CURRENT CONTROVERSIES IN CRITICAL CARE
A regular feature of the American Journal of Critical Care, Current Controversies in Critical Care addresses the ethical and administrative issues faced by healthcare professionals working in today’s critical care environment. We welcome letters to the Editors regarding this feature and encourage the submission of scenarios for future discussion.

ATTENDING DEATH AS A HUMAN PASSAGE:
CORE NURSING PRINCIPLES FOR END-OF-LIFE CARE

By Patricia Benner, RN, PhD, FAAN, Sally Kerchner, ARN, BA, Inge B. Corless, RN, PhD, FAAN, and Betty Davies, RN, PhD, FAAN. From the University of California, San Francisco, Calif, School of Nursing, Department of Social and Behavioral Sciences (PB) and Department of Family Health Care Nursing (BD), Riley Hospital, Indianapolis, Ind (KS), and MGH Institute of Health Professions, Charleston Navy Yard, Boston, Mass (IBC).

As part of our work on an Expert Panel on End-of-Life Care in the American Academy of Nursing, the authors of this column sought to articulate core nursing principles and concerns about end-of-life care. Attending to death as a human passage was central to these deliberations.

Sally A. Kerchner provides a narrative about end-of-life care that illustrates that meeting the patient and family and understanding their world is essential to attending to the difficulties that humans experience when facing death. A narrative is useful because each person and family has their own storied approach and understanding of death, and death is most often understood narratively. The particularity of the person/family story is central to honoring death as a human passage. One narrative about dying and end-of-life care can remind the reader of other stories that illuminate other human concerns. Dying is central to human identity, and it forms a part of everyone’s history. All human beings are finite. Human death is biographical, not just physiological. Death forever changes the world of those who experience the loss of the person dying. We invite AJCC readers to comment on the following nursing and ethical precepts and illustrative narrative related to the care of the dying.

• Dying is a human passage that everyone will confront. How that passage transpires is reflective not only of the person and significant others but of the caregivers and their respect for dying as a human passage. Whenever possible, dying as a human passage should be acknowledged. It is the mark of a less than attended death when death is approached only as a clinical phenomenon. Death is an essential human passage for the person dying and those grieving.

• The ones caring for someone who is dying may find that the dying person wishes a balancing between levels of comfort attainable through pain medications and sedation and the person’s alertness and ability to talk and/or experience the presence of others. Clinical precepts of optimal pain management and sedation should not usurp the dying person’s preferences and concerns.

• Palliative care should address symptom management comprehensively and flexibly so that the person’s comfort and dignity are preserved and wishes regarding state of consciousness are respected. Some particular symptoms (eg, resulting from infections or bone fractures) may not be tolerable for the patient. Treatment may be introduced even if it results in prolongation of the dying process so long as it serves to enhance the quality of what remains of the person’s life.

• While we endorse enhancing the dying person’s and their significant others’ autonomies, it is misleading to present the dying process only in terms of diagnostic and treatment “choices” or strategic clinical decision making. The physical constraints and vulnerabilities of embodiment present finite limits to the choices available to the person approaching death. Dying itself limits the treatment options and human responses and possibilities for the patient and family. Caregivers should avoid giving the dying person and their significant others unrealistic expectations that the primary determinants of death are related only to the treatments available or the treatment choices they make when, in fact, the range of possible “rescues” is narrow.
• Facing one’s death when it is inevitable and imminent situates the person differently depending on the context and immediate past history. For example, coming to terms with an imminent and inevitable death in a hospice setting offers different situated possibilities than does dying as a result of acute trauma or in a critical care unit where there were recent expectations and therapies offered for recovery. In the case of unexpected and untimely death, the patient and family may require more time and guidance in coming to terms with an imminent death. Consequently, the timing and context of the person’s dying alters the patient’s and significant others’ meanings, decision making, and approach to death and loss.

• While death occurs for the individual irrevocably and permanently, for significant others, grieving and coming to terms with someone’s potential or imminent death and, finally, death itself occurs over time and is potentially lifelong. Death of a significant other radically and permanently alters the lifeworld of those whose worlds and identities are bound up with the dying person. Therefore, the significant others and the person who is dying should be given every possibility for leave-taking, spiritual practices, and time to spend with one another.

• How the dying person and his or her significant others are cared for at the end of life makes both an immediate and long-term impact on the emotional and physical well-being of those grieving. If significant others are unwillingly separated from their loved one, or witness neglectful or disrespectful care, then their grieving is made more difficult. Just as birth has the social significance of the beginning of a human life, the dying passage has meaning in terms of the biography and human community of the person who is dying. Therefore, the attuned care of those grieving is essential to good end-of-life care and the health and well-being of significant others.

