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Hopeful Thinking and Level of Comfort Regarding Providing Pediatric Palliative Care: A Survey of Hospital Nurses

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ABSTRACT

OBJECTIVE. The purpose of this work was to test the hypothesis that individual nurses' level of hope is associated with greater self-reported comfort and competence in providing palliative care.

METHODS. We conducted a Web-based cross-sectional survey at the Children's Hospital of Philadelphia, a large referral hospital, during the spring of 2005 with all of the employed nurses. The response rate was 44% (410 of 932 eligible nurses). The questions were adapted from published studies or written for this study regarding nurses' knowledge, attitudes, practices, and experiences regarding various aspects of palliative care. We used the Adult Dispositional Hope Scale.

RESULTS. Respondents, asked to rate their degree of agreement (+2, strongly agree to -2, strongly disagree) with the statement that they were "comfortable working with dying children and their families," reported a mean score of 0.5. Regarding whether they "find it very difficult to talk about death and dying with children and families," the mean score was -0.1. Nurses specifically reported feeling most competent regarding pain management and least competent regarding talking with children and families about dying. After multivariable adjustment, greater number of years in nursing practice, more hours of palliative care education, and higher scores on the Hope Scale, each were significantly associated with higher levels of comfort working with dying children and the families, lower levels of difficulty talking about death and dying, and higher levels of palliative care competency.

CONCLUSIONS. Nurses' level of hope is associated with their self-reported comfort and competence regarding palliative care.

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†Deceased.

Ms Santucci and Dr Feudtner conceived of, designed, and implemented the study in consultation with Drs Kang and Rourke; Dr Feudtner and Mr Feinstein performed the data analysis with advice of Drs Snyder and Rourke; all authors participated in the interpretation of the data; Dr Feudtner drafted the article; all authors revised the article for key intellectual content; Dr Feudtner had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis; and all authors read and approved the final manuscript.

Key Words

end of life, nursing care, palliative care, hospital care

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WHY DO SOME health care providers feel more comfortable providing pediatric palliative care than do other providers? Among various possible answers to this question, some explanations assume that this variation is attributable chiefly to differences in medical knowledge or procedural skills, gained either through education or experience. An alternative explanation posits that significant variation in providers' palliative care comfort level is because of differences in how they think, feel, and react when they confront clinical tasks in the psychosocially intense situation of a child's impending death. Determining the relative merits of these different explanations, and subsequently tailoring interventions for health care providers, could advance efforts to improve the quality of palliative care received by dying children and their families.

Currently, a variety of educational programs on palliative care exist, designed for nurses and physicians.^{1,2} Fewer programs explicitly focus on augmenting or enhancing health care providers' palliative care experiences, although the advent of hospital-based palliative care services and community-based hospice services has likely performed such a function. Virtually no attention, however, has been directed toward understanding and addressing providers' underlying cognitive and affective processes (their beliefs and feelings or habits of heart and mind) that may influence how they respond to a broad range of difficult and distressing problems. If these processes or habits were strongly associated with individual providers' competence and comfort when caring for dying patients and their families (and, ultimately, to staff stress, distress, burnout, and turnover), then interventions quite different from any that presently exist might be warranted.

If we want to enhance the ability of health care providers to address difficult situations, the emerging field of "positive psychology" may provide a fertile resource for theoretical concepts, validated measures, and a variety of potential individual- or group-level interventions. Specifically, we have focused on what the psychologist Snyder^{3,4} calls "hope theory." Moving beyond vague notions that hope is a "good" thing (or, conversely, that false or unrealistic hope is a "bad" thing), Snyder^{3,4} conceives of hope as having 3 main components. First, individuals who are able to anchor their thinking about the future to specific desired goals are more likely to be hopeful. Second, people who can imagine or plan ways to achieve these goals (step by step along a pathway toward the goal) have greater hope. Third, individuals who think that they themselves are capable of pursuing goals successfully, who believe in their own capacity to get what they want, are more hopeful. A person's degree of hopefulness depends on the interaction of these 3 capacities. To illustrate this model of hope in a palliative care situation,⁵ let us consider a person in a hospital who knows that death is

