

# PRACTICE OF EXPERT CRITICAL CARE NURSES IN SITUATIONS OF PROGNOSTIC CONFLICT AT THE END OF LIFE

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- **BACKGROUND** *Prolonging the living-dying process with inappropriate treatment is a profoundly disturbing ethical issue for nurses in many practice areas, including the intensive care unit. Despite the frequent occurrence of such distressing events, research suggests that critical care nurses assume a limited role in end-of-life decision making and care planning.*
- **OBJECTIVES** *To explore the practice of expert critical care nurses in end-of-life conflicts and to describe actions taken when the nurses thought continued aggressive medical interventions were not warranted.*
- **METHODS** *A qualitative design was used with narrative analysis of interview data that had a temporal ordering of events. Interviews were conducted with 21 critical care nurses from 7 facilities in the southwestern United States who were nominated as experts by their colleagues.*
- **RESULTS** *Three recurrent narrative plots were derived: protecting or speaking for the patient, presenting a realistic picture, and experiencing frustration and resignation. Narratives of protecting or speaking for the patient concerned preventing further technological intrusion and thus permitting a dignified death. Presenting a realistic picture involved helping patients' family members reframe the members' sense of the potential for recovery. Inability to affect a patient's situation was expressed in narratives of frustration and resignation.*
- **CONCLUSIONS** *The transition from curative to end-of-life care in the intensive care unit is often fraught with ambiguity and anguish. The expert nurses demonstrated the ability and willingness to actively protect and advocate for their vulnerable patients even in situations in which the nurses' actions did not influence the outcomes. (American Journal of Critical Care. 2006;15:480-491)*

## CE

### Notice to CE enrollees:

A closed-book, multiple-choice examination following this article tests your understanding of the following objectives:

- Describe the most disturbing ethical dilemma faced by most critical care nurses
- Analyze different reaction patterns of critical care nurses
- Discuss the most common support group of critical care nurses

According to a recent study by Redman and Fry<sup>1</sup> on ethical issues in nursing practice, prolonging the living-dying process with inappropriate measures is one of the most profoundly disturbing experiences nurses face. Puntillo et al<sup>2</sup> reported similar findings in an investigation to determine the knowledge, beliefs, and ethical concerns of nurses caring for patients dying in intensive care units

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(ICUs). In that study,<sup>2</sup> 42% of the sample (N = 906) thought aggressive medical treatments were prolonged to a great extent, and 49% thought that interventions were sometimes prolonged beyond what was reasonable. Although such distressing events occur frequently, Miller et al<sup>3</sup> report that most research findings suggest nurses have a limited role in end-of-life decision making and care planning. In contrast, Drought and Liaschenko<sup>4</sup> maintain that expert nursing practice is characterized by frequent questioning of the goals of care and active resistance to the “technological imperative.” As described by Callahan,<sup>5</sup> the technological imperative is an unspoken mandate that life-sustaining technology must be used if the technology is available.

*Expert nursing practice is characterized by questioning the goals of care and active resistance to the “technological imperative.”*

The purpose of the qualitative study reported here was to explore end-of-life conflicts as experienced by expert nurses who practice in adult critical care units. A specific aim was to describe and analyze actions taken by the participants in the study when they thought continued aggressive medical interventions were not warranted. Each description was evaluated for narrative properties, defined as a discrete story of personal experience characterized by a temporal ordering of events with a recognizable beginning, middle, and end structured around a plot that had a point or moral.<sup>6-8</sup> The use of narrative as an interpretive process integral to shaping and understanding a story is at the heart of human knowing.<sup>9</sup>

## Methods

### Sample

After approval of the study by the appropriate institutional review board, 9 members of a critical care consortium in San Antonio, Tex, were sent a letter describing the purpose of the proposed research. This consortium is a local working group of the American Association of Critical-Care Nurses whose members practice as clinical nurse specialists and/or nurse educators. Because of the group’s extensive practice background and familiarity with the preparation and practice of individual staff members, we thought that members of the group would be able to identify expert critical care nurses in the members’ institutions. To help members of the consortium identify expert nurses, we included infor-

mation on the work of Benner et al<sup>6,7</sup> on expert practice in the letter requesting the members’ participation.

The number of experts nominated by each consortium member varied from 4 to 17. A total of 39 prospective participants in 3 urban teaching medical centers and 39 in 3 urban private, religious affiliated facilities and 1 community hospital were identified as expert nurses, for a total of 78 possible respondents. To ensure equal representation, prospective participants were chosen in an alternate fashion from each of the 7 facilities by using a random numbers table. As advised, an information letter inviting participation was then mailed to each nominee’s place of employment or specified home address or was sent to the clinical nurse specialist/nurse educator at the nominee’s facility and placed in the nominee’s mailbox. Reminder postcards were mailed 1 week later. If a response was not received after 2 weeks, another name was randomly chosen from that institution.

