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Nurses' Perceptions and Experiences With End-of-Life Communication and Care

Denise Boyd, RN, BSN, OCN®, Kristen Merkh, RN, BSN, OCN®, Dana N. Rutledge, RN, PhD, and Victoria Randall, RN, MFA

Purpose/Objectives: To characterize oncology nurses' attitudes toward care at the end of life (EOL) and their experiences in caring for terminally ill patients, hospice discussions with patients and families, and the use of palliative care practices.

Design: Descriptive correlational survey study.

Setting: A Magnet®-designated hospital in southern California with more than 500 beds.

Sample: 31 oncology nurses.

Methods: Nurses completed the adapted version of the Caring for Terminally Ill Patients Nurse Survey.

Main Research Variables: Attitudes toward care at EOL and care experiences with terminally ill patients.

Findings: Despite having fairly positive attitudes toward hospice and having discussions about prognosis with terminally ill patients, nurses reported missed opportunities for discussions and patient referrals to hospice. On average, nurses cared for more than seven terminally ill patients during a three-month period while only discussing hospice care with a third of these patients and their family members. Most nurses acknowledged that patients would benefit from earlier initiation of hospice care. Specific palliative care practices used by nurses in the past three months varied, with active and passive listening and requesting increased pain medications used most frequently and aromatherapy and guided imagery used least.

Conclusions: Missed opportunities may reflect nurses' attitudes. However, lack of patient and family member acceptance was the most important barrier to discussion of hospice.

Implications for Nursing: Strategies to enable nurses to have a stronger voice during this critical time for their patients are needed and, when developed, supported in practice to ensure that they are used.

Seriously ill patients at the end of life (EOL) and their families report that honest communication is vitally important (Heyland et al., 2006). Challenges and opportunities for communication exist for healthcare providers who come into contact with these patients and their families. When carried out, discussions of prognosis can be important catalysts for later discussions of preferences for treatment and care. Unfortunately, communication about prognosis occurs with only a minority of patients with advanced cancer (Bradley, Hallemeier, et al., 2001; Wright et al., 2008). Communication about prognosis is necessary to facilitate decisions about treatment options, such as hospice and palliative care, and has been associated with significantly fewer aggressive medical interventions near death, more hospice care, and enhanced quality of life in patients and bereaved family members (Wright et al., 2008). Hospice care has been available to terminally ill patients and their families in the United States since 1982. However, only 39% of deaths occur in hospice facilities (National Hospice and Palliative Care Organization [NHPCO], 2009, 2010). Lack of communication and lack of hospice care usage result in many patients at EOL and their families being unable to experience a "good death."

Conceptual clarity is necessary when considering EOL communications and care. EOL care encompasses care delivered in an unspecified period close to a patient's death (Coyle, 2005). Hospice care specifically aims to ameliorate suffering that may focus on physical, spiritual, psychological, and practical concerns of dying patients and their family members; symptom management is a domain within hospice care. Hospice care is a specific benefit provided by many insurers, both public and private, and it requires a formal referral by a licensed healthcare provider (NHPCO, 2010). Palliative care more broadly is offered to patients facing serious life-threatening illnesses, and to their families (Coyle, 2005); these patients may not be imminently dying. According to the National Consensus Project for Quality Palliative Care, care planning should be based on values and needs of patients and their families and developed with professionals who guide and support decision-making processes (Coyle, 2005).

Nurses are in an ideal position to assume an important role in these processes because of the frequency and continuity of contact nurses have with their patients. However, nurses vary in their attitudes toward communication with terminally ill patients and hospice or palliative care (Beckstrand, Moore, Callister, & Bond, 2009; Cramer, McCorkle, Cherlin, Johnson-Hurzeler, & Bradley, 2003; Feeg & Elebiary, 2005). They may not feel comfortable discussing important issues with patients and families (Bradley, Cherlin, et al., 2001; Wotton, Borbasi, & Redden, 2005). Physicians are the most likely providers to discuss prognosis; however, one study of medical records audited from hospitalized patients with advanced cancer (Bradley, Hallemeier, et al., 2001) showed that nurses or social workers discussed patient care prognosis with about 25% of patients when such discussions were documented.

Although nurses may seem to be ideally situated to facilitate and support communication concerning prognosis and hospice referral between patients, family members, and other professional caregivers (Schulman-Green, McCorkle, Cherlin, & Bradley, 2005), they may not act on their ability to enhance communication for many reasons. Obstacles to nurses' discussions of prognosis and hospice referrals in the United States may result from perceptions that patients and their family members are unwilling to accept a terminal prognosis or hospice. Other barriers include patients' inability to communicate, the belief in physician reticence, nurses' discomfort, or nurses' desires to maintain hope for patients and family members (Schulman-Green et al., 2005). These obstacles were mirrored by Japanese nurses (Sasahara, Miyashita, Kawa, & Kazuma, 2003) who experienced difficulty caring for terminally ill patients and, in particular, communication problems with patients and family members, as well as by critical care nurses in the United States (Downey, Engleberg, Shannon, & Curtis, 2006) who experienced patient and family barriers, nurse-nurse and nurse-physician communication challenges, and difficulty meeting family needs.

