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The pendulum swings

However, some former advocates of expanded opioid use are warning that prescribing has gotten out of hand — particularly for patients whose pain is chronic and not the result of a terminal illness or sudden, acute injury.

"The pendulum swung all the way in the other direction a few years ago," notes **Steven D. Feinberg**, MD, a physician and pain management specialist with the Bay Area Pain Program in Los Gatos, CA, and former president of the American Academy of Pain Medicine. "It has come to everybody and their brother writing prescriptions for opioids. This is good in some cases. But as a chronic pain doctor, I started seeing a lot of people coming into my office who were literally narcotized. I have a big problem when someone walks

ED staff uncomfortable with parental presence

✓ *Staffers reluctant to be observed by parents*

Should parents be allowed to stay with their children in the emergency department (ED) while invasive procedures are performed? Who should make the ultimate decision about whether, and in what circumstances, they should be there? Although prior studies of patients and family members have indicated they favor the practice, a recent survey of nurses and physicians in 10 EDs around the country indicates that providers may be more reluctant. The majority of respondents felt that permitting parental presence should be decided on a case-by-case basis, with the decision-making shared by both providers and parents 41

Genetic screening draws fire from ethicists

✓ *IVF pre-implantation diagnosis under question*

Should prenatal genetic diagnosis be used to screen human embryos for genetic predispositions to certain diseases, not just as a tool to detect genetic markers that definitely indicate the presence of a medical condition? That's the challenging question raised in a recent report in the Feb. 27, 2002, issue of the *Journal of the American Medical Association*. In the report, Verlinsky and colleagues at the Reproductive Genetics Institute of Chicago detail the case of a 30-year-old woman with a genetic marker linked to the development of early-onset Alzheimer's disease. Although currently asymptomatic, the woman's sister, brother, and father all have the illness, and genetic testing has shown that she has the same mutation. In what is thought to be a medical first, the woman underwent two cycles of an in vitro fertilization (IVF) procedure, with all embryos screened for the genetic mutation prior to implantation in her uterus. As a result, the woman gave birth to a baby girl without the mutation and has used the screened IVF procedure to become pregnant a second time 44

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into my office on massive amounts of medication but they don't seem any better."

A difficult history

In the 1960s and 1970s, prescribing dependency-producing drugs to treat pain was unheard of for any reason, says **R. Norman Harden**, MD, director of the Center for Pain Studies at the Rehabilitation Institute of Chicago and an associate professor in the department of physical medicine and rehabilitation at Northwestern University Medical School.

"There were these huge concerns, probably inappropriate concerns on behalf of the medical community, about dependency and diversion and abuse and addiction," he says.

In the 1980s, with the advent of the government's "war" on the use of illegal drugs, many doctors became even more nervous about using opioids — most of which are Schedule I or II controlled substances. The Drug Enforcement Agency also got into the act by monitoring physicians' prescribing practices to detect practitioners who were more "liberal" prescribers than their peers.

State medical boards suspended or revoked the licenses of physicians deemed to be prescribing too many pain medications, and subpoenas sometimes tied up a physician's medical records for years.

By the late 1980s and early '90s, however, pain management specialists were beginning to push for a more balanced and humane approach to treating pain. At the same time, research was helping clinicians better understand the issues of tolerance and dependency vs. abuse.

"People were really upset that we had good, strong analgesic drugs, yet people with cancer were dying in agony," Harden continues. "My first involvement with this controversy was as an advocate of patients being able to get the strong narcotics who needed it."

To Harden, the people who need the drugs are people with cancer and other life-threatening conditions who are terminally ill and in excruciating pain. Concerns about dependency and increasing tolerance are, understandably, secondary to the need to treat these patients' pain, he says.

And, patients who have recently had major surgery are good candidates for these drugs, he adds.

"Interestingly, people who had just had operations — post-op patients — just had to tough it out because doctors were not prepared to give the

appropriate analgesic medication,” he explains. “These drugs certainly have some issues that surround their use, but ethically, humanitarianwise, we just have to take care of these people and not let them suffer.”

Chronic pain a tricky issue

Increasingly, however, some pain specialists and general practitioners are using opioids to treat all kinds of pain, including pain from chronic, ongoing, but non-life-threatening conditions.

People with chronic lower back pain or repetitive strain injuries are often given strong narcotics to manage their pain, even though they will have to live with their condition — and the medical management — for years, possibly the rest of their lives, Harden says.

“The big controversy comes in when someone says, ‘Well, a patient came in to see me, and I put them on Motrin and it didn’t work, so the next thing I tried was OxyContin,’” he explains.

