Pediatric Nurses' Individual and Group Assessments of Palliative, End-of-Life, and Bereavement Care

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Abstract

Background: Although pediatric nurses working in children's hospitals often provide care to dying children, little is known about their palliative care beliefs and experiences as individuals or members of groups within the hospital.

Objective: To describe pediatric nurses' ratings of palliative care goals and problems, as individuals and members of clusters of nurses with similar views, and nurses' degree of collaboration with an inpatient palliative care team across hospital units.

Method: A cross-sectional survey of nurses at a freestanding children's hospital in 2005.

Results: Nurses rated the most important goals as managing pain, maintaining the child's quality of life, and improving communication. Commonly cited problems were lack of opportunity to debrief after a patient's death, uncertainty about the goals of care, and the health care team's reluctance to discuss hospice with family. Based on individual views about goals and problems, nurses clustered into 5 groups that differed in terms of the adamancy of their views and the scope of the goals and problems they considered important or significant. The hospital unit was the most important factor in predicting nurses' degree of collaboration with the palliative care team even after accounting for individual characteristics.

Conclusions: Pediatric nurses broadly endorse both the importance of palliative care goals and the presence of problems yet perceive the importance of these goals and problems differently. Further, they vary in their level of collaborative practice with a palliative care team in ways that should be accounted for when planning and implementing palliative care programs.

Introduction

PEDIATRIC NURSES PLAY A CRUCIAL ROLE in the provision of palliative, end-of-life, and bereavement (PEOLB) care to dying children and their families. Although pediatric nurses' experiences with PEOLB care have not been well-described, a substantial body of literature details the PEOLB experiences of nurses caring for adult populations in areas such as oncology and intensive care units.¹⁻⁴ Nurses working in these areas identify the goals of PEOLB care to include good pain management, reducing patient suffering, facilitating a dignified death, and effective communication between the health care team, the patient, and the family.⁵⁻⁸ Additionally, they report obstacles to the PEOLB care they provide including lack of communication among physicians, nurses, and families; lack of a defined treatment plan; discomfort with death and dying; unnecessary prolongation of life; and lack of awareness of end-of-life practices and resources.⁶⁻⁸

In spite of the advancements in understanding the beliefs and experiences of nurses providing adult PEOLB care, we are unaware of equivalent studies that focus specifically on pediatric nurse perspectives of PEOLB care. We therefore surveyed pediatric nurses in a freestanding children's hospital regarding their PEOLB beliefs and experiences in caring for dying children and their families. We sought to describe the PEOLB beliefs and practices of individual nurses, but also to better characterize different groups of nurses based on the similarity of their views about palliative care. Additionally, we examined unit-level variation in pediatric nurses' degree of collaboration with a hospital-based palliative care team when caring for dying children and their families. This aim was motivated by the clinical observation that nurses on different units utilize available palliative care resources differently; although (to our knowledge) this observation has not yet been empirically documented in the literature. We believe that these potential group-level differences are important,

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having practical implications regarding how interventions intended to assist nurses in the provision of excellent PEOLB care are designed and then implemented across diverse groups of nurses (characterized by their attitudes and beliefs) and distinct clinical units.

Methods

The Committees for the Protection of Human Subjects approved the conduct of this study.

Study design, participants, and setting

We conducted a cross-sectional survey of all nurses at a freestanding children's hospital during the spring of 2005. During the year preceding the survey, the neonatal intensive care unit (NICU) had 50 beds and the pediatric intensive care unit (PICU) had 45 beds.

Survey development

We first canvassed the published literature on "nursing" and "palliative" or "end-of-life care," specifically identifying studies of nurses that had used questionnaires.^{9–18} Upon close review of several questionnaires^{9,12,14} and other publications,^{10,11,13,15–18} we created an item pool of questions that addressed nurses' knowledge, attitudes, practices, and experiences regarding various aspects of PEOLB care. After soliciting input from other members of our multidisciplinary palliative care team regarding the pertinence and importance of this large set of questions, we culled the set down to a provisional set of survey questions. We then pilot tested with 10 nurses of various backgrounds and clinical experience to assess the clarity of the questions, making minor modifications in response to feedback. The complete survey questionnaire is available from the corresponding author upon request via e-mail.

