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✓ *Effort to create social change falls to state legislators*

At least 24 states are following Texas' lead in establishing legislation creating legal 'safe harbors' for mothers who abandon infants at public places such as hospitals and fire stations. Although most health care experts support the effort, some express concern that the practice does not address the societal ills that lead to infanticide and abandonment. Experts also fear the legislation places the health care industry in an unfamiliar role. cover

Does your hospital protect vulnerable children?

✓ *Homicide tops list of injury deaths of children under 1*

Sadly, homicide is the leading cause of death by injury in children less than a year old, according to statistics in a report in a recent issue of the *Annals of Internal Medicine*. Ethics committees can help protect children by encouraging a hospitalwide approach at prevention, experts suggest. Committees can teach health providers to prevent child deaths by being alert to signs of abuse in young children who present for medical care and by identifying families at risk for abuse and making strong attempts to connect them with supportive resources . . . 53

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A component to a statewide palliative care program in Kentucky is improving the amount of education and effectiveness of a strong palliative care program. The

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Effort to create social change falls to state legislators

In the first 10 months of 1999, child welfare officials in the Houston area were shocked by a disturbing trend: 13 newborn babies were found abandoned in places as varied as a hospital emergency department parking lot, underneath a shrub in a park, and inside a trash dumpster. Three of the newborns were found dead.

The 15-year-old mother of one of the babies faces murder charges. Her newborn daughter, authorities contend, died of blows to the head before being left in a high school garbage bin.

Gaining national momentum

The problem isn't just in Houston, either. At least 31,000 babies were delivered and abandoned in hospitals in 1998, according to estimates released in April by the House Ways and Means Committee. The House passed a resolution that same month calling for federal, state, and local governments to track the number of newborns abandoned in public places.

Houston, the nation's fourth largest city, which previously had seen one or two cases of abandoned newborns per year, was suddenly faced with a frequency rate of more than one per month.

To combat the problem, Texas state legislators last year passed HB 3423, which allows a parent to anonymously leave a baby younger than 30 days with a licensed emergency medical service provider without fear of prosecution. That state law has

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program's goal is to train at least 70 physicians by year's end and double that number by the end of 2001. Ultimately, the hope is that patients and providers will make timely decisions about when to move from curative to comfort modes of care 55

The Education for Physicians on End-of-Life Care (EPEC) Curriculum

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Learn to spot, handle spiritual conflict

✓ *Teach caregivers to become mediators when opposing views arise*

Conflicts occurring between dying patients and their families can undermine the patients' spiritual care. There are steps ethics committees can take to ensure that caregivers help resolve the many nuances in family and patient relationships, chaplains say. The keys are to understand the patients' views while finding the true reasons for conflict in the situations 57

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become the model for several other state efforts to decriminalize newborn abandonment if the parents bring the baby to a health care facility, fire station, or police station.

At the same time, many questions arise about how state health care systems can be expected to handle those children, and what the long-term ethical implications will be.

"I don't think there is any question that this law will save lives," says **Diana Fite**, MD, FACEP, past president of the Texas College of Emergency Physicians (TCEP) and clinical assistant professor of medicine in the University of Texas-Houston's school of medicine and department of emergency medicine.

"Not only are we trying to prevent the killing of the babies; the babies who were found alive had been exposed and suffered other injuries. The mothers who do this just do not understand that they could just walk into a emergency room and say, 'I can't take care of the baby. I don't want the baby.' And we would take the baby, and she would be OK. It is not just fear of prosecution. Many of these people obviously don't want their families to find out, and if you go through adoption, you end up needing permission from the father to adopt. It is much more involved. So I think that is why people have resorted to killing, drowning, or abandoning the babies."

Even though most health care experts support the effort, some express concern that the practice does not address the societal ills that lead to infanticide and abandonment. Health care experts also fear the legislation places the health care system in an unfamiliar role.

"My concern is what will this do to address why [the parent] is in this situation to begin with?" says **Arlo Weltge**, MD, FACEP, an emergency physician, an associate professor of medicine at the University of Texas-Houston Health Science Center, and another past president of TCEP.

"And the legislators were not specific about the process that the EMS providers should go through once the child is turned over to them. The intent of the legislation is good. We don't want these children abandoned in places that can lead to harm coming to them. It will depend on the individual EMS agencies and emergency centers knowing about this ahead of time and developing a policy of how to accept the child, what should be done with the child at that point in terms of protective services, etc. My concern is that the baby might be vulnerable for a certain

period of time if this issue is not worked out explicitly.”

