

MEDICAL ETHICS ADVISOR®

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Revised consultation guidelines offer models for improving quality

Revision could serve as springboard to better EC processes

Hospital ethics boards now can refer to national guidelines when developing procedural standards and processes for evaluating quality of ethics consultations (EC) and institutional EC processes.

The revised "Core Competencies for Health Care Ethics Consultation," scheduled at press time to be published by early April 2011, contain these and other new sections relating to health care ethics consultations. The original core competencies guidelines, introduced in 1998, and the 2011 revised version are published by the American Society for Bioethics and Humanities (ASBH) in Glenview, IL. (*For ordering information, see resources, p. 39.*)

"These guidelines are one of the most effective and cited documents ever published in the field of ethics consultation in the world," says **Andrea Frolic**, PhD, a clinical and organizational ethicist at Hamilton Health Science of McMaster University Medical Center in Hamilton, Ontario, Canada. Frolic is on the core competencies task force for the second edition of the guidelines.

Frolic has used the revised core competencies guidelines as they were evolving to recruit and train a team of health professionals who desired specific expertise in ethics consultation. "I also used that document for a performance evaluation of their skills, knowledge, and attributes as consultants," Frolic says. "I've found it a guiding light throughout the recruitment period and training process."

The hope of members of the core competencies task force is that the guidelines will serve as a go-to resource for people who are doing ethics consultations in hospitals, says **Anita J. Tarzian**, PhD, RN, associate professor, family & community health, University of Maryland School of Nursing, and program coordinator for the Maryland Health Care Ethics Committee Network, Law & Health Care Program, University of Maryland School of Law, all in Baltimore, MD. Tarzian chairs the core competencies task force for the second edition. "We are looking at

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strategies for getting the guidelines into the hands of people on ethics committees and who are doing ethics consultations,” she says. “When it first came out in 1998, it was seen as a core resource for people on ethics committees. At that time, there was a focus on voluntary standards and a fear that you would usurp the health care providers doing this as part of their job. Since then, we’ve learned you can’t have a handle on medical ethics if you don’t include the clinical piece.”

Healthcare decision-making and ethics consultations have reached a level of complexity that calls

for standardization and a way to assess and ensure quality and competency, Tarzian notes. “It’s time to take ethics consultation to another level, focusing on the standards of the service as opposed to the competency of the individual consultant,” she says.

The revised guidelines carry this philosophy forward with a new focus on procedures and measuring or evaluating quality and effectiveness, Tarzian says. (*See story on new information in the revised core competency guidelines, p. 39.*) The guidelines hold institutions accountable for having some process for measuring the quality of their ethics consultant service, Frolic says. “A lot of academic medical centers already do this,” she adds. “For those folks who have a more informally structured service, this will challenge them to really enhance their program. It’s a radical concept, and I’m excited about that.”

While some ethicists might take issue with the idea of measuring quality and efficiency in this realm, there are some practical reasons why it’s necessary, Tarzian notes. Ethics consultants are responsive to timelines, for example. “To take a month to ponder whether or not it’s OK to allow a family to keep a brain-dead pregnant woman alive on a ventilator so they could keep the baby is not helpful,” Tarzian says. “Also, if you have 30 people involved in formal ethics committee meetings, and you don’t need 30 people, then you are taking up their time and should figure out how to provide a quality service that makes good use of your institution’s resources.”

One model for assessing quality that is cited in the revised guidelines is the Department of Veterans Affairs’ Integrated Ethics model from the National Center for Ethics in Health Care. It’s a comprehensive approach that is implemented throughout the VA health care system’s 153 hospitals, says **Ellen Fox, MD**, chief ethics in health care officer with the Department of Veterans Affairs (VA) in Washington, DC. Fox is on the core competencies update task force. “Much has been written about the need for ethics consultation services to establish clear standards and metrics, but there has not been a great deal of progress,” Fox says. “So in our system we were really responding to that need.”

The guidelines task force looked for models, approaches, standards, and tools to reference and use in the revised document. Repeatedly, they returned to the VA’s integrated ethics approach, Fox notes.

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EDITORIAL QUESTIONS

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“The guidelines are very closely related to the integrated ethics model, and the tools are heavily referenced,” she adds.

The VA also has a web-based program called ECWeb, short for ethics consultation web, that enables an ethics consultant to document consults and generate notes that can be catalogued electronically and, often, placed in the patient’s record. (See *story on EC Web*, p. 41.)

