Nurses' Identification of Important yet Under-Utilized End-of-Life Care Skills for Patients with Life-Limiting or Terminal Illnesses

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Abstract

Rationale: This study was designed to identify nurses' perspectives on nursing skills that are important yet under-utilized in end-of-life care.

Methods: A 45-item survey was administered to nurses (n = 717) in four U.S. states with a response rate of 79%. We identified skills that were endorsed by more than 60% of nurses as extremely important and also endorsed as not currently practiced by more than 25% of nurses. We used Chi square statistics to examine professional characteristics associated with ratings of end-of-life care skills including practice settings, years of experience, and end-of-life care education. Content analysis was used to examine nurses' responses to open-ended questions.

Results: Nineteen items were endorsed as extremely important and also ranked as under-utilized. These end-of-life care skills included communication skills, symptom management competencies especially those concerning anxiety and depression, and issues related to patient-centered care systems. Four complementary themes emerged from qualitative analysis of nurses' comments, which supported the quantitative findings.

Conclusions: This study provides a summary of skills nurses feel are important and under-utilized in their care of patients with life-limiting illnesses. The findings support the need to target both nursing education and healthcare system interventions to improve the use of practical end-of-life care skills by nurses with a focus on communication and symptom management skills.

Introduction

IMPROVING QUALITY END-OF-LIFE care has become a major goal of the healthcare community.¹ The Institute of Medicine (IOM) defines a good death as one that is free of avoidable distress and suffering, in general accord with one's wishes, and is consistent with clinical and cultural standards.² However, the translation of these definitions of a good death into quality end-of-life care remains a challenge. Despite concentrated efforts over the past decade to define and improve end-of-life care, recent reports note that many important gaps remain.³⁻⁵

Compared with other health care providers, nurses often have the most contact with patients and their families at the end of life.⁶ Thus, it is important for nurses to be skilled in end-of-life care. Major efforts have been made to enrich nursing

curricula in the area of end-of-life care such as the End-of-Life Nursing Education Consortium, American Association of Colleges of Nursing End-of-Life Competencies for Undergraduate Nursing Curriculum, and the Toolkit for Nurturing Excellence at End-of-Life Transition.⁷⁻⁹ These programs have developed standard, comprehensive curricula that address skills likely to be needed in end-of-life nursing, including physical, emotional, social, and spiritual domains. However, they have not been explicitly designed to target known gaps in nurses' knowledge or skills and cannot fully address barriers to implementing nurses' skills in practice setting.

Although prior studies in intensive care settings have assessed nurses' perspectives of barriers to optimal end-of-life care as well as their views on the prevalence and cause of conflict both among the critical care team and with the patient's family,^{10,11} no prior studies have examined the

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Accepted January 28, 2010.

specific end-of-life care skills that practicing nurses consider important but do not routinely practice. Thus, the goal of this study was to explore nurses' perspectives on nursing skills that they believe are extremely important to providing quality end-of-life care, but which they report are currently under-utilized by nurses. The identification of valued but under-utilized end-of-life skills could guide the development of interventions to improve and expand the role of nurses caring for dying patients and their family members through targeted educational programs or through interventions to reduce barriers to implementation of these skills. Our research questions were: 1) what skills do practicing nurses identify as extremely important but under-utilized in providing end-of-life care for patients and 2) do nurses' ratings on important but under-utilized skills vary based on professional characteristics including practice setting, end-of-life care training, and years in practice?

Methods

Study design

Data for this study were part of a survey study measuring physician skills at providing end-of-life care^[12]. Participating physicians were recruited from four states: Washington, Oregon, North Carolina and South Carolina. Physicians were drawn from four medical specialties (general internal medicine, oncology, pulmonology, cardiology) and were randomly selected using the following strata: specialty, region, gender, minority status, and urban/rural location. Physicians identified patients with life-limiting illnesses, their families and nurses who worked with the study physicians to receive questionnaires about physicians' skills. Identified nurses received an additional questionnaire, "Nurse Role in End-of-Life Care Questionnaire." Respondents were asked to identify specific nursing skills for end-of-life care not currently being practiced and to rate the importance of these skills to high quality care. Nurses were also able to provide open-ended responses. (The survey is available at <http://depts.washington.edu/eolcare>.)

