

Medical Ethics Advisor®

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Just how private is your patient information?

The biggest culprit might surprise you

When actress and fitness guru Suzanne Somers disclosed her battle with breast cancer on CNN's "Larry King Live," it wasn't a discussion she planned to have. However, detailed information about procedures the famous actress had undergone at a California plastic surgery clinic were published days before in a supermarket tabloid.

Upset by the article's insinuation that she relied on cosmetic surgery and not the diet tips published in a best-selling self-help book, the actress told King she felt forced to reveal her illness and explain that the surgeries were to repair parts of her body she felt were "disfigured" by cancer treatments.

The fact that Somers was coerced into discussing her private medical information on a national television talk show indicates the difficulty health care facilities often have keeping patient medical information private.

Before your ethics committee is asked to investigate an alleged breach of confidentiality, there are steps you can take to avoid similar situations.

Despite the Joint Commission on the Accreditation of Healthcare Organizations' standards on maintaining patient confidentiality, state laws prohibiting the release of personal patient information without consent, and most hospitals making inappropriate disclosure of patient information a firing offense, confidential material sometimes seems to be available for the asking.

"A lot of times, it isn't even the *National Enquirer* that is hacking in getting information. Internal hacking can be a problem. People are *curious*," says **Emily Friedman**, an independent health policy

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patient confidentiality and safety requires you to violate state law? 65

Adolescent Sexual Violence/Abuse Screening Tool

The two-page tool contains Milwaukee Adolescent Health Program’s policy on sexual abuse and violence, including when health care providers must report circumstances to the authorities, such as children suffering from mental illness or mental deficiency or if the provider has doubt as to the voluntariness of the child’s participation in the sexual contact. 66-67

Adolescent Sexual Violence/Abuse Screening Tool assessment

The two-part questionnaire contains a checklist of questions for providers to answer to assist in determining when to report situations to authorities. If the answer to a question is positive, the situation must be reported. Questions include: Is the patient’s partner a caregiver or relative? 68

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We’d like to hear from you

The editors of *Medical Ethics Advisor* are looking for examples of ethics consultations at hospitals throughout the country to highlight in future issues of the newsletter. If your ethics committee has experienced a particularly difficult case, or you’ve developed or revised policies as a result of a case, we’d like to hear from you. Cases will be examined in future issues to educate your peers in other hospitals. Send a brief description of your case and how your committee responded to *Medical Ethics Advisor*, P.O. Box 740056, Atlanta, GA 30374. E-mail: kevin.new@ahcpub.com.

COMING IN FUTURE ISSUES

- **Religion and genetics:** Developing resources for conflicted patients
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and ethics analyst based in Chicago. “If Elizabeth Taylor’s in the hospital, they want to know if Elizabeth Taylor has cancer or not. No harm is intended. But, once one person gets the information, it travels through the hospital by word of mouth. Then, anybody can call the *Enquirer*.”

Put records under lock and key

In some cases, breaches of patient confidentiality occur — not because someone who works for the hospital deliberately disclosed the information — but because medical record information often is left in nonsecure environments. And, the danger to privacy is not just limited to celebrities.

“In one of the hospitals I’ve worked in, I could have seen any chart in the place and I was the lab slip delivery girl,” she says. “I could have taken it, photocopied it, and returned it without anyone knowing.”

A CEO of a large health system in the Pacific Northwest told Friedman that when he first came to his current hospital, staff would transport records on large carts and, if they took a break, would leave the carts unattended in the hall, she continues. “He used to find the carts and take them to his office. The employee would then have to come to his office to get the medical records back.”

Part of the problem is that, because medical personnel deal with patient information all day long, they often forget that the information they work with every day is confidential and could be damaging to the patient if released into the wrong hands.

“I think, in general, hospital employees are aware of the patients’ rights to privacy and that medical information should be kept confidential,” says **Karen Czirr**, MS, RHIA, information security manager at Children’s Hospital of Philadelphia (CHOP). “But dealing with patient information becomes second nature to you. Sometimes, it is hard to remember that there may be people out there who want to find out someone else’s medical information. I have seen minutes from meetings thrown into trash cans near the elevator. The person who drops it there might not even think that anyone would pull that out of the trash to see what was on it — that someone waiting for the elevator might see [his or her] neighbor’s name on that list.”

It is not enough to have polices prohibiting employees from disclosing patient information without consent, say Friedman and Czirr. Hospitals must make every effort to set up security measures to protect information as it moves from one site of care to another and from one

department to the next.

