NURSES’ COMMUNICATION OF PROGNOSIS AND IMPLICATIONS FOR HOSPICE REFERRAL: A STUDY OF NURSES CARING FOR TERMINALLY ILL HOSPITALIZED PATIENTS

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Although nurses are ideally situated to facilitate communication about prognosis and hospice referral among patients, patients’ family members, and hospital staff, nurses do not always assume this task.1,2 Traditionally, it has been the role of physicians to have such discussions with patients, yet research indicates that nurses often have greater opportunity for communication with patients and act as intermediaries between physicians and patients.3-7 Limited discussion between clinicians and patients about prognosis and treatment options can reduce the likelihood of referral to hospice services and may also hinder timely access to and maximum benefit of those services.

In this study, we built on a previous investigation of nurses’ palliative care practices in acute care settings. In that study, 27% of the 174 nurses in the sam-
ple did not discuss prognosis at all with their terminally ill patients. Only 21% did so with all of their terminally ill patients, and less than 50% of the respondents discussed hospice care with any of their terminally ill patients. Nurses more often initiated end-of-life conversations with patients’ family members; 62% routinely talked about prognosis with the families of all patients, and 64% discussed hospice care at least some of the time. In this article, we offer preliminary evidence that may help explain why nurses do not always speak with patients and patients’ families about prognosis and hospice care.

Limited discussions between clinicians and patients about prognosis reduce the likelihood of hospice referral.

Methods
Study Design and Sampling
The investigation was an analysis of data collected in a previous cross-sectional study in which 174 hospital-based nurses completed a self-administered, anonymous survey. In that study, 6 hospitals were randomly selected from all community hospitals in Connecticut with more than 200 licensed medical/surgical beds. Thirty eligible nurses from each hospital were randomly selected to participate in the study.

To be eligible to participate, nurses had to be staff nurses, because practice might differ substantially according to nursing role (eg, staff nurse vs nurse specialist); full-time employees of the hospital (working at least 30 h/wk); employed at the hospital for at least 6 months before the study to ensure that they had adequate experience to complete the questionnaire effectively; and assigned to a medical, cardiology, pulmonary, oncology, or other care unit where terminally ill patients are routinely cared for. Nurses primarily assigned to intensive care units, pediatric units, or in-hospital hospice units were excluded in order to better assess the practice of end-of-life care in the settings that provide care for the majority of terminally ill patients.

Survey Instrument
For the original study, data collection, analysis, and reporting procedures were approved by the institutional review boards of the Yale School of Medicine and the 6 participating hospitals. Before data collection in that study, the survey questionnaires were tested with a sample of 50 clinicians, including several nurses at the Connecticut Hospice in Branford, Conn, to ensure the comprehensibility and comprehensiveness of the instrument. During data collection, questionnaires were hand-delivered to participants by either the research team or the participants’ nurse managers. Completed questionnaires were mailed back to the research team in self-addressed, stamped envelopes enclosed with the surveys. Surveys were checked for completeness by members of the research team, who followed up by telephone to resolve unclear or missing data. All potential participants were followed up in person or by telephone to enhance response rates.

The questionnaire included both open- and closed-ended questions. This article is a descriptive analysis of the responses to the open-ended questions. The open-ended items asked respondents to give common reasons that could account for lack of communication about prognosis and hospice referral, including why hospice care was sometimes not discussed at all with terminally ill patients and the patients’ family members, why some patients and family members were not told the terminal prognosis, or why a delay occurred in telling patients and patients’ family members the terminal prognosis.

Data Analysis
Content analysis was used to analyze data. Three reviewers, a nurse, a social worker, and a gerontologist, independently coded the data. Discrepancies were reconciled through line-by-line review of coded material until consensus was reached. During this process, 5 main coding categories were identified: (1) patients’ influence and issues, (2) influence and issues of patients’ family members, (3) disease process, (4) clinicians’ influence and issues, and (5) other issues. These 5 categories were further subdivided into 56 subcodes. Key themes emerged that identified common obstacles to discussion of prognosis and hospice care, and 24 of the subcodes were grouped to characterize 5 main obstacles to communication. The proportion of nurses who reported common obstacles to discussion of prognosis and hospice referral and the frequency with which each obstacle was reported were described by using standard frequency analyses. SAS, version 8.0, software (SAS Institute Inc, Cary, NC) was used for all analyses.