### Data Collection

Participants contacted the investigator (C.M.R.) by telephone or e-mail, and a mutually agreeable time and place for an interview was arranged. The initial interview lasted approximately 1 to 1½ hours. The following statement, which conveyed the conception of the area of interest as an ethical dilemma and enabled the respondent to disagree or decline to comment, was read at the beginning of the interview:

Sometimes critical care nurses find themselves in situations in which they believe the patient will not regain an acceptable quality of life despite the provision of all therapies and interventions. Caring for the patient at this time can become an ethical dilemma for the nurse if aggressive medical treatment is continued. I would like you to think about whether you have experienced this situation and tell me what you chose to do.

In an effort to generate narrative accounts, each nurse was then encouraged to recall and reflect on one or two situations with patients the nurse had experienced. By capturing the complexity of interpersonal ethical and clinical judgments involved, narratives offer a method to describe nursing knowledge and practice.<sup>8</sup> All interviews were recorded on audiotape. At the conclusion of the initial interview, respondents completed a demographic data sheet. A brief second interview was conducted with 3 participants to clarify obtained information from the first interview to avoid the possibility of misrepresentation of data.<sup>10</sup> Two other nurses were contacted by telephone for the same

purpose. Upon completion of data analysis, 4 participants met with the investigator (C.M.R.) to discuss tentative findings and explore confirmation or alternative impressions.

### Data Analysis

The audiotapes were professionally transcribed, and each transcript was checked against the audiotapes for accuracy. Transcripts were scrutinized across a number of interviews to gain an overall impression of what the expert nurses were saying and then were reread to select segments that took a narrative form. These segments were often identified when the participant began a description of a particular experience with a patient by stating, "Well, we had this patient" or "I remember this one patient." These accounts conformed to the definition of Labov<sup>11</sup> of a narrative of personal experience and had a temporal sequence with a recognizable beginning, middle, and end. Although the original intent was to elicit expert nurses' narratives, the interview also generated shorter responses that did not have a temporal ordering of events structured around a plot or framework. A thematic analysis with approaches described by Coffey and Atkinson<sup>12</sup> yielded 3 main themes and 12 subthemes that are not presented in this article. The narratives contain examples of how some themes and subthemes could be interwoven and elaborated as the stories unfolded.

Analysis of the narratives involved 4 levels of analysis and representation. First, narratives were retranscribed and parsed into numbered lines according to transcription conventions suggested by Riessman<sup>13</sup> and adapted from Gee.<sup>14</sup> In a departure from Labov's functional definition of a clause,<sup>11</sup> the numbered lines consisted of short clauses that contained a single piece of information or "idea unit"<sup>14</sup> often separated by discourse markers such as "and," "then," or "so."

*Patients' advocates help patients make choices that reflect their values and enhance their dignity.*

Second, narrative clauses were organized as scenes<sup>13</sup> that depicted a single event or portrayed a particular topic in the narratives. When retranscribed by using the format of Gee<sup>14</sup> and Riessman,<sup>13</sup> the narratives had a poetic structure that emphasized the rhythms of the original speech and illuminated some of the personal and emotional content.

Third, clauses were identified by adapting the structural framework of Labov<sup>11,15</sup> of 6 common functional elements: abstract, orientation clauses, complicating actions, evaluative clauses, resolution, and coda.<sup>4</sup> Recurring plots or a narrative typology was then identified by using techniques suggested by Polkinghorne<sup>16</sup> and Ayres.<sup>17</sup> Narrative plot is the design and intention of a narrative, or what shapes and gives it a certain direction or intent of meaning. Without recognition of plots, each narrated event appears discontinuous and separate.<sup>16</sup>

*Expert nurses gain support from a core group of peers to attain the best result for the patient.*

Fourth, the narrative data were analyzed through an iterative process that involved moving back and forth between individual elements of the text and the whole text in several cycles. Each cycle integrated 3 levels of analysis: multiple readings of each narrative to identify significant meanings, with particular attention to evaluative statements, verbal emphasis, and word repetition; comparison across narratives to identify similar or dissimilar elements; and comparison of one whole narrative account with another to identify common organizing themes of meaning and significance.<sup>17</sup> The integration of findings from within and across the expert nurses' accounts facilitated the development of a narrative typology organized around 3 recurring plots: protecting or speaking for the patient, presenting a realistic picture, experiencing resignation and frustration.

## Results

### Characteristics of the Sample

A total of 21 expert adult critical care nurses made up the final sample for the study. The Table gives the demographic data. Of the 39 expert nurses identified from the 3 teaching medical centers, 26 were mailed information letters and 17 participated in the study, a response rate of 65%. Of the 39 nominees from the 1 community and 3 private hospitals, 33 were invited to participate and 4 responded, for a response rate of 12%.