Physicians have many other options in the treatment of chronic pain, all of which should be attempted before resorting to powerful narcotics as therapy, Harden believes. “There are literally hundreds of other things we can do — we have nonopioid pharmacology, not to mention the nondrug treatments we use. We have physical therapy, occupational therapy, psychotherapy, recreational therapy, relaxation and imagery techniques, and biofeedback. Everyone knows that the most best way to treat chronic pain is interdisciplinary pain management.”

Treatment vs. palliation

At the heart of the controversy is a dispute between physicians who feel it is their responsibility to completely stop the patient’s pain by whatever means necessary, and those who feel it is their responsibility to treat the underlying condition — if possible — and help patients learn to manage their condition and their pain level so that they can comfortably continue their lives, Harden says.

“My contention is that, yes, it is our responsibility to stop the patient’s pain, but that doesn’t necessarily mean bathing them in morphine sulfate,” he adds. “If you have young people who have to get on with their lives, and they have a

chronic condition, it is inappropriate to use high-dose narcotics, except as a last resort.”

Patients who use opioids will develop increasing tolerance to the drug, meaning that higher and higher doses will be required to achieve pain relief. That issue alone makes the use of opioids in this population, questionable, Harden claims, because it is unlikely that a patient could continue to take the drug for the rest of his or her life.

However, levels of tolerance and ability to function vary from patient to patient, and some chronic pain patients are able to use higher doses of opioids and still function, counters Feinberg.

“The problem with opioids is that many people, not all, develop tolerance — the same amount gives you less relief, and you need more,” he explains. But there really are people out there on fairly decent quantities of this stuff who can function fairly well.”

Tolerance issues aside, placing a patient on high doses of narcotics may essentially disable them, which violates the physician’s edict to “first, do no harm,” Harden says.

In addition to the problem of increasing tolerance, narcotic use, particularly in higher doses, can cause significant side effects, such as diminished cognitive functioning, drowsiness, constipation, and impaired vision.

“If you commit to using them, you are committing your patients to a life of significantly reduced function,” Harden says.

No one, including serious advocates of aggressive opioid therapy, would want someone on OxyContin to drive a school bus, he says, by way of example. “But, what about all the other cars coming down the road in the opposite direction?” he says. “Those drivers may be on OxyContin, too. What’s the deal? Are we going to say that everyone on OxyContin should surrender their driver’s license?”

Effectiveness in question

Opioid medications are not a panacea, even for cancer pain, adds Harden. Studies have shown that 35% of patients do not respond to opioid drugs. And an estimated 40% cannot tolerate the drugs — meaning they reject their use because they find the side effects unacceptable, he states.

Recent research has also called into question opioids’ effectiveness in relieving certain kinds of chronic pain, says Feinberg.

“Remember, we are looking for two things: pain relief — actually, pain reduction is a better way to put it — and increased functioning.”

SOURCES AND RESOURCES

- **Steven D. Feinberg**, MD, 1101 Welch Road, Suite C-8, Palo Alto, CA 94304.
- **R. Norman Harden**, MD, Center for Pain Studies, Rehabilitation Institute of Chicago, 1030 N. Clark St., Chicago, IL 60611.

The following articles may be helpful in examining the issue of opioid therapy for chronic pain:

- Harden RN. Chronic opioid therapy: Another reappraisal. *Am Pain Soc Bulletin* January/February 2002; 12(1). Accessed on-line at www.ampainsoc.org/pub/bulletin/jan02/poli1.htm.
- Gelfrand SG. Commentary: The pitfalls of opioids for chronic nonmalignant pain of central origin. *Medscape Rheumatology*. Accessed on-line March 6, 2002 at www.medscape.com/viewarticle/425468.

“As we are doing more research, we are realizing that for nociceptive pain, which is tissue damage, opioids can be very effective,” he explains. “But for neuropathic pain, they are of only questionable benefit.”

Managed appropriately, people with tissue damage can be placed on opioids and do quite well, Feinberg adds. But it is important to monitor how the patient is functioning and not just whether the patient reports that the pain has gone away.

“Remember, we are looking for two things: pain relief — actually, pain reduction is a better way to put it — and increased functioning,” Feinberg says. “If someone comes to me and says, ‘I have all of these drugs, but I am in bed all day long,’ I have trouble accepting that. I ask patients to show me how the medicine is making a difference in their life, not just that they feel better.”

