



When Death is Expected, Where Should it Happen?
Denise Stahl, RN, MSN, BC-PCM

Volume 7, No. 10

December 2007

Case: The Palliative Care Service was caring for a 43-year old married Middle-Eastern woman of Muslim faith who was suffering with end-stage metastatic breast cancer. She was transferred from an acute care medical unit to a transitional care unit for physical therapy and strengthening. Her condition continued to decline rapidly, and she became unable to participate in aggressive rehabilitation. Her husband was a constant attendant at her bedside and left her only for prayer rituals three times daily. She moaned frequently and had much difficulty finding a comfortable position in bed due to severe lower extremity edema and increased abdominal girth. She called for her husband to reposition her every few minutes, moisten her mouth and stroke her forehead. He shared that while he was appreciative of the care she was receiving on the unit, it was difficult to have staff available to help her as often as was necessary, and he worried that she was as comfortable as she could be. He reluctantly acknowledged his failing endurance and overwhelming fatigue. The couple's two school-age daughters were expected to be discharged from another acute care hospital after treatment for stress-related health problems of their own. He voiced concerns about bringing them to visit the patient because they had not seen their mother since she'd been so ill. Additionally, the patient's mother had not been aware of how grave her daughter's condition was, had not seen the patient for more than ten years, and was not scheduled to arrive in the United States for another 48 hours. He was worried about the mother's reaction and how staff could best support her because she was non-English speaking.

While the patient's husband did not want staff to speak directly to his wife about her declining condition or impending death, he spoke frankly with them about her condition, expectations as death approached, and the family's needs at the time of her death. Goals of care were clarified to focus on comfort measures. He acknowledged that his wife was imminently dying and requested that her body be allowed to remain in her room until her mother's arrival so that sufficient time could be taken to grieve together and carry out Muslim time-of-death rituals. Clinical signs and symptoms indicated that death could be expected within 24 to 48 hours.

Staff on the Transitional Care Unit explained that it would not be possible for the patient to remain in her room for greater than a few hours after her death. He considered more aggressive measures (i.e., transfer to acute care/ICU) to "try to

keep his wife alive until her mother got here" if she could not stay in the room until her arrival. After lengthy discussion with the patient's husband at her bedside, she was transferred to an inpatient hospice facility later that day.

The patient died on the hospice unit two hours before her mother's arrival. The hospice unit allowed her husband and family to wait with her in her room until her mother could get there. Hospice staff were attentive to the needs of the children, and the family was granted time to carry out Islamic rituals after her death, including preparing her body by washing her, perfuming her, and shrouding her.

Discussion: EPEC-O (Education in Palliative and End of Life Care for Oncology) and ELNEC (End of Life Nursing Education Consortium) curricula recommend not making abrupt changes in location of care at the end life of life. However, it is critical to consider the needs of each patient. Given the cultural needs of this patient and her family, the psychosocial stressors within the family unit, and the importance of adhering to religious rituals after her death, it was most important to make sure that her death occurred in a setting that could best meet these needs. Transfer to an inpatient hospice unit, even for a brief period of time, also assured more attentive care to symptom control and custodial care needs and afforded much needed respite for her husband. Data suggests that family members of decedents in traditional institutional care settings are more likely to report unmet needs for symptom management, communication, and emotional support.

References:

- J Am Geriatr Soc. 2005 Dec;53(12):2209-15. Ethnic differences in the place of death of elderly hospice enrollees. Johnson KS, Kuchibhatala M, Sloane RJ, Tanis D, Galanos AN, Tulsky JA.
- JAMA. 2004 Jan 7;291(1):88-93. Family perspectives on end-of-life care at the last place of care. Teno JM, Clarridge BR, Casey V, Welch LC, Wetle T, Shield R, Mor V.
- EPEC-O (Education in Palliative and End of Life Care for Oncology), module 6, May, 2007.
- ELNEC (End of Life Nursing Education Consortium), module 9, November 2006.

For further information please contact the Palliative Care Program at PUH/MUH, 647-7243, beeper 8511,, Shadyside Dept. of Medical Ethics and Palliative Care, 623-3008, beeper 263-9041, Perioperative/ Trauma Pain 647-7243, beeper 7246, UPCI Cancer Pain Service, beeper 644 – 1724, Interventional Pain 784-4000, Magee Women's Hospital, 641-2108, beeper 917-9276, VA Palliative Care Program, 688-6178, beeper 296. For ethics consultations at UPMC Presbyterian-Montefiore, and Children's call 647-5700 or pager 958-3844. With comments about "Case of the Month" call David Barnard at 647-5701.