

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

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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; Steinhauer, 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; Tulskey, 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

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

ONF, 41(3), 311–321. doi:10.1188/14.ONF311-321

hospice nurses to elicit and respond to expressions of concern by patients with cancer and their caregivers in a home hospice setting.

Background

The term *hospice* originated in the Middle Ages, referring to a place of rest and refuge for pilgrims and travelers (Phipps, 1988; Williams & Wheeler, 2001). In the 19th century, the term became associated with a place where terminally ill patients could be cared for and die with dignity (Phipps, 1988; Williams & Wheeler, 2001). The modern conceptualization of hospice is associated with symptom management for patients with a prognosis of six months or less to live and who have chosen not to pursue curative treatment. However, many people do not enter hospice care until death is imminent (Smith et al., 2012). Entering hospice closer to death imparts a sense of urgency, requiring hospice nurses to be adept at eliciting and addressing caregiver and patient needs.

End-of-Life Communication

Communication at the end of life has been deemed critical by patients, caregivers, and healthcare providers, but little systematic or theoretically guided research has been conducted (Cherlin et al., 2005; Fallowfield, Jenkins, & Beveridge, 2002; Lunney, Foley, Smith, & Gelband, 2003; Royak-Schaler et al., 2006; Steinhäuser et al., 2000). The vast majority of health communication research has been conducted with physicians, ignoring the role of other healthcare providers, such as the hospice nurse case manager (Clayton & Ellington, 2011; Kreps & Viswanath, 2001; Roter & Hall, 1997; Roter, Hall, & Aoki, 2002). Other research has shown that hospital nurses can be uncomfortable discussing end-of-life care with patients, inhibiting hospice referrals (Schulman-Green, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2005). Once enrolled, families in hospice care rely on the nurse for coordination of all aspects of care, and nurses ensure that the needs of the patient and family are met in a family-centered and timely manner (Berry & Griffie, 2010; Coyle, 2006). Because of those responsibilities, hospice nurses must possess effective communication skills.

Caregivers

In hospice care, the needs of the family and patient are equally important. Studies have noted the necessity of specific inclusion of caregivers to facilitate better understanding of the caregivers' needs from a variety of perspectives during end-of-life care (Evans & Ume, 2012; McGuire, Grant, & Park, 2012). More than 80% of hospice patients are older than age 65, and more than 33% are older than age 85 years (National Hospice and Palliative Care Organization, 2012). The spouses or partners of those patients, their caregivers, are similar ages and

have their own age-related, comorbid illnesses. The role of caregiver during end-of-life care is often new and can be perceived as daunting by informal caregivers, which results in potential emotional distress (Doorenbos et al., 2007; Proot et al., 2003; Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Coping with the impending loss of a partner or spouse also presents an emotional and physical burden for caregivers and is a strong independent predictor of caregiver distress (Grunfeld et al., 2004).

Caregiver Distress

To provide optimal end-of-life care for patients with cancer and their caregivers, hospice nurses must have strong physical assessment and case management skills as well as advanced communication skills. If the patient experiences distress, the caregiver also may experience deterioration in emotional well-being (Carr, 2003; Kim & Schulz, 2008; Prigerson et al., 2003; Rossi Ferrario, Cardillo, Vicario, Balzarini, & Zotti, 2004; Schulz et al., 2003). To adequately support caregivers, hospice nurses must be able to elicit and address emotional and physical concerns in a way that provides ongoing clarification, assessment of understanding, and acknowledgment of expectations as the illness progresses (Parker et al., 2007).