For example, hospital emergency departments are required under federal law to treat any presenting patient as if he or she were seriously ill, performing a number of diagnostic tests to rule out a life-threatening condition.

“This could subject the baby to unnecessary stress,” he notes. “In addition, it could lead to a number of costly procedures and services.”

The new Texas law requires that the provider accepting the child contact child protective services by no later than the close of business the day after the provider takes the child into custody. The child-services officials would decide how to proceed.

The main point, says Fite, is that the parents would not face charges for leaving the child.

“Most emergency departments have experienced this already. We have had babies abandoned in the parking lot and just outside the hospital,” she notes. “Under the new law, they would also be considered having been left at an emergency facility. It is our property.”

The difference is that no effort is made to track down the parents. The baby is taken into foster care with the same legal status as an abandoned baby, except that the baby is “legally abandoned.”

Long-term consequences

The Texas statute is the first of its kind signed into law in this country. Several other states, including California, Delaware, Georgia, Oklahoma, Oregon, Pennsylvania, South Carolina, Tennessee, and West Virginia, recently introduced similar legislation. A total of 24 states are considering state bills that would allow mothers to leave their children in safe places such as hospitals or fire stations without legal repercussions.

Some states have informal arrangements with hospitals, charitable groups, and law enforcement agencies that encourage parents with unwanted newborns to bring them to a safe place.

A St. Paul, MN, nonprofit organization, A Safe Place for Newborns, has arranged agreements with three area hospitals that allow parents to leave babies anonymously at the facilities without fear of prosecution.

Since 1998, a program in Mobile, AL, has allowed parents to drop off unwanted newborns at participating hospitals with total secrecy. Since the program’s inception, no dead infants have

CME

questions

1. According to **Diana Fite**, MD, FACEP, clinical assistant professor of medicine in the University of Texas-Houston’s school of medicine and department of emergency medicine, mothers who abandon their newborn babies often not only are afraid of prosecution, but:
 - A. Can’t provide adequate financial support
 - B. Don’t want their family to find out
 - C. Are not emotionally capable of parenting
 - D. Fear they cannot provide for the baby
2. **Arlo Weltge**, MD, FACEP, an associate professor of medicine at the University of Texas-Houston Health Science Center, is concerned that the Texas law for baby abandonment does not address the issue of:
 - A. How care expenses will be reimbursed
 - B. Why the parent is in the situation to begin with
 - C. Foster care costs
 - D. Punishment for the mother
3. Health care providers rely too heavily, according to **Susan J. Kelley**, RN, MSN, PhD, professor of nursing at Georgia State University in Atlanta, on which government body to protect vulnerable children:
 - A. Local police
 - B. County social service officials
 - C. Child welfare officials
 - D. All of the above
4. According to **Patricia Schnitzer**, PhD, research assistant professor in the department of family and community medicine at the University of Missouri in Columbia, one form of primary prevention in stopping child abuse is:
 - A. Community outreach programs
 - B. Getting high-risk abusers in treatment programs
 - C. Comprehensive psychological screenings for all pediatric patients
 - D. All of the above

been found, and three new mothers have brought babies to the hospital to surrender for adoption.

Those policies are a good first step to protect society's most vulnerable children, but simply encouraging parents to anonymously drop off an infant does not adequately address the long-term consequences of abandonment, says **Caroline L. Burry**, PhD, assistant professor at the University of Maryland, Baltimore's school of social work.

"Of course, it is good to have a place available, and we want to say to the parent or parents of the baby, 'Yes, we will accept the child with no questions asked.' But it would be much better if we could encourage them to come in with the baby and give some information, medical information, or background that we could have for the child later," she says.

For example, both the Mobile and St. Paul programs ask but do not require the parent to provide a medical history for the baby. The parent, usually the mother, is given an identification bracelet allowing her to return within a specified time to reclaim her child if she decides to do so.

However, some of the new legislation seems to focus on protecting the anonymity of the parent, while there is very little encouragement from society for parents who may need to place their child for adoption and might be willing — with a lot of support — to be identified or leave background information for the child, says Burry.

Society says no to adoption

Burry has worked extensively with adoptive parents, adopted children, and parents who needed to place children, she adds. Children who have some indication of why their parents placed them for adoption, and some sense of where they came from, often have a much easier time later in life, she says.

