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Interpreting and applying law often requires an ethical approach

Law and ethics typically complement each other

While there are certain scenarios regarding patient care when what is written in the law may seem to counter what is ethically appropriate, in general, the law and ethics complement each other in the health care arena, according to those interviewed by *Medical Ethics Advisor*.

As in so many difficult decision-making situations, particularly those related to end-of-life care, good communication among all stakeholders in a particular dilemma is key.

"The first thing I would say is that a good hospital lawyer is always going to tell you that the best way to avoid legal difficulty is to communicate well with patients and families and cultivate good relationships with them," says Nancy M. P. King, JD, professor, department of social sciences and health policy, Wake Forest University School of Medicine, and co-director, WFU Center for Bioethics, Health and Society in Winston-Salem, NC.

King notes that there are "very, very few situations in which there is some kind of incompatibility" between the role of law and the role of ethics in patient care.

"Thinking that law and ethics are incompatible is, I think, very often a misunderstanding about the role and reach of law to begin with," she says. "And it stems in part from the fact that in bioethics in the United States, court decisions and other aspects of law have played a considerable role — and that's not true in bioethics everywhere."

Very often, she says, one of the misunderstandings — particularly among health care providers — is that there is a legal answer to every request.

"The perception is that you plug in the facts, and a legal answer is going to pop out," she says.

And while, she says, law "may actually get at some of the outlines of some of the important bioethics issues," a legal answer is not always possible — and most lawyers know this.

“There really are very few instances in which so-called black letter law, that is, there’s a really clear answer here, and you better just do it, actually fits health care situations, which are nuanced and complex — and usually extend much farther than the law can actually speak to,” King notes.

“The considerations of bioethics are the considerations that fill in that gap between what law can actually contribute to the discussion of a complex problem and the range of morally appropriate actions and decisions that are available to patients and families and their health care team,” she says.

Legal consultants vs. ethics consultants

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Managing Editor: Karen Young, (404) 262-5423, (karen.young@ahcmedia.com).

Associate Publisher: Russ Underwood, (404) 262-5521, (russ.underwood@ahcmedia.com).

Production Editor: Ami Sutaria.

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EDITORIAL QUESTIONS

Questions or comments?
Call Karen Young
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“There’s no question that ethics influences the law, and certainly, to some extent, the law influences ethical discourse, but they’re really looking at problems from very different perspectives — and both become very important for clinicians to know about and to have access [to],” according to **Alexander A. Kon**, MD, CM, FAAP, FCCM, who is, among other appointments, director, clinical bioethics consultation service and chair, bioethics consultation committee at UC Davis Medical Center, as well as director of bioethics, Clinical and Translational Science Center at the University of California, Davis.

However, Kon says that “the role of the ethics consultant is quite different than the role of the legal consultant.”

“While there is sometimes a perception among some people that ethics consultants sometimes are giving legal advice, that’s really not the purpose of the ethics consultant,” Kon explains.

“In general, what ethics consultants will do is encourage clinicians to speak with their legal counsel or risk management to get a legal perspective, but the ethics consultants are giving an ethical perspective, because they are — quite honestly — very different ways of looking at an issue.”

Like King, he suggests that many situations can be resolved through good communication.

“There’s been some data to look at this, and in terms of what ethics consultants do, in general, about 80% of what ethics consultants do is just help people communicate better,” Kon explains.

“So, it’s really just sitting down with patients and families and health care providers to help people have better conversations, where there’s no recommendations being made — it’s just facilitated conversations,” he says. “There’s maybe 10% to 15% [of the time] where the ethics consultants are actually helping figure out what are ethically permissible options — that’s a little different than legal advice, because legal advice is going to tell you, well, this is illegal or we think that this is legal.”

“What good ethics consultants do is they help clinicians understand what are the things that are ethically required, what are the things that are ethically permissible, and what are the things that are not ethically permissible at all and need to be taken off the table,” Kon tells *MEA*.

“It’s a different model,” Kon says. “There are certainly times on our committee — I don’t know if people at other institutions find this — where you are asked legal questions, and the response is always: ‘I can’t give you legal advice; I’m not a lawyer; I’m not hospital counsel; for legal ques-

tions, you really need to talk to hospital counsel — we'll help you with some other things.”

Also, so much of what happens in health care decision making is governed by state law, and state law, of course, varies from state to state.

