



## When Patients Refuse Treatment



### THE CASE

*Mrs. Jones is an 85-year-old woman whose life depends on dialysis treatments three times a week. Hospitalization and treatment for her multiple medical problems have caused her to become disoriented and agitated at times; she cries out and protests when nurses try to care for her. Her physicians recently told her daughter that, in addition to diabetes, end-stage renal disease, and a poorly-healed hip fracture, the patient is developing congestive heart failure. During each treatment, when she must lie still in a painful position, she*

*insists that she does not want to be treated. Medication must often be administered to prevent agitation during the five hours that each treatment requires. At times she must be gently restrained to prevent the dialysis lines from being pulled out.*

*Meanwhile, elsewhere in the same dialysis unit, Mr. Smith is being prepared for treatment after coming to the Emergency Department severely uremic, having missed over a week of dialysis treatment because he is "too busy." He smells of alcohol, although his blood alcohol is slightly below the legal limits for driving. Mr. Smith refuses to cooperate, insisting that he will not undergo treatment, and while in the dialysis unit, attempts to hit one of the nurses.*

### CAN TREATMENT BE FORCED?

Should nurses force dialysis against the explicit wishes of patients like Mrs. Jones or Mr. Smith? Of course we believe that autonomy, the right of each person to make decisions about his or her own treatment, is essential to providing patient care in an ethical manner. Caregivers are obliged to make sure that the patient understands the consequences of treatment refusal. Under such circumstances, even if a competent patient rejects medically beneficial treatment, forcing that treatment upon patients against their will is considered unethical.

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## It's Ethical But is it Legal?: When Your Patient is an Impaired Driver

Your patient is admitted through the ER following a motor vehicle accident and is clearly inebriated. Your elderly patient who just had his license renewed, is showing signs of dementia. Each of these scenarios raises ethical and legal questions: Is my patient an unsafe driver? If so, should I tell anyone that my patient poses a risk to himself and to others?

As you struggle with the second question, you may find yourself in a dilemma. To notify the Department of Motor Vehicles (DMV), a family member, or employer means breaching confidentiality. But if you believe your patient will be unsafe behind the wheel, strict confidentiality means you have done nothing to prevent potentially serious harm. However you resolve the ethical dilemma, either decision could pose a risk of legal liability, unless the law offers guidance and protection.

### THERE MAY BE A DUTY TO WARN

An ethical argument to justify strict confidentiality would proceed along the following lines: There is a strong and time-honored duty to keep the patient's health information confidential. This duty is a cornerstone of codes of ethics for physicians, nurses, and other health care profes-

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# Bioethics *in brief*

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*Bioethics in Brief* is a newsletter of the Center for Bioethics and Humanities, in cooperation with University Hospital's Ethics Committee.

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Would you like to be added to our mailing list? E-mail us at [cbh@upstate.edu](mailto:cbh@upstate.edu)

Have a question about an ethical issue?

We are always happy to talk in confidence about ethical concerns. You may reach us at the Center for Bioethics and Humanities at 315-464-5404. Ethics consultations are available by calling the hospital operator (315-464-5540) and asking for the ethics consultant on call, or by contacting any of the ethics consultants at the Center (Catherine V. Caldicott MD; Robert Daly MD; James Dwyer PhD; Kathy Faber-Langendoen MD; Robert S. Olick JD, PhD; and Joel Potash MD).

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## Impaired Driver

sionals. Confidentiality is an agreement with the patient that grounds trust in the relationship. It allows the patient to freely share information so that physicians and nurses may act in the patient's best interests, respecting the patient's values and wishes. Further, when we know that our confidences will be kept private we are more likely to seek out a physician and enter into a patient-physician relationship. Hence the norm of confidentiality affects us all as patients and serves the public good.

## ENCOURAGE RESPONSIBILITY

A first step in our scenarios is to counsel the patient to take self-corrective action appropriate to the individual's situation. This might include voluntary cessation of driving while seeking treatment and perhaps telling others about his or her condition.