"We even encourage parents, if they are willing, to leave letters for the children or to at least provide some information, either medical or otherwise," she says. "Many parents are willing to take that responsibility, but we as a society do not support adoption as a decision. People, particularly teenagers in this situation, have no information about adoption or how to go about placing their child."

She hopes that hospitals and communities that want to address the problem of infanticide or child abandonment would make an attempt to offer a range of services rather than just an open baby bed and an invitation to surrender

the unplanned-for new life. It would be better if such a program were in conjunction with enhanced outreach to at-risk parents. Information about adoption placement options, for example, and an increased effort to educate parents about social services and aid that are available to help them take care of the baby might be more effective.

"Again, you would want to emphasize that you will accept the baby, no questions asked," she notes, "but I don't think that should be the only option."

Hospitals need a plan

Although the Texas law was passed in September 1999, Weltge says several EMS providers and emergency departments he's contacted have little information about their responsibilities under the new provision.

"One of the EMS medical directors has instructed their departments to develop a policy, but there is a significant degree of variation in the amount of knowledge from provider to provider," he says.

In many cases, if a baby is surrendered to a paramedic or other licensed professional in the community, that person likely would bring the child to the nearest emergency department for a medical evaluation, adds Fite.

However, neither Fite's department nor others with which she is familiar have had the direct experience of taking an abandoned baby into custody, she says. "I am not sure how well the word has gotten out, even to the people who would potentially abandon or hurt their baby. I think we have even had a case of a baby found since the law has been passed. So, evidently, we are not reaching everyone."

If a hospital is considering starting its own "safe place" for babies, it is best to start by forming some kind of advisory panel made up of child welfare advocates, social workers, law enforcement personnel, and hospital staff, recommends Fite.

"In the first place, you need to know what the law is in your state," she says. "In some states, it is illegal to simply come in and attempt to surrender the baby."

There also should be a definite protocol in place for how the state department of child protective services will be notified and whether and how they will assume custody, she says. "It will be interesting to see if this becomes social policy"

SOURCES

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- **Diana Fite**, MD, FACEP, University of Texas at Houston Medical School, 6431 Fannin St., Houston, TX 77030.
- **Arlo Weltge**, MD, FACEP, University of Texas-Houston, Health Sciences Center, 6431 Fannin St., Houston, TX 77030. Telephone: (713) 792-5450.

to allow parents to voluntarily surrender their children without penalty, she adds, noting that the planned laws only cover newborns.

If parents who were unprepared or unable to care for their children were encouraged and supported in a decision to place their children, many cases of child abuse might be prevented, she speculates.

“Some people are not prepared to be parents of children at a certain time or do not want to be parents at all,” she says. “If we had a better way of allowing them and supporting them in a decision to place the child, we might be intervening before that family comes to the attention of child protective services for occurrence of abuse or neglect.” ■

Does your hospital protect vulnerable children?

Homicide tops list of injury deaths of children

A 9-month-old child is brought to your hospital's emergency department with a low-grade fever. While the on-duty physician is treating the baby, she notices what appear to be old bruises on the face and neck. She questions the mother about possible injuries to the child and makes an initial call to her contact at the local division of child protective services.

A nurse in obstetrics notices that a new young mother is apprehensive and frustrated when her boyfriend visits at the hospital and has difficulty coping with her crying newborn. The nurse refers the mother to a home visitation program offering free medical check-ups and parenting advice periodically to new parents over the course of their child's first two years.

Those examples illustrate a couple of strategies hospitals and health systems are using to help protect society's most vulnerable children — babies under 1 year of age. Ethics committees can play a crucial role in this effort by encouraging a hospitalwide approach to prevention, experts suggest.

Homicide leading cause of death by injury

According to data from the U.S. Department of Justice's Bureau of Justice Statistics, more than 200 babies under age 1 are murdered each year. The bureau keeps statistics on murdered children through the year 1976.

Those numbers show 206 babies younger than 1 were killed in that year, with 267 babies killed in 1998, the last year with complete figures. The year with the highest number of murdered infants was 1996, with a record 306 murdered children under 1 year of age.

A study conducted by researchers working with the National Institute on Child Health and Development, published in the May 1999 issue of the journal *Pediatrics*,¹ found homicide to be the leading cause of death by injury in children younger than 1 year.

Researchers examined the birth and death certificates of more than 10,000 infants between 1983 and 1991. Homicide — including battering, shaking, and throwing the child — accounted for 23% of all injury deaths. In addition, another 27% of the deaths were classified as “suspicious” by medical examiners, indicating that an even higher percentage of those children may have been murdered.

