Advance Directives and End-of-Life Decision Making
Survey of Critical Care Nurses' Knowledge, Attitude, and Experience

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Intensive care units (ICUs) are the site of much end-of-life decision making. Decision making in the ICU should be governed by patients' wishes, and advance directives are one way patients can make their end-of-life decisions known. Advance directives are defined as mechanisms by which individuals make known how they want medical treatment decisions made when they can no longer make the decisions for themselves. Advance directives can take the form of living wills, healthcare proxies, do-not-resuscitate orders, and durable powers of attorney. Healthcare providers play an important role in patients' understanding and completion of advance directives. Ideally, advance directives should be completed before an acute illness occurs, in a less hectic and stressful environment. If patients come to the ICU without advance directives, critical care nurses, who spend more time with ICU patients than any other

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provider does, are in the best position to educate competent patients about advance directives and facilitate the completion of such directives. Providers' knowledge of and attitudes toward advance directives can be important aspects that influence the effectiveness of the providers' role in helping patients complete advance directives and in ensuring that patients' end-of-life wishes are carried out. Helping patients' family members understand and cope with end-of-life decision making in the ICU environment is likewise important.

The purpose of this study was to describe critical care nurses' knowledge, attitudes, confidence, and experiences regarding advance directives and end-of-life decision making. The aims of the study were to determine:

- the level of knowledge of critical care nurses regarding advance directives, the Patient Self-Determination Act (PSDA), and the New York State law/statute governing the critical care nurses' practice;
- the attitudes of critical care nurses regarding completion of advance directives and end-of-life decisions by patients and the level of confidence and advocacy in the nurses' practice related to advance care planning by patients and patients' families;
- the professional experiences of critical care nurses with advance directives and end-of-life decision making in patients under the nurses' care; and
- whether relationships exist between (1) selected demographic characteristics and (2) knowledge, attitude, confidence, and experience regarding advance directives and end-of-life decision making.

Background and Significance

Laws Governing Advance Directives

Each of the United States has laws/statutes governing advance care planning in the form of directives. New York State, where this study took place, has healthcare proxy law and a do-not-resuscitate statute. Living wills are legal in New York State on the basis of case law. The federal government enacted the PSDA in 1991; the act mandates that any healthcare institution that receives Medicaid or Medicare funds must inform its patients about the patients' right to self-determine care at the end of life according to the laws of the state in which the institution resides.

Despite more than a decade of laws governing patients' rights to end-of-life decisions, it is estimated that less than 20% of the US population has completed an advance directive.\(^\text{13}\)

Nurses' Knowledge of and Attitudes Toward Advance Directives

Few data are available on nurses' knowledge and skills in advance directives. Crego and Lipp\(^\text{14}\) found that a volunteer sample of nurses (n = 399) from a midwestern acute care teaching hospital had limited knowledge of advance directives. A 44-item questionnaire developed by the researchers was used to assess the nurses' knowledge. The range of scores was wide (40%-95%), indicating marked deficits for some nurses. Also, more than half the nurses indicated that they did not have a good understanding of advance directives. The nurses surveyed concurred, however, that discussion of advance directives is within nurses' professional role. A total of 67% thought that a nurse was the most likely and most appropriate care provider to begin discussion of advance planning and end-of-life decisions with patients.

Similarly, in a small survey of hospital nurses (n = 112), Wood and DelPapa\(^\text{15}\) found that although nurses had favorable attitudes toward advance directives, the nurses' knowledge was inadequate. A total of 76% of the nurses had low knowledge scores on questions about laws regarding advance directives.

Solomon et al.\(^\text{16}\) explored nurses' and physicians' knowledge of and attitudes toward national recommendations regarding patients' rights to forgo life-sustaining treatments. The investigators concluded that changes in the care of dying patients have not kept pace with national regulations, in part, because physicians and nurses disagreed with and were unaware of some key guidelines.

