

ELNEC – For Veterans

END-OF-LIFE NURSING EDUCATION
CONSORTIUM

Palliative Care For Veterans

Module 4 Cultural and Spiritual Considerations in Palliative Care

CASE STUDIES

Module 4: Cultural and Spiritual Considerations in Palliative Care Case Studies

Module 4 Case Study #1 Mr. Li: Cultural Divide Between Family & Interdisciplinary Team

Mr. Li is a 65-year-old Chinese-American Veteran, diagnosed one year ago with lung cancer. The patient has been told by his family that he has a “lung disease.” Despite the fact that his disease is clearly advancing, the family insists that he not be told of his diagnosis or prognosis. Mr. Li is losing weight (20 lbs in the previous two months) and is having increasing back pain and difficulty swallowing. He lives with his wife in a second-floor apartment. His two sons are both married and live in the area. He denies any religious affiliation. The health care team is increasingly frustrated with the fact that Mr. Li is not able to fully participate in decisions about his care and is considering an ethics consultation.

Discussion Questions:

1. What are your impressions regarding this scenario? Is it acceptable, from both legal and ethical perspectives, to not inform the Veteran of his diagnosis, due to cultural considerations?
2. How might the team approach Mr. Li regarding issues of diagnosis and prognosis?
3. Describe ways in which issues related to patient self-determination and informed consent can be approached that respect patient and family values.
4. Describe how you would address his spiritual needs since he denies any religious affiliation. Consider spiritual sources of distress related to existential suffering or other factors such as meaning in life, forgiveness and hope.

Case continued:

While performing a thorough physical assessment during a recent clinic visit, you observe bruises over several areas of the patient’s back. As Mr. Li’s disease progresses, he says he has become more weak and unable to move from bed. When asked how he is feeling, he always whispers “fine” and denies any symptoms. His wife, Mrs. Li, is tearful that her husband’s appetite is diminished. She believes he will be cured if only he will eat and that he must try harder. The nurse observes the patient having difficulty swallowing, potentially aspirating, when given soft food, and explains this to Mrs. Li, who appears unable to understand.

During a home visit by the home hospice nurse and social worker, the sons also are present. Mr. Li is minimally conscious, febrile, tachycardic, and diaphoretic. The oldest son tries to encourage

Mr. Li to eat. He refuses to listen to the hospice nurse about the possible outcome of feeding his father and the gravity of his father's condition. He angrily states that his father is going to get better and requests antibiotics for the fever. The youngest son, speaking privately to the nurse, understands that his father is dying. When the nurse speaks about preparations for Mr. Li's death, the wife and oldest son are unable to participate in the conversation. The next day, the family admits Mr. Li to the hospital, where he dies within 24 hours.

Discussion Questions:

4. What are essential components of cultural assessment that could have impacted care for this family?
5. What aspects of Chinese-American culture are displayed in this scenario?
6. How should the nurse respond to the patient's use of moxibustion?

(Note: Moxibustion is a form of traditional Chinese medicine technique that involves the burning of mugwort, a small, spongy herb, to facilitate healing. This often produces a round burn-like bruise. It is believed to relieve toxins to strengthen the blood and maintain general health. It is occasionally misunderstood by healthcare professionals as a sign of physical abuse. These may also be Mongolian spots, which are discolorations of the skin that look like bruises.)

7. What could an interdisciplinary team have done to improve care at the end of life for this family?

Module 4
Case #2
Jose: Disagreements With Family Regarding Faith

Jose is a 62-year retired Marine who served in Vietnam. He has a history of PTSD, Crohn's disease, hypertension, peripheral neuropathy, and rheumatoid arthritis. He had a triple coronary by-pass 8 years ago, and has struggled with cardiac issues frequently over the past years (he weighs 345 pounds). He is on numerous cardiac and anti-hypertensive medications.

Approximately eighteen months ago he was diagnosed with congestive heart failure (CHF). Despite efforts to encourage him to lose weight, change diet, exercise, etc., his nurse practitioner continues to share diets and provide local places that he can begin a cardiac rehab exercise program. Jose always refuses to make any attempts to change his habits to improve his health.

Jose is married to Anna and they have five grown children. Two of the children live within walking distance of their parent's home. As Jose's breathing has been more labored and as he is now on supplemental oxygen, he wants to sleep a lot. He has become more isolated and does not like to have the grandchildren over much because, "there is too much noise and activity." Jose, who is Catholic, has not been to church since returning from Vietnam. He states that he saw too much and just can not come to peace with a God who would allow such atrocities to occur. Despite Jose's feelings about the church, Anna continued taking the five children to the local Catholic church all of these years.

Anna knows that Jose is suffering so much physically, but also knows that he is wrestling with some spiritual issues. He refuses to have Anna pray for him in his presence and does not want her to read the Bible to him. The local priest comes by to visit, but Jose refuses to meet with him. Anna recalls earlier conversations with Jose, though very rare, where he states he feels guilty about not being able to save some of his comrades who died in the war. "God is punishing me for all the missteps I have made in my life." "Suffering all of this pain will hopefully pay back all the pain I have given to others." "Maybe this is my penance to God."

