

Spirituality and Cultural Considerations in End-Of-Life Care

By Peter Holland, DMin; J. Gordon Harris, PhD; Valerie Hearn, MD

Consideration of spiritual and cultural issues must be addressed in order to deliver effective, compassionate care to patients at the end of life. Even patients who previously had not considered themselves religious, spiritual or ethnocentric may grasp onto these concepts as they deal with their imminent mortality. Issues regarding spirituality and culture may influence decisions about medical treatment and life sustaining interventions. In some cases, patients may raise issues and in other cases patients may not feel comfortable bringing these concerns to the attention of their caretakers and medical providers. In order to better understand patients and provide better palliative care, we need to be aware of these influences and be prepared to help patients with expression of these ideals.¹

In teaching the interdisciplinary Palliative Care Seminar, it would be relatively simple but marginally helpful to teach how to apply facts. It would miss an opportunity for usefully addressing a topic that influences patient healing and hope. Visiting patients and reflecting on the experience helps students adjust their expectations that the seminar will be simply pedagogical and didactic. Throughout, learning to improvise responses² within visits, by challenging students to incorporate their emotional selves into the experience has been one of the philosophies guiding the seminar. The session on “Culture and Spirituality” reinforces learning through participation in the patient’s story.

As spirituality and culture are generally communicated through narrative, students are encouraged to listen to a patient’s primary narrative. They are also asked to reflect upon and understand their personal parallel stories³ as well as how their professional narratives influence their relationships to patients. The teachers in the seminar believe one can most effectively enter the life of the patient as a competent practitioner if one is aware of one’s own story.

Spirituality is a popular but deliberately vague term⁴ that is intended to capture how people make meaningful stories from their experience. It is broad enough to include low moods as well as excitement, while allowing for individual expression. It embraces the individual meditating alone, religious practices and exercises, and it can even embrace the dead who return as spirits.

While professionals draw on scientific knowledge so that they can assess situations consistently, patients/clients/residents/parishioners/customers live outside the world of the helping professions and tell stories to make sense of their experiences. Professionals write and speak to a professional culture, but they try to translate their knowledge into a “bedside manner” to which a layperson can relate. Clients, patients, parishioners, etc., find it in their best interest to also understand the professional cultures into which they have been thrust. In many cases, the failure to appreciate each other’s culture as a relational process can produce unintended and sometimes harmful consequences that restrain rather than release opportunities for healing. Even a person from the professions becoming a patient feels intimidated by prized hierarchies, precisely timed procedures and technical language that reduce lived experience to scientific measurement. However, a patient might also emerge from their medical encounters telling a story of compassion, humor or complaint about the care they received. In the seminar we have been trying to raise awareness about how students might make use of stories to make sense of the culture and the spirituality present in the medical encounter. As an example, one of our faculty members speaks about his encounter with the medical community when his daughter, Joy, was dying. Students have been able to identify with his emotional experience and some have been able to draw the implications about professional sensitivity from his illustrations, which are told in the following account, through the eyes of his wife and mother of the dying child. The case helps us discuss how a palliative care plan impacts family relationships and teaches much about non-medical care of a dying patient. Joy lived for 30 years, most of it with the diagnosis, complications and treatment of cystic fibrosis, including dealing with a lung transplant:

A renal specialist came to inform Joy of the risks and benefits that long-term drug therapy would have on her kidneys. Joy already knew that but said nothing. The heavy drugs during the critical transplant had damaged her kidneys. Her kidneys would never survive another drug combination. They could possibly save her lungs but shut down her kidneys.

I saw interns huddled with a medical school pulmonologist outside Joy's room. Joy's husband and father arrived just in time with a friend. Soon, Joy's pulmonologist came into the room and sat down in a chair beside Joy's bed. He reported that the biopsy from yesterday's bronchoscopy was inconclusive because the tissue they were able to extract from Joy's lungs was too small.

I cannot remember much of his report on the lab cultures. He then told her they could put her on the ventilator with strong drugs to fight the infection. Joy had always said she would never go back on the ventilator, which she had experienced after the double-lung transplant.