End-of-Life Decision Making in the ICU

Critical care nurses are often involved with patients and patients' families in end-of-life decision making. The nature of the critical care environment alone makes addressing advance directives unique compared with other aspects of healthcare. First, the families of most patients are experiencing extremely high levels of stress because of the severity of their loved ones' illnesses and the uncertainty associated with the outcome.\(^\text{4}\) Second, the use of sophisticated interventions and equipment such as ventilators and ventricular assist devices makes it difficult for patients and their families to understand the scope of the interventions that may be used.\(^\text{17,18}\) This lack of understanding leads to increased anxiety and further complicates making decisions about advance directives.\(^\text{19}\) Finally,
patients often cannot participate in
the advance directive process, fur-
ther exacerbating the difficulty of
the decision making.15

An essential contribution of criti-
cal care nurses who work with patients
and patients' families is interpreting
the patients' experience of illness
and treatment to assist the families
in decision making when the patients
are unable to make decisions.11 In
order to interpret patients' experience
of illness and treatment and assist
patients' families in making decisions,
nurses must maintain open lines of
communication with patients and
the patients' families. For example,
critical care nurses' interactions with
patients and/or patients' families
who were signing do-not-resuscitate
consents have been investigated by
using a qualitative perspective
(grounded theory).16,17 The findings
of the studies indicate the importance
of establishing a trusting relationship
with patients and the patients' fam-
ilies, maintaining open communica-
tion with the patients and families,
and serving as the patients' advocate.
Other important roles identified by
nurses include acting as a decision
maker and educating patients and
the patients' family members.15,17 In
a qualitative study of family decision
making for ICU patients, Jacob3 found
that skillful and supportive involve-
ment of care providers was related to
more positive long-term outcomes for
patients' family members. However,
little empirical evidence is available
on critical care nurses' knowledge of
and attitudes toward advance direc-
tives or on the roles the nurses are
actually performing.

Baggs and Schmitt18 assessed
the current research on end-of-life
decisions in adult intensive care.

They concluded that few studies are
available on nurses' involvement in
end-of-life decision making. ICU
nurses reported frustration about
their limited role in this decision
making, and ICU nurses disagreed
and were confused about the best way
to care for patients at the end of life.
Additional data on nurses' knowledge
of, attitudes toward, and experiences
with advance directives and end-of-
life decision making must be collected
and analyzed before an intervention
can be implemented to inform criti-
cal care nurses about the best way to
assist patients and patients' families
with advance directives.

Methods
A survey design was used to con-
duct a descriptive, correlational study
of a random sample of nurses cur-
rently practicing in critical care.

Sampling
A random sample of members of
the American Association of Critical-
Care Nurses (AACN) in New York
State who are registered nurses and
who described their work status as
full-time or part-time on their AACN
membership application received the
mailed survey. A state survey
rather than a national survey was
used because we wanted to measure
critical care nurses' knowledge of
the state laws and statutes governing
completion of advance directives in
the state where the nurses lived and
because the logistics of scoring the
knowledge subscale for all 50 states
would have been prohibitive. Using
power analysis, we determined that
a minimum of 107 subjects would
have 80% power to detect a medium
effect size of 15% at α = .05 for the
multiple-correlation question of
whether relationships exist between
(1) selected demographic character-
istics and (2) knowledge, attitude,
confidence, and experience regarding
advance directives and end-of-life
decision making.

Because of the large number of
items on the survey and the expected
low response rate of mail surveys, the
AACN membership was oversampled.
The AACN membership in New York
State is 4876 nurses; the names of a
random sample of 1000 (20.5%) mem-
bers from New York State were
obtained from AACN. The return rate
for the survey was 21%; a total of 210
surveys were usable for data analysis.

Instrument
The Knowledge, Attitudinal, Expe-
riential Survey on Advance Directives
(KAESAD) instrument was developed
by Jezewski et al19 to measure respon-
dents' knowledge of, attitudes toward,
and experiences with advance direc-
tives and end-of-life decisions. Relia-
Fority and validity of the instrument
were established through an expert
panel (n = 7) and a test-retest pilot
study with 56 oncology nurses. The
panel consisted of experts in end-of-
life care and advance directives and
represented the disciplines of nursing,
medicine, law, and bioethics. The
panel provided feedback about each of
the 110 items in the original draft
of the survey. On the basis of the
opinions of the panel and the judg-
ment of the investigators, changes
were made to 22 items, 9 items were
added, and 4 items were deleted.

