

Author manuscript

Published in final edited form as:

Patient Educ Couns. 2019 October; 102(10): 1793–1801. doi:10.1016/j.pec.2019.06.013.

Hospice Nurse Identification of Comfortable and Difficult Discussion Topics: Associations Among Self-Perceived Communication Effectiveness, Nursing Stress, Life Events, and **Burnout**

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Abstract

Objective: To assess hospice nurses' self-perceived communication effectiveness, identify comfortable and difficult discussion topics, and explore associations between self-perceived communication effectiveness, burnout, nursing stress, and life events.

Methods: 181 nurses completed self-report measures, then listed comfortable and/or difficult patient and caregiver discussion topics.

Results: Nurses were generally experienced (median 9 years, range <1-46 as a registered nurse; median 3 years, range <1-23 as a hospice nurse), reporting overall Effective/Very Effective communication skills (85.6%); 70% desired more communication training. As nursing stress increased perceived overall communication effectiveness decreased ($r_s = -0.198$; p 0.012). As burnout increased overall effectiveness ($r_s = -0.233$; $\rho 0.002$) and effectiveness with difficult topics $(r_s = -0.225; p \, 0.003)$ decreased. Content analysis revealed 9 categories considered both comfortable and difficult to discuss; contextual comments provided fuller explanation (e.g. providing general information on the Dying Process was comfortable, discussing Dying process

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All authors contributed substantially to this research article. Clayton, Ellington, Reblin contributed to the conceptualization and design, funding acquisition, study supervision, analysis, and the writing of this manuscript. lacob contributed to the analysis and writing of this manuscript. All authors read and approved the final manuscript.

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^{&#}x27;Declarations of interest: none'.

during patient death was difficult). Seven additional categories (e.g. Denial) were deemed uniquely difficult.

Conclusion: Hospice nurses perceive themselves as effective communicators, yet want additional training. Perceived communication effectiveness is associated with burnout and stress.

Practice Implications: Communication training that focuses on contextually grounded topics identified by participants may optimize communication between hospice nurses, patients and caregivers.

Keywords

Cancer Communication; Nursing; Hospice; Communication Effectiveness; Burnout; Stressful Events; Comfortable and Difficult Communication Topics; Caregivers

1. Introduction

In the United States, hospice care focuses on preserving quality of life and managing physical and emotional symptoms during the last 6 months of anticipated patient life. In 2016 1.43 million Medicare beneficiaries were enrolled in hospice with the majority having a cancer diagnosis.[1] Currently, the majority of hospice patients receive home based care, with almost 50% of deceased patients receiving the Medicare hospice benefit, indicating a substantial and growing number of families that engage with hospice nurses.[1, 2]

Hospice agencies provide 24/7 nurse availability. A goal of optimum hospice care delivery is for the hospice nurse, patient and caregiver to develop a mutual working/caring relationship tailored to patient and family needs and wishes. Updated clinical practice guidelines from the National Consensus Project for Hospice and Palliative Care for the delivery of quality hospice and palliative care have placed a renewed emphasis on communication across all 8 care standards.[2] Although effective communication at end-of life has been deemed critical by patients, caregivers, and health care providers, to accomplish optimal care delivery hospice nurses must possess communication skills that enable them to elicit and understand patient and caregiver concerns in a culturally respectful manner, and be able to respond in an empathetic way that conveys accurate information and reassurance.[3–5]

Despite the acknowledged importance of end-of-life communication, important gaps remain in our understanding of hospice communication processes among nurses, patients and caregivers. Most communication research to date has addressed structured patient-provider communication interventions to improve delivery and understanding of advanced directives, or implemented decision aides to guide treatment choices.[6, 7] More recently research has focused on communication processes and outcomes, demonstrating that effective communication between hospice nurses, patients and caregivers can reduce caregiver burden and distress, enhance symptom management, and improve bereavement adjustment. [8, 9]

There is a widely held assumption that nurses are innately skilled communicators given their reputation for empathy, and their need to interface between physicians, other healthcare providers, patients, and families. Moreover, caregivers and patients often turn to their hospice nurse as an expert resource and as someone who understands both caregiver and

patient needs. Given the wide range of topical competencies required for the delivery of quality hospice care, as well as the very personal and intense nature of end-of-life discussions, hospice nurses may perceive some conversations as difficult and not feel comfortable or prepared for some discussions. [10].

