

# The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Environment

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**Purpose/Objectives:** To understand the process used by surrogate decision makers who have chosen to withhold and withdraw life-sustaining measures in intensive care units (ICUs).

**Design:** Grounded theory.

**Setting:** Multihospital system in central Texas.

**Sample:** 17 surrogates who decided to withhold and withdraw life-sustaining measures from patients with a variety of diagnoses, including cancer.

**Methods:** Surrogates were identified by review of charts of patients in ICUs. Interviews were recorded on audiotape and analyzed using the process of constant comparison. Saturation of data occurred when no new themes emerged.

**Main Research Variable:** The surrogate decision-making process.

**Findings:** Domains and their respective themes included: (a) the personal domain: rallying family support, evaluating the patient's past and present condition, and viewing past and future quality of life; (b) the ICU environment domain: chasing doctors, developing relationships with the healthcare team, and confirming probable medical outcomes; and (c) the decision domain: arriving at a new belief, getting alone to make the decision, and communicating the decision.

**Conclusions:** Surrogates use a definite process to make decisions regarding withholding and withdrawing life-sustaining measures for patients in ICUs.

**Implications for Nursing:** The results reveal opportunities for healthcare providers to improve education and change practice when supporting surrogates. Additional opportunities exist for further research to expand nursing knowledge related to end-of-life issues.

## Key Points . . .

- Surrogates follow a definitive process in making a decision to withhold and withdraw life-sustaining measures.
- Nurses are in a unique position to foster surrogate decision making in intensive care units.
- The findings of this study indicate a need for further study in testing the proposed model.

pose of this article is to report the results of a study of how surrogate decision makers choose to withhold and withdraw life-sustaining measures. Surrogate decision makers are those who make decisions for people who no longer are able to participate in their own healthcare decisions. The specific aims of the study were to describe the process used by surrogate decision makers who chose to withhold and withdraw life support in an ICU environment and to develop a theory that explains the phenomenon.

## Literature Review

Although approximately 86% of decisions regarding life-sustaining measures are negotiated by someone other than the dying patient (Swigart, Lidz, Butterworth, & Arnold, 1996), only 15% of hospitalized patients have executed some form of advance directive delineating their desires related to life-sustaining measures (Swigart et al.). Family members are asked to participate in decisions or discussions about treatment withdrawal or withholding for about 7%–12% of patients admitted to ICUs; moreover, in end-of-life decisions, family members are consulted regarding 65%–90% of patients who

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Digital Object Identifier: 10.1188/07.ONF.331-339

Because of advances in medical science, Americans are more likely now than in the past to live longer, more productive lives, mostly free from infectious diseases, and to die from chronic ailments such as cancer and cardiac illnesses (Oncology Nursing Society [ONS], 2003). However, the end of their prolonged lives may be burdened with protracted and frequent hospitalizations. Most hospitalizations that immediately precede the end of life take place in intensive care units (ICUs) (Field & Cassel, 1997) until a decision is made to forgo life-sustaining technologies. Common concerns for many at the end of their lives involve the issues surrounding decisions to withhold and withdraw life-sustaining measures and who will be responsible for making that decision, yet little is known about the phenomenon and the stress placed on families and patients who must make decisions to forgo life-sustaining measures. Hence, the pur-

die in ICUs (Pochard et al., 2001). Most advance directives, however, do not give surrogates or healthcare teams clear direction for all situations under which the directives may be enacted (Gilbert, Counsell, Guin, O'Neill, & Briggs, 2001). One report showed that 24% of families with loved ones in an ICU were in "decisional conflict" (Hiltunen, Medich, Chase, Peterson, & Forrow, 1999), meaning that one-quarter of the surrogate population did not know what family members wanted regarding life-sustaining measures in ICU situations. Given that more than 559,650 people are expected to die of cancer this year (American Cancer Society, 2007), understanding the phenomenon will help the medical community to better serve patients with cancer and their families.

Most studies on the topic have been of a retrospective nature, and interviews with decision makers occurred well after their decision-making experiences (Baggs & Schmitt, 2000). Applicable research has focused primarily on the act of terminating nutrition and hydration in terminally ill patients and on the ethical questions surrounding such actions (Goodhall, 1997; Mahoney, Riley, Fry, & Feild, 1999; McIntosh, 1997; Pellegrino, 2000). However, none of the research has focused specifically on surrogates' decision-making process.

Family decision making in forgoing life-extending treatments has been studied (Tilden, Tolle, Nelson, Thompson, & Eggman, 1999; Tolle, Tilden, Rosenfeld, & Hickman, 2000). Factors shown to influence decision making included the surrogates' recognition of the futility of patients' physical states and a reconciliation of their states with the patients' and families' values. Additional factors in the surrogates' decision-making process included the influence of clinicians and the receptiveness of surrogates to face the decision regarding termination of life-extending procedures. Although the study has relevance, it did not focus on the process of decision making itself.

Other researchers have studied families as they made decisions about life-sustaining measures while in a medical ICU (Swigart et al., 1996), explored the experience of surrogates involved in decision making for incapacitated adults (Jeffers, 1998), and examined patients, surrogates (termed families in the study), and healthcare providers (physicians and nurses) to see how the groups collaborated with each other to make decisions regarding treatment options at the end of life (Norton, 1999). The studies by Tilden, Tolle, Nelson, and Fields (2001), Tolle et al. (2000), and Norton et al. (2003) provided significant findings regarding barriers, stress, and conflict, especially as any one of the variables relates to communication needs among surrogates. Hayes (2003) gave credence to a supposition that surrogates' experiences are most likely iterative and multifactorial. Jacob's (1998) study described the experience of family members involved in decisions regarding life-sustaining measures. None of the studies focused on the decision-making process used by the surrogates, and few focused on the ICU environment. None of the studies focused on patients with cancer and their families and the unique needs that the population may experience.

