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Academic centers provide education, resources to colleagues

An obligation to help community institutions

Smaller, community-based hospitals may face many of the same types of patient cases that require ethical decision-making; however, these hospitals often have fewer resources than large urban or academic centers with which to receive training in this area.

And that's where the academic centers — in certain cases — step in to provide education and resources for consultation, when necessary, for their smaller community colleagues.

Susan Tolle, MD, director of the Center for Ethics in Health Care at Oregon Health & Science University (OHSU) in Portland, OR, has referred to this large academic center as the “mother ship for smaller hospitals” in that state, since it is the only health sciences center in the state of Oregon.

She has noted that the those who do serve on ethics committees at smaller hospitals would not otherwise have “the time or ability to pursue additional training, and so we attempt to help them by providing policy and helping on some of their cases.”

In 2009, OHSU won the National Circle of Life Award for “exactly this” type of effort to train and educate smaller hospitals and other institutions, Tolle says.

“It really emphasized the fact that we do make this a very high priority to reach out to our colleagues at smaller hospitals, long-term care facilities, [and] hospice programs all over Oregon,” Tolle tells *Medical Ethics Advisor*.

Likewise, some 20 years ago, Atlanta's Emory University Center for Ethics, headed by the center's current associate director, Kathy Kinlaw, used a small grant to parlay that grant into what is now known as the Health Care Ethics Consortium of Georgia (HCECG).

Today, HCECG has about 50 member organizations, including larger hospitals, community hospitals, nursing homes, and hospice organizations, as well as some individuals who are not affiliated with a particular institution but are interested in health care ethics, Karen Trotochaud,

MN, MA, assistant director for the HCECG and senior program associate for the Center for Ethics, tells *MEA*.

Tolle explains that in order to provide the services that OHSU offers to its statewide colleagues in ethics, she is required to fund-raise.

Trotochaud says that Emory charges modest fees to its member organizations for its workshops and other programming, but HCECG is also supported by the Emory University Center for Ethics.

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EDITORIAL QUESTIONS

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Structured training

In June, OHSU's Center for Ethics and Health Care will hold a statewide conference at the convention center in Portland to offer training to colleagues at smaller institutions, and about 500 people typically attend, Tolle says. The focus of the conference is palliative care.

"Last year, they represented 52 cities," she notes. "That means you're reaching pretty small cities in Oregon . . . we're down to towns of 5,000 who are coming." It is a day spent partnering with the smaller institutions and to address whatever policy questions "might be troubling them the most," Tolle explains.

"Our goal is not that they keep needing us, but that we strengthen that region, so that they are better able to partner with others to honor the talent they do have," Tolle says, noting that such individuals "may have significant contributions that they can make in their region."

Tolle says it is "not unusual" for OHSU to conduct a conference in a different region of the state that partners with smaller hospitals in the area. Often, if the area is remote, there may be only one hospital serving it, she says.

At the local conferences, a local person always chairs the event, Tolle says, even if OHSU assists that person with his or her presentation. Those local conferences are co-chaired by an individual trained specifically in bioethics from OHSU.

The community individuals who attend the OHSU conferences are referred to as "change agents, because they are people who are our partners around the state," Tolle says. There is a "recruitment for change agents that's a mutual agreement, just as we invite people in the community to be chair of a [local] conference."

At the conferences, OHSU staff will assist with whatever policy concerns the community hospital or other institution has, as well as meet with its ethics committee, if those community members are interested.

"So, then, we would meet with the ethics committee and walk them through the policies [and] adapt it to their facility," Tolle says. "Being a smaller facility, there might be just some logistical adaptations of how it was handled . . . and we teach them enough about the policy so that they can then do their own education about the policy."

The consortium organized by Emory's Center for Ethics was originally known as the Georgia Ethics Committee Consortium. Emory, when first

forming the consortium, “broadly invited provider organizations to join what we refer to as the consortium. And if they joined, what they would get in return was educational programming, access to those at the Center for Ethics with expertise in health care ethics, as well as the ability to network with other providers who were interested in health care ethics,” Trotochaud says.

