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Arthur R. Derse, MD, JD (Board Member), Allison Mechem Weaver (Editor), Coles McKagen (Associate Publisher), and Jill Robbins (Managing Editor) report no consultant, stockholder, speakers' bureau, research, or other financial relationships with companies having ties to this field of study.

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HPV vaccine: Doctors welcome it but question mandate of anticancer shot

Ethicist says school access shouldn't hinge on being vaccinated

The vaccine that provides protection against four types of human papillomavirus (HPV), a leading cause of cervical cancer, is recommended by the Centers for Disease Control and Prevention and the American Academy of Pediatrics (AAP), but drives to mandate it for adolescent girls have created a storm of controversy.

While most health care associations have stated support for a vaccine that could curb the threat of cervical cancer, there are mixed views on the ethics of mandating the vaccine and making school attendance dependent upon it.

"Making school attendance conditional on HPV vaccination does not make sense, because girls who are not vaccinated pose no threat — as they would with communicable diseases such as mumps, measles, and polio — to other children attending school," says **Paul Cieslak, MD**, a communicable disease manager for the Oregon Department of Human Services and a member of the Wynnewood, PA-based Catholic Medical Association (CMA).

Texas Gov. Rick Perry issued an executive order in early 2007 mandating that vaccination with Gardasil (Merck & Co., Whitehouse Station, NJ) be a requirement for all girls entering sixth grade in his state. Getting lesser attention is the fact that the HPV vaccine is subject to the same exemption policies already in place in Texas, by which parents who want to decline the vaccine for their daughters for philosophical reasons may do so by completing a paper or on-line form.

At issue among parents, doctors, and legislators, however, are a number of ethical issues:

- Will vaccination against the sexually transmitted HPV lead to careless sexual practices due to a false sense of protection against sexually transmitted diseases (STDs)?
- Is the vaccine effective enough to warrant legislative mandate, and should it be tied to school admission?

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Healthy prevention or hasty reaction?

According to the CDC, there are 40 types of HPV, and genital HPV is the most common sexually transmitted virus in the United States. About 20 million people in the United States are infected, and an estimated 6.2 million more get infected each year.

Gardasil is an inactivated vaccine that protects against four types of HPV — two types that the CDC says cause about 70% of cervical cancer, and two types that cause about 90% of genital

warts.

Critics say the vaccine is too new to be mandated, that its effectiveness and safety aren't fully known. The CDC says the vaccine was tested in more than 11,000 girls and women worldwide, with few adverse effects (primarily soreness at the injection site) reported.

The 2007 childhood immunization schedule from the American Academy of Pediatrics recommends vaccination for girls 11 to 12 years old and "catch-up" immunization for girls age 13 to 18. The vaccine is given as three injections over a six-month period, and at \$360 for the series is among the most costly vaccines on the market. Developed and sold as a vaccine against the HPV virus, Gardasil has been approved by the FDA to prevent cervical cancer in females between 9 and 26 years of age.

About 20 states are considering making the HPV vaccine mandatory, but Gov. Perry's executive order requiring the vaccine drew condemnation as well as praise.

"Requiring young girls to get vaccinated before they come into contact with HPV is responsible health and fiscal policy that has the potential to significantly reduce cases of cervical cancer and mitigate future medical costs," Perry said in a statement following the order.

A conservative Republican, Perry drew fire from his own party for what they viewed as mandating a vaccine that could promote sexual promiscuity — the argument being that by protecting against the STD women could let their guard down and neglect safe-sex practices and annual gynecological exams.

Harold Vanderpool, PhD, ThM, medical ethicist at the University of Texas (Galveston) Medical Branch, says to equate vaccination against a STD with sexual promiscuity "is a stretch."

"[A girl's] parents and her peers have more influence on her sexual decisions than the fear of cancer," says Vanderpool. "The legitimate ethical debate on this vaccine is about whether it should be mandated or optional; that's an issue we need to discuss as a society."

As critics weighed in on his executive order, Perry countered that the opt-out provision preserves parents' rights.

"Providing the HPV vaccine doesn't promote sexual promiscuity anymore than providing the hepatitis B vaccine promotes drug use," Perry says. "If the medical community developed a

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Editor: **Allison Mechem Weaver**.

Senior Vice President/Group Publisher: **Brenda Mooney**, (404) 262-5403, (brenda.mooney@ahcmedia.com).

Associate Publisher: **Coles McKagen**, (404) 262-5420, (coles.mckagen@ahcmedia.com).

Managing Editor: **Jill Robbins**, (404) 262-5557, (jill.robbins@ahcmedia.com).

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Editorial Questions

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vaccine for lung cancer, would the same critics oppose it claiming it would encourage smoking?

