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

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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).

Caregiver support at the end of a patient's life often comes from an informal network of family and friends who support the caregiver by assisting as needed with physical care of the patient and also providing emotional support. Despite good intentions, other family members and friends may not have the previous experience or skills to provide all types of caregiver support needed during the actual day of patient death. For example, they may not understand the dying process or may be unfamiliar with post-death tasks and requirements (Hebert et al., 2009).

Understanding what to expect as patient death approaches can be facilitated by communication with healthcare providers and has been associated with improved quality of death and dignity at end of life (McLeod-Sordjan, 2014). As such, caregivers often turn to their hospice nurse as an expert resource and as someone who has intimately known the caregiver and patient during end-of-life care. The holistic care nurses provide in this situation often results in lasting caregiver impressions. For caregivers, memories of the final nursing visit, events occurring on the day of death, and the quality of patient death may be remembered for many years (Higgins, Garrido, & Prigerson, 2015; Williams, Lewis, Burgio, & Goode, 2012).

Hospice nurses often develop close relationships with the families they care for because of the personal and intense nature of end-of-life care. Within these relationships, nurses are in a position to support the patient and caregiver by addressing questions and concerns (Strang, Henoch, Danielson, Browall, & Melin-Johansson, 2014). This can include practical issues, such as explaining the physical dying process and what to do after the patient dies, as well as addressing emotional issues (e.g., distress, uncertainty, anxiety) for patients and their caregivers (Adelbratt & Strang, 2000; Clayton, Reblin, Carlisle, & Ellington, 2014; Hebert et al., 2009; Strang et al., 2014). In addition to practical and emotional needs, many caregivers and patients have spiritual needs during end-of-life care. Facilitating spiritual care is considered a component of optimal end-of-life care (Lynch & Dahlin, 2007; National Consensus Project for Quality Palliative Care, 2013), but it is a topic that has been found to be difficult for nurses to address (Molzahn & Sheilds, 2008; Reblin, Otis-Green, Ellington, & Clayton, 2014).

Conversations on the actual day of patient death can be particularly challenging and are known to be extremely important to caregivers and families, but they are not frequently studied, likely because of the difficulty in systematically capturing these events (Williams et al., 2012). Effective end-of-life communication using a relationship-based care approach that encompasses biopsychosocial support, particularly during the last week of the patient's life, has been associated with better caregiver bereavement outcomes and quality of life (Hebert et al., 2009; Wright et al., 2008). When a patient is actively dying, most supportive nursing communication is directed at his or her caregiver because most patients are unable to fully respond (Morita, Tei, & Inoue, 2003). Home hospice nurses engage in supportive discussions with caregivers on the day of patient death to facilitate caregiver support and meet caregiver needs. In this observational study, the authors present a highly unique investigation of hospice nurse–caregiver communication occurring on the day of patient death.

Methods

Design

The authors conducted a descriptive secondary analysis of 44 audio-recorded home hospice nursing visits occurring on the day of patient death, representing 42 caregiver–patient dyads; two patients received two home visits on the day of patient death, accounting for the two additional audio recordings. These visits were previously audio recorded as part of the nurse–caregiver communication project from the multisite, longitudinal Cancer Caregiving Study I that investigated hospice nurse–family interactions from hospice enrollment until patient death (NCIP01CA138317; principal investigator: Mooney). This study was approved by the institutional review board of the University of Utah in Salt Lake City. After informed consent was obtained, demographic and descriptive data from hospice nurses and caregiver–patient dyads were collected at enrollment in the parent study.

Procedures

A directed content analysis was conducted by two trained coders to identify and describe nursing supportive communication processes on the day of patient death (Hsieh & Shannon, 2005). Both coders had extensive professional end-of-life care experience. To avoid bias and achieve consensus and rigor, weekly team meetings were held to review coding decisions. In addition, regular meetings ensured that selected codes were representative of the data and important content was captured. An audit trail was created to record modifications that were made to the codebook and reflect coder notes and general visit impressions.