Most acute care nurses have little training and lack knowledge about many palliative care practices that often are appropriate for patients at EOL. Therefore, they may not use them even when appropriate (Bradley, Cherlin, et al., 2001; Wotton et al., 2005). According to Johnson and O'Brien (2009), the use of nonpharmacologic methods to manage pain, depression, and fatigue may prolong survival and help patients at EOL and their family members improve communication and experience love, thereby enriching their relationships. Changing care delivery at EOL may require fundamental shifts among hospital nurses toward terminal illness and hospice (Bradley et al., 2000).

Survey results from family members of patients discharged from the authors' hospital indicated potential areas for improvement related to discussions of EOL issues and provision of clear information on signs of approaching death. Knowing how nurses perceive hospice care and their perceptions of discussions with terminally ill patients and their family members is critical in developing programs to enhance communication about these issues among staff, families, and other healthcare providers. The purpose of this study was to characterize oncology nurses' attitudes toward EOL care and their experiences in caring for terminally ill patients, hospice discussions with patients and families, and the use of specific palliative care practices.

Methods

This descriptive, correlational survey study was designed to fulfill the study purpose. An additional aim was to compare findings from a sample of oncology nurses from a Magnet®-designated hospital facility in southern California with published findings from earlier studies

Table 1. Sample Characteristics

Characteristic	$\bar{X}$	SD	Range
Years working as a nurse (N = 29)	15.6	12	1–45
Years employed at hospital (N = 30)	9.9	7.5	1–28

Characteristic	n
Female	29
Work setting	
Inpatient	19
Infusion center	1
Radiation therapy	1
Cancer center	7
Other	3
Ethnicity	
Hispanic or Latino	4
Race	
Asian	5
Native Hawaiian or other Pacific Islander	1
Caucasian	21
Other	3
No response	1
Highest level of nursing education	
Associate degree	11
Bachelor's degree	14
Master's degree	5
No response	1
Religious affiliation	
Roman Catholic	8
Protestant	8
None	2
Other	12
No response	1
Had hospice training during nursing education	18
Received hospice training within past five years	19

N = 31 unless otherwise noted

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involving East Coast medical-surgical nurses, including oncology nurses (Bradley et al., 2000; Bradley, Cherlin, et al., 2001; Cramer et al., 2003; Schulman-Green et al., 2005). The hospital institutional review board approved the study.

Sample and Setting

Oncology nurses in inpatient and outpatient areas of the hospital and cancer center were invited to participate in the study (N = 66) by a letter sent to their work mailboxes. The hospital has a 24-bed inpatient oncology unit, an infusion center, a radiation oncology department, and a nurse navigator team for the cancer center.

Measures

The Caring for Terminally Ill Patients Nurse Survey (CTIPNS) was developed by researchers at Yale School of Medicine as the basis for a series of studies (Bradley et al., 2000; Bradley, Cherlin, et al., 2001; Cramer et al., 2003; Schulman-Green et al., 2005). The authors adapted the tool with Bradley's permission as follows: eliminated questions about knowledge of hospice care (not a study aim); modified the demographic questions to fit the staff at the authors' institution; and, for the barriers to nurse communication items, added a response set that corresponded to findings from the Schulman-Green et al. (2005) study while keeping an open-ended option. Therefore, the adapted 55-item CTIPNS included both open- and closed-ended questions. In the survey, terminally ill patients were defined as those expected to die within three to six months.

The final survey consisted of 13 demographic questions; 13 questions about patients and patient care (e.g., number of terminally ill patients cared for in last three months who were referred for hospice care); 10 Likert-type questions requiring participants to consider reasons for care or care decisions (e.g., level of agreement that patients were not referred to hospice because of unwillingness of patient or patient family to accept hospice care), ranging from 1 (strongly agree) to 5 (strongly disagree); 20 attitudes about hospice care and communication at EOL, requiring Likert-type responses ranging from 1 (strongly agree) to 5 (strongly disagree); use of nine palliative care practices, ranging from 1 (all) to 4 (none); and four open-ended questions, asking nurses to identify reasons for care decisions. On the Likert-type items, lower scores indicated more agreement; regarding the palliative care practices, lower scores indicated more use.