“The ethics don't vary,” Kon notes.

The fear of a lawsuit

One of the reasons some think there may be an incompatibility is the fear of being sued — either as an individual provider or an institution, King says. In fact, she says that “the perennial question that comes from the health care team is, ‘How can I keep from getting sued about X?’”

And that, of course, is a concern for hospital legal counsel and those in risk management for hospitals.

“The proper answer — even though very often it is not a very satisfactory answer — is you can't keep from getting sued, because there are lots and lots of grounds on which somebody can bring a lawsuit,” she explains. “But if you do the right thing, you're not going to lose.”

SOURCES

- **Paula Goodman-Crews**, MSW, LCSW, Bioethics Director, Kaiser Permanente, San Diego, and Southern California Region. E-mail: Paula.Goodman-Crews@kp.org.
- **Nancy M.P. King**, JD, Nancy M. P. King, JD, professor, department of social sciences and health policy, Wake Forest University School of Medicine, and co-director, WFU Center for Bioethics, Health and Society in Winston-Salem, NC. E-mail: nmpking@wfubmc.edu
- **Alexander A. Kon**, MD, CM, FAAP, FCCM, who is, among other appointments, director, clinical bioethics consultation service and chair, bioethics consultation committee at UC Davis Medical Center, as well as director of bioethics, Clinical and Translational Science Center at the University of California, Davis. ■

Law, ethics sometimes create misperceptions

Ethics needs to be balanced with the law

Although most patient care scenarios can be worked out through careful communication with all those involved, there are certain situations where even greater diplomacy may be required on the part of ethics consultants.

One situation in particular where this is often

the case relates to advance directives and the selected surrogate decision-maker, who makes decisions for the patient when he or she is incapable of making decisions for himself or herself, according to **Nancy M. P. King, JD**, professor, department of social sciences and health policy, Wake Forest University School of Medicine, and co-director, WFU Center for Bioethics, Health and Society in Winston-Salem, NC.

Kaiser's **Paula Goodman-Crews**, MSW, LCSW, bioethics director in San Diego for 10 years with Kaiser Permanente and now also regional bioethics director of the Southern California Region, provided two examples “where the law might not follow ethics and vice versa.”

also suggests that advance directives and surrogate decision-makers represent an area often ripe with disagreement within families.

“Take, for example, the situation where someone has an advance directive and/or a surrogate decision maker, and together, either the advance directive or the surrogate decision maker — or both — say, ‘Action X is the best action for this patient under these circumstances.’ And the family comes in and says, ‘Don't you dare do that. We think Y is the best thing,’” King says, noting that this type of situation occurs regularly.

“Cousin Fran may be upset that she wasn't chosen; it may be that the patient has a very different view of the decision-making process than the family, who doesn't feel like they're ready to let the patient go,” King explains.

And this is where the scenario becomes complex.

For example, someone on the team caring for the patient may think that the best way not to get sued is to follow the family members' wishes.

Somebody on the team might maintain that if what the family wants is for the patient to be kept alive as long as possible, that's what should be done, since there's “very little case law saying that somebody who fails to honor an advance directive and keeps the patient alive longer has actually done cognizable harm to a patient that can be effectuated through a lawsuit,” says King.

In a hypothetical situation, King says that a team member who wants to avoid being sued, may wish to choose care that is counter to what is in the advance directive, noting that “nobody's ever going to bring that lawsuit, and they may not sue, because the patient was kept alive and because it's very difficult to bring lawsuits like that.”

That would be the wrong decision to make, according to King.

“This is . . . a situation where somebody is really expecting that it is really possible to keep everything quiet by doing something that’s morally wrong,” King says. It’s these kinds of situations that “may be what cause people to believe there is an incompatibility between law and ethics, when there really is not.”

“It’s clear that in that kind of a situation, the advance directive carries substantial weight and should be honored, but, in fact, the right way to proceed with a situation like that isn’t to say, ‘Hey, law is on our side, as well as ethics, but to sit down with the family — and really, again, take that initial time. One of the reasons why it’s easy to . . . try to take mental shortcuts and say there’s an incompatibility here is that the best way to address perceived incompatibilities like that is very time-consuming and involves some very difficult conversations,” King explains, noting that “there’s a lot of hard work that needs to be done.”