• Depending on the person’s dying trajectory and ways of facing death, he or she may socially withdraw and retreat to a close inner circle prior to death. Even so, it is thought to be a tragedy when social death, as in the abandonment of the one dying by significant others or caretakers, occurs before physical death. Consequently, nonintrusive presence and attending to the physical, emotional, and spiritual comfort of the one dying is essential to humane care. However, prescriptions, judgments, and expectations about “appropriate behavior” in approaching death violate the personhood and identity of the person who is dying. How one approaches death is integral to the person’s life story. Responses to one’s death vary widely and should be accommodated to the extent possible.

Exemplar: Maria and Franco

Maria is a simple woman, quiet and sometimes difficult to read. During the 18 months that I got to know her and her 8-year-old son, Franco, she shared with me that she had been unhappy and unreliable before she “got saved by Jesus.” She had joined a “healing” church and was fully devoted to following God through the leadership of the church.

The day I met Maria and Franco was at the clinic. They were coming to get a consult for suspected osteosarcoma of Franco’s right leg. During the morning report before they arrived, the oncologist shared a brief history of Franco: “One year ago, Franco had seen a doctor for leg pain. X-rays revealed nothing. No treatment was given. His pain persisted, and his mother took him to church for prayer. The church prayed over him, and he was ‘healed.’ One week ago, the pain returned along with a lump on his leg and difficulty walking. Now x-rays show a rather large mass on the distal femur. Mother is bringing x-rays with her today.”

I was the nurse assigned to work with consults that day. Maria did not bring the x-rays with her. She had left them with her pastor so that “the elders could pray over them.” I said, “I’m so glad you have someone praying for you and Franco. Prayer really helps.” Maria said, “Are you saved?” I said, “Yes, I am and I believe in the power of prayer. But I also believe that your pastor can pray for Franco without having the x-rays, but our doctors cannot attempt to help Franco without the x-rays. Could you possibly call your pastor and have him bring those x-rays over here to us?” She did get us the x-rays that day but only on the condition that she could have them back so that “the church could pray over them. This was how it was to be with Maria every step of the way over the next year-and-a-half of treatment—bargaining, negotiating, and lots of waiting.

Franco did have osteosarcoma of the right distal femur with multiple mets to his left lung. A plan of treatment for Franco was explained to Maria. It included placing a central line for access; a biopsy to confirm the diagnosis; several rounds of inpatient chemotherapy; frequent visits to the clinic for monitoring of labs and evaluation of therapy; and surgery to remove the tumor, which would more than likely involve amputation of his limb, followed by more chemotherapy and outpatient visits.

Maria would not agree to begin the treatment plan until she had time to discuss it with her pastor and pray about it. After talking with him, she agreed to a biopsy but was certain God would heal Franco’s mass and it would not be cancer, so there was no need to place a central line. Our bargaining began: “If the biopsy is positive, can we go ahead and place the line?” Maria
answered: “Yes, but I need to see the proof.” After proof was presented, we began treatment.

Each time there was, what I would call, “a crisis of belief for Maria,” there would also be a prolonged discussion and rounds of negotiating with her. When Franco’s counts dropped (wbc, hg, hct, plts) and we talked about possible transfusion needs, Maria’s response was “God will heal his blood without a transfusion.” When Franco’s hemoglobin levels dropped below 8, his doctor had to insist on a transfusion. “Maria, God often works through the power of medicine. Can you let Him do his work for Franco?” I said. She bowed her head, prayed, and then let us help Franco.

The work to prepare Maria for Franco’s surgery was ongoing. Once she allowed chemotherapy to be given, she was then convinced God would heal him through chemotherapy and surgery would not be necessary. Her doctor continually talked about surgery as an absolute, and Maria continually said that surgery would not be necessary. Periodic magnetic resonance imaging (MRI) revealed that although the tumor was shrinking, surgery would still be necessary.

Ultimately, Franco’s case was taken to the Ethics Committee because Maria continued to vacillate between giving permission to schedule surgery and canceling surgery. I attended the committee meeting along with Maria and Franco’s oncologist and orthopedic surgeon. When asked for input, I spoke of Maria’s love for her son and for the Lord. Maria told the committee, “I am not stupid. If my son needs surgery so he can live, I will agree to it. All I want is another MRI the morning of surgery so we can all see that God has healed him.” The best compromise that could be made was to have an MRI the day before surgery. That MRI showed that the tumor was unchanged. Franco’s leg was then amputated above the knee.

He continued chemotherapy for 6 more months and was considered “off treatment” in the spring of 2002. Franco relapsed 6 months later, with tumors developing in his lungs and chest. He underwent a thoracotomy and more chemotherapy. Maria never stopped believing that God would heal Franco, and she never stopped negotiating his care.

We all watched Franco decline over the last 6 weeks of his life. His doctor tried continually to talk with Maria about end-of-life care, but she would become agitated and argumentative and refuse to discuss anything but ways to see evidence of God’s healing. She wanted more MRIs and any test that would show healing. Franco’s doctor tried to get Maria to agree to do-not-resuscitate (DNR) status and a plan for home care service to provide pain management for Franco.