For two questions, nurses were asked to rate the magnitude of five barriers resulting in patients not being referred to hospice care or resulting in patients and family members not being told of terminal status. Barriers came from the Schulman-Green et al. (2005) study findings and included (a) patient and family unwillingness to accept a terminal prognosis, (b) sudden changes in patient status, (c) physician hesitance to discuss the prognosis, (d) nurse discomfort in discussing prognosis, and (e) nurse desire to maintain patient and family hope. Nurses also were asked to list other reasons for these occurrences.

Procedure

Nurses received a packet in their mailboxes at work. Packets included an invitation letter that described the study. Nurse involvement in the study indicated consent to participate. Nurses returned completed surveys by mail to the hospital nursing research office. They were encouraged to return the surveys within two weeks. At the end of one month, all nurses received a reminder letter and survey, again being encouraged to complete and return the surveys within two weeks. Surveys were not coded, so the possibility exists that a nurse could have

Table 2. Number of Terminally Ill Patients Cared for by Nurses and Actions Taken Related to Hospice in the Past Three Months

Variable	n	$\bar{X}$	SD	Range
Terminally ill patients cared for	–	7.2	6.5	0–30
0	3	–	–	–
1–3	4	–	–	–
4–19	20	–	–	–
More than 19	2	–	–	–
No response	2	–	–	–
Terminally ill patients with whom nurses discussed hospice care	–	2.2	2.2	0–10
0	9	–	–	–
1–4	17	–	–	–
More than 4	4	–	–	–
No response	1	–	–	–
Family or primary caregiver of terminally ill patient with whom nurses discussed hospice care	–	2.3	2.3	0–10
0	6	–	–	–
1–4	20	–	–	–
More than 4	4	–	–	–
No response	1	–	–	–
Times patient, family, or caregiver asked nurse about hospice care without nurse initiating the conversation	–	1.2	1.4	0–6
0	10	–	–	–
1–2	17	–	–	–
More than 2	3	–	–	–
No response	1	–	–	–
Terminally ill patients referred for hospice care (not necessarily by the nurse)	–	4.3	5.3	0–25
0	3	–	–	–
1–4	16	–	–	–
5–10	6	–	–	–
More than 10	3	–	–	–
No response	3	–	–	–

N = 31

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responded twice, but the researchers considered this unlikely given the length of the survey.

Data Analysis

Descriptive statistics were used to describe frequencies and measures of central tendencies. Hospice attitudes were ranked from highest to lowest on the basis of mean scores to determine with which items the nurses most agreed. Following the description of frequencies of nurses reporting specific palliative care practices (e.g., therapeutic touch, guided imagery), an index of palliative care practices was calculated (nine items were summed; the total was divided by nine so that scores were in the same metric as the response set for palliative practices). Associations among select predictors (work setting, numbers of cases, nursing education, and attitudes) with outcomes (number of discussions of hospice with patients and family members, palliative care practices) were calculated using Pearson correlation coefficients. Analyses were done using PASW®, version 18.0. Significance level was set at 0.05.

Results

Sample

Thirty-one nurses participated in the study, a 47% response rate. Predominately female and Caucasian, 13% of the sample indicated having a Hispanic or Latino heritage, while 19% reported Asian or Pacific Islander as their race (see Table 1). Religious affiliation and educational attainment in nursing varied. Forty-five percent of the participants had received a bachelor's degree in nursing. These were experienced nurses with a mean of 15.6 years in nursing and 9.9 years of hospital employment. Most of the sample worked in the inpatient oncology unit, whereas the rest worked in other oncology settings within the hospital or cancer center (e.g., infusion center, radiation therapy). Twenty-one (68%) were in staff nurse positions, 58% of the sample were exposed to hospice during their nursing education, and about the same percentage had received training about hospice within the past five years. The average number of terminally ill patients cared for in the past three months was 7.2 (SD = 6.5), although 16% of the sample (n = 5) had either not cared for terminally ill patients or did not respond to this question (see Table 2).

Experiences With Hospice Care Discussions

On average, nurses indicated discussing hospice care with 2.2 patients and 2.3 family members or primary caregivers in the prior three months. More nurses had discussed hospice care with family members than with patients (81% versus 71%). A substantial number of nurses (66%) had family members inquire about hospice prior to any nurse-initiated discussion.

When asked who typically initiates discussions of hospice and makes the final decision for patient receipt of hospice care, nurses gave different responses. More nurses reported initial discussions from several individuals jointly (32%), nurses only (23%), and oncologists only (13%) than patients, hospitalists, and the palliative care team. None of the nurses reported that patients' family members or friends initiated discussions. Nurses were more likely to report that patients (29%) and family members (26%)—rather than healthcare professionals—made the final decision to receive hospice. Most nurses reported having one or more patients with whom hospice care was not used and perhaps should have been, or hospice care was used but perhaps should have been used sooner (see Table 3).