I asked her pulmonologist if there were other options. He said the only other option would be to hook Joy to an IV that would allow her to rest comfortably and peacefully and gradually ... I did not hear the rest of his words. Without hesitation Joy said that's what she wanted. I jumped from my chair and walked to the window and back. The group of doctors who had politely stood outside the walled curtains suddenly appeared and moved silently into the room. I guess that was part of their education. How do you tell a patient she is going to die? Maybe they wanted to see my reaction. I was not about to give them the satisfaction.

Joy then told her pulmonologist she wanted to go home. The doctor said he would see what could be arranged. He left with the interns. He returned shortly to report that Joy would have to be transported by helicopter air ambulance. They would try to make arrangements. He left again.

I pulled my chair to the other side of Joy's bed. So many thoughts were going through my head. Should I share them? Yes, yes. "Joy, I should be there on that bed, not you," I said as she shook her head vigorously. "I've lived my life. You are young, more gifted, so much to live for and to offer." She continued to shake her head. I continued, "Just think, you will have a new body. No more treatments. No more pain, suffering. You will see Jesus and live with Him." There was so much more I could have said, but I was still in shock. I think I told her I wanted to go with her. I wanted to say I loved taking care of you especially during those six months after transplant surgery. During the last month of June we had so much fun exploring Minneapolis and the surrounding area. Then I made a stupid comment, "You had almost three years of life after the transplant."

"But I wanted to live to 40," Joy said. Of course she did! Her love for Mike (her husband of 16 months) was complete.

Joy absolutely loved life and was willing to go the length

and breadth to be used by God. But God knew better. He said, "Come to me. You are weary. I will give you rest." Joy said several times, "I'm tired." I'm tired, as if to apologize for giving up her body. She had fought hard and vigorously all her life. But it was time. I understood. She knew it and acted upon it. As I have reflected on those moments, Joy seemed to relax. The expression on her face lacked that struggled, pained look. She was at peace. Joy knew her Father. She was not afraid. He would be there to welcome her. She was willing to let go and let God take care of her.

The pulmonologist returned again and said it would be too risky to take Joy to Sioux Falls by helicopter or ambulance. The medical staff worked all the angles but could not justify it for Joy's sake. Joy accepted that. Looking back, it was the best decision.

I saw the pulmonologist in the hall. He was Joy's primary pulmonologist during and after her transplant. I knew he would be in to see Joy. I sat Joy in a chair and pulled up a second chair. He soon came in and sat beside Joy. They talked. I realized his personal feelings for Joy. He was truly touched by her life. A few weeks later he wrote in a letter to us:

... I would like to express to you what a terrible loss we all feel with Joy's death. Her spirit was an example for all of us. She did more with her ailing lungs than most of us manage to accomplish in perfect health. I enjoyed helping to take care of her, and I will miss her. Clearly, she touched many people.

As the day progressed into early afternoon, Joy asked her father to get the Bible. He found one in the room set aside for families of ICU patients. Joy asked him to read that scripture. Gordon asked, "What scripture?"

"You know," she said, "that scripture." After fishing for more information, Gordon finally figured it out – Lamentations 3:21-26. **Editor's Note:** *The Bible verses referred to here from Lamentations focus on the goodness of God, the Lord of hope, love, faithfulness, salvation and restoration, in spite of all evidence to the contrary.*

Our time in that room and hospital became a sacred place. I sat close beside Joy's bed, Mike on the other side. Joy turned toward Mike and stayed facing him. Joy kept repeating, "I'm tired," as if to apologize. Mike time and again said, "It's OK." I wanted to scream, "It's not OK." It was all I could do to hold my tongue. Thankfully, I said nothing.

Joy's discharge and clinic nurse and social worker came to Joy's side. The nurse hugged me for a long time. A pastor and his wife arrived. She sang the hymn, "Great is Thy

Faithfulness.” How could she know this would be the theme of Joy’s funeral? A colleague walked in. I was surprised to see him in the Twin Cities. He later commented that God’s presence was overwhelmingly real when he walked into that room. It was heavy with God’s spirit. A doctor friend sat in the room sharing in our sorrow. Close friends of Joy and Mike drove from Sioux Falls to be with Joy. Friends also called to tell Joy they would miss her. She responded, “I will miss you, too.” Her sister called again.

