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America's veterans have unique needs at EOL for a peaceful death

VA, NHPCO to offer hospice programming specific to veterans

It's not unusual for soldiers who have returned from war never to discuss the war with their families or friends, creating an aura of mystery or a sense that their loved ones somehow cannot fully understand them now that they have returned to civilian life.

What may be surprising is that often those very soldiers who attempt to shield themselves or others from their wartime experiences may re-experience the associated emotions — pain, fear, guilt, helplessness, etc. — at the end of life, according to **Deborah Grassman**, ARNP, nurse practitioner at Bay Pines VA Medical Center in St. Petersburg, FL, who has been with the Veterans Administration (VA) for 26 years and has been the director of the hospice program at the VA for 15 years.

Grassman was a plenary presentation speaker on "Wounded Warriors: Their Last Battle" at the 11th Clinical Team Conference and Pediatric Intensive, "Performing in the Key of E: Excellence in Interdisciplinary Care" in Atlanta sponsored by the National Hospice and Palliative Care Organization (NHPCO) in Alexandria, VA.

Because soldiers, particularly those who have seen combat, often have unique needs at the end of life, the VA and the NHPCO have teamed up to offer a program available to all hospices that has been developed to meet these special needs of America's veterans. The program can be accessed at www.WeHonorVeterans.org later this year and is designed to address the following: military history checklist; veteran benefits and the VA organizational structure; recognition ceremonies; veteran-to-veteran programs; outreach materials; and staff and volunteer training modules.

Contrasts from different wars

There may be different trauma, too, depending on how the veterans were received by the public after returning to the United States. In

World War II, “everyone was involved in this war effort,” Grassman noted.

For example, the Red Cross and other organizations would send pictures to soldiers overseas so that they would know that they were supported. “Also, there was no television coverage in World War II for the most part. Therefore, that meant that war could be glamorized; the American public could be shielded from the brutality of war, which fostered a lot of unity for the war. Also, the mission was pretty clear and largely undisputed in World War II, especially after Pearl Harbor.”

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EDITORIAL QUESTIONS

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World War II soldiers returned to the United States as victors, and because transportation was not as advanced at that time, “it took a while for them to get home, so there was time . . . to externalize some of those war stories that they had experienced.”

By contrast, the Korean War is often called the “forgotten war,” and was officially only a “conflict” or a “police action,” she said.

“I think those labels reflect how we often tend to minimize . . . what our Korean War veterans have gone through,” Grassman explained.

In Vietnam, due to television coverage, Americans “were no longer shielded from the brutality of war,” she said, noting that it was “a very political war” about which the country was divided. Therefore, when Vietnam veterans returned, it was to quite a different reception than World War II vets received.

“You think about how our soldiers from Vietnam were being treated. How did we meet and greet them when they came back?” she asked. Sometimes as “baby killers” or simply as “murderers” by war protesters.

Although all wars involve brutality, one of the challenges with any veterans’ death is complicated by whether they have caused harm, in addition to whether they have been harmed, she said. The fighting in Vietnam was more face-to-face, and the enemy was hard to determine.

Grassman said that as a result, it is easy to understand that a Vietnam veteran’s memories like this “can sometimes complicate their peaceful dying.”

Post-traumatic stress syndrome

Post-traumatic stress syndrome (PTSD) can be diagnosed in anyone who has had exposure to a traumatic event that is experienced with fear, horror, or a sense of helplessness, Grassman said. Bad memories of war often lead veterans to do “what most of us would do, which is to avoid any thought, any memory, any trigger that . . . would cause them to have these memories,” she said.

According to the Diagnostic and Statistical Manual (DSM-IV), there are many criteria, or symptoms, of PTSD. The three major categories are:

- The “traumatic is persistently re-experienced.”

- Avoidance of associated trauma (a veteran hears a balloon pop at a party, for example, which reminds him or her of the war, so that individual never goes to parties again).

- Persistent symptoms of increased arousal

(irritability or outbursts of anger, difficulty concentrating, etc.).

According to Grassman's presentation, "some resources say that the single most influential risk [factor for PTSD] is having killed. This complicates EOL care."