drawing near but who also: (1) clearly desires to be at home with loved ones (a goal); (2) can imagine being discharged from the hospital and going home with hospice care (a specific pathway to the goal); and (3) believes that he or she is the kind of person, surrounded by the kind of family, that can work through great emotion and adversity to accomplish a precious goal (all of which are thoughts of self-efficacy or agency); in our view, this individual has hope. Although people tend to display a fairly stable range of hopefulness over time, specific interventions to develop the capacity of goal specification, pathway thinking, or agency thinking can enable individuals to achieve higher levels of hopefulness generally and even more so regarding their ability to respond to specific challenging situations.

In the present study, we examined these competing explanations or theories about what factors cause variation in health care providers' level of comfort about providing palliative care. We conducted a survey of nurses working at a large tertiary care children's hospital, assessing both the nurses' self-reported levels of comfort about palliative care and the nurses' responses to a validated instrument that measures important aspects of hopeful thinking and feeling, as well as their education about and experience in providing palliative care. We specifically tested the hypothesis that nurses who are more inclined toward hopeful ways of thinking and feeling are also more comfortable regarding providing palliative care.

METHODS

Institutional Review Board Oversight

The Committees for the Protection of Human Subjects approved the conduct of this study. Respondents provided their tacit consent to participate in this voluntary and anonymous survey when they completed the questionnaire.

Study Design, Participants, and Setting

We conducted a cross-sectional survey of all of the nurses at the Children's Hospital of Philadelphia during the spring of 2005.

Instrument Development

We first reviewed the published literature on nursing and palliative or end-of-life care, specifically identifying studies of nurses or other health care providers that had used questionnaires.⁶⁻¹⁵ We then created an item pool of questions that addressed nurses' knowledge, attitudes, practices, and experiences regarding various aspects of palliative and end-of-life 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 selected a smaller set of survey questions.

We next added 8 questions from the Adult Dispositional Hope Scale, which has been rigorously validated and used in a wide variety of populations as a measure of individual differences in hopeful thinking.¹⁶ We then pilot tested with 10 nurses of various backgrounds and clinical experience to assess the clarity of the questions, making a few minor modifications of question wording or formatting in response to feedback. The complete survey questionnaire is available on the Internet (www.pediatric-generalists.org/files/feudtner/RN_Survey.pdf).

Study Implementation

We administered the survey by means of a Web-based questionnaire (hosted by Inquisite, Austin, TX). All of the nurses received an initial solicitation to participate in the study via e-mail; the solicitation included a Web site 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 generated or collected that could link a particular respondent to his or her response or that could distinguish respondents from nonrespondents. Once the enrollment period had expired, the Web-based survey was halted, and the survey responses were collated and obtained via a tab-delimited spreadsheet downloaded from the Web-based survey service server.

Analysis

After first examining the responses to each question, we generated descriptive summary statistics. To assess the performance of the Hope Trait instrument, in addition to the descriptive statistics reported in the results section, we also calculated the Cronbach α for the overall hope score (.82) and the Pearson product moment correlation coefficient between the overall hope score and the subscores of pathway (.88) and agency (.90) and of the 2 subscores (.57); we also calculated the mean and SD for the pathway (12.9 and 1.7) and the agency (13.5 and 1.6) subscores, respectively; these are similar to findings in other samples of research participants who have completed the instrument. We generated graphic depictions of bivariate relationships between respondent characteristics (years in practice, hours of pertinent education, and hope score) and outcomes (reported levels of comfort, difficulty, and competence with palliative and end-of-life care) using fractional polynomial models of the bivariate relationship along with the associated 95% confidence intervals.

