Published in final edited form as:

Int J Palliat Nurs. 2015 March ; 21(3): 109–112. doi:10.12968/ijpn.2015.21.3.109.

Communicating with Patients and their Families about Palliative and End of Life: Comfort and Educational Needs of Staff RNs

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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 care.

Method—A non-experimental design was utilized. Sixty inpatient nurses completed the End of Life Professional Caregiver survey.

Results—Effects for years of experience and unit were found [$F(9,131.57)=2.22$, $p=0.0246$; Wilk's $\Lambda=0.709$ and $F(6,110)=2.49$, $p=0.0269$]. For all three domains (Patient and Family-Centered Communication, Cultural and Ethical Values, and Effective Care Delivery) years of nursing experience was positively associated with comfort in communicating about end of life care. Oncology nurses reported were most comfortable with regard to patient and family-centered communication.

Discussion—The success and sustainability of this service is dependent on education for healthcare providers. Studies are needed to determine best ways to meet this educational challenge.

Keywords

Palliative Care; End of Life Care; End of Life Professional Caregiver survey; Patient-Centered Communication

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Conflicts of Interest

The authors have no conflicts of interest to report.

Introduction

Our review of the literature and our own experiences led us to postulate that inpatient staff nurses may not be prepared to provide optimal care to end of life (EOL) and palliative care patients and their families (Chan and Webster, 2011; Patel, Gorawara-Bhat, Levine, and Shega, 2012; Prem, Karvannan, Kumar et al., 2012; Agustinus, Wai Chi Chan, 2013). Palliative care patients can continue to seek curative treatments while evaluating their goals and care needs. End-of-life (EOL) care patients usually are 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 to them. Nurses skilled and comfortable in communicating with patients and families about EOL (hospice) and palliative care may improve the quality of life and patient satisfaction in the hospital setting.

Some patients transition during a hospital stay from curative-based care to hospice care. 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, Tornquist, Brostrom and Edberg, 2012; Brummen and Griffiths, 2013). Palliative care options should be provided in a way that helps patients understand its goals and how it differs from end of life care. However, many people opt for palliative care only when they are very close to the end of their lives (Rajmakers et al., 2011; Wilson, Gott and Ingleton, 2011).

It seems reasonable to think 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 educational needs of inpatient staff nurses in our facility when communicating with patients and families about palliative and EOL care.

Study Design / Methodology

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

To measure palliative and EOL educational needs among nurses (i.e., their current degree of comfort in caring for this population) the End-of-Life Professional Caregiver Survey was distributed to a convenience sample of clinical nurses working exclusively in telemetry, oncology and critical care units (EPCS; Lazenby, Ercolano, Schulman-Green and McCorkle, 2012). Permission to use the EPCS was granted by the authors. 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 Likert-style scale is presented where 1=Not at All, and 5=Very Much. Items represent care-provider comfort 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. 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). See Lazenby et al (2012) for factor loading (p.429).

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 was collected over a one month period. We had sixty participants respond.

The survey was conducted at a 378 bed hospital in the intermountain region. Telemetry, oncology, and critical care units were chosen for their patient populations; that is, patients on these units were most often among those transitioning from curative based care to end of life 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 also posted on the selected units to inform nurses of the project and request participation. Online and paper-and-pencil survey options were available. Both options were anonymous. Paper and pencil surveys were made available on each unit. An investigator-addressed envelope was attached to each paper survey for nurses to return the completed instrument through interoffice mail to retain anonymity. The paper and pencil surveys was kept in a locked office and shredded after data collection was complete. The online survey was hosted by REDCap at the University of Washington, Institute of Translational Health Sciences (<https://www.iths.org/>).

Data Analysis and Results

Sixty nurses participated. Based on the number of active email addresses within the three units, this reflects a 34% participation rate. Data were analyzed using SAS 10.0. Descriptive statistics and Chi-Square were used to analyze 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, unit, and years of nursing experience across domain scores. Duncan's Multiple Range Test was used to conduct post-hoc domain comparisons as appropriate.

Sample distribution by unit was similar, with about 37% of respondents were from Critical Care, about 26% from Oncology, and about 37% from Telemetry. The majority of respondents were under 50 years of age: 41% were younger than 30, 43% were between 30 and 49, and only 16% were 50 or above. Participant age did not differ by work unit [Likelihood Ratio χ^2 (6, $N = 58$) = 5.68, $p = .46$]. The majority of respondents had two to 10 years of nursing experience: 12% had less than two years, 33% had two to five year, 29% had five to ten years of experience, and 27% had more than 10 years. Years of experience did not differ by work unit [Likelihood Ratio χ^2 (6, $N = 60$) = 9.98, $p = .13$].