"You see, it is one thing to have witnessed trauma; it is another thing to have caused trauma," she said. "That is a deeper level of traumatization . . . that is the injury that sometimes surfaces as people come to the end of their lives."

And she said that some research suggests that one-third of Vietnam veterans suffer from PTSD, but 60% do not report it.

"PTSD is a mental, emotional, social, spiritual, moral, familial, intergenerational injury," Grassman writes in her presentation. "Healing requires interventions that address all dimensions of suffering."

"Combat Response Trajectories"

With all the veterans that she has dealt with in her years with the VA, she told the audience that they tend to "sort out" into three combat response trajectories: integration (healing from the war); apparent integration (delayed-onset PTSD; subclinical PTSD; latent PTSD); and incomplete integration (PTSD).

With trajectory one, the combat trauma is "successfully integrated." Among the comments she has heard from veterans who fall into this category are:

"I've faced death before in the war. I'm not afraid of death anymore."

"I must have been spared for a purpose."

"I faced death before, and every day since has been a gift."

With the third trajectory, Grassman says that she has heard the following comments from veterans or family members of veterans:

"Most of my brother remained in Vietnam."

"I didn't know the person who came back."

"I lost my soul in Vietnam."

"90% of me died in that war."

One of the main criteria for PTSD is "estrangement from others," along with suspicion and lack of trust; alcohol use; anxiety; agitation; unfulfilled longing for the life not lived," Grassman writes in her presentation.

Don't push for stories

Grassman suggests that in working with

patients at the end of life, it is "very important that we do not push people to tell their stories," she told the audience, noting that providers can inadvertently "do damage when we don't know" how to respond with an appropriate emotional environment.

Regarding intervention, Grassman suggested not asking someone, "Are you a veteran?"

"The reason I don't want you to ask it that way, there are some veterans who don't think they're veterans; they think veterans are only people who have been in combat [or] only those [who] have used the VA," she told the audience. "Ask the question instead, 'Have you ever served in the military?'"

Another step is to identify those among volunteers at a particular hospice or other facility who may be veterans themselves, and assign those volunteers to the patients who are veterans.

"There is a camaraderie that forms very, very quickly," she said.

"We need to affirm the feeling aspect of their death experience, especially the tears and the fears, which the military culture taught them to disdain," she said. "We need to anticipate that they might underreport their physical and emotional pain and fear. We need to thank them for serving our country and giving us our freedom. And there are a lot of ways you can do that."

SOURCE

Deborah Grassman, ARNP, nurse practitioner at Bay Pines VA Medical Center in St. Petersburg, FL. ■

MDs perspective on EOL spiritual care

Meshing spiritual with science

Rabbi Barry M. Kinzbrunner, MD, suggests that in addressing spiritual care for their patients at the end of life, physicians often face the challenge of how to mesh the spiritual concerns with objective science — a challenge that sometimes results in a "significant disconnect" with patients.

Kinzbrunner, who is senior vice president and chief medical officer of Vitas Innovative Hospice Care in Miami, was a speaker at the 11th Clinical Team Conference and Pediatric Intensive held in Atlanta Sept. 13-15 and sponsored by the National

Hospice and Palliative Care Organization in Alexandria, VA.

Because pain can be psychosocial, spiritual, as well as physical, to illustrate all the contributors to “total pain,” Kinzbrunner, who is trained as an oncologist, offered The Portenoy Model, published in 1988 in the *CA: A Cancer Journal for Clinicians*.¹ One of the major contributors to suffering at the end of life, according to that model, is fear of death, along with other contributors, such as loss of work, physician disabilities, and financial concerns.

The word “spiritual,” he noted, is derived from the Latin “spiritus,” meaning breath.

