

Jenna Fritsch, Sandra Petronio, Paul R. Helft, and Alexia M. Torke, "Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates," *The Journal of Clinical Ethics* 24, no. 2 (Summer 2013): 125-34.

# Making Decisions for Hospitalized Older Adults: Ethical Factors Considered by Family Surrogates

*Jenna Fritsch, Sandra Petronio, Paul R. Helft,  
and Alexia M. Torke*

## ABSTRACT

### Background

Hospitalized older adults frequently have impaired cognition and must rely on surrogates to make major medical decisions. Ethical standards for surrogate decision making are well delineated, but little is known about what factors surrogates actually consider when making decisions.

### Objectives

To determine factors surrogate decision makers consider when making major medical decisions for hospitalized older adults, and whether or not they adhere to established ethical standards.

### Design

Semi-structured interview study of the experience and process of decision making.

### Setting

A public safety-net hospital and a tertiary referral hospital in a large city in the Midwest United States.

### Participants

The study included 35 surrogates with a recent decision-making experience for an inpatient aged 65 or older.

### Measurements

The key factors that surrogates considered when making decisions. Interview transcripts were coded and analyzed using the grounded theory method of qualitative analysis.

### Results

Surrogates considered patient-centered factors and surrogate-centered factors. Patient-centered factors included: (1) respecting the patient's input, (2) using past knowledge of the patient to infer the patient's wishes, and (3) consider-

**Jenna Fritsch, BS**, is a Medical Student at Indiana University School of Medicine in Indianapolis, Indiana.

**Sandra Petronio, PhD**, is Senior Affiliate Faculty at the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health and is a Professor at Indiana University-Purdue University Department of Communication Studies.

**Paul R. Helft, MD**, is Director of the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health; is an Associate Professor of Medicine at Indiana University; and is an Oncologist at the Indiana University Melvin and Bren Simon Cancer Center.

**Alexia M. Torke, MD, MS**, is a Scientist at the Indiana University Center for Aging Research at the Regenstrief Institute; is Senior Affiliate Faculty and Fellowship Director at the Charles Warren Fairbanks Center for Medical Ethics at Indiana University Health; and is an Associate Professor of Medicine in the Division of General medicine and Geriatrics at the Indiana University School of Medicine, [atorke@iupui.edu](mailto:atorke@iupui.edu).

©2013 by *The Journal of Clinical Ethics*. All rights reserved.

ing what is in the patient's best interests. Some surrogates expressed a desire for more information about the patient's prior wishes. Surrogate-centered factors included: (1) surrogate's wishes as a guide, (2) surrogate's religious beliefs and/or spirituality, (3) surrogate's interests, and (4) family consensus.

### Conclusion

Our study indicates that surrogate decision making is more complex than the standard ethical models, which are limited to considerations of the patient's autonomy and beneficence. Because surrogates also imagine what they would want under the circumstances and consider their own needs and preferences, models of surrogate decision making must account for these additional considerations. Surrogates' desire for more information about patients' preferences suggests a need for greater advance care planning.

## INTRODUCTION

Approximately 40 percent of hospitalized patients lack decision-making capacity due to cognitive impairment,<sup>1</sup> and, in such cases, physicians must work with surrogate decision makers to determine an appropriate course of care. This need for surrogate decision making is likely to grow as life-sustaining technology expands, the population ages, and the prevalence of diseases like Alzheimer's and other forms of dementia increase.<sup>2</sup>

Bioethical standards for surrogate decision making have advocated basing decisions on the patient's previous autonomous wishes as well as on the patients' best interests.<sup>3</sup> Surrogates should first honor the patient's wishes by following the patient's advance directive or relying on substituted judgment. If a patient's wishes are unknown, a surrogate should then advocate for the patient's best interests. Courts have similarly argued that surrogate decisions should be based on prior knowledge of the patient's wishes or on the patient's best interests.<sup>4</sup> This emphasis on the patient's wishes is further supported by the U.S. Patient Self-Determination Act and by statutory documents for advance directives that allow patients to specify their desired care and decision makers.

