



On the Ethical Issues That Arise When Religion and Treatment Collide in End-of-Life Decision Making

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This article explores the ethical issues that arise when patients' and families' religious beliefs collide with clinicians' views of appropriate end-of-life decisions. The article begins with a case study drawn from clinical experience that focuses on the need for a surrogate decision maker for a deeply religious patient in the intensive care unit with life-limiting cancer. The patient's adult children, also religious, against the health care team's clinical advice, want all life-extending measures taken as they await a divine miracle. The conflict between the family and the health care team points to (1) the ethical issues of patients' and families' status of vulnerability and the health care team's necessary moral response to this status; (2) the moral obligation of the health care team to show their trustworthiness to the family by showing the family the team's competence, honesty, and reliability; and (3) the moral obligations of the health care team to provide the patient and family spiritual support.

KEY WORDS

decision making, end-of-life treatment, ethics, religion, spirituality, trustworthiness, vulnerability

CASE STUDY

The electrocardiogram monitor tick-tocks 60-some beats a minute, as if it were keeping time for Bach's *Pathétique* sonata, its evenness reassuring but its pace woeful. The pneumatic blood-pressure machine buzzes, squeezes air into the white cuff on her left arm and then hisses out: 120 over 80. Vasopressors, dosed just right, keep it there. Blood, dried and dark, cakes her gums. She breathes on her own; but soon, the nurses say to each other, she will need support. At 67 years old, she's too young for all this. Irinotecan-induced diarrhea has left her eye sockets cavernous and cheeks gaunt. Colon cancer, diagnosed a year ago, has ravaged her liver and lungs. For the past 12 hours,

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she has lain in the intensive care unit (ICU) in a city cancer hospital that is a 2-hour drive from her home.

She's been a widow for the last 3 years. She had cared for her husband until he died of Parkinson disease. He was a full 15 years older than her. When she was still in the rebirth of middle age—kids grown and gone, and time to do what she wanted to do—she had to toilet, bathe, and dress her debilitated husband. “My man-child,” she'd mutter as she tried to pull his pants up his stiff legs. He had gotten pneumonia; she could tell from his breathing. His doctor had come to the house, listened to his lungs, and wrote out a prescription for antibiotics. She didn't fill it. He died a few days later. She didn't tell anyone what she did, or hadn't done—2 sins of omission. She'd told them that he had slipped off in the middle of the night—1 sin of commission. She couldn't take it any more: the demands on her body were too much, and she could no longer look at the pain in his eyes.

She still lives in the small town where she and her husband were born, were married, and had raised their 3 children. She's been a member of the small town's Pentecostal church all her life.

Her oncologist comes to the small town once a week to see his patients. He sees them in a clinic room in the small town's 50-bed hospital. The diarrhea started a few days ago. She wanted to wait to tell him until he came to town. She didn't like calling his office and telling the nurse over the phone all about her private matters. Even if she had wanted to, she couldn't: she passed out while trying to get to the bathroom yesterday afternoon. Her oldest son, who now lives with her after an acrimonious divorce that left him penniless, loaded her into his pickup and sped along the country roads to the small town hospital.

The emergency room doctor, an independent contractor who comes to the small town every other week to pull a 48-hour shift, didn't have access to her medical records. The oncologist keeps them in his office in the city. The emergency room doctor didn't know she was on irinotecan and bevacizumab. “She's got bad diarrhea” is all her son told him. Without a computed tomography scanner, the doctor couldn't see that her bowel had perforated, probably from the bevacizumab. But he knew she had a fever and was hypotensive. He suspected infection. He called



the oncologist, who suggested she be transferred to the cancer hospital in the city right away.

She arrived by ambulance around midnight, in full-blown sepsis and with the clinical signs of disseminated intravascular coagulation (DIC). Antibiotics and fluids were hung, and hemodynamic, metabolic, coagulation, and fluid monitoring begun. Then vasopressors were given.