At its beginnings, there were a large number of member organizations, she says, “but the health care environment has changed in the last 20 years a great deal; many organizations merged and closed, and we’ve had lots of changes in the way health care has been provided.”

Emory Center for Ethics programming

When an institution joins the HCECG, each employee of that institution is considered a member, she explains, so any individual within an organization can benefit from the Emory University Center for Ethics programming, Trotochaud tells *MEA*.

Emory typically has three or more workshop-type programs a year, plus one two-day conference.

“Our smaller programming is usually focused on the more nitty-gritty,” Trotochaud says.

For about the past five years, the Center for Ethics has held an annual program that it calls the Ethics Committee Workshop, which typically has anywhere from 30 to 50 attendees. That workshop covers such topic as the history of ethics committees, for example.

“We talk about some of the moral theories and principles that are important in looking at ethical questions in health care; and we talk about how ethics committee are organized,” Trotochaud notes. “There are a lot of different ways they’re organized, but we give them some of the usual ways they’re organized.”

The most sought-after information at these gatherings is typically information about ethics case consultations. The basic workshop is only five and a half hours, she says. So, the Center for Ethics offered a second workshop this past year that only focused on case consultation.

Trotochaud says Emory’s Center for Ethics staff are also available to all member organizations for consultation, if the smaller institution concludes that other perspectives are necessary.

Trotochaud says the center get calls from its member organizations often, fielding requests for help in thinking through various situations and potential next steps, as well as sometimes discuss-

ing problems within their individual organizations.

Dilemmas similar at all sizes of institutions?

Those interviewed by *MEA* suggested that problems are fairly similar at all levels of institutions, with the exception of certain services that might create their own dilemma, such as organ transplantation services, which involves scarce resources.

“I would argue that the questions are very similar: disclosure of medical errors — [small facilities] have the problem too; respect for conscientious objection — they have the problem, too; but the way it plays out in process when you are so intimate with each other” is very different, Tolle notes.

Tolle suggests a high level of sensitivity in communicating with colleagues in smaller communities.

“How you handle disagreements and conflicts has to be so much more sensitive with your fellow health care professionals,” Tolle says. “And it means that someone coming in [from] outside to help you can be, for example, the bad guy [who is] suggesting something that would be hard to bring forward in your community.”

In a small community, the practice of saving face is also very important, she says, noting that as smaller facilities implement new policies or procedures related to ethics, one must be “particularly sensitive to how the health care professional will be treated and respected — and not embarrassed in the process of your implementation.”

SOURCES

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Flagler ethics committee focuses on self-training

Approach relies on case “work-ups”

Flagler Hospital - St. Augustine on Florida’s east coast may offer practices or lessons for other

mid-size to smaller community hospitals.

After serving on the ethics committee for Flagler Hospital – St. Augustine, FL, for several years, **Michael C. Sanders, MD**, a solo practitioner, was asked to chair that committee for the hospital about five years ago at this mid-size hospital.

“And I said, ‘Only if I can run it the way it needs to be run,’” Sanders tells *Medical Ethics Advisor*.

Since then, he has recruited 16 members for the hospital ethics committee, about half of whom are physicians, with other members including an attorney, a minister, staff nurses, social workers, community members, and two members trained in bioethics.

The previous structure for the committee comprised about five or six members, who routinely focused on the facts of a particular case before sharing opinions on that case.

“There was no formal ethics training, nor was there any evaluation,” Sanders recalls. “So, one of the things that I said we needed to do was not only have an ethics committee, but when they were appointed, it had to be for a minimum of five years; otherwise, you get someone trained, and they rotate off and you’ve lost [that training and knowledge].”

As a training/education tool, Sanders selected a book titled “Clinical Ethics,” which includes an ethical case workup for each case that comes before the committee. The workup was originally called the “four boxes method.” In the last volume, it was referred to as the “four topics method,” he says, noting that this process “essentially breaks every case down to the medical indications, patient preferences, quality of life, and contextual features.”