Table 3. Nurse Experiences Related to Hospice Care

Variable	n
Who typically initiates hospice care discussion?	
Patient	2
Family member	–
Friend	–
Oncologist	4
Hospitalist	2
Nurse	7
Palliative care team	2
Joint decision across aforementioned individuals	10
Other	2
No response	2
Who makes the final decision for the patient to receive hospice?	
Patient	9
Family member	8
Friend	–
Oncologist	5
Hospitalist	–
Nurse	–
Palliative care team	1
Joint decision across aforementioned individuals	5
Other	1
No response	2
In terminally ill patients seen in prior three months where hospice was not used or used late, number of cases where care of patient or family would have been better with hospice	
0	2
1–2	11
3–5	7
More than 5	5
No response	6
In terminally ill patients seen in prior three months where hospice was not used or used late, number of cases where the patient should have received hospice sooner	
0	2
1–2	13
3–5	6
More than 5	4
No response	6

N = 31

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Nurses responded to questions concerning possible reasons that the terminally ill patients they cared for in the past three months were not referred to hospice or were not told that they were dying (see Table 4). Nurses reported that patient and family unwillingness, changes in patient status, and physician hesitancy to engage in discussion were more important factors than their own discomfort and their desire to maintain hope for their patients and family members. Other reasons given by nurses included the following.

- Denial. "We've told them, but they don't hear." (n = 6)
- Desire to continue treatment or current level of care; pressure to "keep fighting" (n = 5)
- Family unable to take patient home; patient not wanting to leave hospital (n = 3)
- Misperception or fear of hospice care; "complex idea for patients/family, many from different cultures, that the chances of continued treatment may prolong life, but the quality of life may be poor" (n = 3)
- Physician not ready to give up; physician feels like hospice means failure (n = 2)
- Nurse not sure of the treatment plan (n = 3)
- Particular patient circumstances (e.g., newly admitted, unresponsive, already hospice patient, awaiting results from tests) (n = 4).

Hospice Care and Discussions With Terminally Ill Patients

On a scale of 1 (strongly agree) to 5 (strongly disagree), nurses' mean attitudes toward hospice care and communication with patients ranged from 1.4–4.9 for the 21 items (see Table 5). The item most agreed with was that dying patients should be told their prognosis ($\bar{X}$ = 1.4), and the item least agreed with was that hospice supports physician-assisted suicide ($\bar{X}$ = 4.9). For the most part, attitudes were favorable toward hospice and hospice care. Nurses perceived both nurses and physicians as having specific professional responsibilities related to hospice care and frank EOL discussions. Nurses disagreed with the idea that conventional care would be better than hospice care for symptom management ($\bar{X}$ = 4.5). Regarding their own competencies, nurses perceived themselves as having midrange skills (2.3–2.5 on a scale of 1–5, with 1 being more positive) related to caring for terminally ill patients and discussing hospice care.

In the top 10 attitudes, four potential barriers to patient receipt of hospice care exist: (a) some patients want doctors to determine the best course of care, (b) physicians may be reluctant or (c) find it difficult to communicate a terminal prognosis, and (d) many patients are not receiving hospice care when appropriate.

Palliative Care Practices

Specific palliative care practices used by nurses in the last three months varied (see Table 6). Those practices used most frequently were active and passive listening and requesting increased pain medications. Aromatherapy and guided imagery were least used.

Nurse Discussions of Hospice and Palliative Care Practices

Table 7 shows significant correlations of a predictor and an outcome among associations calculated. Moderate associations were found with greater numbers of patient and family discussions about hospice and caring for terminally ill patients and fewer years of employment as a nurse. Disagreeing that physicians find EOL discussions difficult was significantly associated with higher numbers

Table 4. Nurse Perceptions of Why Terminally Ill Patients Cared for in the Past Three Months Were Not Referred for Hospice Care or Told They Were Dying

Variable	n	$\bar{X}$	SD	Agree or Strongly Agree (n)	Identified as a Barrier (n)[a]
Reason for no hospice referral					
Unwillingness of patients or patients' family to accept	28	2.4	1	16	11
Sudden death of the patient or sudden change in patient status	28	2.8	1.2	11	8
Physician hesitance to discuss hospice care	27	2.7	1.3	10	8
Nurse discomfort in discussing hospice care	28	4.6	0.8	8	6
Nurse desire to maintain hope among patients and patients' families	28	4	1.1	9	4
Reason for terminally ill patients not being told they were dying					
Unwillingness of patients or the patients' family to accept a prognosis	27	1.9	1	19	11
Sudden death of the patient or sudden change in patient status	27	2.6	1.2	10	8
Physician hesitance to discuss prognosis	27	2.6	1.4	11	5
Nurse discomfort in discussing prognosis	27	3.9	1.3	4	2
Nurse desire to maintain hope among patients and patients' families	26	3.3	1.5	6	1

N = 31

[a] Based on information from Schulman-Green et al., 2005.