Pediatric informed consent

All those interviewed by *MEA* suggested that it is very important for ethics consultants to be aware of the laws, particularly those within their state, which may constrain their recommendations to patients or their families.

“Clinicians need to know what are the legal constraints that they really need to talk to legal counsel about to understand...and then they need to understand what are the ethical concerns, and that’s where the ethics consultants can frequently be very helpful, according to **Alexander A. Kon, MD, CM, FAAP, FCCM**, who is, among other appointments, director, clinical bioethics consultation service and chair, bioethics consultation committee at UC Davis Medical Center, as well as director of bioethics, Clinical and Translational Science Center at the University of California, Davis.

“There are certainly times when recommendations from the two might be somewhat different,” Kon says. “In general, the law and ethics go hand-in-hand, but that’s not always the case.”

One example where the two may not go hand-in-hand, from his perspective, is the age of majority in informed consent. As an associate professor of pediatrics and bioethics at the University of California, Davis School of Medicine, Kon has had experience with this situation.

“From an ethical perspective, what we look at in capacity for informed consent is people’s cognitive ability to understand the ramifications of the

decisions that they’re making and what’s being proposed — and some of these other issues,” Kon explains. “In fact, there are some people who are not yet at the age of majority who have that capacity, and then there are some people who are over the age of majority [who] do not have quite that capacity.”

For example, he provides the scenario of a teenager who is capable of making his or her own decision, but who was not yet at the age of majority.

“From an ethical perspective, it may be very appropriate to allow that person to make decisions for himself or herself,” he says. “From a legal perspective, that wouldn’t be legal. How one works in those types of situations can sometimes be a little difficult, because we have to look at both sides of the issue, and then clinicians need to make some decisions based on what makes the most sense to them.”

“Physician-assisted dying”

One of those examples is physician-assisted dying. Physician-assisted dying is now legal in three states — Oregon, Washington, and Montana.

“Now, from an ethical standpoint, that may not really comport with one’s own values or viewpoints — or it might,” Goodman-Crews notes.

“So, let’s say I live in California, and I want a physician to give me a lethal dose; while we may think we should be able to do that and that’s the right thing to do, in California, it happens to be illegal,” she explains.

While she notes that the fact that it is illegal ends the legal portion of the discussion, “then what you see — and this gets into really kind of frightening territory, where there are physicians, especially, I would say, hospice physicians, who almost on a daily or weekly basis are probably approached by patients or family members asking, ‘Please, can you do something?’”

That is a scenario that does occur, and while the physician has to respond to the patient’s request by saying that this action on his part would be illegal, that physician may not be aware that one practice that some patients follow is to stockpile pain medications to bring about their own death.

While physicians may, in fact, prescribe pain medication with the intention of reducing suffering, they cannot prescribe a lethal dose.

So, should that be considered patient autonomy?

“I guess it could be considered an act of autonomy, but what happens when the law prohibits [this]? One might say the final act of autonomy is

the taking of one's life. But the law prohibits you from doing that [with a physician's assistance]," she says.

If a hospice patient were to choose to overdose, the legal framework would dictate that the police be sent to the residence or site of death, where it would then be determined if this is a coroner's case. If it is determined to be a case for the coroner's office, the police may be suspicious that there was foul play involved in the overdose of the patient.

"Now, most of these patients are in a setting where they are dying or have grave disability, [but] they are really cases that are looked at case-by-case by the coroner's office," Goodman-Crews explains.

While she says she isn't sure how common this is, it is common enough such that Kaiser has had ethics cases centered around failed suicide attempts in such circumstances, i.e., where a patient tried unsuccessfully to end his or her own life.

If that patient already has a Do Not Resuscitate order (DNR), then that means don't put the patient on life support.

"But let's say they're coming in with an assisted suicide attempt; then it gets really confusing . . . so you have competing ethical obligations," Goodman-Crews says. "So, what are those obligations? Well, if a patient comes in with an attempted suicide, are we obligated to continue to respect their autonomy, in which case we might be aiding or helping the patient complete the attempt of suicide?"

In other words, if a patient has a DNR order, "is it ethically defensible to override their autonomy by treatment — [or] is it ethically required?" she says. ■

Hospital counsel: To serve on ethics committees?

Experts: institutions differ

At the University of California, Davis, the legal counsel and the ethics consultation services are "completely separated," according to Alexander A. Kon, MD, CM, FAAP, FCCM, who, among other appointments, serves as the director, clinical bioethics consultation service and chair, bioethics consultation committee.