Preventive efforts should be strengthened

Most communities and health providers tend to rely heavily on child welfare officials to prevent and stop child abuse and protect vulnerable children, but that is not enough to halt the cycle, says **Susan J. Kelley**, RN, MSN, PhD, professor of nursing at Georgia State University in Atlanta and a nationally recognized consultant on the issue of child abuse.

“Child welfare officials are overwhelmed and do not have the resources to handle this problem alone,” she says.

Health care providers can help prevent child deaths by being alert to signs of abuse in young children who present for medical care and by identifying families at risk for abuse and making

strong attempts to connect them with supportive resources, she says.

Child welfare officials become involved only after an incident of abuse or neglect is alleged. In some cases, those problems may be prevented, adds **Patricia Schnitzer**, PhD, research assistant professor in the department of family and community medicine at the University of Missouri in Columbia.

“If you can use these studies to determine who might be most at risk for abusing their children and then get them involved in some sort of program, that would be primary prevention,” she explains. For example, several research studies have indicated that nurse visitation programs work very well in preventing child abuse and even indicate long-term benefits for the children,

says Schnitzer. **(See suggested reading list at end of article.)** “These are very specific, prescribed programs with specific criteria for participation, focusing on low-income, first-time mothers,” she says. “Trained nurses make home visits every week or two during pregnancy and for two years after the baby is born. They focus on the mom, mom’s family, and social supports and link that mom to community services if needed.”

Follow-up studies, which surveyed the progress 15 years later of children whose parents received nurse visitation, found lower rates of juvenile delinquency and other problems in adolescence, she says.

Those programs also have been attempted with trained laypersons performing the visitation, says Kelley, but the research indicates better results with nurse visitation. “The mothers respond well because it is not like someone is checking up on them. They know the nurse is there to examine the baby and help the baby, and they appreciate that.”

The nurses’ training also may prepare them better to recognize potential medical problems or injuries that a layperson might miss, she adds.

Determining who is at risk and might need a referral for such a program is another challenge for primary providers — hospital obstetricians and gynecologists, nurses, and emergency physicians, say Kelley and Schnitzer.

Several studies have indicated that nurse visitation programs work well in preventing child abuse.

So far, most studies of child injury and infanticide have focused on maternal risk factors for abuse, such as age younger than 20 with one or more children, lack of high school education, and lack of prenatal care, says Schnitzer. “We really have almost no information on paternal risk factors,” she notes.

Some research performed at her institution, using information on families of children who have been killed, indicates that a male in the household who is unrelated to the child is a risk factor for abuse, she says. “We hope to publish our information soon, because we believe it is very compelling.”

Recognizing signs of abuse

Reporting suspected child abuse to child welfare officials so they may intervene to help the child and others in that household is the secondary means of preventing infant and child homicide, says Schnitzer.

Even for trained medical professionals, recognizing early signs of abuse or signs of past abuse can be challenging. “We have a physician at our hospital who is an expert on child abuse and performs a lot of educational programs to our providers,” she says. “Unless you see it a lot, signs of abuse can be difficult to detect.”

Abusive head trauma, better known as “shaken baby syndrome,” is a good example, she says. “Those injuries can be very difficult to identify in an infant that presents in the ER, because they don’t always have real specific symptoms.”

Bruising in a child younger than 1 year, especially bruising above the neck, also should set off suspicion of child abuse but is often missed, says Schnitzer. “Children that young cannot walk or get around by themselves, so it is very unusual for them to have bruises, particularly in the head and neck area. That should be a high suspicion for abuse.”

She recommends instituting a program of inservice training on the signs of abuse for emergency providers and primary providers. “There are things that child abuse experts know, but that people on the front line really aren’t aware of if they are not trained to look for it.”

Another obstacle to better monitoring of vulnerable children is the fear by some physicians that reporting suspicions will violate the trust of the parents and prevent them from seeking medical care, Schnitzer adds.

“Many physicians do not want to report the family unless they are sure, but that is not the criteria that is required for reporting,” she says. “In most cases, child protective services will investigate, and it does not necessarily mean that the child will be taken out of the home.”

Reporting a suspicion of child abuse should be seen as an act to help the family, not hurt the family in the name of saving the child, she says. “One of the big myths about child abuse is that parents intentionally do this to their children.