If the patient refuses to take responsibility, and keeping the patient's secret may cause harm to others, the duty of confidentiality is not absolute. We need to assess the factors that justify a breach of confidentiality.

If the harm to be prevented is great, the likelihood that it will occur is high, and there is a reasonable chance that disclosure will abate the harm, it may justify a breach of confidentiality and the need to warn. The American Medical Association frames the analysis in similar terms: "In situations where clear evidence of substantial driving impairment implies a strong threat to patient and public safety, and where the physician's advice to discontinue driving privileges is ignored, it is desirable and ethical to notify the

Department of Motor Vehicles." (AMA Ethical Opinion E-2.24)

We must still ask to whom is a duty owed, and who should be notified? The law typically imposes no duty to the public at large. There must be an identifiable third party at risk. Among ethicists there is disagreement on the scope of the duty to warn. For many, but not all, the fact that the patient may pose a risk to the general driving public is not sufficient to justify disclosure. And all of the factors noted above that may support disclosure should be balanced against potential negative consequences of disclosure for the patient, such as loss of license or employment or the challenges of finding alternate transportation. The facts of each situation are critical. How far has the elderly patient's dementia progressed, and when will it constitute a significant driving impairment? Is there a particular person at risk (a spouse?) or is it the general population of other drivers that concerns us? Is the patient likely to drive under the influence again, or was this an isolated incident?

## NEW YORK LAW: CONFIDENTIALITY IS PARAMOUNT

Disclosing that your patient is an impaired driver is sometimes ethical, but is it legal? Under New York's Education Law §6530, disclosure of personally identifiable health information "obtained in a professional capacity without the prior consent of the patient" is professional misconduct. The law sometimes carves out exceptions and specifically permits or requires notification or reporting, such as with HIV status. But as discussed below, New York has no such law that applies to impaired drivers. If there is no law that permits or requires disclosure, breaching

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## **Impaired Driver**

confidentiality puts the professional at risk of a charge of misconduct.

The absence of express legal authority also increases the chances a patient could hold the professional legally liable for breaching confidentiality. The duty to protect personally identifiable health information under HIPAA strengthens the legal argument for confidentiality.

Keeping confidentiality (doing nothing) because the risk to other people is not strong enough to justify disclosure leaves many uncomfortable. Numerous states (but not New York) have enacted laws that either require or permit physicians to report impaired drivers to the state DMV. (Note that HIPAA defers to state law here and allows states to establish exceptions to confidentiality such as these.) As a state agency, DMV is empowered to protect the public

safety, and has authority to investigate, require testing, and suspend or revoke a person's driver's license. Notifying the DMV, as opposed to directly contacting your patient's family member, also follows the principle that when confidentiality is broken disclosure should be narrowly tailored and targeted to achieve its objective of harm-prevention. Limited disclosure shields the patient's privacy from those who know him or her, and protects the patient's interests. It also acknowledges the hesitation and obstacles faced by family members called upon to "take the keys" from a loved one along with the loss of freedom and independence it represents.

Reporting to the DMV is, however, an imperfect solution: an approach that may work well for some situations but less well for others. When your patient poses an imminent risk to others reporting to the DMV may not be the best way to prevent

potential injury; it may merely transfer the ethical hot potato to a government agency. If an accident occurs pending administrative action, physicians or nurses may well wonder whether they should have done more. Whether the law in other states permits physicians to do more is beyond the scope of this essay.

## **AN UNEASY COMPROMISE**

Following New York's legal mandate to keep confidentiality may resolve the immediate problem, but it may not offer a satisfactory answer to the ethical quandary. If efforts to persuade the patient to take responsibility for addressing his or her driving impairment fail, you may be left with the uneasy compromise of doing what's legal, but not necessarily what's ethical. Or perhaps there is a persuasive ethical argument to disclose, even at risk of legal consequences.