"[P]arents need to know that they have the final decision about whether or not their daughter is vaccinated. I am a strong believer in protecting parental rights, which is why this executive order allows them to opt out."

(Editor's note: In late March, the Texas House passed a bill overturning Perry's order, and the Senate is expected to vote on it in late April. If the executive order is repealed by the Legislature, Perry will have the option to veto it; however, legislative support for overturning the mandate is expected to mean any veto could be overridden. In addition, State Attorney General Greg Abbott told some legislators that Perry's mandate of the HPV vaccine is "unenforceable," according to media accounts.)

Drug maker drops lobby efforts

Following a vigorous effort in Texas and other states to lobby legislators to mandate the vaccine, drug maker Merck & Co. in February announced it would curb its efforts.

Georgetown University Law Center's **Lawrence Gostin**, JD, director of the O'Neill Institute for National and Global Health Law, says it is inappropriate for pharmaceutical companies to lobby for something from which they will directly benefit, as Merck did for mandatory vaccination laws.

"[The HPV vaccine] is a marvelous public health intervention, but it should be part of a large-scale, national campaign to reduce the prevalence of sexually transmitted diseases," says Gostin.

SOURCES

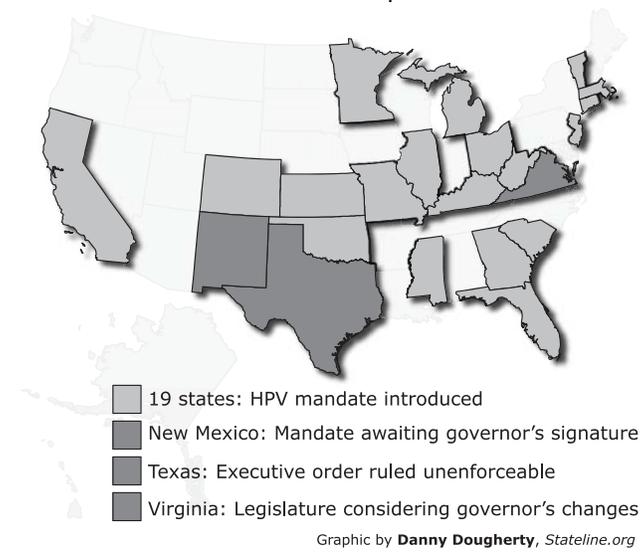
For more information, contact:

- **John Brehany**, PhD, STL, executive director and ethicist, Catholic Medical Association. Phone: (712) 202-2283. E-mail: brehany@cathmed.org.
- **Harold Vanderpool**, PhD, ThM, professor, Institute for the Medical Humanities. University of Texas Medical Branch, Galveston. E-mail: hvanderp@utmb.edu.
- Centers for Disease Control and Prevention. Quadrivalent human papillomavirus vaccine: Recommendations of the Advisory Committee on Immunization Practices (ACIP). *MMWR* 2007; 56 (RR02): 1-24. Available on-line at www.cdc.gov/mmwr/preview/mmwrhtml/rr5602a1.htm. (Accessed 3/28/2007.)

Stateline.org

State HPV vaccination policies

Each state decides for itself which vaccines to mandate for children attending school. This year, 22 state legislatures considered mandating the HPV vaccine. States already require a wide variety of other shots and differ on when to make exceptions to those rules.



Sources: The Centers for Disease Control and Prevention, the Food and Drug Administration and the National Network for Immunization Information

The HPV vaccine offers the best protection when administered before a girl becomes sexually active. Girls can contract HPV as teenagers through sexual activity, and not develop cervical cancer until years later.

Though some opposition to the mandate — not the vaccine itself — suggests that requiring the vaccine for all girls could encourage risky sexual practices, most critics question whether states should be linking the vaccine to schools.

Ethicist **John Brehany**, PhD, STL, executive director of the Catholic Medical Association, says that while the CMA endorses abstinence outside of marriage, the fact that HPV is spread primarily by sexual contact does not render vaccination against it unethical.

"Healing and preventing diseases, no matter what their source, are acts of mercy and a moral good," Brehany says.

Less ethical, says CMA member Cieslak, is tying HPV vaccine compliance to school attendance.

"Raising vaccination rates is an important public health goal, but that doesn't justify every measure that might get us there," he says. "Depriving children of an education in the name of a broad public health goal isn't being fair to them." ■

Hospice as continuation of care not just end of the road

Open access could help patients avoid 'terrible choice'

Hospice evolved from the need to provide medical and social support to terminally ill patients in the last weeks of their lives. But while the benefits hospice can provide have expanded, the perception that hospice is where patients go to die has, until recently, stayed the same.