Sometimes, different members of the ethics committee are charged with working up a particular topic, and then they meet as a committee.

“If it’s a pressing case, we may do it at the same meeting,” Sanders says, noting that while the committee has discussed bringing in outside speakers on ethics topics, it generally fares much better by working through the four topics methodology from the book.

Also, each formal, documented case is filed in the medical staff office for “the committee itself to refer back to when there may be a similar case or similar problems. We’re building, really, a case file of the problems that we’ve encountered,” he explains.

Another accomplishment by the committee is

the development of an operating manual for the ethics committee itself, i.e., its policies and procedures.

“We [formalized] not only the way in which we go through these cases, but we really established an institutional policy . . . for Flagler Hospital,” he says. The manual is between 120-130 pages.

Once the institutional ethics policy was developed, the ethics committee presented it to the medical staff, who approved it. At that point, the policy was put online, so hospital employees can reference it, when needed.

“We simply use that as reference, and nurses in the hospital, physicians in the hospital, ancillary staff can refer to that manual and know, how do I get a referral, and what do we do, what is it that you are looking for, how does it work, what kinds of things we should bring to the ethics committee, and what does the ethics committee really do,” Sanders explains.

Sanders emphasizes that by presenting cases in general staff meetings, he is able to educate the staff about what the ethics committee does, “so people know how the system works [and that] we’re not just sitting in a room and saying, ‘Well, that sounds like a good idea.’” “But we actually go back to published literature from the 1700s on ethical reasoning and try to have people understand, one, what are the principles of bioethics, what is the principle of double-effect, and how does that happen, because it comes up very frequently in medicine,” he says.

Simple cases, complicated questions

Sander notes that he disagrees with any suggestion that smaller hospitals — Flagler Hospital – St. Augustine has about 300 beds — lack the complex cases that a larger, urban hospital might have.

“I would disagree with the logic,” he says. “I’ve certainly heard that before, but most of the time, the ethical issues and dilemmas are not necessarily associated with complicated cases. So, I would suggest that even small, community hospitals of 100 beds or less are going to run into the same problems we do.”

Sometimes, he says, complicated medical cases can actually be quite simple from an ethical perspective.

Sanders provides an example of a man who had tried to commit suicide presenting to a small emergency department (ED). The ED physician inserted

a nasogastric tube to pump that patient's stomach, but the patient began objecting, saying, "No, I don't want this done."

"How do you approach that? That problem can exist in any size hospital, and it's a problem that needs to be dealt with immediately, which is why we have an emergency consultation service for the hospital, so that if something happens, we can do the consults immediately," Sanders says.

Emergency consults conducted

When there is an emergency situation, members of the ethics committee respond, if an ethics consult is needed. That group typically includes Sanders, as the chair, or the vice chair, as well as two or three other members of the ethics committee.

"We'll go to the emergency room; we'll gather the facts; we'll talk to the attending; we'll talk to the patient or the family and try to put the case together and decide whether or not this really is an ethical problem, if it needs a full committee review — and if it does, we'll hold a meeting right then," Sanders explains.

Otherwise, if it turns out to be a misunderstanding, Sanders or the vice chair and the rest of the team explain what they think the problems are — and why this particular case does not present an ethical issue.

"If that's acceptable to the patient or the family or the physician, then the team that's gone to do the [emergency consult] will write up this problem, and at the regular committee meeting, they will present the case," Sanders says.

Continuous learning is critical

Learning from previous experiences is the most important aspect, says Sanders, describing himself as "an Edward Deming guy."

Deming in the 1950s developed Continuous Quality Improvement, a business process approach he took to Japan after it was shunned in the United States, and "the rest is history," as Sanders says.