Importance of Communication Skills for Hospice Nurses

A widely held assumption exists that nurses are innately skilled communicators with their reputation for empathy and their need to interface between physicians, other healthcare providers, patients, and families (Wilkinson, Perry, Blanchard, & Linsell, 2008). Communication strategies for how to interact effectively and elicit patient and caregiver concerns at the end of life often come from on-the-job experience and consultations with more experienced nurses rather than formal communication skills training and evaluation. Recognizing the need for more systematic preparation for communication skills during end-of-life care, professional organizations have incorporated communication skills training into their educational programs. The Hospice and Palliative Nurses Association publishes a regularly updated *Core Curriculum for the Generalist Hospice and Palliative Nurse* (Berry, 2010) that addresses communication practices. The End-of-Life Nursing Education Consortium program, a national train-the-trainer program for end-of-life care, also has a communication skills module (American Association of Colleges of Nursing, 2009).

Evidence that communication is an important skill for hospice nurses is found in qualitative research addressing patient perception of the communication skills of hospice nurses. Johnston and Smith (2006) described the importance to patients and families of caring and effective

nursing communication to elicit and address patient and caregiver needs, finding that most patients thought that their hospice and palliative care nurses were adept at eliciting, listening, and responding to their needs. That research suggests that hospice may provide a venue for examination of effective nursing communication behaviors to address patient distress.

Eliciting Concerns

Most of the research involving eliciting emotional concerns has been conducted among patients and physicians rather than caregivers and hospice nurses, similar to examination of end-of-life communication. Despite the importance of emotional disclosure, few patients and caregivers express their emotional concerns directly and spontaneously. Instead, they may offer only indirect cues to their healthcare providers, and those cues may not be addressed (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Heaven & Maguire, 1997; Suchman, Markakis, Beckman, & Frankel, 1997). When patient and caregiver expressions of emotion are missed or inhibited, less optimal working relationships and more difficulty when establishing mutually agreeable goals of care may occur (Beach, Easter, Good, & Pigeron, 2005; Jansen et al., 2010; Osse et al., 2002). One study found that physicians often missed the opportunity to respond to emotional cues (Levinson, Gorawara-Bhat, & Lamb, 2000), and another study found that they responded with distancing behavior rather than acknowledgement or exploration (Uitterhoeve et al., 2009).

When healthcare providers recognize and respond to distressing emotional concerns, satisfaction, care, and quality of life are likely to improve (Street, Makoul, Arora, & Epstein, 2009). Conflicting research exists on which communication strategies are most effective when trying to encourage expressions of patient and caregiver concern, such as reassuring tactics (e.g., silence, minimal encouragers), affirmations (Eide, Quera, Graugaard, & Finset, 2004), and direct questions (Fallowfield, Jenkins, Farewell, et al., 2002; Maguire, Booth, Elliott, & Jones, 1996). Research also fails to indicate the influence of setting (e.g., hospice, hospital, clinic) on effective communication strategies to elicit and respond to issues that patients find distressing.

Zimmermann, Del Piccolo, and Finset (2007) conducted a comprehensive literature review of patient cues and concerns, noting that patient expressions were defined and coded in different ways in 58 studies conducted from 1975–2006. In that review, definitions of cues and concerns ranged from relatively unemotional reasons for the visit (e.g., a chief complaint of physical symptoms) to implied or explicit expressions of high emotional anxiety and distress. On average, 1–7 emotional cues and concerns per medical visit were presented to physi-

cians in those studies. Similar to other studies, emotional cues and concerns were relatively under-identified by physicians, when compared to more physical cues and concerns (Fallowfield, Ratcliffe, Jenkins, & Saul, 2001; Zimmermann et al., 2007).

Conceptual Framework

Patient-centered communication serves as the overarching conceptual framework for the current research describing communication behaviors of hospice nurses (Epstein & Street, 2007). Patient-centered communication specifies a dialogue between patient and provider, underscores the importance of reciprocal conversation rather than a one-way flow of information, and is inherently flexible (Epstein & Street, 2007). Flexibility allows the hospice nurse to be responsive to the ebb and flow of multiple patient and caregiver concerns during end-of-life care. In hospice care, patient-centered communication may be extended to represent family-centered communication practices, consistent with the hospice model of care that addresses the needs of patients and their families.

