Beyond the Supreme Court Decision: Nursing Perspectives on End-of-Life Care

Betty Ferrell, PhD, FAAN, Rose Virani, RNC, BSN, MHA, OCN®, Marcia Grant, DNSc, FAAN, Patrick Coyne, RN, MSN, CS, CRNH, and Gwen Uman, RN, PhD

Purpose/Objectives: To describe nurses' views of care of the terminally ill.

Design: Descriptive cross-sectional survey.

Sample: 300 nurses who completed a survey published in *Nursing98* and *Nursing Management* and 2,033 nurses randomly selected from the Oncology Nursing Society (N = 2,333).

Methods: Mailed end-of-life (EOL) care survey.

Main Research Variables: Dilemmas, barriers, and effectiveness of EOL care and education and attitudes regarding assisted suicide and euthanasia.

Findings: EOL care dilemmas are common in nursing practice, and many barriers exist to providing quality EOL care. Issues of euthanasia and assisted suicide are particularly significant to nurses who struggle to provide pain and symptom relief amid a system characterized by deficiencies in EOL care.

Conclusions: Improved care is contingent on adequate education of nurses as the primary caregivers of patients and families who are facing the end of life. Study findings provide direction for improved care of the terminally ill.

Implications for Nursing Practice: Oncology nurses are centrally involved in care of the terminally ill. Major reform is needed to provide quality EOL care.

Key Points . . .

- Nurses face many barriers and ethical dilemmas in end-of-life (EOL) care.
- Oncology nurses commonly care for the dying and need increased education to provide competent and compassionate care.
- For the most part, basic nursing programs do not teach students about EOL care.
- In their role as providers of EOL care, nurses are in a position to receive requests from patients and their family members to assist with dying or to administer lethal doses of medication to relieve suffering.

The controversy regarding assisted suicide reached an historical milestone in 1997 as the United States Supreme Court considered the "right to die" (Burt, 1997). The court's decision that no such constitutional right exists redirects society's attention to the paramount issues and needs of the terminally ill. Because of the Supreme Court decision, healthcare professionals now must reevaluate their commitment to end-of-life (EOL) care and formulate strategies to address the major deficiencies that became so glaringly evident during the Supreme Court deliberations. As the primary group of professionals caring for the dying, nurses must respond to this ethical and social mandate for change. This article reports the results of a survey completed by 2,333 nurses in 1998 regarding dilemmas, barriers, educational needs, and effectiveness of EOL care. One survey respondent expressed the need for increased attention to nursing education with the following.

My most vivid memory of end-of-life care content in my basic diploma program is from a postconference. My roommate raised questions about all the care being given in an intensive-care unit setting to a dying patient. The instructor dismissed her concerns. When she persisted in arguing the futility of the care, the instructor dismissed her! We learned—don't bring up ethical issues regarding dying patients.

This survey was an attempt to describe nursing perspectives of several key issues related to care of the dying.

Literature Review

Several studies were conducted from 1996–1998 regarding EOL care. Interestingly, most of these studies fo-

Betty Ferrell, PhD, FAAN, is a research scientist, Rose Virani, RNC, BSN, MHA, OCN®, is a research specialist, and Marcia Grant, DNSc, FAAN, is a research scientist, all at City of Hope National Medical Center in Duarte, CA. Patrick Coyne, RN, MSN, CS, CRNH, is a clinical nurse specialist at the Medical College of Virginia Hospitals in Richmond, and Gwen Uman, RN, PhD, is a statistician at Vital Research in Los Angeles, CA. *This research was funded by a grant from the Robert Wood Johnson Foundation. (Submitted June 1999. Accepted for publication November 2, 1999.)*

cused only on the topics of assisted suicide and euthanasia rather than other topics of importance in caring for the terminally ill. During these same years, the actions of Jack Kervorkian, MD, the Supreme Court ruling on the "right to die" (Burt, 1997), and the Institute of Medicine's report, "Approaching Death: Improving Care at the End of Life" (Field & Cassel, 1997), increased attention to this topic and undoubtedly prompted these studies.

Several studies have focused on physician views of assisted suicide and euthanasia. In 1998, Meier et al. published the results of a national survey of physician specialists in the United States who were most likely to receive requests from patients for assistance with suicide or euthanasia. The mailed survey resulted in 1,902 responses. Of the respondents, 11% said that they would be willing to prescribe medication to hasten a patient's death under certain circumstances and 7% reported that they would administer a lethal injection under current legal constraints. When asked what they would do if these practices were legal, 36% and 24%, respectively, said they would prescribe medication or administer a lethal injection. Eighteen percent reported having received a request from a patient for assistance with suicide. Eleven percent reported receiving a request for lethal injection. Of the physicians receiving requests, 16% (3% of the entire sample) reported that they had written at least one prescription to be used to hasten death and 5% reported that they had administered at least one lethal injection. In this study, oncologists were more likely to have received requests for a prescription, but physicians in other specialties were more likely to be willing to provide assistance under current law.