After the changes were made, the
test-retest pilot study with the 56
oncology nurses was done. A con-
venience sample of 18 graduate nurs-
ing students was also used to
establish test-retest reliability. Test-
retest reliability and the Cronbach α were analyzed. The results of the analysis indicated test-retest scores for the various scales (r = 0.51-0.90), test-retest proportion of agreement for individual items (0.71-1.0), and internal consistency for the various scales (Cronbach α .58 to .95).

The KAESAD instrument used in this survey consists of 115 items. Table 1 gives the principal components of the survey, the numbers of items in each section, and the internal consistency (Cronbach α) of the attitude, confidence, and experience subscales for the data from the pilot study.

Of the 115 items, 85 are divided into 5 scales designated to measure knowledge, attitudes, confidence, and experience regarding advance directives and experience with end-of-life decision making. The first of the 5 scales encompasses 30 items that contain questions about critical care nurses’ knowledge of advance directives. The 30-item scale comprises 3 subscales related to general knowledge of advance directives, the PSDA, and state laws governing advance directives. Scores for each of 3 subscales and a total knowledge score were calculated. Respondents were asked to respond to each ques-

<table>
<thead>
<tr>
<th>Component</th>
<th>No. of Items</th>
<th>Internal consistency, Cronbach α</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General knowledge of advance directives</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Knowledge of the Patient Self-Determination Act</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Knowledge of New York State laws on advance directives</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>Attitudes toward advance directives and end-of-life issues</td>
<td>20</td>
<td>.58</td>
</tr>
<tr>
<td>Experience with advance directives</td>
<td>7</td>
<td>.93*</td>
</tr>
<tr>
<td>Confidence in assisting patients with advance directives</td>
<td>11</td>
<td>.95</td>
</tr>
<tr>
<td>Experience-based end-of-life decision making</td>
<td>20</td>
<td>.59</td>
</tr>
<tr>
<td>Demographic data</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Open-ended question related to nurses’ needs in helping patients complete advance directives</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>115</td>
<td></td>
</tr>
</tbody>
</table>

*Based on 5 items.
tion by checking yes, no, or don't know. The don't know choice was provided to minimize guessing the correct answer.

The second scale consisted of 20 items about nurses' attitudes toward completing advance directives and end-of-life decision making. Nurses were asked to respond to each item by using a 6-point Likert scale (1 = strongly disagree to 6 = strongly agree). Items addressed nurses' attitudes toward patients' rights, starting and stopping life support, artificial hydration and nutrition, nurses' role in informing patients, and assisted suicide.

The third scale consisted of 5 items to assess nurses' clinical experience with advance directives. Nurses were instructed to answer yes or no to the items. Two additional items not included in the scale asked nurses (1) Have you provided treatment to patients whose advance directive indicated otherwise? and (2) Have you observed others providing treatment to patients whose advance directive indicated otherwise? Nurses responded yes or no. These questions were separated from the third scale in order to improve the internal consistency of the scale.

The fourth scale consisted of 11 items on nurses' confidence in helping patients complete advance directives. Items addressed the nurses' confidence in answering the questions of patients and patients' families, teaching others about advance directives, mediating in disagreements related to advance directives, and advocating for patients' advance directives. Nurses responded by using a 5-point Likert scale (1 = not at all confident to 5 = very confident).

The fifth scale consisted of a series of 20 statements about the nurses' professional experience with end-of-life decision making. Again the nurses were asked to respond to each item by using a 6-point Likert Scale (1 = strongly disagree to 6 = strongly agree). Items included statements about professional opinions related to communicating prognosis, how patients make decisions, whether the presence of advance directives encourages communication, and nurses' roles.

The instrument also contained 26 items on demographic characteristics. The responses to these items were used to assess personal, professional, and institutional variables. Personal variables included race, religion, sex, marital status, age, and whether the respondent had completed an advance directive for himself or herself. The professional variables included professional education preparation, clinical practice site, current position, AACN certification status, work status, and amount of formal instruction on advance directives. Institutional variables included geographic location of the workplace, the presence of an ethics committee in the workplace, and how patients' advance directives are formally communicated within the workplace.

The last item of the instrument was an open-ended question: What do critical care nurses need most to increase their ability to assist patients with advance directives? The written responses to this question are being analyzed by using qualitative techniques and will be reported separately.