Nursing curricula are beginning to integrate communication skills with end-of-life care delivery practices.[11, 12] However, nurses who graduated over a decade ago and are now considered "experienced" members of the work force may not have received end-of-life communication skills training, leading to uncertainty in how to approach challenging communication situations. For example, a self-perception of a lack of communication skills, such as not knowing what to say when discussing death and/or engaging in emotionally-laden conversations, are reported as challenging discussion topics.[10, 13, 14]

Communication may also be influenced by other stressors such as working in a hospice environment, burnout, and the events inherent in nurses' personal lives, negatively impacting nurses' communication with patients, caregivers and their families. [15, 16] Other research suggests that the converse may also be true, that a lack of confidence in communication skills may contribute to burnout and nursing employment-related stress over time. [17] Burnout, and the associated impact on communication, has been found among oncology nurses, in part due to the longer length, intensity and personal nature of relationships with patients and caregivers. [15, 18] In end-of-life care relationships develop more quickly, and are just as intense. While most hospice nurse-patient-caregiver relationships are of shorter duration than those during curative oncology care, the mean length of stay in hospice is lengthening. The 2016 median length of stay in hospice care was 24 days (Mean 71 days). [1]

The importance of effective nurse communication in end-of-life care is well established. However, few studies have addressed the self-perceived communication skills of hospice nurses in relationship to burnout and/or nursing stress, nor identified topics that hospice nurses report as comfortable or difficult to discuss with patients and caregivers. Moving forward, it is critical to better understand how nurses perceive their communication skills, and the association between self-perceived communication effectiveness, burnout and nursing stress, as a first step to optimizing hospice nurse-patient-caregiver communication. These aspects are key to the development of communication skills training programs. Thus, the aims of this study were to: 1) Evaluate hospice nurse self-reported communication effectiveness overall, when discussing topics nurses perceived as difficult, and in relation to self-reported nursing stress, life events, and burnout, 2) assess nurses' desire for further communication skill training, and 3) identify topics that hospice nurses consider comfortable and/or difficult to discuss with caregivers and/or patients.

2. Methods

We report on self-report data collected from home hospice nurses upon their enrollment to a large multi-site, longitudinal, Institutional Review Board approved, program project grant investigating multiple aspects of end-of-life caregiving from cancer patient home hospice admission through caregiver bereavement. [5, 19, 20] Overall, data include over 2000 hours

of audio-taped home hospice nursing visits, caregiver self-reported information and bereavement experiences, and patient symptom data. Nurses were recruited from 11 hospices in 4 different geographical regions of the United States during hospice nursing staff meetings; cancer patient-caregiver dyads were recruited from enrolled nurse caseloads. Complete recruitment procedures have been described elsewhere, but as an overview, nurse recruitment and nurse written informed consent involved introduction and explanation of the study, including the wearing of an audio-recorder during scheduled home hospice visits.[21] The sample for this analysis consisted of all nurses who answered open-ended questions listing topics they felt were comfortable or difficult to discuss with patients and caregivers, resulting in a sample of 181 out of the total enrolled 223 hospice nurses.

2.1 Data Source and Measures.

Using the approach and self-report questions of Baile [22] and Roberts [23] for assessing and evaluating communication skills of oncology providers, hospice nurses caring for admitted cancer patients provided demographic data then answered two questions about 1) their self-perceived overall communication effectiveness, and 2) self-perceived effectiveness with difficult topics (1=Not at all effective to 5=Very effective). Nurses then responded using free text to questions asking them to list topics under parent categories of the most comfortable and/or most difficult to discuss with patients and caregivers. Nurses were also asked about their desire for further communication skills training and preferred delivery options.

Nurses completed self-report measures of life events, employment-related nursing stress and burnout. The Holmes and Rahe 41 item Social Readjustment rating scale was used to obtain a summary of the number of stressful life events experienced by nurses, yielding a sum of experienced events.[24] The Nursing Stress Scale (7 subscales; 34 items rated from 1 (Never) to 4 (Very Frequently) was used to measure employment related stress. [25] Scores are summed (maximum possible score =136; subscale maximum scores range from 28 for the Patient Death and Dying subscale to 12 for the Inadequate Emotional Preparation and Lack of Support subscales) with higher scores reflecting greater nursing employment-related stress. The abbreviated version of the Maslach Burnout Inventory was used to assess nurse burnout. [26, 27] This measure consists of 12 items rated from 1 (Never) to 7 (Every day) and four subscales (Satisfaction, Personal Accomplishment, Emotional Exhaustion, and Depersonalization; maximum score for each subscale = 21). An overall burnout score (maximum total score 84) is computed by reverse scoring items in the Satisfaction and Personal Accomplishment subscales. Higher total scores indicate greater emotional exhaustion and depersonalization, and less personal accomplishment and satisfaction.