To better define and put into effect the content of patient-centered communication during end-of-life care, the key domains of quality end-of-life and palliative care (i.e., structure and processes of care; psychological, physical, social, cultural, and spiritual aspects of care; physical process of death; and ethical and legal aspects of care) were used (Dahlin, 2013). Those multidimensional domains were established by a coalition of leading palliative care organizations and a 20-member steering committee, with additional review by 100 nationally recognized palliative care professionals (e.g., physicians, nurses, social workers, chaplains, therapists). Each of the domains has preferred practices that serve as a blueprint for implementing high-quality end-of-life and palliative care.

Methods

Using recorded data collected in 2009 from a previous mixed-methods study (Ellington, Reblin, Clayton, Berry, & Mooney, 2012) of home hospice nurse and caregiver interactions, a secondary analysis was conducted to examine hospice nurse and patient and caregiver communication that occurred during regularly scheduled home hospice visits. Institutional review board approval was obtained from the University of Utah for the secondary analysis. All recordings were obtained using a portable audio recorder.

In the parent study, collaborative relationships were established with two local hospices in Salt Lake City, UT. Hospice nurses in the parent study were recruited after a short informational session at hospice staff meetings. Management was not present at these meetings to avoid creating the impression that nurses were required to

participate in the parent study and ensure that nurse participation was voluntary. Consenting hospice nurses were trained on how to use and wear the digital audio recorder around their necks during regularly scheduled hospice home visits. More nurses consented to participate than were eligible. Eligibility requirements included that the nurse's case load had to include a consenting patient and caregiver dyad managing an end-of-life cancer diagnosis.

For patient and caregiver recruitment, the hospice alerted the research team to newly admitted patients that met inclusion criteria (i.e., older than age 50, spouse or partner caregiver living in the home, end-stage cancer diagnosis). Caregivers were telephoned to explain the study and, if agreeable, set up a home meeting for informed consent.

Prior to entering the home of a consenting caregiver and patient, the hospice nurse was instructed to turn on the audio recorder, state her assigned research study nurse ID, the caregiver ID, and the date and time of the hospice home visit. The nurse was instructed to remind the patient, caregiver, and any other people present that the visit was being recorded. Recording continued for the entire home hospice visit unless anyone requested that it stop. All visits proceeded without stopping the recording.

Research assistants performed follow-up with hospice nurses on a weekly basis to retrieve and download data. Data were downloaded from the recorders directly to a designated laptop computer, and then the recorder was erased and returned to the nurse.

Coding

Data were coded using the Roter Interaction Analysis System (RIAS), a system that codes the smallest unit of expression to which a meaningful code can be assigned, which is generally a complete thought or utterance (RIASWorks, 2012). RIAS is a widely used coding system with demonstrated levels of reliability and validity (RIASWorks, 2012). The system has been applied to a variety of healthcare settings and specialties such as end-of-life consultations (Ellington et al., 2012), genetic counseling (Ellington, Kelly, Reblin, Latimer, & Roter, 2011), emergency department consultations (Sandhu, Dale, Stallard, Crouch, & Glucksman, 2009), pediatric consultations (Wisow, Brown, & Krupnick, 2010; Wisow, Roter, & Wilson, 1994), and veterinary consultations (Shaw, Adams, Bonnett, Larson, & Roter, 2008).

In general, RIAS coding is performed by listening to audio recordings; the recordings are not transcribed. For each utterance or thought, coders identify the speaker and make multiple simultaneous judgments about each utterance. Multiple RIAS codes are applied to a person's entire speaking turn, whether a person says a single sentence or speaks at length. RIAS codes capture communication processes (i.e., behaviors), the affective tone of conversations, and global topical area,

but not the specific topical content of each utterance. For example, RIAS codes identify communication behaviors (e.g., question asking, information giving) and capture the general topical area of the interaction (e.g., questions about physical issues, lifestyle topics, psychosocial topics), and the affective categories focus exclusively on the process and tone rather than the specific topical content. Negative affect is coded as a concern, defined as a statement indicating worry or distress. Positive affect is coded as statements that indicate empathy or offer reassurance.