**Procedure**

The 1000 nurses were mailed the KAESAD survey. Those nurses who might have discarded their survey were given a telephone number on a separate sheet of paper to request a new survey if they desired. This strategy was selected, rather than a second letter only to nonrespondents, to ensure anonymity of respondents. The survey was mailed by using a bulk mail permit and the university mailing service. A stamped self-addressed envelope was included to facilitate return of the survey.

Approval to conduct the study was obtained from the University at Buffalo institutional review board.

**Data Analysis**

Data were entered into Excel (Microsoft Corp, Redmond, Wash) and imported into SPSS, version 10.0 (SPSS Inc, Chicago, Ill). Those questionnaires with small amounts of missing data, less than 20% (eg, 1-2 items per knowledge, attitude, or experience subscale), were included in the analysis with the missing data imputed by the substituted mean. SPSS statistical software was used for the analysis. Statistical significance was set at $P < .05$.

Knowledge questions were answered true, false, or don't know. In order to determine knowledge scores, don't know answers were treated as incorrect. Nurses' attitudes toward completing advance directives and experience with end-of-life decision making were reduced to 2 levels. The 3 choices reflecting some level of agreement (strongly agree, moderately agree, agree) were used to represent agreement. Similarly, the 3 choices reflecting some level of disagreement (disagree, moderately disagree, strongly disagree) were used to represent disagreement. Because the Cronbach $\alpha$ values for the attitude scale (.58) and professional based
Table 2  Demographics of the sample

<table>
<thead>
<tr>
<th>Characteristic (No. of respondents who answered the question)</th>
<th>Values*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (188), mean (range), y</td>
<td>45.57 (24.42-65.58)</td>
</tr>
<tr>
<td>Sex (207)</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>12 (5.8)</td>
</tr>
<tr>
<td>Female</td>
<td>195 (94.2)</td>
</tr>
<tr>
<td>Ethnicity (205)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>171 (83.4)</td>
</tr>
<tr>
<td>Other</td>
<td>34 (16.6)</td>
</tr>
<tr>
<td>Marital status (208)</td>
<td></td>
</tr>
<tr>
<td>Married or living as married</td>
<td>141 (67.8)</td>
</tr>
<tr>
<td>Other</td>
<td>67 (32.2)</td>
</tr>
<tr>
<td>Religion (209)</td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>40 (19.1)</td>
</tr>
<tr>
<td>Jewish</td>
<td>5 (2.4)</td>
</tr>
<tr>
<td>Catholic</td>
<td>132 (63.2)</td>
</tr>
<tr>
<td>None</td>
<td>13 (6.2)</td>
</tr>
<tr>
<td>Other</td>
<td>19 (9.1)</td>
</tr>
<tr>
<td>Highest educational degree (209)</td>
<td></td>
</tr>
<tr>
<td>Diploma</td>
<td>13 (6.2)</td>
</tr>
<tr>
<td>Associate degree</td>
<td>17 (8.1)</td>
</tr>
<tr>
<td>Baccalaureate degree</td>
<td>103 (49.3)</td>
</tr>
<tr>
<td>Master's degree</td>
<td>70 (33.5)</td>
</tr>
<tr>
<td>Doctorate</td>
<td>3 (1.4)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (1.4)</td>
</tr>
<tr>
<td>Years practicing as a registered nurse (207), mean (range)</td>
<td>18.75 (1-42)</td>
</tr>
<tr>
<td>Years practicing in critical care (207), mean (range)</td>
<td>14.62 (0-33)</td>
</tr>
<tr>
<td>Current position (207)</td>
<td></td>
</tr>
<tr>
<td>Staff nurse</td>
<td>119 (57.5)</td>
</tr>
<tr>
<td>Nurse manager</td>
<td>29 (14.0)</td>
</tr>
<tr>
<td>Nurse educator</td>
<td>20 (9.7)</td>
</tr>
<tr>
<td>Nurse practitioner</td>
<td>10 (4.8)</td>
</tr>
<tr>
<td>Clinical nurse specialist</td>
<td>8 (3.9)</td>
</tr>
<tr>
<td>Other</td>
<td>21 (10.1)</td>
</tr>
<tr>
<td>Primary role direct patient care (207)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>65 (31.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>142 (68.5)</td>
</tr>
<tr>
<td>CCRN certification (206)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>69 (33.5)</td>
</tr>
<tr>
<td>No</td>
<td>137 (66.5)</td>
</tr>
<tr>
<td>Hours of education on advance directives (208), mean (range)</td>
<td>1.9 (0-50)</td>
</tr>
<tr>
<td>Formal instruction at current workplace on advance directives (208)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>73 (35.1)</td>
</tr>
<tr>
<td>Yes</td>
<td>135 (64.9)</td>
</tr>
</tbody>
</table>