“It improves ethics consultation practices by tracking, trending, and documenting the critical steps taken throughout the documentation process,” Fox says.

Revision addresses organizational ethics

Members of hospital ethics committees could expand their role if they embraced organizational ethics, which is another area highlighted in the revised guidelines, says **Mary V. Rorty**, PhD, MA, an adjunct clinical associate professor in the Center for Biomedical Ethics at Stanford (CA) University. Rorty also is on the guidelines task force.

Clinical, organizational, and ethical ethics all are part of a broader and more inclusive term called health care ethics, according to the guidelines.

“There are broader ethical concerns that don’t have to do with didactic bedside clinical consultation but have to do with the ethical issues associated with quality in hospitals and concern for the ethical climate in their institutions,” Rorty says.

The task force deliberately chose not to distinguish between subspecialties such as clinical ethics, organizational ethics, and professional ethics, opting instead to use the broader and more inclusive term health care ethics, the guidelines state. The guidelines gave examples of overlaps in ethics subspecialties, including these two:

- “Hospital purchasing offices choosing the least expensive sterile supplies, although their reliability in care is poor (business, organizational, and clinical ethics).”
- “Hospitals opening a new, revenue-generating service with resources that clinical staff would prefer to invest in improvements in an existing service (business, clinical, organizational, and professional ethics).”

The revised guidelines also are notable for what has remained the same in the 13 years since they first were published, Frolic says. “Most of the

tables on knowledge and skills were only changed very minimally,” she says. “That speaks to the staying power of the work that was done in the 1990s. They got a lot right in basic skills and competencies.”

SOURCES/RESOURCE

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- Copies of the revised “**Core Competencies for Health Care Ethics Consultation**” are available directly from the web site for the American Society for Bioethics and Humanities (ASBH): www.asbh.org. Click on “Publications” and then click on “Core Competencies” for the order form. One copy is \$12 with a shipping charge of \$5. ■

Learn the key items in new guidelines

Focus is on quality, measurement

The revised “Core Competencies for Health Care Ethics Consultation,” by the American Society for Bioethics and Humanities (ASBH) contains new sections and tables addressing procedural standards and quality assessment.

“The report looks at what is the minimum infrastructure of an ethics consultation,” says **Anita J. Tarzian**, PhD, RN, associate professor, family & community health, University of Maryland School of Nursing, and program coordinator for the Maryland Health Care Ethics Committee Network, Law & Health Care Program, University of Maryland School of Law, all in Baltimore, MD. “The initial core competencies report focused on what individual ethics consultants need. This revised document recognizes there needs to be an infrastructure and

institutional support.”

Hospitals need a policy that defines who can request ethics consultations, how these are handled, and how to evaluate them, Tarzian says.

Here are some of the new features of the core competencies guidelines:

- **Establish a framework for clinical and organizational ethics consultation.**

Andrea Frolic, PhD, a clinical and organizational ethicist at Hamilton Health Science of McMaster University Medical Center in Hamilton, Ontario, Canada, says, “What I like about this new version is they include both clinical and organizational ethics consultation. The skills often are overlapping, and we see them as related rather than distinctive practices.”

The revised guidelines expand the traditional scope of ethics consultants from being patient-specific to recognizing they might be consulted about business ethics issues, policy ethics issues, and other issues in the organizational realm, Frolic says.

“I like how this document addresses the broader practice and has a much more inclusive definition of the role of an ethics consultant, and it mirrors a lot of people’s actual practice, which I think is helpful,” she says.

- **Address HCEC evaluation and quality improvement practices.**

The report evaluates consults in terms of ethics services, says Mary V. Rorty, PhD, MA, an adjunct clinical associate professor at Stanford (CA) University. “It’s more about whether you have a machine that could do the job that the outcome of the job that’s done,” Rorty explains.

The guidelines include a table that divides the category of evaluating quality into three sections, related to structure, process, and outcomes. Examples of the recommendations under each of these sections are as follows:

— **Structure.** “Identify root causes, underlying structural gaps (e.g., staff shortages, historical precedent, lack of funds for continuing education).”

— **Process.** “Identify major root causes underlying process gaps (e.g., lack clear policy standards, resistance to change, unable to formulate ethics question, competing demands on staff time).”

— **Outcomes.** “Identify major root causes underlying any satisfaction gap (e.g., misunderstanding of the consultation process, lack of timeliness, role confusion).”