The secondary analysis focused on the individual affective RIAS code for patient and caregiver concern. In RIAS, a concern is defined as any statement that includes enhanced negative affect, indicating worry or distress. Identifying the degree of distress using RIAS is not possible; researchers can only identify that distress is present. When negative affect is present, it trumps other coding options; the speaking turn is coded as a concern regardless of topical content.

For the current analysis, instances of expressed concerns representing an entire speaking turn were consolidated (i.e., two utterances of concern in the same speaking turn became one data point). The focus was on expressions containing negative emotional affect of patients and caregivers because existing research has noted that emotional conversations present unique challenges for healthcare providers. In addition, previous interviews with practicing hospice nurses and the authors' clinical experience suggested that home hospice care presents a unique healthcare context that is laden with emotionally charged discussions (Ellington et al., 2013).

Analysis of hospice nurse communication behaviors was conducted using RIAS (Roter et al., 1997). Nurse communication codes included physical questions, psychosocial or lifestyle questions, gives medical information, gives psychosocial or lifestyle information, criticism or disagreement, positive emotion, emotional responses, and partnering (i.e., developing rapport or establishing a relationship). Giving psychosocial or lifestyle information included counseling the patient's or caregiver's lifestyle and any personal conversations that occurred. Criticism or disagreement, which was not found in the current sample, included showing criticism or disapproval. Positive emotion included reassuring the patient or caregiver or showing optimism, giving the patient or caregiver a compliment, or laughing. Positive affect included showing empathy and legitimizing the patient's or caregiver's concerns, and negative affect included showing concern. Partnering included actions such as asking for opinions, permission, understanding, or reassurance, as well as orienting or approving the patient or caregiver. Partnering also included self-disclosure, approval, and checking for understanding. To better understand the degree of

patient centeredness of hospice nurse and patient and caregiver visits, the content of patient and caregiver concerns was examined, guided by the key domains.

Analysis

The final dataset included a set of patient and caregiver concern statements containing negative emotional affect and a set of nursing communication codes, indicating the communication behaviors used by hospice nurses. The analysis plan consisted of seven steps. The steps included (a) calculating descriptive statistics for participant demographic information and (b) calculating the total number of patient and caregiver concern statements in all home hospice visits, as well as (c) consolidating the total number of patient and caregiver concern statements into speaking turns, with each turn conceptualized as an unbroken thread of patient and caregiver distress. The plan also included (d) calculating the frequency of specific nurse communication behaviors surrounding patient and caregiver speaking turns using the RIAS. The analysis also involved (e) calculating the relative proportion of nurse communication behaviors in the speaking turns before and after each patient and caregiver concern (i.e., the specific communication behaviors in a nurse's speaking turn before a patient and caregiver concern divided by the number of total communication behaviors in that turn) and calculating the proportion of nurse communication behaviors for the total visit (i.e., counts of particular communication behaviors in a nurse visit divided by the number of all communication behaviors in the visit). Finally, the plan included (f) comparing the proportions calculated in the previous step to determine if certain communication behaviors that were more or less likely to be used by hospice nurses to elicit or respond to patient and caregiver concerns and (g) categorizing the specific content of all identified patient and caregiver concerns using domains identified by the National Consensus Project for Quality Palliative Care (Dahlin, 2013).

To assess the content of patient and caregiver concerns, patient and caregiver concern statements were assigned to the corresponding domain of care, listening to the audio recording for a minimum of 10 seconds before and 10 seconds after each timestamped patient and caregiver concern utterance. Coding and content domain decisions were reviewed by the research team to achieve consensus. On occasion, that required listening to longer portions of the recording to better understand the context of the patient and caregiver concern statement.