According to **Richard Payne**, MD, director of the Duke Institute on Care at the End of Life at Duke University Divinity School in Durham, NC, patients at end of life who might benefit from what hospice has to offer — medical, social, and spiritual support — have been faced with what has come to be known as the “terrible choice:” To qualify for Medicare hospice benefits, most patients have had to resign themselves to giving up advanced medical treatments such as chemotherapy and dialysis.

But that’s changing, as evidenced by a movement toward “open-access” hospice programs that allow patients to continue the treatments that, while not life-saving, can make the quality of the end of life much better.

“We’re not talking about people like Elizabeth Edwards or Tony Snow, who have incurable conditions but who aren’t likely to die in six months,” says Payne, referring to the wife of presidential candidate John Edwards and the White House spokesman, both of whom recently have had recurrences of cancer.

“But what hospice can do is provide open access to people who are likely to die in six months but who can be made more comfortable through palliative chemotherapy or radiation, antiretroviral drugs — treatment that is not going to cure them, but will make the last weeks or months of their lives much more comfortable,” he explains.

‘Terrible choice’ forced by money

Medicare’s rules on hospice care do not require that hospice programs deny patients advanced medical care. But at a benefit of \$130 per day for such care, the ability for a hospice program that’s not backed by a larger institution to offer that kind of care to its dying patients is not likely.

To qualify for hospice benefits, a patient must

be diagnosed with a condition that is likely to result in death in six months or less. For many patients and their doctors, that requirement in and of itself is enough to delay entering hospice.

“Physicians in their training are taught to cure,” points out **Roseanne Berry**, RN, chief compliance officer for VistaCare, an Arizona-based national hospice provider. “There is much more education going on now in end of life [in medical schools], but some doctors have had little or no training in how to help their patients die.”

The challenge for hospice providers, Berry says, is to help patients and physicians see hospice not as the end of the road in treatment, but as another layer in the continuum of care — a natural continuation of the care the patient has had up to the point where hospice becomes a consideration.

“We’re getting there, but we still have about one-third of hospice patients die within a week of admission, and while we’re glad to provide that care, it certainly doesn’t give us the chance to provide the best care we could for those patients,” Berry adds.

In 2005, only about a third of the 2.4 million people who died in the United States were in hospice care, Payne says, perhaps half as many as could have benefited from hospice programs.

He says Medicare policy makers argued that by giving patients a choice of staying in traditional health care or opting into hospice care that would allow the government to save money and still give patients what they need to die comfortably.

“But where do you draw the line?” asks Payne, addressing advances in medicine that blur the line between palliative and curative care. “How do you decide if something is given with palliative intent vs. curative intent?”

Larger hospices can offer more in the way of palliative care because they can spread their costs over a larger population, he points out.

“If you have 1,000 patients and 900 are getting relatively low-intensity therapies that cost less than \$130 a day, you can spread around the remainder to provide higher-cost care to the other 100 patients who need it,” he says.

As the baby boom generation and its parents age, they are demanding more choices than just a place to die comfortably, Berry says, so hospice services are changing to meet that demand.

“I bet you have seen more changes in this area in the last two years than you’ve seen in the 10 years prior to that,” she suggests. “But you have to have those conversations. We’re great at planning parties, planning vacations, planning every-

SOURCES

For more information, contact:

- **Richard Payne**, MD, director, Duke Institute on Care at the End of Life at Duke University Divinity School, Durham, NC. E-mail: rpayne@div.duke.edu.
- **Roseanne Berry**, RN, chief compliance officer, VistaCare, 4800 N. Scottsdale Road, Suite 5000, Scottsdale, AZ 85251. Phone: (480) 648-4545.
- **Ronald J. Crossno**, MD, medical director, VistaCare Hospice, Temple, TX. Phone: (254) 742-2000.

thing but the end of our lives; but having those conversations lets us say, 'If you're eligible for hospice care, if your doctor has certified that you are, then let's remove the barriers and look at hospice as another part of your treatment.'"

The question that remains, Payne says, is how to afford it. While Medicaid is saving money by paying only \$130 per day in benefits, for many patients the costs skyrocket because of expensive trips to the emergency department or hospital admissions that could be avoided with advanced care provided within the hospice setting, experts say.

"It's a good thing to do to offer patients these options, and it does diminish the psychological barrier of the terrible choice," says Payne. "If there is a way to provide the care they need in hospice — team-oriented, physical, psychosocial, and spiritual well-being — and provide some medically oriented therapies with palliative intent, it makes a lot of sense medically, and it's a reasonable health policy."

Open access means providing these types of therapies, Payne continues. A hospice does not get paid any differently when advance treatment is provided, so open access can mean providing more care at a financial loss. And if Medicare determines that the treatment is curative, not palliative in intent, it could withhold funds for that patient completely.

Removing obstacles and fear

Patients who might be eligible for hospice often are kept away by fear and lack of understanding, Berry and Payne agree.