Measures

Nurse role in end-of-life care questionnaire. This questionnaire was developed from the "Quality of End-of-life Care Questionnaire" (QEOLC). The QEOLC survey was designed for patients, families and nurses to measure physician skill at end-of-life care.¹² It was developed using focus groups that included patients with HIV/AIDS, cancer, or COPD; families of patients who had died; and nurses and physicians providing palliative care.^{13,14}

Using the qualitative methods of grounded theory, 54 items were developed and categorized into five domains: a) communication skills; b) technical skills; c) affective skills; d) patient-centered values; and e) patient-centered care systems.¹³ Two nurse investigators with expertise in end-of-life care reviewed the QEOLC items to determine which items could be translated to nursing skills and which items were not transferable. Forty-five items were retained to be used with nurses in the current study.

Nurse respondents were asked to rate the importance of each end-of-life care skill on a scale from 1 (not at all important) to 5 (extremely important). If the skill was already

practiced they were instructed to mark "already practiced" and no importance ratings were provided. Survey instructions explained that identification of important end-of-life skills that were not already practiced might provide ideal targets for future nursing interventions designed to improve end-of-life care. Respondents were invited to provide comments about end-of-life care skills using open-ended questions, providing complementary qualitative data. In order to describe the sample and test associations between skills and nursing characteristics, the following professional characteristics were measured: age, gender, race/ethnicity, practice setting, nursing educational preparation, specialization certification, years of nursing experience, and end-of-life care training. The Institutional Review Boards at the University of Washington and the Medical University of South Carolina approved all study procedures.

Data collection and recruitment

Data were collected between October 2002 and November 2005 using two approaches: 1) if physicians provided nurses' names and addresses, we contacted the nurses by mail; 2) if physicians referred us to organizations (e.g., hospitals, long-term care facilities, hospices), study staff contacted site managers who either provided names and addresses for a mailed approach or distributed surveys themselves. After four weeks, non-respondents received reminder postcards. At some sites, surveys were completed anonymously and thank-you/reminder postcards were distributed by managers. All surveys, whether mailed by study staff or distributed by site managers, were self-report and returned by mail.

Analyses

We initially examined the response distributions for the "already practiced" and "not at all important" endorsements with the *a priori* goal of identifying a reduced set of approximately 20) skills that could be targeted for improvement. These distributions suggested that items identified by 25% or less of the sample as "already practiced" were considered under-utilized end-of-life skills. Those items that were endorsed by 60% or more of the sample as "extremely important" (rated as a 5) were defined as "important skills." Items meeting both criteria were retained for further analyses.

Qualitative data were analyzed using traditional content analysis methods.^{15,16} Concepts were collated and organized into a coding scheme. To assess trustworthiness of the analysis, a team member (DD) blinded to the study results re-coded the random sample of comments ($n = 30$, 13%). Results of the re-coding exercise yielded 100% agreement.

We analyzed the association between nurses' professional characteristics and their identification of important but under-utilized skills. Practice settings were categorized as hospice or home care, hospital, or out-patient. Continuing education in end-of-life care since graduation was collected from the nurse surveys in the following three categories determined *a priori*: a) none; b) less than 6 hours; and c) 6 hours or greater. Number of years in nursing practice was analyzed in four categories determined by the sample's distribution into quartiles: 1) 0–12 years; 2) 13–18 years; 3) 19–27 years; and 28–54 years. Chi square statistics (e.g. Pearson statistics for nominal variables, Kendal Tau-C for ordered variables) were used with a *p* value

of 0.05 without correction for multiple comparisons reflecting the exploratory nature of this analysis.