Issue not cut and dried

Opioids are a powerful — and necessary — tool for pain specialists to have at their disposal, say both Feinberg and Harden. Neither physician claims that the drugs should never be used to treat chronic pain.

But, says Harden, physicians must be willing to try other options first and use opioids in these situations only as a last resort. And these patients should be closely monitored to ensure that the medications designed to ease their suffering don't contribute to more suffering in the long term. ■

UPenn brings bioethics resources to classroom

‘High School Bioethics’ is useful educational tool

They're not just dissecting frogs anymore. Increasingly, high school students across the country are being asked to consider bioethical issues along with formulas and theorems in their biology and chemistry classes.

“We are discussing bioethical topics, and the topic that I have chosen is in vitro fertilization,” reads a recent posting by a high school student on an Internet bulletin board devoted to bioethics discussion. “I tried to decide if it is an ethical form of reproduction and if it is worth the effort and money. In the end, I concluded that in vitro fertilization was an ethical form of reproduction and was worth it.”

“I am writing a paper on the ethical issues of genetically programming fetuses so that when they are born, they will possess certain traits that their parents desire, i.e. hair color, eye color, height, etc.,” reads another post. “It would be much appreciated to hear other people's opinions on this matter.”

(Editor's note: The posts were taken from The Bioethics Discussion Pages, moderated by Maurice Bernstein, MD, and located on the web at: www.hsc.usc.edu/~mbernste/.)

The above postings are not unusual, says **Dominic Sisti**, MBe, a researcher and staff member at the University of Pennsylvania's center for bioethics in Philadelphia.

“At the center, we get thousands of queries every month from high school students wanting help with papers, projects, asking questions, asking to interview scholars, etc.,” he notes. “And it is interesting. They are actually doing some seriously cutting-edge work in high school biology classes now, including using PCR [polymerase chain reaction] and other interesting and timely lab activities. And all of those activities have interesting applications.”

Web site dedicated to high school

As a response to the overwhelming requests for information, and because it is part of the center's mission to educate the public about bioethical decision making, the center started the High School Bioethics Project — a cooperative arrangement between it and the U.S. Department of Education.

- **Dominic Sisti**, Mbe, University of Pennsylvania, Center for Bioethics, Suite 320, 3401 Market St., Philadelphia, PA 19104-3308.

The main feature of the project thus far is a web site featuring information sections on the subjects of genetic privacy, genetically modified organisms, gene patenting, and reproductive genetics.

The sections give a brief background of the issues and technology involved and raise specific questions and ideas for the students to consider, as well as links to more information elsewhere on the web.

The site also provides an interactive “helpline” that allows visitors to directly send questions to the center staff and receive an e-mail reply.

Bioethics tutors from the center’s master’s program or the research staff answer the questions.

“It is actually pretty fun,” he says. “There are students out there who really have some great questions. They are not as unsophisticated as you might think. They have come to us with some great novel questions and issues. I have done some teaching with adult community groups that don’t come up with the questions that the high school students do.”

In addition to the web site, Sisti periodically goes out to give talks to high school classes, and groups of students and teachers visit the center as well.

The leaders of the center— director **Arthur Caplan**, PhD, and **Glenn McGee**, PhD, a senior fellow and its associate director for education — have long been interested bringing bioethics to the public, to “everyone, high school students, communities at large through the mass media,” says Sisti.

“This was one way to do it, and we received notification from the government that they were interested in this area as well,” he adds.

The center received a grant from the U.S. Department of Education to develop materials to educate students about genetics and ethics, reports Sisti. And most of the student queries involved questions in these areas.

Ethics committees and the community

In addition to considering the individual consultations that arise and educating hospital clinicians and administrators about bioethics, committees need to work to educate their larger community, says Sisti.

“I think that is a responsibility that is often overlooked,” he explains. “You can wax philosophically about ethical theory, but when the public doesn’t understand it, it doesn’t do you all that much good. What the High School Bioethics

Project enables the students to do is discuss bioethics issues outside of their own value system, if need be. They can approach a situation and open their mind to other viewpoints and respect those viewpoints. I think it helps with tolerance for other points of view and gives them a way to resolve conflicts and, in a more general sense, bioethics is a good tool for that.”

High School Bioethics can be accessed on the web at: www.bioethics.net/hsbioethics. ■

ED staff uncomfortable with parental presence

Staffers reluctant to be observed by parents

Should parents be allowed to stay with their children in the emergency department (ED) while invasive procedures are performed? And who should make the ultimate decision about whether, and in what circumstances, they should be there?

