

Oncology Nurses' Knowledge, Attitudes, and Experiences Regarding Advance Directives

Mary Ann Jezewski, PhD, RN, FAAN, Jean K. Brown, RN, PhD, FAAN, Yow-Wu Bill Wu, PhD, Mary Ann Meeker, RN, DNS, Jui-Ying Feng, RN, DNS, and Xiaoyan Bu, RN, MS

Purpose/Objectives: To determine oncology nurses' knowledge of, attitudes toward, and experiences with advance directives (ADs).

Design: Descriptive, correlation survey.

Sample: Usable responses from 794 (21% return) of 3,840 randomly selected members of the Oncology Nursing Society. The typical respondent was female, Caucasian, married or living as married, middle-aged, and Christian.

Methods: A mailed survey using the Knowledge, Attitudinal, and Experiential Survey on Advance Directives instrument.

Main Research Variables: Knowledge, attitudes, experiences, confidence, and ADs.

Findings: Overall, oncology nurses were most knowledgeable about ADs in general (70% correct) and less knowledgeable about the Patient Self-Determination Act (51% correct) and their state laws (53% correct). The mean total knowledge score based on the three subscales was 17.4 out of a possible 30, or 58% correct. The nurses' experience with ADs was measured using a five-item subscale with a mean score of 4 (SD = 1.11). They were less confident in their ability to assist patients with completing ADs. Respondent attitudes reflected an advocacy role in end-of-life decisions. Attitude items were reviewed individually. Respondents strongly agreed (97%) with the statement that patients should receive sufficient medication to relieve pain even though it may hasten death, which reflects the emphasis in oncology on adequate pain management at the end of life.

Conclusions: Nurses' knowledge scores were low. Nurses in the study were not highly confident in their ability to assist patients with ADs. Demographic variables generally did not influence knowledge, confidence, or experience scores.

Implications for Nursing: More education related to ADs is needed and could be administered through in-service classes or continuing education. Nurses' responses indicated that they need more time to assist patients with completing ADs. This is difficult in the current practice environment but must be recognized as critically important.

Because of the nature of cancer treatment, oncology nurses have an opportunity to establish long-term relationships with their patients. Over time and with the development of a trusting relationship, oncology nurses, more than other healthcare providers, are in an optimal position to assist patients and families with decision making regarding advance directives (ADs). The purpose of this study was to determine oncology nurses' knowledge of, attitudes toward, and experiences with ADs. In addition, the study was designed to describe (a) the extent of oncology nurses' knowledge regarding ADs, the Patient Self-Determination Act (PSDA), and individual state laws and statutes governing their practice; (b) the attitudes of oncology nurses regarding the completion of

Key Points . . .

- ▶ Oncology nurses' knowledge of advance directives (ADs) was deficient.
- ▶ Oncology nurses' attitudes reflected an advocacy role in end-of-life decisions.
- ▶ Even though nurses reported that they were experienced in assisting patients with ADs, they were not highly confident in their ability to do so.

ADs and end-of-life decision making; (c) the experiences of oncology nurses with patients who have completed ADs and the confidence of nurses in facilitating AD decisions; and (d) the relationships among personal and professional characteristics and knowledge, attitudes, confidence, and experience.

Literature Review

The PSDA is a mechanism for fostering patient autonomy in healthcare decision making. Since the inception of the PSDA in 1991, healthcare facilities that receive Medicare and Medicaid funds have been mandated to inform their patients of their right to make decisions regarding care according to individual state laws. Although every state has legislation addressing ADs, the laws and statutes that govern ADs vary from state to state; as a result, this fairly straightforward mandate has remained a complex health issue (Ewer & Taubert, 1995; Jezewski & Finnell, 1998).

Although the PSDA has been enacted for some time, the number of patients executing ADs has not increased significantly. Except for several intense intervention studies (Brown,

Mary Ann Jezewski, PhD, RN, FAAN, is an associate professor and associate dean in the Center for Nursing Research; Jean K. Brown, RN, PhD, FAAN, is an associate dean and associate professor; Yow-Wu Bill Wu, PhD, is an associate professor; Mary Ann Meeker, RN, DNS, is a research assistant professor; Jui-Ying Feng, RN, DNS, is a research instructor; and Xiaoyan Bu, RN, MS, is a doctoral student, all in the School of Nursing at the University at Buffalo, State University of New York. This study was funded by an ONS Foundation/Oncology Nursing Certification Corporation Nursing Education Research Grant. (Submitted February 2004. Accepted for publication April 27, 2004.)

Digital Object Identifier: 10.1188/05.ONF.319-327

Beck, Boles, & Barrett, 1999; Ho, Thiel, Rubin, & Singer, 2000; Molloy et al., 2000) only 20% of the general population or less has ADs (DeLuca Havens, 2000; Dexter et al., 1998; Emanuel & Emanuel, 1994; Goldblatt, 2001; Gross, 1998; Leslie & Badzek, 1996; Mansell, Kazis, Glantz, & Heeren, 1999; Mezey, Leitman, Mitty, Bottrell, & Ramsey, 2000). The research indicates that the rate of AD completion may be higher among older adults (Gorden & Shade, 1999).