Results

Sample

Most of the respondents were female, white, married, and Catholic (Table 2). The majority (176/209, 84.2%) had a baccalaureate degree or higher. Most (119/207, 57.5%) were staff nurses, and one third (69/206, 33.5%) were CCRN certified. Almost two thirds (135/208, 64.9%) had formal instruction in advance directives at their place of work. Respondents were asked to estimate the number of hours of instruction in advance directives they received during their nursing education. Scores ranged from 0 to 50 hours (mean 1.88 hours, SD 4.80 hours). A small percentage (7/193, 3.6%) of the respondents were members of their institution’s ethics committee. Almost half (100/210, 47.6%) of the critical care nurses had an advance directive for themselves,
Table 2 Continued

<table>
<thead>
<tr>
<th>Characteristic (No. of respondents who answered the question)</th>
<th>Values*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ethics committee at workplace (206)</td>
<td></td>
</tr>
<tr>
<td>Don't know</td>
<td>8 (3.9)</td>
</tr>
<tr>
<td>No</td>
<td>4 (1.9)</td>
</tr>
<tr>
<td>Yes</td>
<td>194 (94.2)</td>
</tr>
<tr>
<td>Member of ethics committee (195)</td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>188 (96.4)</td>
</tr>
<tr>
<td>Yes</td>
<td>7 (3.6)</td>
</tr>
<tr>
<td>Advance for themselves (210)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>100 (47.6)</td>
</tr>
<tr>
<td>No</td>
<td>110 (52.4)</td>
</tr>
<tr>
<td>Immediate family member with an advance directive (210)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>129 (61.4)</td>
</tr>
<tr>
<td>No</td>
<td>81 (38.6)</td>
</tr>
</tbody>
</table>

*Values are number of respondents (percentage) unless otherwise indicated. Because of rounding, percentages do not all total 100.

Table 3 Knowledge of advance directives

<table>
<thead>
<tr>
<th>Scale</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>General knowledge of advance directives (10-item questionnaire) (n = 210)</td>
<td>7.07 ± 1.22</td>
</tr>
<tr>
<td>Knowledge of the Patient Self-Determination Act (7-item questionnaire) (n = 207)</td>
<td>3.68 ± 1.39</td>
</tr>
<tr>
<td>Knowledge of New York State laws on advance directives (13-item questionnaire) (n = 204)</td>
<td>7.07 ± 2.05</td>
</tr>
<tr>
<td>Total knowledge of advance directives (30-item questionnaire) (n = 204)</td>
<td>17.80 ± 3.17</td>
</tr>
</tbody>
</table>

Knowledge

Critical care nurses' knowledge was measured by calculating the knowledge scores on 3 subscales and then determining the total knowledge score on the basis of the scores on the 3 subscales. Table 3 is an overview of the mean and percentage correct scores for the 3 knowledge subscales and the total knowledge scores.

The first knowledge subscale was used to measure the nurses' general knowledge of advance directives. The 10-item measure included definitions of advance directives and the various types of advance directives (living will, durable power of attorney, healthcare proxy), role of proxy decision makers, and legal issues related to advance directives. Respondents' scores were highest for this subscale. A 1-way analysis of variance was carried out to detect statistically significant findings. The results indicated that the scores of nurses who were CCRN certified differed significantly from the scores of nurses who were not certified ($F_{1, 206} = 5.02, P = .03, n = 206$). Certified critical care nurses (n = 137) scored higher (mean 7.23, SD 1.20) than did non-certified critical care nurses (n = 69, mean 6.84, SD 1.17).

The second knowledge subscale focused on questions related to the principal components of the PSDA. Items in this subscale included healthcare facilities, obligations, legislation enacted, requirements to inform patients about their rights, and training of staff. Respondents scored lowest on this knowledge subscale.

The third knowledge subscale was used to measure respondents' knowledge of the laws of New York State on advance directives. Questions on this subscale focused on the age when a person can complete an advance directive, what the law permits regarding withdrawing and withholding care, and legality of advance directives from other states. The respondents' score was 54.4%.