### Protecting or Speaking for the Patient

Of the 21 nurses interviewed, 7 had narratives about protecting or speaking for the patient; 1 participant provided 2 accounts. In these narratives, the expert nurses discussed patients whom they perceived as vulnerable. The concept of vulnerability is ethically significant because it reflects the belief or perception that

Characteristics of the sample (N = 21)		
Characteristic	No. of respondents	%*
<b>Age, y</b>		
30-35	2	10
36-40	4	19
41-45	5	24
46-50	9	43
51-60	1	5
<b>Sex</b>		
Male	4	19
Female	17	81
<b>Highest degree obtained in nursing</b>		
Diploma	2	10
Associate degree	3	14
Bachelor of Science	14	67
Master of Science	2	10
<b>No. of years in nursing</b>		
5-10	7	33
11-15	4	19
16-20	2	10
21-25	7	33
26-30	1	5
<b>No. of years in critical care nursing</b>		
5-10	9	43
11-15	4	19
16-20	5	24
21-25	3	14
<b>No. of years in present position</b>		
1-5	8	39
5-10	10	48
11-15	1	5
16-20	2	10
<b>Type of critical care unit employed in</b>		
Medical	5	24
Cardiac	5	24
Surgical	5	24
Combination	6	29
<b>Type of facility</b>		
Private	4	19
Teaching	17	81
<b>CCRN certification</b>		
Yes	15	71
No	6	29
<b>Membership in professional organization</b>		
American Association of Critical-Care Nurses	15	71
American Heart Association Task Force on Cardiovascular Nursing	3	14
None	3	14

\* Because of rounding, percentages may not all total 100.

persons are innately capable of being injured. In the narratives related, injury was conceived as occurring in additional realms of human experience besides health to include patients' agency or patients' ability to initiate meaningful action and determine the ends of life.<sup>18</sup> The

circumstances of vulnerability described by the nurses concerned preventing further technological intrusion and honoring the wishes of patients and patients' families, thus permitting a dignified death. The narratives showed an expertise in integrating clinical, relational, and ethical assessment that appeared to be a prerequisite for taking action in the situations described.

The opening scene of the following example provides an abstract or summary of what the narrative will be about. The summary is followed by an orientation that briefly describes the situation, participants, and what the expert nurse considered.

This was about a patient who no longer wanted any more surgery. The patient wrote a note saying, "No more surgeries, no more, you're hurting me, this is killing me." She had been through 25 surgeries at that point. But her doctor kept saying, "No, you need these." And I felt uncomfortable because the patient was alert and oriented. I'm doing my neurological assessment, so what I'm documenting on a legal document says that she is alert and oriented. And then I felt that the things I was being asked to do were things that were against her will. And so I refused to do those things.

Receiving mechanical ventilation and effectively being without a voice, the patient attempted to communicate her wishes through writing. It is not known how long the patient had been in the ICU, but presumably, after 25 surgeries, it had been a considerable time. Although not directly naming the ethical principles in the evaluative statements, the nurse indicated concern that the patient's autonomy was being violated. The narrative continued:

And I actually stood there while he [the attending physician] told a mistruth, not a total fabrication of the situation but just some misleading information to try to make them sway his way. And then finally I just spoke up right there because I have to live with myself, and he practices his medicine, and my role as a nurse is patient advocate. . . . They [patients] still have a right to refuse. And he said, "But she's a little confused; she's been ill for a long time." But those are excuses to me. And I said, "Well, I look at her and she's clear of mind." And I mean a patient has a right to say no.

Liaschenko<sup>18</sup> has suggested that the end or aim of nursing is helping each patient have a particular life,

considered the patient's own, which entails enabling the patient's agency or ability to initiate meaningful action. Acting for the patient poses the greatest ethical challenge at the intersection of 2 manifestations of power, the personal and the institutional, because a nurse can choose to act for institutionalized medicine as well as for the patient. The narrative continued:

So we stepped outside the room, and then he was furious with me for not being supportive of him. Because several times she looked to me, because I've been with her, and she was looking for some support. Her husband was trying to say it, but he wanted her to live at any cost. So when somebody offers a ray of hope, then why wouldn't you go for it? He [the husband] was doing it out of love. And he [the physician] told me that I was just the nurse and who did I think I was saying things when he is trying to tell the patient what is going on. And I said, "Well, I'm a patient advocate, and what the patient is telling me is she is not in agreement with what you say." And then he said I work for the hospital and I work for him. And I said, "No I don't; I work for the patient." And so I think I am very protective of my patients as if they were my own children. Because sometimes we are the only thing as nurses that stand between something that can be good for them or something that can be bad for them.

The patient "looked" to the nurse for support because she had "been with her." Their mutual engagement resulted in what Rafael<sup>19</sup> has described as "empowered caring," which involves a responsibility for others. Being responsible, however, does not imply paternalism, but mutuality and helping patients discern and make choices that reflect their values and enhance their dignity. In the scene described, the patient's agency essentially had been disavowed. Consequently, this expert nurse identified herself as a patient advocate and spoke for the patient.