“Paper medical records need to be kept in a secure area,” says Friedman. “For patients in the hospital, that is more difficult because those records might be needed right away for patient care. But records of patients not currently admitted should be under lock and key. And, there should be a sign-out procedure. If someone wants the record, they sign a sheet and show hospital ID.”

Systems must be in place to keep info secure

Systems should in place because, with more and more contract health care workers, floating shifts, and outside vendors working in hospitals, staff cannot be expected to recognize who is authorized to look at records and who is not, she adds.

“In a small, rural facility, you might have a shot at it,” she continues. “At a large, academic medical center — no way.”

The issue of electronic records is much more tricky.

“We have the technology to make electronic medical records, but we don’t have the technology to make them totally secure,” Friedman believes. Good computer hackers looking for patient information can get it. “If Microsoft can be hacked, you can be hacked,” she adds.

CHOP is moving toward having a completely electronic patient medical record, says Czirr. And, information technology personnel have implemented extensive security measures to secure the information, limit access to information, and track who sees what patient information in case a problem arises.

“It is very controlled, and there are lots of levels of access,” she explains. “I don’t train the people who work for me; they go to our training center and are trained and given their computer password. I don’t know their passwords and they don’t know mine.”

In addition, the hospital managers can monitor “audit trails” of which employees access which files, she says. “We have nursing managers who look at what the nursing personnel are doing,” Czirr says. “Is a nurse on 2 West looking at patient data on 4 East? We look at particularly sensitive data, communicable diseases, HIV, child abuse cases [and], information that is in our database because of violent acts. We look at who is accessing this information. As security manager, I have access to everything, but there are some things I don’t know how to use. And, if someone sees my name on an audit trail maneuvering around the

CME

questions

1. According to Emily Friedman, an independent health policy and ethics analyst, most breaches of patient confidentiality within hospitals occurs:
 - A. from external computer hackers.
 - B. internally.
 - C. from the media.
 - D. from patients' families.
2. In addition to security policies for enforcing patient confidentiality, Karen Czirr, MS, RHIA, information security manager at Children's Hospital of Philadelphia, recommends that hospitals:
 - A. conduct external security audits.
 - B. eliminate paper-based medical records.
 - C. adopt a culture of confidentiality.
 - D. all of the above
3. Establishing a policy for adolescent sexual abuse and rape is difficult, says Jane Dimmitt Champion, PhD, FNP, CS, assistant professor in the department of family nursing at the University of Texas Health Science Center, because:
 - A. there is no predominant guidance available.
 - B. clinicians decide cases autonomously.
 - C. confusion prevents clinicians from addressing underlying issues.
 - D. all of the above
4. Adopting a paternalistic approach to health care, suggests Steven C. Matson, MD, associate professor of pediatrics at the University of Wisconsin, involves:
 - A. providing services in a safe manner.
 - B. ensuring sexual activity, if present, is safe and appropriate.
 - C. ensuring patients are not coerced or violence is not involved.
 - D. all of the above

system in the lab, something would pop up on my screen or I would get a phone call asking if I had a reason for doing this.”

In addition to setting up security protocols and technology, it is essential that hospitals strictly enforce patient privacy regulations and severely punish employees who violate them.

“You have to create a culture of privacy, of maintaining confidentiality,” says Friedman. “Part of all training and re-education should

include reminders of patient privacy standards.”

Some hospitals have signs in the corridors and in elevators reminding employees not to discuss patient information in public areas, she says.

“You want to say that, ‘We are here to take care of people and part of that is to keep their business private,’ she explains. “If somebody is playing fast and loose with patient information, if someone is talking in the elevator, they can be reported, be it a patient care associate, the CEO, or the chief of staff.”

Adopt strict policies

At CHOP, employees go through a formal patient privacy awareness program when they are hired and are required to attend retraining on the topic annually.

“We go over privacy of medical records, use of the computer messaging systems, use of e-mail, the difference between our intranet and the Internet,” says Czirr. “Many people don’t realize that even though mail sent over our system internally is encrypted, once it goes to another facility — even one around the corner — it is no longer protected.”

The program also covers information that is left on patient or physician office answering machines, she notes.

The hospital also has strict policies governing punishment for violations of its privacy standards — even if no harm occurs.