Perhaps the most notable intervention study focusing on end-of-life decisions is the Robert Wood Johnson Foundation multisite, five-year research project titled *The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT)*. The SUPPORT investigators sought to understand patient treatment preferences and physician communication with patients regarding advance care planning. After five years of study, including an intervention component, the SUPPORT team found that patients did not receive the end-of-life care they wanted and that physicians did not routinely and effectively communicate with their patients about ADs (“A Controlled Trial to Improve Care,” 1995).

Even though the SUPPORT intervention study employed nurses to initiate, coordinate, and document communication among patients, family members, staff, and physicians as a mechanism to improve deficiencies in communication and decision making, the intervention tested was physician centered. Nurses were not involved in the design of the study. The controlled clinical trial design did not allow latitude for nursing autonomy or advocacy and thus limited the role of nurses. In their discussion of the SUPPORT study, Oddi and Cassidy (1998) echoed the words of many other investigators.

Nurses, the professionals most uniquely and intimately involved with patients on a day-to-day basis, and the ones who deal most intimately with dying patients and their families are not recognized as having the knowledge and skill necessary to address the complex issues surrounding care at the end of life (p. 167).

No consensus has been reached concerning who is best prepared to assist patients with making end-of-life decisions, how healthcare providers should be prepared, or the variables that influence the decision-making process. Although numerous discussion articles in the nursing literature agree that nurses play an important role in informing patients about ADs, little empirical evidence exists to show they actually do. The American Nurses Association affirmed that nurses should play a primary role in implementing the PSDA (Task Force on the Nurse’s Role in End of Life Decisions, 1992). Still, few studies have explored nurses’ knowledge of, attitudes toward, and experiences with ADs. Crego and Lipp (1998) investigated nurses’ knowledge of ADs at a 600-bed teaching hospital. The mean knowledge score was 78%; however, nurses in this study reported that they did not have a good understanding of ADs. Leith (1998) studied a small sample of Canadian critical care nurses and found that they required further education to implement ADs effectively. Solomon et al. (1993) explored nurses’ and physicians’ knowledge of and attitudes toward national recommendations regarding patients’ rights to forgo life-sustaining treatments. They concluded that changes in the care given to dying patients have not kept pace with national regulations, partly because physicians and nurses disagreed with or were unaware of some key guidelines. Other researchers also have explored nurses’ roles and experiences with different aspects

of ADs (Haisfield et al., 1994; Jezewski & Finnell, 1998; Jezewski, Scherer, Miller, & Battista, 1993). Haisfield et al., as well as the studies by Jezewski, found that advocacy was an important aspect of the nurse’s role. Jezewski and Finnell explored nurses’ interactions with patients and families who signed do-not-resuscitate (DNR) consents. The sample for the study was composed of oncology nurses practicing in four states. This qualitative study did not focus on advocacy in particular, but the nurses’ descriptions of their experiences illustrated the implementation of the advocacy role. Haisfield et al. conducted focus groups with patients with cancer and their providers to understand the preferences of both groups regarding ADs. The study identified advocacy as one aspect of oncology nurses’ role in ensuring patient autonomy, needs assessment, and the delivery of timely information related to ADs.

The process of completing ADs can be emotional and value-laden and requires provider knowledge, commitment, experience, and sensitivity to help patients and families make decisions and complete directives. The principles of autonomy and self-determination guide this process. Because healthcare providers are integral to the completion of ADs, their knowledge, attitudes, and experiences influence the process. A dearth of studies examine nurses’ knowledge, attitudes, and experiences regarding ADs, and the current study’s principal investigator did not locate any research that explored these issues among oncology nurses.

Patients often are given information about ADs under less-than-ideal conditions (e.g., admitting offices, reception areas), where a knowledgeable person is not available to answer questions. Nurses have an important role in providing information to and assisting patients with the completion of ADs (Oddi & Cassidy, 1998; Pinch & Parsons, 1992; Weber & Kjervik, 1992). Researchers should study nurses’ knowledge, attitudes, and experiences before beginning an intervention that will aid patients in the completion of ADs. Although percentages vary, many researchers report quite limited provider awareness and use of patients’ existing ADs (Goold, Williams, & Arnold, 2000; Heintz, 1997; Leslie & Badzek, 1996; Miles, Koepf, & Weber, 1996). Understanding nurses’ knowledge, attitudes, and experience in the arena of ADs is necessary to accurately target interventions for them.

Methods

Design and Sample

A questionnaire survey was used in this correlational study. Four states (California, Illinois, New York, and Texas) representing distinct geographic areas of the United States were selected as the study settings. The study included only four states because the investigators wanted to measure the oncology nurses’ knowledge of state laws and because the logistics of developing and scoring the knowledge subscale for all 50 states would have been prohibitive.