Total knowledge scores were calculated by using the 30 items from the 3 subscales. The total knowledge mean score was 17.80 of a possible 30 or 59.3%.

Attitudes Toward Advance Directives and End-of-Life Decision Making

The nurses were asked to respond to the series of 20 items regarding the nurses' attitudes toward advance directives and end-of-life decisions. Table 4 presents the mean scores, SDs, and percentage of agreement for some of those items. Percentage of agreement was determined by reducing the agree, moderately agree, and strongly agree responses into a single category. Internal consistency in this study according to the Cronbach α was .57 (n = 210).

Responses to several items reflected a role of nurses as advo-
Table 4: Scores on and percentage agreement for selected attitudes regarding advance directives and end-of-life issues*

<table>
<thead>
<tr>
<th>Item/statement</th>
<th>Score Mean SD</th>
<th>% Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nurse Is responsible for conferring with the doctor if a patient’s rights have not been considered</td>
<td>5.56 0.86</td>
<td>97.6</td>
</tr>
<tr>
<td>Nurses should help inform patients of the patients’ condition and treatment options</td>
<td>5.44 1.01</td>
<td>96.2</td>
</tr>
<tr>
<td>Appropriate to give pain medication even if it hastens death</td>
<td>5.56 0.89</td>
<td>96.1</td>
</tr>
<tr>
<td>Uphold patients’ wishes when nurses’ view conflicts with patients’ view</td>
<td>5.54 0.95</td>
<td>94.8</td>
</tr>
<tr>
<td>Nurses should actively help patients complete advance directives</td>
<td>5.10 1.30</td>
<td>89.0</td>
</tr>
<tr>
<td>Actively assisting some patients to die should be made legal</td>
<td>3.20 1.61</td>
<td>42.2</td>
</tr>
<tr>
<td>Starting or stopping life support is ethically the same</td>
<td>2.88 1.63</td>
<td>31.7</td>
</tr>
<tr>
<td>Acceptable for healthcare providers not to offer treatment to the terminally ill</td>
<td>2.00 1.42</td>
<td>16.7</td>
</tr>
<tr>
<td>Advance directives lead to acceptance of euthanasia</td>
<td>2.06 1.34</td>
<td>12.4</td>
</tr>
</tbody>
</table>

*Scores are based on a 6-point Likert scale (1 = strongly disagree to 6 = strongly agree); % agreement is sum of Likert scale scores 4-6 divided by the total responses per question; reliability coefficient (Cronbach α) = .57.

Provided treatment to patients whose advance directives indicated otherwise, and 149 (71.3%) of 209 had observed others providing treatment to patients whose advance directives indicated otherwise. Because treatment was not operationally defined, the specifics as to what the treatments included cannot be elaborated on.

Level of Confidence

The respondents’ confidence in their role of assisting patients and patients’ families was measured by using the 11-item scale. Internal consistency for this study was excellent for the confidence scale: Cronbach α = .93, n = 210. Subjects responded by using a 5-point Likert scale (1 = not at all confident to 5 = very confident). The total mean score for confidence was 40.2 (maximum score = 55) with an SD of 8.97. The nurses were least confident (scores < 3) about knowing the PSDA (mean score 2.60, SD 1.14) and about knowing state laws on advance directives (mean score 2.89, SD 1.05). Respondents were most confident (scores > 4) on items dealing with confidence in initiating (mean score 4.06, SD 1.05) and answering patients’ (mean score 4.03, SD 0.98) and patients’ families’ (mean score 4.03, SD 0.96) questions about advance directives.

Professional Experience With End-of-Life Decision Making

The nurses were also asked to respond to 20 statements about professional experience with end-of-life decision making. Internal consistency was low: Cronbach α = .54, n = 210.

Table 5 gives mean scores, SDs, and level of agreement of respondents with the statement for some of the statements. Agreement was

cates for patients. For example, most respondents (94.8%) agreed that nurses should uphold a patient’s wishes even if the wishes conflict with the nurses’ own view. Also, agreement was high that nurses are responsible for conferring with a physician if a patient’s rights have not been considered (97.6%) and that nurses should help inform patients of their condition and treatment options (96.2%). Interestingly, almost half of the respondents (42.2%) agreed that actively assisting some patients to die should be made legal. Only 31.7% agreed with the statement that starting or stopping life support is ethically the same. The respondents felt strongly (96.1% agreement) that patients should receive the pain medication the patients need even though the medication may hasten death. This response reflects the current emphasis on adequate pain management at the end of life.