REFERENCE

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SOURCE

Michael C. Sanders, MD, Solo Physician Practice and Chair

of the Flagler Hospital – St. Augustine Ethics Committee. St. Augustine, FL. E-mail: mikesandersmd@bellsouth.net. ■

Oregon POLST registry Secures 18,000 forms

Data is at 5 months post-launch

A registry that serves as a collection point for Physician Orders for Life-Sustaining Treatment — known as POLST forms — has collected forms from about 18,000 people in Oregon since the registry went live Dec. 3, 2009, according to **Susan Tolle**, MD, director of the Center for Ethics in Health Care at Oregon Health & Science University (OHSU) in Portland, OR, and who leads registry educational efforts.

According to OHSU, the POLST Program was established in 1990 to help ensure people with serious illness have their wishes for medical treatment met if they are incapacitated. The POLST form, which is pink, must be completed by a physician, nurse practitioner, or physician assistant, based on patient treatment preference.

An OHSU news release explains that the form provides specific medical instructions to health care professionals at a time when the patient cannot speak for himself or herself. However, in times of crisis — in emergency situations — that information was not immediately available to emergency medical personnel.

The new registry, which is voluntary, changes that and makes medical treatment preferences available to emergency personnel on a 24/7 basis. Also, the registry, which OHSU says is the first of its kind in the nation, was established through the OHSU Department of Emergency Medicine under the auspices of the new Oregon Health Authority, which was established through Oregon's health reform bill passed by the legislature in June of last year.

"Other people have created freestanding advance directive programs, and they tend not to have the kind of impact people would hope to be used at nearly the rate our registry is being used," Tolle tells *Medical Ethics Advisor*. "They tend to need a PIN number, which is something only the individual has, to get in and access the data," and there is no search function using other demographic information.

For example, if EMTs in Oregon don't have the identification number for a patient, they can search for their POLST form using other demographic information, which can be an address or a primary care provider. "That process takes on average 1 minute and 7 seconds to provide this information as a computer match — to collect the parts, where we're not just scanning the document in," Tolle notes.

While many other registries are available in the United States, Tolle suggests they work "more like a safety deposit box." One aspect of the program that has worked well is that, like the color of the form itself, people who register are given a bright pink business-sized card with a magnet, which they can then keep with them at all times, if they choose.

"They're not inside health care," she says. "Our registry lives inside the statewide trauma system, so if you wanted to transfer a patient who was a Level 1 trauma patient, you would call [a particular] phone number as an EMT, and it's a number you already know."

This most recent effort is actually an expansion of an existing 24/7 registry that allows for patient form searches if the ID number for that patient's form is not readily available. It cost about \$150,000 to design the computer programming.

Tolle notes that the type of emergency medical system a state has would influence how it set up the registry, so Oregon's model might have to be adapted in certain states, because every state is different.

"California is by county; we are statewide; all of those things would matter in setting up [a registry]," she says. "But people start talking about a national registry; that won't work. This is something that needs to be on the speed dial of your EMT, and it's not something that's outside the health care system."

A philanthropic model

The OHSU ethics center uses a philanthropic model "with every effort to contain conflict of interest," Tolle says.

"Everything that the ethics center does, and all of my time, are completely supported by private philanthropy, so I fund-raise to be able to do this, is the bottom line," she says. "And we do not accept gifts from [health care] industry [sources] and never have."

For example, Tolle has an endowed chair, to

which 330 people donated money to fund, she says, even though the position bears an individual's name.

"So, our ethics center represents the people of our region, mostly Oregon — a little bit southwest Washington," she says. "And we are happy to give away what we create and learn, and we are, of course, rolling out the POLST program all over the country now."

"I would argue the Oregon public is more sophisticated about end-of-life options than the public in any other state," Tolle notes. "We are a part of that; we are not the whole reason. But once you reach a certain tipping point, POLST, advance care planning, [and] hospice become the norm."

She also notes that by the way everything is structured — "we will fight for you either way. You want everything at the end of life; you want some things and not others [for care]; you want more extensive limits; if you understand and are informed about what your choices are, we will fight that you have what you want."