Using power analysis (Cohen, 1988), the investigators determined that a minimum of 200 subjects from each of the four states ($N = 800$) would be required to answer the research questions using regression analysis with alpha set at 0.05, an effect size of 0.15, and a power of at least 0.90. Because of the large number of items on the survey and the expected low response rate for mail surveys, the Oncology Nursing Society (ONS) membership was oversampled. A stratified random sample of 4,000 ONS members was obtained. One thousand

ONS members in each of the four states who indicated “patient care” as their primary functional area and described their employment status as full- or part-time on their membership application were selected. From these 4,000 members, a random sample of 40 members from each state was selected and used to pilot test the reliability of the study instrument. The nurses who participated in the pilot study were not included in the survey study. Therefore, a total of 3,840 surveys (960 per state) were mailed to the remaining sample. The return rate was 23%, with a total of 794 (21%) usable surveys for analysis.

Instrument

The **Knowledge, Attitudinal, and Experiential Survey on Advance Directives (KAESAD)** instrument was developed to measure the knowledge of, attitudes toward, and experiences with ADs in end-of-life decisions. The instrument’s reliability and content validity were established through a pilot test-retest and by an expert panel before the survey was administered. The panel members were experts in end-of-life care and ADs and represented the disciplines of nursing, medicine, law, and bioethics. The panel provided feedback on each of the 110 items included in the original draft of the survey. Changes were made to 22 items. Nine items were added and four items were deleted based on the opinions of the panel and the judgment of the investigators.

The final instrument used for the survey consisted of 115 items. The principal components were (a) general knowledge about ADs (10 items), (b) knowledge of the PSDA (7 items), (c) knowledge of individual state laws regarding ADs (13 items), (d) attitudes toward ADs and end-of-life issues (20 items), (e) experience with ADs (7 items), (f) experience related to end-of-life decision making (20 items), (g) confidence assisting patients with ADs (11 items), and (h) demographic data (26 items). The final item was an open-ended question that asked nurses about their needs related to assisting patients with completing ADs.

The survey included 30 questions related to oncology nurses’ knowledge in three subscales (general knowledge of ADs, the PSDA, and state laws governing ADs). Respondents were asked to check “yes,” “no,” or “don’t know” for each question.

Twenty items surveyed nurses’ attitudes toward completing ADs and end-of-life decision making (Cronbach alpha = 0.58), such as patient rights, starting and ceasing life support, artificial hydration and nutrition, nurses’ roles in informing patients, and assisted suicide. Nurses were asked to respond to each item using a four-point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree).

Seven items assessed nurses’ experience with ADs. Nurses were instructed to answer “yes” or “no” to the items. Five of these items formed a subscale (Cronbach alpha = 0.93) to measure the level of experience with patient ADs. The five-item experience subscale assessing nurses’ clinical experiences with patient ADs included (a) caring for patients with an AD, (b) reading institutional policy related to ADs, (c) witnessing ADs for patients, (d) initiating an AD discussion with patients, and (e) counseling patients about ADs. Two additional items not included in the subscale asked, “Have you provided treatment to patients whose AD indicated otherwise?” and “Have you observed others providing treatment to patients whose AD indicated otherwise?” In addition, nurses were asked to respond to a series of 20 statements related to end-of-life decisions based on their professional experiences.

The topics covered how prognoses are communicated, how patients make decisions, whether the presence of ADs encourages communication, and nurses’ roles, and were answered based on a four-point Likert scale (i.e., 1 = strongly disagree to 4 = strongly agree) (Cronbach alpha = 0.59).

Eleven items were used to measure nurses’ confidence in assisting patients completing ADs (Cronbach alpha = 0.95), answering patient and family questions, teaching others about ADs, mediating disagreements related to ADs, and advocating for patients’ ADs. Nurses responded to a five-point Likert scale ranging from 1 (not at all confident) to 5 (very confident).

Twenty-six items assessed personal, professional, and institutional characteristics. Personal characteristics included race, religion, gender, marital status, age, and whether the nurse had completed an AD for him or herself. The professional characteristics included professional education preparation, clinical practice site, current position, ONS certification status, work status, and amount of formal instruction on ADs. Institutional characteristics included geographic location of the nurse’s workplace, the presence of an ethics committee, and how patient ADs are communicated within the workplace.

The last item on the survey asked, “What do oncology nurses need most to increase their ability to assist patients with advance directives?” Of the 900 nurses who returned the survey, 677 (75%) responded to the open-ended question. For the qualitative analysis, all 900 surveys were considered usable, in contrast to the quantitative analysis, where only 794 of the returned surveys were usable. The results of the qualitative analysis are reported elsewhere (Jezewski, Meeker, & Schrader, 2003).

For questions about knowledge, participants could select “true,” “false,” or “don’t know.” To determine knowledge scores, “don’t know” answers were treated as incorrect. The purpose of including “don’t know” as a possible answer was to minimize guessing. Total knowledge scores ranged from 0–30. Nurses’ attitudes toward completing ADs and end-of-life decision making were reduced to two levels: agree (i.e., strongly agree, agree) and disagree (i.e., disagree, strongly disagree). No total attitude score was calculated; rather, individual items were used in the analysis because of low internal consistency. Experience subscale scores (5 items) were based on “yes” answers receiving a score of 1; therefore, scores ranged from 0–5. Confidence scores were based on an 11-item, five-point Likert scale (i.e., 1 = not all confident to 5 = very confident). Scores ranged from 11–55.