But trying to define what spiritual care is can be difficult. For example, a literature review uncovered 92 definitions of spirituality, he said, with seven “definitional themes,” including:

- “relationship to a higher power or reality greater than self;
- “not of the self;
- “transcendence or connectedness unrelated to belief in a higher being;
- “not of the material world;
- “meaning and purpose in life;
- “life force of the person; integrating aspects of the person;
- “summative definitions that combined multiple themes.”²

Spiritual vs. religious

In other definitions of spirituality, he noted that religion is seen, in some sense, as a subset of spirituality. And he also explained that in the guidelines on chaplaincy and spiritual care in the NHS in Scotland that “Spiritual care is not necessarily religious. Religious care, at its best, should always be spiritual.”³

“One does not necessarily exclude the other,” Kinzbrunner says.

In a study of palliative care physicians and spirituality by Seccareccia and Brown, the study found, according to Kinzbrunner’s presentation, that “Physicians described spirituality as a multidimensional construct that may involve:

- a search for meaning and purpose
- a sense of connectedness
- a relations to a higher being or power
- transcendence”⁴

The study also found that “spirituality is different than religion,” he says, with the study suggesting that “religious patients often were described

as experiencing distress related to what they perceived as punishment from God.”⁴

Another finding, according to the presentation, was that “the authors conclude that the impact of a physician’s personal spirituality on practice and practice on spirituality were inextricably woven together.”⁴

The message from this study’s findings, according to Kinzbrunner, is that “physicians have to be spiritual, as well, to make this work; if there is no spirituality by the [physician], then it’s very hard for the patient to express [spiritual/religious concerns].”

Kinzbrunner also noted that the latest Pew research showed that 90% of Americans believe in and pray to a higher power. However, in one study by Curlin et al., 66% of physicians say that in treating patients, they do not consider “what would God want me to do.”⁵

In a 2009 study by Fitchett et al. on physician’s experience and satisfaction with chaplains, of the 1,102 physicians surveyed, the respondents identified themselves as 59% Christian; 16% Jewish; 14% Other; and 10% No religious affiliation. However, 41% of respondents agreed with the statement, “My whole approach to life is based on my religion.” Also, 50% of respondents believed it was appropriate to pray with patients, Kinzbrunner notes.⁶

Kinzbrunner explained that in a 1999 study by Ehman et al., 51% of 177 respondent patients in a pulmonary outpatient clinic identified themselves as “religious,” while 90% responded that they believed that prayer may sometimes influence recovery from an illness.

In a 2008 study by Jacobs et al., it was found that “57.4% of the public and 19.5% of the professionals believe that divine intervention could save a person when physicians believe treatment is futile.”⁷

“More than half of the public believes in a miracle,” according to that study, Kinzbrunner noted. “The public is more often looking for a miracle than the people taking care of them, and that, to me, speaks volumes.”

A 2007 study by Balboni et al. found that 88% of 230 patients “considered religion to be at least somewhat important,” according to Kinzbrunner’s presentation.⁸ Also, “spiritual support by religious communities or the medical system was significantly associated with patient quality of life,” with 47% reporting that “spiritual needs [were] minimally or not met by [the]

religious community”; while 72% reported that “spiritual needs [were] minimally or not met by [the] medical community.”

Another finding of the Balboni study was that “religiousness was significantly associated with wanting all measures to extend life.”

Kinzbrunner suggested, too, that Americans are “much more tolerant of cultural diversity than religious diversity.”

“I think what’s beginning to happen in this country is that if you’re religious, what you want must be wrong,” he said. He also noted that just as we tend to think outside the box on how to provide patient care to those with cultural diversity, we should try to do the same for those with religious diversity.

Another study by Balboni TA et al. on the impact of spiritual care on the perception of the quality of medical care and quality of life near death “shows you how important spiritual care is,” Kinzbrunner said.⁹ So, even for people who are not religious, spiritual care is important at the end of life, and it requires the participation of the entire health care team, including physicians, he said.

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How to partner with your faith community

Help in meeting spiritual needs

Jeanne S. Twohig, MPA, senior advisor, Duke Institute on Care at the End of Life, unabashedly asserted that there is a crisis in our country as to the quality of the vision for our health care futures.

Twohig, who notes the Durham, NC-based institute with which she is affiliated is housed in the divinity school vs. the medical school at Duke University, is a program developer focused on how we can build better systems and better delivery of spiritual care. The goal is to design more rigorous systems as health care facilities strive to offer quality palliative care to patients.