The early morning sun's rays danced on the ICU floor. The respiratory therapist stood at the nurses' station. He had been called by the night nurse, who'd just gone off shift. "The patient would need to be put on the ventilator soon," she had told him. "Come up now so you're here when anesthesia arrives. We are just waiting for the order."

"Who's going to make the decision?" The therapist asked the patient's day nurse, who'd just come on shift. "And when?"

"I wish I knew," the nurse said as she watched the telemetry monitor. "The night nurse said that her son came in a few hours after she arrived. He said that his mother's other 2 children lived a ways away but were coming. She didn't know who'd be making decisions."

Noon. Still no family. Patient has deteriorated. The nurse wrote in her notes as she picked up the phone and called the intensivist. "Decerebrate posturing," she said.

"When's the family coming? Do you know? I don't want to intubate without having spoken with them. Have to wait. Have to explain the situation to them," the intensivist said over the phone. "Probably cerebral infarcts and hemorrhages going on at the same time. Maybe even hepatic encephalopathy. Her liver function's in the toilet. Is her son here?"

"He was in here about an hour ago. I got his cell phone number. I'll call." The nurse hung up with the intensivist, fished around in her pockets for the scrap paper she had scribbled the son's phone number on, and dialed. The son answered right away. She explained that he and his siblings should come up and talk with the ICU doctor as soon as possible. He replied that his brother and sister had just arrived. They'd come up to the ICU directly.

The intensivist met them in their mother's room. The oldest, the son who lives with her, looked to be in his mid-40s, and his younger sister and brother both in their 30s. The intensivist stood beside their mother's bed and ran through the medical facts. He ended his practiced soliloquy with his tried-and-true phrase: "We hope for the best, but it's time now to plan for the worst."

"We are hoping for the best," the oldest son said as he looked down at the floor. "We're trusting in the Lord."

The intensivist suggested to the children that they all have a meeting—the 3 of them, their mother's oncologist, her nurse, and him. "We need to make a plan for her care," he said, trying his best to look them in the eyes.

They agreed. The nurse called the oncologist. He had time in an hour. She walked into the patient's room and

told the children, and on her way back to the nurses' station, she passed by the intensivist's office and told him.

They all sat in the consultation room just outside the entrance to the ICU. A hospital chaplain, a woman in her early 30s dressed in dark blue slacks and a gray top with a white clerical collar, joined them at the intensivist's request. The children scrunched together on a sofa. The others sat on portable chairs in a semicircle facing them. The intensivist, oncologist, chaplain, and nurse introduced themselves in turn. Then the intensivist said in a soft voice, "Your mother is not well. She has a hole in her bowels that has resulted in a massive infection. And her body shows signs that her brain is being damaged by all that is going on. The chances of her recovering are slim."

The daughter, with unblinking eyes, ignored the intensivist and looked directly at the oncologist. "You're her doctor. What are her chances?"

The oncologist, a man in his early 60s with a bushy gray beard and bald head, looked up from his smartphone, on which he had been busying himself. "If we can get her through this rough patch, we have targeted agents we can use," he said. "She has a chance; it's slim, but it's a chance."

"She has a chance. You hear that? She has a chance," she said looking straight at the intensivist. "We have to do everything possible," the daughter said with a volume just under a yell. "God's going to heal her. We want to do everything possible and wait upon the Lord to do His work."

The chaplain leaned in toward her. "I hear you. You want to do everything possible medically to allow God the time to heal your mother. You love her so much; it's clear. You know that whatever happens to your mother now, God will heal her. God's greatest miracle is the resurrection of the body and the life of the world to come."

The daughter wore her hair up in a tangle of a bun. She hadn't cut it since she was 12 years old. Her hair is her glory, her mother taught her. Nor had she worn makeup, jewelry, or pants, lest she "look like a Jezebel," to use her mother's phrase. "Listen," the daughter said as she looked the chaplain up and down. "I don't know what God you believe in. But it sure isn't my God. It's in my God's Word that with His stripes we are healed," she said, screaming now. "God's going to heal Momma. Here and now. In this hospital."

The daughter looked at the intensivist first and then at the nurse. "Everything possible. Everything," she said, and then she led her siblings out of the consultation room and into the ICU.