To capture supportive nursing communication on the day of patient death, the authors operationalized Cutrona and Suhr's (1992) descriptions of the types of support needed by spouses during stressful events by adapting Williams et al.'s (2012) descriptions of effective end-of-life communication to reflect

supportive day-of-death conversations. This resulted in five codes, presented in Table 1: (a) emotional support (e.g., providing comfort or reassurance); (b) esteem (e.g., validating feelings, giving caregiver compliments); (c) informational support (e.g., offering explanations of the dying process or post-mortem care); (d) network support (e.g., facilitating awareness and/or connections with other services); and (e) tangible support (e.g., discussions related to ensuring patient comfort and dignity). This framework and coding approach did not include spiritual support. Because of the recommendations of the National Consensus Project For Quality Palliative Care (2013), and the authors' own previous research and clinical experience, the authors added spiritual support to the coding approach (see Table 2).

Analysis

Audio-recorded conversations were coded using Noldus Observer® event-logging software. A comment field was used to summarize general visit impressions and capture words, phrases, and concepts that contributed to the general impression of events during each visit (Saldana, 2012). Ratios of the type of support across all visits and by patient status (died prior to visit, died during visit, or actively dying) were calculated. Overall, codes represented broad domains of supportive communication offered by nurses to caregivers and patients on the day of patient death.

Data were analyzed descriptively to characterize the sample of nurses and caregiver–patient dyads. Based on categorizations of optimal end-of-life care defined by the National Consensus Project For Quality Palliative Care (2013), generalized linear models were created to assess differences in the relative amount of time spent in general physical, psychosocial, and spiritual discussions, and for spiritual discussions by reported caregiver–patient religious affiliation versus no affiliation (McCullagh & Nelder, 1989). Calculations were performed using SAS®, version 9.4. Results were considered statistically significant if $p < 0.05$.

Results

Descriptive data about nurses, caregivers, and patients are presented in Table 3. Across the 44 recordings of 42 caregiver–patient dyads (2 patients had a visit before and after death), 11 audio-recorded visits were to homes where the patient had died immediately before the nursing visit, 3 patient deaths occurred during the hospice nurse home visit, and 30 recorded home visits captured conversations for patients who were actively dying during the nursing visit but died after the hospice nurse had left the home.

TABLE 1. Types of Support and Associated Nursing Communication Behaviors Adapted for Day-of-Patient-Death Discussions

Type of Support	Nursing Communication Behavior
Providing emotional support	• Providing reassurance (e.g., offering comfort, reassurance, and solace) • Being a compassionate presence
Providing esteem	• Offering compliments or validation of perceptions and feelings
Providing informational support	• Providing information (e.g., explanations of the dying process, discussions of post-mortem events and care) to the caregiver, family, and patient
Facilitating networking opportunities	• Facilitating engagement with, or referrals to, other services (e.g., ensuring that caregivers are aware of the availability of pastoral support or grief support groups)
Discussions of tangible or instrumental support	• Facilitating and/or explaining final acts (e.g., saying goodbye, discussing the need for medication disposal) • Honoring patient dignity (e.g., discussing how to provide patient care and comfort)

Note. Based on information from Cutrona & Suhr, 1992; Williams et al., 2012.

Nurses represented nine hospices across three states. Six nurses held certification as a Certified Hospice and Palliative Nurse®. Nurses' mean nursing experience was 16.5 years (range = 1.5–46), and their mean hospice nursing experience was 5.8 years (range = less than 1–20). Overall, nurses felt that their communication skills were not as effective when discussing difficult topics as compared to their overall communication effectiveness, although none felt they were ineffective communicators (Roberts et al., 2005).