2.2 Analysis

Descriptive statistics were used to characterize participants, and to summarize self-reported communication effectiveness, desire for further communication training, life events, nursing stress, and burnout. Spearman's rank order correlation coefficients (i.e., Spearman's rho) were used to assess associations between communication effectiveness variables, burnout, life events, and nursing stress.

2.2.1 Open Ended Lists of Comfortable and Difficult Discussion Topics—

Categorical content analysis was used to summarize nurses' lists of comfortable and difficult communication topics. [28] Using broad categories of most difficult and most comfortable discussion topics developed prior to data collection, nursing responses to open ended questions were initially grouped into subcategories (e.g. symptom management). Two coders engaged in discussion of nursing responses relative to subcategories until consensus was reached about how a listed topic should be subcategorized. Refinement of subcategories occurred, again with discussion between coders until consensus was reached. Some content subcategories were found in both difficult and comfortable initial categories. Contextual examination of listed topics within comfortable or difficult parent categories provided greater explanation about why nurses listed a topic in their difficult or comfortable lists, and with whom they found the topic difficult or comfortable to discuss. Counts of nurses who listed a topic by patient or caregiver were calculated yielding a score of how many nurses listed a particular topic as difficult or comfortable, and with whom.

3. Results

3.1 Participant characteristics

Hospice nurses were predominately female (91%), Caucasian (91%), and generally experienced (median 9 years, range <1-46 as a registered nurse; median 3 years, range <1-23 as a hospice nurse). Seventy five percent of nurses had been a nurse for 4 or more years. The mean age of hospice nurses was 44.5 (range 21-71) years. Extremely few nurses held nationally recognized specialty certifications (Table 1). One nurse listed a topical area of certification but did not list the specific credential.

Most nurses considered themselves effective communicators overall (52%) with 33% reporting that they were very effective communicators. When asked about their self-perceived communication effectiveness when discussing difficult topics, again most nurses thought of themselves as effective communicators (57%) but fewer nurses perceived themselves as very effective communicators (21%; Table 2). Most desired additional communication training (N=121; 70%) selecting one or more preferred delivery methods. The most preferred way to receive additional communication skills training was a workshop during working hours, chosen by 85 nurses. "Other" was selected by 26 nurses with free text explanations showing that 13 hospice nurses wanted information by email, 4 wanted access to an online class with the remainder wanting information presented using written material such as handouts (Table 2).

3.2 Burnout.

The average level of burnout among hospice nurses in this study was at 33.98 (maximum possible 84). Subscale analysis showed high levels of satisfaction and personal accomplishment with low levels of depersonalization and emotional exhaustion (Table 3). As anticipated, burnout and nursing employment related stress were positively correlated (($r_s = 0.231$; p = 0.003).

3.3 Nursing Stress.

The average level of stress attributed to hospice nursing employment was 63.6, (maximum possible 136) however, this measure had a wide range (39-112) with some nurses reporting very high nursing stress. Subscale analysis showed that the highest level of nursing stress was attributed to the subscale Death and Dying (reflecting items such as feeling helpless when patients fail to improve, and listening or talking to a patient about approaching death), followed by workload (unpredictable staffing, not enough time to provide emotional support or complete nursing tasks) (Table 3).

3.4 Life events.

On average nurses listed an average of 5 life events out a possible 41. The most frequently listed life event was taking a vacation (77 respondents). 42 nurses reported a death either of a spouse (3) or a close family member (39), and 35 selected major changes in the health of a family member. 10 nurses reported spending Christmas alone. 44 hospice nurses listed major changes in work responsibilities, though the nature of this change is unknown (Table 3).