The intensivist turned to the nurse, sighed, and said, "OK. Call anesthesia and respiratory. Let's do this."

"And then what? How long are we going to keep her on the vent? And how long will you keep her in our ICU? She's not recovering. You know this," the nurse said as she slouched in her chair. She had just wasted her lunch break, probably the only break she would get in her 12-hour



shift—wasted it on this pointless family meeting. She looked at the intensivist, whom she respected and worked well with. “Why didn’t you tell them there’s no chance of her recovering. No chance. This is futile care if I’ve ever seen it. And you know it.” She got up and left the intensivist and the chaplain sitting together.

She looked through the glass wall into her patient’s room and saw the 3 children standing at the foot of their mother’s bed holding hands. She heard them singing a song about heaven. She put her elbows on the nurses’ station’s counter, cradled her head in her hands, and mumbled to whomever was there charting, watching monitors, doing whatever they needed to do. “Will someone call anesthesia and respiratory for me? I just can’t do it. Not again. Not another time. I can’t do this any longer. I can’t watch that woman suffer because no one has the guts to tell her children that she’s dying.”

The heart rate monitor taps a steady rhythm of 60 beats a minute. The blood pressure cuff inflates and deflates in time with its metronome. But now the ventilator’s piston interrupts with slower, unexpected beats, syncopation, more fugue than sonata. The children have gone to find dinner. The nurse, no longer caring about monitoring, sits down by her patient’s bed, picks up her hand, unfurls her clawed-up fingers, and rubs them with lotion.”

COMMENTARY

Upon reading this case study, 3 ethical issues may arise in the reader’s mind: the issue of a patient’s capacity to make treatment decisions, the issue of surrogate decision making in the absence of advance directives, and the role of religious belief in making decisions about treatment that some on the health care team may think of as futile. Although legitimate issues, they are but one way of looking at the moral vortex of this case.

Another way to look at the moral *sturm und drang* in this case is to move away from codified moral responses regarding treatment decision making and instead to consider the patient’s and family’s state of being and their relationship with the health care team. In this more patient- and family-centered approach to the ethics of the case, we find issues of the patient’s and family’s vulnerability, the health care team’s trustworthiness, and the need for providing spiritual support. These 3 issues coalesce to form the moral winds blowing through the family meeting at the end of the case. After the family meeting, 1 other moral issue presents itself: the nurse’s vulnerability. It is these issues—vulnerability, trustworthiness, and spiritual support—to which we turn as the moral issues of this case.

The Moral Weight of Vulnerability

The patient in this case is dependent on her children and on the health care team to make decisions for her about

her care. Because the patient is dependent on someone else to make these necessary and urgent decisions, she is vulnerable. In a sense, patients, by virtue of being patients, are vulnerable; they are dependent on the health care team to provide care for them during their sickness.^{1,2} They are vulnerable to our actions and choices, and as such, they are susceptible to being harmed or even to being exploited.³ Vulnerability is the state of being in a position that is susceptible or open to harm—physical, social, emotional, spiritual, or financial harm. This is the central ethical issue I find in the case study: the absolute vulnerability of the patient.

One of the reasons we ask patients to complete advance directives is to lessen their vulnerability. In this case, we can assume the patient did not have advance directives. We also can assume that if she did she would have chosen not to resuscitate and not to intubate, based on her actions while caring for her husband. More fundamental than the patient’s own choices as conveyed in advance directives, however, her children may not have agreed with her choices. If the patient’s daughter had been named the surrogate decision maker, the daughter might have still said to intubate her mother, even if her mother had stated otherwise in her advance directives. We all have seen this happen. Advance directives are a blunt instrument to try to lessen patients’ vulnerability in the clinical setting of end-of-life care.

However, the sharper instrument is the relationship between the health care team and the patient and family, and the moral fulcrum of this relationship is vulnerability. Because vulnerability is the moral fulcrum, the health care team acquires special moral duties to protect the patient from harm.³ Let us consider the patient’s vulnerability in more detail.