In summary, the relevant literature reveals a gap concerning understanding of the process that surrogates use to make decisions regarding withholding and withdrawing life-sustaining measures for incompetent patients in ICUs. Further insight into the phenomenon will help members of healthcare teams better understand how decisions are made, thus improving their ability to support surrogates during such difficult times.

## Methods

Because the study was intended to examine a question of process (Morse, 1994), grounded theory was selected as the appropriate methodology. The works of Glaser and Strauss (1965) and Strauss and Corbin (1998) were used to design the study.

### Sample and Setting

A purposive sampling of surrogates who had made a decision for a loved one while in an ICU in a multihospital system was undertaken. Theoretical sampling was used to encapsulate a wide range of surrogate experiences. The settings were four hospitals with a combined average of 130 ICU deaths per month. The hospitals were included because all four contain ICU environments where surrogates have made decisions about life-sustaining measures and because they all provide oncology services. The settings ensured the inclusion of a wide range of diagnoses, ages of patients and surrogates, and racial, gender, and socioeconomic makeups. The hospital system in which all four hospitals operate is managed by the local diocese of the Catholic church.

### Procedure

The study was reviewed and approved by an institutional review board. To ensure confidentiality, the recruitment procedure was designed to prevent the researcher from knowing the identities of people who met the inclusion criteria. The researcher requested from each hospital a list of all deceased patients who had spent time in the ICU from November 2003–March 2004. Several staff nurses employed by the hospital system volunteered to review patients' medical records for evidence that life-sustaining measures were withheld and withdrawn and to identify surrogates who were involved in decisions about such matters. Life-sustaining measures included artificial ventilation, artificial hydration and nutrition, chemotherapeutic agents, surgical interventions, cardiopulmonary resuscitation, medications to control heart rate or blood pressure, blood and blood products, and hemodialysis.

A surrogate was defined as a person legally designated or legislatively directed to act for a person incapable of participating in his or her own healthcare decisions (Texas Health and Safety Code, 1999). Each surrogate was required to speak and read English, be 21–99 years of age, and have had a prior relationship with the patient before making a decision regarding life-sustaining measures. Those who did not meet the criteria were not included in the study. Surrogates of pediatric and trauma patients also were excluded because the researcher believed that their experiences were qualitatively different from those sampled. The hospital system's risk manager reviewed the list of deceased patients and excluded surrogates who had litigation or arbitration pending.

A two-part cover letter was sent to the surrogates. It described the purpose of the study from the hospital's and researcher's perspectives. The first part of the letter was signed by the managers of the ICUs. It informed potential participants that no confidential information about themselves or their loved ones had been shared directly with the researcher and that participation in the project was solely at the surrogates' discretion. The second portion of the letter

described the study's purpose and identified the researcher. Surrogates who were interested in participating in the study were asked to reply to the researcher by telephone, e-mail, or standard U.S. mail. Postage-paid, return envelopes were included. The researcher mailed 198 letters to potential participants. Of the 21 individuals who responded to the initial inquiry, 17 became study respondents. The other four potential participants declined to participate or did not meet the inclusion criteria. Surrogates were interviewed at the time and place of their choosing. Figure 1 provides samples of the interview questions.

## Data Analysis

Tape-recorded interviews were transcribed verbatim using standard word-processing software. The researcher read the data transcripts line by line to identify words or phrases that might signify important themes. Coding was completed in a sequential fashion, in that the researcher examined all newly transcribed interviews alongside all previously transcribed interviews. The comparison allowed for logical grouping and ordering of words and phrases, also known as axial coding, by which larger logical groupings, known as themes, could be identified. The themes later were unified to form a theory that expressed the phenomenon under consideration. When no new themes were identified (i.e., data saturation), the themes were ordered in a way to express the theory. Storage of the data, compilation of themes, and organization of the data were accomplished using Ethnograph qualitative data analysis software, version 5.07 (Qualis Research Associates, Colorado Springs, CO).

### About the precipitating event—the grand tour question

- “Can you tell me something about what brought your loved one to the hospital for the last time?”

### About the surrogate's perceptions about the experience

- “What part of the process was especially difficult for you?”

### About the environment

- “What went right while you were in the intensive care unit?”
- “What went wrong while you were in the intensive care unit?”
- “What would you wish the doctors and nurses would have done differently?”

### About the process

- “Some people believe that there is a process to follow when making the decision to withhold and withdraw life-sustaining measures. Was this so for you?” Some alternate forms using substitute language follow.
  - “Can you list the steps you used to decide to stop all the medicines and machines?”
  - “If you could write a book about what happened, what would the chapter titles be?”
  - “If you were sending a recipe about this to a friend who had to do the same thing that you did, what would you put on the card?”
  - “Tell me how you made the decision to withhold and withdraw life-sustaining measures from your (e.g., husband, wife, daughter).”
  - “Tell me about the decision to withhold and withdraw life-sustaining measures from your (e.g., husband, wife, daughter).”

### Other questions

- “I was wondering if you talked to other people—family, friends, neighbors, or any healthcare professionals.”
- “Did you get opinions from anyone else? Who?”