Note. Scores ranged from 1 (strongly agree) to 5 (strongly disagree).

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of discussions with patients, whereas disagreeing that hospice meets family needs better than conventional care was associated with higher numbers of discussions with families. A substantial correlation was found with work setting and the palliative care index with nurses in inpatient setting doing more of the palliative care activities. The palliative care index also was associated significantly with years worked as a nurse, hospice training, nurse comfort with discussing prognosis, and the following beliefs: discussing prognosis is essential, nurses should be well-trained in terminal care, and the use of hospice would decrease support for physician-assisted suicide.

Table 5. Attitudes About Hospice Care From Current Study Sample Compared With Attitudes From Medical-Surgical Nurses

Variable	N	$\bar{X}$	SD	Current Sample Agree (%)	Medical-Surgical Agree (%)
Self-Rated Knowledge					
I feel knowledgeable enough to discuss hospice care with patients and families.	31	2.3	1.3	62	30
I am well trained to care for terminally ill patients.	31	2.5	1.3	61	32
Comfort With Initiating Hospice Discussion					
I think it is essential for a dying patient to be told of his or her prognosis.	30	1.4	0.6	90	81
Talking with patients and families about dying is difficult for me.	30	3.5	1.2	23	44
I never raise hospice as an option unless the physician has discussed it already with the patient or family and primary caregiver.	30	3.2	1.4	26	28
Added Benefit of Hospice					
Many patients would benefit if hospice care were initiated earlier in the course of their illness.	31	1.6	0.8	90	72
In my experience, physicians usually order enough pain medication for terminally ill patients.	31	3	1.3	38	26
Hospice care generally meets the needs of the family better than conventional care does.	31	2	1.2	71	81
Most patients' symptoms, such as pain, shortness of breath, and nausea are not controlled any better with hospice care than with conventional care.	31	4.5	0.8	3	12
Perceived Physician Comfort and Responsibility					
Most physicians believe they do not have a role in hospice care.	31	3	0.9	26	32
When physicians first discuss the possibility of hospice, patients and families often lose hope.	31	2.9	1	29	53
Talking with patients and families about dying is difficult for most physicians.	30	2	1.1	74	70
Usually, physicians are reluctant to tell a patient directly that he or she is dying.	30	2	0.9	71	–
Patient Perceptions of Care and Prognosis					
Most older adult patients want their doctors to determine what care is best for them.	30	2	1.1	69	–
Most patients know they are dying before the physician tells them.	30	2.6	1.2	52	–
Results of Palliative or Hospice Care					
Many terminally ill patients who should receive hospice care *do not* receive hospice care.	30	2	1	71	–
More widespread use of hospice would lessen support for physician-assisted suicide.	30	2.2	1.1	60	–
An interdisciplinary team approach can interfere with patient care.	31	4.5	0.8	3	–
Hospice supports physician-assisted suicide.	31	4.9	0.3	–	–
Facilitation of End-of-Life Care for Nurses					
I would like to work more closely with the palliative care team.	31	1.7	0.8	81	–
Physician and Nurse Turf Issues					
Physicians often disagree with the recommendations made by home hospice nurses.	31	3.9	0.9	7	–

Note. Scores ranged from 1 (strongly agree) to 5 (strongly disagree).

Note. From "Nurses' Attitudes and Practice Related to Hospice Care," by L.D. Cramer, R. McCorkle, E. Cherlin, R. Johnson-Hurzeler, and E.H. Bradley, 2003, *Journal of Nursing Scholarship, 35,* p. 252. Copyright 2003 by John Wiley and Sons, Ltd. Adapted with permission.

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Discussion

Despite having fairly positive attitudes toward hospice and having discussions about prognosis with terminally ill patients, nurses in the sample reported missed opportunities for discussions and patient referrals to hospice. On average, nurses cared for more than seven terminally ill patients during a three-month period, while only discussing hospice care with a third of these patients and their family members. The majority of the sample acknowledged that patients would benefit from the earlier initiation of hospice care. Missed opportunities may reflect nurses' attitudes, such as the following: difficulty talking with patients and families about dying for physicians (74% of the sample agree) or nurses (23% agree), never raising hospice as an option without prior physician discussion (26%), the perception that discussing the possibility of hospice leads to the loss of hope (29%), and the notion that older adult patients want their doctors to determine the best care plan (69%).