The Vulnerable Patient. The patient’s vulnerability begins far earlier than her diagnosis of advanced cancer. Her years of caregiving placed her in the vulnerable position of having no choice about being in harm’s way. She may have experienced depression,⁴ among other physical and mental effects of caregiving.⁵ Moreover, caregivers who care for older spouses and experience emotional or mental strain are more likely to die than people who do not provide care for older spouses.⁶ Did the patient in the case neglect to get a routine colonoscopy because she did not have the time to attend to her own primary health care needs? Alas, the outcome we see in the case, a woman dying of metastatic colon cancer who spent years caring for her older spouse, began long before her diagnosis. We cannot speak about the ethics of this case without speaking about the ethics of providing routine caregiver support—as a matter of health outcomes—so that caregivers can attend to their own health care needs. Until then, the vulnerability of caregivers will continue long after they stop caregiving.

The patient was also vulnerable because she lived in a rural area underserved by cancer care professionals. Had



she been close to the cancer center in the city and able to go in to urgent care the moment the diarrhea started, would she have progressed to septic shock and DIC? We cannot speak about the ethics of this case without speaking about the ethics of providing equitable access to quality cancer care.⁷

These past vulnerabilities may have taken her to her present state, but still the patient's present state is one in which she lies septic, with the neurologic sequelae of DIC, and unable to say what she wants done. Her present vulnerability is the loss of her ability to determine her care for herself. The right of self-determination, in the moral sense, is the patient's right to decline life-extending health care. Insofar as she cannot exercise this right, she lies in one of the most vulnerable states imaginable.

She cannot speak, and if she could, could we tell whether she had capacity to make such profound decisions about life and death? In the United States, there is no universal legal definition of capacity. However, Grisso and Applebaum⁸ have compiled major legal standards for determining whether a patient has capacity to make decisions. They are the ability to

- communicate a choice;
- understand (ie, to grasp the fundamental meaning of) the relevant information;
- appreciate the situation and its consequences; and
- reason about treatment options.

We know the patient in the case study cannot communicate, by mouth, nod of the head, or wink of the eye. She cannot tell us whether she wants to be intubated and have the ventilator breathe for her. So we know that she is legally incapable of making decisions. If she could have communicated, however, we could have determined whether she understood the basic medical facts, appreciated what may happen either way the decision is made, and manipulated this understanding and appreciation such that we could tell whether her decision was for her, in her circumstances, rational.⁹

The Vulnerable Family. The patient's vulnerability, right now, rests in the extent of her sickness—and how it has deprived her of her capacity to make decisions about her own health care, thus opening her up to the potential of harm. In such situations, we rely on a surrogate decision maker, who, in our case, appears to be the daughter, who, by virtue of being the surrogate decision maker, is vulnerable. She is subject to influence by the health care team, to worry and fear about making the wrong decision, to emotional strain, and to possible family disruption if her brothers disagree with her.

The American Medical Association's Code of Medical Ethics¹⁰ states that if there is no advance directive naming a surrogate decision maker and there is a dispute among family members about what to do, the health care team should seek institutional ethics review (Opinion 2.20).

Sadly, we do not know whether the 2 brothers agree with their sister. We do not even know whether they agree that their sister alone should be making decisions. In this situation in which there is no named surrogate decision maker, the 3 children as a single unit is the unit of capacity. It is thus morally incumbent on the health care team to treat the 3 children that way. The health care team could do this by polling each sibling on who is the decision maker. After the sister has made the decision according to her understanding, appreciation, and reasoning about the facts, the health care team could poll the 2 brothers on whether they agree with their sister's decision. In this case, no one on the health care team did this. By not doing this, the health care team treated the brothers' sister as the only member of the family who had capacity. Herein the health care team compounded the brothers' vulnerability by not including them in the unit of capacity.

Trustworthiness Is the Moral Response to Vulnerability

There is another, more fundamental reason the health care team needed to treat the family as the unit of capacity. It has to do with what the bioethicist and philosopher Onora O'Neill calls *trustworthiness*.^{11,12} Have members of the health care team shown themselves to be trustworthy? Do the patient's children view the health care team as trustworthy? The sister, it seems, does not.