SOURCE

Susan Tolle, MD, Director of the Center for Ethics in Health Care at Oregon Health & Science University in Portland, OR. To learn more about the Oregon POLST Program and the new POLST registry, visit www.polst.org. ■

Reciprocal responsibilities of patients and proxies

Lessons for advance care planning

A study of the roles and responsibilities of patients and their proxies has implications today for hospital ethics committees and associated consult services, particularly with regard to the weight given to the voice of the proxy, according to "Contracts, Covenants and Advance Care Planning: An Empirical Study of the Moral Obligations of Patient and Proxy."¹

In an effort to "better understand the moral obligations of the patient-proxy relationship," researchers at Weill Medical College of Cornell University and others surveyed patient-proxy pairs, in addition to individuals "who had acted as proxies for someone who had died."¹

The resulting paper, published in 2005 in the *Journal of Pain and Symptom Management*,

assessed “whether respondents believed that proxies should follow explicit instructions regarding life-sustaining therapy and act contractually or whether more discretionary or covenantal judgments were ethically permissible.”¹

What the researchers found in the statistically significant data was that the use of “interpretive or covenantal judgment was desired by patients and proxies when the prognosis was grim, even if initial instructions were to pursue more aggressive care,” according to the study abstract. “Nonetheless, there was a valence effect: patients and proxies intended that instructions to be left alone be heeded.”

According to the study, the researchers’ data “indicate that the patient-proxy relationship exists on a contractual to covenantal continuum and that variables such as disease trajectory, the clarity of prognosis, instructional valence, and the quality of patient instructions result in statistically significant differences in response.”

“I think what [the study] does is it helps us understand that we should give equal weight to people’s choice as representatives,” says **Joseph J. Fins**, MD, FACP, division chief, medical ethics, at Weill Medical College of Cornell University in New York City. “We’ve taught a generation of people to focus really on substantive preferences . . . as to what they want, and sometimes what they say they want is somewhat cryptic. I think we need to balance that against . . . what I call the procedural moral authority of [the] person chosen to represent you.”

Contradictions exist

However, “under prevailing ethical and legal norms, the surrogate, if called upon, is obligated to follow the wishes expressed by the patient while competent. In lieu of explicit preferences, the surrogate is expected to invoke the substituted judgment or best interest standards. In this moral hierarchy, the discretionary judgments of a surrogate under the guise of either substituted judgment or best interests are viewed as inferior to following the articulated preferences of the patient.”¹

But, the study authors suggest in the introduction, “if the act of being chosen is [at] least as important as the articulation of preferences, then the proxy has two sources of moral authority. One is substantive, what he or she knows of the patient’s wishes. The other is procedural, which stems from the act of being chosen.”

“So, the fact that one has been chosen out of the 6 billion people on the planet,” Fins tells *Medical Ethics Advisor*, “to me and through this research, confers a degree of moral authority that is different than if you hadn’t been chosen, and gives people some discretion to use that ‘chosenness’ as a way of interpreting the situation, weighing both the context of the situation and the prior wishes.”

Negative right stronger

In the study, there was, according to Fins, what is termed a “valence effect.”

Patient in this study included 50 patient-proxy pairs and 52 individuals who had previously acted as proxies for someone who had died.

“Because patients in this study wanted their chosen persons, their proxies, to use their — what I call discretionary moral authority — to make judgments, especially in situations where the prior instruction was to do everything no matter what, in the face of a dire prognosis, it was suggested that patients wanted their proxies to make more proportionate choices.

However, Fins notes, “there was a valence effect that when the patient said ‘no,’ — no means no — and no wasn’t open to interpretation. So, if somebody said, ‘I don’t want to receive aggressive care,’ patients in the study weren’t hoping for their proxies to countermand the negative right to be left alone.”

The study results suggest that the proxy should be allowed to “interpret the evolving prognosis — to be informed by the prognosis. But I think it also shows the importance of the negative right being stronger than the positive entitlement; the negative right to be left alone is stronger than the entitlement to have something done to you,” Fins explains.

Other conclusions

One conclusion that Fins draws from the research findings is that health care providers and the health care team “have to appreciate the burden imposed on the proxy, or health care agent, who has been chosen, and the responsibility of the patient and the health care team to make sure that they’re prepared for this obligation — that they understand the patient in his or her depth and what his or her wishes are in order to represent them.”