Results

Sample

A total of 885 surveys were obtained from 976 nurses, for a response rate of 91%. Most subjects were Registered Nurses (81%, 717/885) but the sample also included some licensed practical nurses and nurses' aides (19%, 168/885). For the purpose of our research questions, only surveys completed by Registered Nurses were included in the analysis. The majority of respondents were female and white (Table 1). Approximately 80% of respondents held associate or baccalaureate degrees and 50% had advanced sub-specialty certifications. Three quarters of respondents worked in hospital settings and 50% had been practicing for more than 19 years.

Extremely important but currently under-utilized nursing skills for end-of-life care

Nineteen items were ranked as extremely important to providing quality end-of-life care by more than 60% of the sample and endorsed as already practiced by fewer than 25% of the sample (Table 2). These 19 items included each of the five domains of the survey with most from the *communication skills* and *patient-centered care systems* domains. Eight items from the *communication skills* domain and five items from the *patient-centered care systems* domain met criteria. By contrast, items that nurses assessed as *already practiced* included basic communication and nursing skills. Some examples of these

skills were listening to patients, being responsive to emotional needs, treating the whole person and respecting patients' cultural and religious beliefs.

Open-ended comments about nursing skills for end-of-life care

Comments were provided on 90% (647/717) of surveys. Of these, 35% (229/647) were specifically about end-of-life care skills. The remaining comments addressed issues related to working relationships with physicians or specific end-of-life courses taken. Four categories emerged from the content analysis of the 229 eligible comments and are presented in descending order of frequency: 1) communication skills; 2) interdisciplinary coordination; 3) system barriers; and 4) symptom management and treatment.

The most common theme was the need for increased knowledge and practical experiences for nurses in order to improve end-of-life communication skills. A nurse talked about this need stating:

"Nursing schools and workplace orientations do not focus on communication skills enough. This results in nurses feeling uncomfortable talking about death, thus avoiding it."

The second most common theme identified challenges associated with coordination of services, interdisciplinary communication and delineation of health professionals' roles. One nurse expressed concern about the lack of interdisciplinary communication and undefined role responsibilities:

"Nurses need to know what the patient and family has been told. Do they [patients] know they are dying? Who will tell them? What should we [nurses] do or what are we allowed to say?"

TABLE 1. CHARACTERISTICS OF NURSE SURVEY RESPONDENTS (N = 717)

Characteristics		n	(%)
Sites	Pacific Northwest	519	(72.4)
	Southeast	198	(27.6)
Characteristics	Female	659	(91.9)
	White	657	(91.6)
	Age ($M = 50$, $SD = 9.4$)		
Education Levels $\pm$	Associate Degree	315	(43.3)
	Bachelors Degree	271	(37.3)
	Diploma	77	(10.6)
	Masters or Nurse Practitioner	44	(6.1)
Advanced Certification $\pm\pm$	None	244	(34.0)
	Oncology/Palliative Care	130	(18.2)
	Critical Care/Emergency	135	(18.9)
	Other (Nurse Practitioner or Medical-Surgical Nurse)	93	(13.0)
End-of-Life Continuing Education $\pm\pm\pm$	None	109	(15.2)
	Continuing Education <6 hrs	154	(21.5)
	Continuing Education >6 hrs (i.e.ELNEC)	405	(56.5)
Practice Settings $\pm$	Hospice (in-patient, outpatient and home care)	96	(13.2)
	Hospital	516	(72.0)
	Out-patient (clinic or private practice)	95	(13.4)
No. of years in practice $\pm\pm\pm\pm$	≤ 12	180	(25.5)
	13 - ≤ 18	160	(22.3)
	19 - ≤ 27	186	(25.9)
	≥ 28	179	(25.0)

$\pm$ 10 missing values.

$\pm\pm$ 115 missing values.

$\pm\pm\pm$ 49 missing values.