“Violation of privacy or confidentiality here hits on two levels,” she explains. “If it was unconscious, you weren’t thinking, for example, and logged in on your computer system and left the desk. Or, you are dashing to a meeting and don’t have time to send a new employee to training and you let them log in with your password and they wander into an area they are not supposed to be in, etc. A lot of people are hurrying and trying to get their work done, and they just don’t think about it. For that, you can be suspended for up to three days with or without pay. In every instance, if you are not terminated, your password and access to data are taken away and you have to go through retraining and re-sign the confidentiality agreement before you can go back to work. Everybody has to meet with me or someone on my team, watch a video, and listen to us lecture you. For employees who have been here a long time and who genuinely just made a mistake, it is humiliating to them.”

Second, for employees who deliberately violate patient confidentiality, the punishment usually is termination.

“We have fired people for deliberately going into databases and accessing data that they were not supposed to, and it has not been limited to people who punch a time clock, or middle management,” she adds. “We have fired upper management and physicians on our payroll who have consistently violated our policies on patient confidentiality.”

No such thing as a little leak

Although leaks of patient information about celebrities, presidential candidates, and others grab the headlines, hospitals need to be especially vigilant about the “small” ways that patient confidentiality can be compromised, often without bad intentions, by hospital employees, says Czirr.

A worker employed by a hospital contract vendor was working in their patient records department and previously had been employed by one of CHOP’s physician offices, she relates.

“We do not release incomplete records from our department unless it is for patient care,” she continues. “So, if a physician still has to sign the operative note or the discharge summary, they have a certain number of days in which to do that, but the record cannot leave the department.”

A particular physician office wanted information from a patient’s record that was not complete, and the office was told it would have to send someone down in person to examine the record.

Not wanting to go to the trouble, someone at the office contacted the contract worker who had been a former employee. The worker obtained the record, made photocopies, and was on her way out the door when she was stopped, says Czirr.

“No. 1, she was not an employee,” she says. “No. 2, we caught her leaving the department with the copies. We just happened to be in the right place at the wrong time, from her perspective. We told the vendor that they didn’t have to terminate her, but she could no longer work in our hospital.”

In another situation, a staff person’s grandchild was brought in to the hospital emergency department, Czirr says. The staff member accessed the lab results of toxicology tests administered to see whether the child, a teen-ager, had tested positive for drug or alcohol use. The employee’s name turned up on an audit trail. “She felt justified in that it was her grandchild, and she lived with her daughter,” she says. “But she was not the party responsible for his medical care, and we had to tell her she had no right to the information and could not violate his confidentiality.”

SOURCES

- Karen Czirr, Children's Hospital of Philadelphia, 34th Street and Civic Center Boulevard, Philadelphia, PA 19104-4399.
- Emily Friedman, 851 W. Gunnison St., Chicago, IL 60640.

Recommended reading

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No hard, fast rules on reporting sexual abuse

Best option is to develop a case-based approach

Susan, a 31-year-old, married mother of three, has been seen in your reproductive health services' clinic three times in the past two years. Each time, she has required repeat treatment for different sexually transmitted infections. She reports that although she is faithful to her husband, he continues to have extramarital relationships and frequently forces her to have sexual intercourse. Because she is financially dependent upon him, she does not feel able to leave the relationship and does not want to confront him about the infections.

Should your clinicians report the husband for spousal abuse? Contact him about receiving treatment? Or, should they honor Susan's request for treatment for her existing infection, not tell her husband, and remain silent about the abusive situation?

Alicia, 15, presents in your hospital emergency department complaining of chronic abdominal pain and pain during sexual intercourse. She is subsequently diagnosed with chlamydia and pelvic inflammatory disease. During her visit, she states that her current boyfriend is older, age 19, and doesn't like to use condoms. She fears losing him if she asks him to be tested for chlamydia or insists on safer sexual practices.

In your state, Alicia's boyfriend could be charged with second-degree sexual assault for having intercourse with a minor under the age

of 17. Should you report the relationship to the police?

The two situations mentioned above are common occurrences for many health care professionals who provide reproductive health services. Although deciding whether to report abuse or illegal activity is an ethical dilemma faced by providers in many settings, laws requiring the reporting of cases of sexually transmitted diseases (STDs), abuse, and sexual contact with minors make clinical dilemmas in reproductive health even more complicated.

Where do you draw the line between patient confidentiality and protecting public health? Is it ever appropriate to honor a patient's request for a specific medical intervention and allow other health problems to go unacknowledged? What if maintaining patient confidentiality and safety requires you to violate state law?

Many providers are so confused about how to handle those situations that they end up choosing to work with blinders on, experts say, preferring not to deal with the underlying personal issues that may be contributing to the patients' medical problems.