Risk is inherent in advocacy,<sup>6</sup> and this nurse risked incurring institutional reprimand in addition to the physician's diatribe. In the evaluative statements, she described the reasons for her actions as being "protective" of the patient and helping the patient attain what was "good." This reasoning of what constitutes the "good" in this and other narratives in the study illustrates what Gadow<sup>20</sup> has described as essential to a "relational narrative." Gadow maintains that a relational narrative is "not a solution to an ethical problem but a form of shelter, a provisional account of the good con-

structed by the patient and nurse as a way of making the situation inhabitable."<sup>20(p9)</sup> The narrative continued:

So, I called the ethics committee. I had to explain the situation, which I fully expected. They talked to me, and they talked to the patient. They talked to the patient's family. And then they talked to the physician. It seemed like they came with their minds already made up. The physician still really has the final say. I felt very underserved by the whole situation. They did not give any guidance. So, the patient went for one more surgery. And then finally, because a group of us felt good about speaking on her behalf, he just kind of got worn down, the surgeon. He realized this was all he could do. And then she quietly passed away. And that is sad because we did not expand her quality of life and the time she had left. We sure could have made it better. If she hadn't had so many surgeries where she had sedation hanging on. Each time it took longer and longer for her to come back to us. And we never changed the outcome one iota.

Rushton and Brooks-Brunn<sup>21</sup> have noted that ethics committees are designed to educate, promote dialogue, and resolve disputes. However, in some hospitals, access may be limited to certain members of the healthcare team, or the committee may merely focus on maintaining the status quo. In our study, the participants' perception of the usefulness and availability of various consultation services such as ethics committees and pastoral care/chaplaincies varied considerably from institution to institution. Consequently, when encountering ethically challenging situations such as the one depicted in the preceding narrative, nurses may have limited supportive resources. Similar to other participants in our study, the expert nurse spoke of gaining support from a core "group" of her peers to attain what she thought to be the best result for the patient. Wlody<sup>22</sup> has noted that nurses often identify other nurses as their strongest support for their advocacy, and Rushton<sup>23(p395)</sup> observed that "nurses must create a supportive community that exercises their individual and collective authority to achieve optimal outcomes for patients and families."

With few exceptions, research indicates that the presence of advance directives does not increase the likelihood that patients' wishes will be adhered to or change the amount or type of care given.<sup>23,24</sup> In several narratives of protecting or speaking for the patient, achieving optimal outcomes addressed honoring advance directives



that were not being followed. The following excerpt concerns a man whom the nurse described as “extremely ill” with an ejection fraction of 0.13:

He had an advance directive. And what he had specified was that he wanted to be kept on a ventilator for 7 days and after that 7 days, he wanted it turned off. And the doctors questioned it and said, “Well, you know, 7 days is not enough because a lot of people live past 7 days.” The 7 days came and went. But it went on and on. The nurses and doctors were really at each other. And of course they kept doing all this stuff. And it was like I felt so guilty, I felt so guilty. You know you have your breaking points. And finally the daughter asked, “Why do you keep doing that to my father when I begged you not to?” And that was it. You wonder . . . don’t I have the right to say, “You know, I’m sorry, I just can’t do that anymore?” So, I told the resident, “You can call the ethics committee or I will because they have to be involved.” And after that discussion [with the ethics committee], it seemed like the doctors were at rest because they finally understood it too.

### Presenting a Realistic Picture

In narratives of presenting a realistic picture, 6 expert nurses spoke of helping patients’ family members reframe the members’ sense of the potential for recovery of their loved one. The following example concerns a woman with chronic obstructive pulmonary disease who had been admitted to the medical ICU of a private hospital and who had intubated several times in the past:

She knew she did not want to be on a ventilator again even though she wasn’t very old. She had no advance directive or living will. But when I was admitting her, she had said, “I don’t want to be on a ventilator again, [nurse’s name]; I have done this for too many years.” I said, “I understand that.” And I knew she was not going to do well. . . . I said, “Do you realize if we don’t put you on the ventilator, you’ll die?” She said, “Yes. I don’t care.” I called the physician and gave him a rundown and what she had said. And before I knew it he [the physician] was there. He told her it’s just pneumonia and we can get you through this. But she was shaking her head no. Now there were 2 other nurses and a respiratory therapist in the room. They were trying to put in another IV [catheter], do an EKG [electro-

cardiogram] and give her more oxygen, but she was still shaking her head no. The doctor said, “Your ABGs [arterial blood gases] are very bad; you’re not going to live if we don’t put you on the machine.” Then the daughter came in, and she was screaming, “You’ve got to save her; don’t let my mother die!” I said, “She doesn’t want this; she’s had enough.” But no one seemed to be listening; it was out of control. Then the doctor said real loud, “Do you want to live or do you want to die?” So she kind of nodded her head, and they intubated her.

*Nurses feel compelled to clarify for the family what the “silent” patient is experiencing.*

In expert clinical nursing practice, many crises are anticipated before a patient’s condition actually deteriorates. This expert nurse realized that the patient’s pulmonary status would necessitate mechanical ventilation and, having known her from previous admissions, attempted to clarify the patient’s wishes and communicate them to the physician. As the scene evolved, however, we are again provided with a situation in which the patient’s agency was denied, resulting in what could be construed as coercion. The narrative continued:

And I got back in the morning, and she wrote me a very firm note that said, “I told you no.” And this is what I think I did right. I had an opportunity to talk to the daughter. And I said, “Before you go in there, I want to let you know that your mother’s very angry that she’s on a ventilator again.” “Oh, but it makes it so much easier to breathe,” [the daughter said]. I said, “No that’s a misunderstanding you have; it only ensures that she will breathe. It doesn’t make it easier to breathe. It’s very difficult to breathe on a ventilator. You’re used to breathing through this much and now you’re breathing through that” [using fingers]. And I tried to give her a realistic picture with those explanations. I said, “You have to realize this isn’t your decision; it’s hers. Make judgments for your mother she would want you to make. She’s not living a life that’s consistent with life for her; it’s mere existence.”