Audio recordings averaged 52 minutes (SD = 32.8 minutes). Although the authors initially coded supportive nursing communication to the caregiver and patient, nursing supportive communication comments were collapsed for this analysis because the vast majority of supportive comments were directed only to the caregiver. Overall, the ratio of specific types of supportive communication behaviors to all supportive nursing communication demonstrated that conversations about the provision of tangible support were most prevalent (35% of total overall supportive communication), followed by emotional support (25%), informational support (23%), offering esteem (15%), and facilitating networking opportunities (3%). Not every type of support was found

in every visit. Examining how the ratio of types of support changed in relation to patient time of death showed that nurses varied the support they offered to caregivers and patients based on patient status (see Table 4). On average, tangible supportive comments remained the most common type of nursing support, particularly when the patient died just prior to the nursing visit. Informational support increased relative to other types of support when the patient died during the visit, although this finding should be interpreted with caution because only three audio recordings represented patient death during the nursing visit.

Assessing the amount of time spent in general conversational categories showed that overall conversations about physical care predominated, representing 80% of the average amount of conversation time during a hospice home visit occurring on the day of patient death. Lifestyle and psychosocial discussions represented 14% of the average amount of talk, and spiritual discussions represented 6% of the overall average amount of visit talk. Spiritual discussions were observed in only 7 of 44 hospice home visits. Using a mixed-effects model for trends about the relative time spent in spiritual conversations, those previously declaring no religious affiliation had a significantly increased duration of spiritual conversation (β = 119.16, standard error [SE] = 36.73, p = 0.0032; no affiliation $\overline{X}$ = 30 seconds, SD = 50.7; religious preference $\overline{X}$ = 3.7 seconds, SD = 14.4).

Discussion

The recognition of the critical association between communication processes and caregiver outcomes on the day of patient death is essential. To that end, the authors have described a unique and extremely understudied event: home hospice nurse supportive communication of caregivers and patients occurring on the day of patient death.

Current national guidelines describing optimal end-of-life care suggest that nurses must effectively acknowledge and inform family members of the processes of death, including the inevitable occurrence of symptoms; share symptom management plans; educate and support caregivers and patients who are imminently dying; provide information about the availability of spiritual care services, as well as assist in making spiritual care available; and provide

TABLE 2. Examples of Nurse Supportive Communication

Support Code	Nurse to Caregiver	Nurse to Patient
Discussions of tangible support (35% of all supportive communication)	"I will let the hospice team know he passed for you." "Would you like to help me wash his body?" "Do you have the number for the funeral home?" "I need to get rid of his pain medicines now. I'll be right back."	"I'm giving you medicine to make your breathing easier." "We're going to give you a bath."
Providing emotional support (25% of all supportive communication)	"I'll come back whenever you need me." "How are you holding up?"	"It's going to be OK."
Providing informational support (23% of all supportive communication)	"I think she's getting close." "These are normal things you see when someone is dying."	"More pain medicine would probably help you be more comfortable. I don't think it will knock you out."
Providing esteem support (15% of all supportive communication)	"You're doing everything right."	"You look beautiful." "You're a fighter."
Facilitating networking opportunities (2% of all supportive communication)	"Did you know that [church] has a group for people whose spouses have died?"	–
Spiritual discussions (occurred in 7 of 44 visits)	"We could pray together if you want." "If you are asking me personally, yes, I believe in the soul, in angels, too." "We really don't know, but I have heard patients talk to family members that have passed."	"You see your mother? How wonderful."

Note. The percentage of spiritual discussions in relation to overall support was not assessed because spiritual support was not part of the original nursing supportive communication coding theme.

a plan for future bereavement support (Lynch & Dahlin, 2007; National Consensus Project for Quality Palliative Care, 2013). Therefore, communication is one of the primary ways optimal and supportive end-of-life care practices are implemented (Hebert et al., 2009). Hospice nurses play a critical role on the day of patient death by providing informational and tangible support that helps caregivers and family members understand what is happening and make informed decisions, and by assisting caregivers in making sure the patient is as comfortable as possible. Nurses also have an important role in the provision of other types of support (e.g., emotional) to help caregivers and families to manage distress and uncertainty. Another type of support, networking support, facilitates connections to additional services as appropriate, helping to meet caregivers' current and future needs.