Results
Study Sample
Of the 219 nurses who were approached to participate in the original study, 39 declined; these nurses were replaced with randomly selected nurses until sur-
veys from 30 nurses from each hospital were collected, reflecting an 82% participation rate. Those who declined to participate did not vary significantly from those who did participate in terms of hospital affiliation, unit assignment, or sex. Because of the limited data available on nonparticipants, response bias could not be assessed in terms of years in practice, education, or nursing license. Surveys from 6 licensed practical nurses who had completed the survey because they were considered to be in a staff nurse position were dropped from the study because of the small number. Thus, the final sample consisted of 174 nurses.

Most participants were female (94.8%) and white (94.3%) (Table 1). The sample was well-educated and experienced; 59.2% had a bachelor’s or a more advanced degree, and 44.2% had practiced nursing for at least 10 years. Among the participants, 33.3% worked in internal medicine, 27% in cardiology, 10.3% in oncology, and 4% in pulmonary medicine. The remaining 25.3% practiced in other areas, such as critical care, emergency medicine, medical-surgical, and general acute medicine. The mean number of terminally ill patients cared for by each participant within the previous 3 months was 7.5, although the number reported varied widely (SD = 9.0).

### Common Obstacles to Communication

Five major obstacles to communication of prognosis and referral to hospice were identified:

1. unwillingness of a patient or the patient’s family to accept a prognosis and/or hospice care,
2. sudden death of a patient or sudden change in the patient’s status that prevented communication,
3. belief of physicians’ hesitancy,
4. nurses’ discomfort, and
5. nurses’ desire to maintain hope among patients and patients’ families.

Table 2 gives the percentages of nurses who reported that each obstacle had occurred within the past 3 months as the nurses cared for terminally ill patients.

**Unwillingness of a Patient or the Patient’s Family to Accept a Prognosis and/or Hospice Care.** Unwillingness to accept a terminal prognosis or the prospect of hospice care was ascribed to patients’ and families’ nonacceptance of the patient’s terminal status, fear of the patient’s death or need for hospice care, discomfort with hospice philosophy or regulations, the desire to maintain patients’ hope, and/or the wish to continue aggressive treatment.

**Sudden Death of the Patient or Sudden Change in the Patient’s Status That Prevented Communication.** A

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**Table 1** Description of the sample (N = 174)

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. of respondents</th>
<th>%*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female sex</td>
<td>165</td>
<td>94.8</td>
</tr>
<tr>
<td>White</td>
<td>164</td>
<td>94.3</td>
</tr>
<tr>
<td>Nonwhite</td>
<td>10</td>
<td>5.7</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocational degree or diploma</td>
<td>30</td>
<td>17.2</td>
</tr>
<tr>
<td>Associate degree</td>
<td>41</td>
<td>23.6</td>
</tr>
<tr>
<td>Bachelor’s degree or higher</td>
<td>103</td>
<td>59.2</td>
</tr>
<tr>
<td>Practice area</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Internal medicine</td>
<td>58</td>
<td>33.3</td>
</tr>
<tr>
<td>Oncology</td>
<td>18</td>
<td>10.3</td>
</tr>
<tr>
<td>Cardiology</td>
<td>47</td>
<td>27.0</td>
</tr>
<tr>
<td>Pulmonary medicine</td>
<td>7</td>
<td>4.0</td>
</tr>
<tr>
<td>Other service</td>
<td>44</td>
<td>25.3</td>
</tr>
<tr>
<td>Years in practice</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10</td>
<td>97</td>
<td>55.7</td>
</tr>
<tr>
<td>10 to &lt;20</td>
<td>39</td>
<td>22.4</td>
</tr>
<tr>
<td>≥20</td>
<td>38</td>
<td>21.8</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>12.3 (10.5)</td>
<td>NA</td>
</tr>
<tr>
<td>No. of terminally ill patients cared for</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;4</td>
<td>6</td>
<td>35.1</td>
</tr>
<tr>
<td>4-19</td>
<td>91</td>
<td>52.3</td>
</tr>
<tr>
<td>20 to &gt;20</td>
<td>16</td>
<td>9.2</td>
</tr>
<tr>
<td>Unknown</td>
<td>6</td>
<td>3.4</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>7.5 (9.0)</td>
<td>NA</td>
</tr>
</tbody>
</table>