Kaufman<sup>25</sup> has noted that family members of patients in the ICU experience a kind of “existential crisis” because the members are unprepared for the decision-making role required of patients’ families. Many of the nurses in our study expressed concern that patients’ family members did not understand the practical implications of the biomedical choices and treatments presented to the families. Consequently, reframing the potential for recovery was delayed. In these instances, nurses indicated that they often felt morally compelled to clarify for the family what the frequently “silent” patient was experiencing as a result of the nurses’ daily interventions:

So a few more days went by, and she wasn’t getting any better. I talked to the daughter a few more times because it takes more than one conversation. I didn’t ask her to leave when I was doing various things. I didn’t want to scare her [the daughter], but she needed to see what was happening—the suctioning, turning—she had a decubitus [ulcer] too. Because they were talking about putting in a trach [tracheostomy] and PEG [percutaneous endoscopic gastrostomy]. And I think she came to understand that we were just prolonging it. So they decided to extubate her soon after that. And her daughter was with her. And she [the patient] died peacefully.

In the scene just described, the expert nurse used several strategies similar to those used by other participants when helping patients’ family members reframe the members’ sense of their loved ones’ potential for recovery. She provided information about the reality of being treated with mechanical ventilation in plain, understandable language, demonstrated what everyday care was like for the patient, and encouraged reflection on what the patient would have wanted or valued in the situation. As did other respondents, this expert indicated her understanding that reframing and acceptance of probable death were evolving processes that took time.

Family members of patients in ICUs are often so overwhelmed by the technology and interventions continually performed that they lose sight of what is actually happening to “the person in the bed.”<sup>25</sup> In the following narrative excerpt, the expert nurse endeavored to present a realistic picture of the patient as “person”:

There was this mother of a very young boy who had cancer. And what I have found very helpful with families . . . I have them stand in front of the patient and I’ll say, “Tell me what you see.” And the family member will be

looking at them, and they’ll start crying. It’s almost like they hadn’t realized. And so I told this mother, “Stand right here with me, and tell me what you think.” And we just stood there for about 5 minutes. And 5 minutes is a long time when you’re waiting for somebody to answer. And she said, “He’s dead.” I said, “Yes, ma’am.” She said, “The doctors told me we should do all this stuff.” And I said, “Well, you have the right to say no.”

### Experiencing Resignation and Frustration

Corley and Selig<sup>26</sup> noted that moral distress is a common response of nurses to the ethical challenges of critical care and occurs when a person knows the right thing to do but the institution or colleagues make it difficult or impossible to do what the person thinks is best.<sup>27</sup> A total of 5 participants expressed the anger, guilt, and despair that commonly occur when a nurse feels morally responsible but is unable to change what is happening, as demonstrated in the following excerpt:

This patient came in for a liver transplant. She was here for 6 months. She had a lot of complications. The nurses knew she wasn’t going to do well, but the doctors kept saying, “She’s going to be fine.” We tell them [the physicians] our opinion, ask why they are continuing to do this. But they’ll flat out tell you [it’s] because the life is viable. We were keeping her alive, and she was very angry with us. She was so mad that we brought her back. Worked on her for half an hour, shocked her 3 times. She was so totally mad; she would hardly look at us.

C.M.R.: Why did she code?

We think she stopped her breathing. Put her finger in her trach. She was so tired of it and she was hurting all the time. She was like a little skeleton. We had to rotate care because we would go insane. I mean enough is enough. I felt so tired for her, and I would never have my loved one like that. But our hands were tied.

As in the preceding narrative, the following excerpt about a young man in whom sepsis developed after a bone marrow transplant conveys resignation and, ultimately, moral failure, with the patient as victim:

If we let him wake up, we couldn’t ventilate him. He was 4 times his size and had a wife of about a week and a very aggressive mother. And the mother was saying that God told her in dream that her son would be better. We were

telling her, “We’re torturing him,” and she said that she didn’t care if her son was in pain as long as he was alive. We called the ethics committee and essentially they said, “We can’t tell you anything,” and they gave the mother a very mixed story. So he went through absolute hell and died a very, very ugly death because his mother would not withdraw care and his wife was not strong enough to say, “This is enough.”

Frustration about the use of scarce resources with no perceived benefit was expressed by several participants, as in the following narrative selection:

They [physicians] weren’t telling them [the patient’s family] his prognosis is horrible and he’s had an ischemic stroke. So the family wanted everything done. And we could have called the ethics committee, but the ethics committee has very little power in the hospital. They will not take a stand. They will not get involved. The patient finally died after all those resources were wasted. So, I think I am really frustrated now. From lack of nurses and the number of nurses who are leaving. Our ability to get supplies. There are 5 other people waiting for this bed. We don’t have nurses; no one wants nursing.

