COMPANIONING CAN HELP MEET COMPLEX NEEDS

The memorable movie "Psycho" and its bizarre protagonist, Norman Bates, are imprinted upon my moral consciousness. While most people immediately recall the movie's heart-stopping shower scene, I most vividly recollect a scene in which Norman, the devoted son, carried on a conversation with his dead, upright, stuffed mother. In a consummate denial of death, the deranged man ensured that he had his mother always with him.

SR. PATRICIA TALONE

In my 30-year professional practice as a medical ethicist, I frequently have been reminded of Norman's ultimately futile effort to hold on to his mother's life and physical presence. Contemporary media almost continually focuses on extraordinary right-to-die cases. Some, like the Karen Ann Quinlan case, examine the removal of ventilator support, while others, like the Nancy Cruzan case, focus on removal of artificial nutrition and hydration. More recently, the Charlie Gard case in England drew international attention and commentary regarding pediatric decisions. But these kinds of cases are not the ones that ethics committees experience and address on a daily basis.

My practice in two large Catholic health systems and service on numerous hospital and long-term care ethics committees indicates to me that the more widespread cases are those in which families insist on heroic, futile care — when doctors say "no" and families say "go." Too many adult children of elderly, dying parents demand that "everything be done" for Mom or Dad, even when the treatment in question will exacerbate the parent's precarious condition, or the parent has indicated in an advance directive his or her wishes for no extraordinary means of life support.

The Catholic belief in a life after death, as well as our historic and venerable tradition of evaluating burdens and benefits of treatment for each patient, can provide an antidote to some families' inability to deal with the approaching death of an elderly loved one. Moreover, the centuries-old practice of caring for one another, or bearing one another's burdens,[1] urges us to extend our care far beyond physical amelioration or cure of sickness.

CONFLICTING DIRECTIONS

The patient, Mildred,[2] was a 94-year-old woman who had been remarkably healthy throughout her long life, living independently until the age of 89. When she became increasingly forgetful and adamantly refused to move in with any of her four children, they regretfully placed her in an excellent Catholic nursing home. "The best in the city," her daughter noted with some pride.

Despite excellent care, Mildred's health gradually deteriorated. Some of her ailments, like hypertension, arthritis and osteoporosis, could be treated with medication, but her deteriorating cardiopulmonary disease caused her to be hospitalized five times within an eight-month period.

While she was still mentally acute, Mildred had executed not one but two advance directives. One of these was dated 1992, the other was from 1994, when she had gone to stay for a short time with her son in Arizona. He noted that she desired to have a directive valid in that state. In her documents, Mildred said that she did not want "extraordinary means" to prolong her life, should she be either near death or in a permanent unconscious state.

At the time of Mildred's final hospitalization, the nursing home contacted Mary, her daughter who lived closest to the facility. The eldest of Mildred's children, Mary also happened to be a retired attorney. Mary arrived at the emergency room shortly after the ambulance brought her mother from the nursing home. She demanded to see the ER doctor caring for her mother and told him that she wanted "everything done" for her mother. The nursing home had sent Mildred's advance directive along with the transfer sheet to

the ER, so the physician, who had cared for Mildred on her four previous visits, knew that the patient did not desire CPR or ventilator support. He believed that Mildred's successive hospitalizations indicated a decline in her overall condition.

Mary insisted that if the physician did not do "everything," he would have a major lawsuit on his hands. Medications helped Mildred initially to rally from the episode that had caused hospitalization, but subsequent consultations with her primary care physician, as well as a cardiologist and pulmonologist, attested to the fact that her lungs were deteriorating rapidly, placing greater stress upon her already failing heart. If placed on a ventilator, it would be impossible to wean her from it. And Mildred had clearly stated she did not want to be on a ventilator. Furthermore, to perform CPR on a frail woman in her 90s often causes fracture of the ribs and perforation of the heart and/or lungs.

The attending physician called a meeting with Mary and her siblings, inviting two medical specialists and four ethics committee members (physician, pastoral care chaplain, social worker and ethicist) to attend. As the group convened, it quickly became clear that Mary's sister and two brothers did not agree with her insistence on using any and all medical intervention to prolong their mother's life. It also was clear that Mary intimidated her siblings, just as she had alarmed the ER staff. When families are "stuck" regarding a medical treatment decision, often the problem is not the medical care but something deeper within the fiber of the family itself. Such was the case with Mildred's family.