"We view our functions as very separate, and so we keep it separate," Kon tells *Medical Ethics*

Advisor. "I will say, we have historically had lawyers and retired judges on our ethics committee — actually doing consultations — but they're not doing it as an active lawyer; they're doing it as a member of the committee. And we see that it's very helpful to have a very broad group looking at these issues.

And while these ethics committee members provide helpful information on legal issues, if there is a scenario with a patient that involves legal issues, the ethics committee seeks out the advice of the hospital legal counsel, he says.

Kon says that the committee has "good communication" with the hospital legal counsel, and periodically counsel will attend the ethics committee meetings, or Kon will attend meetings with legal counsel.

"There are other institutions where routinely, the legal counsel is a member of the ethics committee, and I think there are many different ways of doing it," Kon explains. "I think the benefit of having legal counsel on the ethics committee is it helps to ensure that the ethics consultants really know what the laws say about recommendations that they're making, so that if they're saying something that raises some legal questions, they're very aware of it."

But there can be a downside to the participation of legal counsel, he says.

"The downside is that sometimes it can potentially cause ethics consultants to start thinking that they know more about the law than they do know — and have a tendency then to give some legal advice, which is certainly a very bad idea . . . but we try very hard to make sure that ethic consultants are always aware that they are not there to give legal advice," Kon says.

Nancy M. P. King, JD, professor, department of social sciences and health policy, Wake Forest University School of Medicine, and co-director, WFU Center for Bioethics, Health and Society in Winston-Salem, NC, shares a similar sense related to hospital counsel serving on ethics committees.

"In my experience, it's usually considered not a good idea to have either people who are from the hospital legal office or from risk management serve on the ethics committee in their ex officio functions, because . . . their prioritization of their roles with respect to the hospital may detract or distract from [what] the ethics committee is trying to do," King says. "And that's very true."

However, she says that in her experience serving on ethics committees, she has served with "thoughtful lawyers and risk managers who

viewed their role on the ethics committee as not representing the institution, but as being an information conduit, helping the committee understand . . . what the relevant law was or what relevant hospital policy was — but not saying, ‘Oh, don’t do that, because it’s bad for the institution.’”

Kaiser’s **Paula Goodman-Crews**, MSW, LCSW, director of bioethics in San Diego and for the Southern California region for Kaiser, concurs. In her experience, she says, she has found that the best attorneys to sit on an ethics committee are those “who are not associated with hospital risk,” but, instead, may be academicians in the community. ■

Health care reform to have impact on ethics

Effects will be revealed over time

One health care lawyer suggests that there will be a phased implementation of the health care reform bill, the Patient Protection and Affordable Care Act, which was passed in March.

“I think that health care reform . . . has been structured so that some of the positives come upfront; for instance, in states where you can currently exclude somebody based on pre-existing conditions under certain conditions — that’s going to be eliminated almost immediately,” says **Alan Lambert**, MD, JD, sole practitioner in health care law in New York City.

“By contrast, some of the issues with respect to denial of certain types of coverage or the phase-in of taxes on luxury or high-benefit plans are phased in, or become effective, over a period of years,” he tells *Medical Ethics Advisor*.

Even though, according to Lambert, almost every poll showed that a majority of Americans are insured and “appear to be happy with their health insurance to a large extent,” the bill still passed.

“I think the issue that people are concerned about is that they would like to see other people insured, but they don’t necessarily want to see that at the expense of giving up their own health benefits,” he notes.

“Basically, the way that I see things evolving, starting with the electronic medical records, [is] the electronic medical records are going to be linked

in to connect data through health information exchanges. And so, for instance, hospitals in the New York area that are going to their medical staff and trying to integrate, through a particular type of software, records that can be accessed in the hospital and the office, to maximize the exchange of information for efficiency purposes,” Lambert says.

“But then, they’re going one level further, and what they’re doing is they’re going to be collecting what they’re identifying as patient safety and quality data, and they’re going to take this data and ultimately filter it up through committees that are going to be organized to look to develop what is called ‘best practices,’” Lambert explains.

Those best practices — not a new term in the health care arena — are going to determine what will be emphasized or prioritized in the delivery of medical care, he says.