After nearly every conversation with the doctor, which usually involved information Maria did not want to hear, the doctor would say to me, “Maybe you can go in and talk some sense into her.” Our conversations were always the same and went something like this: “Have you seen miracles at this hospital?” Maria would ask. “Yes, Maria, I have seen God’s miraculous work through the caring and wisdom of the doctors and others at this hospital. All that we are able to do in medicine today is because God has shown us how. Isn’t that a miracle, Maria?” One day she asked me, “Do you believe God will heal Franco?” I said, “Maria, I know that Franco loves the Lord, and the Lord loves Franco. Yes, God will heal Franco, but in His way, not necessarily your way or my way. He will heal him in this life or in Heaven. My prayer for you is that you will understand that God’s way may be different from your way.” She seemed to listen attentively, but did not say anything. When she left that day, I did not sense that there was any change in her resolve or any agreement with our plan.

The last week of Franco’s life was excruciating for all of us. We saw him nearly every day for either a transfusion, intravenous (IV) hydration, or to manage his pain with a Fentanyl patch and IV morphine. The last day Franco came in to the clinic he was tachypneic, pale, anxious, and in pain. Maria was pale, anxious, and holding onto Franco like a lioness protecting her cub. He had come in for a transfusion, as his hemoglobin was 6.1, but it was clear more was going on with him. He was brought back to the infusion room and hooked up to oxygen per rebreather mask. His oxygen saturation levels were in the high 80s before being given oxygen. He did not have central IV access at the time, and we had to start a peripheral IV. It was difficult to place, as he was dehydrated, anemic, and probably shutting down. This made Maria angry and uncooperative. All of it made Franco more anxious, which made his breathing more labored. We gave Franco some morphine for the pain and increased his oxygen to 8 liters by mask. A respiratory therapist was called to manage his oxygen requirements.

If Maria would not agree to DNR status, Franco would have to go to the intensive care unit (ICU), as his oxygen requirements exceeded what was acceptable in a non-ICU environment (without a DNR). His doctor suspected that Franco was bleeding into the tumor in his chest and death was hours, or, at the most, days away. We all felt that it would be wrong for Franco to spend his final hours or days in the ICU with staff members whom he and Maria did not know. It would be best for them to be cared for on the hematology/oncology unit by staff who knew them well.
Maria would not leave Franco so that his doctor could speak with her privately. Negotiating began and Maria finally agreed to stand away from Franco but somewhere that she could still see him while we talked. The doctors were frank about what would likely happen soon and what would be best for Franco. They said that if he was a DNR, he would be admitted and given oxygen and pain medications to make him comfortable. He could eat if he wished. We would maintain IV access to give him medications, but we would not take x-rays or do anything invasive to prolong his life.

Maria wanted to talk with her pastor and that was arranged by phone. Her pastor told her to “do what the doctors feel is best for Franco.” Maria went back to sit with Franco and sat there, saying: “Jesus, Jesus, Jesus, heal my son, heal my son.” Franco was continuing to work hard at breathing and was showing signs of fatigue, alternating with panic. It was clear we needed to make a decision now. Franco needed to get out of the outpatient center and into the hospital.

I said, “Maria, you need to make a decision now. Franco needs to go upstairs to a room. Do you want to sign the DNR or not?” She looked at me with a panic-y, pleading look and just kept saying, “Jesus, my baby, Jesus, my baby.” I said, “Maria, look at me, please.” She looked up. “God is not bound by a DNR letter. If he wants to heal Franco right now or after you have signed the paper, he can. Your decision will not affect God’s decision. He will do what is best for Franco. Will you let Him?” She looked at me with a look that said to me that she understood for the very first time! I wrapped my arms around them and prayed for her and Franco.

When we were done, she laid out her plan. She wanted to sign the DNR, she wanted Franco’s recliner from home brought to his room in the hospital, and she wanted the doctors and nurses to leave them alone as much as possible. Maria sat in that recliner with her son on her lap for the next 3 days until he died peacefully in her arms.

In Conclusion

There is no one way to accompany the person dying and their loved ones. The possibilities for care and for attending death as a human passage are situated and constrained by the possibilities and understandings of the ones cared for. Such care cannot be standardized, but that does not diminish the importance or helpfulness of Sally Kirchner’s ability to meet Maria on the common ground of their shared religious beliefs. Other staff members called on Nurse Kirchner to assist in understanding and translating Maria’s concerns because of Nurse Kirchner’s own situated understanding of Maria’s faith. Such connection cannot be guaranteed but can usually be found within the resources of the hospital and community once the importance of such connection is understood for attending to death as a human passage.
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Am J Crit Care 2003;12 558-561
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