—Robert S. Olick

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## **Should Vaccination for HPV Be Mandatory?**

In February 2007, to the surprise of many, Governor Rick Perry of Texas issued an executive order making the recently approved vaccine for human papillomavirus, or HPV, mandatory for all girls entering the sixth grade. Six weeks later, the Texas legislature nullified the order. The Texas exchange is just one episode in a debate unfolding across the country as state legislators consider whether to require that pre-teen girls be vaccinated against the sexually transmitted virus.

The Food and Drug Administration (FDA) in June 2006 approved a vaccine, called Gardasil, against HPV. Hailed as a public health achievement, Gardasil protects women from the four most virulent strains of HPV: types 6 and 11, which cause 90 percent of genital warts, and types 16 and 18, which cause 70 percent of cervical cancers. HPV is the most common sexually transmitted disease in the U.S., affecting 20 million people at any one time and more than half of

all sexually active people at some point in their lives. Most cases of HPV are asymptomatic and resolve themselves; a minority (3.4%) progress to cervical cancer. Thus, while HPV is prevalent, cervical cancer is relatively rare. The American Cancer Society estimates that 11,150 women in the U.S. will be diagnosed with cervical cancer in 2007 and 3,670 will die from it.

The CDC's Advisory Committee on Immunization Practices (ACIP) added Gardasil to its list of recommended childhood immunizations. But it refrained from recommending whether vaccination should be mandatory, leaving the matter to states. The American Cancer Society recommends routine HPV vaccination for girls 11 to 12 years old, with availability for girls 8 to 18. Because the vaccine is most effective when the recipient has not had previous exposure to HPV, it is likely to be of greatest benefit when given before a girl becomes sexually active.

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## **Treatment Refusal**

When an “end stage renal disease” (ESRD) patient refuses a dialysis treatment, either by verbally insisting “No” or by physically acting out in a way to prevent treatment, but the patient seems either unable or unwilling to engage in a reasoned discussion about treatment decisions, what should a nurse do? Four things should be kept in mind:

### **TRY TO RESTORE CAPACITY AND ADDRESS “FIXABLE” ISSUES THAT ACCOUNT FOR THE REFUSAL**

First, capacity for decision making is not fixed in stone, and may depend on a variety of changeable factors. Since refusal of dialysis will lead to death, it is essential for the health care team to do everything possible to optimize the patient’s condition so that he or she fully understands the consequences of treatment refusal. For acutely uremic patients, this might include temporary dialysis over their objection, in order to restore sufficient mental functioning to have a conversation about the patient’s desire for continued dialysis. A patient’s understanding might be clouded by medications, serious infection, mental illness, or inadequate pain control. The patient may fear the procedure or equipment. Inconvenient schedules may pose burdens that seem greater than the treatment’s benefit. Sometimes treatment refusals reflect issues that potentially could be addressed, such as lack of social support, transportation issues, or insufficient kindness. Insofar as possible, addressing these seemingly “secondary” issues may help the patient and health care team re-establish ground for shared decision making.

### **REMEMBER: MEDICAL CARE IS BASED ON A PARTNERSHIP**

Second, patients are not uniformly compliant with the complex demands of treatment. Because of the close monitoring required, dietary restrictions, and frequent appointments at busy dialysis centers, some dialysis patients find either the actual experience of dialysis or lifestyle restrictions to be extremely challenging. Mrs. Jones’ example is not unusual. As ESRD patients live longer, many elderly patients whose lives are being sustained by means of treatment no longer desire to endure the rigors of treatment.

On a pragmatic level, health care generally requires a partnership between the health care team and the patient; it is very difficult to make patients “well” over their objections. Patients need to breathe deeply and hold their breath for a good quality chest X-ray; no one else can do it for them. Patients sent home with a week’s prescription for antibiotics must remember to take them. Patients with diabetes must monitor their diets, check blood sugars, and adjust insulin dosages. Dialysis patients must sit or lie quietly while large-bore catheters purify their blood. If this can only be done by heavily sedating the patient, and if the patient does not, while competent, agree to this sedation, long-term dialysis is ethically problematic, and pragmatically may not be feasible.