“So, which diseases receive priority in terms of coverage for benefits, what types of medical care are considered cost-effective for treating the disorders, and so on . . . and basically, I think they may take a look, for instance, at certain categories of people — and not necessarily just outright deny care, but say that it’s not necessarily efficacious for particular people, let’s say, to receive a kidney transplant, or a liver transplant, or other type of procedure,” Lambert says.

Possible implications for ethics

Marc D. Hiller, DrPH, associate professor in the department of health, management and policy at the University of New Hampshire in Durham, NH, writes in an e-mail response that in the more immediate future, “passage of the health reform law could precipitate some elective and/or non-emergency services” to require a longer waiting period from the time an appointment is made to the actual time of service.

“However, it should not have a significant impact on rationing or not involve any denial [of] medically determined necessary medical care or surgery,” he notes.

Passage of health care reform “makes the topic of possibly greater relevance to physicians and hospitals, who may see a surge in new (or first-time) patients being able now to enter the system and claim medical care through venues other than the hospital emergency room (as was the major source for care for the uninsured in the past),” Hiller writes.

The surge might prompt more training of primary

care physicians and “other public health professionals involved in patient education and counseling, as was seen after the passage of Medicare and Medicaid in the mid-1960s,” he writes.

Hiller notes that from a public health perspective — and with more patients coming into the system, “it becomes more essential that more efforts be made — both by public health professionals and primary care providers — toward prevention. Prevention can be cost-effective and have a substantial impact [on] disease prevention that could result in lessening the need for added medical care visits, and equally — if not more important — in reducing the spread of communicable diseases among individual contacts and the public at large,” Hiller notes.

Hiller notes that for ethics committees, “reform may not produce major new issues beyond those associated with ensuring that institutional policies remain sensitive to assuring fairness (particularly amid increased patient populations) and respect for individuals (particularly with regard to confidentiality and privacy as traditional medical records increasingly are being converted to electronic formats and require more substantial safeguard and protections. . . .)”

It will also be important to maintain a commitment to informed consent with patients.

He notes that ethics committees may pursue “ways to enhance the completion of advance directives [for] patients, as compliance with this practice continues to remain lower than ideal.”

Hospital ethics committees might also, he writes, “develop and adopt medical futility policies to help assure that hospital resources are used most effectively in delivering needed and useful medical care.

“Also, depending on whether there are changes in reimbursement levels among the different health insurance options that might evolve, could conceivably lead to — in some cases — certain groups of patients [receiving] different levels of attention/services, i.e., in the same manner that some providers prefer privately insured patients vs. those of Medicaid,” Hiller writes.

He also notes that health care reform could potentially lead to physicians having even less time to spend with patients, due to a surge in the demand for services.

SOURCES

• **Marc D. Hiller**, DrPH of the Department of Health Management and Policy in the College of Health and Human Services at the University of New Hampshire, Durham, NH. E-mail: marc.hiller@unh.edu.

• **Alan Lambert**, MD, JD, sole practitioner, New York City. www.lamberthehealthlawyer.com. ■

Compassion & Choices in public ed effort

Campaign highlights assisted suicide ruling

In early April, Compassion & Choices President Barbara Coombs Lee said at a press conference to announce that “aid in dying” — more often referred to as assisted suicide — is being implemented in Montana following a Montana Supreme Court decision to allow it in late December. (See the February 2010 issue of *Medical Ethics Advisor* for the article on the Montana Supreme Court ruling, p. 17.)

The press event also, she said, marked the second phase of a public education effort under way by Compassion & Choices. The group also released results of public opinion polls conducted on this topic in the state.

“Our purpose, with this public education effort, is to prompt citizen awareness — to make the citizens of Montana aware that the Montana Supreme Court has granted them the right to ask for aid in dying — and also, to prompt citizen involvement,” Lee said.

There is a contrast between Oregon and Washington, the first and second states in the United States respectively to permit assisted suicide with a lethal dose of medication prescribed by a physician.

“Montana is different from Oregon,” Lee said. “The state that pioneered aid in dying had its citizens involved right from the beginning. It was passed by citizen initiative. Citizens knew about it, and they were invested in it; and they knew that this is what they wanted for themselves, right from the get-go.”

Lee noted that when the Oregon legislature sought to overturn that state’s Death with Dignity law, it was citizens who prevented their success in overturning the law.