TABLE 3. Sample Characteristics by Group

Characteristic	Caregivers (N = 42)		Patients (N = 42)		Nurses (N = 27)	
	$\overline{X}$	Range	$\overline{X}$	Range	$\overline{X}$	Range
Age (years)	56.7	22–82	66.9	38–98	45	23–69
Characteristic	n		n		n	
Gender						
Female	26		19		26	
Male	16		23		1	
Race						
White	38		40		25	
Black	–		–		2	
Other	3		–		–	
Unknown	1		2		–	
Ethnicity						
Hispanic	8		1		2	
Non-Hispanic	34		41		25	
Religion						
Latter-Day Saint (Mormon)	22		22		12	
Catholic	6		3		2	
Protestant	2		4		1	
Jewish	–		1		–	
Other	3		3		3	
No religious affiliation	8		8		9	
Unknown	1		1		–	

Similar to findings of caregiver and patient support across the overall hospice trajectory, hospice nurses visiting on the day of patient death frequently engaged in discussions of task-based, tangible support related to patient care and comfort; emotional and informational support were also prevalent (Reblin et al., 2015). Discussions of networking opportunities for caregiver support from additional services were observed much less frequently, as were discussions related to spiritual concerns. The current findings also support studies investigating the relative amount of overall time spent in general physical, psychosocial, and spiritual discussions across the longer hospice trajectory, showing that physical care conversations predominate and spiritual conversations are exceptionally minimal across the patient's hospice trajectory (Ellington et al., 2015). The overall predominance of conversation time related to physical care and the minimal amount of time spent in spiritual discussions did not change for conversations occurring on the day of patient death.

Spirituality may be considered an additional type of needed caregiver support and a form of support that is provided much less frequently by nurses. Nurses may be somewhat uncomfortable or feel less effective discussing spiritual matters (Molzahn & Sheilds, 2008; Reblin et al., 2014). It is also possible that other hospice team members, such as chaplains or the family's spiritual advisors, engage in these conversations with patients and caregivers, and nurses feel that they can focus on different caregiver and patient needs. The current findings that nurses spent slightly more time discussing spirituality on the day of patient death for those without a previously declared religious affiliation may indicate the emergence of new and acute spiritual concerns about death that should be addressed.

Nurses provide a supportive role that other members of a caregiver's support network may be unable to provide. For example, nurses may have intensively known the patient during end-of-life care when distant relatives were not present and can emotionally support the caregiver. Hospice nurses are also in a unique position to have experienced multiple patient deaths and have a familiarity with the physiologic processes of death. This enables hospice nurses to provide tangible and informational support to caregivers that is reliable and accurate, such as what is to be expected during the dying process and what to do after the patient dies. This type of support is extremely important to caregivers, helping to manage uncertainty about current and future events (Hebert et al., 2009).

Because of the intensive and intimate nature of the home environment, nurses tend to build personal relationships with family caregivers (White & Gilstrap, 2015). In the current study, the personal relationship between nurses, caregivers, and patients was frequently seen during the provision of emotional support and when offering esteem (e.g., providing encouragement, compliments, and a compassionate ear). In addition, nurses can provide emotional support by eliciting and addressing fears or concerns and providing appropriate reassurance. These emotionally positive and supportive conversations can ease the tension of the moment and may have increased importance to caregivers as they remember the day of patient death (Reis et al., 2010).