Joy could not hold the phone by this time so I held it to her ear. They talked a long time. I do not know what was said. Joy listened; Jami talked. After Jami’s phone call, Joy said she could not take any more calls.

Later in the afternoon the head nurse came in and said very abruptly, “We have to move Joy to another floor. It’s hospital policy.” The staff began rushing around. I could not understand and thought it disrespectful. But we complied with her directions. We were moved to another room one floor above. The nursing staff brought Joy into the room on a wheeled gurney. The doctor had decided to transfer Joy to a room with more privacy where we could be alone and rest.

I left the room and went into the hall where Mike, Gordon and friends waited. I said I just could not bear to watch them move Joy from the gurney to the bed. When they left, we all gathered in the private room to which she had been moved. Tears were trickling down Joy’s cheeks. She probably was confused by the quick transport. She may have thought we had left her, abandoned her. No way. We all found places to sit. We sang hymns as Joy lay quietly.

At 10 p.m. Joy’s friends indicated they had to depart. We understood. Nurses brought in cots for the four of us to sleep. All the time Joy was half sitting up, propped by pillows with eyes closed. The only medical equipment was the very slow drip from the IV. I never once saw the medication drip. It kept Joy comfortable, not struggling. I was thankful for that. But then I thought, let’s stop this whole thing. Joy can come back. It’s not too late. Then I realized it was too late. They’re killing my baby. I knew it was indeed too late. Weeks later I shared those thoughts with Gordon. He said it was not the drug that killed Joy. It was the massive infection in her lungs. I could live with that.

We decided to take shifts. Gordon would take the first two hours. I would take the next two hours, and Mike the last hours. We each gave Joy a kiss and told her we loved her then settled down to sleep. When it was my turn, Joy lay

still, so quiet and peaceful. After about two hours, Mike stirred and said he would take the next watch. I said, “It’s OK. I am fine. I can sit with Joy.” He repeated his request, and I finally relented. I lay on the cot where he had slept. As I rested, I heard voices. In a sleepy daze I thought Joy and Mike were talking. I did not want to disturb them and lay back down. In a flash I pulled myself up realizing Joy could not speak.

In a few minutes Mike spoke to us and said Joy had taken her last breath. I quickly was up, but Gordon was beside her bed first. Gordon said a prayer as we held hands around Joy’s bed. We lingered there quietly. The nurses came into the room to check her vital signs. They clocked the time, 3:30 a.m., then left.

I looked at Joy. I was shocked. She changed so suddenly. She was gone. She had left us. So matter of fact, Mike told us what he said to Joy. “During the last moments I had with Joy, I took her hands, kissed her, and told her of my love for her. I shared that we would be OK. Your friends love you; your mom and dad love you; Jami loves you; I love you ... it’s OK. It’s OK.” Joy was waiting for her lover. It was their last good-bye, and she knew it was OK. She gave up her body and moved into the very presence of God and into the loving arms of her Savior.

Mastering the broad topics of spirituality and culture is not a function of language and concepts, but an adventure in relating to others characterized by the nature of one’s presence, ability to define boundaries, openness and ability to manage anxiety.

Cultural Considerations

Changing demographics across the country and our region make it likely that health care providers will care for patients from cultural backgrounds other than our own. This could lead to difficult provider/patient interactions as providers may not understand certain patient actions or decisions that are culturally based. Challenges may also arise between cultural differences from the patient’s background and traditional western medical practice. Recognizing and addressing these potential differences will allow us to work toward becoming more culturally competent.⁶

Cultural competence is defined as “A set of congruent behaviors, attitudes and policies that come together as a system, agency or among professionals and enables that system, agency or those professionals to work effectively in cross-cultural situations.” One should think of cultural competence as a journey or continuum, not a limited destination.⁷

There are four commonly recognized, essential components of cultural competency.⁸

1. An awareness of self and one's own value system;
2. An understanding of the concept of culture and its role as a factor in health and health care;
3. A sensitivity to cultural issues for each patient; and
4. An understanding and ability to use specific methods to deal effectively with cultural issues in interacting with individual patients, their families, members of the health care team and the wider community.