“So, the citizens of Montana need to be aware, and the citizens of Montana will need to be involved in protecting this court ruling,” she said.

An earlier element of the public education effort was to run ads during the Winter Olympics in Vancouver. The group also published ads in newspapers in Helena, MT. Lee said there would also

be direct mailings.

“For younger people glued to electronic devices, there will be Internet banner announcements, and we will also have broadcast placements,” she said.

A goal of the press conference, held at the Montana Capitol Building, was to “assure people that the Montana Supreme Court ruling in Baxter [v. Montana] is being implemented,” she said.

“Doctors are learning about the ruling; they’re responding to their patients’ requests, according to the court’s guidelines and according to their personal, ethical, [and] moral position,” Lee explained. “Hospices and provider institutions are developing policies, and they are serving their patients, according to these policies.”

Lee described the “progress” in implementing the court ruling decision in Montana was similar to the progress that had been made shortly after laws came online in Oregon in 1997 and in Washington in 2008.

“It’s perfectly fine to begin conversations with your family, with your loved ones, and with your doctor about aid in dying,” she said.

She noted that in Montana, the court’s ruling indicated there would be no criminal prosecution of a physician who provides a lethal prescription for a patient to then ingest.

The ruling in Montana is different from Oregon in that it does not have complex regulations that physicians and patient must follow to legally pursue assisted suicide. However, Lee noted in a Q&A session that the Montana Supreme Court’s decision was “not without guidelines.”

That ruling “specified that this is for terminally ill people — or people who are likely to die within six months. It’s for mentally competent people — people who are fully decisionally capable. It’s for adults, and it’s for people who can self-administer the medication — it’s not that the doctor would be administering the medication,” Lee explained.

When asked how many people Compassion & Choices was aware of who had taken advantage of their right to assisted suicide, Lee said that she would only say “one or more.”

“I think out of concern — really quite an enormous concern for discretion and protecting people from what might turn into sort of vigorous investigation to try and discern who they might have been, I think that I would like to leave it to one or more patients have used the law and died by ingesting life-ending medication in Montana,” Lee said.

Voter opinion poll results

Two separate public opinion surveys were conducted in Montana by David Binder Research, based in San Francisco. Binder, who participated in a related teleconference of the event, said the first survey was conducted with voters between Jan. 20 and 24 with 600 voters statewide, following the Dec. 31 ruling.

After running ads during the Winter Olympics, the research firm conducted a second survey between March 3 and 5.

“So, in two separate surveys, we found very consistent findings, and those findings are consistent in the sense that they show strong support for end-of-life choices.

In the March survey, for example, Binder said the following question was put to voters who participated in the survey: “Recently, there’s been some discussion in the news about the issue of end-of-life choice. In general, do you support or oppose allowing dying patients in severe distress to make their own end-of-life choice to receive a prescription for life-ending medication?”

The survey found 60% of Montana voters said they support end-of-life choices, while 24% opposed.

“We also found that that figure did not significantly differ by political party affiliation,” Binder said. “There was more support from Democrats than Republicans, but Republicans also showed a majority support: 69% of Democrats; 53% of Republicans, and 61% of Independents.” ■

Helping parents of kids with leukemia

Program encourages families to ask questions

In the days after a child has been diagnosed with leukemia, parents often must wrestle with decisions about participation in clinical trials. It’s a busy and stressful period, as family members are still dealing with the trauma of the diagnosis.

To try to help families through this difficult time, researchers must not only get information to them in an understandable way, but without inconveniencing them as they deal with demands of their child’s clinical care.

Rebecca Hazen, PhD, a psychologist at Rainbow Babies and Children's Hospital in Cleveland, OH, says she noticed while working on studies that it was difficult to schedule with families to relay information to them.

"Sometimes it was hard to get parents to agree to sit down for an extra session with a nurse to go through this information," she says. "In some studies we had done, we had a pretty high participation rate, but we were finding there were a fair amount of people who said they just didn't have time for this."

So when her team developed an anticipatory guidance to help lead families through the informed consent process, they instead used a DVD presentation, which made it available for the family to review on their own time.

The guidance is not for a particular study, but seeks to explain to families what they should expect from informed consent in general. Hazen says the goal was not necessarily to increase participation — she says most children with leukemia end up participating in clinical trials — but to better prepare the parents for dealing with the informed consent process, and in turn improve understanding.