Despite the missed opportunities, nurses in the current study reported having more communication with patients and families about EOL issues than did medical-surgical nurses in Bradley, Cherlin, et al. (2001). In that study, 52% of nurses had never discussed hospice with their terminally ill patients and 36% never discussed hospice care with family members. In the current study, 29% of nurses had never discussed hospice care with patients and 19% never discussed hospice with family or primary caregivers.

Nurses in the current study reported that hospice care discussions were typically initiated following joint decisions with other members of the healthcare team or by the nurse or the oncologist. They reported that the final decision for receipt of hospice care usually came from the patient, family member, or joint patient and family discussion, which the authors deemed highly appropriate. Barriers to hospice referrals and obstacles to not discussing prognosis in the sample paralleled those found by Schulman-Green et al. (2005). More nurses in the current study agreed that specific barriers led to the lack of hospice referrals. The reason for the differences may be because of actual nurse perceptions or may result from the questions in the current study having fixed responses, whereas the Schulman-Green et al. (2005) results came from open-ended responses. In both samples, nurses were likely to agree that the lack of patient or family member acceptance was the most important barrier. As Schulman-Green et al. (2005) stated, "This issue is complex because if the nurses' perceptions were correct, then perhaps not having a discussion was best" (p. 67). However, if these were misperceptions, then patients and family members are unable to choose hospice care. The negative impact of late referrals to appropriate care has been recognized by multidisciplinary healthcare providers (Melvin & Oldham, 2009). Nurses must be careful to assess accurately the willingness of patient and family members to accept hospice care or a terminal prognosis. This may require direct questioning.

Table 6. Palliative Care Practices Used With Terminally Ill Patients in the Last Three Months by Oncology Nurses Compared to Use by Medical-Surgical Nurses

Practice	$\bar{X}$	SD	Current Sample Usage (%)[a]	Medical-Surgical Usage (%)[b]
Active and passive listening	1.8	0.9	93	86
Requesting increased doses of pain medication to ensure patients are pain free	1.9	0.9	93	82
Supportive counseling	2.1	0.9	93	54
Therapeutic touch	2.2	1.1	76	39
Administration of medication to relieve suffering, knowing it might shorten the patient's life	2.4	1.1	72	64
Other relaxation techniques	2.8	0.8	86	32
Warm and cold compresses	2.9	0.9	76	35
Guided imagery	3.4	0.6	55	8
Aromatherapy	3.9	0.4	10	–
Palliative care total	2.6	0.5	2	1

[a] N = 29

[b] Based on information from Bradley, Cherlin, et al., 2001 (N = 174).

Note. Scores ranged from 1 (all of the time) to 4 (none of the time).

Only 3% of nurses in the current study reported discomfort in discussing hospice care in contrast to 21% in Schulman-Green et al. (2005). On average, the current study's experienced oncology nurses cared for a similar number of terminally ill patients as the medical-surgical nurses, but were more likely (63% versus 36%) to have had training in hospice within five years (Bradley, Cherlin, et al., 2001). The high comfort level suggests that additional interventions with nurses may enhance future communication.

Barriers and obstacles to EOL discussion found by other researchers since the implementation of the current study indicate the opportunity for additional evaluation. In a study of randomly selected inpatient nurse members of the Oncology Nursing Society, Beckstrand et al. (2009) reported that 8 of the top 10 obstacles to providing EOL care to patients with cancer were family related; some of these included anger, not accepting prognosis, anxiety, over-optimism, not wanting patients to be oversedated, and intra-family fighting. The 9th- and 10th-ranked obstacles were difficult-to-control

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Table 7. Correlations of Characteristics and Attitudes and Palliative Care Practices and Hospice Discussions

Variable	Hospice Discussions With Patients	Hospice Discussions With Family or Caregivers	Palliative Care Index
Work setting (inpatient or other)	–0.23	–0.09	0.64*
Number of terminally ill patients cared for in the past three months	0.37*	0.39*	–0.09
Years working as a nurse	–0.4*	–0.38*	0.4*
Having had additional training about hospice in past five years	–0.17	–0.04	0.45*
Nurses' discomfort discussing prognosis	0.21	0.14	–0.46*
Difficulty for physicians to talk about dying	0.4*	0.19	–0.03
Essential to tell dying patient of his or her prognosis	–0.08	–0.11	0.38*
Hospice meets needs of families better than conventional care.	0.29	0.48*	–0.18
Nurses are well trained to care for terminally ill patients.	–0.18	–0.29	0.43*
Widespread use of hospice would decrease support for physician-assisted suicide.	–0.1	–0.06	0.4*

* $p < 0.05$

Note. Reported correlations for discrete variables (e.g., work setting) are Spearman correlations; for those using Likert-type responses (e.g., all attitudes), Pearson correlations are reported.

pain (patient-related) and physician reluctance to refer patients to hospice or palliative care (physician-related). The current study did not specifically address the same family- or patient-related barriers to EOL care, but 38% of the sample reported physician reluctance to refer patients to hospice or palliative care. Future researchers may want to investigate some of the obstacles found by Beckstrand et al. (2009), particularly those related to families.