**Figure 1. Sample of Interview Questions**

**Trustworthiness:** Member checking was used to obtain trustworthiness of the results. Letters asking for feedback about the researcher's interpretation of the study results were mailed to 14 surrogates who had asked to be informed of the study results. However, only one surrogate responded to the inquiry for feedback and offered this statement about the study results: “It is difficult to believe that this issue can be brought together by such a ‘simple’ model; but it is true.” Because only a single surrogate responded, qualitative trustworthiness could not be established. However, credibility or “confidence in the truth of the data” (Polit & Hungler, 1999, p. 427) was sought through a review by faculty members who examined the data.

Additionally, five faculty members reviewed the study to ensure the integrity of the science and methodology. Faculty members reviewed the study results to determine appropriate representation of the participants' voices. Two faculty members reviewed original transcript data against the results and found no discrepancy in the representation of the themes or theory. In that way, the data were found to be credible.

## Results

### Participants

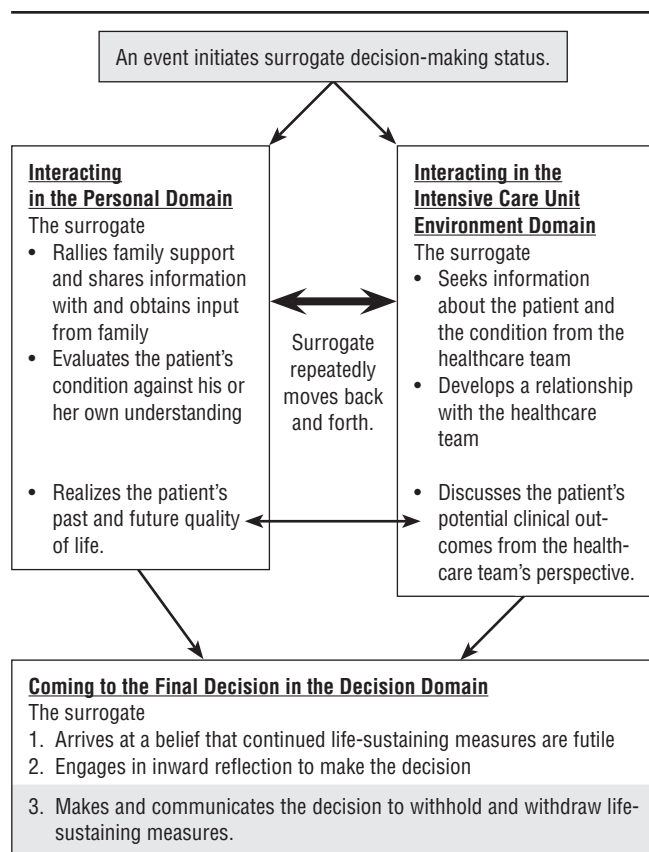
The age range of the 17 surrogates was 23–82 years ( $\bar{X}$  = 55). The patients ranged in age from 42–93 years ( $\bar{X}$  = 66). Six patients had oncology-related diagnoses (e.g., leukemia, colon cancer). The other 11 patients were diagnosed with cardiac ( $n$  = 4), neurologic ( $n$  = 4), or multisystem organ failure ( $n$  = 3). Four nonwhite surrogates participated; two were Hispanic, and two were African American. Surrogates' ethnicity categories matched the ethnicity categories of the patients. Fourteen surrogates were well educated, with some college or bachelor's or master's degrees. Religious preference was represented by mostly Protestant faiths.

Surrogates in the study demonstrated a process that has been synthesized into a grounded theory explanation as to how surrogates make decisions to withhold and withdraw life-sustaining measures in an ICU environment (see Figure 2). Analysis of the surrogates' stories revealed a process that is expressed in three domains and nine themes. Surrogates move back and forth between the familiar personal domain and the unfamiliar and often-frightening domain of the ICU environment. At the end points of the two domains, the domains intersect one another, and surrogates are moved into the decision domain. The movement of surrogates into the decision domain ultimately assists them to make the decision to withhold and withdraw life-sustaining measures from incompetent patients.

### Thematic Analysis

Thematic analysis of the 17 stories produced a total of nine themes. The themes then were clustered into three areas, or domains, representing the decision-making process. Themes in their respective domains were (a) the personal domain: rallying family support, evaluating the patient's past and present condition, and viewing past and future quality of life; (b) the ICU environment domain: chasing doctors, developing relationships with the healthcare team, and confirming probable medical outcomes; and (c) the decision domain: arriving at a new belief, getting alone to make the decision, and communicating the decision. Although the domains are presented as





**Figure 2. The Process Used by Surrogate Decision Makers to Withhold and Withdraw Life-Sustaining Measures in an Intensive Care Unit Environment**

separate entities, many parts of the decision-making process were interconnected and were, at times, related to other domains or themes. Moreover, a surrogate's course of decision making was an iterative process in which the surrogate repeatedly moved back and forth between domains.

**Personal domain:** This refers to the processes that surrogates used to engage family members and the processes used to gain information and weigh options. In the domain, surrogates interacted with family and self to come to understand the patient's condition or disease. Surrogates' families were asked to assist the surrogates with opinions about the patients and possibly to aid the surrogates in recollection of the patients' wishes regarding the end of life. Surrogates sought others' opinions about the patients and the desire to continue life-sustaining measures and obtained family agreement about the course of action for the incompetent patients. Surrogates experienced the limit of this domain when they were able to visualize the patients' potential for poor quality of life.

**Rallying family support:** Surrogates rallied or brought their families together before, during, or after decision-making processes had been completed. Rallying was done in person or virtually, such as by telephone, and allowed surrogates to stay in contact with family members. Family seemed to be important to all of the surrogates in the study, even when families were not present at the actual time of decision making. For example, one surrogate stated

My son was the first to be there because I had to go get Mom. So I drove . . . and picked up Mom. And that's why I sent my son. And my brother, unfortunately, was in Oklahoma at the time, and his wife. And he was driving home as fast as he could, and my son kept him up via cell phone of what was going on.