When speaking of diversity and providing care, we also need to be aware of variables other than race. The major diversity categories include geography, culture, gender, spirituality, language, disability, sexuality and age.⁹ Each of these factors influences one's attitudes and beliefs both between and within cultures. There is a great deal of variability in preferences within ethnic minorities; therefore, it is important to learn about different cultures, but avoid stereotyping.

Being culturally competent requires knowledge and application of communication skills, use of interpreters/translators and attention to nonverbal communication. The physician may not instinctively know how to go about conducting a cross-cultural interview. There are several mnemonics that can be helpful in facilitating the interview process in a way that conveys respect, acknowledges differences, builds trust, shows interest in one's heritage, and yet elicits needed information. ETHNIC was developed by educators at UMDNJ and provides a framework for culturally competent clinical practice.¹⁰

E: Explanation: What do you think may be the reason you have these symptoms?

T: Treatment: What kinds of medicines, home remedies or other treatments have you tried for this illness?

H: Healers: Have you sought any advice from alternative/folk healers, friends or other people (non-doctors) for help with your problems? Tell me about it?

N: Negotiate options that will be mutually acceptable to you and your patient that do not contradict but rather incorporate your patient's beliefs.

I: Intervention: Determine an intervention with your patients. This may include incorporation of alternative treatments, spirituality and healers, as well as other cultural practice (e.g., foods eaten or avoided, in general and when sick).

C: Collaboration with patient, family members, other health care team members, healers and community resources.

In addition, cross-cultural issues for end-of-life care need to address the patient's preferences. Ask how much a patient wants to know about his or her condition. Ask who should make medical decisions. Ask which family members to speak to or not. Confirm understanding especially when using an interpreter/translator. Find out views on serious illness and treatment based on family, community and religious beliefs. If necessary, assess the patient's level of comfort in discussing issues with a provider of a different ethnic background.¹¹

By addressing spirituality and cultural competency in end-of-life-care situations, patients and providers will have better satisfaction and outcomes as communication and understanding are improved. This does not mean that all of the questions will be answered or that there will be no disputes or conflicts; however, a foundation that acknowledges and respects differences while delivering high-quality, patient-centered care will be established.¹²

REFERENCES

1. Lo B, Ruston D, Kates L, et al. Discussing Religious and Spiritual Issues at the End of Life, a practical guide for physicians. *JAMA*. 2002; 287:749-754.
2. Schon, Donald. *Educating the Reflective Practitioner*. San Francisco: Jossey-Bass Publishers 1987
3. Wimberly, Edward. *Recalling Our Stories: Spiritual Renewal for Religious Caregivers* San Francisco: Jossey-Bass Publishers 1997
4. Bergman, Lucy. "Defining Spirituality: Multiple Uses and Murky Meanings of an Incredibly Popular Term" *Journal of Pastoral Care* Fall 2004 Vol.58 No.3 p.157-167
5. Harris JG, Harris J. Palliative Care, Spirituality, Non-medical Model. From personal journals and case study published in *Blessed in Joy* 2007.
6. Crawley L, Marshall P, Lo B, Koenig B. Strategies for Culturally Effective End-of-Life Care. *Ann Intern Med*. 2002;136:673-679.
7. Cross TL et al. *Toward a Cultural Competent System of Care: a Monograph on Effective Services to Minority Children Who are Severely Emotionally Disturbed*, Washington, D.C.: Georgetown University Child Development Center, CASSP Technical Assistance Center, 1989
8. *Contemporary Issues in Medical Education*, February 1998, Vol.1 No.5
9. Hopkins WE: *Ethical Dimensions of Diversity*, Thousand Oaks, CA: SAGE, 1997.
10. ETHNIC developed by Steven J. Levin, MD, Robert C. Like, MD, Jan Gottlieb, MPH. Department of Family Medicine. UMDNJ-Robert Wood Johnson Medical School
11. Seabright H, Gafford J. Cultural Diversity at the End of Life: Issues and Guidelines for Family Physicians. *Am Fam Physician* 2005;71:515-22.
12. Kagawa-Singer M, Blackhall L. Negotiating Cross-Cultural Issues at the End of Life "You Got to Go Where He Lives". *JAMA*. 2001;286:2993-3001.