There are, however, problems in the application of these standards.<sup>5</sup> These include the

fact that the majority of patients do not have advance directives<sup>6</sup> and that surrogates frequently make inaccurate predictions of the patient's wishes<sup>7</sup> or make decisions that clinicians do not think are in the patients' best interests.<sup>8</sup> Additionally, advance care planning and surrogate decision making often require that decisions be made about life situations that the decision makers themselves have not experienced.<sup>9</sup> Studies report that despite advance care planning, chronically ill patients change their mind about their medical treatment over time and as their health status dissipates.<sup>10</sup> This instability in patients' wishes adds to surrogates' challenge to respect patients' autonomy.

Making decisions is clearly complex for family members and other surrogates, yet there is little data about how surrogates go about making decisions. A qualitative study in Norway reported that relatives acting as surrogate decision makers for nursing home patients used the patients' preferences and patients' best interests as well as other factors, such as surrogates' preferences, fear of loss of a loved one, and feelings of guilt for not trying everything possible when making decisions.<sup>11</sup> Another study examining surrogates for patients with advanced Alzheimer's disease, in a suburban long-term care facility as well as in a subspecialty clinic in the U.S., found that reaching a family consensus, determining a patient's quality of life, and advice from healthcare authorities are major contributors to the surrogate decision-making process.<sup>12</sup> A study of surrogates considering past and future decisions for veterans found that surrogates consider patients' preferences, values that the surrogates shared with patients, surrogates' own beliefs, and input from others.<sup>13</sup>

Surrogates for hospitalized older adults often face life-threatening decisions and sometimes must make decisions under significant time pressure. However, we have little information about surrogates' approaches to decision making in this setting. To gain better insight into the ethical factors considered by surrogates during their decision-making process, we interviewed the surrogates of hospitalized older adults during or soon after the surrogates had made a major medical decision.

## METHODS

### Study Design and Population

Semi-structured, in-depth interviews were conducted with surrogate decision makers from two urban hospitals: a public safety-net hospital and a tertiary referral hospital, both part of an urban, university-affiliated, academic health center. Patients were recruited for this study as part of a larger observational study of surrogate decision making. For the present investigation, surrogates of inpatients aged 65 or older who were admitted to an internal medicine or medical intensive care unit who had considered at least one major decision in the first 48 hours of hospitalization were eligible. Eligible surrogate decision makers were identified by briefly interviewing the patients' primary inpatient physician or advanced practice nurse to determine whether the medical team had considered a major intervention for a patient during the current hospital admission and whether there was surrogate involvement in decision making. For purposes of this study, major medical decisions included: (1) decisions regarding procedures and surgeries; (2) decisions regarding life-sustaining care such as code status, intubation, artificial nutrition, et cetera; and (3) decisions about hospital discharge to a nursing facility or similar institution. Eligible procedures were any that required signed informed consent based on hospital policy. The study was approved by the Indiana University Institutional Review Board, and informed consent was obtained from each surrogate prior to the interview.

### Data Collection

Semi-structured, in-depth interviews were conducted by two investigators using an interview guide (see figure 1). Open-ended questions were asked of the surrogates, followed by optional prompts, which were included in the interview guide in order to maintain consistency in the interviews. Surrogates were interviewed within one month of having made a major medical decision for an inpatient. This was done to minimize recall bias. In the case of a patient's death, surrogates were interviewed between two and five months later, to allow time for acute

grieving prior to the interview. Interviews were audiotaped and transcribed verbatim.

### Data Analysis

After the first five interviews had been conducted, two investigators (AMT and SP) reviewed the transcripts to identify themes or topics that merited further attention in successive interviews, with particular attention to those we considered to have ethical dimensions. The investigators continued to meet after approximately every five interviews to discuss emerging themes and determine whether theme saturation had been achieved. For the current analysis, all of the interviews were read and coded independently by two researchers (AMT and JF) using methods of grounded theory.<sup>14</sup> Segments of the transcripts pertaining to the surrogate's justification for their decisions and the decision-making factors they relied on were identified and coded. The two researchers met weekly to review coding and to identify overarching themes that described the factors surrogates relied upon to make decisions. Discrepancies in coding were discussed and consensus was reached. This reoccurring process allowed for ideas and themes to be refined and clarified throughout the data collection process in accordance with standard qualitative methods.<sup>15</sup> The two coders met with a third member of the research team (SP) to discuss the codes and emerging themes.