"We want to remove the obstacles. We tell patients you don't have to have a caregiver in your home. You don't have to have a [do not resuscitate] order, you don't have to have advance directives to come into hospice,"

explains Berry. "Medicare allows hospices to have their own philosophies, so we do what we can to remove as many of the obstacles as we can, get them into hospice, and then work with them to plan how they want their end of life to be."

Payne says the psychological barrier of looking at hospice as a place to go to die is one of the biggest obstacles.

By not choosing hospice, or by choosing it only in the last days of life, Berry says, many people are giving up a valuable system of care and support.

"Most of our services are provided in the patient's own home," she points out, often with providers the patient has come to know and trust.

"One big concern among patients at the end of life is abandonment. They don't want to be abandoned by their primary care or oncology provider," she says. "In hospice, we can tell them that we will work with their providers, and we are just another layer of care and another set of providers who are here to enhance the care their doctors say they should have."

Payne advocates educating patients and their health care providers and support systems (family, clergy) about hospice, so that the decision to choose hospice is made ahead of time as a part of continued care, not as a last resort.

"The No. 1 complaint I hear from patients is, 'Why didn't we get this sooner?'" says **Ronald J. Crossno**, MD, medical director for VistaCare Hospice in Temple, TX. "Thirty-five percent of eligible U.S. patients receive hospice care. Twenty-five percent of these patients get hospice care for less than seven days [before they die]."

"An earlier referral means the patient can still go see the grandchildren and it improves the transition. If you're hurting or in pain, you can't deal with the other issues relative to dying."

Berry says that patients who enter hospice shouldn't think they have to give up hope.

"But you have to have the prognosis [of death likely in six months], and those prognoses are very hard for physicians because they want to be optimistic," she explains.

Palliative care physicians can be a good resource if a patient — or his or her physician — is having a difficult time concluding that hospice is an option.

"Palliative care specialists deal with all of the issues that terminally ill patients face. The specialist makes arrangements and goes beyond the social worker," Crossno explains. He says 25% of U.S. hospitals had palliative care specialists in 2005, but expects that number to jump by 2010. ■

Need to blow the whistle? A disclosure policy will help

Full disclosure can eliminate finger-pointing

For a doctor, telling a patient or patient's family that a medical error has happened in the course of his or her care is hard enough. But what if the error was committed by another provider?

As one physician wrote in the *Journal of the American Medical Association*, "Whistleblowing is not an appealing activity."¹ The literature reveals numerous approaches and rationales for handling the disclosure — or not — of errors committed by others: Commonly suggested options include confronting the errant physician and asking that he or she make the disclosure; arranging a meeting involving yourself, the other physician, and the patient; telling the patient about the mistake without consulting the physician who committed the error; and, least preferably, saying nothing. Each has its drawbacks, authors have concluded.

According to **Doug Wojcieszak**, founder of the Glen Carbon, IL-based Sorry Works! Coalition, whistleblowers aren't necessary when a hospital implements a policy of full disclosure. Sorry Works! is an organization of doctors, lawyers, insurers, and patient advocates that is dedicated to promoting full disclosure and apologies for medical errors as a "middle-ground solution" for medical liability.

Under the Sorry Works! protocol, if a standard of care was not met (as shown by a root-cause analysis) in a bad outcome or adverse event, the providers (and their insurer) should apologize to the patient/family, admit fault, provide an explanation of what happened and how the hospital will ensure that the error is not repeated, and offer compensation. Five states now have mandatory disclosure laws on their books, and numerous health care systems (including the Veterans Administration) have implemented full disclosure and apology policies.

The result, they say, is better patient and physician satisfaction with outcomes, and reduced financial costs related to malpractice lawsuits.

Whistleblowing a sign disclosure is needed

A survey published in 2006 in the *Archives of Internal Medicine* reveals that almost every doctor polled (98%) supports disclosing major medical

SOURCES

For more information, contact:

- **Doug Wojcieszak**, spokesman, Sorry Works! Coalition. P.O. Box 531, Glen Carbon, IL 62034. Phone: (618) 559-8168. E-mail: doug@sorryworks.net. Web site: www.sorryworks.net.

errors to patients, and 66% agree that disclosing serious errors reduces malpractice risks.² The American Medical Association's code of ethics requires disclosure of errors.

Whistleblowing — or health care providers feeling the need to disclose errors by others — is one sign that a disclosure policy might be needed, says Wojcieszak.

"It goes on a lot in institutions where there's not disclosure and apology — where everyone knows there's been a mistake, and that it's being covered up, until someone with a conscience gets with the family and lets them know that something has gone wrong," he explains.

That scenario, Wojcieszak insists, benefits no one involved.