Unfortunately, not all caregivers and patients receive a nursing visit on the day of patient death, despite the fact that the Medicare hospice benefit does not restrict visit number and that patient symptoms are often exacerbated as death approaches (Teno, Plotzke, Christian, & Gozalo, 2016). Teno et al. (2016) reported on patients who did not receive a hospice visit within 48 hours of death, finding concerning disparities using an analysis of hospice administrative data (Teno et al., 2016). Patients who were Black were 30% less likely to get visits, one in five persons dying in a nursing home did not get a hospice visit, and one in five dying on a Sunday did not get a visit (Teno et al., 2016). This precludes supporting caregivers and patients during a particularly vulnerable time. When this support does not occur, regardless of the reason, caregivers are left to independently navigate an unfamiliar event (death at home) that has legally required tasks and duties, in addition to personally desired traditions and duties. These data point strongly to the need for future comprehensive examination of how nurses support imminently dying patients and their caregivers.

Implications for Nursing

In line with other research, the current findings suggest that nurses communicate their support to caregivers and patients by primarily focusing on the emotional, informational, and tangible care aspects of a dying patient. This is understandable, given the nature of a home hospice visit and the tasks to be completed; however, national guidelines include additional domains of end-of-life care, such as addressing spirituality and facilitating networking with other supportive services that could be offered to caregivers to ensure optimal end-of-life care. These forms of support address important caregiver needs, offering additional ways to support the caregiver. For example, if requested, nurses could ensure that caregivers are aware of and connected to supportive services, such as groups that offer support for those who have experienced the death of a spouse (facilitating networking)—potentially assisting the caregiver during future bereavement—a service of hospice that is often perceived as less than optimal (Tabler et al., 2015).

Nurses need to be aware that spiritual support may be particularly necessary for caregivers and patients without a previously declared religious affiliation because they may experience new and acute concerns regarding what happens to the patient after death. If requested by caregivers or deemed appropriate by the hospice nurse, engaging in spiritual discussions for those with and without prior religious affiliation can be accomplished by asking about family traditions and providing conversational "space" that allows the caregiver to explain and discuss religious and/or cultural practices, thereby providing more holistic end-of-life care (Reblin et al., 2014).

Educational support and communication skills training can enhance the comfort and self-reported effectiveness of nurses and other healthcare professionals when engaging in caregiver and patient supportive conversations, including unanticipated spiritual support needs (Curtis et al., 2013). Coyle et al. (2015) demonstrated that nursing communication confidence about engaging in discussions of death, dying, and end-of-life goals of care could be increased after nurses attended an end-of-life communication skills training program.

Conclusion

As home hospice care increases, supporting caregivers at the end of patient life becomes increasingly important and relevant to caregiver well-being

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TABLE 4. Nursing Supportive Comments by Visit in Relation to Patient Time of Death

Patient Status	Tangible Support (%)	Emotional Support (%)	Informational Support (%)	Esteem Support (%)	Networking Support (%)
Death prior to visit (n = 11 recordings)	46	21	16	15	2
Death during visit (n = 3 recordings)	33	24	31	8	4
Actively dying (n = 30 recordings)	32	24	25	16	3

Knowledge Translation

- By providing support to caregivers, nurses become part of the events surrounding patient death that may be remembered for years.
- Nurses can support caregivers by addressing caregiver needs across multiple supportive domains.
- The recognition of emerging acute spiritual concerns, particularly for caregivers without a previous religious affiliation, should be anticipated and is included in a model of holistic hospice care.

and adjustment to bereavement. Nurses provide caregivers and patients with many types of supportive communication on the day of patient death. This support is important to caregivers and becomes part of the events surrounding patient death that may be remembered for years. In this secondary analysis of 44 home hospice nursing visits to patients on the day of death, nurses primarily provided emotional, tangible, and informational support, offering less esteem and networking support. Spiritual discussions with caregivers were minimal but were more prevalent for those without a previously reported religious affiliation, suggesting an emerging area to explore when considering how to best support caregivers on the day of patient death. Using enhanced communication skills, hospice nurses can anticipate or facilitate supportive conversations surrounding imminent patient death, thereby increasing communication confidence when managing emotionally laden discussions on the day of patient death.

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