We tested our main hypothesis, that higher scores on the Hope Trait instrument would be associated with higher ratings regarding the comfort level of working with dying children and regarding self-reported competence in aspects of palliative and end-of-life care, with lower ratings regarding the difficulty of talking about dying and death with patients or families, using a mul-

tivariable linear regression model that adjusted for the respondents' years of nursing experience (which we had specified a priori as an important potential confounder variable). Inferences were based on multivariable models of 0-skewed log transformation of the outcome variables, which satisfied the requisite assumptions for valid linear regression-based inferences; point estimates are based on models of untransformed outcomes. We also confirmed that a parallel analysis using a multivariable ordinal logistic regression model of the outcome (reported level of comfort or difficulty) arrayed as ordered categories yielded the same results and level of statistical significance.

We assessed the possibility of nonrespondent bias by examining whether earlier responders to the survey differed in their responses compared with later responders, reasoning (as have others who postulate a "continuum of resistance" model to differentiate among early, late, and nonresponders to surveys¹⁷) that any difference between early and late responders would suggest that nonresponders would have further deviated from the early responders' answers. No significant temporal trend among respondents, however, was observed for any of the 3 main predictor variables (hope score, years of nursing experience, and hours of palliative care education) or the 3 main response variables (comfort providing palliative care, difficulty talking about dying or death, and composite competence score). Although this is an imperfect test for the presence of nonrespondent bias, our result is reassuring. All of the analyses were performed with Stata 9.1 (Stata Corp, College Station, TX).

RESULTS

Of the 410 nurses who responded to the survey (44% response from the 932 eligible nurses), most were women, <40 years of age, and agreed that they have strong spiritual convictions (Table 1). Respondents worked in a wide variety of clinical units located throughout the hospital. Regarding the 3 main predictor variables of this study, the majority of respondents had a decade or less of nursing experience, had ≤ 4 hours of previous palliative care-specific education (Table 1), and displayed a level of hopeful thinking comparable to other groups of healthy adults that have completed the Hope Scale instrument (Table 2).¹⁸

Respondents, on average, reported only moderate degrees of agreement regarding whether they were "very comfortable working with dying children and their families" and were essentially neutral to the statement that, "I find it very difficult to talk about death and dying with children and their families" (Table 3). They reported that they felt most competent regarding pain management, least competent regarding talking with children and families about dying, and exhibited substantial variation

TABLE 1 Characteristics of Respondents

Characteristic	No.	Percentage
Age, y		
20–30	126	30.7
31–40	148	36.1
41–50	103	25.1
>50	33	8.1
Gender		
Female	366	89.3
Male	38	9.3
Not answered	6	1.5
Clinical units		
PICU	70	17.1
Oncology	62	15.1
Emergency department	47	11.5
Cardiac ICU	38	9.3
NICU	33	8.1
Multiple units	28	6.8
Rehabilitation	21	5.1
General pediatrics	12	2.9
Pulmonary	10	2.4
Renal	5	1.2
Integrated care service	4	1.0
Neurology	1	0.2
Other	79	19.3
Years in nursing		
0–5	130	31.7
6–10	77	18.8
11–20	130	31.7
> 21	72	17.5
Not answered	1	0.2
Palliative care education, h		
0	96	23.4
1–4	159	38.8
5–8	65	15.9
9–12	35	8.5
≥13	55	13.4
I have strong spiritual convictions		
Strongly agree	108	26.3
Agree	162	39.5
Uncertain	113	27.6
Disagree	19	4.6
Strongly disagree	6	1.5
Not answered	2	0.5

TABLE 2 Responses Regarding Hope

Variable	Mean	Interquartile Range
Scores on Hope Scale questions (range of possible scores: 1–4; higher score = strong agreement)		
I've been pretty successful in life	3.4	3–4
My past experiences have prepared me for the future	3.4	3–4
I meet the goals I set for myself	3.3	3–4
I energetically pursue my goals	3.3	3–4
I can think of many ways to get important things in my life	3.3	3–4
There are lots of ways around any problem	3.3	3–4
I know I can find a way to solve a problem	3.2	3–4
I can think of many ways to get out of a jam	3.2	3–4
Hope Scale score (range of possible scores: 0–32; higher score = more hopeful)	26.4	24–29

among respondents regarding their overall composite score of palliative care competency (Table 3).