In addition to two investigators independently coding the interviews, other measures were taken to ensure the credibility and trustworthiness of the data. The three researchers were familiar with all of the interviews, each of whom offered a unique disciplinary perspective to the qualitative analysis; they included a practicing physician with bioethics training (AMT), a medical student with a biology and business background (JF), and an expert in the fields of health and family communication (SP). The interview process continued until theme saturation was reached (that is, the point at which no new themes emerged). Finally, our findings were presented to a group of physicians who practice inpatient or geriatric medicine to confirm the validity of our conclusions.

## RESULTS

### Subjects

A total of 35 surrogates were interviewed (see table 1). At the public hospital, 87 surrogates were enrolled in a larger observational study, of whom 30 consented to an interview. At the tertiary referral center, 13 surrogates were enrolled in an observational study, and five completed an interview. We found that 68 percent of the surrogates interviewed made a decision on the patient's behalf about life-sustaining therapy; 80 percent made a decision about a procedure or surgery; and 40 percent made a decision about where the patient would go upon discharge from the hospital. All of the surrogates except one were relatives of the patient

(see table 1). Surrogate/patient relationships prior to the patient's acute illness varied in their intimacy, from surrogates who only saw the patient occasionally to relatives who lived with or served as the primary in-home caregiver for the patient. Below we describe primary and secondary themes related to the surrogate's decision-making factors, the process of decision making, and the outcomes of the decisions.

### Decision-Making Factors

We found that decision-making factors could be grouped into two primary themes: patient-centered factors and surrogate-centered factors. We also found that many surrogates incorporated several decision-making factors into their reasoning for a single decision.

**Figure 1. Interview guide**

**1. Introduction**

Tell me about [patient] and what brought [him/her] to the hospital.

**2. Information disclosure**

During the time [patient] was/has been in the hospital, how did you find out what was happening to him/her?

**3. Relationship building**

What was your first impression of the hospital staff? Was there anyone at the hospital you could rely on? Why or why not? Tell me a little about how things have been for you since [patient] was in the hospital? Sometimes people have both positive and less positive experiences when they are in the hospital. In the time that [patient] was most recently in the hospital, could you tell me a little about the positive experiences?

**4. Decision making [repeat questions 4 through 6 for up to three decisions]**

One decision that [patient's] physicians have considered is [target decision]. What, if any, conversations with the doctors or other hospital staff can you recall about this decision? What part did you play in making the decision? How did you decide what to do? In the end, did you think the right decision was made? Why or why not?

**5. Possible interventions**

Can you think of anything that could have been done to help you make this decision for [patient]?

**6. Decision-making outcomes**

When you look back on this decision, what do you think would be the best possible outcome for [patient]? What about for you? Do you think [patient] was fully able to make the decision for him/herself, partially able to make the decision, or not at all able to make the decision?

**7. General outcomes**

When you look back on [patient's] time in the hospital, what seems most important to you?

**8. General interventions**

Can you think of anything that could have been done to make the hospital experience better for you or [patient]?

**9. Additional information**

Is there anything else you would like to tell me about your experience when [patient] was in the hospital?

*Patient-Centered Factors*

The primary theme of patient-centered surrogate decision making is represented by three secondary themes: (1) respecting the patient's input, (2) using past knowledge of the patient to infer the patient's wishes, and (3) considering what is in the patient's best interests.

*The patient's input.* We identified two ways that surrogates respected patients' wishes through the use of the patients' input. First, surrogates often actively shared in decision making with the patient by discussing options with the patient and reaching an agreement. Second, several surrogates left the entire decision up to the patient, even though, in the opinion of the treating physician, the patient was not fully capable of decision making. For example, one surrogate noted, "I was just really in the background to support her decision when she made it so she didn't feel like she was by herself and really just support her." In some cases, surro-

gates acknowledged that the patient may have been unable to fully understand the decision, but still they honored the patient's decision.