What could the health care team do such that the 3 siblings would judge the team as trustworthy? According to O'Neill,¹¹ the health care team should show their competence, honesty, and reliability to the family.

The health care team's technical competence is established, one might say, by the fact that they are working at a well-established urban cancer center. But this alone does not establish competence to the patient's children. If the health care team were competent, the children might ask why their mother ended up in the ICU at death's door? First, the health care team could have established competence with the children by providing opportunity for the patient's children, who are vulnerable from lack of knowledge, to understand and appreciate what has happened clinically.

The health care team not only needed to leave space in the conversation for the patient's children to check their understanding and appreciation of what happened, but second, to challenge the health care team. Such a challenge might have focused on how the situation got this bad. The patient's children might have asked: "Why did you let my mother get so sick? Shouldn't someone have been in touch with her to see how she was doing before she got so sick?" In a sense, the daughter is doing this; she is challenging the health care team—and holding them accountable for the messiness of the clinical situation. The health care team needed to be open to the daughter's challenge.



The health care team could have been honest about the patient's chances of recovery. The first step toward that honesty would have been to find out what recovery means to the children: to the physical and functional condition their mother was in before she was diagnosed with cancer? Or to the physical and functional condition their mother was in on the day the diarrhea and bowel perforation began? Or preservation of their mother's current state from here on out? Honesty implies that everyone is talking about the same thing, and in this case, they were not. The definition of *chance* for the oncologist was an academic definition based on statistics, and his definition of *recovery* meant recovered enough to continue anticancer treatment. The children were not using these definitions; they had mental images of their mother in a certain physical and functional state. These images were their definitions of *recovery*, and to them, *chance* may have meant a very good possibility of seeing the mother of their imaginations in real life in a few days. In the difference between the meanings of these words lay grave dishonesty. The children may have known this, too. Their eyes did not betray them when they looked upon their mother's sick, pale, and mottled body. The health care team's dishonesty compounded the children's vulnerability.

In this dishonesty was the missed chance to open up in the family meeting a space for the children to inhabit, a space in which the children were the subjects, a space in which they became part and parcel of the unit of care, a space in which they mattered.^{13,14} The intensivist and the nurse, as well intentioned as they were, were the subjects of their own concern: *they* did not want to intubate their patient; *they* did not want to see these circumstances yet again. Against this, the daughter asserted her existence in that room, as if to say, "We will not be made vulnerable by your foisting upon us your wishes. It is our wishes that matter." The lack of effective communication in the family meeting resulted in the daughter's assertion of her right to inhabit the space of being the decision maker. Providing spiritual support is 1 communication strategy; the health care team could have used to make the family meeting an inhabitable space for the patient's children—an inhabitable space for them to make the decision *they* wanted to make.

Spiritual Support

When patients receive a diagnosis of cancer, they go through a period of asking the big questions of life and death. This period is called *existential plight*.^{15,16} In this case, it may not be the patient who is going through an existential crisis but rather her children.

The patient and the children, had the team inquired in the family meeting about how they cope with existential crises, would probably have reported that they rely on

their faith. In 1 study, patients who reported that they coped by relying on their faith and reported that the health care team did not support their spiritual needs used more aggressive end-of-life care than did patients who reported that their spiritual needs had been supported by the health care team.¹⁷ In response to the facts of the case study, one might ask, "Didn't the health care team try to support the spiritual needs of the children during the family meeting? And why should we, as health care providers, try to support patients' and families' spiritual needs? It's not our duty."

The Moral Duty of Providing Spiritual Support. Indeed, what is the duty of the team vis-à-vis the spiritual needs of the patient and her children? One can answer broadly that the health care team owes a duty to the health care system if supporting spiritual needs reduces health care costs. It does: patients whose spiritual needs were not supported by the medical team used more ICU care and less hospice care and, as a result, had higher end-of-life care costs than patients whose spiritual needs were supported.¹⁸ But the greater financial good to the health care system is not the sole reason we should support patients' and families' spiritual needs.

