

syphilis while testing penicillin.

Obama personally apologized to the Guatemalan people and government in October 2010, after **Susan Reverby**, MA, PhD, a professor of women's studies at Wellesley College in Massachusetts, made the discovery while researching the infamous Tuskegee study of the 1940s through the 1960s. In that study, black men with syphilis were left untreated for years, despite the availability of antibiotics.

The Guatemalan study followed prison inmates, women, and mental patients. Investigators appeared to have deliberately exposed inmates to syphilis for the purpose of then treating them with an experimental antibiotic.

Obama established the Presidential Commission for the Study of Bioethical Issues on Nov. 24, 2009, for the stated purpose of advising the president on bioethical issues that could emerge as a consequence of biomedicine and technological advances, according to Executive Order 13521, dated Nov. 30, 2009.

In March 2011, the president's bioethics commission named an international research panel to report on the effectiveness of current international standards and U.S. rules for the protection of human subjects in studies funded by federal grants. "Last October's revelations about STD research studies in Guatemala were particularly disturbing because they involved vulnerable populations," says **Valerie Bonham**, JD, executive director of the Presidential Commission for the Study of Bioethical Issues of Washington, DC.

"It is another reminder of historic injustices in medical research programs and the need to make it right," Bonham says.

A society has an ethical responsibility to protect people who are participants in scientific research, which has driven many of the important advances in medicine, she adds.

"There is nothing more ethically important than protecting people who are participants in scientific research. Many of the most important advances in medicine were driven by research that involved human participants," Bonham says. "If we can't assure people that they will be safe and treated ethically, they won't volunteer for studies, and without volunteers, critically important research suffers and society suffers."

The international research panel includes medical ethics experts, researchers, and others from the United States and nations around the world, including Argentina, Brazil, China, Egypt, Guatemala, India, Russia, Uganda, and Belgium.

The panel includes ethicists, scientists, physicians, and researchers.

"Their diverse backgrounds and commitment to the highest ethical standards will help inform the bioethics commission's report to the president which is due at the end of the year," Bonham says.

Bonham explains that the international research panel is expected to meet to discuss existing research subject protections worldwide, as well as any conflicts that might exist between U.S. norms and international standards.

"The commission works with the goal of identifying and promoting policies and practices that ensure scientific research, healthcare delivery, and technological innovation are conducted in an ethically responsible manner," she adds.

SOURCE

• **Valerie Bonham**, JD, Executive Director, Presidential Commission for the Study of Bioethical Issues, 1425 New York Ave. NW, Suite C-100, Washington, DC 20005. Telephone: (202) 233-3960. E-mail: info@bioethics.gov. Web: www.bioethics.gov. ■



Where the nation stands with end-of-life care

The National Hospice and Palliative Care Organization (NHPCO) has published a report about end-of-life care, emphasizing the importance of more personal and private discussions about the topic.

"Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care" is a call to action, NHPCO says. It provides a framework and national agenda for consumer engagement in end-of-life issues.

The report details specific areas to address, including the following:

“Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care” is a call to action.

- Individuals need to talk about and document their wishes for care at the end of life.
- Healthcare providers need to initiate honest, timely, and culturally relevant discussions with those for whom they are caring.
- Policymakers need to eliminate barriers that prevent timely access to hospice and palliative care.
- Employers need to support staff who are living with a serious illness or are caregivers or grieving.
- The media needs to explore ways to demystify dying and help normalize the experience for the general public.

The report highlights the stories of Karen Ann Quinlan, Nancy Cruzan, and Terri Schiavo. All three women died after prolonged life-sustaining treatment, and in each case their treatment and eventual deaths brought national media attention to end-of-life decisions and advanced directives.

The report was written and published by NHPCO’s Caring Connections, the organization’s consumer engagement initiative that provides free information on care, caregiving, and community engagement. Funding for the report was provided by the Robert Wood Johnson Foundation of Princeton, NJ.

Death issues are sometimes ignored and other times become part of polarized debate in American society. One example is the anger generated in the summer of 2009 over the rumors of death panels dictating American healthcare decisions under healthcare reform. More education and open discussions are needed, according to NHPCO.

Caring Connections, launched in 2004 through Robert Wood Johnson Foundation funding, works to support these important efforts. The report details real and perceived barriers in people seeking quality care when facing a serious or life-limiting illness. For example, there is the common misconception that a patient and doctor have “given up” when they elect hospice. Studies of hospice and palliative care have shown that these types of care can improve quality of life and family caregiver satisfaction. There are even some cases in which patients live longer than if more conven-

tional treatments were chosen.

RESOURCE

- “Private Conversations and Public Discourse: The Importance of Consumer Engagement in End-of-Life Care” is available as a free download at the Caring Connections web site at CaringInfo.org. Click on the report’s title link, which is underlined in the top right corner of the home page. ■

CME INSTRUCTIONS

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 with the June issue, you must complete the evaluation form provided and return it in the reply envelope provided to receive a credit letter. When your evaluation is received, a credit letter will be mailed to you.

CME OBJECTIVES

Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and healthcare system approaches to bioethical issues applicable to specific healthcare systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and healthcare delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

COMING IN FUTURE MONTHS

- Dispelling myths about pediatric palliative care
- Advances in neuroimaging science and ethical implications
- Hospitals begin to move toward ACO model
- VA’s integrated ethics is starting to catch on

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CME QUESTIONS

17. A new study has found that Medicaid patients facing serious or life-threatening illnesses who received palliative care had hospital costs that were significantly different from a similar group of patients who received usual care. How were those who received palliative care different?

- A. They were \$2,392 more expensive on average
- B. They were \$4,880 more expensive on average
- C. They were \$2,777 less costly on average
- D. They were \$6,900 less costly on average

18. According to medical ethics sources, palliative care goals overlap with ethics committee goals in what way?

- A. Both embody a focus on ethics education for patients and families.
- B. Both work toward improving medical care quality while cutting healthcare costs.
- C. Both work toward identifying the patient's and families' goals and considering treatment matches those goals.
- D. All of the above

19. According to the 'just culture' framework, devised by David Marx, JD, what is a healthcare institution's ethical obligation when it comes to staff medical mistakes?

- A. To align its response to the root cause of the error
- B. To align its response to the outcome of the error
- C. To fix the problem, punish the mistake-maker, and educate the entire staff
- D. None of the above

20. When an ethics consult meeting is held, which of the following questions should be asked and considered to engender a more thorough and thoughtful process?

- A. Whose voice was shut down?
- B. How did the process work?
- C. Did the family feel supported?
- D. All of the above

Answers: 17. D 18. C 19. A 20. D

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