Howard, Fairclough, Daniels, and Emanuel (1997) conducted a study in which they surveyed only oncologists. These researchers interviewed 355 randomly selected oncologists about their attitudes and practices related to euthanasia and assisted suicide. Approximately 48% reported that they could imagine a situation in which they might desire euthanasia or assisted suicide for themselves. Of those who could imagine such a situation, 86% found these actions acceptable for their patients. Of those oncologists who could not imagine such a situation, 42% still found these interventions ethical for their patients. Only 7% of oncologists reported that they would desire these actions for themselves while finding them unacceptable for patients. This study provides an interesting perspective on the association between personal beliefs and professional practice.

Emanuel, Fairclough, Daniels, and Clarridge (1996) also conducted a study involving physicians. Telephone interviews were conducted with 155 patients with cancer, 355 oncologists, and 193 individuals from the public. In this study, two-thirds of the patients and the public supported assisted suicide and euthanasia as acceptable for patients experiencing unremitting pain. Interestingly, patients surveyed who actually had pain themselves were less likely to support assisted suicide or euthanasia. More than 25% of patients had seriously thought about these issues, and 12% had discussed them with their physician or others. More than half of the physicians reported receiving requests for assisted suicide or euthanasia. Significant findings of the study were that one of seven physicians reported actually carrying out assisted suicide or euthanasia and that patients who were depressed were more likely to request assisted suicide. Therefore, the researchers emphasized that patients who request such an intervention should be evaluated and treated for depression before euthanasia is discussed.

Several studies involving nursing attitudes or practices related to assisted suicide or euthanasia also have been conducted. Asch's (1996) study involving 1,139 critical-care nurses was one of the most controversial. The analysis was based on responses to a written survey from 852 critical-care nurses who practiced exclusively in the intensive-care unit. Of these nurses, 17% reported receiving requests for euthanasia or assisted suicide and 16% reported having engaged in such practices. Of the respondents, 4% also reported hastening death by pretending to provide life-sustaining treatments. This study received tremendous response and criticism from the nursing community. Scanlon (1996) responded with an editorial in the *New England Journal of Medicine* that cited many flaws in the research, including lack of testing of the survey instrument and many vague and confusing terms that challenge the validity of the findings. The controversies surrounding this study remained, and, in 1998, Maeve wrote an additional follow-up criticism of the Asch study. One of the major concerns cited by Maeve was the potential harmful effects that occur when such findings are reported. Maeve stated that such reported findings alarm family members and create fear that their loved ones might be endangered in the care of critical-care nurses. Both Maeve and Scanlon also challenged the appropriateness of a physician (Asch) studying nurses in isolation.

In an additional response to the Asch (1996) study, Leiser, Mitchell, Hahn, and Abrams (1996) reported findings that were similar to the critical-care survey from a study of the AIDS population. In a letter to the editor published in the *New England Journal of Medicine*, these authors reported findings of a survey of 428 nurses involved in care of patients with AIDS. Of the nurses who received surveys, 50% responded. Of these 50%, 15% reported assisting in the suicide of a patient with AIDS and 37% reported receiving direct requests to end the life of a patient with AIDS.

Two previous studies have used Oncology Nursing Society (ONS) members to evaluate similar issues with nurses. Young, Volker, Rieger, and Thorpe (1993) received 1,210 responses to a random survey of 2,000 ONS members. The survey included vignettes and questions. When asked about a terminally ill patient with whom the nurses had a long-term relationship, 44% agreed with the concept of physician-assisted death and would remain with the patient through the ordeal. Twenty-nine percent disagreed with this concept but would stay with the patient, and 24% disagreed and would not remain present with the patient if death were assisted. The investigators found that nurses held widely divergent views regarding these topics. Although many nurses favored physician-assisted death, they also expressed reluctance to administer medication that would cause death.

Matzo and Emanuel (1997) examined a sample of 600 New England-region ONS members. Four hundred forty-one nurses (73%) responded to a survey that was a replica-

tion of work previously done with the physician sample (N = 355). The investigators compared results from the nurse sample with results from the physician sample and found that although 11% of physicians had assisted in a patient's death, only 1% of nurses reported doing so. However, nurses were more likely than physicians to have performed patient-requested euthanasia (4% versus 1%). Nurses reported frequently consulting with others, particularly physicians, about patient requests for assistance with dying, but nurses rarely consulted each other or nursing supervisors.

The controversial issues of assisted suicide and euthanasia have prompted great attention to EOL care (Coyle, 1992; Davis et al., 1995). As Meier et al. (1998) acknowledged, the debate about these topics is only one portion of the overall problem of EOL care. Although the literature has focused predominately on contrasting differences and opinions, both sides of the debate generally have strongly agreed that EOL care needs to be improved. Many professional organizations, including the American Nurses Association (1994) and ONS (1995), have issued position statements on euthanasia, assisted suicide, and other EOL care issues.

