

MEDICAL ETHICS ADVISOR®

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August 2010: Vol. 26, No. 8
Pages 85-96

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Paternalism: Does it still have a place in modern medical practice?

"The paternalistic model assumes that there are shared objective criteria for determining what is best. Hence the physician can discern what is in the patient's best interest with limited patient participation . . . the physician acts as the patient's guardian, articulating and implementing what is best for the patient...The conception of patient autonomy is patient assent, either at the time or later, to the physician's determinations of what is best." "Four Models of the Physician-Patient Relationship." JAMA. April 22/29, 1992 — Vol 267, No. 16.¹

While some suggest that paternalism is part of a bygone era, a label with a negative connotation harkening back to a time when many physicians thought it appropriate, for example, not to burden their patients with a cancer diagnosis, others think some aspects of this model of the physician-patient relationship still have merit in today's practice of medicine.

This model of the physician-patient relationship is sometimes called the "parental or priestly model."¹

"The term 'paternalism' has, I think, been forever sullied to such an extent that it's never going to be put forth as an ideal. And strong paternalism — what has been described as strong paternalism — which is doing things to patients without their consent and without regard to their wishes — is, I think, properly discarded," says Farr Curlin, MD, associate professor of medicine at the Pritzker School of Medicine, University of Chicago.

"But paternalism in the more limited sense of relating to the patient as one who makes it his responsibility to care for the patient, according to one's own judgment, will always be alive, because it is a necessary component of good clinical practice. So, it is never going to be sufficient, and I think there is a growing appreciation for this across the board . . . to suggest that a good physician merely presents options to patients and provides them technically competent health care services," Curlin says.

"That's never going to be sufficient," he notes, "in part because



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patients are not like other consumers; they are, by virtue of being sick, or having their health threatened, they need someone to care for them — not just to provide them with what they think they might want.”

Others think paternalism is more appropriate to a bygone era of medicine, and that the word has a decidedly negative connotation today. Still, its vestiges may be alive and well, in some of its aspects of seeking to care for and protect the patient.

“Well, I don’t think anybody will admit to

[paternalism], but I think physicians and how they approach their patients in terms of their decision-making fall along a continuum, and I suspect some are more towards the shared decision-making, equal-level-with-the patient end of the spectrum, and others might be more, ‘I’m in charge,’” says Joseph A. Carrese, MD, MPH, associate professor of medicine at Johns Hopkins School of Medicine in Baltimore; chair of the ethics committee at Johns Hopkins Bayview Medical Center; and a core faculty member of the Johns Hopkins Berman Institute of Bioethics.

Carrese notes that “as recently as 50 to 60 years ago, doctors’ approach to their relationship with patients was very much one of doctors were in control and doctors limited the amount of information they gave patients in order to limit the patient’s role in the decision-making process. It was very much one-sided, and that’s what we’re referring to — that’s what we have in mind — when we think of the term, ‘paternalism,’ [i.e.,] that it’s very much doctor-centered and doctors in control,” Carrese explains.

With the paternalistic model, the physician still has obligations to the patient, “including that of placing the patient’s interest above his or her own and soliciting the views of others when lacking adequate knowledge.¹

Selecting relevant information

One of the challenges in communicating with a patient is knowing how much information to share with him or her — and how much might be simply more than the patient can comprehend.

“How do you as a clinician select what information is relevant? How do you know if information is likely to be overwhelming?” says Ronald M. Epstein, MD, professor of family medicine, psychiatry, and oncology, and director, Center for Communication and Disparities Research, University of Rochester (NY) Medical Center.

Epstein suggests that paternalism and this approach to the physician-patient relationship is a

CORRECTION

In the April 1, 2010, issue of *Medical Ethics Advisor*, the name of Robert G. Bryzski, MD, PhD, of the University of Texas Health Science Center at San Antonio was stated incorrectly as John. We regret the error.

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EDITORIAL QUESTIONS

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relevant topic.