Each of the 3 predictors was significantly correlated with the 3 outcomes (Fig 1); specifically, greater numbers of years in nursing practice, more hours of palliative care education, and higher scores on the Hope Scale were each associated with higher levels of comfort working with dying children and their families, lower levels of difficulty talking about death and dying with children and families, and higher total palliative care competency score. The pattern of relationships among the 3 predictors and the 3 outcomes was also apparent even with multivariable adjustment for each predictor: that is, the predictors were each associated with significantly higher levels of comfort working with dying children and their families, lower levels of difficulty talking about death and dying, and higher levels of palliative care competency (Table 4). Among the predictors, the hours of palliative care education were consistently the most substantial explanatory variable for all 3 of the outcomes, with smaller but similar effect sizes for both years of nursing practice and hope score.

An alternative explanation of the association between hope scores and the 3 main outcomes is that respondents who were more hopeful simply scored themselves more optimistically. To assess for this possibility, we tested the relationship between hope score and other self-ratings that we had not hypothesized would be associated with hopefulness. We did not find evidence in support of this alternative explanation; specifically, hope scores were not associated with self-reported comfort giving opiate medications at the end of life ($P = .599$), with the belief that it is normal for care providers to grieve for their patients who die ($P = .431$), or with the view that group debriefing sessions for care providers after the death of a patient were helpful ($P = .769$).

DISCUSSION

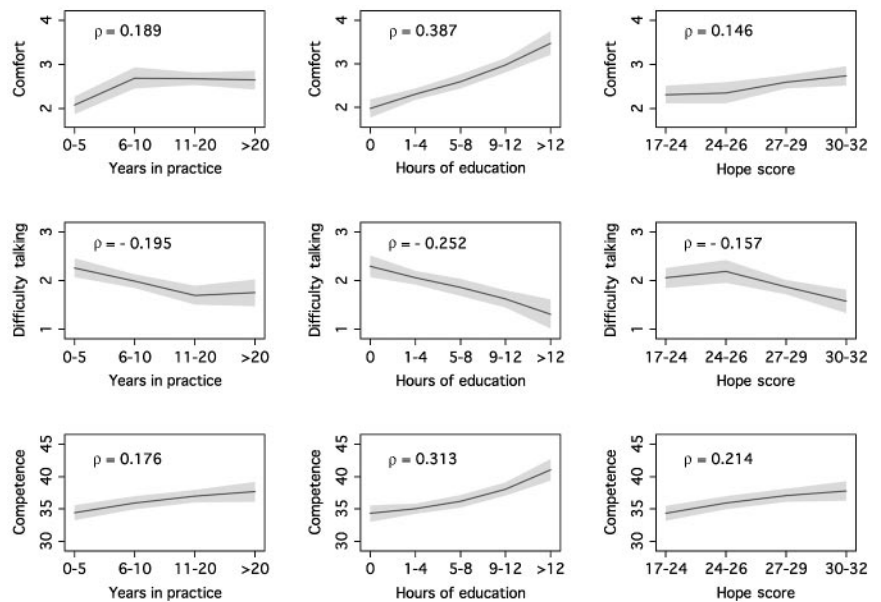
In this cross-sectional survey of pediatric nurses at a large tertiary care children's hospital, we found that nurses who reported greater levels of comfort working with dying children, less difficulty talking about death and dying with children and their families, and a greater depth of competency in the provision of pediatric palliative care were significantly more likely to have more years of nursing experience, more hours of palliative care-specific education, and higher levels of personal hopefulness. The association between a nurse's personal degree of hopefulness and greater reported levels of comfort and competence regarding palliative care tasks persists even with adjustment for the nurse's years of nursing experience and exposure to palliative care-focused education. If this association is substantiated in future research, then interventions to enhance nurses' (and other health care professionals') hopeful patterns of thoughts and feelings about the challenges confronted