3.5 Associations between communication effectiveness and nurse characteristics.

Although nurses reported that they were generally effective communicators, both overall and with difficult topics, nursing stress and burnout were correlated with communication effectiveness. As total nursing employment-related stress increased nurses' self-reported communication with overall communication effectiveness (\mathbf{r}_s = -.198; p= 0.012) decreased. The association between nursing stress and perceived communication effectiveness when discussing difficult topics narrowly missed significance, \mathbf{r}_s = -.153; p= 0.053. As burnout increased both self-perceived overall communication effectiveness (\mathbf{r}_s = -0.233; p= 0.002) and effectiveness with difficult topics (\mathbf{r}_s =-0.225; p= 0.003) decreased. No associations were found between years as a registered nurse or life events, with self-perceived communication effectiveness.

3.6 Comfortable versus difficult topics

Hospice nurses listed topics they felt were most comfortable or most difficult to discuss with patients and caregivers. Topics were grouped into subcategories, for example, the Dying Process and Symptom Management. Final analysis resulted in 16 subcategories (Tables 4, 5), Nine subcategories were found in both difficult and comfortable parent categories (e.g. Symptom Management and Emotion). Seven subcategories were uniquely identified as difficult to discuss with either caregivers or patients (Table 5). Contextual examination provided greater explanation about why nurses listed topics as difficult or comfortable to discuss with patients and/or caregivers.

3.6.1 Comfortable discussion catesories.—Noting that nurses could list as many topics as they desired, the most frequently listed comfortable topic to discuss with both patients and caregivers was Symptom Management (listed under patients by 75 nurses; and under caregivers by 81 nurses) followed by the Dying Process (patients, 37 nurses; caregivers, 62 nurses) (Table 4). Contextual examination showed that nurses felt that providing information or explanation (regardless of subcategory) was comfortable to discuss

with both caregivers and patients. Discussions of Emotion and Family Dynamics were comfortable to discuss when discussions involved reminiscing, joy and happiness, or anticipating the arrival of family members (reuniting).

Difficult discussion categories.—Nine subcategories listed as comfortable to discuss were also found in lists of topics that hospice nurses considered difficult to discuss with patients and caregivers, however, the context of subcategories changed when nurses listed topics as difficult to discuss (Table 5). For example, discussing the Dying Process when the patient was actively dying (as opposed to providing future general information) was considered difficult to discuss with both patients and caregivers (with patients, 22 nurses; caregivers, 25 nurses). Emotion (with patients, 20 nurses; caregivers, 10 nurses) was considered difficult when tension and/or conflict was present (as opposed to happiness and joy) and Family Dynamics was considered difficult if there was tension among family members. Discussions of the patients' Prognosis were considered difficult to engage in with both patients and caregivers when discussing an expectation of imminent patient death (as opposed to general disease trajectory), and was the most prevalent difficult subcategory related to discussions with caregivers (listed by 43 nurses). Discussions of Care Delivery were considered difficult when the family was requesting services beyond what hospice could provide. Regarding Religiosity, some nurses listed this subcategory as difficult, writing that they just didn't like to discuss religion with anyone.

Seven subcategories were uniquely listed as difficult to discuss with patients and caregivers (Table 5). There was a clear distinction between discussions of general prognosis (progression of illness leading to death) whether comfortable or difficult to discuss, and discussions addressing denial of the patients' prognosis and/or the need for hospice care. Denial of prognosis and/or the need for hospice care was a uniquely difficult topic to discuss with both caregivers and patients (listed by 24 nurses for discussions with patients; by 30 nurses for caregivers). Other uniquely difficult subcategories emerged but only for discussions with either the caregiver or patient, not both. For example, conversations about caregiver Medication Diversion and patient Abuse or Neglect were only found within lists of caregiver difficult discussion topics, and patient Suicide was only found in lists of difficult patient discussion topics (Table 5). Additional uniquely difficult subcategories included Hospice Discharge (outliving hospice benefit eligibility) and Financial concerns (Table 5).