Twohig, speaking at the National Hospice and Palliative Care Organization’s (NHPCO) 11th Clinical Team Conference and Pediatric Intensive held Sept. 13-15 in Atlanta, noted that there are now 77 million baby boomers, or those born between 1946 and 1964, with the oldest boomers at 64 and the youngest at 46.

“Our country is getting older,” she noted, explaining that it is the “oldest of the old” demographic group that is growing at the most rapid pace. For example, she noted that in 2000 there were 85,000 centenarians, but by 2050, it is projected that there will be 850,000 centenarians.

Another aspect of the aging is that women typically outlive their companions, leading to the question of who will care for the traditional caregivers. Fewer people, she said, will be contributing to Social Security, leading to the question, “Who is going to care for us, and how is it that we want to be cared for?”

What patients want at EOL

Twohig referenced the 2000 study in *JAMA* by another Duke researcher, Steinhauser et al., regarding the “attributes rated as important by more than 70% of patients but not physicians,” which included:

- “be mentally aware
- “be at peace with God
- “not be a burden to family
- “be able to help others
- “pray
- “have funeral arrangements planned
- “not be a burden to society

- “feel one’s life is complete.”¹

According to Twohig, “Faith communities are natural allies, and providers of palliative care need alliances with community spiritual providers.” Such alliances are a well-organized way to engage with a community as a whole, she said.

Spirituality, she said, is important to people, although we live in what is largely a medicalized society, or what she calls the DMZ, or the “divinity-medical zone.” She noted that there are many cultural issues associated with this, as well as “tremendous” role confusion, since physicians historically have not been trained in meeting spiritual needs and even now courses on spiritual care are not routinely taught in the divinity school or the medical schools.

Other challenges to providing quality spiritual care include quality “measurement issues” and a “fragmented notion of what spirituality is,” Twohig told the audience.

Twohig said her goal is to develop new ways to meet the spiritual needs of this “tsunami of baby boomers” that is coming, to rethink the ways to provide care, because “the way we are doing it is insufficient.” And because, she said, “boomers are not quiet about getting their needs met,” there is likely to be a coming demand for better spiritual care.

The recommendations from the February 2009 Consensus Conference on “Improving the Quality of Spiritual Care As a Dimension of Palliative Care” include the suggestion that spirituality should be considered a “vital sign,” just like any other physical vital sign.

“That gets at the question: ‘Are you at peace?’” Twohig said.

Another target for improving the quality of spiritual care is at the point the discharge plan is developed — meaning, if the patient has had spiritual care as an inpatient, how can that plan of care be carried to the outpatient setting? Twohig said. And, she asked, what is a way to unite the inpatient and outpatient delivery systems and the community?

The answer may be found with the faith community, or community religious and spiritual leaders. She said that some of the reasons hospices and palliative care teams should reach out to the faith community in their area is answered by the fact that eight out of 10 people identify with a particular faith community.

A faith community is a naturally occurring community, she said, and there is often good commu-

nication within such networks.

“Faith leaders need the skills that hospices have,” because while community clergy tend to be comfortable with formal rituals, i.e., delivering the funeral sermon, they are not as comfortable with the “end-of-life conversations,” she said.

There is an opportunity, she said, to leverage what hospice now offers by linking with the faith community.

“Hospice is a movement as much as a type of health care delivery . . . the power of one becomes exponential in all this,” Twohig said.

Chaplains’ reach can be limited

With the growing immigrant community in the United States, there are times when a patient may not choose to share with a hospice chaplain. With the changing face of America, there may be some belief systems that “may not yet have been embraced by chaplaincy,” she said.

The point of reaching out to the faith community in a hospice/palliative care service area is this, she said: “What it is really about is embracing that patient.”

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Palliative Care Act is law in New York

Providers must provide info on care option

A bill recently signed into law in New York state will require a patient’s health care provider to provide information and counseling to that patient on palliative care, prognosis, and end-of-life options, once the patient is diagnosed with a terminal illness.

If the provider determines that a patient lacks decision-making capacity, the provider must give that information — orally or in writing — to the patient’s surrogate.