Barriers to timely referrals of patients to palliative care were identified in a phenomenologic study of Australian providers, including five nurse participants (Melvin & Oldham, 2009). These barriers included (a) lack of knowledge by general medical practitioners, (b) provider thinking that referral to palliative care means giving up on the patient, (c) physician fear of losing control of the patient, and (d) fear of failing the patient if life-sustaining treatments were not used. The perception that palliative care meant "giving up" on the patient also was found in nurse specialists in the United Kingdom who participated in a qualitative study exploring challenges faced in delivering EOL care in the acute setting (Willard & Luker, 2006). All of these barriers were found among oncology nurses in the current study and should continue to be addressed in future studies.

The administration of palliative care nursing practices is related to caring for terminally ill patients. When asked how often they use nine palliative care practices, most oncology nurses in the current study (72%–93%) reported using seven specific practices in the past three months with all, most, or a few of their terminally ill patients. They were more likely to use these practices than were inpatient medical-surgical nurses (Bradley, Cherlin, et al., 2001). Bradley, Cherlin, et al. (2001) found that nurses who were more recently trained, had previous hospice training, and had more hospice knowledge used palliative care practices more frequently than others. In the current study, inpatient nurses, those with more experience, and those with recent hospice training used a greater number of practices. The authors also found that attitudes affected use of these practices. Increased use occurred in nurses with less discomfort discussing prognosis and those who believed it essential to discuss prognosis and believed nurses to be well trained in caring for terminally ill patients.

The authors' findings regarding the frequency of use of palliative care practices indicate that oncology nurses integrate these practices into patient care. However, the fact that fewer nurses used guided imagery and, particularly, aromatherapy suggests that additional integration of these practices into care of terminally ill patients may be possible. The authors have started working on an evidence-based practice initiative to explore use of aromatherapy with oncology inpatients. The first step was to determine evidence support for specific essential oils; administration issues such as dose, timing and frequency; and symptoms to be targeted. The authors then created a policy and are piloting this on their institution's inpatient unit as this article goes to press. The authors are conducting both a patient and nurse evaluation to determine which symptoms are most affected and how feasible use of aromatherapy is to nurses.

Missed discussion opportunities point to the need for enhanced nurse involvement with EOL discussions. Beckstrand et al. (2009) reported ways in which nurses suggested supporting these discussions (see Table 8). Two strategies include role modeling by experienced nurses and providing support to other nurses when good care is given. Both of these are low risk and should be implemented when possible. Other potential interventions to enhance communication between patients and family members and nurses include use of a question prompt list (Clayton et al., 2007), specific

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nursing education programs such as those offered by the End-of-Life Nursing Education Consortium (ELNEC) that stimulate interest in palliative care and subsequent training (Coyne et al., 2007), and making available relevant journals. In fact, a prompting tool for EOL discussions is being used throughout the authors' institution. Nurses also participated in an all-day onsite conference focusing on palliative care and EOL issues.

Some experts consider using triggers to initiate discussions of limited prognosis and consideration of hospice for patients with cancer (Casarett & Quill, 2007; Twaddle et al., 2007). Triggers may include performance status indicators or signs and symptoms such as liver metastasis or carcinomatous meningitis. Casarett and Quill (2007) urged discussions of hospice that include an assessment of patient understanding of prognosis, patient goals for care, and needs for care (e.g., financial, spiritual), followed by a discussion of "the facts." This would include an introduction of hospice as an option. Although the physician determines whether hospice is appropriate, the nurse—as part of the team—would base discussions on patient goals and prognosis and assist patients and family members to prepare for discussions with physicians. This would prevent the barrier noted by several nurses that they were unaware of patients' plans of care.

New evidence-based guidelines for clinician-patient communication focus on the approach for discussing disease progression (Rodin et al., 2009). The authors of the guidelines stress empathetic listening and creating an optimal environment for openness where patients and families consider themselves free to talk. These methods promote the hope-maintaining potential of EOL discussions. Other suggestions for enhancing referrals to palliative or hospice care include an interdisciplinary approach (Melvin & Oldham, 2009), such as having a palliative care nurse present during initial discussion of prognosis or disease progression. Staff members in the inpatient oncology unit are currently investigating the use of a mandatory consent for treatment that involves queries related to goals of therapy and prognosis; this process is based on standards related to chemotherapy planning (Jacobson et al., 2009). Having these queries built into documentation may open doors for conversations (i.e., if goals for a given patient were palliative, nurses may feel more comfortable initiating discussions about hospice or EOL issues).