A random sample of 40 nurses from each state was used to establish reliability. Fifty-six oncology nurses completed the test-retest pilot survey. A convenience sample of 18 graduate nursing students also was used to establish test-retest reliability after minor revisions to the instrument were made following the first test-retest reliability test. The reliability of the pilot survey test-retest over a three-week period ($r = 0.51$ – 0.90), the test-retest proportion of agreement for individual items (0.71–1.0), and internal consistency (Cronbach alpha = 0.58–0.95) were acceptable. Cronbach alphas equal to 0.58 and 0.59 were obtained for the attitude subscales.

Procedure

After the study was approved by the Health Sciences Institutional Review Board at the University at Buffalo, State University of New York, the KAESAD survey was mailed to 3,840 nurses. Only this initial mailing was used for data collection.

Data Analysis

Data were entered into a spreadsheet program and imported into SPSS® version 10.0 (SPSS Inc., Chicago, IL) for analysis. Questionnaires missing less than 20% of data (e.g., one to two items per knowledge, attitude, or experience subscale) were included in the analysis with the respective group mean scores imputed in lieu of the missing data. Statistical significance was set at $p < 0.05$.

Descriptive statistics (i.e., mean, standard deviation, range, percentage) appropriate to the level of measurement were calculated for the personal, professional, and institutional characteristics of the sample as well as for the first three research aims of describing the nurses' knowledge, attitudes, and experiences with ADs. Several strategies were used for data reduction to ensure more powerful and clinically relevant analysis. First, data were analyzed to determine whether significant differences existed in nurses' answers based on the state in which they resided. Although some statistically significant differences were found for a few subscales, they were not clinically significant. For example, the mean difference in total knowledge scores between nurses in Texas and those in New York were statistically significantly different at the 0.05 level, yet the total knowledge score for New York nurses was 57%, versus 61% in Texas. Total knowledge scores showed no clinically significant differences between nurses in different states. For example, actual knowledge scores reflected a lack of knowledge. The differences among low scores across states may have been statistically significant, but nurses in all four states had low knowledge scores. This also was true for other areas of the survey in which some statistical disparities occurred among nurses in the different states but did not reflect clinically meaningful results. Therefore, aggregate data were analyzed for nurses in all four states.

The relationships among nurses' personal and professional characteristics and their knowledge of, attitudes toward, experiences with, and confidence in assisting patients with completing ADs were determined using multiple regression analysis.

Results

Sample

Many oncology nurses who returned the survey were Caucasian, female, married or living as married, and Christian. The majority (71%) had a bachelor's or master's degree, and 65% were Oncology Certified Nurses® or Advanced Oncology Certified Nurses®. Table 1 provides an overview of demographic and professional characteristics within the sample. Only 37% of the nurses in the study had an AD for themselves, and 57% had a family member with an AD. Fifty-five percent of the nurses had received some form of AD education at their current workplace. Ethics committees were active in the workplace of 78% of the respondents, yet only 6% were members of these committees. Respondents were asked to estimate the number of hours of instruction about ADs they received during their professional nursing education. Their answers ranged from 0–45 hours, with a mean of 1.3 hours (SD = 3.21).

Knowledge of Advance Directives, the Patient Self-Determination Act, and State Laws

The oncology nurses' knowledge was measured by calculating the three knowledge subscales individually and determining total knowledge scores using all items from the

Table 1. Oncology Nurses' Demographic and Professional Profile

| Characteristic | n | % |
|---|-----|----|
| Age (N = 794) | | |
| X = 46 years | – | – |
| SD = 9.22 years | – | – |
| Range = 24–70 years | – | – |
| Gender (N = 794) | | |
| Female | 774 | 97 |
| Marital status (N = 794) | | |
| Married or living as married | 561 | 71 |
| Ethnicity (N = 791) | | |
| Caucasian | 722 | 91 |
| Other | 69 | 9 |
| Religion (N = 790) | | |
| Protestant | 276 | 35 |
| Catholic | 382 | 48 |
| Jewish | 24 | 3 |
| None | 43 | 5 |
| Other | 65 | 8 |
| Education (N = 790) | | |
| RN diploma | 73 | 9 |
| Associate degree | 135 | 17 |
| Bachelor's degree | 301 | 38 |
| Master's degree | 264 | 33 |
| Doctoral degree | 17 | 2 |
| Current position (N = 794) | | |
| Staff nurse | 357 | 45 |
| Manager | 115 | 15 |
| Advanced practice nurse | 130 | 16 |
| Other | 192 | 24 |
| Work status (N = 794) | | |
| Full-time | 642 | 81 |
| Direct care | 495 | 62 |
| Workplace location (N = 783) | | |
| Urban | 468 | 60 |
| Suburban | 256 | 33 |
| Rural | 59 | 8 |
| Oncology certified (OCN® or AOCN®) (N = 794) | 515 | 65 |
| Years of practice in oncology (N = 794) | | |
| X = 12.7 | – | – |
| SD = 6.55 | – | – |
| Range = 0–35 | – | – |