Compassion & Choices drafted and sponsored the act, along with its New York affiliate, according to Compassion & Choices President Barbara Coombs Lee.

The legislation was opposed in New York by the New York Medical Society; however, no representative of that physician's organization was available to speak to *Medical Ethics Advisor*.

Lee tells *MEA* that this is the second state in which this type of legislation has been passed, with California being the first, in 2008. In California, however, the bill, also originally drafted by Compassion and Choices, was known as The Right to Know End of Life Options Act, she says.

The New York law is called the Palliative Care Information Act (PCIA).

"I don't think we ever really seriously considered a Death with Dignity Act for New York," Lee says. Instead, the organization thought that the PCIA was "doable, and it would have a substantial impact on the quality of end-of-life care and the quality of the information that patients had and their ability to make end-of-life decisions."

Lee says that Compassion and Choices, which has sponsored the Death with Dignity Acts in Oregon and Washington, and fought for its passage through the courts in Montana, realized that most people aren't aware of the end-of-life options they legally have in the "other 50 states of the union."

"And they often die in agony and suffering needlessly, because they don't know about simple options like, 'Oh, gee, I could have my implantable defibrillator deactivated, or I could stop my cardiac pacemaker, or I could actually have some palliative care to support me [with] my symptoms; I don't have to end my life in an intensive care unit on a ventilator and tied to the bed,'" Lee says. "It's just a glaring problem."

Lee says that what really alerted her organization "to the acuity of the problem was the *New England Journal of Medicine* article about procedures, treatment, that physicians feel authorized to keep secret from their patients if they do not agree with them in particular," among them palliative sedation.

"It was alarming — to us, anyway — that even people who had every reason to look forward to a tortured death, you know, a death with agonizing symptoms, [that] a large number of physicians felt justified in not advising patients that they could be sedated to unconsciousness at the end, if their symptoms became unbearable," Lee notes.

"Not only did they feel justified in not advising people of that option, but they also felt justified in not referring the patient to someone else who would advise them, and perhaps, offer it," she explains. "Some patients are going to accept,

and some patients are not going to accept [this]. But it just seems unjust to keep a patient hostage to a physician's personal beliefs and personal biases against certain ethical end-of-life treatment choices."

National goals for legislation

Lee says she would like to see similar legislation passed nationally, or in every state.

"We would love to see that principle of a fully informed patient who asks to be fully informed, having the right to that information, in effect in every state, absolutely," Lee says.

"It just seems like a natural consequence of an informed consent process, but because there is so much research indicating that patients are woefully uninformed, and do suffer needlessly at the end of life, apparently our current advance directives and informed consent laws are not sufficient. So, we need something that spells out the duty with greater specificity," Lee says.

SOURCE

Barbara Coombs Lee, President, Compassion and Choices. See www.compassionandchoices.org. ■

Providers need better info on preemie outcomes

Janvier: They underestimate survival

If they were better informed on the outcomes of premature infants, physicians might be more inclined to intervene more often, according to **Annie Janvier**, MD, PhD, FRCPC, a neonatologist and clinical ethicist practicing at St. Justine Hospital in Quebec and associate professor of pediatrics at the University of Montreal.

Speaking to an audience at the Sixth Annual Pediatric Bioethics Conference in Seattle, sponsored by Seattle Children's and the Treuman Katz Center for Pediatric Bioethics there, Janvier said instead, physicians, nurses, and resident are "not well informed about outcomes of pre-term infants: They underestimate survival and overestimate disability."

Janvier also maintained in her presentation that what is described as beneficial treatment, futile treatment, or as occurring in the gray zone is "relative and subjective."

Twenty or 30 years ago, nature decided what happened to neonates and children with disease or who had been in accidents, because there were fewer treatments to propose, she said.

“Nature decided, and doctors were really good, because they didn’t have much to do but hold the patients’ hands and be nice doctors,” she told the audience.

Then came medical developments, along with increases in available treatments and in survival.

“So, nature doesn’t decide anymore, meaning patients, physicians, and society have to decide whether to resuscitate or treat,” she said. However, she noted that there are some interventions that patients, physicians, or families may find unreasonable.