Study implementation

We administered the survey by means of a web-based questionnaire (Inquisit SurveyTM, Inquisit Inc., Austin, TX). All nurses received an initial solicitation to participate in the study via e-mail; the solicitation included a URL link to the web-based questionnaire. Three follow-up solicitations and reminders followed via e-mail. Nurses were also informed about the survey at staff meetings throughout the hospital. In the conduct of the study, no data were collected or generated that could link a particular nurse to his or her response, or that could distinguish respondents from nonrespondents.

Variables

We asked nurses to provide basic demographic information including age, sex, years in nursing practice, religious/spiritual background and values, and primary unit of employment. To understand their PEOLB beliefs, we asked nurses to rate their agreement with a series of statements regarding their perceived goals of and obstacles to PEOLB care using a Likert-type scale ranging from 0 (strongly disagree/extremely unimportant) to 4 (strongly agree/extremely important) on four general domains: 1) physical care, 2) psychosocial care and decision making, 3) care addressing specific palliative care tasks, and 4) care sensitive to cultural,

spiritual, and ethical considerations. To discern differences in the extent of nurses' collaboration with the pediatric palliative care (PPC) team across units, we asked respondents to gauge the percentage of time they involved the team when caring for a dying child (0%, 25%, 50%, 75%, 100%). At the time of the survey nurses were not able to initiate a consult to the PPC team independently, but were able to work collaboratively with the team once a consult had been established. We also asked nurses to enumerate the number of patients cared for in the past year that had died as well as the total number of hours of PEOLB education they had attained over their career. Finally, we queried nurses regarding their personal and/or professional experiences with a hospice program.

Analysis

We generated descriptive summary statistics of various items related to nurses' PEOLB experiences. We employed agglomerative hierarchical cluster analysis using Ward's linkage to examine the natural grouping patterns of nurses' perceptions of a) the goals of PEOLB care and b) problems encountered in PEOLB care. To study PEOLB practices reliably at the unit-level, we limited analysis to units with 10 or more nurse respondents, resulting in 272 nurses in seven units. We used analysis of variance techniques to obtain an estimate of the intra-class correlation of palliative care team involvement within units and constructed multivariate logistic regression models to test for the effects of nurse characteristics (hours of end-of-life education, years of nursing experience, and number of patients cared for in the previous year that died) and hospital unit on the likelihood of having ever involved the palliative care team when caring for a dying child. Robust variance estimators were used to account for the interdependence of nurses within units and the final model demonstrated a pseudo- R^2 value of 0.40, a C-statistic of 0.90, and a Hosmer-Lemeshow test statistic indicative of satisfactory goodness-of-fit ($p = 0.73$). The level of statistical significance was set a priori as $p < 0.05$. All analyses were conducted using Stata statistical software version 11.0 (StataCorp., College Station, TX).

Results

Pediatric nurse characteristics and PEOLB experiences

Of the 410 nurses who completed the survey (44% response from the 932 eligible nurses), respondents were mostly female (90.6%), normally distributed across age categories, and represented 11 units including 3 intensive care units (neonatal, cardiac, and pediatric) and 1 emergency department (ED). Nurses reported an average of 12.1 (standard deviation [SD] 8.9) years of nursing experience and 66% described themselves as having strong religious or spiritual convictions. Table 1 highlights the respondents' PEOLB education and experiences. Fifty-five percent reported between 1 and 8 total hours of end-of-life education obtained during their nursing career, whereas 23% of nurses reported no formal end-of-life education. A majority of nurses (59%) had cared for 1 to 5 patients who died in the past year, with nurses in intensive care units caring for dying patients more frequently. The small percentage of nurses who reported caring for 11 or more dying patients in the past year were largely from the oncology