*Knowledge of the patient's prior wishes.* Some surrogates based their decisions on statements of preference made by the patient some time in the past or by using their knowledge of the patient's values and interests to determine what the patient would have wanted. To demonstrate, one surrogate stated, "She always told us, even when we were younger, that she never wanted to be a burden on anybody, where, um, she was just like a vegetable laying there hooked up to machines and really wasn't productive or . . . or couldn't live a life, she doesn't want that." Additionally, surrogates based their decisions on the patients' stated wishes through the use of an advance directive.

On many occasions, surrogates who lacked knowledge of a patient's preferences expressed a desire to have more information so they could better decide in accordance with the patient's wishes. This lack of knowledge tended to add stress and difficulty to the decision-making process. "Um . . . it was difficult in the emergency room to have to make that decision for someone. When they are not able to tell you, you know, how they feel or what they want done," explained one surrogate.

*The patient's best interests.* Surrogates often considered what was in a patient's best interest when making decisions. Their emphasis on the patient's best interests was displayed in four different ways. First, surrogates often considered what decision would most help to improve the patient's health. When asked, "When looking back on [the patient's] time in the hospital, what seems most important to you?" surrogates frequently gave a response such as the patient's receiving the best possible care or the patient's getting healthy. Sometimes surrogates viewed specific procedures or undertakings as necessary or the only way to improve the patient's health, and so did not consider the choice to be an actual decision. For instance, one surrogate stated, "There was no decision with us . . . I mean they thought hey . . . she needs it."

Second, surrogates viewed the patient's best interest in terms of the patient's suffering or

**TABLE 1.** Subjects' characteristics (N = 35)

Characteristic	Number of surrogates	%
<b>Race</b>		
African American	18	51.4
White	17	48.6
<b>Gender</b>		
Female	28	80.0
<b>Education</b>		
9 to 12 years	20	57.1
13 to 16 years	11	31.4
17+ years	4	11.4
<b>Religion</b>		
Protestant	29	82.9
Roman Catholic	3	8.6
Spiritual	1	2.9
None	2	5.7
<b>Relationship of surrogate to patient</b>		
Daughter	21	60.0
Son	5	14.3
Sister	2	5.7
Spouse	2	5.7
Other*	2	14.3

\*"Other" includes nephew, niece, grandson, cousin, and friend (one each).

quality of life. Surrogates would often note that they did not want the patient to suffer any longer and thus refused life-sustaining therapies. For example, one surrogate explained, "To me, she's suffering because she can't see. She can't walk. . . . So, I made that decision based on that and that way she don't have to suffer. I don't want her to go through the pain that will be put on her with them trying to resuscitate her." In other instances, surrogates noted that the use of life-sustaining therapies simply maintained a body, but not a life, and therefore opted against using such therapies. This reasoning was also applied in other types of decisions, such as surgeries and resuscitation code status.

Third, some surrogates would weigh the risks and benefits of procedures when trying to make a decision in the patient's best interests. This often included gathering information from clinicians or from another source, such as the internet. Some surrogates reported feeling uneasy about making decisions when they felt they did not have adequate information.

Finally, surrogates often sought the advice of a physician or other professional when making decisions. Surrogates reported that they valued a clinician's opinion because they trusted the clinician to place the patient's best interest first and foremost. However, surrogates seemed to only consider the clinician's advice when they trusted the clinician. One surrogate stated, "The belief that you folks [medical professionals] have our wellness and goodness first and utmost in, you know, that has to be a belief. We are in a huge trust factor here." Trust and consideration of a clinician's opinion tended to be mentioned hand in hand.

### *Surrogate-Centered Factors*

The primary theme of surrogate-centered decision making is represented by four secondary themes that include: (1) the surrogate's wishes as a guide, (2) the surrogate's religious beliefs and/or spirituality, (3) the surrogate's interests, and (4) family consensus.