Critical care nurses suffer when they think they are performing procedures that are harmful or of low efficacy and when their advocacy is ineffective. Prolonged, unrecognized suffering can be detrimental and can lead to disengagement and silence.<sup>23</sup> Habitual silence or silencing in the face of perceived wrongs can result in permanent, deleterious changes in ethical values.<sup>28</sup>

## Discussion

Explanations for the differences in response rates for the 2 groups of expert nurses in this study could be related to several variables. The larger response from the teaching institutions may indicate more experience with the phenomena of interest, greater desire to share that information, or other unknown factors. The lower response rate from the private and community hospitals may have been influenced by some lack of understanding of the study purpose, lack of experience with the issues, or lack of prior research opportunities.

The expert nurses in these narrative examples, as well as elsewhere in the study, often shaped the processes surrounding end-of-life decision making. They demonstrated the ability and willingness to advocate for their vulnerable patients even when the nurses’ actions

did not influence the outcomes. This conclusion differs from the perceived powerlessness of nurses in the investigations of Krishnasamy<sup>29</sup> and Penticuff and Walden.<sup>30</sup> The difference may be attributed to the expertise and maturity of the nurses in our study and to the ethical climate of the units in which they were employed.

The unpredictable nature of the dying process in the ICU creates a “vanishing line” between life and death.<sup>31</sup> This inability to identify a patient as terminal often results in adherence to curative regimens almost to the moment of the patient’s death. The expert critical care nurses in this study were often the first to acknowledge recognition of this equivocal transition from possible recovery to an understanding that further efforts would be futile. This finding concurs with the observation of Curtis and Patrick<sup>32</sup> that nurses often come to this conclusion earlier than physicians do.

*Postponing palliative care until death is imminent is both impractical and inhumane.*

Although many of the expert nurses demonstrated active resistance, the ICU environment depicted in these narratives and others remains dominated by the technological imperative. Health professionals often accept and endorse this dominance. However, as Miller et al<sup>3</sup> observed, generally a vast difference exists between what healthcare providers understand and what laypersons are able to comprehend. This incommensurability of knowledge was evident in the participants’ narratives and was exacerbated by the conveying of “false hope” or “false optimism” to patients and patients’ family members.

In one study,<sup>33</sup> researchers suggested that false optimism is associated with “medical activism” or a strong need for control over death, which is prevalent in the western world. The et al<sup>33</sup> observed that use of ambiguous words such as “treatment” contributes to medical activism and that such words may have a more positive meaning for patients because the words imply that “something can be done about it.” Medical activism and false hope also make it more difficult for patients and their families to accept a patient’s imminent death, obstruct saying farewell, and cause delays in making arrangements.

Disabling the technological imperative, bridging the gulf between medical and lay knowledge, and creating an ethical environment will require the introduction of a new model. Important elements of this end-of-life care model include shared decision making<sup>3,34</sup> and the incorporation of palliative care concepts.<sup>35-37</sup>



Karlawish<sup>34</sup> and others<sup>3,38</sup> maintain that shared decision making requires understanding and achieving meaning through the sharing of narratives. For example, the plot of a physician's narrative may focus on disease; the plot of the narrative of a patient and/or the patient's family members may be one of suffering, illness, and loss; and a nurse's narrative may include a more holistic interpretation of the situation. Karlawish maintains that in the practice of critical care, narratives are the substance of shared decision making and states the following<sup>34(p395)</sup>:

Narratives enable those involved in the ICU to negotiate the meaning of critical care for the patient. Narrative functions as an interpretive procedure that allows diverse persons—nurses, physicians, patients, and patients' families—to make sense of critical care . . . and supplies a theory and instrument for negotiating meaning throughout the process that respects the realities and limitations of such care.

Indeed, Charon,<sup>38(p1897)</sup> a physician, suggests that the effective practice of medicine requires "narrative competence . . . the ability to acknowledge, absorb, interpret, and act on the stories and plights of others." The narratives of many of the expert nurses in our study perhaps illustrate that competence.

The difficulty in recognizing and acknowledging the transition from possible recovery to acceptance of death was evident in many narratives. Therefore, postponing palliative care until death is obviously imminent most likely is impractical and inhumane. Integration of palliative care as a component of comprehensive intensive care would be more appropriate for all critically ill patients, including those pursuing aggressive treatments to prolong life.

The development of a satisfactory, integrated model will require research and extensive interdisciplinary education. Clarke et al<sup>37</sup> recently identified a framework for quality end-of-life care in the ICU that integrates palliative care concepts, illustrates that the goals of cure and care are compatible, and recognizes the unique contribution of critical care nurses. In addition, Levy<sup>39</sup> identified 4 caregiver strategies and abilities necessary to improve end-of-life care in the ICU, many of which were demonstrated by the participants in our study: the development of a personal relationship with death; the ability to communicate in a compassionate, direct manner; the ability to create a healing environment; and a willingness to express emotion and uncertainty.