Although prior studies of patients and family members have indicated they favor the practice,^{1,2} a recent survey of nurses and physicians in EDs around the country indicates that providers may be more reluctant. The majority of respondents felt that permitting parental presence should be decided on a case-by-case basis, with the decision-making shared by both providers and parents.

Presence depends on procedure

The survey results, reported in the February 2002 issue of *Academic Emergency Medicine (AEM)*,³ found that the majority of respondents favored allowing parents to be present for some invasive procedures, but as the invasiveness of the procedure increased, fewer physicians and nurses favored allowing parental presence.

“Most of the responses were that each case should be handled differently based on the initial

interactions with the parents,” says **Brian K. Sloan**, MD, assistant clinical professor of emergency medicine at Indiana University School of Medicine in Indianapolis and a co-author of the *AEM* article. “The minority responses by the physicians were that parents should not be present because they [the providers] feared litigation if the outcome was poor, that high levels of anxiety would put pressure on the providers. Others commented that they were concerned about the need for space to perform procedures, and space is limited in treatment rooms.”

Survey design and results

Researchers surveyed a total of 645 ED staff members (306 physicians and 339 nurses) at 10 different hospitals between April and September 1998.

The survey presented the respondents with six emergency procedures of increasing invasiveness: peripheral IV start, laceration repair, lumbar puncture, conscious sedation, major resuscitation, and major resuscitation with the likely death of the patient. The providers were then asked whether the parents of a child undergoing each of these procedures should be allowed to stay in the room.

The percentage of physicians who responded that parents should be present was 91.3% for an IV start, 93.3% for laceration repair, 65.7% for lumbar puncture, 83.1% for conscious sedation, 31.9% for major resuscitation, and 35.6% for major resuscitation where death was likely. The percentage of nurses who responded that parents should be present was 86.8% for peripheral IV start, 89.6% for laceration repair, 55% for lumbar puncture, 74.9% for conscious sedation, 41.4% for major resuscitation, and 54.3% for major resuscitation where death was likely. The participants also were asked if they had invited parents to a child’s bedside in the past, and space was provided for individual written comments.

Surprisingly, the results didn’t indicate a significant difference of opinion between the physicians and nurses, says Sloan.

“We did feel that nurses would be more willing to allow patients to be present than physicians, but we now understand this to not be completely true,” he says. “So much of the willingness to have parents present correlated with the experience of the provider and their comfort level with their skills.”

Although it is his opinion that parental presence

SOURCES

- **Cynda Hylton Rushton**, DNSc, RN, FAAN, Johns Hopkins Children’s Center, 525 N. Wolfe St., Room 434, Baltimore, MD 21287.
- **Brian K. Sloan**, MD, 1110 W. Michigan St., Indianapolis, IN 46202.

is a good thing for the family of the injured child, Sloan says he does not think that hospitals should make a definite policy one way or the other.

“If the situation warrants it, then I feel that families should be invited,” he says. “I only think that if the providers would like the family to be present for any procedure, then they should be allowed to be present. Again, a decision should be made on a case-by-case basis.”

Staff concerned with legalities

It’s important for decisions about family presence to be made on an individual basis, agrees **Cynda Hylton Rushton**, DNSc, RN, FAAN, clinical nurse specialist in ethics at Johns Hopkins Children’s Center in Baltimore. But it is important for hospitals to examine the specific reasons some providers are opposed to parental presence and attempt to address and resolve the concerns, she adds.

“A lot of the reasons that I have heard people suggest for why they don’t want to do it have to do with the health care professionals feeling exposed and vulnerable,” she explains. “And they worry about the legal implications of errors that have been made or the perception of themselves as providers. So these reasons seem to be more about the professionals than it is about the patients and the families. And I think that needs to be explored.”

If the reasons that family presence is not permitted in a given situation have more to do with caregiver comfort than what is best for the patient and family, then providers have an ethical responsibility to work to remove those barriers to allowing the parents to have the choice to be present, she states.

“This really brings us back to the fundamental question of what we mean by shared decision making and how we understand the balance between professional needs and also patient and family needs,” she says.

Ethics committees can have a role in facilitating

Being present: One parent's experience

Physicians who are uncomfortable with allowing family members to be present during difficult and invasive emergency procedures might change their minds if they understood the reasons that parents want and need to be there and the possible benefits they could provide to both the child patients and the caregivers, says Plano, TX, resident **Susie Hott**.