$\pm\pm\pm\pm$ 12 missing values.

TABLE 2. ITEMS WITH ENDORSEMENTS >60% AS "EXTREMELY IMPORTANT" AND ≤25% AS "ALREADY PRACTICED" (N=717)

<i>Skill</i>	<i>n</i>	<i>% extremely important</i>	<i>n</i>	<i>% already practiced</i>
Communication skills				
1. Telling patients how their illness may affect their life	474	66.2%	124	17.1%
2. Giving enough information so that patients understand their illness and treatment	477	66.6%	158	21.7%
3. Talking with patients about what their dying may be like	497	69.2%	54	14.2%
4. Helping family understand what the dying process might be like	499	69.2%	101	14.2%
5. Talking with patients in an honest and straightforward way	506	70.6%	170	23.4%
6. Giving bad news in a sensitive way	516	71.8%	159	22.1%
7. Being willing to talk about dying	542	75.2%	115	16.1%
8. Being sensitive to when patients are ready to talk about death	543	75.2%	120	16.5%
Technical skills				
1. Acknowledging and treating anxiety and depression	505	71.0%	108	14.9%
2. Knowledgeable about care patients need during the dying process	520	72.4%	149	20.6%
3. Helping patients and families understand how to provide symptom and pain control	524	73.0%	146	20.2%
Affective skills				
1. Considering patients' social situations when making treatment plans	438	61.2%	168	23.1%
Patient-centered values				
1. Not blaming or judgmental about lifestyles	452	62.7%	157	22.0%
2. Being comfortable with people who are dying	455	63.3%	179	24.9%
Patient-centered care systems				
1. Avoiding keeping patients waiting without explanation	440	61.3%	131	18.2%
2. Minimizing interruptions and focusing on the patient during care	459	64.0%	129	17.1%
3. Making patients feel confident that they will not be abandoned prior to death	494	68.9%	167	23.1%
4. Helping patient and families get consistent information from healthcare team	498	69.0%	126	17.6%
5. Taking as much time as needed with patients	503	69.7%	97	13.6%

The third theme concerned system barriers that prevented nurses from implementing quality end-of-life care, such as inadequate staffing or time to devote to dying patients and families. One nurse described threats to quality end-of-life care when the health care system is overburdened and there are not enough nurses to meet patients' needs:

"All these skills should be practiced if nurse-patient ratios are kept to a reasonable number. If that ratio [is poor], the adequacy of the end-of-life care suffers."

Finally, nurses identified a need for knowledge to help with the assessment and treatment of anxiety and depression as these are challenging symptoms afflicting patients with life-limiting illnesses. One nurse stated:

"Without acknowledging and treating anxiety and depression, a patient can be incapacitated from dealing with intimate end-of-life issues."

Survey respondents' comments reinforced their quantitative responses on the closed-ended survey items. The domains were similar and included communication skills, symptom management, and systems for patient-centered care.

Associations between important but under-utilized skills and professional characteristics

Nurses' professional characteristics were significantly associated with importance ratings on eight under-utilized end-of-life care skills (Table 3.) First, setting was associated with three skills. As compared with nurses working in hospice or hospital settings, nurses working in outpatient settings were more likely to endorse the following two items: "telling pa-

tients how their illness may affect their life" and "considering patients' social situations when making treatments plans." As compared with nurses working in hospital or outpatient settings, hospice nurses were more likely to endorse as the item, "not blaming or being judgmental about lifestyles." Second, nurses with the highest number of years of professional experience were significantly more likely to report "being comfortable with dying patients" as an important but under-utilized skill. Finally, nurses with fewer hours of continuing education in end-of-life care were less likely to endorse the following four skills: "being comfortable with people who are dying", "making patients feel they will not be abandoned prior to death", "not blaming or being judgmental about lifestyles", and "being willing to talk about dying."