Our findings suggest that expert nurses often perceive other nurses as the strongest support for the experts' advocacy. Responsibility and empathy may

be reinforced within a group, because members are encouraged to exchange narratives of patient and family care.<sup>7</sup> Expert ethical practice may also be enhanced by listening to and observing the actions of identified expert staff nurses and advanced practice nurses.<sup>40</sup> Practices such as presenting a realistic picture and speaking for the patient could be incorporated into an end-of-life teaching module. In our study, the integration of the expert nurses' clinical, relational, and ethical assessment that was requisite to taking action was a process that took time. This finding has relevance for ICU practice settings in terms of adequate staffing and nurse-patient ratios. Continuity of care, when possible, is necessary for salutary outcomes for patients and the resolution of ethical conflict. Flexibility in assigning patients is also needed, however, to prevent emotional distress and distancing.

Practice settings must provide support services for nurses contending with end-of-life conflicts. When nurses experience frustration and emotional stress caused by unresolved ethical issues, they may withdraw from patients and patients' family members. Institutional ethics committees should be proactive, available, and unbiased. However, if having such a committee is an unrealistic expectation within a facility, then the formation of a nursing ethics committee might be considered. This strategy would also strengthen the moral community of nurses and provide a forum for those who are uncomfortable bringing their concerns forward to an institutional ethics committee.

To implement their moral agency at the bedside, nurses must be supported in their actions and not constrained or undermined by organizational economic and political forces. Leaders have an obligation to maintain an environment in which ethical comportment is valued and the distress and suffering of caregivers are understood and addressed in a supportive and constructive manner. For compassionate caring to occur, nurses must be the recipients of compassion themselves.

Hinshaw<sup>41</sup> maintains that end-of-life research is a field of study in which nurses as clinicians and investigators should be major contributors. She notes that although nurses have advanced perspectives on palliative care, the focus of research should be broadened to encompass decision-making processes that occur for patients, patients' families, and healthcare providers during the end-of-life transition stage.<sup>41(p120)</sup> Although our findings offer an initial description, additional research should be conducted to explore the practice of expert nurses during end-of-life transitions in different clinical areas such as pediatric and neonatal ICUs. The findings could enhance understanding of expertise in end-of-life nursing practice.

## Limitations

A possible limitation of our study is the way the subject was introduced to the participant as an ethical dilemma in the introductory statement at the beginning of the interview. This introduction might have influenced the participants' choice of situations or events or the expression of ideas. We do not know if asking what a nurse would choose to do in the situation predetermined an answer that doing something was actually a choice, including choosing to do nothing. Although not identical, similar language was used in the cover/information letter sent to prospective participants, a step that may have influenced the resulting different response rates from different sites, including lack of participation by nurses in nonteaching hospitals. In addition, although the aim of study was to explore the actions of expert nurses, exclusion of nurses considered nonexpert may have limited the depiction of conflict and of end-of-life practice.

## Conclusions

Approximately half of all deaths in the United States currently occur in hospitals, and patients often spend those final days surrounded by the impassive technologies of healthcare embedded in the highly specialized, sophisticated setting of an ICU. Critical care units are environments of both promise and uncertainty. Nurses are often caught in the middle—an ethically untenable position—as they attempt to comply with medical directives and simultaneously protect and advocate for their patients.

The nature of expert clinical practice continues to be explored and explicated. Benner in collaboration with others<sup>6,7</sup> proposes that expert practice requires more than skillful clinical performance; mastery of the ethical dimension is also called for. The expert nurses in our study were active moral agents, even when they could not change or guarantee a patient's outcome. The vital role of critical care nurses in humanizing end-of-life care and shaping decision-making processes around the event warrants continued study.

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**CE Test** Test ID A0615052: Practice of Expert Critical Care Nurses in Situations of Prognostic Conflict at the End of Life. Learning objectives:

1. Describe the most disturbing ethical dilemma faced by most critical care nurses. 2. Analyze different reaction patterns of critical care nurses. 3. Discuss the most common support group of critical care nurses.

**1. Which of the following was the main data collection method in this study?**

- a. Questionnaire
- b. Interview
- c. Observation
- d. Group discussion

**2. What recurring plots did the researchers develop based on their findings?**

- a. Presenting a realistic picture, experiencing denials, protecting the family
- b. Defending the family, protecting the patient, presenting the truth
- c. Speaking for the patient, presenting a realistic picture, experiencing resignation
- d. Speaking for the patient and family, defending the patient, ethical dilemmas

**3. Why do the authors believe the concept of patient vulnerability is ethically significant?**

- a. Vulnerability is equivocal with respect to children's behavior.
- b. Vulnerability reflects the belief that people can be injured.
- c. Vulnerability creates ethical dilemmas.
- d. Nurses are fiercely protective by nature.