*Because of rounding, percentages may not all total 100. NA indicates not applicable.

**Table 2** Nurses’ most commonly reported obstacles to communication of prognosis and referral to hospice care (N = 174)*

<table>
<thead>
<tr>
<th>Obstacle</th>
<th>No discussion of prognosis or hospice care</th>
<th>No referral to hospice care</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>No. of respondents</td>
<td>%</td>
</tr>
<tr>
<td>Unwillingness of patient or patient’s family to accept prognosis and/or hospice care</td>
<td>68</td>
<td>39.1</td>
</tr>
<tr>
<td>Sudden death of patient or sudden change in patient’s status that prevented communication</td>
<td>51</td>
<td>29.3</td>
</tr>
<tr>
<td>Belief of physicians’ hesitancy</td>
<td>54</td>
<td>31.0</td>
</tr>
<tr>
<td>Nurses’ discomfort</td>
<td>37</td>
<td>21.3</td>
</tr>
<tr>
<td>Nurses’ desire to maintain hope among patients and patients’ families</td>
<td>28</td>
<td>16.1</td>
</tr>
</tbody>
</table>

*Many nurses described more than 1 of the 5 obstacles.
second reported obstacle was the sudden or imminent death of a patient before the patient’s nurse could initiate a conversation about the patient’s prognosis or hospice care or a change in the patient’s status that prevented communication, such as unconsciousness (e.g., the patient was in the intensive care unit, on life support, or in a coma) or confusion (e.g., the patient had dementia or was being given sedatives).

**Belief of Physicians’ Hesitance.** A third obstacle was nurses’ sense of physicians’ hesitancy to discuss prognosis and hospice care. Several reasons for this obstacle were reported, including the perception that physicians did not feel it was their responsibility to conduct such conversations and the physicians’ desire to continue aggressive treatment. Some respondents reported that they thought physicians were hesitant because of a difficulty in determining a prognosis, which was sometimes attributed to waiting for laboratory reports but more often to different definitions of “terminal” among clinicians, that is, how close a patient had to be to death to be considered terminal.

**Nurses’ Discomfort.** Respondents reported their own discomfort as an obstacle to communicating about prognosis and hospice care. This discomfort seemed to originate from a general discomfort with death and dying. Some respondents thought it was not their responsibility to facilitate discussions about prognosis and hospice care, whereas others thought they were too busy or that it was too much trouble to initiate communication on prognosis and hospice care.

**Nurses’ Desire to Maintain Hope Among Patients and Patients’ Families.** A final obstacle was nurses’ desire to bolster positive thoughts among patients and patients’ family members. Respondents reported putting off discussions about terminal prognosis or referral to hospice care until they thought a patient or the patient’s family could handle these conversations. Fear of the reaction of a patient and/or the patient’s family members to bad news or of causing upset were also reported as obstacles.

Some nurses thought it was not their responsibility to discuss prognosis and hospice referral.

**Discussion**

In this study, the perceptions of the unwillingness of patients and their families to accept prognosis and referral to hospice care were those of the nurses. This issue is complex because if the nurses’ perceptions were correct, then perhaps not having a discussion was best; however, if the perceptions were wrong, then patients and patients’ families might have lost the opportunity to be informed and to make patient-centered choices. Helping patients and their family members be more open to discussion of treatment options could be part of the nurses’ role.