Members of ethics committees could evaluate

their programs by collecting data on the types of ethics consults referred to the committee and break these down by department, Tarzian suggests.

“They could see that we’re getting a lot of consult requests on when you can stop the ventilator in patients with X syndrome, so maybe we need to develop an educational intervention to help staff with this,” she says. (*See elements for a health care ethics consultant, below.*) ■

Advance consults with process standards

17 elements to include

The revised “Core Competencies for Health Care Ethics Consultation,” by the American Society for Bioethics and Humanities (ASBH) suggests including these elements in process standards for a health care ethics consultation (HCEC):

- responding in a timely fashion to consultation requests;
- analyzing relevant information to decide if a request is appropriate for ethics consultation and what ethics question(s) need(s) to be addressed;
- notifying individuals involved in the consultation, if appropriate (e.g., attending physician and patient/family for a case consultation);
- formulating the ethics question;
- reviewing the medical record;
- visiting the patient;
- interviewing involved parties;
- gathering ethics knowledge;
- determining whether a formal meeting is needed;
- facilitating moral deliberation;
- identifying the ethically appropriate decision maker;
- synthesizing and communicating information;
- making recommendations;
- documenting consultations;
- following up with participants;
- identifying underlying systems issues;
- evaluating and improving the consultation process. ■

Web-based ethics consult serves as best practice

Process highlighted in guidelines

Hospital ethics boards seeking a solution for efficiently and effectively documenting and assessing ethics consultation work could find a best practice in the ethics consultation web (ECWeb) program developed by the Department of Veterans Affairs (VA) in Washington, DC, experts say.

“The VA has a tremendously impressive database,” says **Anita J. Tarzian**, PhD, RN, associate professor, family & community health, University of Maryland School of Nursing, and program coordinator for the Maryland Health Care Ethics Committee Network, Law & Health Care Program, University of Maryland School of Law, both in Baltimore, MD. Tarzian is the chair of the core competencies task force for the second edition of the “Core Competencies for Health Care Ethics Consultation,” produced by the American Society for Bioethics and Humanities (ASBH) in Glenview, IL.

“ECWeb is a way of documenting ethics consultation services at all VA hospitals,” Tarzian says. “They can pull data on all kinds of metrics from that database.”

The VA’s ethics program addresses ethics at every level of the organization, notes **Mary V. Rorty**, PhD, MA, a core competencies update task force member and an adjunct clinical associate professor in the Center for Biomedical Ethics at Stanford (CA) University. “I greatly admire the VA process because of its range of scope,” Rorty says.

ECWeb is a tool that helps to improve the quality of ethics consultation, says **Ellen Fox**, MD, chief ethics in health care officer with the VA. “ECWeb reinforces standards for ethics consultation and aids in the evaluation of consult service quality,” Fox says. “It also facilitates workload management and provides a repository of ethics knowledge.”

The VA worked on ECWeb for many years before launching it nationwide throughout the VA’s health care system in 2008. Fox describes the system’s features, as follows:

- **Document ethics consults electronically.**

ECWeb walks consultants through the consultation process step-by-step, beginning with the moment when there is a request for an ethics con-

sultation.

“The first steps in our process involve clarifying the ethics question,” Fox says. “The consultant would obtain preliminary information from the person requesting the consult, then go into ECWeb and open a new consultation record.”

Later when the consultant interviews another person, he or she will return to ECWeb to record that interaction. “It’s intended to be used in real time rather than to have you complete the consult and do the whole record at once,” Fox says.

Also, consultants can search through the database for information about previous consults. “When you enter data for a consultation it not only documents that one consult, but it also goes into a consultation database that helps to guide future consults by showing you how previous issues were addressed,” Fox says.

- **Evaluate and monitor quality of the ethics consult service.**

Members of ethics committees and quality improvement officers can use ECWeb data to track ethics consult processes and pull up trends. They can evaluate the quality of consultations through comparison with previous consults, Fox explains. For example, ethics committees can refer to the revised report, “Core Competencies for Health Care Ethics Consultation” by the American Society for Bioethics and Humanities (ASBH) for examples of tools and quality measures.

“By systematically analyzing consultation activities and comparing them to clearly defined standards, they can identify strengths and weaknesses in their hospitals’ processes,” she adds. “We also routinely use an evaluation form, based on the ASBH core competencies report, to get feedback from individuals involved in a consult. ECWeb can automatically generate chart notes, and it can generate reports.” For example, the system could generate reports in answer to these questions:

- How many consults were requested by doctors, nurses, or patients?