Note. Because of rounding, not all percentages total 100.

three subscales. Table 2 presents an overview of mean and percentage correct scores for the three knowledge subscales as well as total knowledge scores. The first knowledge subscale focused on measuring the nurses' general knowledge of ADs. Items included definitions of ADs, the types of ADs (e.g., living will, durable power of attorney for health care, health-care proxy), the role of proxy decision makers, and some legal issues related to ADs (e.g., whether a notary is needed, the meaning of patient capacity, whether legal permission is needed to stop life-sustaining treatment). Respondent scores were highest for this subscale, with a mean score of 7 out of a possible 10 (70%).

The second knowledge subscale focused on questions related to the principal components of the PSDA (i.e., healthcare facilities' obligation, legislation enacted, requirements to inform patients about their rights, and training of staff). Respondents' scores were the lowest on this knowledge subscale with a mean

Table 2. Knowledge Scores of Nurses Related to Advance Directives

| Scores | \bar{X} | SD | \bar{X} Correct |
|--|-------------|-------------|-------------------|
| Knowledge scores | | | |
| General advance directive (10 items) | 7.0 | 1.29 | 70% |
| Patient Self-Determination Act (7 items) | 3.6 | 1.46 | 51% |
| State law (13 items) | 6.8 | 2.11 | 53% |
| Total knowledge score (30 items) | 17.4 | 2.45 | 58% |

N = 794

of 3.6 out of 7 (51%). Interestingly, participants selected “don’t know” for 28% of their responses on the PSDA subscale, compared with 4% on the general knowledge AD subscale.

The third knowledge subscale elicited respondents’ knowledge of their state’s laws governing ADs. Nurses in all four states were asked the same questions, but some of the answers differed according to the individual state laws. Questions for this subscale focused on the age requirement for completing an AD, the withdrawal and withholding of care, the legality of ADs from other states, who can witness an AD, whether living wills are legal, and the legality of a pregnant patient’s AD. Respondents’ mean score for this subscale was 6.8 out of a possible 13 (53%). Nurses selected “don’t know” for 26% of their responses in this subscale.

Total knowledge scores were calculated using the three subscales for a total of 30 items. Respondents’ total knowledge mean score was 17 out of a possible 30 (58%).

Attitudes

Oncology nurses were asked 20 questions related to their attitudes toward ADs and end-of-life decisions. Table 3 presents selected attitude items and the mean scores, standard deviations, and level of agreement of the respondents. Because of the low alpha score for the attitude subscale, the items were analyzed and interpreted individually. The level of agreement was determined by reducing the “agree” and “strongly agree” responses into one category. Those surveyed had a high level of agreement with four items: “It is appropriate to give medication to relieve pain even if it may hasten a patient’s death;” “Nurses should uphold the patient’s wishes even if they conflict with the nurse’s own view;” “Nurses should help inform patients about

their condition and treatment alternatives;” and “Patients with decision-making capacity who are not terminally ill should have a right to refuse life support even if that decision may lead to death.” Nurses agreed least with items stating that ADs will lead to acceptance of euthanasia and that denial of treatment for terminally ill patients because of cost is acceptable.

Experience and Confidence

Oncology nurses’ experiences with ADs were measured using a five-item subscale with “yes” and “no” answers indicating whether respondents had experience with AD situations. The respondents’ mean score was 4 (maximum score = 5), with a standard deviation of 1.11. More than 80% responded that they had cared for a patient with an AD, read their institutional policies and procedures concerning ADs, counseled patients and families about ADs, and initiated discussion about ADs with a patient. Sixty-two percent had never witnessed an AD. Two items that reflected incongruence in providers’ respect for patients’ wishes were not part of the experience subscale. Seventeen percent answered that they had provided treatment to patients whose AD indicated otherwise, and 42% had observed others providing treatment to patients whose AD indicated otherwise.

Oncology nurses’ professional experience regarding end-of-life decision making was determined by a series of 20 statements with responses on a four-point Likert scale. Table 4 presents selected items with mean scores, standard deviations, and percent agreement with the statement. The highest agreement (86%) was with the statement that the presence of a living will encourages discussion of patient preferences. Respondents agreed that nurses can answer patients’ questions about ADs (66%), some patients are excluded from decision making because they are judged inappropriately as lacking capacity for decision making (60%), information in ADs is usually adequate to guide treatment (58%), and nurses often have insufficient time to discuss ADs with patients (52%). Twelve percent believed that nurses spend enough time discussing ADs with patients, and 24% responded that patients are approached early enough to allow time to make informed end-of-life decisions. A large proportion of participants did not agree that healthcare providers know the wishes of their patients (33%) or that patients have enough knowledge about their condition or options to prepare ADs (37%).