The frequency with which the sudden death of a patient was mentioned was striking because all patients about whom these acute care nurses were reporting experiences were terminally ill and were expected to die within 6 months. This finding highlights the complexity of prognosticating; even patients with terminal illnesses seemed to die suddenly when the death was not expected or was not adequately planned for. This finding also highlights the need to be proactive about end-of-life communication, because acute care nurses often report having little warning before the moment of a patient’s death. Because of the discomfort of discussing sensitive topics, conversations about prognosis and hospice referral may be put off longer than nurses may realize.

A possible effect of physicians’ hesitancy to discuss a patient’s prognosis is that the patient and the patient’s family may be given an unrealistic idea of how long the patient has to live, a situation that can affect care choices. Discussion of hospice care may be put off if a patient is not considered terminal. For example, if a physician considers a patient to be terminal only in the last 24 to 48 hours of life, then the patient is unlikely to get to a hospice facility in time to receive complete hospice care. Delay in prognosticating terminal status may also contribute to the sense of the suddenness of death for nurses and patients’ family members.

Physicians’ hesitancy may also keep nurses from speaking to patients about prognosis and referral to hospice care. For instance, if a nurse sees a physician hesitate in telling a patient or the patient’s family the patient’s prognosis, the nurse may be hesitant to lead a discussion with the patient and the patient’s family. In fact, such delay might be reinforced by the healthcare team; despite adequate opportunity to communicate with patients and patients’ families about end-of-life choices, nurses may be unable to affect end-of-life discussions if other members of the healthcare team, including physicians, do not support such communication.

Although some respondents reported discomfort, the actual number of nurses who did not address prognosis and hospice referral because of discomfort with the topic may have been underreported because of the social desirability of having such discussions with patients and patients’ families. For nurses who reported that it was not their responsibility to discuss prognosis
and referral to hospice care, that they were too busy, or that it was too much trouble to initiate such conversations, the lack of attention might have been due to the nurses’ discomfort. Yet, there is a reality to having limited time to engage in what can be a lengthy and emotionally taxing discussion, a reality more pressing during shortages of nurses. Hospital-based nurses care for large number of patients because of understaffing and may not have the time, expertise, or designated responsibility to take on the task of discussing prognosis and referral to hospice care. Assuming this responsibility may enable patients to better understand their prognosis and ease the transition from curative to hospice care.

Finally, maintaining hope is an important aspect of treatment. Nurses face the difficult task of balancing sensitivity to the emotional needs of patients and patients’ families with being realistic enough about time limitations to allow enough time for patients to absorb the terminal status and discuss care options. Apprehension of being the one to convey bad news may prevent nurses from taking on this task. Discussions of prognosis and referral to hospice care may be delayed or may not happen at all in the well-intentioned attempt to maintain hope among patients and patients’ families, when it is perhaps the nurses’ hope that may be maintained by doing so. Nurses who responded that they did not discuss referral to hospice care because they did not want to reduce the hope of patients or patients’ family members appeared not to understand a critical aspect of hospice care, which is to maintain hope in the face of incurable disease. By enabling patients to live each day as fully as possible for the time they have left, hope for high-quality life can be maintained despite the progression of disease.

The Figure provides a conceptual model of the relationship between the 5 most commonly reported obstacles to communication about prognosis and referral to hospice care. The model presents each obstacle and the responses representative of each obstacle. As the arrows indicate, each obstacle can prevent the discussion of prognosis and hospice care and prevent referral to hospice care.

### Nurses did not discuss hospice referral in an attempt to maintain patients’ hope, even though a critical focus of hospice care is to maintain hope.

#### Implications for Nursing Practice

An interesting finding of this study is the perception that the death of terminally ill patients is sudden. What does this finding say about clinicians’ expectations for terminal patients, and how do clinicians’ expectations affect planning and preparation for patients’ deaths? Adequate care planning anticipates the death of terminally ill patients so that treatment can proceed accordingly, patients can complete unfinished business, and patients’ friends and families can assist and spend time with the patients. Death of a terminally ill patient that comes as a surprise may indicate clinicians’ discomfort with death and lack of appropriate care planning.