- How many consults included a review of an advance directive document or an interview with a patient?

- How many person-hours did it take to complete each consult, over how many days?

- How frequently did questions about resource allocation or informed consent arise in the system?

- How frequently did a particular question arise in the system?

“By analyzing these data and comparing the information to the standards, a consultation ser-

vice leader can provide feedback to hospital leadership and to individuals performing consults on the team,” Fox says. “They can use this information to formulate strategies for improvement.”

Also, data can be aggregated for developing benchmarks and comparisons between facilities, Fox says. “We have over 5,000 consults in our database,” Fox says. “All of our facilities use the system and track the same data fields on every consultation.”

- **Improve ethics consultation processes.**

ECWeb contains branching logic and interactivity with consultants.

“For example, if you indicate the patient lacks decision-making capacity, it then asks whether the patient has a surrogate, and it has you complete the information,” Fox says. “If our guidelines suggest the consultant should visit the patient and the consultant didn’t, then there is a pop-up question asking why the consultant did not visit the patient.”

ECWeb also includes features that increase consistency and efficiency, Fox says. “Consultants can use ECWeb to set reminders, write notes to themselves or to other consultants, attach documents to the consultation record, or refer a consult to another member of the team,” she says.

The ECWeb program is not yet available outside of the VA. However, the National Center for Ethics in Health Care is working to collaborate with other health care organizations to make ECWeb available everywhere, Fox notes. “The vision is that each hospital would keep data behind its own firewall, but aggregated data would be shared,” she explains. “This sort of shared database could be a game changer for our field. It would increase the quality of consultation everywhere, virtually overnight.” ■

CMS reverses plans for advance care planning

Media attention led to change

President Obama’s administration reversed its decision to revise a Medicare regulation to include paying physicians to discuss good advance care planning with patients. This decision is a setback from an ethical and health care perspective, according to advocates for end-of-life planning.

“The administration was reluctant to do any-

thing that might cause an uproar,” says **Paul Malley**, president of Aging with Dignity, a non-profit organization based out of Tallahassee, FL. “The unfortunate side effect is it has become more difficult to talk about good end-of-life care, palliative care, and hospice care.”

The Centers for Medicare and Medicaid Services (CMS) first proposed including the language about advance care planning in a proposal, published in the Federal Register on Nov. 29, 2010. CMS defined the new annual wellness visit, providing personalized prevention plan services as provided by the Patient Protection and Affordable Care Act of 2010. The change was set to take effect on Jan. 1, 2011. But CMS withdrew the few sentences pertaining to this issue shortly after the new year on the heels of a December 2010 article in *The New York Times* about the proposed policy change, Malley says.

In an amendment to payment policies under the physician fee schedule, published in the Federal Register on Jan. 10, 2011, the Department of Health and Human Services (HHS) wrote that HHS had added the advance care planning proposal in response to requests for its addition by several people who responded during the comment period of the proposed rule, published on July 13, 2010.

“The proposed change added advance care planning to a list of things a physician should talk about at an annual Medicare wellness check-up,” Malley says. “The only thing this did was say the physician should ask about advance care planning each year at the check-up. It was made voluntary and one of the many things on a checklist of topics to cover.”

Unlike the eight pages of language inserted in an early version of the health care reform bill, which would have given physicians specific instructions about an advance care planning conversation, this simple new guideline was written to be flexible, Malley says.

The original health care reform act wording gave birth to the talk of health care death panels in the summer of 2009, says **Jon Radulovic**, vice president of communications at the National Hospice & Palliative Care Organization (NHPCO) of Alexandria, VA. “Those were unfortunate rumors that spun out of control,” he says. “That language was taken out of the health care legislation, and we were disappointed by that.”

There is nothing about advance care planning that equals death panels, Radulovic adds. Last

fall's proposed change by CMS simply would have allowed physicians to bill for advance care planning, he says.

"It's not a new idea," Radulovic says. "This new rule just would have made the opportunity for the patient to request advance care planning as part of the annual check-up, making it more widely available."

However, when media and online blog reports stirred up the issue, returning to the fears of death panels, the Obama administration took out the regulation, he adds. "I think the White House was so apprehensive about seeing a firestorm of discussion about death panels again that they pulled back on what would have been a Medicare guideline," Radulovic says. "It was a defensive move which we were disappointed about."