In 1994, Hott's 14-year-old son, Donnie, was critically injured in a fall from a tree. Flown by helicopter from a local hospital to Parkland Health and Hospital System in Dallas, Donnie underwent surgery to repair his lacerated liver and was admitted to the intensive care unit. The next morning, however, he went into cardiac arrest.

Although it ran contrary to hospital practice at the time, Hott and her husband were allowed to enter the room where the resuscitation was under way and talk to and touch their unconscious son as the medical team attempted to save him.

Even though their efforts were unsuccessful, the providers' decision to allow her and her husband to be present helped them cope with the tragedy of his death and, she believes, allowed them to comfort their son in the last moments of his life.

"It gave us a choice in the midst of almost total loss of control," says Hott. "My husband, during all of this, apologized to Donnie for an argument they had. I think Donnie needed to hear those words, and my husband needed to say them. If he hadn't been able to, I think it would have haunted him."

Her imagination of what was happening during the resuscitation would have been much worse than seeing the actual procedure had she not been allowed into the room, Hott adds. "There would have been no

explanations that could have convinced me of the grim reality that needed to be accepted by both of us or of the decisions we had to make, such as about the doctor stopping, if we had not been in there," she says. "[We went in] and went over by the wall near the head of the bed, almost cheering him on, then we went back to the wall, and I remember the fifth-year resident in there saying, 'We are going to get the defibrillator and we are going to defibrillate him, but if this doesn't work, I recommend that you let him go.'"

Seeing how hard the medical team worked to save her son helped her understand that nothing more could be done and that he truly had died, she says.

"If we had not been in there, I would have forever wondered if he could have come back if he had heard us," Hott says. "I would have always wondered if I could have touched him and done something that would have made him stay."

Years after her son's death, Hott read a newspaper article about the nurse at Parkland who accompanied her into her son's room and how she had gone against accepted practice at the hospital to allow her to do so.

Hearing that many emergency departments and hospital intensive-care units do not permit this has prompted Hott to become an advocate for family presence, often speaking to groups of doctors and nurses about the benefits of allowing parents into the treatment room.

"When we went in there, I had no idea that we were doing anything out of the ordinary. I didn't think it was a big deal. I just thought she had to say to them, 'OK, we're coming in,'" she says. "A hundred years ago, death was seen as a part of life. Families experience death as a part of life. Why try to protect me from it? It is still a reality, I might as well experience it, especially if it is my choice." ■

discussions among the providers about their feelings and fears regarding allowing family presence and to determine what changes can be made that would make allowing parental presence more comfortable.

Providers sometimes raise objections that have more to do with treating the patient than with whether or not they feel comfortable with it; these concerns should be addressed, Rushton says.

For instance, some providers are concerned that parents will panic if they do not understand what is going on, that they will get upset and interfere with a procedure or distract the caregivers.

"The places that I know of that have done this well have designated a person — just like they

would do for any emergency situation — to perform certain tasks, and one person is designated to support the family," she explains. "If the family becomes upset, then it is that person's job to remove them from the situation or to interpret what is going on for the family."

Thinking and planning ahead is crucial

Managers should definitely think and plan ahead of time how they will approach parents and family members, and how these people will be supported if they choose to be present with their child.

"You have to think it through, so that we just don't place people in the situation without

putting in place safeguards to support them, to deal with the issues that the team may be concerned about, whether they will get in the way, etc.," she says.

Develop an ethical framework

Ethics committees can also help ED providers by discussing with them the values that they want to protect and adhere to and how their policies reflect this, says Rushton.

"I would frame it as an issue of respect for the patient and for the family involved," she explains. "I think it is a process in every instance, and part of the thinking about shared decision making is to think about what the boundaries of parental involvement should be, and do the boundaries extend to permit giving them choices about

participating in life-threatening events. And if it is not going to be permitted, then what would be the reasons to justify not giving the parents the option?"

References

1. Meyers TA, Eichhorn DJ, Cuzzetta CE. Do families want to be present during CPR? A retrospective survey. *J Emerg Nurs* 1998; 24:400-405.
2. Boie ET, Moore GP, Brummett C, et al. Do parents want to be present during invasive procedures performed on their children in the emergency department? A survey of 400 parents. *Ann Emerg Med* 1999; 34:70-74.
3. Beckman AW, Sloan BK, Moore GP, et al. Should parents be present during emergency department procedures on children, and who should make that decision? A survey of physician and nurse attitudes. *Acad Emerg Med* 2002; 9:154-158. ■

Genetic screening draws fire from ethicists

IVF pre-implantation diagnosis under question

Should prenatal genetic diagnosis (PGD) be used to screen human embryos for genetic predispositions to certain diseases, not just as a tool to detect genetic markers that definitely indicate the presence of a medical condition?