It is the duty of the health care team to provide spiritual support because the unmet need for spiritual support deepens the patient's and the family's vulnerability. The patient and family act—indeed, make decisions about life and death—within the frame of needing care to lessen their vulnerability. Thus, in order to provide the conditions necessary for making decisions with lessened vulnerability, it is the moral responsibility of the health care team to provide that care, which in this case includes spiritual support. In the absence of spiritual support, the moral balance teeters on the fulcrum toward the health care team's side: the health care team remains more powerful in the provider-patient/family relationship.

How to Provide Spiritual Support. The health care team could have provided spiritual support by taking a spiritual history using a tool such as FICA.¹⁹ The FICA spiritual history tool (Table 1) is a guide of questions that open up the conversation about religious beliefs and practices.²⁰

In the case, it seems as though the chaplain tried to provide spiritual support. But the daughter's response to the chaplain makes sense: the chaplain, without taking a spiritual history, did not show herself as competent in the family's religious beliefs. Surely, the family felt unsupported spiritually by the health care team in the family meeting, and no one on the health care team tried to redress this lack of support after the family meeting was over—even as the siblings gathered around their mother's bed to comfort themselves by singing hymns. The health care team proved their unreliability by not returning to the family to do what the health care team should have done in the first place: take a spiritual history and, from that



TABLE 1 The FICA Spiritual History Tool

Faith – Do you consider yourselves spiritual or religious people? Do you have spiritual beliefs, values, or practices that help you cope with stress? And how about your mother? Tell us about her faith.

Importance – What importance does your faith or belief have in your lives? Tell us about how important your mother's faith is to her.

Community – Are you and is your mother a part of a religious community? Is this community of support to you and your mother?

Address/Action in Care – How should we address these issues in your mother's care?

Adapted from Puchalski.²⁰

history, make the arrangements necessary to provide spiritual support.

The health care team, in the eyes of the patient's children, has proven itself incompetent, dishonest, and unreliable. And so we are left with a rather rational question: Why would the patient's children put their trust in the health care team when it comes to their mother, who, they know, is in her most vulnerable state ever? This is not a rhetorical question. For the patient's children, it is a moral question. They have a moral duty to protect their mother from harm: in the absence of knowing what she would have wanted done in this situation, they have to decide how best to defend her in her vulnerability. If the health care team has not proven itself trustworthy, why should the children listen to them? Why should the children not take refuge in their faith, which, to them, has proven itself trustworthy? See Table 2 for suggestions on how the team could have proven trustworthiness.

It seems that the nurse is too overwhelmed to take steps to prove her trustworthiness. She "just can't do this any longer." She cannot witness what she takes to be the suffering of the patient. The truth is, the nurse suffers herself. From this suffering arises her own vulnerability.

The Nurse's Vulnerability

Some may say that the nurse's suffering arises from moral distress. If moral distress is the distress that arises from knowing the right action to take but being constrained from taking it,²¹ then perhaps the nurse did not necessarily experience moral distress. In this case, more than *knowing* the right (that is, moral) action, the nurse had *desires* about actions to take: *she* did not want to intubate, or put positively, *she* wanted to allow natural death. She may have felt that these desires were being thwarted by the oncologist and the patient's daughter. The chaplain and the intensivist may have felt this way, too. The moral actions for the nurse

to have taken would have been those actions that would have proven to the patient's children that she was a trustworthy health care provider—the actions that would have not fulfilled the nurse's *desires*. The nurse's suffering arises from her desires not coming to pass. The nurse's suffering did not necessarily come from *knowing* the right action to take—not from moral distress. Perhaps what the nurse felt, instead of moral distress, is compassion fatigue and burnout.

