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## Communicating with Patients and Their Families About Palliative and End-of-Life Care: Comfort and Educational Needs of Nurses

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# Communicating with patients and their families about palliative and end-of-life care: comfort and educational needs of nurses

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**R**eview of the literature and the authors' experiences have revealed that inpatient staff nurses may not be prepared to provide optimal end-of-life (EoL) and palliative care to patients and their families (Chan and Webster, 2013; Patel et al, 2012; Prem et al, 2012; Agustinus and Chan, 2013). Palliative care patients can continue to seek curative treatments while evaluating their goals and care needs. EoL care patients are usually no longer receiving aggressive curative treatment, instead they are receiving comfort care only. In the US, the word 'hospice' is interchangeable or synonymous with EoL care. These patients usually die at home or in the intensive care unit, limiting the contact a regular staff nurse may have in providing care for them. Nurses who are skilled and comfortable in communicating with patients and families about EoL (hospice) and palliative care may improve the quality of life for these patients in the hospital setting.

Some patients will make the transition from curative-based care to hospice care during a hospital stay. Whether the transition is made smoothly and gradually, depends on the kind of communication and education patients receive from doctors, nurses, and other caregivers while in the hospital (Adams, 2005; Beck et al, 2012; van Brummen and Griffiths, 2013). Palliative care options should be provided to patients in a way that helps them understand the goals and how it differs from EoL care. However, many people opt for palliative care only when they are very close to the end of their lives (Raijmakers et al, 2011; Wilson et al, 2011).

It seems reasonable to assume that a lack of education and accompanying uneasiness among clinical nurses in discussing palliative care with patients and their families may negatively impact the transition from curative-based care to hospice care. The current research focused on the role of the nurse during the transition in patients' lives from curative to palliative care. The study aim was to determine the perceived

## Abstract

**Introduction:** Effectively discussing palliative care with patients and families requires knowledge and skill. The purpose of this study was to determine perceived needs of inpatient nurses for communicating with patients and families about palliative and end-of-life (EoL) care.

**Method:** A non-experimental design was used. In total, 60 inpatient nurses from one hospital in Idaho completed the End of Life Professional Caregiver Survey (EPCS), which examines three domains: patient and family-centered communication, cultural and ethical values, and effective care delivery. **Results:** The number of years' experience nurses had ( $F(9,131.57)=2.22$ ,  $p=0.0246$ ; Wilk's  $\Lambda=0.709$ ) and the unit they worked on ( $F(6,110)=2.49$ ,  $p=0.0269$ ; Wilk's  $\Lambda=0.775$ ) had a significant effect on their comfort discussing EoL and palliative care with patients and their families. For all three domains, years of nursing experience was positively associated with comfort in communicating about EoL care. Oncology nurses were most comfortable with regard to patient and family-centered communication. **Discussion:** The success and sustainability of this service is dependent on education for health-care providers. Studies are needed to determine the most effective ways to meet this educational challenge.

**Key words:** Palliative care ● End-of-life care ● End-of-life Professional Caregiver Survey ● Patient-centered nursing

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educational needs of inpatient staff nurses in the authors' facility when communicating with patients and families about palliative and EoL care.

## Methods

A non-experimental survey design was used to examine differences based on the age of the nurse, years of nursing experience, and the unit on which he/she worked.

## End-of-Life Professional Caregiver Survey (EPCS)

To measure educational needs among nurses with regard to communicating about palliative and EoL care and their current degree of comfort in caring for this patient population, the

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End-of-Life Professional Caregiver Survey (EPCS) was used in this study. The EPCS was distributed to a convenience sample of clinical nurses working exclusively in telemetry, oncology and critical care units (Lazenby et al, 2012). Permission to use the EPCS was granted by the survey designers. The EPCS is a 28-item, psychometrically valid scale developed to assess the palliative and EoL educational needs of professionals, and was validated in a large study encompassing doctors, nurses and social workers (Lazenby et al, 2012). For each item, a 5-point Likert-style scale was presented (range: not at all to very much). Items represent care-provider comfort and skill with a variety of situations related to palliative and EoL care (e.g. ‘I am comfortable helping families to accept a poor prognosis’). Higher scores indicate greater skill or comfort and skill. Three distinct factors were identified by Lazenby et al (2012): (1) patient and family-centered communication (PFCC), (2) cultural and ethical values (CEV), and (3) effective care delivery (ECD) (Lazenby et al (2012: 429).

### Data collection

Data were collected over a 1-month period in 2013. The survey was conducted at a 378-bed hospital in Idaho. Telemetry, oncology, and critical care units were chosen because patients on these units were most often among those transitioning from curative-based care to EoL care. The three units employed a combined clinical nursing staff of approximately 215 (telemetry unit 90, oncology 35, and critical care 90).