"On the other hand, if you have a disclosure and apology policy that's rolled out throughout the entire institution — one strong voice for the whole institution — you lessen the chance for finger pointing, or 'jousting,' as someone referred to it recently," he explains.

When a hospital implements a disclosure policy, "everyone knows when an error occurs how to follow through with reporting it."

Not that disclosure is a universally accepted idea, Wojcieszak acknowledges.

"Say you have Doctor X, an old-time doctor taught from the minute he first put on his white coat that you never admit fault, you never apologize. He thinks this disclosure thing is a fad," says Wojcieszak. "Then, an incident happens [involving one of his patients] — what happens?"

If the doctor doesn't believe the patient or family should be told of the error, there are channels that allow the disclosure process to simply bypass that doctor, with the hospital going forward with disclosing the error and making apologies.

"The good thing about medical errors is that it's usually not just one person who's involved," Wojcieszak points out. "And the good thing about a disclosure program is that it gets everything back to the risk management department, to people who are trained on what to do with the

information.”

The disclosure model works most easily at self-insured hospitals, where everyone is insured and employed by the same entity.

“You can have some tricky circumstances where one doctor is insured by his own [outside] insurance company, but the hospital will have had a conversation with this insurance carrier long before any incidents come up,” he says. “The hospital talks with the insurer, and the insurer helps bring the doctor on board.”

Finally, a disclosure policy not only assures that patients are informed, but that they are informed accurately and fully.

“It does away with errant disclosures — where, for example, a resident thinks he did something that caused a patient to die, and tells the family he accidentally killed the patient,” he says. “It turns out he didn’t, but it’s not helpful that he said he did. That’s how you get nonmeritorious claims filed. Full disclosure and apology [policies] provide a channel for reasonable, well-thought-out disclosures.”

References

1. Fost N. Ethical issues in whistleblowing. *JAMA* 2001; 286:1,079.
2. Gallagher TH, Garbutt JM, Waterman AD, et al. Choosing your words carefully: How physicians would disclose harmful medical errors to patients. *Arch Intern Med* 2006; 166:1,585-1,593. ■

Minimally conscious patients not being tracked

As many as 100,000 are under ‘custodial care’

While the media glare on cases like those of brain-damaged, “vegetative” patients such as Terri Schiavo and Terry Wallis has brought plenty of attention to the questions surrounding the recovery of severely brain-injured patients, it has done little to clear up confusion, according to medical ethics experts.

But a nationwide epidemiological study on how such severely brain-injured patients are being cared for long term could provide more concrete answers, according to New York Presbyterian/Weill Cornell Medical College ethics director **Joseph Fins**, MD.

SOURCES

For more information, contact:

- **Joseph Fins**, MD, Chief of the Division of Medical Ethics, New York Presbyterian–Weill Cornell Medical Center. Address: 435 E. 70 St., Suite 4-J, New York, NY 10021. Email: jjfins@med.cornell.edu.

The questions don’t just deal with how patients are being cared for, he points out. “Right now, we don’t even know how many Americans with conditions such as the vegetative state or the minimally conscious state are being cared for in medical centers and nursing homes nationwide,” he points out.

Fins and colleagues recently reported on an Institutes of Medicine (IOM) exploratory meeting on disorders of consciousness, and their findings appear in the January issue of the American Academy of Neurology journal *Neurology*.¹

“Getting those numbers [of patients being treated] in a countrywide survey is an essential first step for the kind of research that would help us in the diagnosis, prognosis, and treatment of these severely debilitating conditions,” adds senior author **Kathleen Foley**, MD, who chaired the IOM exploratory meeting. Foley is professor of neurology and neuroscience and professor of clinical pharmacology at Weill Cornell, and an attending neurologist at New York-Presbyterian/Weill Cornell.

“Without national data, we don’t know how many patients are in this situation. In fact, we don’t even know how frequent or likely recoveries like [Terry Wallis’] might be,” she notes. “Obviously, we need to do a better job of keeping track of all patients with disorders of consciousness, including periodically reassessing them for any changes in neurological function. That sort of database would greatly enhance research.”

Wallis — Different from Schiavo case

The case of Terri Schiavo, a Florida woman whose family waged a war over her right to die vs. her right to remain alive in a nursing facility, grabbed headlines for more than a year, ending in her death in 2005 after her husband was granted permission to have her feeding tube withdrawn. Prior to her death, Schiavo had been diagnosed by neurologists as being in a permanent vegetative state, and an autopsy later confirmed the diagnosis, showing large areas of fluid-filled

space in her brain.

Terry Wallis' case took a much different turn. The 42-year-old Arkansas man had been severely brain injured in a motor vehicle accident in 1984, and spent the next 20 years in a minimally conscious state in a nursing facility, receiving little more than what Fins and his co-authors call "custodial care." However, in 2003, he began talking and moving, and is now able to form sentences and move his legs and one arm.