Ferrell, Grant, and Virani (1999) recently conducted a survey of faculty and deans of nursing schools and representatives of state boards of nursing to evaluate the current status of nursing education and EOL care. The 725 respondents identified gaps in all aspects of EOL care in nursing school curricula; however, most respondents recognized EOL care as important for all nurses and also perceived faculty members and schools as interested in making change. Following this survey of nursing faculty, the investigators determined that having input from practicing clinical nurses related to overall needs of EOL care would be useful. This study was designed to contribute to the literature by providing data regarding numerous EOL care issues as well as the specific topics of assisted suicide and euthanasia from the perspective of nurses.

Methods

Study Questions

The following questions guided the survey.

1. What are the most common dilemmas experienced by nurses in EOL care?
2. What are the most common barriers perceived by nurses in EOL care?
3. How do nurses rate the effectiveness of EOL care and EOL education?
4. What are nurses' beliefs and practices regarding assisted suicide and euthanasia?

Procedures

For this descriptive study, the investigators developed and used a mailed survey. The survey instrument included items that covered dimensions of dilemmas, barriers, and effectiveness of EOL care and education and issues of euthanasia and assisted suicide. Eight consultants reviewed the survey, which then was revised extensively. The project consultants had expertise in EOL medical care, palliative nursing care, ethics, and nursing education. The eight consultants provided input on the survey content, item construction, and format. The investigators developed the content of the survey based on previous literature, including the key studies previously cited in this article and, to reflect current issues of EOL care, key sources such as the Institute of Medicine's *Approaching Death: Improving Care at the End of Life* (Field & Cassel, 1997). The final survey included 30 items: four items to assess barriers to effective EOL care, three items related to EOL education, six items to assess self and colleagues' knowledge of and effectiveness in providing EOL care, nine items related to assisted suicide and euthanasia, seven demographic items, and one open-ended question inviting comments.

The investigators attempted to avoid some of the problems that other researchers have encountered in similar studies, such as those noted in the Asch (1996) study. They consulted Colleen Scanlon, RN, JD, and used input from her and the project consultants to extensively refine the tool. To avoid confusion in terms, for example, the investigators constructed clearly defined items (e.g., Rather than asking, "Have any of your patients requested assisted suicide?" the item asked, "Has any patient requested your help in getting a prescription for medication to use with the primary intention of ending his or her own life?"). All items, particularly the nine items exploring issues of assisted suicide or euthanasia, were worded similarly to offer clear understanding. The survey then was published in *Nursing98* (Ferrell, 1998) and *Nursing Management*. Three hundred responses were received. Because the investigators were seeking a larger sample, they decided to mail directly to oncology nurses involved in EOL care. A random sample of 5,000 nurses from the ONS membership was obtained. These individuals received the survey, a letter of instruction, and a return envelope. A total of 2,033 responses (40% return) were received from this one-time mailing by the cut-off date, which provided a total of 2,333 responses to the survey. A response of approximately 2,000 ONS members provides 95% confidence that the sample is representative of the total ONS membership ($p = 0.05$).

Results

Demographics

Table 1 presents the demographic data of the 2,333 respondents to the survey. The mean time since becoming licensed as a nurse was 23 years, and the mean age was 46 years. The predominant location of practice was hospital (52%) followed by ambulatory care/outpatient (28%). Respondents identified the most common clinical areas as oncology (70%) and medical/surgical (13%). The predominant education level obtained was a master's degree (40%). Respondents most frequently identified staff/clinical nurse (33%) and clinical specialist/nurse practitioner (25%) as their job title.

End-of-Life Care Dilemmas

Table 2 presents a summary of the dilemmas that the subjects most frequently experienced in their clinical settings. Respondents were asked to rate these dilemmas based on their occurrence as "not common," "somewhat common," or "very common." The dilemmas are presented from highest rate of occurrence to lowest rate of

Table 1. Demographics

Characteristic	n	%
Years licensed as a nurse		
$\bar{X}$ = 23	–	–
Age (years)		
$\bar{X}$ = 46	–	–
Range = 18–80	–	–
Employment setting (n = 2,310)[a]		
Hospital	1,200	52
Ambulatory care/outpatient clinic	651	28
Hospice	209	9
Home health care	159	7
Rehabilitation	21	1
Other	407	18
Clinical area (n = 2,307)[a]		
Oncology	1,603	70
Medical/surgical	301	13
Administration	133	6
Education	122	5
Critical care	82	4
Pediatrics	47	2
Emergency	22	1
Operating room/postanesthesia	10	< 1
Other setting	462	20
Education level (n = 2,220)		
Diploma	242	11
Associate	221	10
BSN/BS/BA	725	33
MSN/MS/MA	883	40
PhD/EdD/DNSc	75	3
Other	74	3
Job title (n = 2,262)		
Staff/clinical nurse	746	33
Clinical specialist/nurse practitioner	558	25
Nurse manager	260	11
Nurse director/executive	156	7
Charge nurse	143	6
Other	399	18

N = 2,333

[a] Some subjects indicated more than one employment setting and clinical area.

occurrence. The most frequently occurring dilemmas were use of advance directives and preserving patient choice/self-determination, which 37% and 23%, respectively, cited as very common. Interestingly, 93% of respondents cited requests for assisted suicide and requests for euthanasia as not common dilemmas, and 6% cited these requests as somewhat common. More than one-third of all nurses reported seven of the nine dilemmas, excluding those of assisted suicide and euthanasia, as somewhat common or very common. Acknowledging the diversity in responses to these dilemmas is important. For example, although 37% of respondents reported use of advance directives as very common dilemmas, 31% of the respondents reported this area as not common.