HHS rescinded the provision involving voluntary advance care planning because of the wide range of views on this subject held by a broad range of stakeholders, including members of Congress, according to the Jan. 10, 2011, amendment. In that amendment, CMS Administrator Donald M. Berwick wrote, "While we believe that we acted within our authority in including voluntary advance care planning as an additional specified element of the new annual wellness visit in the final rule, it has become apparent that we did not have an opportunity to consider prior to the issuance of the final rule the wide range of views on this subject held by a broad range of stakeholders."

If the Medicare wording had continued to encourage end-of-life discussions between community physicians and patients, the best case scenario might have been a gradual reduction in patients entering the emergency department (ED) and intensive care unit (ICU) who have given no thought to end-of-life planning, Radulovic and Malley say. These types of situations in which patients are dying while on life support are among the most common cases brought to hospital ethics boards for review or ethics consultation, they say.

As it is now, physicians still can bring up end-of-life issues with patients or refer them to other organizations, such as Aging with Dignity. The organization distributes the widely used "Five Wishes" advance care planning toolkit. Also, there is free, downloadable, state-specific advance care planning information available through NHPCO's Caring Connections. (*See resource section, right, for more information.*)

However, there is no financial incentive for

physicians to ask patients about their advance care planning at annual visits. Hospitals are required to ask patients about their advance directives when people are admitted to the hospital, but this conversation often takes place at the moment of personal crisis when families and patients might feel pressured and overwhelmed, Malley says. "The goal is to have the conversation further upstream and talk about it with physicians before there is a crisis," he says.

Some physicians, such as oncologists, increasingly are making end-of-life talk a part of their practice, but more buy-in among community doctors is needed, he adds. It will take broader physician buy-in to move the field to the next level where most patients have given advance care planning some serious thought and have completed forms that express their wishes, Malley says.

"We put the focus on what good care means to the patient, and it's important to let people know we're not just talking about feeding tubes and ventilators," he says. "Good care means keeping a person comfortable and honoring their dignity."

This focus should be a part of the natural conversation between physicians, hospital nurses, social workers, and patients, he says. "This is a great opportunity for collaboration between hospitals and physician groups," Malley says. "If doctors feel empowered to have these discussions with patients and their families, that's the best scenario."

SOURCES/RESOURCES

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- **Jon Radulovic**, Vice President of Communications, National Hospice & Palliative Care Organization, 1731 King St., Suite 100, Alexandria, VA 22314. Telephone: (703) 837-1500. Web: <http://www.nhpco.org>.
- **Aging with Dignity**, Tallahassee, FL. To obtain a copy of the "Five Wishes" advance care planning toolkit, selling for \$5 for individual copies with free shipping or \$1 per copy for orders of 25 or more (depending on quantity, shipping costs \$10+), visit its web site: <http://www.agingwithdignity.org>. Click on "Five Wishes" icon, and then select the toolkit for ordering.
- Caring Connections of the National Hospice and Palliative Care Organization of Alexandria, VA. Helpline: (800) 658-8898. The web site contains free, state-specific advance care planning information at <http://www.caring-info.org>. Click on the icon that says "Download Your State Specific Advance Directive." ■

Conducting donation after cardiac death

Educate hospital staff about DCD

Hospital ethics committees sometimes are called to handle cases involving donation after cardiac death (DCD), but handling these cases can be a challenge, an expert says.

“Some of the ethical issues you see particularly with ethics committees are concerns about withdrawing life-sustaining treatment,” says **James M. DuBois**, PhD, DSc, the Hubert Mader chair of health care ethics at Saint Louis (MO) University. DuBois also is an adjunct professor of medicine at the Washington University School of Medicine and director of the Bander Center for Medical Business Ethics, the Social Science Research Group at Saint Louis University, and the Center for Research Ethics and Integrity, all in St. Louis.

Controlled DCD typically involves a ventilator-dependent patient who is still alive, but a decision has been made to discontinue life-sustaining treatment, DuBois says. “In most cases involving withdrawing life-sustaining treatment, there is no disagreement, no chance of recovery, and both families and staff are comfortable with removing the ventilator,” he says.

However, when providers approach the family about donating the patient’s organs and administering medications to the patient solely for this purpose, the ethical issues are highlighted, DuBois adds. “With standard donation, the patient is already dead before you approach the family to talk about organ donation, and the patient is dead before you prepare him for surgery,” he says. “With DCD, the patient is still alive when you have to talk with the family to get permission for organ donation, and this can impact the location of the patient’s death.”