Another surrogate's comments demonstrated that assistance during the decision-making process from people not related by blood or marriage to the surrogate or patient could be effective support. "Primarily, I have a huge support system. 'We both did. My husband and I both did. Friends from our church. Just people. They're like our family, because we don't have any family here.'"

**Evaluating the patient's past and present condition:** One surrogate reported that extraordinary means were used to keep her mother alive. The surrogate saw the past recovery that her mother had made and found halting life-sustaining measures difficult. "Ten times she went through [defibrillation]. After about the eighth time, she seemed to stabilize, but then it happened again after the tenth time. And her heart was still racing." Another surrogate eloquently described the sentiment that drove the decisions. "And even though my mother was in that kind of shape, I didn't really want to give her up—selfishly, I did not."

**Viewing the past and future quality of life:** One of the surrogate's comments underscored how knowing a patient's past quality of life before the final hospitalization influenced the decision-making process for the future. "Well, I know her quality of life is terrible, you know. [Life-sustaining measures] can go on and on forever until something happens and she doesn't make it. And at that point, that was when I said, 'No, I just don't want that.'"

Another surrogate seemed to show the process of moving between knowledge of the patient's preferences and evaluation of future quality of life. She reported the following after hearing from her mother's physician that the patient's future quality of life would be poor. "And then I did start thinking about . . . what [she] would want and what the quality of her life would be, and if she'd want to [continue life support], and I just didn't think she would want to [be kept on life support]."

**Intensive care unit environment domain:** This domain represents surrogates' activities and actions as they interacted with nurses, physicians, social workers, therapists, and other members of healthcare teams, as well as their families. The term is used to describe not only the personnel but also the environment in which the surrogates found information and learned about patients' conditions. In the domain, surrogates could obtain information about their loved ones that was crucial to decision making. Many surrogates expressed the feeling that they were "chasing doctors" to obtain the information necessary for decision making. Surrogates developed varying relationships with healthcare providers and sought confirmation of probable medical outcomes.

**Chasing doctors:** One of the surrogates in the study gave a tongue-in-cheek account of seeking information from the healthcare team. She called the process "chasing doctors." Although the surrogate was seemingly humorous in her words, her intent was evident.

When you're under that kind of emotional stress and you're chasing doctors [laugh]. You know the last thing

you're really, you're just not up to chasing after people. You know? It's just too hard. And so it would help if those people could see you a little bit more.

That level of effort was not unique. For example, one of the surrogates reported, "[I would] try to catch the doctor in the hall to get a word out of him. I'd just have to come chase him down."

*Developing relationships with the healthcare team:* In this theme, surrogates described a variety of relationships with the healthcare team, with nurses seen as supportive and caring of patients and surrogates more often than other professionals. The relationships eventually culminated in trust of members of the healthcare team, which ultimately assisted surrogates in moving forward in the decision-making process. Surrogates expressed a desire to participate in all treatment decisions and often obtained information from nursing staff. When healthcare teams used jargon or technical language or when different physicians gave conflicting opinions regarding patients, surrogates often expressed animosity toward healthcare team members. For example, a surrogate spoke about a poor relationship with one of her mother's physicians, the surgeon. The physician spoke in direct opposition to what the surrogate and her family had heard from other physicians.

The relationship with the surgeon . . . and he also made comments like, "I can't believe [she is] still living." I mean, "I can't believe she's still living." . . . He really upset me, and not just me . . . the rest of my family. He was . . . too matter of fact, too blunt. "Your mother's going to die."

Another surrogate spoke about the trust level she had with physicians as a result of conflicting or differing medical opinions.

I didn't feel like I could trust any one of [the physicians] because they weren't communicating with one another. . . . [The surrogate's husband] didn't know any of these doctors. The only person he trusts was his doctor in [our home town]. And he continued to tell me, "Whatever my doctor in [our home town] says to do, that's what I want to do." And so I did call [the physician in our home town], and I said, "This is what they're telling me. What do you think?"

Surrogates sought information from nurses, who most often were seen as assisting surrogates to understand the patients' conditions. Surrogates eventually learned to trust healthcare teams' information that patients were terminal. The recognition of futility led the surrogates to move into the next step in the decision-making process and the next domain. Positive experiences with nurses were quite memorable for surrogates. One of the surrogates in the study had a positive experience with one nurse in particular. The surrogate's story illustrates the role of nurses in caring for patients as well as surrogates.

There was a nurse in the ICU. She was very comforting to me. She was very sweet with my mother. She was just very nice, very soft spoken, very sweet, very sensitive. But she was just always asking me if I wanted to call anybody, did I want her to call anybody, you know. Could she do anything for me? And I even got off without my coat. And I went outside, and she loaned me her coat.

*Confirming probable medical outcomes:* This theme is represented by surrogates being told of patients' expected outcomes once healthcare teams came to understanding the terminal nature of the patients' conditions. The step was difficult for surrogates to comprehend, and many surrogates were given the information more than once. However, until the surrogates reached a point in the process in which the information was received and acted upon, the surrogates did not progress in the decision-making process. Surrogates often needed to hear repeatedly that the patients would not recover and would die with or without life-sustaining measures. Hearing the confirmed terminal nature of the patients' diagnoses was a critical part of the surrogates' decision-making process.

A surrogate related the story of hearing from a physician that her husband would not recover from his condition.