Experience With Advance Directives

Critical care nurses’ experiences with advance directives were measured by using a yes or no response to a series of 5 questions. Internal consistency for this scale was low: Cronbach α = .58, n = 210. The respondents mean yes score was 4.24 (maximum = 5) with an SD of 1.05. Most of the respondents had cared for patients who had advance directives (98.0%), counseled patients and patients’ families about advance directives (84.8%), and initiated discussion with patients about advance directives (82.9%). Two additional questions were asked about experience with advance directives. Approximately half of the respondents, 100 (48.1%) of 208, had
Table 5  Agreement with selected items on professional experiences with end-of-life issues

<table>
<thead>
<tr>
<th>Item/statement</th>
<th>Score Mean SD</th>
<th>% Agreement</th>
</tr>
</thead>
</table>
| Presence of a living will encourages discussion between a patient and healthcare
  providers about the patient’s preferences                                       | 4.36 1.21      | 82.2        |
| Generally nurses can answer patients’ questions about advance directives         | 4.26 1.17      | 78.4        |
| Some patients are excluded from making decisions because they are inappropriatelyjudged to lack capacity to make decisions | 3.79 1.26      | 82.5        |
| Very often not enough time to discuss advance directives                          | 3.78 1.35      | 59.1        |
| Nurses usually know the wishes of their patients regarding advance care planning | 3.69 1.17      | 58.5        |
| Information in an advance directive usually is sufficient to direct treatment    | 3.30 1.28      | 42.5        |
| Most patients have enough knowledge about their medical condition and potential treatments to prepare advance directives | 2.88 1.18      | 29.3        |
| Patients are approached early enough to make informed decisions about end-of-life care | 2.50 1.32      | 23.1        |
| Terminally ill patients with a do-not-resuscitate order receive less care overall | 2.28 1.41      | 18.3        |
| The amount of time nurses spend discussing advance directives with patients is sufficient | 2.41 1.09      | 12.6        |

*Scores are based on a 6-point Likert scale (1 = strongly disagree to 6 = strongly agree); % agreement = sum of Likert scale scores 4-6 divided by the total responses per question; reliability coefficient (Cronbach’s α) = .54. Because of the length of the instrument used, only items for which some level of conclusion can be drawn are given in this table.

low for the statements that the amount of time nurses spend discussing advance directives with patients is sufficient (12.6%) and that patients have enough knowledge about their medical condition and potential treatments to prepare advance directives (29.3%). Generally, respondents agreed that there is not enough time to discuss advance directives (59.1%) and that nurses usually know the wishes of their patients about advance directives (58.5%). Less than half (42.5%) agreed that information in an advance directive is sufficient to direct treatment.

Knowledge, Experience, and Confidence Scores and Selected Demographics

In evaluating the relationship between (1) personal, professional, and institutional characteristics and (2) knowledge, experience, and confidence scores, we found several significant, although weak, correlations. Total knowledge scores were positively correlated with total experience scores \( r = 0.16, P = .05 \), total confidence scores \( r = 0.31, P = .01 \), age \( r = 0.18, P = .05 \), and years in practice \( r = 0.22, P = .05 \). Total knowledge scores did not correlate with hours of education on advance directives. However, total confidence scores did correlate with hours of education on advance directives \( r = 0.18, P = .05 \).

Establishment of an advance directive by immediate family members was significantly correlated with the respondents’ experience, confidence, and total knowledge scores. Nurses whose family members had an advance directive had significantly higher scores for experience with advance directives \( P = .005 \), confidence \( P = .004 \), and knowledge \( P = .005 \) than did nurses whose family members did not have advance directives. Also, nurses with advance directives of their own had higher scores for experience with advance directives \( P = .01 \) and confidence \( P = .001 \) than did critical care nurses without advance directives of their own.

In addition, education in the workplace on advance directives was significantly correlated with experience and total knowledge scores. Nurses who had education in the workplace on advance directives had significantly higher knowledge scores \( P = .01 \) and more positive experience with advance directives \( P = .03 \) than did nurses who had no education on advance directives.