Fins' co-author **Nicholas Schiff**, MD, a neurology professor at Weill Cornell, who has worked extensively on the Wallis case, says that unlike Schiavo, minimally-conscious patients like Wallis show "intermittent but unmistakable" signs of consciousness.

Schiff says his research suggests that Wallis' brain has been slowly forming new neuronal connections since his accident, allowing him to eventually wake from the minimally conscious state.

"Cases like those of Schiavo and Wallis tend to blur the lines between the minimally conscious state and the vegetative state," says Fins, pointing out an important distinction often lost in media accounts about cases of brain injury.

"But we have an opportunity now, with advances in brain imaging technology, to improve our understanding. Even a modest investment in epidemiological and clinical research will pay off with better diagnostics, and better means of giving loved ones realistic expectations of patient outcomes — good or bad," he adds.

Identifying, differentiating cases crucial

Schiff, Fins, and Foley say in their report that identifying and encouraging the recovery of patients such as Wallis is one reason scientists need the resources to track the care of brain-injured patients in the United States.

Fins says the Wallis case "demonstrates that, even years after injury, the minimally conscious brain has the potential, in rare cases, for recovery. It also lays out the possibility that this process might even be accelerated and helped."

More than 100,000 patients in the United States are thought to be in long-term care facilities under custodial care, which involves little consistent follow up, the authors say. If those patients were tracked and periodically re-evaluated, Fins writes, scientists could get a better grasp of disorders of consciousness and how they vary from patient to patient and over time.

"For example, 16% of patients in the vegetative state six months following traumatic brain injury recover consciousness at one year, with about a quarter of them recovering independent function," Fins explains. "It is inaccurate to think that all disorders of consciousness are immutable and fixed."

But currently, a diagnosis of these patients is riddled with confusion and error, the authors state. According to some estimates, as many as 40% of patients in the minimally conscious state may be misdiagnosed by doctors as being in a vegetative state, which carries little or no hope of recovery. In Wallis' case, his family struggled with Medicaid requirements that limited the amount of therapy Wallis could receive, because it was based on how fast his progress was — and his progress was very slow.

"Again, it all comes back to our need for more insight into these conditions, their relative prevalence, and the changes that may or may not be going on neurologically over time," says Fins.

Reference

1. Fins JJ, Schiff ND, Foley KM. Late recovery from the minimally conscious state: Ethical and policy implications. *Neurology* 2007; 68:304-307. ■

The limits of privacy with patients with STDs

Disclosure to patient's partner must come from patient

If a patient has a sexually transmitted disease and you are fearful of him or her infecting others, you may be tempted to inform the patient's spouse or significant other. However, this is the patient's decision to make... not the doctor's.

"If you tell the patient they should discuss this with their husband or wife, and they say no, then under no circumstances can you do so," according to **Jonathan D. Lawrence**, MD, JD, FACEP, a physician and medical staff risk management liaison at St. Mary Medical Center in Long Beach, CA. "If you spill the beans with the significant other, that's a violation of the law."

However, you can encourage the patient to inform their spouse or sexual partners about their STD. You also can — and should — tell the patient that you are required by law to report to the health

department any STD that is listed by your state as a reportable disease, and make them aware that the health department may contact their significant other. But that's as far as you can go.

"If you can't convince your patient to tell them, you can't take it upon yourself to go inform the person's contacts," says Lawrence. "You can try to be as convincing as possible, but you can't make the person either get treated or inform their partners."

If you do, you are leaving yourself open for violation of HIPAA, and accusations of negligence, with both criminal and civil liability coming into play, says Lawrence. In essence, you do not have a duty to the patient's spouse; you only have a duty to the patient, he says.

The basic rule is that an STD is like any other medical information — a private matter between the physician and the patient, unless the patient gives permission to disseminate it to anyone else. "Otherwise this information should be shared only with those who, by statute, require notification," says **Matthew M. Rice**, MD, JD, FACEP, chief medical officer at Northwest Emergency Physicians of TeamHealth in Federal Way, WA.

Other medical professionals may be informed if they are participating in the patient's care and have a need to know, says Rice. Other individuals should not be notified unless there is a compelling reason such as a judicial order, valid legal summons for information, or life-and-death situation. "If the beans are spilled and there are damages, then litigation could successfully occur," says Rice.

Damages from litigation are very case and locality specific, and disclosure of confidential information can invoke financial penalties under federal, and possibly state, confidentiality laws, says Rice.

When a patient is diagnosed with an STD, he or she also must be notified of appropriate medical precautions to take, and reasonable strategies to prevent transmission to others. The physician should recommend the patient's sexual partners be notified and treated, advises Rice. "If the individual is married, then you should tell the patient to notify that party and all others who may be at risk," he says.