Barriers to Effective End-of-Life Care

Table 3 presents a summary of barriers to effective EOL care. Respondents were asked to rate how much of a barrier each factor was to providing good EOL care in their settings. The items were rated as "not a barrier," "somewhat of a barrier," or "a severe barrier." Respondents most frequently cited "influence of managed care on end-of-life care" (25%) as a severe barrier followed closely by "lack of continuity of care across settings" (23%). The barriers reported as common and the diversity of these barriers illustrate the complexity of effective EOL care. The respondents identified not only system barriers (e.g., continuity of care, influence of managed care) but also cited patients' (70%) and family members' (73%) avoidance of death as somewhat of a barrier. Other prominent barriers were healthcare providers' lack of knowledge and personal discomfort with death.

Effectiveness of End-of-Life Care

Table 4 presents data from two survey questions that were related to effectiveness of EOL care. The first question asked respondents to rate the effectiveness of various aspects of EOL care in their setting. The aspects were rated as "not at all effective," "somewhat effective," or "very effective." Pain assessment (52%) and management (50%) were rated as very effective followed by symptom management (44%) and psychological support for dying patients (41%). Attention to spiritual needs and bereavement support were rated as least effective. Respondents also were asked to rate the effectiveness of care of the dying today as compared to five years ago. Of the respondents, 4% felt that it was worse, 30% rated it as about the same, and 66% rated it as better than five years ago.

Respondents were asked to rate how effective they were in caring for the dying. Results indicated ratings of 0.5% as being not effective, 28% as being somewhat effective, and 71.5% as being very effective. The respondents then were asked to rate the effectiveness of their nursing colleagues. Subjects rated their colleagues as less effective than themselves, with only 47% rating their colleagues as very effective as compared to the 71.5% who rated themselves as very effective. The final question in this category asked the nurse respondents to rate the effectiveness of physicians in their setting in caring for dying patients. Physicians were rated as not effective (11%), somewhat effective (60%), and very effective (29%).

End-of-Life Education

Table 5 presents data regarding several items evaluating EOL education. Of the respondents, 72% said that they cared for dying patients during nursing school and 87% stated that they cared for dying patients in their current role. The resources identified as most often used for EOL care information were journals (90%), seminars (89%), and colleagues (89%). Of the respondents, 64% used textbooks. Only 20% reported using the Internet for EOL information.

Subjects also were asked to rate the adequacy of their basic nursing education in preparing them for aspects of EOL care. Less than 13% of the subjects rated all of the nine aspects of nursing education that were offered in the survey as very adequate. The areas most frequently rated as not adequate were pain management (71%), overall content on EOL care (62%), and roles/needs of family caregivers (61%). The respondents were asked the importance of EOL care content to basic nursing education, and

Table 2. Frequency of Occurrence of End-of-Life (EOL) Care Dilemmas

Dilemmas	Very Common	Somewhat Common	Not Common
Use of advance directives	37%	32%	31%
Preserving patient choice/self-determination	23%	48%	29%
Uncertainty about patients' prognosis	13%	44%	43%
Fear of causing death by giving pain medication	11%	34%	55%
Discontinuing life-sustaining therapies	11%	48%	41%
Withholding/withdrawing medically provided nutrition/hydration	8%	42%	50%
Legal issues at EOL	7%	39%	54%
Requests for assisted suicide	1%	6%	93%
Requests for euthanasia	1%	6%	93%

N = 2,333

10% reported that it was somewhat important, with 89% rating EOL content as very important. Of the respondents, 35% rated themselves as somewhat knowledgeable and 65% as very knowledgeable.

Assisted Suicide

The survey asked questions related to assisted suicide, beginning with a question that asked subjects whether they supported the legalization of assisted suicide (see Table 6). Of the respondents, 30% reported yes and 20% reported that a patient had requested their help in getting a prescription for medication to use with the primary intent of ending his or her own life. The next question asked subjects to list how many of their patients had requested help in obtaining such a prescription since they began to work as a nurse. The mean score was 1.78, with 77% of respondents reporting no requests and 16% reporting one to five requests. The range of requests was from 0–300. The nurses then were asked specifically about such requests during the prior 12 months. The mean was reduced to 0.24, and the range also reduced to 0–30. Of the respondents, 90% reported no such requests during the prior 12 months, with 9% reporting one to five requests during the previous year.