**4. What is the concept of empowered caring?**

- a. Maternalism
- b. Making decisions for the patient
- c. Empowering the family to make decisions
- d. Mutual responsibility

**5. When dealing with an ethical dilemma, whom do nurses often turn to for support?**

- a. Other nurses
- b. Ethics committees
- c. Pastoral care
- d. Social work

**6. To help present a realistic picture to the family, what technique did the nurses use?**

- a. Clarified what the patient was going through
- b. Provided a channel for the family to speak with the physician
- c. Reiterated the patient's wishes
- d. Created elaborate scenarios for families to understand

**7. What common thread regarding death did the researchers discover among expert nurses?**

- a. Family members can make end-of-life decisions quickly
- b. Most family members are in complete denial
- c. Families will always honor advance directives
- d. Acceptance of death takes time

**8. According to Corley and Selig, what is a common response of nurses to ethical challenges?**

- a. Frustration
- b. Anger
- c. Moral distress
- d. Guilt

**9. According to this study, what commonly occurs as a result of prolonged unrecognized suffering?**

- a. Disengagement
- b. Depression
- c. Anger
- d. Aggression

**10. This study differed from studies by Krishnasamy and by Penticuff and Walden in what way?**

- a. Nurses felt powerless.
- b. Nurses were willing to advocate for their patients.
- c. Young nurses are strong advocates.
- d. More mature nurses feel disengaged.

**11. To create a bridge between the ICU environment and the "lay" patient's family, the researchers suggest what methodology?**

- a. Suggesting hospice care
- b. Weekly family meetings
- c. Use of more psychosocial personnel
- d. Shared decision making

**12. What was one limitation of the study?**

- a. Predetermination
- b. Taping the interview
- c. Transcription errors
- d. Inclusion of nonexpert nurses

Test Answers: Mark only one box for your answer to each question. You may photocopy this form.

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## JOURNAL CLUB ARTICLE DISCUSSION POINTS

In a journal club, research articles are reviewed and critiqued. General and specific questions help to aid journal club participants in probing the quality of the research study, the appropriateness of the study design and methods, the validity of the conclusions, and the implications for practice.<sup>1</sup>

When critically appraising this issue's *AJCC* journal club article, "Practice of Expert Critical Care Nurses in Situations of Prognostic Conflict at the End of Life," consider the questions and discussion points listed below.

**Study Synopsis:** This was a qualitative study that examined the practices of critical care nurses on the topic of end-of-life conflicts and the actions taken when they believed continued aggressive medical interventions were not indicated. Interviews were conducted with 21 critical care nurses who were considered experts in adult critical care. A narrative analysis was conducted of the interview data and 3 recurring narrative plots were identified: protecting or speaking for the patient, presenting a realistic picture, and experiencing resignation and frustration. The study participants demonstrated the ability and willingness to actively protect and advocate for their vulnerable patients in situations pertaining to end-of-life decision making and care planning.

### A. Description of the Study

- What was the purpose of the research?
- How was the study conducted?
- Why is the area of focus of the study significant or important?

### B. Sample

- Who were the subjects?
- How were they identified for participation in the study?
- What methods were used to ensure equal representation of subjects from different settings?

### C. Methods and Design

- Describe the study methods.
- What methods were used to clarify interview information?

### D. Results

- What were the findings of the research?
- Discuss the narrative plots that resulted from the narrative analysis.

### E. Clinical Significance

- What are the implications of the study for clinical nursing?

**Information From the Authors:** Catherine McBride Robichaux, RN, PhD, CCRN, lead author of this journal club article, provided additional information about the study. She noted: "The idea for the study arose from my clinical experience with end-of-life conflicts in the adult intensive care unit, specifically when continued aggressive medical interventions appeared futile." Dr Robichaux further explained that subjects were identified by focusing on several criteria.

"To assist in the identification of experts," she related, "I included the following general and specific characteristics derived from Benner et al<sup>2,3</sup> that describe expert practice as having both clinical and ethical components: [the practitioner] (a) has been practicing for 5 years or more; (b) is sought out by others for advice in solving clinical problems; (c) is considered an excellent preceptor; (d) possesses a clinical grasp and response-based practice that is evident in [his or her] ability to 'read' a clinical situation and respond quickly and fluidly with seemingly little conscious thought; (e) possesses embodied or skilled know-how that includes behaviors such as teamwork, having the environment prepared, and sequencing activities as needed by the patient's clinical condition; (f) possesses perceptual acuity that is evident in his or her ability to identify or define a clinical or ethical problem; and (g) possesses moral agency, which is the ability to act upon or influence a situation."

Dr Robichaux also explained that the study results highlighted the significant role of the nurse in advocating for the patient. "Once the nurses believed that the patient had a poor prognosis and continued interventions were perceived as futile and inflicting unnecessary pain, they were often extremely persistent, vocal, and—especially when they were interacting with physicians—quite 'fearless'! For the most part, they appeared unconcerned about possible repercussions."

**Implications for Practice:** The results of the study have implications for critical care nurses. Most significantly, the study provides evidence of the vital role nurses play in advocating for patients during end-of-life conflicts. Dr Robichaux relates: "We hope that the nurses' narratives presented in this article will both inform and motivate the readers to promote and seek participation in end-of-life discussions regarding their patients and [to] pursue additional education in palliative, end-of-life issues."

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*Journal Club feature commentary is provided by Ruth Kleinpell.*

## **Practice of Expert Critical Care Nurses in Situations of Prognostic Conflict at the End of Life**

Catherine McBride Robichaux and Angela P. Clark

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