Fins says he thinks another important point

that the study findings suggest is that, “in the various scenarios . . . the patient always knew their mind better than the proxy did. There was more certainty in the choice — the patient had a more extreme view, as it were, to the contract or covenant side of the equation than the proxy did.”

For that reason, “it obligates us to share our thoughts and feelings with our chosen proxies, because . . . at the very moment that the health care proxy’s authority goes into effect, the one person they’re most going to want to speak to is unable to speak for herself,” says Fins.

“The real import here is this notion of covenant . . . that there’s a reciprocity, that we have a covenant with each other and responsibilities to each other,” Fins explains. “[Just] as I have a responsibility to speak for you, when you cannot speak for yourself . . . the reciprocal responsibility is the patient has a responsibility to the proxy, while he can speak, to give a kind of moral guidance.”

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SOURCE

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Social networking: An ethical hazard?

Is searching for online patient information ethical?

Online social networking sites have fans ranging from the very young to the very old. Some physicians, including psychiatrists, are not immune to a curious peek into the lives of their patients — or at least what they can find online — but is that a line that should be crossed in the physician-patient relationship?

Two recent articles explore that topic, one in the *Journal of Medical Ethics* in 2009, and the second, focused primarily on psychiatrists, in the *Harvard Review of Psychiatry* earlier this year.^{1,2} David

H. Brendel, MD, PhD, a physician at McLean Hospital in Belmont, MA, where he is assistant professor of psychiatry and assistant medical director of The Pavilion, as well as co-chair of the McLean Institutional Review Board, was a co-author on each of these published papers.

The second article, focusing on psychiatrists, is titled “Patient-Targeted Googling: The Ethics of Searching Online for Patient Information.” The study notes that attention has been given in previous literature to such topics as the “pros and cons of online searches for information regarding diagnosis, treatment and research”; patients’ searches online for health information, as well as patients’ searches to learn information about their own physicians “both professional or personal.”

The authors write that “little consideration has been given, however, to the converse situation — namely, to physicians’ searching online for information about patients.

“We believe that this practice — which we call patient-targeted Googling (PTG) — is widespread and deserving of professional and ethical consideration,” the authors write.²

“I think before our paper, it had not received any consideration. I am not aware of any papers in the medical or psychiatric literature that actually addressed the question,” Brendel tells *Medical Ethics Advisor*.

Relying on informal surveys and observations with colleagues, the authors found that “most psychiatrists have engaged in PTG,” something that crosses a broad range of practice settings, including “emergency rooms, inpatient units, and long-term outpatient psychotherapy relationships.”

By searching online, the paper indicates, physicians potentially have access to a broad range of “personal information about patients: photographs, videos, news stories, criminal records, and details of substance use, intimate relationships, sexual activity, and finances.”

But the authors also point out that “content may also include clinically important material, such as suicide plans.”

The important question may come down to: What is the motivation for the online search by the physician?

Motives must be checked

“There’s a wide range of things that may be driving [PTG]; those . . . come out in the concerns

we developed,” Brendel tells *MEA*. “On the one hand, people are looking for more information,” which he notes could be considered praiseworthy and an ethical thing to do.

“It’s information that’s in the public domain, and it could be really helpful to the treatment to obtain that information,” he says. “On the other hand, there are situations that we are aware of where it seems to be driven more by curiosity or voyeurism. And sometimes, it’s a combination of both things — there’s both a voyeuristic interest, but there’s information that may help with the treatment.”

Brendel says that the researchers “tried to focus on different aspects of the moral psychology [as to] whether to search for information online, and again, to develop some guidelines, which really don’t provide an answer as to whether you should or should not Google a particular patient.

While Brendel says that “the emotional dynamics within the patient-psychiatrist relationship are often intense . . . in any doctor-patient relationship, the concern, I think, could be there.”

Harm to patient-physician relationship?

Brendel explains why there may be a downside to PTG, especially as it relates to a psychiatric physician-patient relationship.