**... MANY ELDERLY PATIENTS WHOSE LIVES ARE BEING SUSTAINED BY MEANS OF TREATMENT NO LONGER DESIRE TO ENDURE THE RIGORS OF TREATMENT.**

In the last decade, there has been an increase in the number of complaints about disruptive and abusive ESRD patients undergoing dialysis. Although such patients need the life-sustaining treatment, the nursing staff responsible for administering the treatments in the face of such behavior are often put at risk. Is there a limit to the risk that dialysis nurses must assume?

A national task force of physicians, nurses, social workers and government officials was convened to clarify the rights and obligations of both patients and providers in ESRD programs across the nation. The task force produced a statement issued in 2005, entitled “Decreasing Dialysis Patient Provider Conflict,” giving providers guidance regarding ethical, legal and regulatory issues related to the management of difficult ESRD patients.

The report states that it is unethical for patients to be left without treatments based solely on non-adherent behaviors that pose a risk only to themselves (such as not following a prescribed diet). At the same time, the statement asserts that providers have legal authority to refuse to treat patients who are acting violently or are physically abusive, thereby jeopardizing the health, safety or well-being of staff or other patients. Thus, in the case of Mr. Smith, the nurses are ethically justified in refusing to provide dialysis treatment, particularly if they can not do so safely. The fact that he is acutely uremic (and thus, may be temporarily confused) suggests that consideration might be given to chemically or physically restraining him acutely, in order to

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## **Treatment Refusal**

reverse the uremia and give him an opportunity to see if he can follow the necessary treatment. However, if repeated abusive behaviors occur and pose a risk to staff safety or make it impossible to deliver care to other patients, ethical grounds exist for the dialysis team to consider refusing to dialyze Mr. Smith further.

## **CONSIDER OUTSIDE RESOURCES**

Finally, the nurse should not feel alone in such difficult situations. She or he should seek out the advice and support of peers and supervisors, and raise these issues with the dialysis physician. The ethics

consultation service is also available to help nurses (and others involved in these situations) sort through their ethical obligations.

In summary, patient choice in health care is not absolute. Steps should be taken to try to restore the decision making capacity of incapacitated patients. Patients should not be treated over their well-reasoned objections. Even if patients are decisionally incapacitated, certain behaviors may make dialysis impossible to carry out in a way that is safe for the specific patient, other patients in the unit, or staff, and in such circumstances, consideration should be given to stopping dialysis.

—Barb Fero and Kathy Faber-Langendoen

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## **HPV**

### **HPV AND SEX**

The vaccine would not be so controversial if it merely prevented cervical cancer. But because it prevents the sexually transmitted virus that causes cervical cancer, it has attracted the ire of religious conservatives and others who believe that vaccination would encourage promiscuity among teens and undermine abstinence education. There are two kinds of opponents: those who oppose the vaccine altogether, and those who only oppose making the vaccine mandatory, via state legislation. The conservative advocacy group Focus on the Family, for example, believes that the vaccine should be available to parents who want it, but that no one should be required to get it. The debate now turns on whether states should require vaccination for pupils to attend school, as they do for measles, mumps, and other diseases.

Just because Gardasil is available, as some point out, does not mean that it should be mandatory. Even some who want their daughters vaccinated oppose mandatory vaccination. In their view, mandatory vaccination constitutes undue governmental involvement in parental decision-making. Supporters counter that HPV constitutes a public epidemic that requires a public response. In the 1950s and '60s, vaccination campaigns for measles, mumps, polio, and rubella showed that more people got vaccinated when they were required to. Some may believe that if a vaccine isn't mandatory, it's not worth getting.

Why should school entry be linked to vaccination? Opponents of mandatory vaccination point out that sex and sexual activity are lifestyle choices. No one acquires HPV by sitting in math class. But supporters note that schools are social as well as educational institutions. They argue that it's important to link school entry and vaccination not only to increase vaccination rates but to target the arena where many teenagers meet their sexual partners. In their view, abstinence is an unrealistic goal, as almost half of all high school students have sex every year, according to the CDC. Vaccination is most effective before girls have been exposed to the virus. Parents may be unwilling to recognize that their teenagers have premarital sex. Some parents may worry that recognizing this reality by inoculating their daughters would be tantamount to approving of it. Thus public conversation about HPV has reached an impasse.