"Absolutely, because sometimes, you're in a position where you do have to make a decision on the patient's behalf. Consider an extreme situation for a patient who is suicidal; you won't just listen to what they say they want. Rather, you're going to make a decision; you may have to hospitalize them involuntarily. And if that isn't a paternalistic decision, what is?" Epstein asks.

But how a physician may or may not employ a paternalistic approach depends on the situation of a particular patient.

"Importantly, most of us do act paternalistically in ways that we often don't realize, and we have to examine whether we want to do that or not," Epstein explains. "For example, even the tone of voice you use to describe each option, or order in which you present a choice to a patient, may influence a patient's decision. We know that from psychological research. So, if you present A and B, patients may be more likely to choose A simply because it was offered as the first choice. And so, I think we are unwittingly paternalistic some of the time. . . If you favor a certain option, you'll present it and frame it a bit differently."

"Paternalism may not be all bad. Sometimes we need help knowing what the best thing is for us, but patients almost always should still be offered a choice."

Unbridled paternalism not an option

"Unbridled paternalism is a terrible idea," Epstein says. "But, if you think about the positive side of it, that is, acting as an agent for the patient with a deep knowledge of the patient's values, I think there's a place for it.

"Paternalistic actions have to be conscious; they have to be aware; and they have to be concordant with the patient's values. Sometimes, patients say they value something, and then their actions speak otherwise," he notes.

When he believes that patients are making a decision that may not be in their best interests, he will "try to cajole and nudge and convince patients" of this, i.e., that it may not be the best approach.

"That's different from forcing people to do things; generally, patients should be offered choices and options. Making recommendations — and sometimes even making strong recommendations — is part of our job."

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Physician-patient collaboration strategies

"Shared mind" is one approach

While there are uncomplicated patient cases where physician-patient communication is fairly straightforward, such communication also can range to the other end of the continuum involving end-of-life care and related decision-making.

However, in a 2009 *JAMA* commentary titled "Beyond Information: Exploring Patients' Preferences," Ronald M. Epstein, MD, and Ellen Peters, PhD, suggest that the concepts of patient-centered care and communication, as well as shared decision-making between the physician and patient both "assume that patients can articulate preferences based on stable guiding principles or values."¹

"While this may be true in straightforward situations, in novel, unanticipated, and emotionally charged situations, preferences may not be elicited as much as they are constructed — shaped by how information is presented and by the opinions of family, friends, and the media," the authors write.

In other words, they include the impact of external factors that ultimately come into play to shape a patient's preferences related to medical care.

"Stable" vs. "constructed" preferences

Epstein, who is professor of family medi-

cine, psychiatry and oncology, as well as director, Center for Communication and Disparities Research, at the University of Rochester Medical Center in New York, tells *Medical Ethics Advisor* that there is “information about the illness that only the patient can tell you.”

The patient may be able to tell a physician something about his or her values, “but you may need to help the patient discover their values, because often people haven’t thought about their values quite in that way until they encounter a difficult circumstance,” Epstein says.

For example, an upper respiratory infection has a number of treatment options, and “the situation is simple [and] consequences are few,” the authors write.

“However, preferences are more likely to be unstable in unfamiliar, high-stakes, and uncertain situations, with potential outcomes that have not been considered or have not been imagined,” the authors write.

A more complicated situation, such as prostate cancer, might be viewed very differently by different patients.

“Even though the patients may be well informed, their preferences may be influenced by personal health beliefs — one patient may fear that surgery can spread cancer, where the other prefers surgery because he wants all cancer removed; both avoid watchful waiting because doing something is better than doing nothing,” the authors write.

The authors also note that “values underlying preferences also may change as patients get sicker.”

“If you ask people would they rather win the lottery or have a colostomy, most people would rather win the lottery,” Epstein says. “But if you look at how happy people are a year later, in fact, they’re equally happy. The people with the colostomy are happy because it saved their lives.”

“That is what’s called ‘affective forecasting’; so, I think that’s one thing that clinicians have to help patients with is to [enable] them to understand how they might feel in an unfamiliar and unanticipated circumstance,” Epstein explains.