4. Discussion and Conclusion

4.1. Discussion.

Effective communication among nurses, patients, and caregivers during end-of4ife care is important and can ultimately improve patient and caregiver outcomes. [8] This study supports other research demonstrating that a nursing perception of effective communication, especially when discussing difficult topics, is associated with nurse personal factors such as burnout and employment-related stress. [15, 16] Consequences of a perception of ineffective communication, can result in less than optimal end-of-life family-centered care. [3]

4.1.1 Burnout—Although the level of burnout in this sample was relatively low, nurses who experienced greater levels of burnout perceived themselves to be less effective

communicators, however, causal inference cannot be inferred. It is also possible that a perception of less effective communication skills contributed to burnout. [17] As posited by other researchers, burnout may also be a consequence of personal and intense relationships developed with patients and caregivers during end-of-life care. [15, 17, 18]

4.1.2 Nursing Stress

- **4.1.2.1 Patient Death:** The level of nursing employment-related stress was also associated with a self-perception of less effective communication. Subscale analyses revealed that the most prevalent areas of nursing employment stress were Patient Death and Dying, and Workload. Nursing Stress and Burnout were positively associated with each other, with subscale analyses supporting the fact that conversations about death and dying are a contributing factor to nursing employment-related stress. Although this scale is intended for general employment across settings, and nurses in all fields experience patient death, it is not a far reach to consider that hospice nurses who experience death on an almost daily basis would endorse this as a stressful aspect of their employment.
- **4.1.2.2 Workload:** With respect to subscale analyses addressing workload, findings from this study indicate that nurses are experiencing employment related stress due to workload. Nurses employed in home hospice care have caseloads reflecting varying numbers of patients with differing acuity in their disease and end-of-life trajectory.[1] No research could be located that provides evidence for the optimal staffing caseloads in end-of-life care that can be definitively linked to optimizing quality care delivery, instead it is recommended by the National Hospice and Palliative Care Organization that caseloads per nurse be made on an individual hospice basis.[29] Recommendations include an evaluation of individual hospice models of care (e.g. models of admission, on-call care provision, bereavement care provision) and close monitoring of variables such as nursing staff turnover as a way to gauge the stress caseloads place on nursing staff.[29]
- 4.1.3 Difficult and Comfortable Communication—Nurses in this study were clearly able to identify comfortable and difficult discussion topics, indicating an awareness of communication effectiveness. Nurses provided explanations of contextual circumstances that determined whether a subcategory was considered comfortable or difficult to discuss with patients and/or caregivers. Overall nurses identified comfortable caregiver or patient discussion subcategories as those where they could provide information and explanation, and where there was a lack of conflict and/or tension among family members. Conversely nurses identified subcategories where there was denial of the patient's prognosis and/or the need for hospice care as difficult to discuss with both patients and caregivers. Some subcategories such as discussions of patient suicide, patient abuse or caregiver medication diversion were not found in the parent category of comfortable to discuss, and were considered uniquely difficult to discuss with either patients or caregivers. These findings point to a need for contextually based communication skills training where nurses can focus on communication topics they perceive as difficult and where they feel less effective.

Surprisingly nurses' self-perception of communication effectiveness was not associated with years of experience as a nurse. We had initially included this variable because we thought

that there was a possibility that more years as a nurse would be associated with greater self-perceptions of communication effectiveness in that nurses would have familiarity and experience with multiple discussion topics and might have engaged in common discussion topics with patients and caregivers multiple times. In this study, the majority of nurses had been in the workforce for many years. Upon reflection this may indicate that they did not receive communication skills training as part of their original educational curriculum. Regardless of years of nursing experience, most nurses wanted additional communication skills training, provided in an accessible way. In this study, the most selected communication skills training delivery choice was a workshop delivered during working hours. Other preferred delivery modes included workshops and teleconferencing. Very few nurses wanted literature, handouts, or online education.

Recognition of the need and desire for additional communication skills training has led to the development of a wide range of communication skills training programs for nurses in both inpatient and outpatient settings. Examples include, the well-known ELNEC program (End-of-Life Nursing Education Consortium), a program of the American Association of Colleges of Nursing, and VitalTalk, a program to empower clinicians to communicate about serious illness empathetically and effectively in a culturally sensitive manner.[14, 30, 31] A secondary goal of VitalTalk is to empower clinicians as a way to avoid burnout.[31]

Additional educational opportunities for hospice nurses include specialty training and certification that incorporates the importance of communication. Nurses can earn the Certified Hospice and Palliative Nurse (CHPN) credential from the Hospice & Palliative Credentialing Center. In addition, the HPNA (Hospice and Palliative Nurses Association) publishes a regularly updated *Core Curriculum for the Hospice and Palliative Registered Nurse* (4th edition) which includes information on the importance of communication.[32] Based on nursing feedback, the End of Life Nursing Education Consortium (ELNEC) program, which began in 2001, developed a new communication course, *ELNEC Communication*, in 2018. *ELNEC Communication* is grounded in the National Consensus Project Guidelines for Quality Palliative Care[2] and teaches nurses how to integrate communication into each of the identified 8 standards of care.