The survey asked the nurses to move beyond requests for assisted suicide to identify the number of patients that they had helped to obtain such a prescription since they began to work as a nurse and then specifically during the prior 12 months. Since beginning to work as a nurse, subjects reported helping a mean of 0.14 patients to obtain such a prescription, with a range of 0–25. Of the respondents, 97% reported never having helped patients obtain such a prescription and 2% reported assisting one to five patients. When asked specifically about the prior 12 months, the mean was reduced to 0.04, with 99% of nurses reporting no such action and 1% reporting assisting in the range of one to three patients.

Euthanasia

The final section of questions in the survey focused on euthanasia (see Table 7). Of the respondents, 23% supported the legalization of euthanasia. This was less than the 30% supporting legalization of assisted suicide. Subjects were asked to approximate the number of patients who had requested their help in injecting a lethal dose of medication since they began working as a nurse and during the prior 12 months. Since beginning to work as a nurse, the mean number of patients requesting euthana-

Table 3. Strength of Barriers to Effective End-of-Life (EOL) Care

Barriers to EOL Care	Severe Barrier	Somewhat of a Barrier	Not a Barrier
Influence of managed care on EOL care	25%	52%	23%
Lack of continuity of care across settings	23%	54%	23%
Family members' avoidance of death	19%	73%	8%
Healthcare professionals' personal discomfort with death	17%	56%	27%
Lack of knowledge by healthcare providers	15%	57%	28%
Patients'/families' fears of addiction	12%	63%	25%
Increased use of unlicensed personnel in care of the dying	11%	28%	61%
Legal restrictions placed on healthcare professionals in prescribing pain medications	11%	36%	53%
Cultural factors influencing EOL care	10%	64%	26%
Avoidance of dying patients by healthcare professionals	10%	39%	51%
Healthcare professionals' fear of causing addiction by administering pain medications	10%	34%	56%
Patients' avoidance of death	8%	70%	22%

N = 2,333

Table 4. Effectiveness of End-of-Life (EOL) Care

Aspects of EOL Care	Not at All Effective	Somewhat Effective	Very Effective
Pain assessment	3%	45%	52%
Pain management	3%	47%	50%
Other symptom management	2%	54%	44%
Psychological support for dying patients	8%	51%	41%
Attention to spiritual needs	15%	51%	34%
Grief/bereavement support	18%	54%	28%

	Worse Than Five Years Ago	About the Same	Better Than Five Years Ago
Compared to five years ago, rate the care of the dying today.	4%	30%	66%

	Not Effective	Somewhat Effective	Very Effective
How effective are you in caring for dying patients?	< 1%	28%	72%
How effective are your nursing colleagues in caring for dying patients?	1%	52%	47%
How effective are the physicians in your setting in caring for dying patients?	11%	60%	29%

N = 2,333

sia was 1.3, with a range of 0–200. Of the respondents, 78% reported no requests and 17% reported requests in the range of one to five. In the prior 12 months, the mean dropped to 0.19, with a range of 0–30, and 93% reported no such requests. Almost 7% of nurses reported a range of one to five requests. The survey then asked the nurses the number of patients to whom they had administered a lethal injection at the patients' request. The mean was 0.04 patients, with a range of 0–11, and 98% of nurses reported giving no such injections. During the prior 12 months, the mean was 0.01, with only 0.1% reporting having administered a lethal injection at the patients' request.

The final question asked the nurses the approximate number of times that they have felt obliged by the situation to administer a lethal dose of medicine without having it requested by patients or family members. The mean was 0.4, with a range of 0–100 instances. Approximately 95% reported no instances, with 3% of nurses reporting in the one to five range. When asked about the prior 12 months, the mean was 0.04, with 99% reporting no instance of feeling obliged to administer a lethal dose of medicine and 1% reporting a range of one to five patients. The second part of this question asked the number of times that nurses not only felt obliged but also actually had administered a lethal injection without specific request. Most (97%) nurses reported no such instances, and 3% reported one to five instances since beginning to work as a nurse. During the prior 12 months, the numbers were reduced to 99% reporting no instances and less than 1% reporting one to five instances.

Open-Ended Responses

The survey also invited respondents to add any comments regarding EOL care that they wished to share. Figure 1 provides a summary of comments made on the survey regarding EOL issues that the investigators selected to further illustrate the major findings. The comments provided insight to and a better understanding of the quantitative survey results. Nurses' experiences with unrelieved pain and poorly managed deaths were related to their beliefs about assisted suicide and euthanasia. The comments also often reflected confusion in terms, such as nurses' beliefs that medicating imminently dying patients constituted assisted suicide. As one respondent wrote, "At one time, a terminal patient was due morphine for pain. Her respirations were dropping, and everyone was afraid to medicate her. There was fear of causing her death. I gave the injection and the patient died."

The need for education frequently was expressed and included education of patients, their families, nurses, and physicians. The nurses' written comments were an important reminder of the intense personal nature of care of the dying. The comments also frequently included acknowledgments by respondents of the importance of this area of research. As one participant wrote, "The questionnaire is designed for measurable answers; behind every pen is a nurse with a unique personality, unique life experiences, and unique feelings that cannot be reduced adequately to a moment in time on a piece of paper. Thank you for working to make a difference in the very special part of the human life cycle."