“I think there are a couple of different things,” Brendel says. “First of all, the patient may feel that it was intrusive or a breach of privacy, if the physician obtains information online and either intentionally or unwittingly reveals that information to the patient.

“The patient [might] say, ‘Well, how do you know that? I didn’t tell you that!’ And then you may be forced to tell the patient, ‘Well, I was doing a Google search. And then the patient may [say], ‘Well, who told you you could do a Google search? I didn’t give you permission.’ So, it feels like a violation of respect for privacy in this relationship,” Brendel explains.

If the physician found out something about the patient in the course of his or her PTG that was negative, “it could feel like a breach of privacy to the patient and lead to medical/legal questions about documentation in the medical record,” Brendel suggests.

This could be helped by physicians — psychiatrists or other physicians — employing the guidelines outlined in each of the papers, Brendel says.

Potential benefits of PTG

As an example of how PTG could benefit the treatment of a patient, Brendel uses an emergency room scenario. He suggests that in some cases it may be life-saving to get additional information about a patient who may be unconscious, if “you can learn something about where the patient lives, family members, or friends that might be able to assist in medical decision-making.

“In that case, patient Googling might be ethically obligatory,” Brendel says. “Regardless of the setting and regardless of the medical specialty, the considerations are very context-dependent, and very much involve the moral psychology of the physician.”

“Physicians need to be self-reflective about what’s driving the search,” he says.

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SOURCE

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NEWS FROM ABROAD

UK bioethics council considers organ donation

Unmet demand for organs, tissues prompts research

The Nuffield Council on Bioethics in London has set up what that organization terms a working party to study the issue of whether the UK can ethically increase organ or tissue donation by offering incentives.

The council is looking at associated issues with whole organs, blood, skin, corneas, bone, sperm, eggs and embryos, as well as clinical trials designed to test the safety of new medications in humans for the first time.

“There isn’t one sort of obvious event that’s been a trigger [for the research],” **Katharine Wright**, assistant director of the council and the leader of this particular project, tells *Medical Ethics Advisor*. “I think it’s been more of a growing awareness that there’s a real demand for bodily material in the UK and elsewhere. . . and demand massively exceeds supply. And the obvious response to that tends to be, what can we do to maximize supply? What we felt would be really helpful would be to take a step back and think about how we should respond to demand, say, are there ethical limits on what we should do in encouraging people [to donate]? And obviously, the questions there arise around if [organs or tissues are] won by paying people, should one do it, or are there ethical reasons for not doing that?”

Like many developed and wealthier countries, there is also the issue of “transplant tourism,” i.e., British citizens in need of a transplant going to lesser-developed countries to find organs.

“It is known that it does go on, but [the evidence] tends to be very anecdotal,” Wright says.

According to a release from the council, the current system of organ donation in the UK relies on people donating to help a loved one or society as a whole, i.e., as an expression of altruism. The council indicates that the National Health Service (NHS) “has been working to increase organ donation by improving transplant infrastructure and encouraging people to sign the organ donor register.”

The council also notes that about 8,000 people are waiting for an organ transplant in the UK, and there is also a demand for “roughly 1,200 more egg donors and 500 more sperm donors. Scientists also need people to donate human tissue for research.”

“We ourselves or one of our relatives may one day need donated organs or tissues, and most of us are likely at some point to use NHS medicines that have been tested on healthy volunteers or human tissue. Given this, perhaps donating parts of our bodies should be seen as a moral obligation for all of us,” said Professor Dame **Marilyn Strathern**, chair of the working party and professor of social anthropology at Cambridge University, according to the news release.

The working party was convened in January. In

addition to being led by Strathern, a wide range of expertise is represented via other members, including experts on organ transplantation, law, health psychology, tissue research, and ethics, among other specialties.

“The council as a whole identifies what it thinks is an important ethical issue, where it can make a difference,” Wright tells *MEA*. “And I think making a difference is an important thing to emphasize, because we don’t want to produce academic reports, or we don’t want to duplicate other people’s work; we want to find something where there’s a real question, and where we can make useful policy recommendations.”