Despite the existence of specialty training and national education programs, our results suggest that the desire for communication skills training is still not being met. Nurses indicated a high desire for additional communication skills training, with many preferring in-person training during working hours and/or face-to-face options such as teleconferencing. Moreover, we found an extremely low amount of national certifications that would indicate in part that nurses received additional formal communication skills training.

4.2 Strengths and Limitations.

Although the level of burnout and the number of life events were not correlated with each other nor with self-perceptions of communication effectiveness, sub-analyses were not performed by specific life event type. For example, to see if those nurses who had experienced death of a family member or family health status changes experienced higher burnout or less perceived communication effectiveness than the general sample. In addition,

even though the free-text form of comfortable and difficult topics and the associated contextual explanations provided by nurses allowed initial identification of a broad list of subcategories that nurses felt were difficult or comfortable to discuss with patients and caregivers, lists and associated subcategories cannot be interpreted as comprehensively representing all comfortable and difficult communication subcategories. Some nurses listed many topics and others fewer topics. If presented with additional topics, such as in a drop down list, it is possible that nurses would select additional topics as difficult or comfortable to discuss with caregivers and/or patients. Finally, very few nurses held specialty certifications or indicated additional training in communication or for hospice/palliative care. It is unknown how self-perceived communication effectiveness would change if more nurses held specialty education or certification in hospice care or related areas.

4.3. Conclusion.

Our findings support and add to research by Bannerje who reported that oncology nurses face communication challenges in part due to patient family dynamics, emotion, and a lack of knowledge about how to empathetically discuss specific topics.[10] Other nursing identified challenges included discussions of symptom management and denial of prognosis. [10] In our study hospice nurses identified similar communication challenges when interacting with cancer patients receiving end-of-life care and their caregivers. Finally, our research supports that of other scholars identifying limited opportunities for in-person communication skills training despite the availability of national programs, and emphasizes the need and desire of nurses for accessible communication skills training opportunities.[33, 34]

4.4 Practice Implications.

It is important to consider hospice nurse stress and level of burnout when trying to optimize communication with caregivers and cancer patients at end-of-life, and by extension provide optimal family-centered care. Communication skills training for hospice nurses may be most useful for optimizing quality hospice care when programs are focused on contextually grounded communication topics specifically identified by hospice nurses and presented during conveniently scheduled sessions during working hours.

"I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story."

Acknowledgments

This work was supported by the National Institutes of Health P01CA138317. The sponsor had no role in the design, conduction, data analysis and interpretation, or writing and submission of this paper.

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Highlights

- Hospice nurses perceive themselves as effective communicators.
- Most hospice nurses want addition communication skills training.
- Self-perceived communication effectiveness is associated with burnout and stress.
- Challenging communication topics such as Denial can be identified by hospice nurses.
- Addressing self-identified communication challenges may optimize end-oflife care.

Table 1.

Hospice Nurse Characteristics

Variable (Respondents)	Result	Mean (SD)	Median (Range)		
Age (Years) N=176		44.5	44.0		
		(11.5)	21-71		
Gender N=181	Female 164 (91%)				
	Male 17 (9%)				
	White 165 (91%)		_		
	Black 5 (3%)				
Race N=178	American Indian/Alaskan 2 (1%)				
Race N=1/8	Asian 4 (2%)				
	Hawaiian 1 (1%)				
	Other 1 (1%)				
Ethnicity N=163	Hispanic 8 (4%)				
	Non-Hispanic 155 (85%)				
Experience as RN (Years)		13.9	10		
N=164		(11.6)	1-46)		
Experience as Hospice RN (Years) N=141		5.33	3		
		(5.08)	(1-23)		
	1 Certified Hospice & Palliative Nurse CHPN)				
Certification N=181	1 National Hospice & Palliative Care Organization (NHPCO)				
	6 Oncology Certified Nurse (OCN)				
	1 Certified Wound Care Nurse (CWCN)				
	1 AIDS Certified Registered Nurse (ACRN)				
	1 Maternal - Child - Obstetrics (exact certification unknown)				

 Table 2.

