Nursing Support of Home Hospice Caregivers on the Day of Patient Death

Margaret F. Clayton, PhD, APRN, Jennifer Hulett, PhD, APRN, Kirandeep Kaur, MS, RN, Maija Reblin, PhD, Andrew Wilson, PhD, MStat, and Lee Ellington, PhD

Clayton is an associate professor and assistant dean for the PhD program and Hulett is a postdoctoral fellow, both in the College of Nursing at the University of Utah in Salt Lake City; Kaur is a graduate student in the College of Nursing at Brigham Young University in Provo, UT; Reblin is an assistant member at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL; and Wilson is an associate professor and Ellington is an associate professor, both in the College of Nursing at the University of Utah.

This research was funded by a grant (P01CA138317) from the National Cancer Institute and an award from the Gamma Rho Chapter of Sigma Theta Tau International.

Clayton, Hulett, Kaur, Reblin, and Ellington contributed to the conceptualization and design and collected the data. Clayton, Hulett, Kaur, and Wilson provided statistical support. Clayton, Hulett, Kaur, Wilson, and Ellington provided the analysis. All authors contributed to the manuscript preparation.

Clayton can be reached at margaret.clayton@nurs.utah.edu, with copy to editor at ONFEditor@ons.org.

Submitted August 2016. Accepted for publication October 20, 2016.

Keywords: hospice; support; end of life; family caregivers; cancer communication


doi: 10.1188/17.ONF.457-464

Purpose/Objectives: To describe nurse–caregiver communication on the day of patient death.

Design: A descriptive secondary analysis of 44 audio-recorded home hospice nursing visits on day of death.

Setting: Nine hospices in Utah, Oregon, and Massachusetts.

Sample: 42 caregiver–patient dyads, 27 hospice nurses.

Methods: Transcripts of audio recordings were coded for supportive nursing communication and relative time spent in physical, psychosocial, and spiritual discussion.

Main Research Variables: Tangible, emotional, informational, esteem, and networking supportive communication; nurses’ self-reported communication effectiveness; caregiver religious affiliation.

Findings: Nurses reported that their communication skills were less effective when discussing difficult topics as compared to their overall communication effectiveness. Eleven patients died before the nursing visit, 3 died during the visit, and 30 died post-visit. Nurses primarily engaged in discussions facilitating caregiver emotional, tangible, and informational support. More informational support was observed when patient death occurred during the nursing visit. Time spent in general conversation showed that physical care conversations predominated (80% of the average overall amount of conversation time), compared to lifestyle/psychosocial discussions (14%) and spiritual discussions (6%). Spiritual discussions were observed in only 7 of 44 hospice visits. Spiritual discussions, although short and infrequent, were significantly longer, on average, for caregivers without a religious affiliation.

Conclusions: Nurses support caregivers on the day of patient death using multiple supportive communication strategies. Spiritual discussions are minimal.

Implications for Nursing: Communication skills programs can potentially increase self-reported communication effectiveness. Emerging acute spiritual concerns, particularly for caregivers without a previous religious affiliation, should be anticipated. Spiritual support is included in the hospice model of holistic care.

During the past five years, hospice use has increased by almost 20%, with most home hospice patients receiving care provided by informal caregivers, often family members and friends (National Hospice and Palliative Care Organization, 2015). Taking on a caregiving role can be physically and emotionally burdensome and has serious implications for caregiver physical health and well-being (Williams & McCorkle, 2011). Patients with advanced cancer admitted to hospice often experience a rapidly deteriorating physical status, contributing to caregiver burden (Teno, Weitzen, Fennell, & Mor, 2001). Research has shown that supporting the caregiver can reduce the burden of caregiving (Epstein & Street, 2007; Hebert, Schulz, Copeland, & Arnold, 2009; Williams & McCorkle, 2011).