“Most of these families are really households in chaos. The goal is to look at those people who may need services as wanting and benefiting from some help, as opposed to thinking that they are doing something on purpose to their children. And I believe that most children that are abused and neglected, it is not a purposeful thing on the part of the abuser. It is their environment. We need to get away from viewing the reporting as punitive and as part of the provider’s duty to treat the patient and provide care to that family,” Schnitzer explains.

Reference

1. Brenner RA, Overpeck MD, Trumble AC, et al. Deaths attributable to injuries in infants, 1983-1991. *Pediatrics* 1999; 103:968-974.

Suggested reading

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SOURCES

- **Susan J. Kelley**, Georgia State University, University Plaza, Atlanta, GA 30303.
- **Patricia Schnitzer**, University of Missouri, Department of Family and Community Medicine, MA 303 Medical Sciences Building, University of Missouri, Columbia, MO 65212.

Teaching MDs to spread palliative care message

KY coalition stresses interdisciplinary approach

Navigating both patients and providers toward improvements in palliative care has by no means been a short-lived journey. Recently, 23 coalitions of providers, insurers, and academicians undertook efforts to reverse the trends that have been a hindrance to improving end-of-life care. Sponsored by the Princeton, NJ-based Robert Wood Johnson

Foundation’s grant program, Community-State Partnership to Improve End-of-Life Care, the coalitions hope to create a clearer road map.

One of the coalitions is called Kentuckians for Compassionate Care,

a partnership of 50 agencies and individuals. The group received a three-year grant of more than \$375,000 in January to coordinate a community-wide effort to engage senior groups, physicians, clergy, and policy leaders in efforts to improve care for all seriously ill and dying people in the state. The program is called Journey’s End — A Kentucky Partnership for End-of-Life Care.

One of the highlights of the Journey’s End project is its training program for physicians and nurses. Education for Physicians on End-of-Life Care (EPEC) not only provides information for professionals, it relies upon physicians and nurses who have gone through the program to spread the word on palliative care.

“We all acknowledge that medical schools in this country don’t provide enough education on palliative care. EPEC fills that gap,” says **Mark Pfeifer**, MD, vice dean for clinical services at the University of Louisville’s school of medicine and principal investigator for the Kentucky coalition.

“We’re limited in our ability to reach all physicians and nurses,” says **Carla Hermann**, PhD, RN, an associate professor with the University of Louisville’s school of nursing and a co-investigator with the project. “It’s expensive to try and reach everyone. This works for us because we can train a few people who will train others.”

“We all acknowledge that medical schools in this country don’t provide enough education on palliative care. EPEC fills that gap.”

Community-State Partnership to Improve End-of-Life Care Program Curriculum

- **Module 1: Advance Care Planning**
 - Define advance care planning and explain its importance.
 - Describe the steps of the advance care planning process.
 - Describe the role of patient, proxy, physician, and others.
 - Distinguish between statutory and advisory documents.
 - Identify pitfalls and limitations in advance care planning.
 - Utilize planning to help the patient put affairs in order.
- **Module 2: Communicating Bad News**
 - Know why communication of “bad” news is important.
 - Understand a six-step protocol for delivering bad news.
 - Know what to do at each step.
- **Module 3: Whole Patient Assessment**
 - Describe elements of suffering (physical, psychological, social, and spiritual).
 - Demonstrate ability to assess.
- **Module 4: Pain Management**
 - Compare and contrast nociceptive and neuropathic pain.
 - Know steps of analgesic management.
 - Know use of adjuvant analgesic agents.
 - Know use of nonpharmacological approaches.
 - Know adverse effects of analgesics and their management.
- **Module 5: Physician-Assisted Suicide (PAS)**
 - Identify root causes of suffering that prompt PAS or euthanasia requests.
 - Define PAS and describe its current legal status.
 - Explain key steps for responding to requests.
 - Understand alternative strategies for addressing a patient’s suffering and fears.
- **Module 6: Anxiety, Delirium, and Depression**
 - Identify major depression in patients facing the end of life.
 - Distinguish major depression from normal reactions.
 - Describe management plans for anxiety, delirium, and depression.
- **Module 7: Goals of Care**
 - Name at least five potential goals of care that patients may have.
 - Identify clinical junctures at which priorities should be clarified.
 - Discuss how priorities should be determined.
- Know how to assist the patient to identify reasonable goals.
- **Module 8: Sudden Illness**
 - Describe the features of sudden illness that require special skills.
 - Know how to communicate effectively in the face of sudden illness.
 - Know how to guide decision making in the face of sudden illness.
 - Explain the benefits and risks of using a time-limited trial approach.
- **Module 9: Medical Futility**
 - List factors that might lead to futility situations.
 - Know how to assist in resolving each factor.
- **Module 10: Common Physical Symptoms**
 - Describe general guidelines for managing non-pain symptoms.
 - Explain the impact of symptom control.
 - Assess and treat each nonpain symptom.
 - Explain how the principle of double-effect applies to symptom management.
- **Module 11: Withholding/Withdrawing Treatment**
 - List medical orders relevant for terminally ill patients.
 - Apply this knowledge to clinical situations.
 - Describe common misconceptions about withholding or withdrawing therapy.
- **Module 12: Last Hours of Living**
 - Prepare and support the patient, family, and caregivers (professional and volunteer) through the dying process.
 - Assess and manage the pathophysiological changes of dying.
 - Identify and manage initial grief reactions.
- **The Plenary Modules**
 - I. Gaps in End-of-Life Care.*
 - Describe the current state of dying in America.
 - Contrast this with the way people wish to die.
 - II. Legal Issues in End-of-Life Care.*
 - Describe legal consensus points.
 - List common legal myths and pitfalls.
 - III. Elements of End-of-Life Care.*
 - Describe a conceptual framework for suffering.
 - Describe the elements of end-of-life care.
 - Define palliative care.
 - Compare/contrast palliative care to hospice care.
 - IV. Next Steps.*
 - List the important themes from the conference.
 - Identify barriers to good end-of-life care.
 - Develop potential solutions.