Recruitment emails were sent to 175 clinical nurses (identified from the 215 as having active email addresses) employed on the designated units, requesting participation in the research project. In addition, recruitment flyers were posted on the selected units to inform nurses of the project and request participation.

Both online and handwritten survey options were available, and both options were anonymous. Handwritten surveys were made available on each of the telemetry, oncology and critical care units in the hospital. An investigator-addressed envelope was attached to each paper survey for nurses to return the completed instrument through the hospital’s internal mail system to retain anonymity. The handwritten surveys were kept in a locked office and shredded after data collection was complete. The online survey was hosted by REDCap (Research Electronic Data Capture) at the University of Washington, Institute of Translational Health Sciences (<https://www.iths.org/>).

### Ethical considerations

Data collection began following approval from the hospital Institutional Review Board (IRB). Permission to distribute the survey was also acquired from individual unit managers prior to distribution.

### Data analysis and results

In total, 60 nurses participated in the survey. Based on the number of active email addresses within the three units, this reflects a 34% participation rate. Data were analysed using SAS 10.0 software. Descriptive statistics and Chi-Square were used to analyse demographic information. PFCC, DEV and ECD domain scores were calculated as described by Lazenby et al (2012). Multivariate analysis of variance (MANOVA) was used to determine overall effects of age of the nurse, unit the nurse works in, and years of nursing experience across domain scores. Duncan’s Multiple Range Test was used to conduct post-hoc comparisons to determine within-domain differences.

Sample distribution across the units was roughly even, with about 37% of respondents were from critical care units, 26% from oncology units, and 37% from telemetry units.

The majority of respondents were under 50 years of age: 41% were younger than 30 years, 43% were between 30 and 49 years, and only 16% were 50 years or older. Participant age did not differ between the hospital units included (likelihood ratio  $\chi^2(6, n=58) = 5.68, p=0.46$ ).

Most of the respondents had 2–10 years of nursing experience: 12% had less than 2 years, 33% had 2–5 years, 29% had 5–10 years, and 27% had more than 10 years’ experience. In all, years of experience did not significantly differ between work units (likelihood ratio  $\chi^2(6, n=60) = 9.98, p=0.13$ ).

MANOVA revealed that there was an overall effect of experience and unit, but no effect of age [Experience:  $F(9, 131.57) = 2.22, p=0.0246$ ; Wilk’s  $\Lambda = 0.709$ ; Unit:  $F(6, 110) = 2.49, p=0.0269$ ; Wilk’s  $\Lambda = 0.775$ ; Age:  $F(9, 126.7) = 1.19, p=0.3083$ ; Wilk’s  $\Lambda = 0.821$ ].

In contrast to the effect of years of experience on comfort level, only the PFCC domain revealed differences by unit. Oncology nurses reported significantly higher comfort levels than critical care or telemetry nurses with regard to patient and family-centered communication (see *Table 1*).

### Discussion

The transition to palliative and/or EoL care can be difficult for patients and their families. During this transition, they may have many questions as they sort through the emotional and logistical aspects

of the situation. Questions might include: What is the difference between palliative and EoL care? How does one access these services? What can one expect from them? In order to answer these questions, health-care staff must possess a basic knowledge of palliative and EoL care.

Overall, the data suggest that the nurses in this study self-report a moderate to high comfort level with their skills in the areas assessed by the EPCS, with more experienced nurses scoring higher than those with less nursing experience. Oncology nurses scored highest in all domains and significantly higher than their telemetry counterparts, on the PFCC domain. This likely reflects their greater degree of experience communicating with patients and their families about palliative and EoL care options, validating both the instrument and the nurse populations in our study.

Scores were lowest within the ECD domain, suggesting that all nurses, across patient population areas, may benefit from EoL care education in order to increase their own skill and comfort in caring for these patients. ECD items focus on familiarity with palliative and EoL care, effectiveness at helping in EoL patient situations, and resource availability (Lazenby et al, 2012). Anecdotally, several nurses reported to the study team members that they thought EoL education would benefit them in communicating with patients and their families.

### Future research

This study demonstrated that the less experienced nurses expressed some discomfort in communicating with patients at the end of life and their families. Hence, the authors suggest that further exploration of educational needs among staff nurses regarding palliative and EoL care is required. This exploration may lead to the development of educational interventions designed to increase nurses' comfort in speaking to patients and their families. Therefore future studies should focus on assessing specific educational needs of non-oncology clinical nurses. These nurses are unlikely to routinely care for EoL patients and may not understand the dilemma patients and their families face when transitioning from palliative to EoL care.