Table 8. Strategies That May Enhance End-of-Life Discussions With Patients and Family Members

Group	Strategy
Family	Enhancing family member acceptance of prognosis Establishing rapport by supportive staff before the active dying process Assigning one family member for contact purposes Teaching families at the bedside Allowing time to educate families about the dying process Adequate time for families to spend with patients after death
Multidisciplinary	Social work and palliative care as part of team
Physicians	Agreement about direction of care
Nurses	Role modeling by experienced nurses Support from other nurses as to good care given

Note. From "Oncology Nurses' Perceptions of Obstacles and Supportive Behaviors at the End of Life," by R.L. Beckstrand, J. Moore, L. Callister, and A.E. Bond, 2009, *Oncology Nursing Forum, 36,* p. 451. Copyright 2009 by the Oncology Nursing Society. Adapted with permission.

Limitations

This study involved a small number of experienced oncology nurses from one hospital in southern California. Their opinions may differ from less experienced colleagues. Findings were obtained using self-report with no validation of actual nurse behaviors. Nurses were not asked about communication or behaviors related to palliative care services, which differ from hospice services. The results of this study, which sampled West Coast oncology nurses, may not be truly comparable to results found with East Coast medical-surgical nurses (i.e., those in Bradley, Cherlin, et al. [2001]); however, given study similarities, the comparisons may assist others in hypothesis generation about why similarities and differences were found.

Conclusions

Oncology nurses must respect the perceptions of seriously ill patients and their family members who consider the most important elements of quality EOL care to be trust in the treating physician, the avoidance of unwanted life support, effective communication, continuity of care, and the ability to prepare for the remainder of patients' lives (Heyland et al., 2006). Missed opportunities for EOL discussions with patients and families should be diminished so that care decisions can be based on better evidence and that care outcomes can be improved. Strategies should be developed to enable nurses to have a stronger voice during this critical time for their patients. Effective strategies then would promote EOL discussions promoted by nurses that may lead to appropriate but less aggressive care.

Implications for Nursing Practice

The authors' findings direct thinking for future research, education, and practice strategies. Additional

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research is needed in this area, with larger samples of oncology and medical-surgical nurses to determine whether findings from this "snapshot" of nurse perceptions are generalizable to larger groups of nurses. Qualitative work is needed to address research questions in at least two areas: (a) patient and family perceptions of communications with nurses related to the EOL, and (b) RN barriers to discussions and palliative care that may be gender or culture related.

Education implications include the need to develop programs to improve the capacity of nurses to deliver effective interventions to terminally ill patients with cancer. Programs like ELNEC are invaluable, but not all nurses are able to attend and organization-specific programs also may be needed. These may take the form of moderated discussions based on particular cases that can engender thoughtful discussions and reflection around topics such as initiation of hospice care discussions and palliative care practice strategies. Another untested education strategy is to have experienced nurses role model effective EOL discussions in front of other nurses who would then "try out" new techniques. This could be done in an educational context to enhance learner confidence.

Practice implications include development of evidence-based policies and procedures related to discussions and practices (e.g., aromatherapy, guided imagery) followed by implementation of practice changes. These policies may need to be preceded by obtaining resources and offering staff education. Interventions related to top barriers to discussions with patients and families should be developed and tested. For example, how can nurses intervene with patients or families who are unwilling to accept a terminal prognosis? Organizational practices that may enhance discussions related to EOL are those previously mentioned, such as question prompt lists (Clayton et al., 2007) and documentation of treatment goals (Jacobson et al., 2009). These may decrease patient reticence to take part in conversations and enhance nurse likelihood of initiated discussions.

Denise Boyd, RN, BSN, OCN®, is a staff nurse IV and Kristen Merkh, RN, BSN, OCN®, is a clinical coordinator, both at St. Joseph Hospital in Orange, CA; Dana N. Rutledge, RN, PhD, is a nursing research facilitator at St. Joseph Hospital and a professor in the School of Nursing at California State University in Fullerton; and Victoria Randall, RN, MFA, was a student in the School of Nursing at California State University in Fullerton at the time this article was written. No financial relationships to disclose. Rutledge can be reached at dana.rutledge@stjoe.org, with copy to editor at ONFEditor@ons.org. (Submitted May 2010. Accepted for publication July 28, 2010.)

Digital Object Identifier: 10.1188/11.ONF.E229-E239

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