Compassion Fatigue. Coetzee and Kloppe²² define compassion fatigue in nursing practice as:

The final result of a progressive and cumulative process that is caused by prolonged, continuous, and intense contact with patients, the use of self, and exposure to stress. It evolves from a state of compassion discomfort, which if not effaced through adequate rest leads to compassion stress that exceeds nurses' endurance levels and ultimately results in compassion fatigue.^{22(p237)}

The nurse's actions, and her comments after the family meeting, suggest she has moved from a state of compassion

TABLE 2 Suggestions on How the Team Could Have Proven Its Trustworthiness

Competence	• Using plain, everyday language to explain the situation
	• Being open to challenge
	• Supporting the family spiritually
Honesty	• Determining what the family means by terms such as <i>chance of recovery</i>
	• Using terms in the same way and with the same meaning as the family, especially regarding prognosis
	• Giving honest answers about the patient's chances of recovery
Reliability	• At all decision-making points throughout treatment, learning from the family what spiritual support they need through taking their spiritual histories
	• Clarifying what the family hopes for when they say God is going to heal their mother and listening to their answers
	• Repeatedly inviting the family to ask questions about what will happen if they do and do not intubate their mother
	• Consistently providing the patient the health care the patient and the family wants, ie, the health care the family can believe in, including spiritual support



discomfort to full-blown compassion fatigue. This case is, as it were, a retraumatizing of past cases; “not again,” she says. And her vibes of emotional exhaustion, cynicism, and feelings of ineffectiveness are signs that her compassion fatigue has progressed even further to burnout.²³ Yet, the nurse’s satisfaction with her job is associated with her satisfaction with her ability to care.²⁴ Something must be done about her compassion fatigue and burnout, or the nursing care she gives will suffer. Nurse burnout is associated with health care–associated infections,²⁵ patient satisfaction,²⁶ and nurse retention.²⁷

The institution owes the nurse a response to her vulnerability that arises from her compassion fatigue and burnout. The cancer center owes a duty to the occupational well-being of the health care team, and from this duty, the cancer center should institute a compassion fatigue program, which has been shown to reduce nurses’ compassion fatigue and burnout.²⁸ One response the nurses at the nurses’ station could have taken, upon hearing the nurse’s emotional exhaustion, cynicism, and expressions of ineffectiveness, would have been to band together to advocate for a compassion fatigue program in their cancer center. We who hear our nursing colleagues express their despair must respond.

The Issue of “Futile Care”

There is 1 last issue to deal with, the issue of “futile care.” The term *futile care* is an oxymoron: how could care, if it is truly care, ever be futile? The AMA Code of Medical Ethics rightly points out the term *futile care* “cannot be meaningfully defined (opinion 2.035).”¹⁰ What is at stake when people use the term is the ethical dilemma of whether the health care team *must* provide treatment that will not benefit the patient. The answer is simple: they do not.¹⁰ If the health care team thought that mechanical ventilation would not benefit the patient at all, then they could have called the institution’s ethics committee for a consultation—or not offered it as a treatment in the first place. However, to deal more squarely with the moral issues involved in this case, the focus needs to be shifted from a clinical calculation to determine the ratio of benefit from providing mechanical ventilation to a plan of care that reduces the patient’s and family’s vulnerability, a plan of care that proves the health care team’s trustworthiness and, in this case, a plan of care that provides spiritual support for the family. Such a plan of care deals with the conditions that are prior to the issue of deciding whether treatment is beneficial.

CONCLUSION

The moral issues in this case have to do with the patient’s, the family’s, and health care team members’ vulnerability. The moral issues also have to do with the health care team’s trustworthiness and the central role religion plays in the pa-

tient’s and family’s decision making. A history of caregiving, a lack of access to quality cancer care, and losing capacity without advance directives place the patient in a position of vulnerability. The family has to make decisions without knowing what their mother would have wanted, and this places the family in a vulnerable position. The health care team can respond to these vulnerabilities by showing the family the team’s trustworthiness through the team’s competence, honesty, and reliability. In this case, the team can show these qualities of trustworthiness by providing spiritual support to the family.