TABLE 3 Reported Self-assessment Regarding Palliative Care

Variable	Mean	Interquartile Range
Perceptions about overall competence (possible scores range: -2 to +2; higher score = stronger agreement)		
I consider myself to be very comfortable working with dying children and their families	0.5	0-1
I have adequate experience in caring for dying children	0.3	-1 to 1
I consider myself to be well trained to take care of dying children and their families	0.2	-1 to 1
I find it very difficult to talk about death and dying with children and their families	-0.1	-1 to 1
How competent do you think you are in the following aspects of end-of-life care? (possible scores range: -2 to +2; higher score = more competent)		
Managing pain	1.5	1-2
Providing comfort care nursing interventions to improve quality of life	1.3	1-2
Managing other symptoms	1.3	1-2
Being sensitive to spiritual needs	1.3	1-2
Recognizing impending death	1.1	1-2
Being sensitive to cultural values and issues	1.1	1-2
Emphasizing goals, not limitations	1.0	0-2
Understanding ethical issues surrounding end-of-life care	0.9	0-2
Understanding advanced directives	0.8	0-2
Understanding the role of hospice	0.8	0-2
Knowing where to find help within the hospital when faced with an ethical dilemma	0.6	0-1
Talking with children and families about dying	0.5	0-1
Composite score of competencies (possible scores range: -24 to +24; higher score = more competent)	12.1	8-17

FIGURE 1

Self-reported comfort, difficulty, and competence in palliative care vary by amount of nursing experience, palliative care education, and hopefulness. "Comfort" indicates the respondent's degree of agreement with the statement, "Overall, I consider myself to be comfortable working with dying children and their families"; "Difficulty Talking" refers to the statement "Overall, I find it very difficult to talk about death and dying with children and families"; "Competence" refers to the composite score of self-reported competence in key tasks of palliative care; "Years in Practice" refers to the years in nursing practice; "Hours of Education" refers to self-reported lifetime number of hours of palliative care education; and "Hope Score" refers to the score on the Adult Dispositional Hope Scale. The plotted lines are fitted values (and in shading the 95% confidence interval) of fractional polynomial models of the relationship between each pair of variables.



around end-of-life care for children might result in improved quality of pediatric palliative care.

We interpret the findings of our study cautiously because of the following 3 major limitations on inference. First, our analysis is based entirely on self-report. Only the Adult Dispositional Hope Scale instrument has been validated. Although we may presume that nurses

can accurately report their personal levels of comfort and difficulty regarding palliative care, the reliability of these self-reports is uncertain. Furthermore, although self-report of one's years in nursing is likely to be highly accurate, recollections of the hours of palliative care education may be inaccurate, and self-reports of personal palliative care competence may not correspond

TABLE 4 Increases in Hopefulness, Years of Practice, and Hours of Palliative Care Education Independently Improve Self-reported Comfort, Difficulty, and Competence in Palliative Care

Increasing:	Impact on:								
	Comfort			Difficulty			Competence		
	β	<i>P</i>	S- β	β	<i>P</i>	S- β	β	<i>P</i>	S- β
Hope score	0.11	<.05	(0.10)	-0.13	<.05	(-0.12)	1.02	<.001	(0.17)
Years in practice	0.15	<.01	(0.14)	-0.18	<.01	(-0.16)	0.88	<.01	(0.14)
Hours of palliative care education	0.34	<.001	(0.37)	-0.21	<.001	(-0.23)	1.49	<.001	(0.28)

Results of 3 separate linear regression models for comfort, difficulty, and competence, with each model regressing one of those outcomes against hope score, years in practice, and hours of palliative care education. The R^2 for each model was 0.19 (comfort working), 0.10 (difficulty talking), and 0.14 (composite competency score); degree of statistical significance was based on linear models of 0-skewness log-transformed outcomes. β indicates unstandardized coefficient; S- β , standardized β coefficient.