"There is really nothing out there that says, if a person comes in and is being abused, you do X, Y, and Z — not really," says **Jane Dimmitt Champion**, PhD, FNP, CS, assistant professor in the department of family nursing at the University of Texas Health Science Center in San Antonio.

"I think that clinicians everywhere are struggling with a lot of these issues and have decided on their own how they will handle certain situations. But I know a lot of them are really interested in finding some organized system of looking at things."

Particularly when care involves reproductive health services to adolescents, many providers are so concerned about damaging their patients' access to care and trust in the providers that they are opposed to delving into issues of possible abuse or coercion, says **Steven C. Matson**, MD, associate professor of pediatrics and director of the Milwaukee Adolescent Health Program at the Medical College of Wisconsin.

"In many cases, providers aren't even attempting to identify it," he says. "It is a combination of factors. There is a key group of people who are advocates for adolescents and their control of their sexual behavior and for getting confidential reproductive health services to kids. So they try to deliver these services to them and then don't delve into things in a real deep manner. Then,

(Continued on page 69)

Source: Milwaukee Adolescent Health Program, Medical College of Wisconsin.

(Continued on page 65)

there is another group of providers who just feel that they are too busy, so they deal with the issue at hand [the STD or other reproductive health matter] and move on.”

However, statistics have shown that adolescents, particularly adolescent girls, involved in relationships with older partners are more likely to engage in unwanted sexual contact, and less likely to practice safe sex,^{1,2,3} says Matson.

“In my mind, you provide these services in the context of a sort of paternalistic kind of approach to health care,” he states. “If you are going to provide these services to kids, you still need to do it in a safe sort of way. You make sure that if they are sexually active, that they are engaging in appropriate adolescent sexual behavior, that it is consensual, and there is no violence or coercion involved.”

Reproductive health providers do not “treat and street” patients, as some people sometimes assume, says Champion. They have a responsibility to address issues in patients’ lives that put their health at risk.

“Some people do think that we just treat the person and send them back out,” she says. “I think if you are really doing that, it is the worst possible thing. It just doesn’t work. You are not really addressing the problem.”

Although some states do have laws requiring health care providers to report cases of domestic abuse and statutory rape or sexual assault, many of the laws are vaguely worded and difficult to enforce.

In Wisconsin, for example, “sexual contact and sexual intercourse” with a person under the age of 13 is a Class B felony, and sexual contact and/or intercourse with a minor under the age of 16 is a Class B/C felony, but the statute does not define “sexual contact,” says **Margaret Flood**, MSW, a social worker and forensic child abuse interviewer with the Child Protection Center of Children’s Hospital of Wisconsin.

Sexual contact and/or intercourse with a person 16 or 17 years of age is a Class A misdemeanor. Following the letter of the law, two 15-year-olds who have sexual intercourse are guilty of a class B or C felony.

“Most statutory rape laws throughout the country are unenforceable because, if they really meant to arrest every 15-year-old that was having sex, it would inundate the system,” says Matson.

State law also requires health care providers to report occurrences to child protection authorities,

unless they are providing reproductive health services, Flood adds. The exceptions to this rule are: the sex partner is a caregiver, relative, or adult authority figure to the minor; the minor reports being forced to have sex or promised gifts or money for sexual contact; the minor reports being under the influence of drugs or alcohol when sex occurred; or the minor is cognitively delayed or disabled.

However, many providers are not asking enough questions of their patients to know whether the sexual relationships meet any of the exception criteria for required reporting by reproductive health providers, says Flood.

“You should be screening for, basically, exploitation — someone taking advantage of the kid because [he or she is] mentally or emotionally disabled, or they are getting [him or her] drunk to have sex,” she says. “But we did a survey of our local ERs and family planning clinics in our community just to find out what they were doing in terms of screening. Pretty much no one could produce anything that showed they even had a policy of asking these types of questions to teen-agers.”

Develop a consensus-based approach

Health care providers actually have an opportunity to come together and develop a consensus on what kinds of sexual activity with and among minors should be reported, even though enforcement of existing laws is spotty, says Matson.

“Most people aren’t reporting these cases anyway,” he says. “But if we could get health care providers to agree on parameters for what is normal adolescent sexual behavior, we could develop criteria that would determine which cases really need to be reported.”

Providers should try to come together to decide, based on their experience, which cases may violate the letter of the law, but are not truly harmful and patient confidentiality should be maintained. Conversely, providers should agree when a relationship is harmful and violating patient confidentiality is in the minor’s best interest, say Flood and Matson.