The ethics consult began not with a review of Mildred's by-then extensive medical chart, but when I asked her children a very simple question: "We don't know Mildred, except as someone who is ill. Tell us about your Mom. Who is she? What kind of woman was she before her illness? What did she value most?"

The children responded eagerly, painting a picture of a competent, capable, humorous woman who definitely knew her own mind and was not afraid to speak it. The youngest son had a picture of his mom taken at her grandson's wedding. An attractive, perfectly coiffed woman, she was dancing with the groom and laughing at the camera.

The chaplain asked the next question, "Tell us about the last death your family has experienced," indicating that perhaps it had been their father's.

Answering this question tells something of the family's story and illustrates their values. Often it can indicate the kind of choices the patient might make. When posed to Mildred's family, however, the question was met with quizzical silence. The staff had supposed that, since Mildred was 94 and no husband was present, his had been the most recent death. Mary brusquely indicated that their father had abandoned the family when Mary was 12 and the youngest child was 2. Mildred immediately had secured a job to provide for and educate her children. Mildred's son John noted, rather touchingly, that Mildred had been both mother and father to them for more than 60 years; she was the only parent they knew.

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Ultimately, with the assistance of an excellent ethics case consult group, careful explanation from physicians (including articles in medical journals attesting to the futility of CPR on failing nonagenarians), Mary agreed with her siblings that what her mother needed from this point on was comfort care. Hospital staff worked with the long-term care facility to ensure that Mildred received the best palliative care possible. Mildred passed on to her eternal reward just two days shy of her 95th birthday.

ETHICAL CONCERNS

Mildred's daughter Mary, acutely aware of her impending loss, had insisted that prolonging her mother's life was an absolute good, and she wanted to supersede Mildred's carefully crafted advance directive, as well as the clinical judgment of medical professionals. To follow Mary's wishes would not have served Mildred's previous wishes or her best interests. Studies published in medical and ethics journals and even by popular news outlets like the *New York Times* and *Reuters* have confirmed that CPR performed on the hospitalized frail elderly prolongs suffering more than it extends their lives. While it might lengthen life

for a brief time, only about 12 percent of patients over 90 are ever discharged from hospitals after CPR.[3] Furthermore, performing CPR on a woman over 90 often causes her brittle bones to fracture, thus exacerbating pain, suffering and anxiety.

Physicians pledge *primum non nocere* or "Above all, do no harm" as they begin their professional practices.[4] In Mildred's situation, the pulmonologist who had joined the case consult quoted this to her family as one reason why he would not perform CPR on their mother. This principle of non-maleficence (do no harm) is but one ethical reason we need to examine when facing family requests to "do everything." Other ethical principles include telling the truth to patient and family and supporting patient and clinical autonomy. Our culture commonly recognizes that competent adult patients possess autonomy and the right to make their own medical decisions. However, physicians and nurses, with years of education, examinations and external professional certification, also hold autonomy over their professional decisions. Furthermore, an evaluation of stewardship of resources is part of any robust ethical discernment. Ventilators are finite resources and limit patient discharge from acute care settings.

The lived tradition of Christ's healing ministry, however, attests to the fact that we have something more to offer suffering patients and families than ethical analysis alone.

PASTORAL CONCERNS

During Mildred's last hours, not all of her children were able to arrive before their mother peacefully passed to her eternal reward. The pastoral care team and staff kept vigil at her bedside, and family members who were absent found consolation in the knowledge that their mother died surrounded by love and prayer.

Our Catholic tradition compels us always to care for one another, even when it is impossible for us to cure. Such caring is not necessarily high-tech — often it is just the opposite. It involves being present or companioning one another. It is sitting quietly, watching with the loved one, attuning oneself to the loved one's breathing, looks, touch. It may involve much-loved music and even familiar scents. Some families, unfortunately, seem more comfortable demanding the full panoply of medical offerings for their loved ones than they are with the centuries-long Christian practice of "companioning the dying."[5]

Long before Catholic health care prided itself

Dressing for Lourdes

By Angela Alaimo O'Donnell

"She [Regina] is reading the Lourdes book and
every now and then announces a fact, such as,
'It doesn't make any difference how much you beg
and plead, they won't let you in.'
'Won't let you in where?'
'In Lourdes with a short-sleeved dress or low-cut.'
'I ain't got any low-cut dress.'
I am going to read it when she gets through."
— Flannery O'Connor