And I said [looking at the imaginary physician], "Well, is there anything that can be done?" and he said, "No." . . . I guess he just told me what happened using the terms like cerebral hemorrhage in the back of his neck . . . then I knew what had to be done.

Another surrogate told the story of making a decision for her sister, who had metastatic cancer. The physician and surrogate were engaged in a conversation about treatment options. "Oh, very important [to hear the diagnosis confirmed], because if they thought that there was something they could do to make [the sister] better. Yes, I would have thought, but I mean, he just let me know she's going to die even if we do the surgery or not. So I just didn't want [my sister] to suffer. . . . It made the choices easier, but at the time, no. It was something I didn't want to hear."

One of the surrogates understood after hearing from a physician that his wife would never return to a state of health because her oxygen levels were too compromised to sustain life. "The biggest decision to me was the increase in requirement for oxygen. So me and the doctor, we talked about it a little bit. Then we turned [the oxygen and ventilator] off. They told me afterward that turning it off was the right decision. That's some dirty boots. There was no right time."

**Decision domain:** This domain represents activities used by surrogates to make the decision to withhold and withdraw life-sustaining measures from incompetent patients. It includes three themes: (a) arriving at a new belief that continued care is futile, (b) retreating into one's self to make a decision, and (c) communicating a decision to the healthcare team. This portion of the decision-making process is linear in nature; one event triggers the next. Once in the decision domain, surrogates arrived at a new belief that continued life-sustaining measures were futile. Even when the surrogates believed in the futile nature of the continued life-sustaining measures, surrogates were plagued with feelings of guilt and uncertainty about the decision. Surrogates reported experiencing an altered sense of reality upon realizing that the decision needed to be made. The surrogates then retreated into their own minds to weigh all of the information about the situation and the patients. The inward reflection allowed the surrogates to make the decision. The decision then was communicated to the healthcare team, and life-sustaining measures were withdrawn or withheld. Some surrogates communicated the decision to their loved ones and some did not. Similarly, some surrogates remained with the patients until death and some did not.

*Arriving at a new belief:* Surrogates often evaluated patients' conditions by watching for physical signs of decline. Through the process of observation, surrogates came to a new understanding or belief about the patients' ability to survive or to live meaningful lives. One surrogate seemed to know when to stop life-sustaining treatments for his wife, based on the amount of treatment being delivered to her. The failure of the treatments to achieve any appreciable effect helped him to make a decision. "I asked them to give her more oxygen. And then they asked me if I wanted them to give steroids to her. They'll ask us if we've got to raise the oxygen again. I said, 'That's enough.'" One surrogate told the story of feeling that she had no decision to make other than the one that she made for her husband. "If he hadn't had been put on life support, he would have died before I got there. And so there wasn't anything that I could do to save him. There was nothing that could be done or that they could do. There was no operation."

*Getting alone to make the decision:* Surrogates spoke of the need to retreat in their own minds to weigh all of the information that they had received. The retreat did not necessitate being physically alone, and the period varied in length for each surrogate. One surrogate, for example, talked about needing to make the decision for his father on his own. Although his sister was present, the surrogate stated that he "got alone in my head" and then made the decision to withdraw life support.

Another surrogate showed a need to be physically alone to make the decision regarding her husband. The physician in charge of the patient's care came to the surrogate the afternoon before the patient died. The patient was to receive a heart transplant, which did not happen.

The afternoon before, [the doctor and the transplant coordinator] and I had sat in an empty ICU room and said, "You know, this is what we're doing if nothing works." I said, "Give me a few minutes alone." They left me in that room by myself. There was a time when I could just sit there . . . so it was my time to get that straight with God [clasps her hands together]. And it was like that at that point, that resolved it for me.

Finally, one surrogate gave a poignant description of needing to be alone mentally and physically to make a decision for her husband. "When I finally decided the process, I felt, I mean, I just went outside and tried to think by myself. I thought, 'If I think about this all by myself, I'll be able to decide.'"

*Communicating the decision to withhold and withdraw life-sustaining measures:* Once surrogates made the decision about life-sustaining measures, the decision was communicated to the healthcare team. This part of the process tended to take place soon after surrogates comprehended the potential quality of life for the patients and after healthcare teams had confirmed the patients' prognoses. Surrogates did not always communicate the decision regarding life-sustaining measures in isolation. The following comment from one surrogate highlights how families participated in the decision making and in communicating with physicians about end-of-life decisions. "I guess when I asked [the patient's physician] if there was any hope and he said, 'No, there was no hope.' Then I said, 'Well, we can't leave him like this, I guess.'"

Another surrogate related the story of hearing her father's diagnosis confirmed by the neurologist and then having her family help her communicate her decision to stop all life-sustaining measures. "After the neurologist answered our questions . . . so

I just looked around at my brother and said, and looked back at the doctor, and said, 'You know what we need to do.'"

Unlike the iterative nature of the personal and ICU environment domains, the decision domain was linear in nature. Although plagued by feelings of guilt and uncertainty, surrogates were able to arrive at a new belief that continued care for patients was futile. Surrogates retreated into their own minds to reflect on all of the information they had received, and they expressed a sense of disbelief about the process. Once surrogates made the decision, they communicated the decision to the healthcare team and said goodbye to the patients.