Results

Patient and Caregivers

Seven patient and caregiver dyads ($N = 14$) were enrolled in the initial study (Ellington et al., 2012). The

mean age of caregivers was 72 years ($SD = 16.5$), and the mean age of patients was 81.5 years ($SD = 3.5$). Dyads had been married or committed for 2–63 years. The majority of caregivers were female ($n = 5$), and 11 caregivers and patients indicated they were Caucasian. Most caregivers ($n = 6$) had at least a high school diploma. Cancer diagnoses included melanoma, lung, and bone cancers. Additional caregivers (e.g., patients' adult children) were present for some visits. The concerns of those additional caregivers were coded in addition to the spouse or partner caregiver.

Hospice Nurses

All nurses at the two collaborating hospices consented to participate ($N = 15$). However, only five nurses were responsible for the care of the seven consenting patient and caregiver dyads who met eligibility criteria. Nurses were an average of 41.75 years old (range = 33–49, $SD = 7.5$), and all identified themselves as Caucasian. Hospice nurses in the current study were experienced and had practiced nursing for an average of 12 years (range = 6–18, $SD = 5.31$) and practiced hospice nursing for an average of 7 years (range = 2–15, $SD = 6.85$). These results represent four of five consenting nurses; demographic information was unavailable for one nurse.

Visit Communication

A total of 33 digital audio recordings were analyzed. The average length of time per visit was 55 minutes ($SD = 22.92$), and nurses visited patient and caregiver dyads between 2–10 times. Interrater reliability for RIAS coding was acceptable ($r > 0.65$). Because two visits did not contain any concern statements, 31 visits are reflected in the results. Patients and caregivers offered a combined average frequency of 8.84 concern statements per home hospice visit ($SD = 11.52$). Concerns often included general statements such as, "What am I going to do about . . . ?" "How am I going to manage?" "What is going to happen to me now?" and statements containing obvious emotion, such as those spoken while crying.

Two-hundred sixty-eight total patient and caregiver concern statements were identified within 1,153 total coded statements from 31 home hospice visits. Nurses spoke 54% ($n = 622$) of all visit statements, caregivers spoke 29% ($n = 334$), and patients spoke 17% ($n = 196$). Examining concerns per patient and caregiver speaking turn, as opposed to the total number of concerns per visit, 88 patient and caregiver concern statements were found to directly follow another concern statement, resulting in 180 distinct speaking turns containing patient and caregiver expressions of concern. Using consolidated concern statements per speaker turn, which was conceptualized as an unbroken thread of patient and caregiver distress regardless of the number of concerns expressed in the speaking turn, patients and caregivers offered a

combined average frequency of 6 (SD = 5.3) speaker turns containing concern statements. Of the original 268 concern statements, 30% (n = 81) of those statements were from patients, 49% (n = 131) were from spouse caregivers, and 21% (n = 56) were from other caregivers (e.g., patients' children).

A lot of variation existed in the number of concerns expressed per visit in the current study. One patient and caregiver dyad had only two hospice home visits but expressed, on average, more concerns per visit than other dyads (i.e., 13 concerns for one visit and 22 concerns for the other). Excluding that dyad, the average number of concerns per visit was 5 (SD = 4.16), indicating that dyad had expressed more emotional distress than the others. A different dyad had 10 home hospice visits, with an average of 4.4 concerns per visit. Concerns were analyzed independently as discrete communication events, not nested within specific hospice nurse case loads or by dyad.