Discussion Questions:

1. If Jose was your patient, how would you respond to his "suffering?"
2. What are the spiritual issues that Jose seems to be grappling with and how would you address them?
3. What part does his culture play in this role of suffering?
4. How can Anna be supported during this time?
4. What other members of the interdisciplinary team need to be involved with this aspect of care for Jose?

Module 4
Case #3
Mr. Thomas: A Multitude of Family

Mr. Thomas is a 59-year-old African-American Veteran, widower, father and grandfather who lives with his daughter and four grandchildren in a 4-story walk up apartment. He is an active member of the Rotary Club, church community, and friends commented that he had so much energy that he exhausted all of them just being around him. At age 56, Mr. Thomas was diagnosed with non-Hodgkin's lymphoma. Busy with helping to raise his grandchildren, 4 months went by before he sought attention for his symptoms and was diagnosed. Despite aggressive treatments with chemotherapy and radiation, his disease progressed, and he was considering undergoing a bone marrow transplant (BMT). Climbing the stairs to the apartment one afternoon, he became very short of breath and collapsed. His ten year-old granddaughter called 9-1-1. At the hospital, he was minimally responsive and in severe respiratory distress. He was intubated and transferred to the ICU. A family meeting with the oncology and ICU team was called to discuss Mr. Thomas's advanced condition, the fact that he would probably not survive further treatment of the lymphoma, and to decide on goals of care. Fifteen family members arrived, including his daughter, pre-teen granddaughter and grandson, three nieces, four nephews, several friends from his church and the minister. On being asked that only the immediate family participate in the meeting, the family and friends became angry, and insisted that all of them be involved in this discussion.

Discussion Questions:

1. Detail the physical, psychological/emotional, social and spiritual aspects of the case.
2. Discuss ways that a team might anticipate possible concerns that may arise during the course of an illness. How would you go about assessment and reassessment of key areas?
3. Discuss what kind of assessments and attention to continuity of care might improve communication in this case.
4. What are other concerns you have with this case and what do you anticipate would happen next?

Module 4
Case #4
James: Seeking Assistance to Determine Future Care

James is a 48-year-old gay man who has been seen in the oncology clinic with a diagnosis of testicular cancer diagnosed eight years ago. James, who served in the first Iraq war in 1992, delayed seeking medical treatment when symptoms first appeared believing that his symptoms were perhaps related to AIDS. However, his initial course of chemotherapy showed response. Unfortunately, he had a recurrence with extensive metastasis to the pelvis and most recently metastatic disease to the spine and lung. James' partner, Don, has been his constant companion at each of the clinic visits and has been very attentive to his needs as his disease had advanced. James and Don have recently expressed concern about "what it will be like at the end," and have explained that in the late 1980s, they both experienced the deaths of several friends from AIDS whose symptoms and end-of-life care were poorly managed. Don is the custodial parent of his 11-year-old daughter from a previous marriage. The daughter, Angie, came to live with Don after her mother died from a drug overdose. Don's parents are very close to Don, James, and Angie. However, James' parents have been estranged from their son since he revealed that he was gay. James currently is experiencing severe bone pain, mild to moderate dyspnea, anorexia, and nausea. James and Don are in the clinic today for a follow-up visit, and have asked if you, the oncology nurse specialist, might have some time to talk with them to help them with symptom management concerns, and also to help them determine if he should continue with the clinical trial that he is currently on.

Discussion Questions:

1. What are special considerations of this family situation and the relationships that might warrant attention by the oncology nurse?
2. What education is needed for Don and James regarding symptom management?
3. What assessment and support should be considered for other members of the family including Angie and the parents?
4. How might you respond to their request for your input on the decision to continue the clinical trial or to discontinue participation and begin hospice care?

Module 4
Case #5
Sophia: Many Problems, Many Fears

Sophia is a 67-year-old Veteran who was diagnosed with Stage IV breast cancer one year ago. She lives in low-income housing, and her only source of income has been her VA retirement and social security. She has no other financial support. Over the past few months, two of her sons have become unemployed, and both have histories of substance abuse and over time both have been incarcerated. They have both moved into her 2-bedroom apartment. Sophia is seen in the VAMC oncology clinic. She didn't show up for the last two scheduled chemotherapy appointments, but has come to the clinic now. She states that she has decided to stop chemotherapy as it is just too difficult to arrange transportation due to recent public transportation strikes and the fact that she lives too far away from the hospital. Sophia is often depressed, but her sons say that this is no different than she has been all of their lives and that they believe she is just "tired" and ready to "go to her Maker." She is hopeful that her landlord will not evict the family from their apartment in the upcoming months and that one of her sons might find employment soon.

Discussion Questions:

1. As the nurse in a clinic setting, what are your thoughts about her future care as she decides to discontinue active treatment?
2. How might her beliefs about end-of-life care be influenced by her personal and family experiences?
3. What options might be considered in terms of follow-up care for her?
4. What are cultural considerations of Veterans who live in poverty or low-income situations that influence issues of symptom management, grief, and end-of-life decision-making?