Reporting requirements vary from state to state, and at times, jurisdiction to jurisdiction, but most states and jurisdictions have reporting requirements for gonorrhea, syphilis, and chlamydia. Generally, requirements to report are similar to other infectious diseases with a public

SOURCES

For more information, contact:

- **Jonathan D. Lawrence**, MD, JD, FACEP, emergency department, St. Mary Medical Center, 1050 Linden Ave., Long Beach, CA 90813. Phone: (562) 491-9090. E-mail: jonlawrence48@cox.net
- **W. Frank Peacock**, MD, The Cleveland Clinic Foundation, Department of Emergency Medicine, Cleveland, OH. Phone: (216) 445-4546. Fax: (216) 445-4552. E-mail: peacocw@ccf.org
- **Matthew M. Rice**, MD, JD, FACEP, chief medical officer, Northwest Emergency Physicians of TeamHealth, 3455 S. 344th Way, Ste. 210, Federal Way, WA 98001. Phone: (253) 838-6180 ext. 2118. E-mail: matt_rice@teamhealth.com.

health risk. "Thus, each physician should check with their local health departments to see what is required reporting by law," says Rice. "This should also be verified with the hospital where you work, since often a report of an STD comes from a lab report and the ordering physician may not be available."

Typically, hospitals have a systematic process to notify reporting authorities according to statutory law, and a process to notify clinical providers for correlation with a test result and treatment.

"HIV testing has always been more complicated, and the disease has been politicized and carefully regulated for many years," notes Rice. "It would be unusual to know of an HIV-positive test without the patient having consented to testing, and strict rules regulate how reporting must be accomplished."

Take steps to reach patient

If you have a positive culture and can't reach the patient, you have to document that you tried and were unsuccessful, says Lawrence. But the question is, how hard do you have to try?

"I don't know of any case where failure to get a hold of the patient ended up being construed as negligent," he says. You must call the patient using the telephone number on record, or send a telegram or letter to the address listed, and if you're unsuccessful because the number is disconnected or information is incorrect, your obligation most likely ends there, says Lawrence.

"If after doing that you still can't get a hold of the patient, you have done all you can do. The

standard of care has not yet reached the point where you have to double check that the number is right. You have shielded yourself from liability if you used the contact information on the chart," says Lawrence.

However, you can increase the likelihood that you will be able to reach the patient with this process: Have the nurse or physician personally ask the patient for the best way to reach him or her if the culture comes back positive. "The admitting office often does a terrible job at getting correct phone numbers, and isn't interested in how accurate they are, so their records may not be updated," says Lawrence.

Failure to contact a patient is a significant legal risk for both the physician and the hospital, says **W. Frank Peacock**, MD, vice chief of emergency medicine research at The Cleveland Clinic Foundation. "That is why I rarely establish a callback routine when a patient wants to leave before all their results are back. Instead, I tell the patient they have to contact me," he says. "That way, if there is a failure to reach them for whatever reason, the onus was on them. I've had patients go out to the bar after leaving the ED. How could I possibly track them down?"

At The Cleveland Clinic, for all culture results that may return several days after the patient has left the emergency department, a callback system is used. When the results come back, the ED physician determines the importance of immediate callback. For example, the patient is called immediately for a positive spinal fluid culture, even if it is 4:00 a.m., but for a positive STD culture, the patient would be called the next morning by an ED nurse.

"Our process requires that the nurse must reach the patient themselves. No message takers or answering machines are allowed," says Peacock.

If an answering machine is encountered, a simple message is left stating that the patient should call the hospital where he or she was treated. When the patient is reached, he or she may be asked to return to the ED or a prescription may be called to a local pharmacy. Appropriate instructions are given, and follow up is arranged if needed.

Since patients often leave inadequate or inaccurate information, timely contact is not always possible. However, when a positive test is known and the problem was not already treated, then it is the responsibility of the medical providers and institutions to have worked out a mechanism of

informing the patient and public health authorities as required by law, says Rice.

Minors and parents

If a minor is brought to the ED by a parent and complains of abdominal pain that turns out to be pelvic inflammatory disease (PID), can the physician inform the parents?

"The law in most states is that most minors can seek care for STDs without their parents' consent. But it doesn't really raise the issue if they are there because the parents brought them," says Lawrence.

In the ED, providers will never be 100% certain that the patient has PID, since culture results won't be available for 48 hours, notes Lawrence. "Instead, you can tell them it's an infection and you are investigating the cause," he says.

If a gonorrhea culture comes back positive for a minor who was discharged from the ED, the provider has every legal right to talk to the parents, and informing them is perfectly acceptable, says Lawrence.

