Communication Behaviors and Patient and Caregiver Emotional Concerns: A Description of Home Hospice Communication

Margaret F. Clayton, PhD, APRN, Maija Reblin, PhD, Mckenzie Carlisle, PhD, and Lee Ellington, PhD

Despite recent calls for better understanding of end-of-life communication practices, little is known about how patient and caregiver emotional issues (e.g., distressing physical symptoms, impending loss) are elicited and addressed by hospice nurses (Epstein & Street, 2007; Kreps, Arora, & Nelson, 2003; Steinhauser, 2005). Although growth has occurred in the use of hospice care, many patients do not enter hospice care until about three weeks before death (Smith et al., 2012). Because of that, caregivers and patients may have immediate and distressing issues they want to discuss with their hospice nurses. Consistent with the hospice model that views the entire family as the unit of care, healthcare providers should address the needs of caregivers in addition to patients (McCorkle & Pasacreta, 2001; Tuisky, 2005).

Recognizing the importance of end-of-life communication processes as part of the cancer care continuum, Croyle (2007) encouraged researchers to pursue more ambitious studies of communication processes that address complexities of cancer care, including end-of-life care for patients with cancer. Examination of how hospice nurses elicit and respond to patient and caregiver disclosure of emotionally laden concerns may provide examples of communication skills that nurses working in other settings (e.g., ambulatory care clinics, medical offices, hospitals) can use to facilitate greater emotional disclosure of patients and caregivers. Healthcare providers may encounter patient and caregiver distress and have limited time to respond, when compared to longer visit times in settings such as home hospice care. In addition, healthcare providers working in less acute environments may have that type of conversation less frequently or be less familiar with managing emotionally laden conversations. Knowledge of how to use specific communication behaviors to quickly and appropriately elicit and respond to patient expressions of distress may facilitate these discussions and better meet the needs of patients. The purpose of the current study is to examine communication behaviors used by hospice nurses to elicit and respond to expressions of concern by patients with cancer and their caregivers in a home hospice setting.

Purpose/Objectives: To identify and describe communication behaviors used by hospice nurses when eliciting and addressing concerns of patients with cancer and their caregivers.

Design: Secondary analysis.

Setting: Home hospice in Salt Lake City, UT.

Sample: Audio recordings from seven patient and caregiver dyads and five hospice nurses.

Methods: Audio recordings were coded using the Roter Interaction Analysis System for patient and caregiver concern statements indicating negative affect and distress and the surrounding nurse communication behaviors. Concern content was categorized using domains developed by the National Consensus Project for Quality Palliative Care.

Main Research Variables: Patient and caregiver concern statements and nurse communication behaviors.

Findings: 180 patient and caregiver speaking turns containing concerns were identified across 31 hospice visits. Patients and caregivers expressed at least one concern in the vast majority of visits. The most prevalent distress areas reflected psychological and physical issues. Nurses used proportionally more positive emotion statements before patient and caregiver concerns, compared to the visit overall. Nurses asked proportionally more physical questions after concern statements. Nurses also used more emotional responses before and after patient and caregiver concerns, relative to the entire visit.

Conclusions: Patients with cancer and caregivers frequently talk about distressing issues. Hospice nurses use specific communication behaviors to elicit and address those issues.

Implications for Nursing: Home hospice provides a venue to examine nurse communication behaviors used to elicit and respond to patient and caregiver distress. These strategies could be taught to nurses who encounter patient distress less frequently or are less comfortable with emotional conversations.

Key Words: anxiety; family; caregivers; end-of-life; hospice; communication