Source: Robert Wood Johnson Foundation, Princeton, NJ.

EPEC was developed by the American Medical Association with grant support from the Robert Wood Johnson Foundation. It was designed to educate all U.S. physicians on the essential clinical competencies required to provide quality end-of-life care. Rather than reinvent a curriculum to teach physicians about end-of-life care, the Kentucky coalition chose to use EPEC because the program fit its educational goals, Hermann says.

The EPEC curriculum consists of four 30-minute plenary modules and 12 45-minute workshop modules. (See box, p. 56.) Developers of the curriculum say its value lies, in part, in its practicality and portability. It teaches fundamental skills in communication, ethical decision making, palliative care, psychosocial considerations, and pain and symptom management, Hermann says.

While the AMA developed the training program for physicians, Journey's End has encouraged physicians who take the course to recruit nurses and social workers to promote an interdisciplinary approach to improving end-of-life care.

Journey's End began training physicians and nurses using EPEC last fall. So far, a little more than a handful of physicians and nurses have gone through the program. Project officials hope to have as many as 70 EPEC-trained physicians and nurses by year's end, and 140 by the time the grant expires. "The hope is that physicians and nurses will talk openly with their patients so that the decision to move from a curative mode to comfort care is made in a timely fashion," Hermann says.

Pfeifer says because the program is taught by physicians in a variety of specialties, it has the potential for wide appeal among physicians because they tend to relate better to other physicians in like specialties. "It's not designed to create experts, but it educates physicians on the basics. Hopefully, it will generate a fair amount of enthusiasm so that they will share what they have learned."

Hermann stresses that EPEC is only part of its overall plan to educate physicians and nurses. The coalition also hopes to revamp the mandatory teaching curriculum in the state's medical and nursing schools. ■

SOURCE

- **The EPEC Project**, Institute for Ethics, American Medical Association, 515 N. State St., Chicago, IL 60610. Telephone (312) 464-4979. E-mail epec@ama-assn.org.

Learn to spot, handle spiritual conflict

Teach caregivers to become mediators

As the 70-year-old man lay unconscious, hovering near death, his wife and family stood at his bedside. The wife, who was raised Lutheran, agonized over her husband's soul. He had never been baptized, and she believed her husband would go to hell unless the sacrament was performed.

The young chaplain who was called to the family's home inquired about the man's wishes. The wife said he was active in the church, and on several occasions — usually when grandchildren were baptized — he would express a desire to do the same. He was to be baptized on several occasions, but backed out each time at the last minute. He was embarrassed because he was an adult accepting the sacrament, the wife told the chaplain.

Would the chaplain baptize her husband before he dies?

"The wife's religious belief taught her that you have to be baptized or you will go to hell," says the Rev. **Jeanne Brenneis**, MDiv, STM, chaplain with the Hospice of Northern Virginia and director of the Bioethics Center, both in Falls Church, VA, and the chaplain who was called to the home years ago. "He clearly did not want to be baptized when he had the opportunity."