That leads to the question of how physicians decide what is beneficial, gray zone, or futile treatment.

As a discussion point, Janvier provided the example of a woman who is about to deliver a pre-term infant at 23 weeks gestation, and she wants to do “everything” for the baby. Questions that the physician would have to ask himself or herself would be:

- Do you think it is in the baby’s best interest to receive intervention?
- Would you offer intervention?
- Would you obtain a court order to withhold or to intervene?

“We don’t have little clicks to vote, but we wouldn’t be” at 100% agreement, she said.

“Everyone has their opinions in [such a] case.”

How should physicians think about such cases in determining their status as beneficial, gray zone or futile? Janvier suggests that providers consider the following factors: survival; outcome; quality of life; best interest; and resource allocation.

In France, for example, “a do-not-resuscitate order is (generally made) for newborns weighing less than 600 g and/or with a gestation of less than 24 weeks since the mortality is 100%.”¹

By contrast, in Germany, resuscitation generally is offered for pre-term infants with gestation greater than 24 weeks. At 22-24 weeks, intervention is offered according to the parent’s wishes. In a study by Herber-Jonas et al., there was 60% resuscitation at 22-24 weeks. And when resuscitated, survival at 22 weeks was 37%, and at 23 weeks 75%.²

The outcomes depend to a large extent on where the patient is, the attitudes of health care providers, who is on call, and “actually what time of the night it is, often,” Janvier said. According to one

study by Haywood et al., pediatricians were found to be “generally pessimistic about survival and disability,” according to Janvier’s presentation.³ Also, pessimists would intervene less often.

In another study by Streiner et al., nurses were found to be even more pessimistic than physicians.⁴

“Nurses are at the bedside, and I think they probably have the hardest work [because they spend] 12 hours poking these babies, suctioning the babies, so they’re more aware of the burden of care,” she told the audience.

In her own research, Janvier used the example of an imminent delivery of an “infant with a 50% predicted survival and a long-term outcome as follows”:

- 50% “within normal limits”;
- 35% with behavioral/learning disabilities;
- 15% to 25% with major disability.

In the study, she asked pediatricians and residents if they thought such a baby should be resuscitated in the delivery room. What she found was that “if you tell them the outcome without telling them it’s a 24-week baby, the average goes up.”⁵

And according to a Canadian researcher, Saroj Saigal, who Janvier says “wrote terrific and astounding articles” and still does research, in all her quality of life (QOL) research, the “QOL is always superior when judged by children and their parents compared to health care providers.”⁶ In her research, Saigal found that only 13% of extreme low-birth-weight infants had no problems; 56% had one to two problems, and one-third, or 32% had three or more problems.

“So, healthwise, they had more problems, but if you asked them about quality of life,” Janvier says, much of the data on factors that determine QOL were the same for these pre-term infants as the control group.

For example, at 23 years, of these infants studied, 35% had a permanent job; 40% had completed school; 10% reported having children (same as control); 30% were living independently (same as control). The ELBW infants reported less sexual activity than normal birth weights (60% vs. 78%). But fewer of the ELBW had problems with the law.

Decision-making and incompetent patients

The guiding principle in decision-making for incompetent patients is the patient’s best interest, which can be determined according to legal decisions, with parents as surrogate decision-makers

and physicians advocating for their patients, according to Janvier's written presentation.

"If an intervention is in an incompetent patient's best interest — and serious harm would follow [by] withholding intervention — refusal of care is generally not acceptable — not ethically nor legally," Janvier said.

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Maternal obligations, rights during pregnancy

Law favors woman's autonomy

Although the law is squarely on the side of the pregnant mother in maternal-fetal conflict, the ethics should be examined to determine how one reaches that conclusion, according to **Mark R. Mercurio**, MD, MA, a neonatologist at the Yale-New Haven (CT) Children's Hospital and director of the Yale Pediatric Ethics Program.

"Some would say that those of us who would be parents have an obligation to prepare for and care for our children long before they're hatched," said Mercurio.