## Discussion

Interactions in the personal domain were dominated by efforts to rally family for support and by discussion with friends and family to determine the best course of action for patients. The surrogates in the study repeatedly gave examples of the need for more education among healthcare providers concerning end-of-life decision making. Programs such as the *End-of-Life Nursing Education Consortium Trainer's Guide* (End-of-Life Nursing Education Consortium, 2001) can help nurses have greater sensitivity to a wide variety of factors facing families when making end-of-life decisions. Information gathering and understanding were at the center of much of the surrogates' work. Attempting to get information from healthcare teams and then discuss that information with family members left room for misunderstanding and confusion on the surrogates' part. Finding ways to communicate information in a more concise manner requires that healthcare providers undergo specific education related to dealing with surrogates and end-of-life care. According to the surrogates in the study, the compassionate delivery of difficult information facilitates trusting relationships between surrogates and physicians. Learning the artful skill of communicating may reduce the burden on surrogates and physicians while ensuring that, through surrogates, patients' wishes are honored and onerous treatments are not endured when not wanted.

Surrogates often perceived the language of healthcare teams as confusing jargon, which further complicated their decision making. Surrogates spoke of conflicting medical opinions from physicians, which added confusion to the decision-making process. Most surrogates, however, asked questions of physicians and nurses to clarify what was being said about ICU patients. The results are consistent with Cohen-Almagor's (2000) finding that physicians use language for the sake of convenience in end-of-life situations, often causing surrogates to agree to unwanted treatment. Crawley, Marshall, Lo, and Koenig, (2002) posited that a lack of culturally competent language is responsible for instances in which treatment decisions are made that are not in keeping with patients' or surrogates' goals for the end of life. This has implications for all healthcare providers practicing in ICUs, in that language that is suitable for communicating such issues to surrogates must be found and used consistently. Finding what is meaningful for surrogates, patients, and families will guide healthcare teams in discussing patients' quality of life. Members of healthcare teams would benefit from choosing to use language that has meaning for decision makers (Cohen-Almagor). Additionally, the use of consistent language among and between healthcare providers can eliminate conflicting information and establish goals concerning care of individual patients.



The current study's results are consistent with Pierce's (1999) finding that end-of-life care can be improved by the involvement of family members. Families as decision-making units have been studied several times (Hiltunen et al., 1999; Swigart, 1994; Swigart et al., 1996; Tilden et al., 1999, 2001). The results also are similar to Meeker's (2004) findings. Some of Meeker's terminology included "standing with," "brokering information," and "working with family." The results also are consistent with work performed by Tilden et al. (1999) and Swigart et al. The current study found, like other researchers' conclusions, that families, as decision-making units, make choices for incompetent patients more readily than do individual surrogates without family support.

Once surrogates developed an understanding of the future quality of life for their loved ones, they often validated their perceptions with the healthcare team. This finding is consistent with Hiltunen et al.'s (1999) observation that families reach a turning point in the decision-making process and that reaching the turning point "requires time, work, and energy for the decision makers" (p. 129). Tilden et al. (1999) published a similar finding, concluding that families often are able to face the question of discontinuing life-extending treatments only after their healthcare teams raise the issue or the patients undergo a significant change in condition. Surrogates' relationships with the healthcare team also played a role in the decision-making process. In the current study, surrogates uniformly reported that relationships developed between themselves and the healthcare team while their loved ones were in the ICU environment. The relationships often included significant enmity that stemmed from the surrogates' perceptions of how physicians communicated with them and other family members. Surrogates wanted to work with healthcare team members to come to a satisfactory decision about end-of-life care, but when animosity was present, surrogates were forced to deal with layers of unanticipated emotion that interfered with the process. This finding is consistent with the conclusions of other researchers. Tilden et al. (1999), for example, discovered that families often believed that physicians were too tentative in their descriptions of patients' prognoses; this led to decisional confusion for the surrogates. Jacob (1998) also found that families experience a need for involvement by the healthcare team when they are attempting to make treatment decisions. Additionally, a study conducted by Norton (1999) suggested that the ease of decision making was dependent on the degree of harmony enjoyed between surrogates and healthcare teams. Finally, Norton et al.'s (2003) study of surrogates who experienced conflict with members of healthcare teams during the decision-making process revealed that effective communication could greatly reduce the chances of disagreement over major decisions between surrogates and healthcare professionals.

Surrogates entered the decision domain when they had arrived at a new belief about the patients and the decision that needed to be made regarding life-sustaining measures. After the surrogates were able to hear from physicians and foresee the patients' potential future quality of life, the surrogates could undertake the process of actual decision making. The surrogates arrived at the new understanding about the patients when they were able to integrate the healthcare team's information with their own understanding of the situation.

The need to arrive at a new belief has been observed by other researchers. Hiltunen et al. (1999), for example, found

that families and surrogates needed to reach a "turning point" before they could terminate burdensome treatments. In addition, Hayes (2003) found that surrogates were able to make decisions for incapacitated adults once they assessed the patients' potential quality of life and considered a variety of personally meaningful criteria, such as the meaning of death and their own spiritual beliefs.

At the conclusion of the decision domain, surrogates retreated into their own minds to come to their final conclusions about continued care. Other researchers have commented on this phenomenon among surrogates, although they have downplayed the role of solitude at that point in the decision-making process. Hiltunen et al. (1999), for instance, found that surrogates needed time to let go of patients in ICU environments. Specifically, they required an opportunity to understand and accept the critical, futile nature of continued aggressive care, including life-sustaining measures. Jacob (1998) also identified a moment of psychological resolution for surrogates, which she described as "looking back and going on" (p. 33). However, none of the researchers described the surrogates' need as retreating in their own minds for reflection and decision making.

## Limitations

The stories shared with the researcher by the surrogates were poignant and informative. The surrogates shared a vast array of experiences that can be used to inform healthcare professionals about how to be helpful to surrogates. However, the research data consist of the surrogates' memories of decisions for loved ones. The results are reflective of the surrogates' understanding of themselves and their decision-making process at the time they related the process—not at the time they experienced the decision-making process.