Shared information and knowledge

The authors suggest that “psychology, ethics, and clinical practice guidelines do not offer sufficient guidance concerning how to respect and respond to patients’ preferences: How would a physician know whether a patient’s preference

is stable, shallow, or incoherent? What does it mean for a physician to help patients construct preferences?”

“The shared information is information about values — and the physician also needs to share appropriate information about the disease, the prognosis, the treatment options,” Epstein says. “And also, the patient may have information that they’ve gotten from the Internet, from friends, or from another doctor, or from another tradition of healing . . . a chiropractor, an acupuncturist.”

“So, by sharing that information, it’s really just kind of putting all that on the table. The trick here is that if you try to present all of the information, everyone gets overwhelmed — you know, [patients] just can’t assimilate it all, so you have to be selective,” he says.

That’s where, he says, a slight bit of a paternalistic approach may be appropriate, depending on the circumstance. Physicians often make decisions about what specific information to present first, as well as the point at which too much information might be overwhelming. (*See cover article on paternalism.*)

“I think we do have to make choices like that,” Epstein says.

Shared deliberation and shared mind

Shared deliberation, another approach to physician-patient communication, is “a kind of back-and-forth that you need to have in order to come to a choice that most people can readily endorse,” he explains.

In the paper, the authors write: “Patient sometimes need help in understanding what they believe and want, especially in unfamiliar circumstances. In this situation, physicians must balance sins of commission (unduly influencing patients’ decisions) and sins of omission (allowing patients to misunderstand or consider an incomplete option set).

Epstein describes a simple situation he encountered in which a patient needed an antibiotic that had to be taken four times a day. When the patient heard this, the patient said there was no way he/she would remember to take a pill four times a day. Through a couple of simple questions, he found that the patient would rather have a more expensive, but once-a-day regimen with another antibiotic.

He describes that as a “simple decision.”

A more complex question might be, “Do you

want to try another course of chemotherapy, even though it only has about a 5% chance of helping you?"

"That would be a more complex kind of decision," Epstein says. "That kind of deliberation — the back and forth — means . . . sharing power, to some degree, but also not burdening the patient with too much responsibility."

Another approach he describes as "shared mind," or "a sense that this decision is not my decision, or it's not your decision, but it's kind of an idea that comes out of the dialogue that neither of us completely owns," Epstein explains.

"I think with shared decision-making, it really works well when you don't feel like it was my decision, or the doctor's decision, but rather that it's somehow shared," he says.

But that level of shared decision-making is "not necessary all the time," he says, "especially when situations are familiar, straightforward, and values are shared."

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When the patient wants to go home to die

Respecting patient autonomy — safely

It's not unusual for a patient to express a desire to go home when facing the end of life, say two experts interviewed by *Medical Ethics Advisor*. But the decision-making to allow this can be fraught with complexity, depending on the patient's medical condition and needs.

"I think if people know they're facing the very end, and they know that [for] whatever condition or disease they have . . . the treatment approaches have been exhausted . . . I think it is pretty com-

mon for people to prefer to be at their home, with their loved ones, and not having an end-of-life experience that is very technological and involving, for example, being in an intensive care unit with feeding tubes and ventilators and blood draws and limitations on when your family can be with you," says Joseph A. Carrese, MD, MPH, associate professor of medicine at Johns Hopkins University School of Medicine; chair of the ethics committee for Johns Hopkins Bayview Medical Center; as well as a core faculty member for the Johns Hopkins Berman Institute of Bioethics, in Baltimore.

If the patient has the support of family members and services like hospice, being at home to face death "can be really facilitated and managed quite effectively," Carrese says.

J. Vincent Guss, Jr., BCC, D.Min., chaplain of Falcons Landing Air Force Retired Officers Community in Potomac Falls, VA, suggests there are "clear bioethical dimensions around end-of-life decision-making in regard to the disposition and location of these patients."