That's the challenging question raised a recent report in the Feb. 27, 2002, issue of the *Journal of the American Medical Association (JAMA)*.¹

In the report, Verlinsky and colleagues at the Reproductive Genetics Institute of Chicago detail the case of a 30-year-old woman with a genetic marker linked to the development of early-onset Alzheimer's disease (AD). Although currently asymptomatic, the woman's sister, brother, and father all have the illness, and genetic testing has shown that she has the same mutation.

In what is thought to be a medical first, the woman underwent two cycles of an in vitro fertilization (IVF) procedure, with all embryos screened for the genetic mutation prior to implantation in her uterus. As a result, the woman gave birth to a baby girl without the mutation and has used the screened IVF procedure to become pregnant a second time.

Using IVF for this procedure (a technique termed pre-implantation genetic diagnosis) instead of traditional PGD, which is ordinarily performed after a woman is already pregnant,

allows patients and clinicians to avoid the ethically questionable practice of selectively aborting fetuses affected by mutations that only indicate a strong predisposition to develop a serious disease later in life.

"Pre-implantation genetic diagnosis has been applied to at least 50 different genetic conditions in more than 3,000 clinical cycles," the researchers wrote. "In addition to traditional indications similar to those in prenatal diagnosis, pre-implantation diagnosis was performed for an increasing number of new indications, such as late-onset disorders with genetic predisposition. These conditions have not been an indication for prenatal diagnosis because of potential pregnancy termination, which is highly controversial if performed for genetic predisposition alone."

And, as the researchers acknowledge, the procedure they performed is not without ethical question. "Because the disease never presents at birth or early childhood — and even later — may not be expressed in 100% of cases, the application of pre-implantation genetic diagnosis for AD is still controversial," they wrote. "However, because there is currently no treatment for AD, which may arise despite pre-symptomatic diagnosis and follow-up, pre-implantation genetic diagnosis seems to be the only relief for at-risk couples."

Will society draw the line?

But many ethicists question whether our society will be willing to draw the line between "relief" for parents facing the strong likelihood of a devastating medical condition and eugenics, allowing

couples to “design” the baby of their dreams.

“One of the notions we were calling into question is how far ought norms — or the closely held beliefs of a majority — determine what is ethically acceptable,” says **Roberta Springer-Loewy**, PhD, assistant clinical professor in the bioethics program at the University of California-Davis. Loewy and a colleague, Dena Towner, MD, co-wrote a commentary on the procedure in the *JAMA* issue featuring the report. “I think some of the important questions here ought to include, ‘Should reproductive freedom be considered an absolute right when acting on that right can be shown to result in an undue burden on others?’”

How far do physicians' responsibility extend?

The study's participant is thought to be at very high risk for developing symptoms of AD before she reaches her 40s, Towner and Springer-Loewy point out. Therefore, it is very likely that she will not be able to continue to care for these children while they are still at a very young age.

The woman's sister, they note, had to be placed in an assisted living facility by the time she was in her 40s, and one of the first manifestations of the illness noted in her case was difficulty caring for her two children.

“A child living under these circumstances would be burdened by the mother's progressive and eventually profound debilitation and eventual premature demise,” they wrote. “Of note, if

this same child were orphaned, current adoption regulations would prevent this same childless couple from adopting.”

While this attitude may seem harsh, they are only trying to point out that medical providers — in fulfilling their duty to patients — should ask the patient to consider all of the available options and alternatives and to consider the different consequences of each option, Springer-Loewy explains.

The parents should consider, for example, the impact that the choices they make will have on the children they conceive, she says. The clinicians themselves should be willing to examine how these choices will affect the larger society. Will these reproductive technologies, amazing as they are, be available only to those who are able to pay? Or will they be available to everyone? If so, what affect would that have?

“To suggest that, by not making assisted reproductive technology [ART] available, physicians or geneticists are accomplices in placing a child at greater risk wrongly implies that there are only two options: pregnancy with ART or pregnancy with no ART. Frankly, there is another responsible option: not to get pregnant. If that sounds harsh, it does so only because so many members of our society have been conditioned to expect to have their desires met, often at the expense of many others not so fortunate,” says Springer-Loewy.

While the average person might see nothing wrong with “screening out” embryos with

Audio conferences target disasters, medical disclosure

Have you missed one of American Health Consultants' (AHC) recent audio conferences? If so, two upcoming conference replays offer another opportunity to take advantage of excellent continuing education opportunities for your entire facility.