Although the surrogates in the study were recruited through a Catholic-managed healthcare system, no evidence suggests that the teachings of the Catholic church influenced surrogates' decisions. Of note, since the time of the study, Pope John Paul II (2004) issued an allocution on March 20, 2004, reaffirming a presumption in favor of artificial hydration and nutrition for those in a persistent vegetative state. The influence of the allocution should be a consideration for future studies in Catholic institutions to determine whether it makes a difference in the way in which decisions about life-sustaining measures are enacted.

Only one of the surrogates in the study was Catholic, and two of the patients were identified as Catholic. Interviewing only Catholic surrogates in a Catholic hospital setting may reveal significantly different results regarding the influence of the Ethical and Religious Directives for Catholic Health Care Services (United States Conference of Catholic Bishops, 2001), particularly in view of the papal allocution. As an example, one study question might be, "Do more patients endure unwanted artificial hydration and nutrition now when compared with those patients who received this type of treatment before the allocution?"

The surrogates in the study were mostly white, educated, Protestant, and middle- to upper-socioeconomic class. Further research is needed, particularly in nonwhite groups. Other studies in end-of-life care also have not been representative of minorities and underserved populations. Decisions to withhold and withdraw life-sustaining measures may be very different among minorities and could be the focus for a repeat of the current study among different types of participants.

## Nursing Implications

The current study found that nurses can and do assist surrogates in making decisions to withhold and withdraw life-sustaining measures. Nurses aid surrogates in ICU environments by helping them and other family members understand complicated medical information. The findings suggest an opportunity to improve nursing practice, particularly in the area of communication and sensitivity to surrogates' needs. Surrogates were confused by conflicting physicians' opinions, use of technical language, and a lack of amicable relationships with physicians. The surrogates advised the researcher that nurses should fill this role and make certain that surrogates and other family members clearly understand the futile nature of the care and the options related to continued treatment versus discontinuation of treatment. This is not to suggest the elimination of physician responsibilities for patient care. Rather, the study results should serve as a wake-up call to nurses and physicians to practice in a way that eliminates confusion for decision makers.

Given that many physicians are not present when surrogates make visits to patients' bedsides, nurses are in a unique position to communicate with surrogate decision makers. Surrogates question nurses regarding prognoses and treatment plans, and a team approach to dealing with surrogates affords surrogates and patients the best possible decisions regarding life-sustaining measures. Nurses can develop consistent language that is helpful for surrogates' understanding.

Nurses with specific expertise in difficult conversations can facilitate discussions regarding life-sustaining measures. Although this type of communication and facilitation role for nurses was proposed in the Study to Understand Prognoses and Preference for Outcomes and Risks of Treatments (SUPPORT) (Hiltunen et al., 1999; Lynn et al., 2000; Murphy et al., 2000; SUPPORT Principal Investigators, 1995), no further research has been undertaken duplicating the effort in the current healthcare climate. An intervention study using nurses who are specifically trained in facilitating surrogate decision making could determine the effect of nurses on surrogate decision making. The results then could be compared to the SUPPORT study results for further indications of the successes or failures of such an intervention.

## Conclusion

The current study was designed to contribute to the understanding of the process that surrogates use to make decisions about withholding and withdrawing life-sustaining measures from loved ones in an ICU environment. The results suggest that the nursing profession is in a unique position to foster decision making among surrogates in that environment.

Effective communication among members of the healthcare team and between surrogates and the healthcare team is an important tool to assist surrogates in their decision-making process. The use of clear, consistent, and connotatively meaningful language to explain patients' conditions helped to foster surrogates' understanding. Surrogates repeatedly expressed the desire for healthcare team members to provide consistent communication and information about their loved ones. Surrogates needed to know that the patients had received every chance for life-sustaining measures to be effective. When treatment regimens no longer were effective, surrogates needed healthcare team members to communicate that reality. Surrogates did not always evaluate the patients' conditions in terms of the burden of treatment.

Although burden of treatment certainly was the most prominent of the factors affecting the surrogates' decisions, the findings of the study suggest that healthcare teams should investigate other measures of patients' experiences, such as preconceived ideas about limiting treatment and whether a plan was ever devised between surrogates and patients.

Allowing surrogates time to understand complicated language and create meaning from that understanding fosters independent and informed decisions by surrogates for incompetent patients. Given the intense nature and sensitivity necessary to fully facilitate end-of-life decision making, nurses can and often do develop caring relationships with surrogates and families. Because nurses spend proportionately more time at the bedside than do physicians, nurses are in the most advantageous position to develop relationships with surrogates, provide surrogates with meaningful information, and positively affect surrogates during this difficult experience.