Mercurio presented on "Autonomy and Responsibility: Possible Conflicts of Rights and Obligations During Pregnancy" at the Sixth Annual Pediatric Bioethics Conference in late July

in Seattle, sponsored by Seattle Children's and its Treuman Katz Center for Pediatric Bioethics.

Despite women's obligations, the law still is decidedly in favor of women's autonomy, although there have been unique instances where the mother was held accountable for behavior causing harm to an unborn child in certain state cases, he said.

He noted that Bonnie Steinbock, PhD, professor of philosophy at SUNY-Albany in New York says that parents, he said, have a responsibility to their future children, although Steinbock does not address obligation to fetuses.

Mercurio also noted that Steinbock, in her writings, cautions against acting counter to women's rights and cautions against "the dangerous concept that the woman is a 'fetal container.'"

In such instances, Mercurio explained that the point of the discussion was regarding those cases "where women choose not to follow medical advice that the providers feel is important" to protect the mother or the unborn child.

Those situations call for careful thought; for example, two studies suggest opposite outcomes in these situations.

In Ohel et al., he writes in his presentation, "refusal of a medically indicated intervention is an independent risk factor for perinatal mortality."¹ In another study conducted more than a decade earlier by Kolder et al., the findings were that "one-third of medical interventions over maternal objections were subsequently proven wrong," he told the audience.²

While it could be interpreted that those two studies combined "prove that we used to get it wrong, but we don't anymore," he countered that, "Actually, we do [get it wrong]."

Possible issues in maternal responsibility

Some of the possible issues that are faced with "maternal-fetal conflict," he noted, are such behaviors as the use of alcohol or illegal drugs; poor compliance with recommended regimens, such as HIV medications; leaving a hospital "against medical advice (AMA)"; and refusal of a procedure, such as intrauterine transfusions or a C-section.

The most dramatic intervention, he suggested, would be the fourth in that list of potential conflicts, calling a C-section the "most invasive of things we might choose to do for a pregnant woman."

In a case where the obstetrician may fear fetal death, for example, or permanent brain damage in a future child, Mercurio asked, "Is it ethically

acceptable to operate, or is it acceptable to operate with or without a woman's consent?"

Mercurio noted the words of Judge Benjamin Cardozo in 1914, who wrote, "Every human being of adult years and sound mind has the right to determine what shall be done with his body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."

Cardozo served for many years as a New York Court of Appeals judge and later as a justice on the Supreme Court.

Mercurio also offered perspective regarding a person's right to refuse by John Stuart Mill, who in "On Liberty" wrote: ". . . the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant . . . Over himself, over his own body and mind, the individual is sovereign."

"He gave us a caveat, which is very important to the question at hand, [i.e.], the only time we can use force against an individual is to prevent harm to others."

For this topic, "others" is the fetus or future child, he said.

Legal precedents

Mercurio provided a snapshot of the case of a pregnant woman, Angela Carder, in 1985. Carder was a 28-year-old woman with cancer, thought to be fatal, and 26 weeks pregnant. In the case, the hospital sought a court order to perform a C-section over the objection of the patient and her husband. However, the court approved the intervention, the C-section was performed, and "both the mother and child died shortly thereafter," he said.

In 1990, the DC Court of Appeals ruled that "a competent woman's refusal should control in 'virtually all cases,'" according to his presentation. That court also stated that "exceptions, if any will be ". . . extremely rare and truly exceptional. . .," Mercurio writes in presentation. "Indeed, some may doubt that there could ever be a situation extraordinary or compelling enough to justify a massive intrusion into a person's body, such as a caesarean section, against that person's will."

In the case of "Mrs. Doe" in Illinois in 1994, a C-section was recommended at 37 weeks for placental insufficiency. The woman refused, citing

religious reasons; however, the hospital sued to force the woman to have the intervention.

Mercurio told the audience that he chose this case "because of the wording of the state's attorney," which, according to his presentation, argued, "the fetus was a real life being kept prisoner in its mother's womb and tied to an oxygen source that is not working."

That argument was rejected by the court, and an appeals court said in a later statement, "a woman's right to refuse invasive medical treatment. . . is not diminished during pregnancy. . . The potential impact on the fetus is not legally relevant."