Concern Elicitation and Response

Nurse communication codes using the RIAS were physical questions, psychosocial or lifestyle questions, gives medical information, gives psychosocial or lifestyle information, criticism or disagreement, positive emotion, emotional responses, and partnering. Examining how nurses elicit or respond to patient

and caregiver concern statements using a speaking turn-based analysis showed that the average number of nurse utterances before a patient and caregiver concern ($\bar{X} = 9.68$) were roughly equal to the average number of nurse utterances in the nurse speaking turn after an expressed patient and caregiver concern ($\bar{X} = 10.33$) (see Table 1). With respect to the type of communication used by nurses before a patient and caregiver concern statement, the three most frequent types of nurse communication behaviors identified were giving lifestyle or psychosocial information ($\bar{X} = 2.26$ utterances per turn), giving physical information ($\bar{X} = 1.93$), and partnering ($\bar{X} = 1.9$). The three most frequent types of nurse communication behaviors after a patient and caregiver concern statement were giving lifestyle or psychosocial information ($\bar{X} = 2.42$ utterances per turn), giving physical information ($\bar{X} = 1.87$), and expressions of positive emotion ($\bar{X} = 1.83$).

Proportions were calculated by dividing the frequency of a particular nurse communication code in the section of interest by the total number of all utterances in the section of interest (e.g., frequency of nurse physical questions before a concern statement divided by the total nurse utterances before a concern statement). That allowed examination of whether the relative proportion of a given nurse communication code was greater surrounding a patient and caregiver concern than in the rest of the home hospice visit. This

Table 1. Mean Frequencies and Relative Proportions of Nurse Communication Codes

Code	Preconcern Nurse Speech				Postconcern Nurse Speech				Total Nurse Speech			
	Frequency				Frequency				Frequency			
	\bar{X}	SD	RP	SD	\bar{X}	SD	RP	SD	\bar{X}	SD	RP	SD
Emotional response	1.03	1.22	0.13*	0.21	1.45	2.08	0.13*	0.2	11.3	14.65	0.02	0.01
Partnering	1.9	2.15	0.2	0.17	1.81	2.12	0.146	0.15	99.61	76.88	0.16	0.06
Physical information	1.93	2.02	0.2	0.23	1.87	2.01	0.22	0.23	125.64	129.75	0.187	0.11
Physical questions	0.68	1.22	0.09	0.18	0.71	0.97	0.12*	0.21	19.3	15.48	0.04	0.04
Positive emotion	1.68	2.27	0.13*	0.14	1.83	2.31	0.13	0.2	39.03	25.2	0.069	0.06
Psychosocial or lifestyle information	2.26	2.99	0.22	0.26	2.42	3.24	0.2	0.2	100	90.48	0.152	0.08
Psychosocial or lifestyle questions	0.61	1.2	0.04	0.04	0.61	1.23	0.05	0.1	16.21	15.99	0.031	0.03
Total hospice nurse utterances	9.68	8.91	–	–	10.33	9.28	–	–	411.75	368.81	–	–

* $p \geq 0.1$

RP—relative proportion

Note. RP is the mean frequency of a particular nurse communication code divided by the total number of nurse utterances in the section of interest.

information was used to determine whether nurses used more specific elicitation communication behaviors for concerns or responses to patient and caregiver concerns.

To determine whether the proportions of nurse communication codes occurring before or after a patient and caregiver concern statement differed from the proportion of codes in the rest of the visit, *t* tests were used. The proportion of each nurse communication code in the speaking turn before and the speaking turn after a patient and caregiver concern statement to the proportion of each nurse communication code from the total dataset, including speaking turns not adjacent to patient and caregiver concerns was compared. The threshold for significance used was $p \leq 0.1$ because of the small sample size. A significant increase was found in nurses' positive emotion ($t = 2.005$, $df = 29$, $p = 0.054$) before the expression of a patient and caregiver concern statement, and significantly more physical questions ($t = 2.178$, $df = 29$, $p = 0.038$) after the expression of a patient and caregiver concern. More emotional responsiveness occurred before ($t = 2.871$, $df = 29$, $p = 0.008$) and after ($t = 2.973$, $df = 29$, $p = 0.006$) the expression of a patient and caregiver concern than in the visit as a whole.

Concern Content

Each of the 268 total concern statements of patients and caregivers was categorized according to the domains of care. Results showed that psychological and physical issues were discussed most frequently. Concerns indicating worry about social and spiritual aspects of care, care of the dying patient, and the structure and process of care were also represented, but to a lesser degree (see Table 2).