• **Disaster Response at Ground Zero: How NYU Downtown Hospital Handled Mass Casualties With All Systems Down**, originally held on Jan. 10, takes participants to the heart of the World Trade Center disaster on Sept. 11. Just a few blocks away from the crash site, NYU Downtown was cut off from crucial lifesaving supplies and power, even as hundreds of injured came through the emergency department doors. HazMat teams on the roof of the hospital had to vacuum all of the debris out of air ducts to maintain air quality and

keep generators running. Physicians and nurses had to balance urgent care with proper documentation. Learn how to prepare your facility for the unthinkable. The replay will be available from 8:30 a.m. on Tuesday, April 16, to 5:30 p.m. on Wednesday, April 17. Current AHC subscribers pay \$249, which includes free CME and CE credit. The cost is \$299 for nonsubscribers.

On April 23 and 24, **What to Say When Something Goes Wrong: Do the Right Thing When Trouble Strikes** also will be available for replay. This successful audio conference covers the major fear factors clinicians experience when confronting issues of medical disclosure. Learn benefits for patient and provider, as well as the risks of litigation and how to avoid costly legal battles. Free CE for your entire facility is included in the \$249 fee for AHC subscribers.

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genetic markers for deadly diseases, who defines what diseases are serious enough to be screened for is a difficult question to answer.

“The rub comes in defining what ought to be included under the rubric ‘disease,’” Springer-Loewy states.

“Quick example: In the past century, masturbation has been, at various times, considered a disease (it once had a recommended surgical cure), a sin, and then a normal part of sexuality. We tend to forget that while concepts like ‘disease’ and ‘pathology’ have a purely biological component, they are also social constructs. Deadly diseases — those associated with significant morbidity and mortality and much pain and suffering — that can clearly be delineated certainly ought to be prevented when possible, but the benefits and burdens of such prevention should be distributed equally.”

A false distinction?

To simply question the ethics of allowing this type of prenatal screening is in some ways a false distinction, says **Adrienne Asch**, PhD, the Henry R. Luce Professor in Biology, Ethics, and the Politics of Human Reproduction at Wellesley (MA) College.

“If people question screening for this, then I would ask them, ‘Why they would screen at all?’” Asch states. “What is the difference? The act is selecting. You are selecting out certain embryos based on specific characteristics. Whether you do it at the embryonic stage or the fetal stage, that is what you are doing.”

It is not up to the medical providers to be the “gatekeepers” of such technology, but our society as a whole needs to examine the possible consequences and decide whether we want to allow screening for genetic characteristics prior to birth or conception, she says.

“If society wants to screen, then, unfortunately, I think we will soon come to the level of screening for every characteristic you can imagine — musicality, tone deafness, color blindness — because somebody will care,” she says.

Reproductive care providers already routinely offer prenatal screening for diseases that are not fatal, she says. What is the true difference between selecting out an embryo that will be affected by a given illness, that has a strong predisposition to an illness or disease, and selecting out for an embryo that will produce a tall child or strong child?

“Physicians are trained to provide medical information — some of which is frequently out of

SOURCES

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- **Andrea Bonnicksen**, PhD, Department of Political Science, Northern Illinois University, DeKalb, IL 60115.
- **Roberta Springer-Loewy**, PhD, Associate Clinical Professor, Health Care Ethics, University of California, Davis, UCDMC — PSSB 2400, 4150 V St., Sacramento, CA 95817.

date,” she adds. “They are not trained very well in discussing different impairments and disabilities and what life is like living with them.”

Providers can refuse to screen for certain conditions because of conscience, if they want to do so, Asch says. But, if they do, they should ask themselves the reason that they screen for anything, she says. “What is wrong with life with Down’s syndrome? What is wrong with life with spina bifida?”

Some ethicists, however, say that concerns about the possible uses and abuses of PGD are overblown. That it will take more time to determine whether the potential even exists for parents to screen for blue eyes and blond hair.

The case covered in the *JAMA* report detailed a very rare genetic condition — one thought to affect only about a dozen families worldwide, and the chance that the woman will develop the disease are thought to be close to 100%, notes **Andrea Bonnicksen**, PhD, professor and chair of the political science department at Northern Illinois University and a member of the ethics committee of the American Society of Reproductive Medicine (ASRM).

“This seems to me to be a pretty straightforward case, because it looks like such a rare and deadly disease,” she says. Since the development of its 1994 ethical guidelines, ASRM has supported the use of PGD to prevent the birth of children with serious genetic disorders, and this would seem to fall within that parameter.