Discussion and Conclusions

Within the context of the limitations of this study (see Limitations), although any attempt to make a valid conclusion on the basis of the data would be suspect, the data do describe various interesting and concerning phenomena that at a minimum warrant further investigation. Other methods or instruments and/or further development, testing, and improvement of the KAESAD instru-
Treatment could be used to provide accurate conclusions about this subject area and critical care nurses. Nevertheless, the data do describe and may suggest the following conclusions about this sample of New York State AACN members.

Overall, the nurses were knowledgeable about advance directives in general but not about the PSDA or the New York State law on advance directives. CCRN certification was positively correlated with general knowledge scores. The possibility exists that CCRN certification may help increase nurses' understanding of advance directives. The finding that nurses who had education in the workplace on advance directives had higher knowledge scores and more positive experiences with advance directives and end-of-life decision making than did nurses who did not have such education may suggest that staff education in the workplace is an effective way to make nurses knowledgeable about advance directives and end-of-life decision making.

Nurses' attitudes reflect a participatory role in assisting/advocating for patients' rights to make decisions about end-of-life care and advance directives. Support for assisted suicide was high, 42.2% of the respondents, and most respondents did not have an issue with stopping treatment once treatment had been started.

Although nurses' confidence was low regarding the PSDA and New York State law on advance directives, the nurses were very confident in their ability to assist patients and patients' families in completing advance directives. The high percentage of nurses who either provided treatment or observed others providing treatment to patients whose advance directives indicated otherwise is disturbing. Although percentages vary, many researchers have reported that healthcare providers' awareness of and use of patients' existing advance directives are quite limited. Baggs and Schmitt noted that despite emphasis on the need to involve patients, patients' families, and care providers in end-of-life decision making, evidence is strong that physicians often make these decisions with little input from others. In a study by Wilson, only 13.1% of do-not-resuscitate orders were based on patients' preferences. Maxfield et al. found that unwanted cardiopulmonary resuscitation was administered to 11% of their study sample who had advance directives. Critical care nurses in our study who had completed their own advance directives had higher confidence scores than did nurses without advance directives, thereby supporting beliefs that individuals who complete their own advance directives are better able to assist others in completing such directives.

Professional experiences with end-of-life issues may reflect the hectic pace and high stress levels encountered in an ICU environment. The responses to our survey also address the ambiguity in advance directive decision making related to the types of care uniquely offered in the ICU. This fact is evidenced by the low percentage of agreement to items such as “Most patients have enough knowledge about their medical condition and potential treatments to prepare advance directives.” Treatment options can be particularly problematic in an ICU environment because ICU care is not simply a matter of agreeing or disagreeing to have cardiopulmonary resuscitation. Many other life-prolonging invasive interventions, such as use of continuous venovenous hemodialysis and ventricular assist devices, that patients and families are unaware of are possible, and once informed about these interventions, patients and patients' families may choose not to have them. Treatment options need to be explained to patients and their families in terms they can understand.

One way that may improve the awareness of a patient's family members of treatment options when advance directives lack sufficient information to direct treatment is the family conference in which family members, physicians, nurses, and social workers can discuss end-of-life care issues. Nurses also need to recognize their responsibility to serve as patients' advocates, making sure that the patients' advance directives are honored and their wishes followed.

Limitations

Limitations in this study affect the interpretation of findings. The pilot study indicated that the test-retest reliability for some of the scales was low (r = 0.51); however, the test-retest proportion of agreement for individual items (0.71 to 1.0) was good. Internal consistency was low in this study for the attitude (Cronbach α = .57), experience with advance directives (Cronbach α = .58), and professional experience with end-of-life decision making (Cronbach α = .54) scales. The limitation of low Cronbach α values was addressed by looking at the items individually, not as scales. Additional use and testing of the KAESAD instrument are needed for additional support of its psychometric characteristic.
Also, the correlations, although statistically significant, are weak and therefore may have little influence on the findings. The findings are representative only of critical care nurses who are members of AACN. The survey was conducted in New York State and may not reflect the knowledge and attitudes of nurses in other states. The response rate was relatively low. The length of the survey (12 pages) may have contributed to the low response rate.

References