Table 3. Selected Attitudes Toward Advance Directives and End-of-Life Issues

| Selected Attitude Item | \bar{X} | SD ^a | Agreement ^b (%) |
|---|-----------|-----------------|----------------------------|
| It is appropriate to give medication to relieve pain even if it may hasten a patient’s death. | 3.8 | 0.50 | 98 |
| Nurses should uphold the patient’s wishes even if they conflict with the nurse’s own view. | 3.7 | 0.64 | 94 |
| Nurses should help inform patients about their condition and treatment alternatives. | 3.6 | 0.72 | 92 |
| Patients with decision-making capacity who are not terminally ill should have a right to refuse life support even if that decision may lead to death. | 3.5 | 0.80 | 89 |
| Nurses should be actively involved in helping patients complete advance directives. | 3.2 | 0.93 | 77 |
| Actively assisting some terminally ill patients to die (i.e., physician-assisted suicide) should be made legal. | 2.0 | 0.99 | 30 |
| Ethically, there is no difference between starting a life support treatment and stopping it once it has been started. | 2.0 | 0.95 | 26 |
| It is acceptable for healthcare providers not to offer certain treatments to terminally ill patients because of the cost. | 1.4 | 0.75 | 12 |
| Advance directives will lead to acceptance of euthanasia. | 1.3 | 0.61 | 5 |

N = 794

^a Rated on a four-point Likert scale (1 = strongly disagree to 4 = strongly agree)

^b Percentage of respondents answering agree or strongly agree

Table 4. Agreement With Selected End-of-Life and Advance Directive Items Based on Nurses' Professional Experience

| Selected Items | \bar{X} | SD ^a | Agreement ^b (%) |
|---|-----------|-----------------|----------------------------|
| The presence of a living will encourages discussion between a patient and healthcare provider about the patient's preferences. | 3.1 | 0.69 | 86 |
| Generally, nurses can answer patients' questions about advance directives. | 2.8 | 0.97 | 66 |
| Some patients are excluded from making decisions about their care because they are inappropriately judged to lack capacity to make decisions. | 2.6 | 0.80 | 60 |
| The information in an advance directive usually is sufficient to guide treatment. | 2.6 | 0.72 | 58 |
| Very often there is not enough time to discuss advance directives with patients. | 2.5 | 0.94 | 52 |
| Most patients have enough knowledge about their medical condition and potential treatments to prepare advance directives. | 2.3 | 0.80 | 37 |
| Healthcare providers usually know the wishes of their patients regarding advance care planning. | 2.2 | 0.78 | 33 |
| Most patients are approached early enough in their terminal illness to allow them time to make informed decisions about end-of-life care. | 1.9 | 0.86 | 24 |
| The amount of time nurses spend discussing advance directives with patients is sufficient. | 1.8 | 0.64 | 12 |
| Terminally ill patients with a do-not-resuscitate order receive less care overall. | 1.6 | 0.83 | 14 |

N = 794

^a Rated on a four-point Likert scale (1 = strongly disagree to 4 = strongly agree)

^b Percentage of respondents answering agree or strongly agree

The respondents' confidence in their knowledge about ADs and in their ability to assist patients and families with ADs was measured using 11 items formatted as Likert scales. The total mean score for confidence was 38.7 out of a possible 55 (SD = 9.43). Two-thirds or more of the nurses were confident (scores of 4 and 5 on the five-point Likert scale) when discussing ADs with patients and families and answering their questions. Sixty percent or more were confident about implementing institutional policies and procedures regarding ADs, complying with provisions of patients' ADs, and advocating for patients' ADs when they conflict with the wishes of the family. Forty-six percent or more of the nurses were less confident (scores of 1–3) in their understanding of the provisions of the PSDA (79%), understanding the state laws regarding ADs (76%), mediating disagreements between patients and family members regarding end-of-life decisions (55%), and teaching others about ADs (46%).

The last item in the KAESAD instrument asked nurses what they needed to help patients complete ADs. The four most prevalent themes that emerged from their responses were (a) the need for education regarding ADs, (b) the need for more time to assist patients completing ADs, (c) support from administrators and physicians regarding the nurse's role in helping patients complete ADs, and (d) the nature of the nurse's role in assisting patients completing ADs. Nurses explained that they should act independently and autonomously in helping patients, honor patients' self-determination, subordinate their own beliefs and values to those of their patients, and most importantly, assure patients that they will receive continued care once DNR consents are signed. The need for constant and open communication was mentioned throughout each of the themes (Jezewski et al., 2003).

Relationship Between Nurse Characteristics and Knowledge, Attitudes, Confidence, and Experience

Multiple regression analysis was used to describe the relationships among personal and professional characteristics of the oncology nurses and their knowledge, confidence, and experience total scores as well as KAESAD item 45, which

reads, "Nurses should be actively involved in helping patients with advance directives," and was used as a key indicator of nurses' overall attitudes about ADs. Eight characteristics that had sufficient variability were entered as independent variables in the regression analysis: age, marital status, years of practice as an RN, whether the nurse's primary role was direct care, oncology certification, current position, work status, and education.

Knowledge, attitudes, confidence, and experience all were significantly related to the eight personal and professional characteristics on which they were regressed. As shown in Table 5, oncology certification, a master's degree, full-time work status, older age, and being married or living as married were significant predictors in these relationships, but the significant characteristics were different for each dependent variable.