Palliative care and EoL patients are found in hospital and community settings; therefore, any educational intervention should include health providers in outpatient areas and especially in home-care services.

### Limitations

There were several limitations to this study. First, the sample was relatively small (despite repre-

**Table 1. Comfort level by unit**

Domain	Unit nurses work on	Mean comfort level ± SD (Duncan Grouping)	Number of participants
Patient and family-centered communication (PFCC)	Oncology	4.18 ± 0.50 (A)	16
	Intensive care unit (ICU)/critical care unit (CCU)	3.96 ± 0.46 (A,B)	22
	Telemetry	3.76 ± 0.70 (B)	22
Cultural and ethical values (CEV)	Oncology	3.67 ± 0.67 (A)	16
	ICU/CCU	3.69 ± 0.59 (A)	22
	Telemetry	3.32 ± 0.83 (A)	22
Effective care delivery (ECD)	Oncology	3.53 ± 0.54 (A)	16
	ICU/CCU	3.18 ± 0.64 (A)	22
	Telemetry	3.18 ± 0.77 (A)	22

Within each domain, means with the same letter are not significantly different.

**Table 2. Comfort level by years of experience**

Domain	Experience (years)	Mean comfort level ± SD (Duncan Grouping)	Number of participants
Patient and family-centered communication (PFCC)	< 2	3.42 ± 0.33 (C)	7
	2–5	3.77 ± 0.65 (B,C)	20
	5–10	4.03 ± 0.44 (A,B)	17
	>10	4.31 ± 0.48 (A)	16
Cultural and ethical values (CEV)	< 2	3.00 ± 0.60 (C)	7
	2–5	3.28 ± 0.80 (B,C)	20
	5–10	3.75 ± 0.51 (A,B)	17
	>10	3.92 ± 0.59 (A)	16
Effective care delivery (ECD)	< 2	2.79 ± 0.37 (B)	7
	2–5	3.18 ± 0.87 (A,B)	20
	5–10	3.33 ± 0.49 (A)	17
	>10	3.55 ± 0.58 (A)	16

Within each domain, means with the same letter are not significantly different.

senting one-third of nurses in the three areas of interest). While a 30% response rate seems reasonable, internal employee surveys can be much higher (EngagedMetrics, 2013; CustomInsight, 2014; Surveygizmo, 2014). However, because this was a voluntary research study of nurses, undertaken by nurses, and not an employer-initiated engagement-type survey, response rates in the 80–90% range are not reasonable or expected. Even so, the results of this study may not be generalisable and should be interpreted with caution. Another limitation to this study was the restricted population of nurses who participated (i.e. all were from one hospital).

A final limitation to this study is a small data collection flaw within the demographic portion

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of the information collected. Specifically, hand-written respondents were asked to indicate their years of nursing experience: less than 2 years, 2–5 years, 5–10 year, or >10 years. Post-hoc, the investigators became aware that those with five years of experience may have chosen 2–5 or 5–10 years. No feedback was received with regard to this issue to suggest which category individuals with 5 years of experience chose. Because the study was anonymous, there was no way to re-survey the respondents in order to ascertain the correct category for this subgroup. As Table 2 shows, the domain scores did not differ for those with 2–5 years and 5–10 years. It is possible that there may have been differences if the categories had been designed with exclusivity (e.g. 2–5, 6–10).

### Implications and conclusions

This study has important implications around the need for enhanced communication with patients and their families about palliative and EoL care, particularly among less-experienced nurses and those not working in oncology units. The transition point from curative to palliative care can be a challenging time for nurses and patients. Nurses developing skills and knowledge in this area will enable them to help patients and their families make smoother transitions. This study shows a moderate level of perceived skill, with a stronger need for additional knowledge among those nurses with less experience both in terms of years as a nurse and patient population. Understanding the best way to develop that education is an important subject for future researchers.

The authors concluded that additional education for less experienced nurses could increase comfort levels in all domains and improve care for EoL patients.

Going forward, the survey used in this study will be applied to home-health nurses to assess their level of comfort with palliative care patients on their service. Using the responses from the survey, online educational modules will be developed by an inter-professional committee to address basic palliative nursing care areas identified by survey participants as an area of educational need.

Palliative and EoL care will expand and move beyond hospitals to home-based care, long-term care and other community settings. The success and sustainability of this service will be dependent upon meaningful training of all health-care providers. Further studies will be needed to determine how best to meet this educational challenge. 

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#### Declaration of interests

The authors have no conflicts of interest to declare.

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