



Palliative Care Nursing: A Matter of Respect

By PATRICIA RINGOS BEACH, MSN, RN, AOCN, ACHPN

It was many years ago that our palliative care team was sitting around a table in a conference room with an elderly woman and her middle-aged daughter. We were talking about medical treatment options for their husband and father, we'll call him John, who was not at the table but in a room a few doors down, unconscious and on a ventilator. He had suffered a massive stroke.

"Dad always told us, if he couldn't get well enough to ride his horses, we should stop treatments." Both women agreed and were resolute in this decision.

Also embedded in my memory is a series of conversations that our palliative care team had at about that same time with a woman who had an aggressive form of scleroderma, an autoimmune disease. Although only 50 years old, the patient — we'll call her Melinda — already had many of the terminal symptoms that scleroderma causes, such as limited, painful mobility, masklike facial movements, gastrointestinal slowness and breathing problems. Her decision to pursue ongoing care and treatment also was resolute.

"God gave you the ability to keep my lungs breathing, to keep my heart beating," she said. "I don't care if I cannot talk or get out of bed. You are not to stop treatment. There is always a chance for a miracle."

Many of us cannot ride horses but still would want medical treatment. Many of us would not want treatment if we were bed-bound and dependent on a ventilator. Many of us have wishes that fall between these two stories. The thing is, you cannot tell, just by looking, what a patient wants. You have to ask what their wishes are. It is through respect for their ability to make the right decisions for their care, or with the aid of a surrogate, that you have these difficult conversations.

PALLIATIVE CARE

I am a palliative care nurse and team member at Mercy Cancer Center, part of Mercy Health, in Toledo, Ohio. Our hospital-based consult service is within the scope of acute care, not hospice.

The palliative care team includes a physician, nurse, social worker and chaplain. Other disciplines are consulted if needed. According to Get Palliative Care, the consumer web site of the Center to Advance Palliative Care (CAPC), palliative care is specialized medical care for people with serious illnesses. It focuses on providing patients with relief from the symptoms and stress of a serious illness; and improving the quality of life for both the patient and the family.

The World Health Organization says, further, that through the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual quality of life is improved. Difficult decision-making and conversations are part of palliative care.

In a Catholic hospital it is our mission to extend the healing ministry of Jesus. One way this is done is through respect for life. But in palliative care, it is more than respect for the beating heart, the breathing lungs or the circulating blood. It is respect for the life that is lived. I believe that is the bottom line of what palliative care nursing does. It is about this sacred respect. As a nurse, two of the





most important things I bring to the patient, family and our team are expertise in symptom management and skill in having difficult conversations.

SYMPTOM MANAGEMENT

Although this article focuses on the conversations, it should be understood that there is no conversation with a patient who is physically suffering. Whether it is pain, nausea and vomiting, breathlessness or another physical symptom, this suffering has priority until it can be relieved or at least lessened. Critical conversations cannot occur when someone is physically distressed.

Not that physical care is more important than emotional, social or spiritual care, but it is foundational. Every nurse has learned Maslow's Hierarchy of Needs. Psychologist Abraham Maslow postulated that reaching self-actualization depended on a degree of physical needs being met.

The relief of physical pain and suffering is a critical part of palliative care. I believe this is what Cardinal Joseph Bernardin meant in *The Gift of Peace* when he, a cancer patient, said, "Pray while you're well, because if you wait until you're sick you might not be able to do it." Excellence in symptom management promotes comfort when possible. Being physically comfortable allows patients to think through information and address other important matters.

DIFFICULT CONVERSATIONS

Respect for human dignity assists the launching of difficult conversations — conversations that may leave people in tears. These may occur at any time, some anticipated and others unexpected. Some anticipated difficult conversations may be: when hearing the bad news of a diagnosis; when a family member who has been absent returns; when learning that treatment is not working; when there is conflict between family members, health care team members or family and health care team members. Again, it is out of respect that you want to understand what the patient's wishes are. This will allow care to be directed by the patient's goals and values.

You do not want to assume to either know what is best or what someone would want.

Mercy Cancer Center palliative care nurse Jennifer Henkle said, "We are there to help patients and families before they come to any final decisions or conclusions. We meet the patients [and]

families wherever they are at, and sometimes it's not a friendly, comforting or reassuring place."