Some incentive inequalities exist in UK

One of the things that interested the council in taking up this project, Wright says, is that in the UK, “there’s a very strong tradition of altruism, with a sense that money somehow sort of muddies the waters, and that financial incentives aren’t right.”

And there are variances in how certain types of donations are incented vs. other types of donations in the UK, she explains.

“So, you have blood donation that’s always being done altruistically; you have donation of organs after death, which is altruistic, and you have donations of organs during life, which would mainly be someone you know, although for the last couple of years, there have been a few examples of people giving an organ to a stranger, in the same way that they would give blood,” Wright explains.

Individuals in the UK who are living organ donors can have their expenses reimbursed; for example, if they have to take time off from work, they will be reimbursed for that absence.

“It’s not an incentive; it’s simply making them not worse off,” Wright says. “Now, there are contrasts, because if you’re donating eggs or sperm, you can’t have a financial incentive; you just have your expenses covered. But if you share your eggs and are undergoing IVF treatment, you can opt to share those eggs and have reduced price or even free treatment, which is obviously not money in hand, but it has significant financial value.”

Wright also points out that it’s always been the case in the UK that individuals who are “lending or giving over their bodies, as it were,” to test new medicines have been paid.

“It’s interesting to explore — if that’s different,

why is it different,” she says. “One of the points in our consultation paper is: Do people feel that difference can be justified? And that’s how regulation develops. Or, is it possible we can identify an ethical basis of why actually money in that case is appropriate, and money in other cases isn’t?”

The working party’s findings, including policy recommendations, will be published in the autumn of 2011. In the meantime, the Nuffield Council on Bioethics is accepting public comment on its consultation paper through July 13. That paper can be accessed at www.nuffieldbioethics.org/bodies.

SOURCE

Katherine Wright, Assistant Director of the Nuffield Council on Bioethics, London, UK. www.nuffieldbioethics.org. ■



NQF endorses measures in psychiatric care

The National Quality Forum (NQF) has endorsed two inpatient psychiatric measures focused on quality improvement in psychiatric hospitals and general hospitals with psychiatric units.

The endorsed measures address the use of restraints and seclusion and complement psychiatric medication management measures recently endorsed by NQF, which is based in Washington, DC.

The goal of both measures is to reduce use of restraints and seclusion, the NQF steering committee noted in its deliberations on the matter. The endorsed standards measure the total number of hours all patients admitted to a psychiatric setting were held in seclusion and the total number of hours physical restraints were used.

An estimated 57.7 people suffer from a diagnosable mental disorder each year in the United States, including 4.5 million who suffer from a serious mental illness like schizophrenia or severe bipolar disorder. Many receive treatment in a psychiatric hospital or the psychiatric unit of a general hospital during an acute episode.

The steering committee was co-chaired by Bruce A. Boissonault, president and CEO of the Niagara Health Quality Coalition and Frank Opelka, vice chancellor of clinical affairs at Louisiana State University.

NQF is a voluntary consensus standards-setting organization. ■

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

■ NHPCO releases statement, commentary on palliative sedation

■ Financial incentives for living organ donors

■ The ethics of neuroimaging

■ HHS and conscience clauses

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CME QUESTIONS

21. Under the expansion of the POLST Registry in the state of Oregon, EMTs can access participating patients' medical care directives on a 24/7 basis, using an individual ID.
A. True
B. False
22. Which institution won the National Circle of Life Award for helping to educate colleagues in medical ethics at smaller, community hospitals?
A. Emory University
B. Oregon Health & Science University
C. Flagler Hospital-St. Augustine
D. None of the above
23. The responsibilities of patients and proxies are not reciprocal, according to Joseph J. Fins, MD, FACP, division chief of medical ethics at New York-Presbyterian Hospital in New York City.
A. True
B. False
24. Patient-Targeted Googling (PTG) is not something that psychiatrists are known to engage in.
A. True
B. False

Answers: 21. A; 22. B; 23. B; 24. B.