Ethical analysis important

As to what current legal precedent is on the subject of maternal-fetal conflict, Mercurio maintains that while the law is important, it is essential first to do an ethical analysis, based on principles, such as:

- respect for autonomy ("People like to make decisions about their own body.");
- beneficence ([providers must] act for good of [their] own patient");
- justice ("Equals should be treated equally.");
- nonmaleficence ("the obligation to do no harm").

The American College of Obstetricians and Gynecology's Committee on Ethics in November 2005 had determined the following: "In the absence of extraordinary circumstances, circumstances that, in fact, the Committee on Ethics cannot currently imagine, judicial authority should not be used to implement treatment regimens aimed at protecting the fetus, for such actions violate the pregnant woman's autonomy."

In other words, Mercurio said, "Maternal autonomy trumps [the] fetal right to beneficence."

It is important to realize, he told the audience, that most solutions to this provider-patient dilemma resulting from a maternal-fetal conflict, are through communication, i.e., by trying to understand the patient and what is going on with her that she would — at least initially — choose something counter to what the physician was recommending.

"We have to accept that women in labor sometimes will make decisions not in the best interest of the fetus or future child," Mercurio said. "Communication should not be carried out with the understanding that we have it right, and she [the patient] needs to get it right."

"Let me leave you with this thought: that just

because someone — in this case, a woman — has a moral obligation, this does not necessarily mean that we have a right to force that obligation,” he said.

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NEJM: Early palliative care has benefits

A study published in mid-August in the *New England Journal of Medicine* found that in patients with metastatic non-small-cell lung cancer, “early palliative care led to significant improvements in both quality of life and mood,” according to the abstract.¹

The abstract states, “As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival.”

Such patients with non-small-cell-lung-cancer “have a substantial burden and may receive aggressive care at the end of life.”

The researchers randomly assigned patients to receive early palliative care that was integrated with “standard oncologic care” or to receive only standard oncologic care, using the Functional Assessment of Cancer Therapy — Lung (FACT-L) scale and the Hospital Anxiety and Depression Scale, respectively, with 151 patients randomized.

The data were collected from electronic medical records, according to the abstract.

“The primary outcome was the change in the quality of life at 12 weeks,” according to the abstract.

“Despite the fact that fewer patients in the early palliative care group than in the standard care group received aggressive end-of-life care (33% vs. 54%, $P=0.05$), median survival was longer among patients receiving early palliative care (11.6 months vs. 8.9 months, $P=0.02$).

The study was performed at Boston’s Massachusetts General Hospital, published Aug. 17, and “general guidelines for the palliative care visits in the ambulatory setting were adapted

from the National Consensus Project for Quality Palliative Care.”

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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 with the **December** issue, you must complete the evaluation form provided 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.

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Upon completion of this educational activity, participants should be able to:

- Discuss new developments in regulation and health care system approaches to bioethical issues applicable to specific health care systems.
- Explain the implications for new developments in bioethics as it relates to all aspects of patient care and health care delivery in institutional settings.
- Discuss the effect of bioethics on patients, their families, physicians, and society.

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CME QUESTIONS

13. According to Deborah Grassman, ARNP, those who provide end-of-life care services to veterans should push for them to tell their stories of military service.

- A. True
- B. False

14. Rabbi Barry M. Kinzbrunner, MD, said a literature review uncovered 92 definitions of spirituality with seven definitional themes. Which of the below is not one of the definitional themes?

- A. Relationship to a higher power or reality greater than self.
- B. Not of the self
- C. Not of the material world
- D. Correct rules of behavior

15. Jeanne S. Twohig of the Duke Institute on Care at the End of Life suggested palliative care organizations and hospices build partnerships with community clergy to meet patients' spiritual needs at the end of life.

- A. True
- B. False

16. According to Annie Janvier, MD, PhD, FRCPC, physicians might be more inclined to provide interventions for neonates if they were better informed of the outcomes.

- A. True
- B. False

Answers: 13. B; 14. D; 15. A; 16. A.