

Issues up close

Helping patients navigate end-of-life issues

By Susan Trossman, RN



ANA workgroup takes a close look at the role of nurses.

IN THE RECENT MOVIE *The Bucket List*, two men (one of them exceedingly wealthy) are at the end of their lives. To fill their last days, they decide to fulfill some of their wishes by driving race cars, skydiving, and visiting the Great Pyramids.

If only it were simply a matter of determining whether to see the Grand Canyon or learn to surf. In real life, conversations around end-of-life care can be complex and fraught with sensitivities. Even seasoned healthcare professionals can find it difficult to navigate discussions with patients and their families.

“Nurses have a primary role within end-of-life care, including helping patients to plan for the end of life and making sure their wishes are carried out,” says Laurie Badzek, JD, MS, RN, LLM, director of ANA’s Center for Ethics and Human Rights and professor at West Virginia University School of Nursing. “We shouldn’t just contact a social worker or the physician and think our work is done. Our *Code of Ethics* requires us to be advocates for our patients.”

Beyond the code, ANA has several position statements that can help guide nurses on end-of-life issues. Each addresses a separate issue: assisted suicide, active euthanasia, patient self-determination, do-not-resuscitate decisions, forgoing nutrition and hydration, and pain management in dying patients. Since early 2007, an ANA end-of-life workgroup comprising members from the Center for Ethics and Human Rights Advisory Board has been engaged in a comprehensive review of these documents, particularly in light of recent research and an evolving healthcare landscape.

“Although we’re still developing draft documents, we know we want to more strongly speak to the role of the nurse in care of the dying and address issues that may cause them moral distress,” says Cynthia LaSala, MS, RN, workgroup chairperson and a clinical nurse specialist practicing in acute care general medicine at Massachusetts General Hospital.

ANA also is participating in another major effort—National Healthcare Decisions Day, a campaign to promote the importance of advance directives. This year, it takes place on April 16.

A place of understanding

One of the nurse’s key roles centers on maintaining a patient’s right to self-determination, including ensuring that federal law is followed. The Patient Self-Determination Act requires that all healthcare facilities receiving federal funding give patients written information about their right to make decisions about their care, including their right to accept or refuse treatment. Facility staff also must provide information about advance directives, although patients aren’t required to have them on file.

“It’s important that nurses be educated about the law, especially because another crucial component mandates healthcare professionals to follow advance directives,” says LaSala, a Massachusetts Association of Registered Nurses member.

One type of advance directive is the living will, which broadly outlines desired care, such as life-sustaining and other treatment preferences. Several states don’t recognize the living will by itself as a legally binding document. If patients choose to have a living will, they also should complete a healthcare proxy (health care durable power of attorney). In this directive, a patient designates a trusted person in writing who can make healthcare decisions if the patient is unable to speak for himself or herself.

“The living will can’t cover every scenario in terms of determining what care to give or not give,” says Kevin Hook, MA, AGNP, a workgroup member and an adult and gerontologic nurse practitioner. “The only way it works well is if there is a health care durable power of attorney, and the proxy can then use it as a template to make decisions.”

Nurses can encourage patients to not only choose a healthcare proxy, but also to have in-depth conversations with their designees about end-of-life wishes, LaSala says. Equally important is giving the potential proxy time to determine if he or she wants the role.

“What I have found is the proxy often has the ability and congruent values to make decisions, but does not realize how important and stressful the role is,” LaSala says.

Another issue around advance directives involves timing. “In my practice, I’ve seen emergency situations where the status of an advance directive is unknown or there are questions about its interpretation,” LaSala says. “So what happens is healthcare providers err on

the side of caution and provide live-saving interventions that might not be wanted.”

Nurses and other healthcare professionals should discuss advance directives and end-of-life care with patients in the primary care setting and not wait for an acute situation to arise. Once an advance directive is completed, all healthcare team members who care for that patient are responsible for knowing its contents and following the patient’s wishes. And nurses play a critical role as patient advocates.

Coming to terms

Broaching the topic of end-of-life care when treatment is failing can be difficult. “Although I have no trouble initiating these conversations, I’ve worked with new or young nurses who struggle with this nursing responsibility,” says Hook, a Pennsylvania State Nurses Association (PSNA) member. “So it’s important that nurses identify their own limitations—whether they’re due to inexperience, feeling uncomfortable, or being morally conflicted about a patient’s choice—and bring in another nurse or other member of the healthcare team to help meet the patient’s needs.”

Pediatric nurses may have additional challenges, because “the patient” is the family, the issue of self-determination is murkier, and the medical approach is often “try anything, try everything.”

“If they are competent, adolescents and even school-age children usually have a good grasp of what’s happening to them,” says Susan Dickey, PhD, RN, a workgroup member and associate professor at Temple University’s College of Health Professions. “Yet parents might not want their children’s wishes to be considered or [their children even to be] told they are dying.

“Ironically, adolescents are recognized as having the cognitive ability to make decisions when they’re involved in criminal cases. But when adolescents’ decisions about care differ from a parent’s or legal guardian’s, nurses can find themselves in the middle of a huge ethical controversy—especially when they know their patients may be facing torturous treatment versus a peaceful end of life.”

When it comes to neonates, the nursing community also needs to be willing to address the futility of treating very-low-birth-weight babies whose outcomes are extremely poor, Dickey says. So a major role for pediatric nurses in end-of-life care centers on family consensus-building, which requires deft communication skills, maintains Dickey, a PSNA member.

Workgroup nurses don’t expect all RNs to be experts in dealing with all aspects of end-of-life issues. However, RNs should have a basic understanding about end-of-life care and terms, such as *hospice* and *palliative care*.

It’s also critically important for nurses to be able to

provide patients and families with the resources they need to make informed decisions, Dickey says. The availability of options, such as hospice care, within a healthcare system and community can vary geographically or can be based on the way funding resources are allocated.

LaSala agrees, saying that some facilities are rich in resources such as palliative care and pastoral teams. These teams can support nursing staff in navigating difficult ethical waters or family conflicts.

Finally, Hook believes nurses need to remember that not all conversations about end of life have to center on death. He recalls one of his patients, a 55-year-old woman scheduled to have high-risk surgery the next day. Earlier in the day, she had admitted to Hook that she was exhausted—although family members and hospital staff mistook her fatigue for a lack of concern

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about the pending procedure. Hook decided to spend extra time with her. She had given her life’s blood to her work and had just retired early so she could do all the things that she had put off. Now she was wondering if her singular focus on work had been worth it.

Hook asked her to describe what kind of manager she was. She talked about her open-door policy and how she always tried to accommodate people’s requests for time off. “I told her it seemed she really tried to provide a humane job environment for the people she worked with, and she told me she never thought of it that way,” Hook says. “I helped her reframe her life.”

Maybe it’s also a case of reframing how nurses think about life and death.

“We can help people reflect on their lives and remember their values, which in turn, can help them make decisions about their end of life,” Hook says.

Current versions of ANA’s position statements are available at www.nursingworld.org. For more information on National Healthcare Decisions Day, visit www.nationalhealthcaredecisionsday.org. ★

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