TABLE 1. NURSES' EDUCATION AND EXPERIENCE WITH PEDIATRIC PEOLB CARE

		N	%
How much education have you had in end-of-life care?	None	96	23.4
	1–4 hours	159	38.8
	4–8 hours	65	15.9
	9–12 hours	35	8.5
	>13 hours	55	13.4
	Not answered	0	0.00
In the past year, how many patients have you cared for who have died?	None	60	14.6
	1	45	11.0
	2	69	16.8
	3–5	127	31.0
	6–10	70	17.1
	>11	36	8.8
	Not answered	3	0.7
How much personal experience have you had with a hospice program?	None	195	47.6
	1–2 experiences	165	40.2
	3–5 experiences	29	7.1
	>6 experiences	21	5.1
	Not answered	0	0.00
How much professional experience have you had with a hospice program?	None	232	56.6
	1–2 experiences	81	19.8
	3–5 experiences	46	11.2
	>6 experiences	49	12.0
	Not answered	2	0.5

and ED units, and the 15% of nurses who reported caring for no dying patients were mostly from the rehabilitation and "other" units. Approximately half of the respondents had no personal experience with a hospice program, and 56.6% had no professional experience with a hospice program.

When asked whether they "had enough experience in caring for dying children to do the job well," 46.8% agreed, and 42.5% considered themselves to be "well-trained to take care of dying children and their families, 36.4% agreed that they found "it difficult to talk about death and dying with children and their families, and 53.2% considered themselves to be "comfortable working with dying children and their families."

Nurse perspectives regarding goals and problems

At the individual level, nurses broadly endorsed all of the goals of palliative care (Fig. 1), and identified as leading problems confronting optimal palliative care the lack of opportunity to debrief after a patient's death, uncertainty about the goals of care, and the team's reluctance to discuss hospice with the family. Cluster analysis revealed that individual nurses fit into 5 groups regarding their views of the importance of goals, and 5 similar groups regarding problems (Table 2). For both goals and problems, large clusters of nurses reported that all the goals were important (25% of all respondents) and all the problems were significant (30%). For the remaining clusters regarding goals, they each endorsed pain control while rejecting one particular type of goal: spiritual care and hospice (26%), symptom management (19%), hospice (13%), or psychosocial and communication support (17%). For the problems, 3 groups differed regarding what they perceived as the most significant problems (unaddressed spirituality concerns, 28%; inadequate clarification of treatment goals, poor communication, and nondiscussion of hospice, 9%; and a cultural bias against PPC and underuse of do

not resuscitate orders, 22%), and a final group viewed no specific problem as especially significant (12%). Interestingly, specific units within the hospital were not associated with the clusters of nurse views regarding goals ($p=0.46$) but were associated with clusters regarding problems ($p=0.03$), suggesting that goals are perhaps more universally held, whereas problems are more unit specific.

Unit-level differences in nurses' involvement with the PPC team

Fig. 2 shows the distribution of the overall percentage of time nurses within units reportedly were involved with the PPC team when caring for a dying child as well as the proportion of nurses that reported ever being involved with the team. Across all units, nurses reported being involved with the PPC team 38% of the time. Nurses working on floor units were involved with the team more frequently than those in ICUs, with minimal variation in involvement among nurses in the floor units and substantial variation among those working in the ICUs and ED. Among nurses in the NICU, only 27% reported ever being involved with the PPC team when caring for a dying infant. Overall, nurses within units were more similar in their level of involvement with the PPC team compared with nurses across units (intra-class correlation 0.47).

Compared with nurses in the oncology unit, nurses in all other units were less likely to be involved with the PPC team. In particular, nurses in the ED, NICU, and cardiac intensive care unit (CICU) were significantly less likely to be involved with the PPC team when caring for a dying child (Table 3). Years of nursing experience and the number of dying children cared for in the prior year did not significantly influence the likelihood of palliative care team involvement, although nurses with 1 to 8 hours of end-of-life education were 3.9

FIG. 1. Nurses' perceived goals and problems of PEOLB.

times more likely to report being involved with the team when caring for a dying child than those with no formal end-of-life education ($p < 0.01$).