As people struggle with serious illness, new realities and important decisions, palliative care may be able to bring clarity through explanations.

There is a certain rubric that can be followed for these conversations, and it starts with showing up, being present. It is almost like going into the burning building when everyone is running out. Palliative care nurses are the fire fighters. Although fearful, we do it because it needs to be done.

Connie Foster, also a palliative care nurse at Mercy Cancer Center, says it eloquently: "I have the opportunity to help someone and their families to transition into a new reality; their lives will never be the same again. I make sure the patient and families are comfortable with decisions being made; that they have and understand the information they need to make these decisions."

There are many templates available for teaching and learning the skill of having a difficult conversation, but all are anchored in respect. Putting respect into action is a crucial skill. In my practice I follow three steps — it is a simplified collage of several models — that help me respectfully prepare, organize and focus on what is needed for the patient and family. Their contribution is the most important.

■ I begin by asking about what has happened. By listening to what stories and details they choose to share when given the opportunity, you learn what is important to them; what is significant in their worldview. Listening actively and earnestly in this stage is important. Do not listen just to respond. And do not be surprised if you are the first person to listen, really listen, to their telling of significant events.

■ I believe that next it is important to express empathy for what has happened. Yes, there are stories that are worse, situations that are more dire, consequences with more impact, but this is their circumstance, their life. With respect I convey I am sorry that this, whatever it is, has happened to them. This is not an apology but an expression of compassion for another's suffering.

■ Then I ask, "What do we do now?" People know that I am not a miracle worker, I cannot stop time. I cannot bring a drug out of clinical trials faster for them, although I wish I could. Very often the key question is, "If I could talk to your mother

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(or husband or whoever the patient is), what would they want to be done?"

This is important because it is the patient's wishes I am trying to understand. The loved ones' perspective may be different. If the patient has decisional capacity, I would have this conversation with him or her, but when it has to be with their surrogate, the important thing is to keep the focus on the patient's wishes.

PLANNING THE NEXT STEPS

At this point a plan is started. It may require subsequent visits and conversations to be fully developed and implemented, but planning the next steps has started.

In the two stories that began this article, the plan for John was to take him off of the ventilator. He died comfortably with family by his bedside shortly afterwards. Melinda's treatment plan included pain management, respiratory support and home care. Only later would hospice be consulted.

If this sounds like it can get complicated, it can.

"Some days I feel that I fill the role of an absent family member, a negotiator, a listening presence, a counselor, a social worker, or the voice of reason," observed Brittney Goldi, a Mercy Health palliative care nurse.

Palliative care nurses must know and be honest with themselves. It is easier to respect decisions you agree with. Complicated situations often have more than one acceptable reso-

lution; more than one approach that is ethically, morally and legally valid. If a decision is revisited over and over again, is it because the patient's wishes are not being followed? Is it because the patient's wishes are not clear or not known? Or is it because the decision is not a popular one that the health care team would choose in similar circumstances? This last is a red flag that must be faced honestly. Sometimes it is helpful to get another perspective either from the palliative care team or an ethics consult. The patient's wishes are what should be paramount.

If you are asking for a palliative care consult or asking when you should request help from the palliative care team, consider what would be brought to the patient with these specialists. Palliative care professionals:

- Facilitate difficult conversations to establish goals of care based on the patient's wishes.

- Provide expertise in symptom management that allows not only these conversations, but the best possible quality of life while living with a serious illness.

These skills are developed out of a basic respect for human dignity. It is rooted in understanding the life that is lived and affording respect based on the healing ministry of Jesus. Most of Mercy Health's palliative care nurses and team members would agree with their colleague Annette Hallett, who said, "When I leave work at the end of the day, if I can look out at the trees and

see so many colors and shades of green, I know I have had a good day. Palliative care nursing has given me such a better appreciation for the life that God has given all of us."

Palliative care is not a one-size-fits-all paradigm or care plan. As a nurse, I try each day with truth and honesty to use skill and respect to honor each life lived. There are not neat and tidy endings, but through working with the palliative care team, there is truth, honesty and respect available for each patient and family dealing with a serious, life-threatening illness.

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