There is something to be said for letting the technology evolve a little more to see where it will head before deciding where the lines should be drawn, she adds. “It is so difficult to anticipate what the new uses will be. The more experience there is with PGD, the more one is able to anticipate the different conditions under which this should be permissible and we will be able to draw the lines more meaningfully.”

Reference

1. Verlinsky Y, Rechitsky S, Verlinsky O, et al. Pre-implantation diagnosis for early-onset Alzheimer's disease caused by V717L mutation. *JAMA* 2002; 287:1,018-1,021. ■

Bill to exempt researchers from patent restrictions

Doctors and medical researchers who want to work with disease-causing genes to develop new treatments and diagnostic tests may soon be exempt from patent protections that currently prohibit them from doing so.

On March 14, Reps. **Lynn Rivers** (D-MI) and **David Weldon** (R-FL) co-sponsored a bill in the U.S. House of Representatives that would prevent entities that own patents on human genes from barring the use of those genes in noncommercial genetics research or diagnostic disease testing.

The U.S. Patent and Trademark Office has issued some 8,000 patents on genes, allowing holders to control the use of genes or demand royalties and license fees for their use in research. Some medical researchers have been sued to prevent them from performing research on specific human genes or DNA sequences covered by patents.

The House bill applies only to diagnostic tests and academic research and does not exempt the development of drugs or other treatments.

The exemptions in the bill would go no further than "fair-use" exemptions that allow copyrighted intellectual property to be used in a noncommercial way by the public, Rivers told *Reuters Health*.

Researchers developing genetic tests under the exemption would not be permitted to commercially market the tests without the clearance of the patent holder, she said.

Rivers also introduced a second bill that would require the White House Office of Science and Technology to perform an in-depth study on genetics patent law and whether the laws affect the cost or innovation of new products. ■

Hospital fined following death of living liver donor

Mount Sinai Hospital in New York City has been fined \$48,000 and prohibited from performing any liver transplants using living donors for at least the next six months following an investigation by the state health commission into the circumstances surrounding the death of a 57-year-old man who agreed to donate part of his liver to his brother.

According to a March 13 report in *The New York*

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CE/CME Questions

CE/CME subscribers: Please save your monthly issues with the CE/CME questions in order to take the two semester tests in June and December. A Scantron form will be inserted in those issues, but the questions will not be repeated.

13. In the article about opioid use for chronic pain, a source indicates that studies have shown opioids to be effective for what type of pain?
A. Nociceptive
B. Neuropathic
C. Malignant
D. None of the above
14. According to the article, the development of the High School Bioethics web site reflects what mission of the University of Pennsylvania Center for Bioethics?
A. To get more young people interested in science.
B. To bring education about bioethics to the public.
C. To publish their views on genetic technology to different audiences.
D. None of the above
15. In the article about parental presence, emergency department clinicians were less comfortable with the idea of parental presence:
A. As the difficulty/complexity of the procedure increased.
B. If they had no prior experience with family presence at all.
C. If they were new to the environment and had little clinical experience to begin with.
D. All of the above
16. According to researchers at the Reproductive Institute of Chicago, use of pre-implantation genetic diagnosis and IVF is less controversial than using PGD to screen for the Alzheimer's trait because:
A. It prevents the possibility of the need for an elective abortion of a fetus found to be carrying the genetic mutation — a mutation that only indicates a strong disposition to develop the illness.
B. Pre-implantation genetic diagnosis is less invasive.
C. PGD is more costly.
D. None of the above

Times, the donor, **Mike Hurewitz**, a reporter for the Albany (NY) *Times Union* newspaper, died on Jan. 13, three days after undergoing the surgical procedure.

While recovering from surgery, Hurewitz vomited blood, inhaled significant amounts of it into his lungs, and choked to death, the report found.

'Woefully inadequate supervision' to blame

New York health commissioner **Antonia C. Novello** indicated the death was due to "woefully inadequate supervision" on the part of an inexperienced, first-year resident assigned to supervise Hurewitz's care as well as the other 34 other patients in the unit at the time.

Living organ transplants have been considered controversial in the medical community because they involve exposing the donor, a healthy person, to the significant risks of major surgery. **(See the article, "Panacea or peril: Do new treatments save lives or endanger them?" in the August 2001 issue of *Medical Ethics Advisor*.)**

Sinai officials admitted that severe staffing shortages likely contributed to Hurewitz's death and that steps have been taken to correct the problem. ■