Discussion

The findings from this study suggest that a number of skills that nurses' view as extremely important for quality end-of-life care are absent from their everyday practice. Hence, a major finding of this study is that experienced nurses have identified unmet end-of-life care educational needs and health care systems deficits that prevent delivery of optimal end-of-life care. The majority of the skills identified as extremely important to quality end-of-life care yet currently under-utilized could serve as a template to develop targeted curricula. These targeted curricula could be taught to practicing nurses within the context of the setting and the patient population they serve.¹⁷ For example, nurses practicing in outpatient settings were more likely to rate "telling patients how

TABLE 3. DIFFERENCES IN "EXTREMELY IMPORTANT" ENDORSEMENTS ON UNDER-UTILIZED SKILLS BY PROFESSIONAL CHARACTERISTICS

Item	Setting				p*
	Hospital (n = 516)	Outpatient (n = 95)	Hospice (n = 96)		
1. Telling patients how their illness may affect their life	80.9%	88.4%	71.4%		0.02
2. Considering patients' social situations when making treatment plans	77.9%	90.3%	86.5%		0.02
3. Not blaming or judgmental about lifestyles	79.5%	82.1%	91.0%		0.05
Experience					
	≤12 years (n = 180)	13–18 years (n = 160)	19–27 years (n = 186)	28–54 years (n = 179)	p**
1. Being comfortable with people who are dying	82.7%	83.7%	78.9%	94.5%	0.007
Training					
	None (n = 109)	<6 hours (n = 154)	>6 hours (n = 405)		p**
1. Being willing to talk about dying	87.4%	86.9%	93.2%		0.02
2. Not blaming or judgmental about lifestyles	73.8%	77.2%	84.5%		0.01
3. Being comfortable with people who are dying	74.1%	83.5%	88.6%		0.004
4. Making patients feel confident they will not be abandoned prior to death	81.6%	89.5%	93.6%		0.004

*p based on pearson chisquare.

**p based on kendall's tau-c chisquare.

their illness may impact their life" as an extremely important and under-utilized skill. An appropriate intervention may assist nurses working in out-patient settings to address aspects of care that allow patients to preserve their quality of life. In addition to identifying educational needs, these findings emphasize that quality end-of-life care could not be adequately delivered without improvements in the systems in which they provide care for dying patients. Together, these findings highlight some of the reasons for under-utilization of specific end-of-life care nursing skills and provide direction for practical solutions to improve care for dying patients and their families.

A second finding supported nurses' expressed need for skills to enable more effective end-of-life communication.^{13,18,19} Nurses in our study identified eight specific communication items as important but under-utilized in end-of-life care. Their qualitative comments on the survey similarly emphasized communication skills as important but under-utilized. Other studies on end-of-life care have identified communication as a key element to providing quality care.²⁰ When nurses in acute care settings were asked about initiating or conducting discussions about hospice or prognosis, more than half (52%) of the nurses reported that they did not discuss hospice and 27% reported that they did not discuss prognosis with any of their terminally ill patients.²¹ While these findings suggest nurses view patient discussions of hospice and prognosis as outside their scope of practice, other studies suggest nurses desire more involvement when these aspects of communication are necessary for advance care planning and coordination of care.^{17,22,23} Families also identify the important role nurses play in communication. In a community-based study, families reported that nurses were

more likely to have discussed symptoms and their treatment than physicians and that discussions with nurses were more understandable than those with physicians.²⁴ These data confirm the importance of nurses in the communication and coordination of care for dying patients and their family members. Our findings support the need to expand nurses' skills and to offer opportunities to participate in end-of-life communication as a way to improve the quality of end-of-life care. Targeted educational programs in combination with healthcare system changes may be needed to support nurses' roles in end-of-life care communication.²³