But the wife persisted, and Brenneis was left with the decision to either perform the sacrament for the family's sake or follow the patient's life-long decision not to be baptized. Unable to ask the man what his wishes were, she decided to honor what the patient had wanted in his own lifetime. "What I did was do everything except the baptism," Brenneis recalls. "I told them in good conscience I couldn't give them exactly what they wanted. I don't think the family was very happy.

"I have talked with other chaplains since this happened, and some said they would have done it. You could say it wouldn't do any harm, but it would be treating the sacrament lightly. I don't think there is a right or wrong answer."

In retrospect, Brenneis isn't sure if she would do things differently. But her story highlights the spiritual conflicts that can occur between dying patients and their families. With the many

nuances family relationships can have, hospital ethics committees and chaplains in particular must learn to spot potential conflict and work toward a resolution to ensure the patient's spiritual care is not undermined by family members who have conflicting views about spirituality and religion.

There are a number of situations in which family members can be at odds: children caring for a dying parent, a parent caring for a dying adult child, or a sibling caring for another sibling. Regardless of the familial makeup, ethics committees should approach resolving the conflict by helping caregivers understand the patient's wishes, says **Kevin O'Brien**, MA, director of education and outreach services for the William Wendt Center for Loss & Healing based in Washington, DC.

Reasons for conflict

Simply enough, spiritual conflict can occur when family members have opposing religious beliefs. But there also can be more complicated dynamics at work. Those types of conflict can manifest themselves in a number of ways: the ability to forgive particular family members, how medication should be used, and how much physical suffering should be endured.

A dying woman is compelled to reduce her pain medication, despite the objections of her husband, so that she feels lucid enough to pray continually in the days before she dies. At the root of this conflict is the woman's desire to exercise her religious practices and her husband's desire to make his wife comfortable.

Often, spiritual conflict is a symptom of a larger problem that needs to be resolved before the two sides can reach a spiritual understanding. For example, two siblings who worship under different denominations and caring for a dying parent may disagree about which sacraments and prayers to perform prior to their mother's death. Instead of spiritual issues driving the conflict, it may be the manifestation of a power struggle between the two siblings.

Be aware of underlying factors, Brenneis advises. "Don't get too distracted by spiritual issues. Look for underlying reasons."

In fact, Brenneis says conflicts that are truly about spiritual matters are often the most difficult to resolve. "When you start talking about religion, it can be an inflammatory discussion. You can get caught in a theology debate."

What ethics committees need to communicate to caregivers is that spirituality is an individual concept. Caregivers frequently make the mistake of assuming that spirituality and religion are synonymous.

Ethicists should counsel caregivers on the difference by explaining that religion is a set of standards and beliefs that accompany a religious practice, while spirituality is the collective wisdom an individual has gained over a lifetime about his or her own existence and place in the universe. Spirituality, caregivers must be told, is what gives meaning and purpose to life. While it is often the primary component of religion, spirituality can exist among those who do not have a set religion.

Consider this: A dying 30-year-old man tells his Catholic mother, who is his primary caregiver, that he doesn't want a priest to counsel him. He wants to spend time in his garden instead. The mother needs to be counseled so she can understand her son's view of his relationship with the universe, and at some level she must learn to accept his wishes rather than impede his spiritual yearning.

O'Brien identifies three components ethics committees must address to help resolve spiritual conflicts:

1. understanding family relationships;
2. taking a long-term approach;
3. using prayer.

Familial relationships provide the basic information from which ethicists will approach the conflict. For example, parents often view themselves as authorities, no matter the age of their children, and are unwilling to relinquish that role. Grown children may have trouble asserting themselves when a parent is imposing beliefs on them. Or, just the opposite, adult children may show little respect for their parent's wishes and impose their own beliefs on the patient.

Identifying those dynamics at work will allow ethicists to get to the heart of the problem and come to a quicker resolution.

Power struggles among siblings can manifest themselves as spiritual conflict. A disagreeable and outspoken sibling can try to impose his or her religious practices as part of the struggle to gain control over all of the decision-making responsibilities.

"Rather than avoid conflict, use it to your advantage," O'Brien advises.

Using conflict in controlled forms can help facilitate understanding on both sides, he says.

For example, a parent and her dying adult child can re-enact religious rituals that were common when the child was younger, allowing mother and son to reconnect using shared pleasant experiences.

Using the existing conflict allows the disagreeing parties to establish a dialogue, O'Brien says, but he reminds ethicists that establishing a dialogue is only the beginning. "It's not going to be resolved in single session."