Discussion

In the current study, the communication behaviors used by hospice nurses to elicit and respond to concerns, indicating negative affect or worry, of patients and their caregivers were examined. Practicing hospice nurses require substantial communication skills to provide care that addresses those concerns. The nature of hospice care requires nurses to manage complex emotional issues in addition to managing highly distressing physical symptoms. In the current study, the hospice nurses were experienced in caring for patients and their spouse or partner caregivers during end-of-life care and had chosen hospice nursing.

The focus was on audio recordings coded as patient and caregiver concerns because recording home hospice encounters has rarely been done. The current study can help improve the understanding of communication interactions that contribute to optimal end-of-life care.

Table 2. Communication Content of Patient and Caregiver Concerns Coded by Domain of Care (N = 268)

Domain	n	%
Psychological aspects of care	120	45
Physical aspects of care	107	40
Social aspects of care	17	6
Spiritual aspects of care	10	4
Care of the imminently dying patient	9	3
Structure and process of care	5	2

Note. The domains of ethical or legal aspects of care and cultural aspects of care were not identified in this dataset.

Although concern statements represented a comparatively lesser portion of overall visit communication, the importance of the emotionally laden concerns to providing high-quality end-of-life care cannot be overlooked. Resolution of those concerns can facilitate optimal patient end-of-life care and caregiver bereavement outcomes (Stroebe, Schut, & Stroebe, 2007; Ylitalo, Valdimarsdóttir, Onelöv, Dickman, & Steineck, 2008).

Nurse communication behaviors surrounding patient and caregiver concerns were identified using codes developed from the RIAS coding system. Although no clearly defined approach exists regarding the best way to respond to patient expressions of emotion (Del Piccolo et al., 2011), negative emotion has been identified as difficult to manage (Sheldon et al., 2009). Emotionally laden patient and caregiver concern statements require the hospice nurse to compose an answer that is empathetic, accurate, and meets patient and caregiver needs. In other words, nurses must use a patient-centered approach when providing end-of-life communication. This approach has been defined as communication that fosters healing relationships, exchanges information, responds to emotions, assists in decision-making and the management of uncertainty, and enables patient self-management (Epstein & Street, 2007).

The relatively greater number of nurse communication behaviors reflecting positive emotional statements (e.g., compliments, optimism) in the nurse speaking turns surrounding caregiver and patient expressions of concern, and the frequent use of emotionally responsive statements to develop rapport with the family indicate that hospice nurses may be using these communication behaviors deliberately as a way of eliciting issues that are responsible for emotional distress as well as indicating receptiveness to the concerns. The success of those types of communication behaviors in eliciting patient and caregiver concerns offers support for previous research showing greater patient emotional expression in response to providers' use of reassurance and affirmations (Eide et al., 2004) rather than direct

questions (Fallowfield, Jenkins, Farewell, et al., 2002; Maguire et al., 1996). These communication strategies may be less intrusive, provide emotional support and space for caregivers and patients to express themselves, and facilitate patient-centered communication and care (Eide et al., 2004).

Although emotional expression can be beneficial (Berry & Pennebaker, 1993; Gross, 1989; Hoyt et al., 2013; Langer, Rudd, & Syrjala, 2007; Pennebaker, Mayne, & Francis, 1997; Petrie, Booth, & Pennebaker, 1998; Stanton et al., 2000; Suls, Green, Rose, Lounsbury, & Gordon, 1997), it also can be taken too far. Rumination and catastrophizing have been related to poorer patient emotional well-being (Porter, Keefe, Lipkus, & Hurwitz, 2005). Nurses should exercise caution when eliciting and responding to patient and caregiver concerns so they do not facilitate greater distress.