References

1. Benner P. A dialogue between virtue ethics and care ethics. *Theor Med*. 1997;18(1-2):47-61.
2. Benner P. The roles of embodiment, emotion and lifeworld for rationality and agency in nursing practice. *Nurs Philos*. 2000; 1(1):5-19.
3. Goodin RE. *Protecting the Vulnerable: A Reanalysis of Our Social Responsibilities*. Chicago, IL: University of Chicago Press; 1985.
4. Smith GR, Williamson GM, Miller LS, Schulz R. Depression and quality of informal care: a longitudinal investigation of caregiving stressors. *Psychol Aging*. 2011;26(3):584-591.
5. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs*. 2008;108(9 suppl):23-27; quiz 27.
6. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. *JAMA*. 1999;282(23):2215-2219.
7. Gruca TS, Nam I, Tracy R. Trends in medical oncology outreach clinics in rural areas. *J Oncol Pract*. 2014;10(5):e313-e320.
8. Grisso T, Applebaum PS. Comparison of standards for assessing patients’ capacities to make treatment decisions. *Am J Psychiatry*. 1995;152(7):1033-1037.
9. Appelbaum PS. Assessment of patients’ competence to consent to treatment. *N Engl J Med*. 2007;357(18):1834-1840.
10. American Medical Association. *Council on Ethical and Judicial Affairs. Code of Medical Ethics: Reports of the Council on Ethical and Judicial Affairs of the American Medical Association*. Chicago, IL: The Association; 1992.
11. O’Neill O. *A Question of Trust*. Cambridge: Cambridge University Press; 2002.
12. O’Neill O. *Autonomy and Trust in Bioethics*. New York: Cambridge University Press; 2002.
13. Butler J, Davies B. *Judith Butler in Conversation: Analyzing the Texts and Talk of Everyday Life*. New York: Routledge; 2008.
14. Ebrary Inc. *The Power of Religion in the Public Sphere*. New York: Columbia University Press; 2011. <http://site.ebrary.com/lib/yale/Doc?id=10449825>. Accessed April 20, 2015.
15. Weisman AD, Worden JW. The existential plight in cancer: significance of the first 100 days. *Int J Psychiatr Med*. 1976;7(1):1-15.
16. Bai M, Lazenby M, Jeon S, Dixon J, McCorkle R. Exploring the relationship between spiritual well-being and quality of life among patients newly diagnosed with advanced cancer. *Palliat Support Care*. 2014;1-9.
17. Balboni TA, Paulk ME, Balboni MJ, et al. Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol*. 2010;28(3):445-452.
18. Balboni T, Balboni M, Paulk ME, et al. Support of cancer patients’ spiritual needs and associations with medical care costs at the end of life. *Cancer*. 2011;117(23):5383-5391.
19. Puchalski C, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. *J Palliat Med*. 2000;3(1): 129-137.



20. Puchalski CM. The FICA Spiritual History Tool #274. *J Palliat Med*. 2014;17(1):105-106.
21. Jameton A. A reflection on moral distress in nursing together with a current application of the concept. *J Bioeth Inq*. 2013; 10(3):297-308.
22. Coetzee SK, Kloppe HC. Compassion fatigue within nursing practice: a concept analysis. *Nurs Health Sci*. 2010;12(2):235-243.
23. Maslach C. What have we learned about burnout and health? *Psychol Health*. 2001;16(5):607-611.
24. Burtson PL, Stichler JF. Nursing work environment and nurse caring: relationship among motivational factors. *J Adv Nurs*. 2010;66(8):1819-1831.
25. Cimiotti JP, Aiken LH, Sloane DM, Wu ES. Nurse staffing, burnout, and health care-associated infection. *Am J Infect Control*. 2012;40(6):486-490.
26. Stimpfel AW, Sloane DM, Aiken LH. The longer the shifts for hospital nurses, the higher the levels of burnout and patient dissatisfaction. *Health Aff (Millwood)*. 2012;31(11):2501-2509.
27. Shang J, Friese CR, Wu E, Aiken LH. Nursing practice environment and outcomes for oncology nursing. *Cancer Nurs*. 2013;36(3): 206-212.
28. Potter P, Deshields T, Rodriguez S. Developing a systemic program for compassion fatigue. *Nurs Adm Q*. 2013;37(4): 326-332.

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