Clinicians have to ask the family for permission to administer medications such as heparin, which are given solely for the purpose of organ donation, he adds.

“This makes the hospital staff feel like they’re in a dual role of caring for the sustained person as both a patient and as a potential donor,” DuBois explains. “This is difficult for intensivists and critical care staff.”

Hospital ethics committees can help clinicians handle these delicate situations by following these recommendations:

- Educate staff about death after cardiac death.

“If a hospital is going to start a DCD program, then they need to start it by having frank discussions with their staff about DCD, giving employees the opportunity to discuss it,” DuBois suggests.

The staff’s buy-in is essential, he notes. “With standard organ donors, it’s easier for the OPO [organ procurement organization] staff to find out who is a potential donor,” he says. “With DCD, the OPOs rely heavily on hospital staff to identify potential donors.”

Thus, if the hospital staff does not buy into the DCD program, then the OPO will receive few referrals from the hospital, DuBois says. “Educating staff is very important for many reasons, including for the purpose of helping staff be comfortable with it ethically, psychologically, and for referral purposes,” he says.

Hospitals can use some of the more efficient educational strategies employed in recent years, such as the brown bag lunch session and training during departmental rounds, he suggests. “Touch on the highlights of the actual hospital protocol that will be used,” he adds.

- Invite OPO representatives to speak with hospital staff.

“OPOs have staff members who are able to facilitate some of these educational discussions,” DuBois says.

Also, there are OPO web sites with educational materials. For example, the Gift of Hope Organ and Tissue Donor Network of Itaska, IL, has free downloadable material about DCD that can be distributed to health care staff and families. Also, the University of Wisconsin School of Medicine and Public Health in Madison has free online brochures about DCD. (*See resource section for contact information, p. 45.*)

- Determine death criteria, and place these in institutional policies.

“DCD has attracted the most controversy over death criteria,” DuBois says.

Hospitals could refer to the standard criteria approved by the Institute of Medicine and more than 15 other institutions and organizations participating in the 2005 National Conference on donation after cardiac death. The work group participants concluded that death occurs when cardiopulmonary function will not resume spontaneously, according to the “Report of a National Conference on Donation after Cardiac Death,” published in 2006 in the *American Journal of Transplantation*. (*See resource information, p. 45.*)

Educate hospital staff about these policies and death criteria to avoid controversy, DuBois suggests. Have the treating team, attending physician, and family in agreement that resuscitation should not be attempted in these cases even if no organ donation is possible, he adds. Also, obtain the family's permission in DCD cases, even if the patient has signed an organ donor card or has joined a registry, he says. "You should get the family's permission to withdraw the ventilator and administer medication for donation," he says.

SOURCE/RESOURCES

- **James M. DuBois**, PhD, DSc, Hubert Mader Chair of Health Care Ethics, Saint Louis University, 3545 Lafayette Ave., Saint Louis, MO 63104-1314. Telephone: (314) 977-6663. Web: <http://chce.slu.edu>.

- Gift of Hope Organ and Tissue Donor Network of Itaska, IL, has free downloadable material about donation after cardiac death (DCD) that can be distributed to health care staff and families. Visit the network's web site at www.giftofhope.org and type "DCD" in search window. Click on first link.

- The University of Wisconsin School of Medicine and Public Health in Madison has free online brochures about DCD at the web site: www.uwhealth.org/files/uwhealth/docs/pdf/OPO_CardiacDeath.pdf.

- "Report of a National Conference on Donation after Cardiac Death" is available at the American Journal of Transplantation website: <http://www.amjtrans.com/view/0/index.html>. Search issues with the report's name and click on pdf link to full article. ■

View the term 'futility' through different context

Case study illustrates dilemma

Hospital ethics committees could clarify and improve the way they handle issues involving life support in the intensive care unit (ICU) if they brought more nuance to any definition of the word "futile," an expert says.

"There are three ways that term can be used: physiological futility, where it just plain won't work; qualitative futility, which includes a value judgment that it's not worth it, and then there's a quantitative futility, which means that you're 99% sure it won't work," explains **Robert D. Orr**, MD, CM, director of clinical ethics and a professor of medical ethics at Loma Linda (CA) University Medical Center. Orr also is the co-chair of the

Healthcare Ethics Council at Trinity International University in Deerfield, IL, a senior fellow with the Center for Bioethics and Human Dignity (CBHD) and chair of the CBHD's advisory board, professor of bioethics at the Graduate College of Union University in Schenectady, NY, professor of bioethics at Trinity International University in Deerfield, IL, and a professor of family medicine at the University of Vermont College of Medicine in Burlington.