*The surrogate's wishes as a guide.* In addition to patient-centered considerations, surrogates often relied on their own wishes, or what they themselves would want if they were the

patient. Sometimes the surrogates used this notion as a primary means to reach a decision, while, in other instances, surrogates used their own wishes as a backup guide when a patient's wishes or interests were unknown. One sister who described her relationship with the patient as somewhat distant stated, "I said, 'I can only tell you what I would want. I cannot tell you what she would want because I don't know.' And, of course, my choices are that no heroic measure be taken if I'm in that bad of shape. It's just time to let go."

*The surrogate's religious beliefs/spirituality.* At times surrogates based their decisions on their own religious beliefs and/or spirituality. Several surrogates explained that the patient's situation was part of God's plan. In some cases, this deterred the surrogate from making a decision that might, in the surrogate's view, interfere with God's plan, and, in other instances, a surrogate made a decision based on other factors, but acknowledged that the outcome of that decision was in God's hands. One surrogate justified her decision to sign a do-not-resuscitate (DNR) order because she did not want to interfere with God's plan. She stated, ". . . I feel that will be the best decision for her and if her heart was to stop beating, I feel like that God was calling her home. . . . To me, that's God's doing so I wouldn't want to mess with God's plan."

*The surrogate's interests.* Beyond the surrogate's wishes, the surrogate's interests played a role in decision making. The surrogate's interests included considerations of how decisions might affect the surrogate's lifestyle and the impact of a decision or outcome on the surrogate and/or family. In several cases, surrogates expressed their inability or discontent with taking care of the patient themselves, when considering the patient's discharge placement or code status. In one interview, a surrogate who lived with a patient and served as his caregiver explained that the patient did not want to go to a nursing home, but, despite the patient's wishes, the surrogate still made the decision to put the patient in a nursing home following discharge. The surrogate explained: "I could never tell if he was hungry, if he didn't want this, if he had to go to the bathroom, so I had no choice,

... there's nothing I can do about that. I couldn't take care of him no more. Not with no communication I can't. There's nothing I can do except clean up constantly, and I don't want to do that." This surrogate expressed a limit to the obligations he was willing to take on with respect to the patient.

Another common consideration when determining discharge placement was how close or accessible a nursing home or similar type of facility was to the patient's family. Many surrogates discussed trying to find an institution in a specific region or radius of the family. Convenience appeared to play little role in other major medical decisions made by the surrogates.

*Family consensus.* Surrogates often felt compelled to reach family consensus on decisions or have the support of their family behind the decisions they made. Surrogates used family consensus as a means to reach what they considered to be the best decision or as a way to remove responsibility from themselves. One surrogate recounted, "I can't make that decision on my own when I got five sisters. . . . They have to be there too . . . I'm not taking responsibility to say, well you should have did everything and they should have did this and they should have did that, and I said no, I'm not taking that responsibility. We either all make the decision or none make the decision."

## DISCUSSION

Our qualitative study of surrogates' approaches to decision making found that, in addition to the patient's wishes and best interests, surrogates considered other factors such as their own wishes, interests, emotional needs, religious beliefs, and past experiences with health-care. Surrogates' decision making is therefore more complex than standard ethical models, which are limited to the patient-centered principles of autonomy and beneficence. In prior research we found that physicians considered surrogate-centered factors and other ethical factors when making decisions for hospitalized patients.<sup>16</sup> We conclude that the standard patient-centered model does not provide a complete framework for surrogate decision making.

Further theoretical work is needed to consider the appropriate role of surrogate-centered factors in decision making.

Patients' preferences were a major consideration for surrogates. Surrogates relied on information about patients' preferences when they were present through the use of advance directives, substituted judgment, or patients' input, but surrogates often expressed the need for more information about what the patient would have wanted when the patient's wishes were not known. Without such information, surrogates struggled to feel confident in their decisions. This study provides further support for the important potential role of advance care planning in preparing surrogates for decision making and mitigating distress in the decision-making role.<sup>17</sup>