Supporters of mandatory vaccination attempt to bypass this issue by framing Gardasil not as a vaccine against a sexually transmitted virus but as a vaccine against cervical cancer. After all, women who are abstinent before marriage can still contract HPV from their husbands. Supporters also argue that girls entering the sixth grade are too young to see vaccination against HPV as a license for sexual promiscuity. They also note that preventing HPV does not mollify teenagers' more pressing concerns about pregnancy and AIDS. So it is unlikely that vaccinating teens for HPV would encourage teens who would otherwise be abstinent to have sex.

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# Conscientious Objection vs Full Disclosure

A recent article in the *New England Journal of Medicine* tackles the growing debate over how the medical profession should handle conscientious objections. Although society seems accepting of a physician's right to conscientious objection, there is less agreement about what should happen if that right conflicts with a patient's right to access care. The authors wondered first, if physicians think they have the right to refuse to provide treatments they find morally objectionable, and second, if they do believe they have that right, do they still have a responsibility to talk to the patient about the treatment and help the patient find someone who will provide it?

## PHYSICIAN SURVEY

The authors surveyed 1820 physicians and received 1144 questionnaires back. The physicians were asked the following three questions: "If a patient requests a legal medical procedure, but the patient's physician objects to the procedure for religious or moral reasons, would it be ethical for the physician to plainly describe to the patient why he or she objects to the requested procedure? Does the physician have an obligation to present all possible options to the patient, including information about obtaining the requested procedure? Does the physician have an obligation to refer the patient to someone who does not object to the requested procedure?"

## CONTROVERSIAL PRACTICES

The questionnaire also asked about the respondents' religious commitments and affiliations as well as attitudes towards three specific controversial clinical practices: giving sedation that leads to unconsciousness in dying patients, providing abortion for failed contraception, and prescribing birth control to adolescents without parental approval.

The results of the survey were intriguing. Sixty-three percent of the physicians thought it was ethical to describe their objections to a patient's requested procedure. Eighty-six percent said a physician does have an obligation to present all possible options to the patient, including information about obtaining the

requested procedure, and 71 percent agreed that the physician should refer the patient to someone who does not object to the requested procedure.

However, the study's authors point out that these percentages may also indicate that **large numbers of patients are being treated by physicians who do not feel they have an ethical obligation to disclose information about available and legal medical treatments.** If the results of the study are representative of physicians in general, then one out of every seven patients does not hear about procedures or treatments to which the physician objects. These physicians who do not think they have that obligation are potentially responsible for more than 40 million patients. And 100 million patients are potentially not being helped to find a physician who will do the requested treatments.

## MALE VS FEMALE

Overall, the study found that "when patients request morally controversial clinical interventions, male physicians and those who consider themselves religious

will be the most likely to express their personal objections and the least likely to disclose information about the interventions or to refer patients to more accommodating providers." Female physicians were more likely to favor full disclosure of possible interventions and referrals to other providers. The study suggested this may be because the controversial issues in medicine so often involve the "sexual and reproductive health of women."

The study also suggests these conflicts provide a means of listening to an ongoing debate in ethics and medicine about paternalism vs. autonomy. Situating oneself on the far end of either pole creates problems for both physician and patient. Patients need to know if their physicians are giving them full disclosure about a course of treatment. Physicians have the right to "moral agency," but as this study reveals, cases can arise when two "rights" would appear to collide, and neither medicine nor ethics is clear about whose right prevails.

—Deirdre Neilen



## HPV

### GOVERNMENTAL AUTHORITY AND PARENTAL EXEMPTIONS

Parents who do not want to vaccinate their daughters can take an exemption. All states except Mississippi and West Virginia allow exemptions from mandatory vaccinations based on religious beliefs. In many states, one need only claim a religious exemption in order to get it; the state does not scrutinize a person's religious beliefs. Eighteen states also allow exemptions for philosophical or personal reasons. As long as legislation allows parents to claim exemptions, it may not be accurate to say that mandatory vaccination intrudes on parental decision-making. Such a policy preserves parental discretion while maximizing the reach of the vaccine.