with more objective measures of competence. Future studies should aim to demonstrate the reliability of health care providers' reports of their palliative care comfort, difficulty, and competency and should clarify the relationship between these self-reports and nonself-report measures that evaluate the performance of palliative care tasks. Second, our sample of respondents was limited to 44% of all of the eligible nurses. This response rate exceeds the response rates of 20% to 33% reported by comparable surveys of nurses^{6,11} and falls within the interquartile range of response rates reported in a national assessment of high-quality surveys published in peer-reviewed medical journals.^{9,19} Furthermore, as we described at the end of the "Methods," we found no evidence that late responders to the survey differed from earlier responders, holding out the possibility that nonresponders would not have differed, either. Nevertheless, we cannot be sure that our findings apply across all of the nurses at our hospital and even less certain regarding nurses outside of our hospital. Third, we demonstrated only cross-sectional associations and not temporally ordered associations or stronger evidence of causation between these factors. Although we have framed our report under the premise that the 3 predictors (years of experience, hours of education, and level of hopefulness) are in some way influencing the 3 outcomes (level of comfort working with dying children and their families, level of difficulty talking with them about death and dying, and total palliative care competency score), it is conceivable that nurses with higher levels of achievement regarding the outcomes are more likely to remain in nursing (thus, having more years of experience), seek out more palliative care education, and report higher levels of personal hopefulness. To distinguish between these possible interpretations, we will require data from longitudinal surveys (analyzing the responses of nurses to these questions over time) or from randomized experimental trials of interventions to supply more palliative care education or to enhance thoughts and habits that promote a personal sense of hopefulness.

Offsetting these limitations, we note that the findings regarding the association of personal hopefulness with greater comfort in performing key tasks of pediatric pal-

liative care are in full accord with previous studies of hope. Hinds and her colleagues,^{20,21} based on their own research and a thorough review of the literature on hopefulness in pediatric oncology patients, their families, and health care providers, judged that information about hope warrants inclusion into patient, parent, and hospital staff educational materials.²² Beyond the realm of pediatric oncology, Snyder¹⁸ has demonstrated that higher hope predicts better coping across a variety of life domains, including one's health, academic and athletic performance, and psychotherapeutic engagement and outcomes. More generally, the associations noted in this study are fully consistent with cognitive behavior theory, which links beliefs like hope with consequent emotional adjustment, like well-being.²³⁻²⁵ Our findings, in other words, are supported by a broader confluence of evidence that the personal attribute of a greater degree of hopeful thinking enhances personal performance and is pivotal in confronting the challenges that life-threatening illness and end-of-life care present.

Any attempts to assist health care providers to expand their range of hopeful thinking regarding life-limiting conditions should be situated in larger, encompassing efforts to provide palliative care education and support for these providers. The most substantial finding of this study is the large association between hours of palliative care education and personal comfort providing palliative care, reduced difficulty talking about dying or death, and self-reported competence. Indeed, couched in the terms of hope theory, education that confers knowledge and teaches skills is essentially enlarging the set of pathway thoughts that an individual has at his or her disposal when considering how to achieve a goal and may also expand the range of potentially desired goals and enhance a sense of personal efficacy or agency to achieve these goals.

If future studies provide additional supportive evidence for the theory that health care providers' level of personal hopefulness influences their comfort level, as well as both their perceived and their more objectively measured competence in providing pediatric palliative care, the development and testing of hope-enhancing interventions would be warranted for nurses (and for

physicians and other health care providers, if these groups demonstrate similar associations between hopefulness and palliative care comfort and competency).^{5,26} In particular, cognitive-behavioral interventions could be developed with a focus on building a core set of hope-promoting cognitive skills and beliefs, corresponding skills at collaborating with patients and parents to formulate meaningful goals, and enhanced capacity to examine their thoughts and concomitant emotions about these goals and their ability to achieve them. Once developed, these interventions should be studied through randomized clinical trials to determine their effectiveness in achieving better patient, family, and health care provider outcomes.

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