Discussion

This study sought to describe pediatric nurses' experiences with PEOLB care, to examine natural groupings of nurses based on perceived goals and problems in providing PEOLB care, and to assess patterns of nurse collaboration with a hospital-based palliative care service from an organizational perspective. Using survey data from nurses in a freestanding children's hospital, we have shown that pediatric nurses report a range of PEOLB education, exposure to hospice programs, and experience in caring for dying children. Further, we have demonstrated that nurses perceive the goals of and obstacles to PEOLB care differently, and moreover, that nurses can be categorized into clusters based upon their views. Lastly, we have identified the significant impact of the hos-

pital unit on nurses' involvement of the PPC team when caring for dying children and their families, more so than individual characteristics of nurses that are frequently targeted as pathways for improving the delivery of PEOLB care.

This study, although limited with regard to assessing only a single children's hospital, nevertheless highlights two significant findings regarding the organization, implementation, and delivery of PPC services in the inpatient setting. First, hospitals consist of clusters of nurses who range from enthusiastic proponents for a broad array of palliative care goals to those who have a much more restricted vision of what PPC should attempt to accomplish. Although this finding is not surprising, this study is the first to document the existence of such attitudinal groupings regarding palliative care perceptions within a hospital setting. We employed a technique (hierarchical agglomerative cluster analysis) that sorted individual nurses, on the basis of their response to all the questions regarding attitudes and beliefs about the problems PPC confronts and the goals it should pursue, into groups

TABLE 2. CLUSTER ANALYSIS OF NURSES' PERCEIVED PEOLB GOALS AND PROBLEMS

Group		Count	Adamancy	Specific items		
Goals	1	“Every item is an important goal.”	101 (25%)	4.0	Endorsed <i>All</i>	Rejected <i>None</i>
	2	“Quality of life and pain control, are important, but spirituality and hospice are not important.”	105 (26%)	3.7	Quality of life, Pain	Spiritual, Hospice
	3	“Pain is important, but other symptoms are not.”	74 (19%)	3.7	Pain	Symptoms
	4	“Pain control is more important than hospice.”	53 (13%)	3.4	Pain, Child psychosocial	Hospice
	5	“Pain control is more important than decisional support.”	67 (17%)	3.2	Pain	Psychosocial, Communication
Problems	1	“Every item is a significant problem.”	116 (30%)	3.2	<i>All</i>	<i>None</i>
	2	“Spirituality problems are more than physical problems.”	107 (28%)	2.3	Spirituality	Pain, Symptoms
	3	“Decisional problems and hospice underuse are more important than other psychosocial or spiritual problems.”	33 (9%)	2	Goals, Communication, Hospice	Psychosocial, Bereavement, Spiritual
	4	“Decisional problems more important than physical problems.”	86 (22%)	1.5	culture, DNR	Pain, Symptoms
	5	“No item is a significant problem.”	47 (12%)	0.8	<i>None</i>	<i>All</i>

DNR, do not resuscitate order.

composed of individuals who were the most similar to other members in that group, and most dissimilar to members in other groups. This is a technique used by marketing research to identify and understand groups of people with similar preferences and values. By direct analogy, our findings regarding discrete groups of nurses, bound together by common but not universally shared attitudes, can be thought of as an initial foray into the social marketing of PPC interventions among hospital-based pediatric nurses. The practical implication of identifying these different "market segments" of nurses (such as nurses who feel that every item is an impor-

tant goal, as in Goals Cluster 1 of Table 2, as compared with nurses who feel that pain control is more important than decisional support, as in Goals Cluster 5) is that hospital-wide PPC interventions need to be tailored and "sold" to each of these different groups, if the architects of the intervention hope to have the members of the group willingly (or even better, enthusiastically) adopt and support the intervention. For instance, if the planned intervention is very comprehensive, one market segment of nurses will see both the need for such a wide-ranging service and approve of its expansive set of goals, but other market segments of nurses will likely be

FIG. 2. Distribution of nurses' involvement of the PPC team across hospital units.