"We're really more interested in improving the process," she says. "It's more about making sure that they actually understand what they're agreeing to participate in."

Encouraging questions

Anticipatory guidance is a technique that also has been used in injury prevention and relaying child-rearing information to families. In this study, it consisted of a 20-minute video that educated parents about the goals of research and treatment, the principle of voluntary participation, confidentiality protections, the idea of randomization and other aspects of informed consent for a clinical trial.

"One of the big goals of this was to help them going in (to the informed consent) to be more active participants during the discussions," she says. "If we prepare them for what's going to happen, it's going to be easier for them to ask questions, to engage in more of a dialogue versus going in and not knowing what to expect ahead of time."

Throughout the video, Hazen says, parents are encouraged to take notes and ask questions. The DVD actually instructs parents to pause the video at various points and write down any questions they have.

"If parents are more engaged and they ask more questions, it leads to better understanding," she says. "So there was a big emphasis in the video on the fact that the physician wants you to ask questions. We wanted to really hammer home that point with them that we want you to be involved in the conversation."

The video features oncology physicians and nurses speaking directly to the camera about the consent process. In the video, parents are told that they can have the consent carried out in the place that is most convenient for them and to decide whom they would like to be present.

They're encouraged to ask for breaks, if needed, during the informed consent, or to ask the doctor to slow down or explain unfamiliar words. "If the doctor moves on to a topic before you are ready, you may want to stop and ask, 'Could you please go back to what you were talking about and tell me a little more?'" a nurse advises in the video.

Hazen's team tested the DVD intervention with a dozen parents at Children's Hospital of Pittsburgh whose children had been recently diagnosed with leukemia. After obtaining informed consent, participants watched the video on a portable DVD player in the child's room with a research assistant. Parents were given paper and pencils to write down questions. While the research assistants did not answer questions themselves, they referred parents to the informed consent conference.

At those later conferences, parents' questions were counted and compared to previous studies looking at communication during informed consent conferences.

The parents who viewed the video had a higher rate of questions during conferences than parents in previous studies. Most parents said the video made it easier for them to understand what the physician was telling them, to think of questions to ask and to feel more comfortable with asking questions.

Parents said they appreciated the brevity of the video, and a few reported watching it additional times with other family members.

The study turned up one unusual finding. While nine of the parents reported that watching the video either decreased their anxiety or had no effect on anxiety, three parents reported that their anxiety increased after watching it (two of them by "a little" and one by "a lot").

Hazen suspects that some people are temporarily made more anxious when they get more

information. Hazen's group theorizes that that anxiety would have occurred later anyway, when the information was presented during the informed consent conference.

Hazen says she'd like to try the intervention with a larger sample to get more data on this and other issues.

The video is available online to members of the Children's Oncology Group or others who might be interested in using it at: <https://members.childrensoncologygroup.org/DISC/bioethics/default.asp>

REFERENCE

Hazen, RA, Eder M, Drotar D, et al. A feasibility trial of a video intervention to improve informed consent for parents of children with leukemia. *Pediatr Blood Cancer* 2010; Jan 8:(Epub). ■



AHRQ issues quality, disparities reports

The Agency for Healthcare Research and Quality (AHRQ) on April 13 released the 2009 National Healthcare Quality Report and the National Healthcare Disparities Report, which are used by a variety of health care stakeholders to evaluate quality and access to care.

Lt. **Karen Ho**, lead staff at AHRQ, tells *Medical Ethics Advisor* the findings were fairly consistent with previous years; however, since the reports have only been published since 2003, it is difficult to detect trends in the data. The reports are mandated by Congress.

"Despite promising improvements in a few area of health care, we are not achieving the more substantial strikes that are needed to address persistent gaps in quality and access," said AHRQ Director Carolyn M. Clancy, MD, in an AHRQ news release. "Targeted AHRQ-funded research in Michigan has shown that infection rates of HAIs can be radically reduced. We are now working to

make sure that happens in all hospitals."

For example, rates of postoperative sepsis increased by 8%. And according to the press release, although rates are improving incrementally, blacks, Hispanics, Asians, and American Indians are less likely than whites to receive preventive antibiotics before surgery in a timely manner.

According to the press release, "Americans with no insurance are much more likely than those with private insurance to obtain recommended care, especially preventive services and management for diabetes. While differences between blacks and whites in the rate of lack of insurance have narrowed in the past decade, disparities related to ethnicity, income, and education remain large."