Like dressing for my own funeral
I want to look stylish for Lourdes. Put on
my best dress so folks'll know I'm a
lady when they wheel me into the heal-
ing waters. Church hat, veil, white Communion
gloves, a bride broke & brittle as china
desperate to be mended again,
to be loved and noticed by God and men
'cause no one is so sick she's not vain.
We all want to look good in our coffins.
So a low-cut dress seems mighty sane
if you've got a chest that makes it worthwhile,
give a cheap thrill to the crazy and lame,
rile up your mother, get dunked in style.

on end-of-life care, the women and men religious who founded our institutions embodied both the spiritual and corporal works of mercy in their care of the sick and dying.[6] A beautiful and often overlooked monument stands today in our nation's capital and attests to this truth. Located across the street from the Cathedral of St. Matthew the Apostle, at the intersection of M Street, Rhode Island and Connecticut avenues NW, is the memorial called "Nuns of the Battlefield" honoring the sisters who cared for ill and injured soldiers during the Civil War. Its inscription reads, "They comforted the dying, nursed the wounded, carried hope to the imprisoned, gave in his name a drink of water to the thirsty."

Although our tradition reverences human life as our greatest good, for centuries church leaders have taught that we need use only ordinary means to do so. Pius XII, in his often quoted address given to an International Congress of Anesthesiologists, noted that "life, health, all temporal activities, are in fact subordinated to spiritual ends."[7] Sadly, Mildred's daughter is not alone in her assumption that by demanding her mother receive the latest and best medical interventions, despite Mildred's written wishes, she was fulfilling her obligations as a daughter. Yet one's needs at life's end are so much more complex and deep than simple physical prolongation. Prayer, sacraments, the presence of loved ones count far more.

Cases like Mildred's are not unusual, but Catholic facilities have ways to address such situations. Virtually all Catholic systems and facilities have ethics committees and recourse to ethics consultation services. The Catholic Health Association has published the invaluable resource *Excellence in Ethics* that describes components of a robust ethics service, outlines ways to assess your system's or facility's service and offers steps to improve your quality of ethics services. All of these steps, while necessary, do not fully address the underlying challenges inherent in cases such as Mildred's. Such struggles are multifaceted and require broader civic and ecclesial discourse, as well as the support of more departments than ethics.

CONCLUSION

The fictional Norman Bates could not prolong his mother's life, so he chose instead to mummify her, keeping her always with him. We recognize that his macabre and pathological response expresses his inability to let go of a loved one. Families who beg caregivers to provide futile, often burdensome, treatment sometimes are expressing the same inability. Continuing a full regimen of futile treatment is not the answer.

But Catholic health facilities have the wherewithal, through robust pastoral care and psychological services, community health links, hospice and palliative care programs as well as ethics consultation services to address the deeper spiritual needs for both patients and families at this critical time in their lives. This is who we are, and it is what we must do for one another.

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NOTES

1. Galatians 6:2.
2. Although this is a real case, names and some circumstances have been changed for privacy.
3. Shereen Jegtvig, "For Elderly Hospital Patients, CPR Often Has Poor Outcome," *Reuters Health News* May 9, 2014. http://uk.reuters.com/article/us-cpr-survival-elderly/for-elderly-hospital-patients-cpr-often-has-poor-outcome-study-idUKKBN0DP1IH20140509.
4. This phrase, while not found in the ancient text of the Hippocratic Oath, has become central to medical education. It is attributed to the 19th-century surgeon, Thomas Inman. See: Daniel K. Sokol, "First, Do No Harm Revisited," *British Medical Journal* Sept. 20, 2014.
5. Daniel Callahan, in *The Troubled Dream of Life: Living with Mortality* (New York: Simon & Schuster, 1993) refers to it as technological monism, or acting as if only scientific and technological actions have meaning. This has never been the Christian tradition.
6. For a helpful commentary on the Catholic tradition of caring for the dying, see the Catholic Health Association's publication *Palliative and Hospice Care: Caring Even When We Cannot Cure*. You can find it through the CHA website: www.chausa.org/ethics/overview.
7. Pius XII, Address to an International Congress of Anesthesiologists, Nov. 24, 1957. www.lifeissues.net/writers/doc/doc_31resuscitation.html.

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