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End-of-life discussions: Who's doing the talking?☆

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ABSTRACT

Purpose: To determine, in a tertiary academic medical center, the reported frequency of end-of-life discussions among nurses and the influence of demographic factors on these discussions.
Methods: Survey of nurses on frequency of end-of-life discussions in two urban academic medical centers. Chi-square tests were used to separately assess the relationship between age, gender, specialty, and experience with responses to the question, "Do you regularly talk with your patients about end-of-life wishes?"
Results: Overall, more than one-third of respondents reported rarely or never discussing end-of-life wishes with their patients. Only specialty expertise ($p < 0.001$) was statistically significantly associated with discussing end-of-life issues with patients. Over half of nurses specializing in critical care responded that they have these discussion "always" or "most of the time." However, for the specialties of surgery (59%) and anesthesiology (56%), the majority of respondents reported rarely or never having end-of-life discussions with patients.
Conclusions: In a survey conducted in two tertiary care institutions, more than one-third of nurses from all disciplines responded that they never or almost never discuss end-of-life issues with their patients. Specialty influenced the likelihood of discussing end-of-life issues with patients.

1. Introduction

The passage of the 1990 Patient Self-Determination Act in the United States requires healthcare institutions that receive any federal funding to inform patients of their rights regarding medical decisions, including decisions concerning end-of-life care and encompassing the right to refuse life-sustaining therapies, such as cardiopulmonary resuscitation [1,2]. End-of-life issues can include topics such as Do Not Resuscitate (DNR), appointing a health care surrogate, or decisions on end-of-life care such as tracheostomy or placement of a feeding tube. In 2014, 24 years after the legislation was passed, the Institute of Medicine published a report — "Dying in America" — that advocated discussions between clinicians and patients concerning advance care planning and end-of-life care preferences [3]. Despite this legislation and further initiatives to increase the incidence of end-of-life discussions, a recent longitudinal survey from the Health and Retirement Study involving next of kin surrogates of cancer patients failed to show an increase in the use of living wills or end-of-life discussions. These authors advocated for increased efforts to improve communication on end-of-life issues [4].

End-of-life discussions can be difficult for medical professionals to initiate and are often biased by experience, culture, and religion. End-of-life issues are complex and could encompass burial wishes, wishes to settle financial affairs, visits with friends, end-of-life resuscitation (including code status), or any number of other concerns around the end of life.

Nurses spend the most amount of time with patients relative to other members of the healthcare team, and thus often have additional understanding of a patient's care goals. These goals of care include those surrounding end-of-life, and the nurse may be instrumental in helping the patient and family recognize the appropriateness of the timing to end treatment [5]. The many hours nurses spend involved with patient care often result in development of close relationships with patients and their family, which may allow them to identify patient needs [6,7] and failures of treatments earlier [8]. Nurses were selected as the field of interest in this study, as previous studies have shown that nurses can foresee more circumstances for end-of-life decisions than other technical, administrative, or domestic staff [9]. In one study, 81.4% of the nurses surveyed in a New York hospital disagreed with the statement that do-not-resuscitate (DNR) discussions should not be initiated by nurses [10]. One factor that has been shown to influence differences in care practices related to end-of-life decisions is years

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of experience, specifically involving neonatal nurses [11] as well as hematology/oncology nurses [12].

The focus of our study was to survey how often end-of life discussions, which include refusal of life-sustaining therapies, are initiated by nurses in a tertiary medical center, and whether factors such as specialty and experience influence these discussions.

2. Methods

The University of Florida Institutional Review Board approved this study. The survey was constructed using Qualtrics (Qualtrics LLC, Provo, UT), an online survey collection program. Qualtrics is a secure site with rigorous privacy standards. The survey included demographic information as well as questions concerning the discussion of patients' end-of-life wishes. An email with a description of the methodology and a basic informed consent was sent to University of Florida College of Medicine and UF Health email databases. Both the Gainesville and Jacksonville campuses were sent links to the anonymous survey.

Demographic data was obtained that included age, gender, nursing specialty, and years in practice. For the present analysis, we focused on responses from nurses. The survey asked recipients: "Do you regularly talk to your patients about end-of-life wishes?" Answer options were: "Always," "Most of the time," "Sometimes," "Rarely," and "Never."

All analyses were conducted in JMP Pro 13.0 (SAS Institute, Cary, NC). Measures were summarized by proportion (%) of respondents. Chi-square tests were used to separately assess the relationship between age, gender, specialty, and experience, with responses to the question, "Do you regularly talk with your patients about end-of-life wishes?" $P < 0.05$ was considered statistically significant.