Influence of Demographic Variables

The investigators also were interested in potential influences of demographic variables of the respondents on EOL attitudes. The survey items were clustered into six key variables that were based on factor analysis that was conducted on the total survey data: effectiveness of EOL education, barriers to EOL care, effectiveness of EOL care, frequency

Table 5. End-of-Life (EOL) Education

	Yes	No
Did you care for a dying patient during nursing school?	72%	28%
Do you care for dying patients in your current role?	87%	13%

	Journals	Seminars/ Conferences	Colleagues	Textbooks	Internet
Sources of information about EOL care	90%	89%	89%	64%	20%

Adequacy of Basic Nursing Education	Not Adequate	Somewhat Adequate	Very Adequate
Pain management at EOL	71%	21%	8%
Overall content about EOL care	62%	31%	7%
Role/needs of family caregivers in EOL care	61%	31%	8%
Other symptom management	59%	32%	9%
Grief/bereavement	58%	34%	8%
Understanding the goals of palliative care	57%	33%	10%
Ethical issues of EOL care	56%	34%	10%
Care of patients at time of death	52%	36%	12%
Communication with patients/families at EOL	52%	37%	11%

	Not Important	Somewhat Important	Very Important
Importance of EOL care content to basic nursing education	< 1%	10%	90%

	Not Knowledgeable	Somewhat Knowledgeable	Very Knowledgeable
Knowledge about EOL care	< 1%	35%	65%

N = 2,333

of EOL dilemmas, belief in euthanasia and assisted suicide, and assistance in death. T-tests and one-way ANOVA were used to determine differences in scales that were based on demographic variables (see Table 8).

Nurses were divided into three age groups: younger than 42 years, 43–49 years, and older than 50 years. These groups were selected based on distribution of the sample responding to the survey. With regard to age, older nurses rated EOL care as significantly more effective than did middle-aged nurses. Younger nurses rated frequency of dilemmas as significantly higher than did middle-aged nurses. With regard to work place, hospital-based nurses identified significantly more barriers to EOL care, more dilemmas, and assisted death more frequently than nurses in other clinical areas. They also found care to be less effective than nurses in other clinical areas. Hospice nurses rated educational preparation as less adequate, EOL care as more effective, and dilemmas as more frequent. Hospice nurses reported being asked to assist with suicide more often but to participate in assisting death less as compared to nurses in other clinical areas.

Oncology nurses rated the effectiveness of EOL care higher than other nurses, educational preparation as significantly less adequate, barriers as less severe, and dilemmas as less frequent. Nurses prepared at the graduate level rated barriers as significantly more severe, EOL care as less effective, and were less often involved in assisting death.

Discussion

Findings of the study provide important insight into nurses' perspectives of EOL care. Nurses voiced their belief that many EOL care dilemmas occur commonly and are diverse in nature. These dilemmas encompass conflicts about direct patient-care issues (e.g., withholding nutrition/hydration) and also reflect conflicts in nursing action (e.g., fear that giving adequate pain medication may result in death). Nurses also recognized many barriers to effective EOL care that were diverse and encompassed patient, professional, and system barriers.

Nurses felt most confident about physical aspects of care provided to patients in their settings as compared to spiritual care or psychosocial needs such as support or bereavement care. Of the survey respondents, 66% rated care of the dying today as better than five years ago. Overall, nurses rated their basic nursing education as having provided inadequate preparation for EOL care. Clearly, continuing education may be an important force because nurses reported feeling at least somewhat adequate in providing care in areas such as pain management even though they rated their education as inadequate in these same areas.

Findings regarding beliefs and actual practice of assisted suicide and euthanasia are troubling. Although overall mean scores are quite low and most nurses reported no requests or action in hastening deaths, even the small num-

Table 6. Assisted Suicide

	Yes	No
Do you support the legalization of assisted suicide?	30%	70%
Has any patient requested your help in getting a prescription for medication to use with the primary intention of ending his or her own life?	20%	80%

Approximate number of patients who have requested help from such a prescription

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 1.78)	0	77
	1–5	16
	6–10	4
	11–25	2
	26–50	< 1
	60–100	< 1
	300	< 1
• During the past 12 months ($\bar{X}$ = 0.24)	0	90
	1–5	9
	6–10	< 1
	11–30	< 1

Approximate number of patients you have helped to obtain such a prescription

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 0.14)	0	97
	1–5	2
	6–10	< 1
	20–25	< 1
• During the last 12 months ($\bar{X}$ = 0.04)	0	99
	1–3	< 1
	16–27	< 1

N = 2,333

Table 7. Euthanasia

	Yes	No
Do you support the legalization of euthanasia?	23%	77%

Approximate number of patients who requested that you inject them with a lethal dose of medication

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 1.30)	0	78
	1–5	17
	6–10	3
	11–50	< 2
	75–200	< 1
• During the last 12 months ($\bar{X}$ = 0.19)	0	93
	1–5	7
	6–10	< 1
	20–30	< 1