Another explanation for the sense of suddenness of death is an unfamiliarity of acute care physicians and nurses with patients. Shortened lengths of stay in hospitals can lead to clinicians’ feelings of unfamiliarity with patients or not having the opportunity to connect with patients. Therefore, clinicians do not always have prior experience with patients that might help them judge if and how a patient’s health status has changed and if death is imminent. Although a patient’s death may seem sudden, the reality can be that the patient’s clinicians do not know the patient well, that the clinicians have not seen the patient before, or that information about the patient has not been transmitted between providers to enable continuity of care. Although physicians were not included in the original study, shared care of patients between attending physicians and house staff, as well as increasing specialization, can inhibit individual physicians’ consistent contact with patients. Under these circumstances, the responsibility of talking to patients can be repeatedly shifted or not taken on by any one healthcare professional.
Assumption of accountability is a task that hospital-based nurses can take on, even if it is not they who initiate end-of-life conversations with patients. If a patient does not have a single clinician who is overseeing and coordinating the patient’s care, then nurses can step in and fill this role when the time presents itself. If not, an opportunity for providing good end-of-life care is missed. Assuming responsibility for care coordination is especially important at the end of life with the increased emphasis on advance directives and living wills. This assumption of responsibility is also particularly important during a hospitalization, because that is when patients’ conditions are most unstable. Nurses in acute care settings are therefore present at the ideal time to assess patients’ situations and create a care plan.

The finding that nurses may not talk about prognosis and hospice referral with patients in order to maintain the hope of patients and patients’ families also has implications for nurse training programs. Along with the need for programs to help increase nurses’ knowledge base of the process of death and dying is the need to help nurses develop skills for communicating with patients and patients’ families, such as breaking bad news in a manner that is both realistic and sensitive. In addition, nurses should be knowledgeable about hospice care in order to educate patients and patients’ family members about hospice philosophy so that the idea of hospice placement is not dismissed because of misinformation. Training programs might also include a component on the experience of working with terminally ill patients and their family members to help nurses become familiar with the nurses’ own feelings about death so the nurses can accurately perceive and respond to situations with patients and patients’ family members and
feel comfortable and effective doing so. (The John D. Thompson Hospice Institute for Education, Training, and Research, Inc, has successfully offered 12 courses to nurses to help improve end-of-life communication. The Yale School of Nursing Home Care Division uses Connecticut Hospice as a training site to help teach nurses how to speak with families about end-of-life issues.)

Nurses reported the death of terminally ill patients as being sudden, suggesting that unfamiliarity with patients and discomfort with death may result in inadequate care planning.

Improved knowledge in all of these areas would be useful not only in nurses’ interactions with patients and patients’ family members but also within the healthcare team. Explicit, informed communication among team members would help prevent role confusion by making it clear which team member would be the one to discuss prognosis and hospice care with patients and patients’ families. Possibly, some nurses do not discuss prognosis and hospice care because they think physicians are conducting these discussions. Better communication would also help the healthcare team have consensus on the definition of terminal prognosis so that there is a sense of when to initiate conversations about prognosis and hospice care. This suggestion is not a call for a universal definition of terminal status, but rather for individual healthcare teams to establish and use a common vocabulary. The Summary Guidelines for Initiation of Advanced Care offer excellent guidance on when referral to hospice care should be initiated; however, these guidelines may not be universally known and applied. Improved skills in all of these areas may help nurses accurately perceive and respond to situations with patients and patients’ families, become familiar with the nurses’ own feelings about death, function well as members of the healthcare team, and thus become more effective in communicating critical information about choices at the end of life.

ACKNOWLEDGMENTS

We thank Robin Moore and Elias Hyams for their assistance with coding the data for this study. This research was supported by the John D. Thompson Hospice Institute for Education, Training, and Research; the Nathan Cummings Foundation; the US Army Breast Cancer Research Program, grant number DAMD17-00-1-0509; a grant from the Claude D. Pepper Older Americans Independence Center at Yale University; and the Patrick and Catherine Weldon Donaghue Medical Research Foundation. This research was performed at Yale University.

Commentary by Mary Jo Grap (see shaded boxes).

REFERENCES

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Am J Crit Care 2005;14 64-70
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