With the passage of health care reform, Ho tells *MEA* that with the increased or first-time access for millions of patients to health care services, there is an expectation that the data will improve once those patients are evaluated across the system in future reports. ■

Hastings Fellows selected for commission

The Hastings Center reported that Hastings Center Fellows Anita Allen, Christine Grady, and Daniel Sulmasy were appointed to President Barack Obama's Commission for the Study of Bioethical Issues.

Amy Gutmann, who was appointed chair of the commission in November, is also a Hastings Center fellow.

"With her pioneering scholarship on democratic deliberation and her great experience as a leader, Amy Gutmann is a brilliant choice as chair . . .," said Thomas H. Murray, president of The Hastings Center. "Anita Allen, Christine Grady, and Dan Sulmasy are eminent bioethics scholars who will be outstanding commissioners. At a time when the promises raised by emerging biotechnology and the public policy challenges posed by health reform make bioethics more relevant than ever, I am delighted that their voices will help guide public conversation."

According to The Hastings Center, the goal of the commission "will be to identify and promote policies and practices that ensure that scientific research, health care delivery, and technological

innovation are conducted in an ethically responsible manner.”

Gutmann is president of the University of Pennsylvania, among other appointments. Prior to her appointment as president in 2004, she served as provost at Princeton University.

Allen is the Henry R. Silverman professor of law and professor of philosophy at the University of Pennsylvania Law School. She also serves as deputy dean for academic affairs of the school and is senior fellow in the bioethics department, School of Medicine.

Grady is the acting chief of the department of bioethics at the National Institutes of Health Clinical Center. She is also a senior research fellow at the Kennedy Institute of Ethics and was elected as a fellow at the American Academy of Nursing.

Sulmasy, A Franciscan Friar, holds the Kilbride-Clinton Chair in Medicine and Ethics in the Department of Medicine and Divinity School and is associate director of the MacLean Center for Clinical Medical Ethics at the University of Chicago. ■

ID gov asks legislature to revisit bill

Compassion & Choices, an advocacy group for “aid in dying” at the end of life, reported in a press release that Idaho Gov. Butch Otter, in a March 29 letter to the Idaho Senate, encouraged the legislature to revisit a particular bill.

The bill will authorize health care workers to ignore the wishes of terminally ill patients, according to Compassion & Choices.

The group hailed the governor’s “concern for honoring decisions within living will and powers of attorney concerning end-of-life treatment.” However, the group, in the news release, expressed disappointment that the governor allowed the legislation to become law without signing it.

According to Compassion & Choices, S 1353 could “potentially affect end-of-life care by removing the patient’s own decision-making and putting the decision in the hands of health care professions, who, based on their own religious or moral beliefs, could choose — or choose not to — follow certain end-of-life directives determined by the patient.

In a March 24 news release, C&C President Barbara Coombs Lee said the bill would “protect

doctors, nurses, and other health care workers who refuse to treat pain and suffering of a dying patient, if they believe in the redemptive power of suffering.”

“If a professional’s faith dictates individuals should face death while conscious, they could refuse to provide the treatment known as ‘palliative sedation’ . . . ,” Lee said. ■

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

After reading each issue of Medical Ethics Advisor, you will be able to do the following:

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

COMING IN FUTURE MONTHS

■ The ethics of neuroimaging

■ Financial incentives for living organ donors

■ Advantages of the POLST form

■ Study shows psychiatrists Google their patients

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CME QUESTIONS

17. While there are situations where it appears that ethical decision-making is sometimes at odds with what is legally permissible, according to Nancy M.P. King, JD, co-director of the Center for Bioethics, Health and Society at Wake Forest University, very rarely do incompatibilities occur.

A. True

B. False

18. Which of the following scenarios is an example of situations where a concerted communication effort with patients and families is required?

A. Assisted suicide

B. Failed suicide attempts

C. Disagreements between advance directive orders by patients and/or surrogates and family members

D. All of the above

19. The consensus of experts interviewed by *Medical Ethics Advisor* is that it is generally not the best practice to have hospital counsel serve in their official capacity on hospital ethics committees.

A. True

B. False

20. What is the third state in the United States in which it has been determined that assisted suicide is permitted by law?

A. North Carolina

B. Illinois

C. Texas

D. Montana

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