Number of patients to whom you have administered a lethal injection at their request

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 0.04)	0	98
	1–4	2
	6–11	< 1
• During the last 12 months ($\bar{X}$ = 0.01)	0	99
	1	< 1

Approximate number of times that you felt obliged by the situation to administer a lethal injection without it having been requested by the patient or family

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 0.40)	0	95
	1–5	3
	6–15	1
	20–50	< 1
	100	< 1
• During the last 12 months ($\bar{X}$ = 0.04)	0	99
	1–5	1
	6–12	< 1

Number of patients to whom you have given a lethal injection because of their situation or without specific request by the patient or family

	Range	%
• Since beginning to work as a nurse ($\bar{X}$ = 0.17)	0	97
	1–5	3
	6–20	< 1
	25–50	< 1
• During the last 12 months ($\bar{X}$ = 0.02)	0	99
	1–5	< 1
	6–9	< 1

N = 2,333

bers of nurses reporting requests for and practice of assisted suicide and euthanasia is quite important and warrants attention. Of the survey respondents, 23% reported receiving a request at some time in their career from patients to obtain a prescription to end their life and 10% reported receiving this request in the previous year. The findings related to actually assisting in obtaining such a prescription or requests for lethal injection were similar in frequency. The findings related to active euthanasia are of even greater concern. Almost 5% of nurses reported feeling obliged to administer a lethal drug without a request during their career, and more than 3% reported actually having done so. Findings of this survey are similar to reported beliefs and practices of physicians (Emanuel et al., 1996; Meier et al., 1998), findings from surveys of oncology nurses in smaller samples (Matzo & Emanuel, 1997; Young et al., 1993), and reports from nurses who care for patients with AIDS (Leiser et al., 1996).

Despite the investigators' attempts to clearly assess beliefs and actions regarding the terms "assisted suicide" and "euthanasia," many subjects' comments suggested that these terms are not clearly understood. In fact, nurses reporting participation in these acts actually may not have but, rather, were interpreting palliative care interventions (e.g., administering morphine) as hastening death. The comments also suggested that nurses' distress in observing unrelieved pain or other symptoms and the continual involvement in inadequate care of the dying strongly influ-

Pain control/in favor of assisted suicide
I have never given a lethal injection but many times have given pain medications that I knew may hasten death by a short time to prevent my patient from dying in severe pain. Many times, I have wanted to be able to give a lethal injection when requested but have not because it's against the law—laws that are stupid and force patients to live longer than necessary. There is nothing wrong with death with dignity.

I morally believe taking a life is wrong and, yet, also do not want patients to endure suffering. I'm afraid if these roads to death were legalized, there would be those who would abuse the power. While I could never be an active participant in either, I would not take steps to prevent a patient from ending his/her life, and I might even provide resources regarding drugs/chemicals that one might use to accomplish the act. I do believe in letting "nature take its course" and therefore could support/participate in withdrawal of life support, hydration, nutrition, etc. if it was the patient's wish.

Pain control/against assisted suicide
I feel very strongly that our goal with terminal patients needs to be "kill the pain, not the patient."

I believe that if a patient's pain and other symptoms are adequately controlled, there would not be the need for assisted suicide. Moreover, I am not afraid of giving a patient sufficient pain medications even though they may die. This is not the same as euthanasia.

Education of healthcare staff
We (doctors and nurses) need much more education about the dying patient and, in particular, pain control. No one should die in pain.

Education of patients
I do spend a significant amount of time not just at work but at church and in my community educating people about the process of dying (e.g., take your pain medicine, be comfortable, don't be afraid of addiction at the end of life). There needs to be more education in this area so people won't suffer needlessly.

Education/ineffectiveness of doctors
Physicians should be more aware of the full scope of hospice care and should recognize that virtually all symptoms are manageable.

When physicians can accept (symptom and pain management) as laudable goals, then the transition from active treatment to supportive care will be easier.

The oncologists that I work with are reluctant to speak to patients' families about a terminal prognosis and will treat patients with chemotherapy even up to the time of death.

Education of family
Sometimes the greatest barrier to effective "end-of-life" care is that patients/families don't grasp that continuation of active treatment is futile, that it is time to "let go." We gently bring them along, but many don't get there and want to pursue "everything possible" to preserve life, or families will try to "protect" the patient from information about prognosis, etc. to avoid "upsetting" them.

We need to educate families that palliative care does not mean that a patient will not receive comfort care, which is a common misconception.

Personal experiences in end-of-life care
I work in the department of pain and symptom management. I have a lot of experience with end-of-life care. I originally went to nursing school in England, where hospice was a rotation. I got my BSN here. End of life was not mentioned.

Relieving pain or assisting death
Although I have never intentionally given a "lethal" injection, on numerous occasions, the appropriate dose given was enough to hasten the patient's death.

The term "lethal injection" is vague. If it's meant to end life, period, never have I done it. If it's meant to give the appropriate amount of pain medication needed to relieve pain (and will, incidentally, hasten death) many, many times I've done that.