A third finding from our study suggests that clarity of team members' roles and interdisciplinary communication are seen by nurses as contributing importantly to quality end-of-life care, yet are lacking in actual practice. Our findings highlight the need for teams to insure that patients do not feel abandoned prior to their death and that they receive consistent information from the health care team.²⁵ Yet our findings also acknowledge the challenges faced by nurses in achieving these goals. A recent study testing the effects of a standardized framework aimed at improving communication among diverse professionals in palliative care demonstrated that nurses valued formal interdisciplinary meetings and physicians preferred informal ad hoc dialogue. The nurses explained that meeting the needs of their patients was often contingent upon receiving information from physicians and formal meetings facilitated information sharing.²⁶ Another study investigated nurses' communication of prognosis and the implications for hospice referral.²⁷ The authors concluded that improved communication among nurses, physicians, patients and family members might result in more hospice referrals. Additionally, their findings supported the need for

clarity regarding the lines of responsibility between physicians and nurses when managing discussions about prognosis and hospice. These findings highlight the need to develop interdisciplinary, formal team meetings so that physicians, nurses and other team members have the opportunity to clarify roles and responsibilities of the health care team in the delivery of end-of-life care.

The fourth main finding of our study is the identification of health care system barriers that prevent effective care for dying patients and their families. These barriers were identified in the quantitative survey under the domain of *patient-centered care systems*. Nurses endorsed the importance of minimizing interruptions and taking time with dying patients, yet identified conflicting organizational demands. The qualitative comments focused on the need to account for patient acuity levels and the time allotted to provide care for dying patients. In a study of end-of-life care for patients with chronic obstructive pulmonary disease, key barriers to referring patients to palliative care included: clinician's lack of time, increased workloads, and paucity of palliative care resources and care facilities.²⁸ While development of end-of-life care skills may facilitate more efficient delivery of care to dying persons, addressing organizational barriers presented by health care systems is simultaneously needed.

This study has a number of limitations. First, the procedure for generating the physician sample may have resulted in a unrepresentative sample. Physicians were asked to commit a significant amount of time to the study and consequently, the physician response rate was low (49%). This may select for physicians with an interest in end-of-life care. Their nurse referrals may similarly reflect this bias although, among referred nurses, the response rate was considerably higher (79%) and suggests that, at least among those referred, the group may be more representative. Despite the potential for bias, the sample was large and geographically diverse from within the U.S. Second, the "Nurse Role in End-of-life Care Questionnaire" had not been validated prior to collection of these data. However, patterns of item completion and written comments did not reveal problems with face validity. Third, the test-wise error rates on the Chi square analyses may have produced statistically significant differences by chance alone and therefore should be interpreted with caution. Finally, the data were collected between 2002 and 2005 and therefore may not represent current nursing practice in some areas. However, to our knowledge, development of end-of-life care curricula for practicing nurses targeted to these areas have not been implemented broadly and therefore most of these skills are unlikely to have been addressed.

Nurses experienced with caring for patients at the end-of-life offer an important perspective on skills and activities that need to be offered to dying patients. This study provides a summary of skills that nurses feel are extremely important but currently under-utilized by nurses caring for patients diagnosed with life-threatening illnesses. These include a focus on communication skills, symptom management, and patient-centered care systems. Our findings suggest skill and knowledge areas that are relevant and appropriate for end-of-life educational curricula and interventions designed for practicing nurses. In addition, this study identified health care system barriers that prevent effective provision of care to dying patients and their families. End-of-life care interventions need to address changes in the care delivery system and

culture in addition to improving individual nurses' skills in order to be effective. Ultimately, the development of improved end-of-life nursing skills and enhanced patient-centered healthcare systems should translate into a higher quality dying experience for patients and family members.

Acknowledgment

Funding was provided by Agency for Health Research and Quality (R01 HS11425 – 02) and an NRSA from the National Institute of Nursing Research (1F31NR010055) and Post-Doctoral Fellowship, VA Health Services R & D (TPP-61-021).

This material is the result of work supported with resources at the VA Puget Sound Health Care System, Seattle, Washington.

Author Disclosure Statement

No competing financial interests exist.

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