"All of the major bioethical principles are involved, specifically: autonomy, or the right to self-determination of a patient who has the capacity to make decisions; non-maleficence, or considering the possible medical/emotional/spiritual harm to the patient by agreeing or not agreeing to discharge; beneficence, or the best interest of the patient [as] met by remaining in the hospital to better manage pain relief or by discharging to the patient's own place of security and comfort with family and justice, or utilization of health care resources when lengthening life is not possible and yet denied to others who can benefit from those resources where life and health can be restored," Guss explains.

"In general, most hospitals with which I have been associated will try to honor a dying patient's wishes to discharge home, referring the patient to hospice or palliative care normally offered in the home setting," notes Guss.

Carrese indicates that in his own practice as a primary care physician, "for the past several years, more of my patients have died in their home, with family — under home hospice — than in the hospital."

A complex case

There are cases when the decision is not made easily, depending on circumstances of the patient's

health needs and lack of family support or adequate resources for home health care or hospice.

Carrese explains such a difficult case — “a chronically debilitated and bed-bound 86-year-old woman,” who despite having no family or financial resources, wished — above all considerations — to return home. Carrese describes the case in his paper, “Refusal of Care: Patients’ Well-being and Physicians’ Ethical Obligations,” published in *JAMA* in 2006.¹

In the paper, he writes, “Honoring patients’ wishes becomes difficult when doing so threatens their well-being.”

After being admitted to the hospital “with an acute change of mental status,” the woman was ultimately stabilized. The patient wanted at all costs to go directly home from the hospital. A representative of Adult Protective Services, who was involved, felt that from a safety perspective, “the patient should not be at home in her current state,” according to the paper.

However, the patient had been determined to be capable of making her own decisions.

“A major challenge in this case is reconciling [two] fundamental ethical obligations that appear to be in direct conflict: 1) the duty to promote a patient’s well-being and protect the patient from harm and 2) the duty to respect the wishes of a competent patient,” Carrese explains in the discussion in the paper.

“Everyone involved in the patient’s care was concerned that her well-being would be threatened and that the potential for harm was great if she returned directly home from her hospitalization,” according to the discussion. “At the same time, all involved were troubled by the prospect of overriding her wishes.”

This case was “challenging,” Carrese says, because his approach to patient decision-making is based on a “shared model — that we’re both engaged [and] that we’re both actively participating.”

For cases where a patient is refusing care, Carrese outlines a “systematic” approach that he shares with his medical students, interns, and residents to try to determine, “Well, what’s going on here; why is somebody refusing something that we think is going to help them, or protect them from harm? And if we can figure out what that is, sometimes we can come up with a solution that’s mutually acceptable.”

Avoiding unsafe discharges

Carrese suggests that everyone involved with

the health care team “wants to prevent an unsafe discharge, and that was sort of a major stumbling block in this case.”

“Everybody was terrified that this woman was going to go home and bad things were going to happen . . . and at our hospital, we work really hard to address this in a team, interdisciplinary fashion,” he explains.

Had the patient not had decision-making capacity, the scenario would have been entirely different, and the medical team could have made the decision to keep the patient hospitalized or discharged to a lower-level health care facility.

“Assessing decision-making capacity is an important part of approaching decision-making — making sure, in fact, that patients have that ability,” he says.

According to Guss, the hospital is in danger of liability if it makes an unsafe discharge.

“It is absolved of liability if it clearly and carefully documents that the patient chooses to leave ‘against medical advice,’” Guss notes.

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Banja: Shortcuts and normalization of deviance

Do workarounds equal unethical behavior?

While not every physician or nurse makes a decision to deviate from standard medical practice or rules and regulations governing that practice, it certainly does happen, according to John D. Banja, PhD, professor, department of rehabilitation medicine and medical ethicist,

Center for Ethics at Emory University School of Medicine in Atlanta.

For example, according to Banja, anesthesia monitoring shortcuts are rather common. In one study, about 17% of anesthesiologists were found to remove blood pressure and/or ECG cables before the patient's emergence from anesthesia and tracheal extubation.¹

Other common deviations or "process variations" are not washing or sanitizing hands sufficiently; not gowning up or skipping some other infection control measures; not changing gloves or instruments when appropriate; not performing safety checks; or not getting required consents or approvals before acting, according to Banja.