Given these findings, this study's researchers examined how well KAESAD knowledge, confidence, and experience total scores predict selected professional attitudes about the nurse's role in ADs and the availability of time to discuss ADs. KAESAD item 45 was used again as a key indicator of professional attitude about the nurse's role, and this attitude item ("Nurses should be actively involved in helping patients with ADs") was regressed for knowledge, confidence, and experience. These KAESAD scores predicted 7% of the variance ($R^2 = 0.068$, $F = 25.43$, $df = 3,790$, $p < 0.001$) for professional attitude, with more experience ($\beta = 0.178$, $t = 4.229$, $p < 0.001$) and greater confidence ($\beta = 0.100$, $t = 2.213$, $p < 0.05$) significantly predicting a higher score. As key indicators of availability of time, the researchers regressed two KAESAD items (item 72: "Very often there is not enough time to discuss advance directives with patients" and item 87: "The amount of time nurses spend discussing advance directives with patients is sufficient") on knowledge, confidence, and experience total scores. These KAESAD scores predicted 2% of item 87 ($F = 5.875$, $df = 3,790$, $p < 0.01$) with more experience significantly predicting a higher score on this item ($\beta = 0.109$, $t = 2.520$, $p < 0.05$); however, no significant prediction of insufficient time (item 72) by knowledge, confidence, and experience total scores was found.

Table 5. Relationships Among Personal and Professional Characteristics and Knowledge, Attitudes, Confidence, and Experience

| Knowledge, Attitudinal, and Experiential Survey on Advance Directives Score | R | F | Significant Characteristics | B (unstandardized) | T-ratio |
|---|------|--------|--|--------------------|---------|
| Total knowledge | 0.17 | 3.045* | Age | 0.05 | 2.577* |
| | | | Work status ^a | 0.89 | 2.802* |
| Attitude (item 45) | 0.18 | 3.354* | Master's versus bachelor's degree ^b | 0.22 | 2.690* |
| | | | Marital status ^c | 0.19 | 2.558* |
| | | | Oncology certification ^d | 0.14 | 1.987* |
| Total confidence | 0.18 | 3.110* | Oncology certification ^d | 1.48 | 2.121* |
| Total experience | 0.14 | 2.094* | Oncology certification ^d | 0.25 | 2.948* |
| | | | Master's versus bachelor's degree | 0.22 | 2.267* |

N = 794

* p < 0.05

^a Full-time = 1, part-time = 0

^b Master's degree = 1, bachelor's degree = 0

^c Married or living as married = 1, single = 0

^d Yes = 1, no = 0

Discussion

Overall, oncology nurses were most knowledgeable about ADs in general and less knowledgeable about the PSDA and their state laws. Although oncology nurses' knowledge of ADs was somewhat lower in this study than the 78% reported by Crego and Lipp (1998), these findings are consistent with theirs and others (Leith, 1998; Solomon et al., 1993) indicating that nurses need more knowledge if they are to implement ADs effectively.

The respondents' attitudes reflected an advocacy role for nurses in end-of-life decisions. The respondents strongly agreed that patients should receive the pain medication they need even though it may hasten death, which reflects the emphasis in oncology nursing on adequate pain management at the end of life. Advocacy also was evident in the strong agreement among respondents that nurses should uphold patients' wishes even if they conflict with nurses' own views and that nurses should help inform patients about their condition and treatment alternatives and should actively help patients complete ADs. These results corroborate the findings of Haisfield et al. (1994) and Jezewski et al. (1993) that advocacy is an important aspect of the nurse's role. In direct contrast to recommendations of the American Nurses Association (Task Force on the Nurse's Role in End of Life Decisions, 1992), the American Medical Association (1991), the Task Force on Life and the Law (1987), and the Hastings Center (1987) that providers not distinguish ethically or legally between withholding and withdrawing treatment at the end of life, only 26% of the oncology nurses in this study agreed with the statement that ethically, no difference exists between starting a life-support treatment and stopping it once it has been started. The nurses' responses are similar to those found by Solomon et al. (1993) when a similar question yielded 27% agreement from nurses and 43% agreement from medical-attending physicians. Generally, respondents of the Solomon et al. study did not believe that ADs would lead to acceptance of euthanasia, and most disagreed that assisted suicide should be made legal.

The nurses surveyed in the current study were experienced in assisting patients with AD completion. Most were

experienced in caring for patients with ADs, reading their institution's policies and procedures regarding ADs, counseling patients and families about ADs, and initiating discussion about ADs but were not experienced in witnessing ADs. Interestingly, almost half of the nurses had observed treatment being provided to patients in violation of their ADs.

Even though the nurses indicated that they were comfortable assisting patients with ADs, the study found considerable disagreement regarding their experience with end-of-life decision making. Most agreed that the presence of a living will provided an opportunity for discussing patient preferences, but respondents also agreed that nurses often did not spend enough time discussing ADs with patients, patients were not approached early enough, patients did not have adequate information to make informed end-of-life decisions, and health-care providers often did not know their patients' wishes. The latter supports the findings of several researchers who have reported limited provider awareness and use of patients' ADs (Goold et al., 2000; Heintz, 1997; Leslie & Badzek, 1996; Miles et al., 1996).