The home hospice environment may facilitate faster, more intense partnership communication behaviors that enable emotional disclosure by patients and caregivers. This may be because of the associated impending loss, comparatively longer visit length, and greater frequency of hospice home nursing visits. Patients in hospice care and their caregivers naturally may offer multiple expressions of emotional concerns in varied domains of care regardless of nursing communication behaviors because of the emotionally charged nature of end-of-life care.

Examination of communication content indicated that six of the eight key domains of care (i.e., physical, psychological, social, spiritual, dying process, and structure of care) were associated with a comment indicating patient and caregiver worry or emotional distress, which implies that nurse responses should address the content of those concerns. Content representing the domains of cultural care and ethical or legal care (e.g., discussions of advanced directives) was not found in the data, which may be because ethical or legal discussions occurred prior to hospice admission or as part of the hospice admission visit that was not captured. Content representing key domains also was found elsewhere in the recordings but did not rise to the emotional level that would trigger coding the statement as a concern. In discussions reflecting physical care and symptom discussions, statements were often coded as information giving and question asking, but they did not possess negative affective tone that would indicate worry or distress. Conversations that contained statements indicating spiritual topics were present in the data as well, but many did not possess increased affective tone.

Limitations

Variation exists within hospice care for patients and nurses. The small sample from the current study

Knowledge Translation

Key domains reflecting quality end-of-life care can be used to guide practice and holistically address patient and caregiver issues.

Hospice nurse communication behaviors used to elicit or respond to emotionally laden concerns could be taught to nurses who may not be as familiar with eliciting or responding to negative patient emotion.

Conversations including statements relating to psychological aspects of care contain the most negative affect.

included all dyads and nurses, even those with more extreme data points. In a larger study, increased power would allow nesting of dyad concerns within specific hospice nurse case loads, providing a more fine-grained analysis. In addition, how nurses responded to specific concerns was not addressed because of analyzing nurse communication by speaking turn. However, specific content areas were captured. A need also exists for greater exploration of racial and ethnic diversity among patients, caregivers, and hospice nurses to explore how those factors affect concerns and nursing communication behaviors. Although the current study examined a comparatively small sample in a single geographic location, the analysis focused on concern statements, nurse communication behaviors surrounding the statements, and content of the concern statements, as opposed to focusing on individual participants. Because of that, the findings are generalizable to other locations (e.g., acute care settings) and participants, suggesting avenues for future research.

Implications for Nursing

Home hospice visits represent a different communication interaction and context than those that occur in short-term ambulatory medical clinics, office appointments, and hospitals. However, end-of-life discussions and other emotionally laden conversations occur in those venues, and that poses communication challenges for nurses (Schulman-Green et al., 2005; Sheldon et al., 2009). Although emotional conversations are expected to occur in settings such as intensive care units or the emergency department, conversations with intense negative emotional affect may not occur as frequently in settings providing more routine health care, such as settings that offer primary care. When those conversations are less frequent, nurses and other healthcare providers may be less familiar with communication behaviors to help manage conversations containing distress and worry. Hospice nurse communication behaviors that are used to elicit or respond to the

emotionally charged concerns represent ways to approach patient-centered communication processes that could be taught to nurses who may not be as familiar with eliciting or responding to the negative emotion from patient and caregiver concerns. Helping nurses learn specific communication behaviors to assist them in engaging in emotional conversations would facilitate high-quality nursing care by preparing nurses for emotional conversations that could occur in any setting.

Conclusion

Caregivers and patients with cancer in the current study frequently shared emotionally distressing concerns with their home hospice nurse, which is a type of health communication interaction that many nurses find challenging. In the current secondary analysis, hospice nurses demonstrated specific communication behaviors (i.e., positive emotional statements, physical

questions, and emotional responses) in their speaking turns surrounding distressing disclosures from patients and caregivers. Because of that, home hospice may provide a venue to study ways to elicit and respond to expressions of emotional distress. Additional investigation into the broader context of those discussions and how hospice nurses elicit and respond to emotional conversations may inform future interventions to assist healthcare providers in feeling more comfortable with and effectively engaging in emotional discussions.

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