The legal right to take an exemption has come under fire from both opponents and supporters of mandatory vaccination. Opponents want stronger objection clauses that specifically recognize personal and philosophical objections. Some supporters, on the other hand, want to minimize the availability of exemptions. They argue that exempted teens should not have to risk suffering from a preventable cancer because of the choices of their parents. The welfare of children is not something that only parents care about. Infringing on parental autonomy, they claim, is a small price to pay for the benefit of greater coverage.

When may the state intervene to safeguard the health of minors? That question is very much at the forefront of the debate over mandatory vaccination. It remains unclear whether the problem is acute enough – and the vaccine effective enough – to justify state intervention. Support for mandatory vaccination has been strained by recent studies that suggest that vaccinating teenagers who have already been exposed to HPV may not be as effective as previously thought. Moreover, because the vaccine eliminates only 70 percent of cervical cancers, health officials recommend that vaccinated women continue to receive regular Pap tests. While Pap tests do not prevent cervical cancer, they do provide early detection, greatly reducing the number of cervical cancer deaths in the United States. Finally, because the vaccine is new, its long-term effectiveness is unknown, and girls may need to be re-vaccinated. Thus, despite the well-recognized right of government to use “police powers” to guard the public's health, many have argued that it is at best premature to invoke that right in the case of HPV.

### OTHER OBJECTIONS TO MANDATORY VACCINATION

Beyond a general libertarian objection to state power, there are other objections to mandatory vaccination. Some fear that the vaccine isn't safe, despite assurances from both the CDC and the American Cancer Society. Some object to compulsory pediatric immunization in general. Others point to the lack of long-term studies supporting the vaccine's effectiveness. Still others favor creating a vaccine for males, who are obviously involved in transmission.

The zealous advocacy of Merck & Co., the vaccine's maker, also raised concerns. After the vaccine was approved, Merck lobbied state legislators for mandatory vaccination and appealed directly to potential consumers through TV and internet ads. Merck has much to gain if the vaccine is made mandatory, arousing the distrust of those who suspect that Merck is primarily motivated by its own financial gain. Public trust was further shaken when it was revealed that the former chief of staff to Texas Gov. Perry, whose executive order mandated vaccination, now worked as a Merck lobbyist. Faced with growing criticism, Merck halted its lobbying efforts.

Other objections focus on cost. Parents would have to bear Gardasil's hefty \$360 price tag, in addition to the cost of three doctor visits since Gardasil is administered in three shots over a six month period. Some of the proposed bills before state legislatures allocate state funds to offset Gardasil's costs or require private insurance companies to cover the vaccine. Some insurance companies already do. For uninsured and underinsured children, as well as children on Medicaid, the cost of Gardasil is covered under the federal Vaccines for Children Program.

Gov. Rick Perry declared in his executive order that “the newly approved HPV vaccine is a great advance in the protection of women's health.” But distributing the vaccine has proven far from simple. Concerns persist over the high cost of the vaccine, the state's authority to mandate vaccination, the scope of parental decision-making in matters affecting children's health, and perhaps above all, the difficulty of conducting public conversation about teenage sexual activity. Amid this tangle, the moral imperative to save lives is not as straightforward as it may seem.

—Eli Braun

A new feature of this newsletter offers excerpts from Upstate's latest issue of *The Healing Muse* published by the Center for Bioethics and Humanities. These pieces speak to the ongoing and dynamic relationship between medicine and ethics.

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## Sign Language

—Bruce Bennett

You showed me on your wrist  
small lines I would have missed,

Thin scars that scored your skin,  
but would not let me in

To what was cracked and broken,  
to what remained unspoken.

Bruce Bennett, author of seven books of poetry, is Chair of English and Director of Creative Writing at Wells College in Aurora, NY.

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