Although the nurses reported that they were experienced in assisting patients with ADs, they were not highly confident in their ability to do so. Most nurses were confident in their ability to discuss ADs with patients and families, answer their questions, advocate for patients' ADs, and implement institutional policies and procedures. They were less confident in their knowledge of the laws governing ADs (PSDA and state), in their capacity to mediate disagreements between patients and families regarding end-of-life decisions, and in their ability to teach other healthcare professionals about ADs. These findings are an interesting paradox because the nurses reported being confident in their ability to work with patients and families regarding ADs, but their knowledge of the laws governing ADs was limited. These findings are the first that begin to ascertain nurses' experience with and confidence in the complex process of assisting patients and families with ADs.

Several characteristics of the respondents were statistically significantly related to their knowledge, attitudes, confidence, and experience with ADs and end-of-life decision making; however, the clinical significance of these

relationships is questionable based on examination of the unstandardized regression coefficients (B). Given that the unstandardized regression coefficient for a dichotomous independent variable is the mean difference between its two categories rather than the rate of change for continuous variables (Darlington, 1990), the statistically significant findings indicated that the total confidence score increased only an average of 1.48 on an 11- to 55-point scale with oncology nursing certification. The total knowledge score increased 0.5 points on a 30-point scale for every 10-year increase in age and 0.89 points on average from part-time to full-time work status.

The researchers believed that nurses with more knowledge, confidence, and experience might have more positive attitudes regarding helping patients with ADs and need less time to do so. The results of the study indicate that more experience and greater confidence predicted higher scores on the attitude item regarding helping patients with ADs; however, more experience predicted greater agreement with the statement that nurses often do not have enough time to discuss ADs with patients. Thus, nurses with more experience had more positive attitudes about ADs but felt they did not have enough time to discuss them with patients.

Limitations

Although a stratified, random sampling strategy was used for this mailed survey of ONS members, only 23% responded, 21% of which were usable for data analysis. Thus, sampling bias may be present based on who chose to respond and because oncology nurses in only four states were surveyed. The knowledge, attitudes, confidence, and experience of nonrespondents and oncology nurses in other states may not be reflected in this study. The 23% response rate is low but consistent with other ONS member surveys (Rutledge & Engelking, 1998; Sarna, Brown, Lillington, Wewers, & Brecht, 2000). The length of the survey (12 pages) may have contributed to the low response rate.

This study used a new survey instrument (KAESAD) that was developed by the researchers. The reliability and validity of the instrument were tested carefully before conducting the main study and were acceptable for most scales. Low internal consistencies were found for the subscales on attitudes about ADs and end-of-life decision making, as well as professional experiences with ADs, but test-retest reliability coefficients were acceptable. Thus, analysis of individual attitude and experience items was conducted instead of using subscale scores. Additional use and testing of this instrument are needed for additional support of its psychometric characteristics.

Nursing Implications

Implications for Future Research

Although replication of this survey is needed, interventions need to be developed and tested to increase oncology nurses' knowledge about ADs, especially the PSDA and state laws. Moreover, attitudes regarding the ethics of withholding and withdrawing life support treatment also should be addressed in interventions because the findings indicated an inconsistency with recommendations by the American Nurses Association, the American Medical Association, state and federal government commissions, and the Hastings Center. By improving knowledge and increasing ethical understanding of ADs and end-of-life decision making, confidence and experience outcomes should improve.

Suggestions for Clinical Practice

The nurses responding to this survey made their needs clear by giving individual responses when asked what they needed to help patients complete ADs (75%). The nurses recognized the need for more education about ADs, which also was reflected in their survey knowledge scores. Providing more education related to ADs could be accomplished through in-service classes or continuing education and would be an excellent topic for an online continuing education offering from ONS as well as instructional sessions at the annual ONS Congress and Institutes of Learning. Nurses also need more time to assist patients in completing ADs. Their individual responses were similar to their attitudes in response to the item, "Very often there is not enough time to discuss advance directives with patients," with which 52% of the nurses agreed. Although including time to discuss ADs is difficult in the current practice environment, it must be recognized as a critically important aspect of nursing care. In addition, nurses need support from administrators and physicians in clinical settings regarding their role in helping patients complete ADs. Oncology nurses are in a unique position to assist patients with ADs because they develop long-term, trusting relationships with patients and families that allow for open discussion without fear of compromising their treatment, which may occur with physicians. Some nurses also discussed their need to approach patients autonomously to discuss ADs without fear of reprisal from medical staff. These responses indicate that oncology nurses want to be able to better assist patients and families with ADs, but they need education, time, and support from administration and physicians to do so.

Author Contact: Mary Ann Jezewski, PhD, RN, FAAN, can be reached at jezewski@buffalo.edu, with copy to editor at rose_mary@earthlink.net.

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