In a December 2008 study, "Adverse Events in Hospitals," from the U.S. Department of Health and Human Services' Office of Inspector General, only 25% of 1,256 hospitals surveyed followed all 27 National Quality Forum safe practice guidelines.

While such lapses in following standards of care may not constitute unethical medical practice, Banja suggests that it is "ethically worrisome."

"It is ethically concerning," he says. "The reason why it's ethically concerning is that, well, there's no question that in many instances, these kinds of shortcuts or workarounds or deviations from the standard of care, policy, procedure or rule, that they will doubtlessly dispose patients to a higher level of risk. And that is what is concerning, because obviously, the higher the level of risk becomes, the more we are endangering patients, and we ought not to be doing that."

Familiar omissions

A huge reason why health professionals feel it is perfectly acceptable to deviate from rules and standards is that when they do so, nothing bad happens, according to Banja.

"Indeed, the deviation almost always occurs because the professional finds it more expedient to do it that way. They never intend to be malicious. Rather, they simply want to perform their tasks more rapidly and efficiently," Banja explains. "So, now, because they can do it faster by omitting step number 3 or 7 or whatever, that deviation becomes routine, and thus, in their eyes, no longer a deviation."

"In fact, they might even teach 'their way' to new personnel," he says. "Disaster occurs when their shortcut mixes with other rule and standard

violations, and the system can no longer intercept mistakes, errors, or the beginnings of an adverse event."

Banja noted that virtually all instances of disasters and catastrophes exhibited a long history of rule and standards violations before the catastrophe occurred.

"Only later, after the untoward event went down, do we shake our heads and say, 'How could we have allowed all this to happen, when we knew that it was dangerous?'" Banja says.

The fact that perhaps nothing immediately bad happens when there is an omission of steps in treatment or a procedure "is what oftentimes will lull us into a state of complacency," he notes.

"Years may go by where people are actually being quite careless and not paying enough attention to weaknesses and flaws and problems in the system, where it might make an error easier to happen, [but] once the error occurs, it might result in a disaster," Banja explains.

That, he notes, is an important point, i.e., to differentiate the error from the harm the error causes.

"In fact, most errors that happen in hospitals don't cause patient harm," Banja says. "It's when, for example, the wrong medicine is coming up to a floor in a hospital from pharmacy, and it's the wrong medicine — it's not the medicine that the doctor ordered. Someone on the unit then gets that medicine, but then doesn't check it out and gives that medicine to the patient. In most instances, most patients don't get harmed by that, but sometimes they do."

Why deviate from standards?

There is a long list of reasons that a physician or nurse may deviate from standards. Often, they think the rules are "stupid, too cumbersome, inefficient, etc." Sometimes, it is because a health care provider has not received proper training — or he or she has received training but is perhaps not able to adapt to a new way of doing things.

Another reason is "nonconformities are not identified or are kept secret," according to Banja, who makes frequent presentations to physicians and nurses on this topic.

Other times, a physician or nurse may think their way is simply better or faster. According to Banja, it could be the mark of a "caring employee," who believes he or she has found a better way to do something that he or she believes will be beneficial.

Shortcuts are often adaptations to the complex hospital environment, which like many large operations, often runs in a “degraded mode,” Banja says.

One of the authorities on this topic of “system failures,” he says, is James Reason, author of “Human Error,” who likes to use the term “resident pathogens,” he says.

“Anything that can weaken a system’s ability to detect and intercept errors, such as sleep-deprived personnel, high levels of stress, admitting patients whose acuity level outstrips resources, equipment failures, poor documentation and communication, even dim lighting — those are pathogens in the system,” Banja explains. “They might not result in catastrophe, but they make the system weaker: less immune, less, so that, when something bad does happen, that bad thing can then proceed to cause a disaster.”