 Self-reported Communication Effectiveness and Desire for Additional Training

Question (Respondents)	Response	N	%
	Not at all effective	0	0
	Not very effective	1	0.6
How effective are your communication skills overall? (N=177)	Neutral	21	11.6
	Effective	95	52.5
	Very Effective	60	33.1
How effective are your communication skills when discussing difficult topics? (N=177)	Not at all effective	0	0
	Not very effective	1	0.6
	Neutral	34	18.8
	Effective	104	57.5
	Very Effective	38	21.0
Are you interested in receiving addition communication skill training? (N=173)	Yes	121	70
	No	52	30
	Workshop during working hours	85	
	In-person	47	
Delivery Choices (Nurses could select all desired)	Teleconferencing	33	
	Workshop evening or weekends	24	
	Other	26	

Table 3.

Nursing Burnout, Stress, and Life Events

Variable (Respondents)	Mean (SD)	Median (Range)
Burnout Total Score (N=175)	33.98	33
	(5.71)	(19-50)
Satisfaction	18.71	19
3 Items; higher score =more satisfaction / less burnout	(2.3)	(8-21)
Personal Accomplishment	18.81	20
3 Items; higher score=more accomplishment / less burnout	(2.2)	(12-21)
Emotional Exhaustion	8.97	9
3 Items; higher score=more exhaustion / more burnout	(3.6)	(3-19)
Depersonalization	4.16	3
3 Items; higher score=more depersonalization / more burnout	(1.8)	(3-11)
Nursing Stress Total Score (N=161)	63.60	63
	(12.01)	(39-112)
Patient Death and Dying 7 Items	14.74	14
	(3.9)	(7-23)
Workload 6 Items	12.4	12
	(3.06)	(7-23)
Conflict with Physicians 5 Items	8.91	9
	(2.0)	(5-19)
Uncertainty concerning patient treatment 5 Items	8.63	9
	(2.2)	(5-19)
Conflict with Nurses 5 Items	6.97	7
	(2.1)	(4-16)
Inadequate Emotional Preparation 3 Items	5.59	6
	(1.2)	(3-9)
Lack of Support 3 Items	4.66	4
	(1.75)	(3-12)
Life Events Total Score (N=181)	5.24	5
	(3.77)	(0-25)

 Table 4.

 Comfortable Discussion Categories and Data Examples

Most COMFORTABLE To Discuss With PATIENTS	Nurses Listing Category	Most COMFORTABLE To Discuss With CAREGIVERS	Nurses Listing Category
Symptom management 1. pain control 2. physical symptoms	75	Symptom management 1. Physical symptoms, pain nausea, SOB [shortness of breath] etc and how to manage those 2. teaching: symptom management, meds for symptoms	81
Dying process 1. signs of dying 2. What will happen at the end of life.	37	Dying process 1. Signs and symptoms of approaching death 2. Dying process, what to expect	62
Emotion 1. memories and life achievements and contributions to the world. 2. Anything that makes them smile or laugh	33	Emotion 1. Loving each other 2. Finding positives in life	30
Hospice Services (providing information about what hospice is/does) 1. The benefits of hospice. 2. role of hospice, my role in their care	20	Hospice Services (providing information about what hospice is/does) 1. philosophy of hospice 2. what I can do for them	19
Medication Administration 1. medications 2. managing their meds 3. how to take their meds	10	Medication Administration 1. How to organize his meds 2. Caregiving needs – educating about meds 3. Med changes and why	19
Family Dynamics 1. I love finding out about their lives, their loves, their hopes and dreams. 2. Life review/things that bring them pleasure	10	Family Dynamics 1. The family history (jobs, children, grandchildren) 2. Memory lane	8
Prognosis Physiology of the disease process and how it changes 1. What to expect physically	7	Prognosis 1. The disease process 2. Telling them what's gonna happen	3
Religiosity 1. God 2. Lifes meaning	5	Religiosity 1. life after death 2. meaning of life	7
Care Delivery	0	Care Delivery 1. how to best take care of the patient 2. comfort measures	15

Table 5.