3. Results

Descriptive statistics are reported in Table 1. Of the 349 respondents, nearly 39% reported rarely or never discussing end-of-life wishes with patients. A majority of respondents were women (90.5%) and were 30 years or older (86.5%). The most highly represented specialties were critical care (31.1%) and surgery (24.9%). Over one third of these respondents had <10 years of experience.

Table 1
Descriptive statistics for sample ($n = 349$).

Variables	n	%
Age		
<24 years	7	2.0%
24–29 years	40	11.5%
30–49 years	131	37.5%
50–69 years	171	49.0%
Gender		
Male	33	9.5%
Female	316	90.5%
Specialty		
Anesthesiology	25	7.7%
Internal medicine	31	9.5%
Family medicine	20	6.2%
Obstetrics and gynecology	11	3.4%
Pediatrics	47	14.5%
Surgery	81	24.9%
Critical care medicine	101	31.1%
Psychiatry	9	2.8%
Years of experience		
0–9 years	125	35.6%
10–19 years	75	21.5%
20–29 years	77	22.1%
30–39 years	60	17.2%
40–49 years	12	3.4%
Do you regularly talk to your patients about end-of-life wishes?		
Always	30	8.5%
Most of the time	73	20.8%
Sometimes	115	32.8%
Rarely	95	27.1%
Never	38	10.8%

Figs. 1–4 present the frequency of discussing end-of-life wishes with patients stratified by specialty, age, gender, and years of experience. There were statistically significant differences in the frequency of discussions about end-of-life wishes across specialties ($\chi^2 = 128.0$, df = 28, $p < 0.001$). By specialty, only 11.9% of critical care nurses reported rarely or never discussing end-of life decisions with patients, while the majority of nurses in anesthesiology (76.0%) and surgery (59.3%) reported rarely or never having these discussions. Furthermore, only critical care and family medicine had over 40% of their nurses reporting always or most of the time discussing end-of life wishes with patients. There were no statistically significant differences for age ($\chi^2 = 0.96$, df = 4, $p = 0.92$), gender ($\chi^2 = 25.71$, df = 16, $p = 0.06$), or years of experience ($\chi^2 = 11.0$, df = 12, $p = 0.53$).

4. Discussion

The goal of this study was to assess the influence of nursing provider characteristics on the frequency of end-of-life discussions with patients in two tertiary academic health centers. Overall, the results showed that more than one-third of providers do not frequently discuss end-of-life issues with their patients.

A literature review conducted to identify nursing roles in end-of-life discussions identified nurses as medical liaisons, facilitators, supporters, and patient/family advocates [13]. In addition, in studies where physicians and nurses collaborated in end-of-life discussions, length of stay was reduced [14-16].

In our study, experience was not an independent predictor of frequency of end-of-life discussions across specialties. However, we did find differences in frequency of discussions across specialties. It is not surprising that critical care nurses were by far the most likely to report frequently discussing end-of-life issues with patients. Conversely, a majority of anesthesiology and surgery specialty nurses reported infrequent end-of-life discussions that could include DNR conversations in the perioperative care arena.

In a survey performed at Indiana University Hospital, located in an urban area, DNR orders were written more frequently and occurred earlier during the course of hospitalization for patients on a medical service than a surgical service [2]. Similarly, in a retrospective study involving chart reviews of DNR orders on medical and surgical patients, the authors found that 61% of medical patients had a DNR note written by a medicine resident, which was statistically higher compared to only 10% of surgical patients having a DNR note written by the surgery house staff [17]. Our survey results with surgery and anesthesiology nurses are consistent with these findings and could reflect culture and differences in patient population.

In some practices, it is routine for DNR orders to be suspended when the patient goes to the operating room for a procedure. Although attitudes are changing, this culture of suspending perioperative DNR orders can spread to the nurses and staff working in the perioperative setting and is likely reflected in the surgical services practices as well [26]. This is consistent with our findings that 76% of the anesthesia and 59.3% of surgery nurses reported rarely or never having end-of-life discussions with patients and families. However, this is not consistent with the American College of Surgeons and the American Society of Anesthesiologists policy. Both organizations have policies that are focused on "required reconsideration" of DNR orders, centering medical attention toward the patient's goals of care and preferences preoperatively [27, 28].

End-of-life discussions with patients and their loved ones are an important and complex issue. More research is needed to understand these specialty differences, particularly in anesthesiology and surgical specialties. Silveira et al. [18] conducted focus groups in primary care clinics to understand barriers to end-of-life care discussions. They found five elements that foster patient trust: "continuity of care,