

## *Virtual Mentor*

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### **CASE AND COMMENTARY**

#### **Cultural Differences at the End of Life**

Commentary by Diane Rapaport, MD

#### **Case**

When Dr. Lim entered the room, Mrs. Drake's son and daughter-in-law were there. Her daughter-in-law's chair was pulled up to the bedside and she sat there holding Mrs. Drake's hand, rubbing it gently. Dr. Lim greeted them and then examined his patient.

Mrs. Drake had suffered a moderate stroke 3 years ago. At that time she had difficulty swallowing and was unable to move her right side. She could no longer verbalize sentences and could only communicate by pointing. A feeding tube was placed. Recently she developed a pneumonia secondary to aspiration. After suffering a cardiopulmonary arrest she required continued mechanical ventilation for the past 3 weeks. She was minimally responsive, but did open her eyes to command and was able to squeeze with her left hand.

Mrs. Drake's daughter arrived and, as soon as the 3 visitors had greeted one another, they asked to speak with Dr. Lim outside the room. There, Mrs. Drake's son and daughter said that they thought that continued treatment of their mother was causing her to suffer and asked whether or not the ventilator could be removed. They did not want to give up on her and asked his advice.

Dr. Lim could not help but disagree. He himself was the eldest of 6 siblings. His own mother had had a stroke 8 years prior. He and his siblings had taken care of her throughout the years. She was bed-bound and contracted, nonverbal but awake. His siblings followed his directions regarding the care of his mother. He was the doctor and the eldest. He knew the quality of her life was poor but he could not reconcile her loss.

But the Drakes thought differently. Dr. Lim suggested that Mrs. Drake's son and daughter might feel regret or even guilt if they allowed their mother to die. "We each get only one mother," he said to them. The Drake children had discussed this very point at length among themselves. They had agreed that what their mother was currently experiencing was not life and certainly not life as she had enjoyed it. She had been, until 3 years ago, a vibrant woman, active in the town's Cultural Arts Council and in her church and oftentimes winner of the Yard of the Month in recognition of her imaginative and tireless gardening activities. No, that was not "Mom" in the bed, and it had not been since the first of her strokes. Now she was

just a body, lying there with no hope of getting off the ventilator. They felt conflicted. They thought she would be furious at the thought of living like that. However, they did not want her life to end. Of course, their decision was not an easy one. They had been hoping for confirmation or assurance from the professional in charge of their mother's care. Instead, Dr. Lim said, in parting, "Well, there's time. Why don't you think about it. If you stop her feedings, she will starve. If you take her off the ventilator, she will die. What do you want me to do?"

### **Commentary**

Understanding our own culture, ethnicity, religion, and customs surrounding death and dying can help us as physicians in providing more compassionate guidance and care for a dying patient. Insights into our own attitudes allow us to have our "own stories," our own identities, and help us understand how our personal and family customs support us during difficult and emotional times. Moreover, it is critical to our work as physicians and as caregivers, not only that we think about our own attitudes toward death but also that we learn about our patients' cultures and customs surrounding death.

Looking at our own stories may help us understand our patients' experiences and accept that each person attaches his or her own meaning to death and dying. For instance, for some patients talking frankly about terminal illness is considered inappropriate. Many cultures accept death as a natural part of the life cycle but may not condone open discussions about dying. We might ask ourselves: Does this patient's culture permit autonomy and informed consent? Although this patient is capable of understanding the consequences of health care decisions, is decision-making in this family customarily left to the elder, the oldest male, or the spouse?

We must familiarize ourselves with the customs of our patients in forging a true and trusting partnership with them. Dr. Lim, in our case study, recognizes that this family is not only speaking on behalf of their mother but also making decisions they consider in her best interest by avoiding aggressive therapies that no longer have a likelihood of therapeutic effect.