Ways to guard against deviations

One of the problems in guarding against or eliminating deviations in standard of care once they have started is that those clinicians and nurses who may be aware of such “problematic actors” don’t speak up, according to Banja.

“You go to any nurse, any doctor who works at a hospital and say, ‘Would you think that 80% of the nurses on any unit know which ones are dedicated, competent, and reliable — and which ones aren’t?’”

And, Banja says, often they will answer, “Sure; we know; we know who they are.”

“But the problem is: These people persist at institutions; they endure at institutions, because it’s very difficult to speak up about them,” he explains.

These “system operators” may “fear speaking up” or believe that if they do speak up and report those engaging in potentially dangerous medical practice, nothing will be done within the system to address it. Or, it could be that monitoring and investigating such incidents never occurs or is completed ineffectively.

Sometimes, “deviant behaviors spawn more deviant behaviors and system failures begin to interact with one another,” according to Banja.

Other times, it is because the individual who considers reporting a problematic physician or nurse fears retribution or doesn’t want to get that individual in trouble.

“Again, it’s very, very difficult to confront

another professional,” Banja notes. “Doctors are notorious about this.”

Because speaking up against another professional is so contrary to “human nature and our own sense of safety, and self-protectiveness . . . organizations have to take the initiative to create what we might call ‘safe’ speaking up environments. In other words, we need to create an atmosphere in these organizations where people will feel safe when they speak up about one another — that is to say — they will have confidence that they won’t be retaliated against, and perhaps they’ll have the confidence that the first reaction, or the first response of the institution to that individual, who is acting in an eccentric fashion, is not going to be . . . blame and punishment.”

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USCCB: “Deficiencies” in conscience protections

Three major points considered

The United States Conference of Catholic Bishops (USCCB) Secretariat of Pro-Life Activities, **Richard Doerflinger**, suggests that following the passage of health care reform, “there’s still a number of deficiencies in conscience protection.”

“One [deficiency] is that many Americans will be required to take abortion coverage in federally subsidized health plans as a condition for getting the health coverage they want, and will not have the option to exclude the abortion coverage,” Doerflinger notes.

“There is a provision in the law for dividing the funding, so that when you are forced to pay for the abortion, you pay for it as a premium, instead of through taxes; but the abortion coverage in many

federally subsidized plans will still be an integral part of what you are required to pay for,” he says. “That’s not true now in any federally subsidized health plans.”

In this case, under health care reform, “the insurer decides whether to cover elective abortions, and then they are still allowed to get federal funds for their entire plan. And anyone who buys that plan must pay the abortion fee,” he says.

A second “deficiency” he cites regards the lack of protection under health care reform that is typically afforded under the Weldon Amendment, which has been part of the U.S. Department of Labor/U.S. Department of Health and Human Services appropriations bills since 2004, he says. The new health care reform law appropriates funds outside the bounds of the Labor/HHS appropriations bills, meaning that they are not covered by the Weldon Amendment’s conscience protections.

“So, it’s not that this law overrides or deletes the Weldon Amendment, but what it fails to do ... is apply the policy of the Weldon Amendment to these new funding streams that are created by the legislation,” Doerflinger explains.

All other major federal health programs are covered under these protections, he says, since they all are funded through the Labor/HHS appropriations.

Although health care providers who decline involvement in abortion will not be required to provide abortions via the new qualified health plans, “they’re not protected from discrimination on the part of governmental entities,” he says.

“So, you cannot have discrimination by the health plans, but providers and overall plans may be discriminated against by some of these new governmental entities that are being set up under the new law,” he says.

The third “concern goes beyond the abortion issue into other areas where Catholic employers and Catholic institutions have had the freedom — until now — to exclude from their coverage procedures that are against Catholic teaching . . . things like sterilization, contraception, and in vitro fertilization.”

HHS to develop policy, implement

Doerflinger explains that under health care reform, the law “creates a new broad list of essential health benefits that are ultimately going to have to be in all health plans . . . The broad cat-

egories are very sweeping, related to prescription drugs, physician services, and so on. We think it likely that a lot of those categories will end up including things that we’ve been able to exclude from our coverage until now.”