As for admitting adolescents with PID, Lawrence recommends obtaining a consultation with a gynecologist to determine whether this is necessary. "That certainly would insulate the ED physician from any accusation that the patient wasn't treated according to the standard of practice," says Lawrence.

Typically, a first-time PID patient is treated as an inpatient to avoid potential litigation, says Rice. "But in some communities, and with new treatment strategies, outpatient treatment may be reasonable if accepted as the community standard," he adds. ■

KS court: Doctors, patients are 'suppliers,' 'consumers'

Providers not included in consumer protection law

A Kansas Supreme Court ruling that defined physicians as "suppliers" prompted swift action by legislators, who have taken action on a

CE/CME answers

17. D; 18. A; 19. B; 20. B.

bill that would exclude health care providers from being sued for deceptive practices under the state Consumer Protection Act.

The Supreme Court ruled that the state's consumer protection law was broad enough to include medical care and errors — not just billing errors, which are accepted as part of consumer protection. Patients, as “consumers,” could sue doctors, the “suppliers,” for deceptive practices if outcomes were not as expected.

The Kansas Medical Society swiftly came out in opposition to the ruling, and legislation was quickly drafted that would exclude health care providers as the “supplier” under the consumer protection law.

The bill passed the state House overwhelmingly in March; the Senate was considering the bill at the time *Medical Ethics Advisor* went to print.

The state Supreme Court's ruling comes from the appeal of a lawsuit filed by a Kansas woman, Tracy Williamson, against her orthopedic surgeon, Jacob Amrani, MD, after fusion surgery was unsuccessful in relieving her back pain.

Williamson claims that Amrani assured her of the likelihood that the surgery would relieve her back pain, but alleges that he actually often had unsatisfactory outcomes with this type of surgery. Amrani alleges he made no promises of success to Williamson, and that she signed multiple consent forms that contained wording indicating no guarantees were made.

Williamson sued under the consumer protection law, rather than under malpractice laws, and the state high court agreed that she could, considering the current wording of the Consumer Protection Act. The court stated in its ruling that it would be up to the legislature to alter wording to exclude malpractice issues from consumer protection lawsuits.

Legislators sponsoring the bill say it will keep malpractice issues out of consumer protection cases, while still leaving questions of false advertising and billing as consumer issues.

Williamson previously had sued Amrani for medical malpractice, but her suit was dismissed

due to lack of expert witnesses. In media accounts of the case, Amrani's attorney said the subsequent suit under consumer protection law was merely an “end run” around the failed malpractice action.

The Supreme Court's ruling sent Williamson's case back to the district court for trial, and a trial is expected to take place later this year. Changes in the law at this point would not affect Williamson's lawsuit against Amrani.

“We do not believe a special group ought to be exempt [from consumer protection actions],” says **Ashley Anstaett**, a spokeswoman for Kansas

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, you must complete the evaluation form provided at the end of each semester and return it in the reply envelope provided to receive a credit letter. When your evaluation is received, a credit letter will be mailed to you. ■

CME objectives

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

- discuss new information about hospital-based approaches to bioethical issues and developments in the regulatory arena that apply to the hospital ethics committee;
- stay abreast of developments in bioethics and their implications on patient care, risk management, and liability;
- learn how bioethical issues specifically affect physicians, patients, and patients' families. ■

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CME Questions

17. According to the American Academy of Pediatrics 2007 immunization schedule, the Gardasil vaccine for human papillomavirus is:
 - A. recommended for girls age 11 to 12 years old.
 - B. given as three injections over a six-month period.
 - C. should be provided as a "catch-up" immunization for girls age 13 to 18.
 - D. All of the above

18. The so-called "terrible choice" posed by Medicare hospice benefits refers to:
 - A. Patients likely having to relinquish advanced medical treatments.
 - B. Patients having to leave their homes and move into hospice facilities.
 - C. Patients having to end their relationships with their primary care or oncology providers.
 - D. Income requirements that deny hospice benefits to many patients.

19. When treating a patient with a sexually transmitted disease who has partner who might be at risk of infection, a physician should advise the patient to tell the partner, and if the patient refuses, should send a letter informing the partner of the infection.
 - A. True
 - B. False

20. According to researchers at Weill Cornell Medical College, what percent of patients in a vegetative state six months following a traumatic brain injury recover consciousness at one year?
 - A. 5%
 - B. 16%
 - C. 25%
 - D. 88%

Attorney General Paul Morrison. "We believe this bill eliminates legal protection for consumers of health care services."

The Medical Society of Sedgwick County, which includes Wichita, issued a statement advocating keeping medical malpractice out of consumer protection lawsuits and not to treat the doctor-patient relationship "as a consumer transaction." ■