TABLE 3. FACTORS PREDICTING NURSES' INVOLVEMENT OF THE PALLIATIVE CARE TEAM

	<i>Odds ratio</i>	<i>95% CI</i>	<i>P value</i>
Hours of end-of-life education (0 is reference)			
1–8	3.90	1.43–10.62	0.008
8 or more	2.79	0.83–9.38	0.096
Clinical nursing experience (years)	0.99	0.95–1.04	0.932
Past exposure to dying patients (0 is reference)			
1–5	0.83	0.20–3.40	0.801
More than 5	0.33	0.07–1.47	0.148
Unit of employment (oncology is reference)			
General pediatrics	0.39	0.03–4.71	0.459
ED	0.02	0.00–0.08	<0.001
PICU	0.38	0.07–2.03	0.257
CICU	0.02	0.00–0.09	<0.001
NICU	0.01	0.00–0.05	<0.001

Note: Nurses on units with 10 or more respondents were included; *n* = 272.

more skeptical, believing the a more narrowly focused intervention is warranted and proper. The converse would also be true: a more circumscribed intervention (say, emphasizing improved pharmacological pain management) would have, based on our market segmentation analysis, fans and foes. Anticipating such reactions can both motivate and guide how the champions for the planned intervention design the intervention and its rollout, anticipating concerns and addressing them prospectively.

A second and likely related finding is the contextual significance of the hospital unit with respect to the PEOLB care problems that nurses perceive and how nurses work with the available palliative care resources. Our study is not the first to note associations between perceptions of PEOLB barriers and the hospital unit; Burns et al.¹⁹ found significant differences in reported barriers to PPC between intensive care unit staff and staff working on general hospital units. One possible explanation for these differences is variation in unit culture. Hospital units can be characterized as having distinct cultures that affect nurses' attitudes and actions as well as the success of care delivery redesign within an organization.^{20,21} Unit culture may also impact the level of acceptance a palliative care service is able to garner among nurses, particularly if nurses view the service as either encroaching on their role as the primary PEOLB care provider or perceive the service as adding to their workloads. Although this study did not examine unit-level PEOLB culture, we suspect that varying PEOLB norms at the unit level may partially explain the findings.

The results of the study also have practical implications for the design and implementation of PPC services in the inpatient setting. As stated above, the first set of findings about clusters of nursing views is similar to marketing research, helping the planners of a PPC service to understand the expectations and possible reactions of nurses whose practice may be impacted by the development of the service. Elsayem and colleagues²² describe significant differences among nurses regarding the acceptance of a newly established inpatient palliative care service at a comprehensive cancer center, differences which ultimately resulted in a substantial

revision of the delivery model for PEOLB services. Administrators may find a preemptive analysis of nurses' views regarding PEOLB care useful before rolling out a new service or model of care delivery in order to anticipate the reception of such services as well as to facilitate their acceptance among staff.

Our findings also suggest that incorporation of a systems-level approach to both understanding the barriers to effective PEOLB care delivery and crafting interventions may be more fruitful than individual-level approaches alone. Common individual-level approaches include formal PEOLB education, retreats, and team-building workshops. Although these pathways may be valuable for building a clinician's repertoire of PEOLB care knowledge and skill set, they do not account for the organizational context in which PEOLB care is delivered. A systems-level approach to PEOLB care, such as identifying and addressing obstacles to the appropriate use of palliative care resources, may complement or synergize individually focused interventions.

In the end, surveys of hospital staff can serve several purposes, the first of which may be simply to create a sense of organizational legitimacy throughout the staff for subsequent palliative care endeavors. Beyond this tactical reason of conducting a survey, for our hospital this survey had very practical implications, shaping our strategy for advancing our palliative care team's mission, recognizing that different units within the hospital had different perspectives and degrees of adamancy regarding pressing patient care problems and appropriate palliative care goals, and making us more mindful during educational outreach sessions that even within units nurses differed regarding what they thought was important, allowing us to better hone our message to different groups of nurses, and hopefully to greater effect.

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Author Disclosure Statement

No competing financial interests exist.

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