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## References

- American Cancer Society. (2007). *Cancer facts and figures 2007*. Atlanta, GA: Author.
- Baggs, J.G., & Schmitt, M.H. (2000). End-of-life decisions in adult intensive care: Current research base and directions for the future. *Nursing Outlook*, 48, 158–164.
- Cohen-Almagor, R. (2000). Language and reality at the end of life. *Journal of Law, Medicine and Ethics*, 28, 267–278.
- Crawley, L., Marshall, P., Lo, B., & Koenig, B. (2002). Strategies for culturally effective end-of-life care. *Annals of Internal Medicine*, 136, 673–679.
- End-of-Life Nursing Education Consortium. (2001). *End-of-Life Nursing Education Consortium trainer's guide*. Washington, DC: American Association of Colleges of Nursing and City of Hope National Medical Center.
- Field, M.J., & Cassel, C.K. (Eds.). (1997). *Approaching death: Improving care at the end of life*. Washington, DC: National Academies Press.
- Gilbert, M., Counsell, C.M., Guin, P., O'Neill, R., & Briggs, S. (2001). Determining the relationship between end-of-life decisions expressed in advance directives and resuscitation efforts during cardiopulmonary resuscitation. *Outcomes Management for Nursing Practice*, 5, 87–92.
- Glaser, B.G., & Strauss, A.L. (1965). *Awareness of dying*. Chicago: Aldine Publishing.
- Goodhall, L. (1997). Tube feeding dilemmas: Can artificial nutrition and hydration be legally or ethically withheld or withdrawn? *Journal of Advanced Nursing*, 25, 217–222.
- Hayes, C.M. (2003). Surrogate decision-making to end life-sustaining treatments for incapacitated adults. *Journal of Hospice and Palliative Nursing*, 5(2), 91–102.
- Hiltunen, E.F., Medich, C., Chase, S., Peterson, L., & Forrow, L. (1999). Family decision making for end-of-life treatment: The SUPPORT nurse narratives. *Journal of Clinical Ethics*, 10, 126–134.
- Jacob, D.A. (1998). Family members' experiences with decision making for incompetent patients in the ICU: A qualitative study. *American Journal of Critical Care*, 7, 30–36.



- Jeffers, B.R. (1998). The surrogate's experience during treatment decision-making. *MedSurg Nursing*, 7, 357–363.
- Lynn, J., De Vries, K.O., Arkes, H.R., Stevens, M., Cohn, F., Murphy, P., et al. (2000). Ineffectiveness of the SUPPORT intervention: Review of explanations. *Journal of the American Geriatrics Society*, 48(5, Suppl.), S206–S213.
- Mahoney, M.A., Riley, J.M., Fry, S.T., & Feild, L. (1999). Factors related to providers' decisions for and against withholding or withdrawing nutrition and/or hydration in adult patient care. *Online Journal of Knowledge Synthesis for Nursing*, 6(4).
- McIntosh, B.J. (1997). Withholding and withdrawing life-sustaining medical therapy. Retrieved Oct 28, 2004, from <http://dcmsonline.org/legislative/righttodie.htm>
- Meeker, M.A. (2004). Family surrogate decision making at the end of life: Seeing them through with care and respect. *Qualitative Health Research*, 14, 204–225.
- Morse, J. (1994). Designing funded qualitative research. In N.K. Denzin, & Y.S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 220–235). Thousand Oaks, CA: Sage.
- Murphy, P., Kreling, B., Kathryn, E., Stevens, M., Lynn, J., & Dulac, J. (2000). Description of the SUPPORT intervention. *Journal of the American Geriatrics Society*, 48(5, Suppl.), S154–S161.
- Norton, S.A. (1999). *Reconciling decisions near the end of life: A grounded theory study*. Unpublished doctoral dissertation, University of Wisconsin–Madison.
- Norton, S.A., Tilden, V.P., Tolle, S.W., Nelson, C.A., & Eggman, S.T. (2003). Life support withdrawal: Communication and conflict. *American Journal of Critical Care*, 12, 548–555.
- Oncology Nursing Society. (2003). *Oncology Nursing Society research agenda 2003–2005*. Retrieved January 31, 2007, from <http://www.ons.org/research/information/documents/pdfs/2003Plan.pdf>
- Pellegrino, E.D. (2000). Decisions to withdraw life-sustaining treatment: A moral algorithm. *JAMA*, 283, 1065–1067.
- Pierce, S.F. (1999). Improving end-of-life care: Gathering suggestions from family members. *Nursing Forum*, 34(2), 5–14.
- Pochard, F., Azoulay, E., Chevert, S., Lemaire, F., Hubert, P., Canoui, P., et al. (2001). Symptoms of anxiety and depression in family members of intensive care unit patients: Ethics hypothesis regarding decision making capacity. *Critical Care Medicine*, 29, 1893–1897.
- Polit, D.F., & Hungler, B.P. (1999). *Nursing research: Principles and methods* (6th ed.). Philadelphia: Lippincott.
- Pope John Paul II. (2004). Address of John Paul II to the participants in the International Congress on “Life-Sustaining Treatments and Vegetative States: Scientific Advances in Ethical Dilemmas.” Rome, Italy: Pontifical Academy for Life.
- Strauss, A., & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preference for Outcomes and Risks of Treatments (SUPPORT). *JAMA*, 274, 1591–1598.
- Swigart, V. (1994). *A study of family decision-making about life support using the grounded theory method*. Unpublished doctoral dissertation, University of Pittsburgh, Pittsburgh, PA.
- Swigart, V., Lidz, C., Butterworth, V., & Arnold, R. (1996). Ethical issues. Letting go: Family willingness to forgo life support. *Heart and Lung: The Journal of Critical Care*, 25, 483–494.
- Texas Health and Safety Code. (1999). Texas advance directives act (166.001–166.166). Austin, TX: State of Texas.
- Tilden, V.P., Tolle, S.W., Nelson, C.A., & Fields, J. (2001). Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research*, 50, 105–115.
- Tilden, V.P., Tolle, S.W., Nelson, C.A., Thompson, M., & Eggman, S.C. (1999). Family decision making in foregoing life-extending treatments. *Journal of Family Nursing*, 5, 426–442.
- Tolle, S.W., Tilden, V.P., Rosenfeld, A.G., & Hickman, S.E. (2000). Family reports of optimal care of the dying. *Nursing Research*, 49, 310–317.
- United States Conference of Catholic Bishops. (2001). *Ethical and religious directives for Catholic health care services* (4th ed.). Washington, DC: Author.