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 $\Lambda=0.821$]. Duncan's Multiple Range test revealed that for all three domains, years of nursing experience was positively associated with comfort levels; nurses with less than two years of experience had significantly lower comfort scores than those with five or more years (see Table 1). In contrast, only the PFCC domain revealed differences by unit; not surprisingly, oncology nurses reported significantly higher comfort levels than critical care or telemetry nurses with regard to patient and family-centered communication (see Table 2).

Discussion

Overall, the data suggest that the nurses in our study are relatively comfortable with their skill in the areas assessed by the EPCS. The scores were moderately high; averaging between 3 and 4 ('Somewhat' and 'Quite A Bit') for most domains with more experienced nurses scoring higher than those with less nursing experience. Not surprisingly, oncology nurses scored highest 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 end of life care options; validating of 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 end of life 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 end of life 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

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 include: what is the difference between palliative and EOL care, how does one access these services and 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. This study demonstrated that the less experienced nurses expressed some discomfort in communicating with patients and families at end of life. Hence, the authors suggest further exploration of educational needs among staff nurses regarding palliative and EOL care. 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 end of life 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 the outpatient areas and especially in home care services.

Limitations

There were several limitations to this study. First, our sample was relatively small (despite representing one-third of nurses in the three areas of interest). While a 30% response rate seems reasonable, internal employee surveys can be much higher (CustomInsight, 2014; EngagedMetrics, 2013; Surveygizmo, 2014). However, because this was a voluntary research study of nurses 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 generalizable and should be interpreted with caution. Another limitation to this study was the restricted population of nurses used (i.e., from one hospital).

A final limitation to this study is a small data collection flaw within the demographic portion of the information collected. Specifically, 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 five years chose. Because the study was anonymous, there was no way to resurvey the respondents in order to ascertain the correct category for this subgroup. As Table 1 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 among those not working in oncology units. The transition point from curative to palliative care can be a challenging time for patients and for nurses as well, and developing skills and knowledge in this area could help patients and their families make smoother transitions. Our 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.

We concluded additional education for less experienced nurses could increase comfort levels in all domains and improve care for end of life patients. Experienced nurses showed the highest levels of skill regarding addressing EOL and palliative care needs, and those with less experience could benefit in particular from education.

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. Utilizing 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.

Acknowledgements

The authors wish to thank Mr. Rick Tivis (Biostatistician), Mr. David Kent (4S Oncology Director), and Ms. Mary Lou Long (Home Care/Hospice former Director) for their contributions to this work. Special thanks to Mr. Danh Nguyen, nursing student research assistant. We also wish to acknowledge the support of the Institute of Translational Health Sciences (ITHS; grant UL1TR000423 from NCRR/NIH).

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Table 1

Comfort Level by Years of Experience

Domain	Mean $\pm$ SD (Duncan Grouping)	N	Experience (Years)
PFCC	3.42 $\pm$ 0.33 (C)	7	< 2
	3.77 $\pm$ 0.65 (B,C)	20	2-5
	4.03 $\pm$ 0.44 (A,B)	17	5-10
	4.31 $\pm$ 0.48 (A)	16	>10
CEV	3.00 $\pm$ 0.60 (C)	7	< 2
	3.28 $\pm$ 0.80 (B,C)	20	2-5
	3.75 $\pm$ 0.51 (A,B)	17	5-10
	3.92 $\pm$ 0.59 (A)	16	>10
ECD	2.79 $\pm$ 0.37 (B)	7	< 2
	3.18 $\pm$ 0.87 (A,B)	20	2-5
	3.33 $\pm$ 0.49 (A)	17	5-10
	3.55 $\pm$ 0.58 (A)	16	>10

PFCC=Patient and Family-Centered Communication

CEV=Cultural and Ethical Values

ECD=Effective Care Delivery

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

Table 2

Comfort Level by Unit

Domain	Mean $\pm$ SD (Duncan Grouping)	N	Unit
PFCC	4.18 $\pm$ 0.50 (A)	16	Oncology
	3.96 $\pm$ 0.46 (A,B)	22	ICU/CCU
	3.76 $\pm$ 0.70 (B)	22	Telemetry
CEV	3.67 $\pm$ 0.67 (A)	16	Oncology
	3.69 $\pm$ 0.59 (A)	22	ICU/CCU
	3.32 $\pm$ 0.83 (A)	22	Telemetry
ECD	3.53 $\pm$ 0.54 (A)	16	Oncology
	3.18 $\pm$ 0.64 (A)	22	ICU/CCU
	3.18 $\pm$ 0.77 (A)	22	Telemetry

PFCC=Patient and Family-Centered Communication

CEV=Cultural and Ethical Values

ECD=Effective Care Delivery

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