Prayer can play an important role in bringing down barriers, O'Brien says. Often, the chance to pray as a group will help heal the chasm that exists between family members. In cases where family members have different views about God and the universe, a simple quiet pause that allows both sides to reflect upon their own beliefs may be appropriate.

In instances where the patient refuses to accept religious practices of caregivers, Brenneis says praying with just the family is helpful. "It's important that you support the family," she explains. "I have counseled families that conversations can occur during times when we think someone is gone."

If the patient can no longer make his or her own decision, and family members want to impose their religious practices on the dying loved one, praying with the family in the presence of the patient may be appropriate, as well, she says.

"I feel saying a prayer won't harm the patient, but it certainly helps the family."

Be realistic about results

Brenneis also is sympathetic to the prevailing time constraints placed on health care providers and how that affects their ability to address every patient need. O'Brien adds that ethicists should be realistic about the results they should expect.

Today's health care trends suggest that most patients will be under acute hospital or hospice care for just a few weeks, sometimes just days before death. That leaves little time to tackle all spiritual conflicts between patient and caregiver.

"We get patients who are so much sicker these days," Brenneis says. "There can be so much anger and so little time. If there's an openness to talk about it, then great."

"You can't expect to change relationships in such a short time," O'Brien adds. ■

NEWS BRIEFS

University hosts medical marijuana conference

The nation's first meeting to discuss the therapeutic use of marijuana was held in early April at the University of Iowa in Iowa City.

The conference was held, according to organizers, in response to the federal government's conclusions in last year's report issued by the Institute of Medicine in Washington, DC. The advisory panel's recommendations stated that marijuana helps fight pain and nausea and should be tested further through scientific trials.

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Editorial Questions

Questions or comments? Call **Kevin New** at (404) 262-5467.

The event was sponsored by the University of Iowa's College of Medicine and College of Nursing with assistance from Howardsville, VA-based Patients Out of Time, an organization supporting the use of medical marijuana.

The national Compassionate Care Program, administered to 15 patients, was discontinued by the federal government in 1992, but some of the patients are allowed to continue using marijuana. Federal law prohibits physicians from prescribing marijuana, but seven states and the District of Columbia have passed legislation allowing physicians to recommend its use for certain diseases, such as glaucoma, multiple sclerosis, and cancer.

The government has to fight state laws because "if they give up their control and pass that control to the health care community, then they're out of a job," says **Al Byrne Jr.**, cofounder of Patients Out of Time. Byrne says he smokes marijuana to relieve eye pressure from glaucoma. ▼

Fear of opiate drug use unfounded, study says

First, the good news: Opiate drug use to treat severe and chronic pain is increasing. Now, the better news: Fear of patients abusing such drugs is by and large unfounded. A report on opiate drug use in treating pain appeared in the April 5 issue of *The Journal of the American Medical Association*.

Pain experts suggest using opiate drugs to treat severe pain in cases such as trauma, surgery, or cancer because they are most effective. Critics fear, however, that prescribing those drugs might lead to abuse. Researchers report, in fact, that cases of drug abuse involving opioid analgesics actually decreased from 1990 to 1996.

Researchers based their conclusions on data from the Drug Abuse Warning Network, a database collecting information on drug abuse cases from hospital emergency departments nationwide. Five types of opioid analgesics were tracked: morphine, fentanyl, oxycodone, hydromorphone, and meperidine.

Morphine was the only drug abused more in 1996 with a 3% increase. Despite increases of use of most of those drugs, reports of abuse declined for the following: meperidine, 39%; oxycodone, 29%; fentanyl, 59%; and hydromorphone, 15%. ▼

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Internet health care gets code of ethics

An international code of ethics for Internet health care was drafted from a set of guiding principles during an eHealth Ethics Summit hosted by the Pan-American Health Organization Jan. 31-Feb. 2, 2000, in Washington, DC. The announcement was made by the Internet Healthcare Coalition. The code addresses privacy, commerce, content, services, disclosure, and the practice of health care on the Internet. The draft, which now contains additional notes and definitions, is available on the Coalition's Web site: www.ihealthcoalition.org/community/ethics.html. It will be revised and released for final publication by the middle of this month. It was created with input from consumers, patients, health care professionals, ethicists, dot-com entrepreneurs, academicians, special interest societies, manufacturers of regulated drugs and medical devices, governmental agencies, and international representatives. ■