The current system allows us to keep patients comfortable. I would be willing to keep a patient comfortable even at risk of speeding up last breath.

General comments about end-of-life care
In oncology, end-of-life care does not have an abrupt start but is woven into care, being mindful of prognosis. I hope this point can be included in developing curriculum for end-of-life care.

Care of the dying patient is long overdue. I am very happy with the strides my staff, the physicians, and I have made to help patients experience a peaceful, painless death!

Government control
I think end-of-life decisions should be made by patients/families and their healthcare provider, who knows them best. I think the legal system does not belong in these decisions. Otherwise, we are back to arresting Al Capone for failure to pay income tax rather than murder!

Managed care/funding
Palliative and end-of-life care are not revenue-producing and therefore not deemed worthy of attention in the healthcare system. Accounting firms are now playing a large role in healthcare consulting, which has resulted in watering down or, in some cases, eliminating services so necessary to quality end-of-life care, such as social workers, chaplains, and adequate clinical staff. Managed care companies force early discharges from hospitals, not supporting the time required to prepare patients and families for end-of-life care in another setting.

Figure 1. Sample Respondent Comments

ence professional beliefs. Future research is needed to provide more in-depth exploration of nurses' experiences and actions when caring for the dying.

Limitations

This study was limited in scope to responses to a survey published in two journals and direct mail to a random sample of ONS members. Thus, the findings are limited in generalizability. The survey provided respondents with an opportunity to add written comments, but no interviews were conducted. The investigators believe that future studies might benefit from the use of nurse interviews to further understand nurses' experiences with EOL care.

Table 8. Influence of Demographic Variables on Factors of End-of-Life (EOL) Care

Demographic Variables	Effectiveness of EOL Education[a]		Barriers to Good EOL Care[b]		Effectiveness of EOL Care[a]		Frequency of EOL Dilemmas[b]		Belief in Euthanasia/ Assisted Suicide[c]		Assistance in Death[c]	
	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD	$\bar{X}$	SD
Age (years)												
18–42 (N = 777)	1.52	0.51	1.78	0.34	2.40	0.36	1.60*	0.37	-0.01	0.58	0.00	0.47
43–49 (N = 706)	1.48	0.51	1.78	0.37	2.38	0.37	1.55	0.35	0.00	0.46	0.02	0.62
50–80 (N = 732)	1.49	0.52	1.78	0.38	2.43*	0.38	1.56	0.35	0.00	0.61	-0.02	0.57
Workplace												
Hospital (N = 1,177)	1.49	0.50	1.80*	0.36	2.37	0.36	1.60**	0.35	-0.02	0.52	0.03**	0.67
Other (N = 1,080)	1.51	0.53	1.76	0.37	2.43**	0.38	1.53	0.37	0.01	0.59	-0.04	0.38
Workplace												
Hospice (N = 200)	1.34	0.43	1.79	0.38	2.71**	0.31	1.71**	0.44	0.16**	0.76	-0.13	0.27
Other (N = 2,057)	1.51**	0.52	1.78	0.36	2.37	0.36	1.55	0.35	-0.02	0.53	0.01**	0.57
Specialty												
Oncology (N = 1,582)	1.47	0.48	1.77	0.35	2.42**	0.35	1.55	0.35	0.00	0.54	0.00	0.57
Other (N = 675)	1.56**	0.57	1.82**	0.39	2.36	0.41	1.62**	0.38	-0.03	0.59	0.01	0.51
Education												
≤ Baccalaureate (N = 1,173)	1.51	0.51	1.74	0.37	2.43**	0.37	1.56	0.36	-0.02	0.53	0.30**	0.64
Graduate (N = 946)	1.47	0.51	1.83**	0.35	2.36	0.37	1.57	0.36	0.01	0.61	-0.03	0.41

[a] Scored on a scale of 1–3, where 3 is more adequate/effective
[b] Scored on a scale of 1–3, where 3 represents more severe barriers and more dilemmas
[c] Standard (z) scores ($\bar{X}$ = 1, SD = 0), where a high score represents stronger belief or more assists
* $p < 0.05$
** $p < 0.01$
Note. Based on ANOVA for three-group comparison of age indicating difference between the highest and lowest scores and t-tests for other two group comparison

Conclusion

The study findings succeeded in informing the investigators and professional community about the views of nurses in EOL care. Major reform in EOL care obviously is needed, as echoed by many recent studies and efforts. This study reminds nurses of the importance of their voice in that dialogue.

The United States Supreme Court has said that individuals have the right to a peaceful death as opposed to the right to die. To ensure that patients experience a peaceful death will require major educational approaches, policy reform, and consumer demand. Nurses also must receive support and guidance in facing the dilemmas encountered in daily practice of EOL care. Continued efforts to understand nursing perspectives and attention to nursing interventions are essential to change EOL care.

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Author Contact: bferrell@coh.org with copy to editor at rose_mary@earthlink.net

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- Last Acts
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- American Society for the Advancement of Palliative Care
  www.asap-care.com/

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