The medical maxim that there is no moral obligation to provide futile treatment applies only to physiological futility, he notes. "The problem is physicians sometimes look at a situation and claim qualitative futility, saying, 'I don't think it's worth it to continue this ventilator on someone who won't ever wake up, so it's futile,'" Orr says. "But if the family says it is worth it to them to keep the family member alive despite the fact that there is a very remote prospect of any return of mental function, then I think we should generally support their desire."

There are exceptions to this ethical stand, including cases in which the patient is experiencing unrelievable suffering, he adds. Also, there might be no insurance or government payer to pick up the cost of keeping a person alive well past the point of reasonable hope for recovery, he says.

It's when cases move into these gray zones that ethics committees and consultants might be called in to help. "This is the biggest part of my job description," Orr says. "Just a few days ago, I spent two hours with a family and three physicians, a nurse, social worker, and four family members discussing whether or not to continue a treatment that is postponing a patient's inevitable death."

The patient had no advanced directives, and the patient's family insisted on continuing treatment, hoping for an unexpected improvement, he says. "The physicians said it was unprecedented to use this amount of medication for this amount of time," he recalls.

The patient was on a paralytic agent to keep his body paralyzed for the purpose of staying ventilated, and it had been going on for three weeks, Orr says. "With continued paralysis, the patient would lose any kind of muscle function and wouldn't come off the ventilator," he explains. "The family wanted to continue the ventilator and antibiotics, and they wanted resuscitation if his heart should stop."

The physicians knew that any resuscitative

efforts would fail, but they wanted to avoid continued confrontation and conflict with the family, so they did not insist on a do-not-resuscitate (DNR) order signed by the family. Orr worked with all parties over two hours and helped them reach a compromise of stopping one of the patient's drugs. "They agreed to stop this one medication, which is almost certainly going to change the course of events," Orr says. "The decision was to wean the patient off the paralytic drug and not resume it."

This is a major clinical change that in most cases would lead to the patient's death, he says.

As an ethics consultant, Orr helped the family and medical team reach this compromise by first laying out some boundaries, including spelling out how this type of case is viewed from medical and other perspectives. "From a clinical, legal, and professional perspective, it would be OK in this patient to stop all treatment," Orr says.

In this case, stopping treatment is an acceptable action to take since there is no possibility the patient will survive and recover even with treatment, Orr explains. Because the medical team supports patient and family values, they are willing to do what the family requests unless it comes to a point where the physicians believe it is absolutely futile physiologically, and the patient is suffering because of the continued treatment, Orr adds.

In cases in which the patient has an advanced directive, then the medical team will side with the patient's wishes, unless the family can demonstrate a clear indication that the patient had changed his or her mind or had not had this particular scenario in mind when signing the advanced directives, he says. "We lean toward favoring the patient's statement unless the family can rebut it in some way, convincing us the statement doesn't apply in this situation," Orr adds.

An effective way to handle these ethical dilemmas is for an ethics committee and/or consultant to make an effort to understand where the family is coming from, he suggests.

"I put high stock in individual values, and that's necessary for a physician and ethics consultant," Orr says. "I try to show the family the implications for others and how this interacts with their own religious beliefs."

These cases are intensely emotional and should not be turned into adversarial situations, he says. "We're trying to work together here," Orr says.

In the case outlined above, he notes that the hospital team recommended that the patient be

placed in palliative care. The family members did not object to the suggestion, but they were not happy with the idea because of a mindset that palliative care equals dying, and they did not think of their family member as dying, Orr says. "We emphasized that our goal was to make him comfortable regardless of the outcome," he adds.

SOURCE

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Family assessment tool expands ethics consults

Hospitals might improve their ethics consultation processes if they design and use a brief ethics family assessment tool to determine families' and patients' values, two ethicists say.

"We have questions we ask families at admission, and they're very important questions to ask," says **Heather Fitzgerald**, BSN, RN, interim nurse ethicist at The Children's Hospital in Aurora, CO. "But they don't help us get closer to an understanding of the specifics of each unique family system and the context for each family with whom we are engaging."