Flood and Matson have proposed such criteria and developed the Adolescent Sexual Violence/Abuse Screening Tool (AVAST). **(See pp. 66-68 for chart and policy.)** The tool is a guided set of questions to be asked of adolescent patients in reproductive health settings, says Flood.

It’s designed to assist providers in deciding whether a minor is involved in a relationship that

violates state law and, if so, whether clinicians providing reproductive health services still should report it.

“We hashed these out in long discussions, both taking into account the law, but also what would be reasonable in the health care setting,” she says.

For example, they came up with a guideline of reporting a sexual relationship with a person under 16 whose partner is five or more years older.

“We felt that was reasonable to report, whereas the general feeling is that two 14-year-olds having sex or two 15-year-olds having sex was not inappropriate,” she says.

The tool also provides a way for providers to document which cases they report, which they don’t, and how the decision is made, says Matson.

“Lots of times, for example, we have not been able to document why we didn’t report a particular situation,” he says. “This, at least, allows you to show that you considered these things: there is not a greater than five-year age difference; there doesn’t seem to be coercion, the contact seems wanted; and there doesn’t seem to be any violence. So in our best effort, we are going to uphold confidentiality here because it seems like a reasonable relationship. You can really say you made a serious attempt to do the best you could to ensure the relationship was safe and protective.”

One size does not fit all

Providers also need an organized approach to dealing with adults who present for reproductive health services and in whom partner abuse is either suspected or confirmed.

“Right now, there are so many new laws, with regard to reporting individuals involved in violent situations, and when you add on top of all of that reporting requirements for sexually transmitted diseases, partner treatment, access-to-care issues — especially in poor and/or rural areas, issues get very complicated,” she says.

It would be very difficult to develop a one-size-fits-all policy to apply in every situation and still meet the needs of the patient, Champion believes.

Using the ethics-based approach — or case-based reasoning — makes more sense in these situations. “Sometimes, if you take a ‘principles-based approach’ and say, ‘Well, I need to do this,’ and then you examine what is actually going to happen to your client, you know you can’t do it,” she says.

Champion relates the story of co-workers in a

rural area who were caring for a woman in a situation similar to “Susan’s” in the first paragraph.

The woman was involved in an abusive marriage. Though she was repeatedly reinfected with an STD by her husband, she did not want her husband to stop having extramarital affairs because he was less abusive and did not force her into sexual contact as often, says Champion. Fearing negative consequences from her husband, the client could only visit the clinic nurse surreptitiously and could not be contacted at home about her care.

The woman also did not feel that she had the financial resources to live on her own and support her child.

Gradually, over the period of a couple of years, Champion and other co-workers were able to obtain financial aid for the woman when she was ready to leave the relationship. In the meantime, however, they treated her for her STD, provided treatment for her husband without telling him he had an STD, and arranged for the health department to document the case without independently contacting the husband.

“Case-based reasoning takes into account all the aspects of the patient’s life and how you can resolve the problem without hurting them,” she says.

There are four basic components to consider:

- 1) the medical indications of the patient’s condition and how it needs to be treated;
- 2) patient preferences, what the patient himself or herself wants to do;
- 3) quality of life — what does the patient currently feel about his or her quality of life;
- 4) contextual features — this is the component that considers the social and environmental factors that influence the decision.

All four components should be considered and balanced to make a decision for that individual. “Contextual features, which in most of these cases have to do with violence and STDs, is very important in making the decision,” says Champion. “You have to examine what will be the overall outcome for that particular patient if we make a certain decision.”

In many cases, a “principles-based” approach doesn’t work in a case in which abuse is involved because the wishes of the people involved may vary so dramatically.

“You have to be very careful that you are not imposing your views on the patient,” says Champion. “We may look at a relationship and feel that it is abusive and the client may just not see it that way. Or we may assume that because a

patient is in an abusive relationship that they necessarily want that relationship to end, and that is not always the case.”

Although you may not handle all situations in the same way, you are still taking a consistent approach to addressing the relevant issues in the patient’s life, she adds.

“You need an ethical basis for examining how to achieve a good outcome and get to that point without causing harm to the individual,” she says.

Providers also must follow up to see how their policies and guidelines really are affecting the care they provide, particularly when it comes to reporting cases of abuse, says Matson.

“When we do report, we still need to look at how damaging that report is to the client-provider relationship,” Matson says. “What is the actual outcome of our intervention? Did something good

actually happen? Or, did nothing happen and you just made everyone mad? We do need to be held to that standard if we are going to intervene.”

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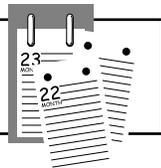
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