Dr. Lim, however, may not yet have come to terms with his thoughts and feelings about the possible death of his own parents. Dr. Lim might try to dissect the issue and examine which thoughts apply to this patient and which he might be transferring onto the patient. We should be able to let our own feelings about accepting death for our loved ones be guiding forces to help us talk sensitively about the matter. At the same time, however, it must be acceptable in our medical community to allow our patients' families time to come to a best decision. As physicians we should be comfortable conveying what is the best care we can offer, and we should not be satisfied with simply asking the question "what do you want me to do?"

From a clinical perspective, resuscitation serves a very limited, perhaps negligible, benefit to most patients who suffer from chronic illness. For some patients, the

discussions surrounding a Do Not Resuscitate order or other end-of-life considerations, such as the removal of artificial feeding or mechanical ventilation, provide a sense of relief and allow the patient to have a feeling of control and dignity. They may take comfort in knowing that at the time of death they will not be subjected to battery or other indignities. For others, however, the discussion may lead to a feeling of resignation, or worse, of guilt and loss. For these patients, end-of-life discussions are an added burden as they may feel they are "deciding for death" rather than choosing to maintain dignity.

Families who are "consulted" regarding resuscitation orders for incapacitated loved ones often feel especially pressured by the way physicians frame these difficult decisions. Some clinicians may unknowingly pose the questions in ways that are fraught with burden such as: "Do you want us to feed your mother?" "If your husband stops breathing, should we put a tube in and breathe for him?" "Would you want us to resuscitate your father if his heart stops?" If the family is being consulted about end-of-life decisions, they must be counseled that the issue is not what they want for their loved one, but what their loved one would be willing to endure to prolong life. Perhaps, if families were truly informed of the pain, often without benefit, of most resuscitations and the true discomfort of life on a ventilator they would be more likely to reject these options.

As clinicians we are often bothered by not knowing what we would do in our patients' circumstances and the guilt we feel at unsuccessfully healing a patient. No one wants those they care for to die, neither physicians nor families, yet the true acceptance of an inevitable death is best engineered with a carefully worded, sensitive plan.

The primary clinician should bear the responsibility of collecting the opinions of the consultants and coherently and compassionately explaining why further aggressive treatment may not be a reasonable option in cases where treatment presents, at best, a painful prolongation of life with no clear benefit. The family is best approached with gentle language and genuine acknowledgement of the gravity of the situation. It is unfair and inappropriate to ask, "shall we resuscitate your loved one?" The more appropriate statement would be "in view of the current circumstances, our team recommends that resuscitation, prolonged artificial feeding, or mechanical ventilation should not be offered for the following reasons..."

This approach helps the family feel included in the discussion, appreciate the thought that went into the recommendation, and allay feelings of responsibility for ending the life of a loved one they cherished. Too often, bad decisions regarding prolongation of life with artificial life support are made because the caregiver feels that the decision not to pursue these avenues means they are "giving up." Acceptance of the inevitable end of a terminal illness must not be equated with "giving up." As physicians, we must confront both our own sense of failure when one of our patients is dying--and our own guilt, when we are asked to allow a

family member to die naturally rather than suffer the burdens of technologies that seemingly prolong life without permitting a dignified death.

By heightening awareness of our own cultural influences we become more compassionate caregivers. As physicians we are trained to save lives, to correct metabolic and anatomical derangements, to maintain health, and to give rigorous attention to detail so that we may help "cure" as often as possible. This remains our mission and rightly so, but nothing in our training supplies a structure to comprehend our own attitudes about death. We are left to formulate these insights on our own. If we, as clinicians, continue to think of a patient's imminent death as our own failure, then we are likely to withdraw and place full responsibility for important end-of-life decisions solely on the patient and the patient's family. Without a framework of understanding of what we, our own family, religion, culture, and customs dictate about death and dying, it is most difficult to assist our patients and their families as they struggle with these issues. This deeper understanding should help us forge an impressive bond with our patients and their families. Without it, we may fail our deepest mission, the relief of suffering.

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*The people and events in this case are fictional. Resemblance to real events or to names of people, living or dead, is entirely coincidental. The viewpoints expressed on this site are those of the authors and do not necessarily reflect the views and policies of the AMA.*

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