While health care reform is law, there are still “many, many provisions” that will require policy development and implementation by HHS, he says.

When dealing with employer health plans, “there’s nothing in the law now that says that HHS should make any accommodation for religious freedom concerns, when they’re dealing with employer health plans.”

“So, that’s our third concern . . . In this broader area of religious freedom, we don’t have any protection against a sort of straitjacket, one-size-fits-all list of essential benefits that even Catholic institutions will have to provide and pay for,” Doerflinger notes.

SOURCE

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Internet research raises institutional review boards

Few IRBs have policies for Internet studies

Internet research has been an issue for institutional review boards since its roots in the 1990s, and the challenges ethics boards face in reviewing such studies are in pioneer territory.

For instance, twelve years ago, IRBs might not have known how to handle informed consent for studies that involved interviewing people met through Internet chat lines. Now the problems have evolved to determining how to protect research subjects when private Internet research information suddenly becomes public, says **Elizabeth Buchanan**, PhD, director of the center for information policy research in the school of information studies at the University of Wisconsin in Milwaukee, WI.

“I’ve sat on two different IRBs, helping them understand the complexities of Internet research,” Buchanan notes. “One was a medical school board and one was a social science board, and there are

different ways of thinking about the issues from the different disciplinary models.”

Buchanan decided to study this issue by surveying IRBs in the United States. Her project was funded through a grant from the National Science Foundation.

“No one had been looking empirically at what was happening,” she says. “IRBs are seeing more online surveys and interviews, but the boards don’t talk to each other about it and there’s a real gap in the literature base and understanding of what is happening at the national level.”

Buchanan and co-researchers spent a year surveying IRBs and received more than 300 responses that formed an interesting dataset of how IRBs were handling Internet research.

Based on 2007-08 data, the study found that about half of the IRBs surveyed considered Internet research a concern or of interest to their boards. The study also found that less than 8% of IRBs had Internet research protocols, including checklists, review tools, policies, and guidelines. Another 17% said these protocols were under development, according to study findings presented at Office of Human Research Protection (OHRP) Research Community Forum 2010, held May 21, 2010, in Chicago, IL.

“IRBs are starting to get more and more of these Internet studies, and the most frequent are Internet survey tools,” she says. “Some boards are more comfortable with these than others.”

Plus, IRB members might find Internet research somewhat confusing, and the issues that concern them are varied.

Online consent

For example, one issue is how investigators might gain consent online. Should they use a checkbox that is similar to an iTunes or software company disclosure that asks you to read the rules and then check the box saying you approve and will proceed?

“Is that an acceptable model of consent?” Buchanan says. “Some IRBs say, ‘Yes,’ and some say, ‘We don’t know.’”

And if a checkbox consent form isn’t acceptable, then what alternative do researchers have?

Other major issues involve privacy, data ownership, and terms of service.

Buchanan outlines these other ethical issues in Internet research:

Is it possible to have an equitable or fair representation in subject pool when most subject selec-

tion is based on type of site?

How does the researcher enter the research space to begin recruiting?

What if some people in a community agree to consent to the study, but others do not? Do researchers have plans for this reality?

With Internet research there are more unknowns in the area of data control, Buchanan notes.

“Suppose a researcher wants to study Facebook data,” Buchanan explains. “Those data do not belong to individuals on Facebook or the researcher — they belong to Facebook.”

In this type of case the stock phrases informed consent documents might include — about how the data will be kept confidential in a storage file for a set period of time and used only for research purposes — do not apply, she adds.

“We can’t use that language anymore because we can’t make those assertions,” Buchanan says.

If the research involves obtaining answers to questions given online and through the Internet, it is reasonable to assume those answers will exist beyond the researcher’s hard drive.

Internet research is subject to cloud computing: “When we store things offsite, we may have a copy of the data on our desktop, and that’s well and good,” Buchanan says. “But there may be another set of data in the clouds, and we don’t know how long that will last.”

