

Most Americans prefer their home as a place of death, but most die in the hospital acute care setting. Nurses are the major providers of hospital-based end-of-life care; therefore, it is imperative to identify family preferences for nursing support during the end of life. An initiative was undertaken to create a blueprint for operationalizing research findings that identified family preferences for nursing support during the peri-death experience of a loved one within acute care. Seven components of an acute bereavement support protocol were delineated: developing room signage, assessing family prioritization parameters of support measures, offering advice on saying goodbye, performing an honoring ceremony, creating a memory keepsake, escorting the family out of the hospital, and sending a sympathy card following the loved one's death.

#### AT A GLANCE

- Elucidate family caregivers' needs for nursing support around the dying process.
- Delineate nursing behaviors and communication approaches that support acutely grieving caregivers.
- Replicate interventional approaches used within hospice home care and acute perinatal bereavement support programs with families whose loved one is dying in acute care.

#### KEYWORDS

nursing care; end of life; peri-death; supportive care; bereavement

#### DIGITAL OBJECT

#### IDENTIFIER

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# Nursing Care at the End of Life

Optimizing care of the family in the hospital setting

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**M**rs. C is married to a patient who has been treated for acute myelogenous leukemia for the past two years. A vigil visitor during these hospitalizations, Mrs. C has stayed overnight with her husband and has left the hospital only episodically for short periods of time. One morning, Mr. C was admitted to the oncology unit from the emergency department with sepsis. The on-call medical oncology fellow informed Mr. and Mrs. C that, after discussing Mr. C's case with his attending, they felt that Mr. C's chances for recovery from sepsis were slim. The fellow then stated that Mr. C could be admitted to the intensive care unit for aggressive supportive care. After hearing this option, Mr. C turned to his wife and said, "That's it, I'm done. I gave it my best shot. I don't want to go to the ICU. They know me here, and this is where I want to be." Mr. C subsequently died on the oncology unit at 5 am the next morning with his wife by his side.

That evening, the oncology clinical nurse specialist (CNS) called Mrs. C to express her condolences. Mrs. C relayed that her husband had received exceptional nursing care during his last hours of life. The CNS then asked Mrs. C if she had received the support she needed during this difficult time. Mrs. C shared the following:

I'm not sure if the staff realizes that when you spend so much time in the hospital, the family's world gets flip-flopped. The hospital becomes

home, and home is like a rental property, where you come and go. The staff becomes family, and your real family become visitors, merely observers on the sidelines. It's the nurses who know what your loved one goes through. Not only did I lose my husband, but I lost the nursing staff who had become my family and primary support system. When I walked out the hospital door alone for the last time, it hit me that I had entered the hospital with a husband and I was leaving with a white belongings bag.

The dying experience primarily remains an acute care phenomenon. An international comparison of death settings in 36 nations revealed that, in 18 countries, at least 54% of deaths occur in hospitals (Broad et al., 2013). In the United States, about 40% of Americans die in the acute care setting, with an increasing number of deaths occurring within or shortly following an intensive care unit episode of care (Bekelman et al., 2016; Centers for Disease Control and Prevention, 2016; Wallace et al., 2015). Despite this predominance, most research depicting the quality of end-of-life care has targeted three foci: (a) home-based experiences, (b) family members' proxy reports of the patient's quality of life at the end of life, and (c) family perceptions of team-based interventions around the time of death.

In the hospital setting, nurses are the constant at the bedside and provide most end-of-life care (Boyle et al., 2017).