Asking patients and families specific ethics and values questions in the first meetings would be one strategy for improving communications between the medical team and patients and families, she says. "We commonly encounter communications breakdowns," Fitzgerald notes. "Part of why the ethics team is consulted is because there is some failure of communication or a difficulty of communication, whether it's between family members or between the family and the hospital team."

People with different values have different ways of viewing a patient's care. "There is some place where communication has not been fully functional," Fitzgerald says. "While it may seem simple to say we need to communicate more effectively, one of the key pieces we've found missing is a deep understanding of the family system."

Hospital ethics committee members and ethics consultants need to understand the family's values and what they are bringing to decision-making. One way to find out these things is by designing a family assessment tool, Fitzgerald adds. "Maybe

we need to flesh out the questions we ask,” she says. For example, an attending physician might ask patients about what they’ve learned about their child’s or the patient’s condition rather than simply asking if they have any questions.

Also, an ethics family assessment tool could be incorporated into the ethics consultation process. For example, long-time ethics consultant **Jackie Glover**, PhD, has developed five questions designed to elicit answers that will help explain a particular patient’s or family’s values and goals in care. “Early on I realized it was so important to take a values history, so I started every ethics consult with these five questions to really have a sense of rapport and understanding,” says Glover, who is an associate professor of pediatrics at the Center for Bioethics and Humanities, University of Colorado in Aurora. Glover does consults at the University of Colorado Hospital and at The Children’s Hospital, both in Aurora.

Questions such as the ones Glover uses can help the ethics consultation process obtain a deeper understanding of the family context, Fitzgerald says.

An assessment tool might use some of the good questions Glover asks so successfully in her consults, she adds. “I call this taking a values history,” Glover says. “Who is this family? How do they make decisions?”

It’s essential to understand a family’s values, but it’s not useful to ask them directly what their values are because they likely will not know how to answer that question, she adds. “Questions are great prompts,” Fitzgerald says. “So if clinicians are going to have conversations with families, they can prompt themselves with these or similar questions.” Here are Glover’s questions:

- What is your understanding of your child’s (the family member’s) condition?

The answers to this question could highlight family dynamics and areas of stress. “How do they make decisions?” Glover says. “Who needs to be there when we talk about the patient’s condition?” For example, it could be the family is huge and the grandparents are the ones to talk to, she adds.

- How has the illness affected your family?

Follow-up questions might include, “What are you going through? What’s most important to you?” she says.

- What is most important to you in the care of your child (family member)? A follow-up question is, “What are you hoping for?” Glover says.

- What do you fear the most? The next question

would be similar, but stated differently: “What do you want to avoid?” Glover says.

- What are your family’s sources of support and strength?

“If it’s a family of faith then they might say their faith is getting them through it,” Glover says. “Or maybe they have a tight-knit family who is here for them.” ■

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.

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

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CME QUESTIONS

13. According to the revised "Core Competencies for Health Care Ethics Consultation," by the American Society for Bioethics and Humanities (ASBH), which of the following is/are an element(s) in process standards for a health care ethics consultation?

- A. Responding in a timely fashion to consultation requests
- B. Formulating the ethics question
- C. Visiting the patient
- D. All of the above

14. On Jan. 10, 2011, the Centers for Medicare and Medicaid Services published an amendment about advance care planning in the Federal Register. What did it change?

- A. The amendment said physicians now are required to discuss advance care planning in their annual wellness visits with Medicare patients
- B. The amendment reversed an earlier decision to include voluntary advance care planning discussions in Medicare patients' annual Medicare wellness visits with physicians
- C. The amendment raised the physician fee schedule for a 15-minute slot of time spent on discussing advance care directives with Medicare patients
- D. None of the above

15. Which of the following best explains why hospitals educate staff about donation after cardiac death (DCD)?

- A. With DCD, the patient is still alive when hospital staff has to obtain permission to administer heparin, which is given solely for the purpose of organ donation, and employees might find this challenging to do
- B. Hospital employees might feel they are in a dual role of caring for the sustained person as both a patient and as a potential donor
- C. Both A & B
- D. None of the above

16. When physicians and ethics committees use the term "futility," there are several ways they can use this term. Which of the following does not describe a definition of this term from an ethical perspective?

- A. Economic futility
- B. Physiological futility
- C. Qualitative futility
- D. Quantitative futility

Answers: 13. D; 14. B; 15. C; 16. A

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