For instance, when an investigator conducts an observation online or interacts with a specific Internet community, the researcher will generate a log or transcript, keeping a copy, Buchanan says.

Participants and the Internet community’s administrator also will have a copy of the interaction. So the questions that an IRB will have to address are as follows:

- Who owns the information?
- How long will the e-data last?
- Has the researcher informed participants about the data’s longevity and potential risk of data intrusion?

A quick study

This uncertainty puts a burden on researchers and IRBs to learn the new Internet rules quickly.

“Researchers and IRBs need to learn and adopt new languages to protect themselves and subjects,” Buchanan says.

IRBs also might encounter research collection methods that begin to cross ethical boundaries.

For instance, Buchanan has encountered the case

of a researcher who wanted to learn more about people's online political views. He proposed studying this by creating a fake Internet persona with which he'd befriend people in an online community.

"He wanted to know how people would express their political views on Facebook," she says. "It was a form of deception where the researcher would present himself as someone different so he could look at the interactions."

On the surface, an IRB might ask if this would even qualify as human subjects research, she notes.

"One could argue, depending on the type of research, that the researcher could have just been looking at language," Buchanan says. "So maybe it's doing a content or discourse analysis and is not human subjects research."

And even if an IRB decides this is not human subjects research, what about the issue of deception, the researcher creating a fake persona to obtain information that was intended for a specific audience, she adds.

"The IRB was unsure if this fell into the realm of deception and how to evaluate it," Buchanan says. "However, the researcher could say, 'If you don't allow me to create this fake persona, then I won't be able to get the responses.'" ■

Behavioral health groups applaud Joint Commission

Four founding partners in a public-private collaboration to advance performance measurement in behavioral health on July 21 applauded The Joint Commission's (TJC) announcement of the next phase of the "Hospital-Based Inpatient Psychiatric Hospitals" (HBIPS) core measures initiative.

The four partners are: the National Association of State Mental Health Program Directors (NASMHPD), the National Association of Psychiatric Health Systems (NAPHS), the NASMHPD Research Institute Inc. (NRI), and the American Psychiatric Association (APA).

In a news release, the groups said that for about a decade, the have represented state hospitals, private-sector provider organizations, and psychiatrists to pool their resources and expertise to advance development of psychiatric core measures.

The groups said that working with TJC, they

have helped to launch and implement a way for hospitals across the United States to gather and report publicly on key data elements that affect the course of an individual's psychiatric hospitalization from the moment they enter the facility through discharge (including the assessment process, the use of antipsychotic medications,

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

CME OBJECTIVES

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

- Discuss new developments in regulation and 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.

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CME QUESTIONS

5. What model of the physician-patient relationship is sometimes called the parental or priestly model?

- A. Informative
- B. Paternalistic
- C. Interpretive
- D. Deliberative

6. According to Ronald M. Epstein, MD, patients sometimes need help from the physician in clarifying their values and treatment preferences.

- A. True
- B. False

7. Which of the following bioethic dimensions is not included by J. Vincent Guss, Jr., BCC, D.Min., around end-of-life decision-making with regard to patients who express a wish to face the end of life at home?

- A. Autonomy
- B. Malfeasance
- C. Beneficence
- D. Justice

8. According to John D. Banja, PhD, physicians do not deviate from standard of care or related rules and regulations with the intent of malice.

- A. True
- B. False

Answers: 5. B; 6. A; 7. B; 8. A.

seclusion and restraint, and discharge summary/aftercare).

"Today marks a historic step forward in performance measurement for inpatient psychiatric hospitals," said NAPHS President/CEO Mark Covall. "This is the first time that we will have standardized definitions and reporting requirements that will enable hospital leaders to view their own performance in comparison to their peers."

"As part of the hospital accreditation process, the HBIPS requirements will generate national data that all constituencies — including those who receive care, those who deliver treatment, and those who pay for hospitalization — can use to better understand and enhance the inpatient hospital experience." ■