Difficult Discussion Categories and Data Examples

Most DIFFICULT To Discuss With PATIENTS	Nurses Listing Category	Most DIFFICULT To Discuss With CAREGIVERS	Nurses Listing Category
Subo	categories Also	Found In Comfortable Listings	
Dying process 1. sometimes dying process if patient isn't accepting. 2. That they really are dying now but I'll help them be comfortable 3. When patients ask how much time is left	22	Dying process 1. impending death and difficult decisions about side effects and when to stop meds. 2. The dying process can be hard to point out to them when it is really happening 3. Sometimes it's difficult to teach on what to do right at death, what to expect if I haven't had time to develop a relationship with the caregiver	25
1. Anger 2. Their dissatisfaction or anger about not receiving a diagnosis earlier - the feeling that they were not listened to by their doctor or medical community	20	Emotion 1. Anger 2. difficult to talk to caregivers about anything when they are angry	10
Prognosis 1. Change in the prognosis that is shorter than expected 2. when they tell me they are afraid to die	16	Prognosis 1. When families are having difficulty accepting poor prognosis and the person is really declining. 2. That the patient has transitioned to actively dying and time is limited	43
Symptom management 1. when symptom management doesn't seem to be helping despite frequent attempts to change and adjust the tx (treatment) 2. The reality that the main symptoms complained about are not going to go away, but be a constant thing to deal with and try to treat, especially as the disease progresses.	9	Symptom management (difficulty)	0
Family Dynamics 1. Family conflict 2. Family issues 3. Family dysfunction	6	Family Dynamics 1. Getting everyone to agree on plan of care and deciding progression of authority as patient declines. 2. Many times at odds with other family members or the patient. 3. Often there are long-standing family conflicts or dynamics at play	14
Religiosity 1. Spiritual 2. God stuff because I'm not well versed in the bible	6	Religiosity 1. I can discuss almost everything except religious beliefs 2. Spiritual distress	3
Care Delivery 1. Telling someone they need a caregiver when they don't want to be a burden 2. Why they need more help. safety - falls, etc	4	Care Delivery 1. need for 24 hour care or SNF [skilled nursing facility] placement 2. Issues dealing with making sure pt (patient) has 24 hour caregiver at end of life	9
Medication Administration 1. When they get confused but still want to be in control and take their pills	3	Medication Administration 1. Meds suggested that they don't want to give or deliberately give differently 2. When they just stop giving the meds and the patient suffers	12
Hospice Services (providing information about what hospice is/does)	0	Hospice Services (providing information about what hospice is/does)	6

Clayton et al.

When patients bring up suicide
 Feelings about wanting to die right then

Nurses Nurses Most DIFFICULT To Discuss With Listing Listing Most DIFFICULT To Discuss With CAREGIVERS **PATIENTS** Category Category 1. what hospice does not provide i.e.: caregiver breaks other than an aid 1 hr per day and that not all patients will go to the hospice house at end of life 2. The definition of hospice and our role (boundaries) 3. treatments they want aren't in line with hospice plan of Subcategories Uniquely Listed As Difficult Denial (of prognosis / hospice need) 24 Denial (of prognosis / hospice need) 30 1. That they really are dying and what is 1. When they are in denial to protect themselves 2. Feeding people who cannot eat or don't want to eat happening. 2. S/S [signs/symptoms] of impending death when pt [patient] is in denial and asking about 3. It's difficult to tell someone he/she is at the end of their life when they don't want to die **Financial Concerns** 3 **Financial Concerns** 6 1. medicare restraints / benefits / coverage \$ 1. Insurance and financial questions. 2. The need for additional care and there is no financial meds, etc 2. when they don't want to spend money on a means to do so helper Hospice Discharge (outliving hospice benefit) 2 Hospice Discharge (outliving hospice benefit) 2 1. Discharge from hospice Discharging a patient 2. Being discharged 0 Abuse/Neglect (of the patient) Abuse/Neglect (of the patient) 9 1. issues r/t [related to] abuse that might come up. 2. If there has been abuse 3. when they are not invested - they want little to do with the care of PT [patient]. Neglectful 0 6 Medication Diversion (caregiver misuse) Medication Diversion (caregiver misuse) 1. Confrontations r/t [related to] missing medications/ narcotics 2. I haven't run into it yet, but drug diversion. 3. if suspected of diverting meds 0 3 **Respecting Patient Choices Respecting Patient Choices** 1. Differences of opinions between what the pt [patient] wants and what the family wants 2. When family members are disagreeing with what the patient wants. 2 0 Suicide Suicide

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