Our study highlights the value that surrogates placed on family consensus in decision making. Many surrogates favored consensus because it distributed the responsibility of decision among several individuals, or because it may have lessened the guilt felt by the surrogate when making decisions such as ending life support, and there are other potential benefits to consensus. Consensus helped to maintain family cohesion through the distress, and made surrogates more comfortable in their role. Most importantly, family consensus might align with a patient's wishes for the decision-making process.<sup>18</sup> Not only do patients want family and caregivers to reach consensus regarding their care,<sup>19</sup> guidelines also advocate working towards consensus in surrogate decision making.<sup>20</sup>

We found that when surrogates lacked information about the patient's preferences, some employed other means to make decisions in addition to considerations of what was in the patient's best interests. Specifically, some surrogates considered what they themselves would have wanted if they were the patient. Using one's own beliefs as a guide to make decisions for another does not appear in the ethical standards for surrogate decision making, although there is evidence that surrogates do rely on their own beliefs to make decisions in other clinical settings.<sup>21</sup> Two additional studies that used hypothetical cases found that surrogates' decisions for patients were more closely aligned with pref-

erences for themselves than with the patient's preferences. The authors regarded this finding and an example of the surrogates' "projection" and noted that this process was conceptually different from substituted judgment, in which a surrogate might imagine what a patient would want, rather than what the surrogate wants.<sup>22</sup> In the present study, surrogates' reliance on what they would want for themselves does seem to be consistent with the golden rule, a fundamental concept in Judeo-Christian ethics. The normative role of a "golden rule" approach is worthy of further study and theoretical consideration, as it may constitute an alternative approach to surrogate decision making that is ethically acceptable.

Consistent with other studies,<sup>23</sup> we found surrogates consider their own needs and preferences when making decisions for patients. This raises the question of whether it is ethically acceptable for surrogates to base decisions on their own needs or whether the traditional model that relies entirely on patient-centered factors should be maintained. Studies report that patients are concerned with burdening their loved ones,<sup>24</sup> recognize that surrogates must live with the decisions they make,<sup>25</sup> and do not perceive deviations from patients' preferences as infractions of their autonomy.<sup>26</sup> Patients therefore give surrogates some leeway when making decisions.<sup>27</sup>

The emotional needs of surrogates, particularly the understandable drive to avoid guilt, also swayed their decisions. Surrogates often made decisions that gave patients every possible chance at recovery, in an effort to avoid feelings of guilt for not trying everything possible, or to fulfill their perceived obligations towards the patients. This highlights the need to reassure surrogates that decisions to refuse life-sustaining therapy do not indicate that surrogates have given up on or are personally responsible for negative outcomes or a patient's death.

Our study had several weaknesses. First, we had a low response rate of 35 percent. This could introduce bias into our results. Our largely female sample may have underrepresented the views of male surrogates. However, our sample is consistent with other studies that

have found that hospital surrogates and family caregivers for older adults are at least 70 percent female.<sup>28</sup> Additionally, we chose to delay interviews when a patient had recently died to allow time for acute grieving. The responses of the subjects whose interviews were delayed due to the death of a patient may have differed from subjects who were interviewed sooner and may be a source of bias.

In conclusion, surrogate decision makers for hospitalized older adults relied heavily on the standard ethical concepts of the patient's preferences and best interests, but also considered other factors such as their own preferences, interests, emotions, experiences, and religious beliefs, factors that are not traditionally included in ethical models of surrogate decision making. Surrogates' desire for more information about the patient's preferences points to a need for more advance care planning. When such information is not known, surrogates may use their own wishes as a decision-making guide, but they may also consider their own beliefs and interests. More work is needed to understand the implications of expanding the ethical models of surrogate decision making, including how to better address these important issues and to consider how they ought to be weighed in the decision-making process.

#### ACKNOWLEDGMENTS

Jenna Fritch was supported through the Medical Student Training in Aging Research (MSTAR) program, administered by the American Federation for Aging Research and the National Institute on Aging. Alexia Torke was supported by a career development award from the National Institute on Aging of the National Institutes of Health under Award Number K23AG031323. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health.

#### NOTES

1. V. Raymont et al., "Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study," *Lancet* 364 (October 2004): 1421-7.

2. F.G. Reamer, "Review," *Social Service Review*

65, no. 4 (1991): 640-3; A.E. Buchanan and D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge: Cambridge University Press, 1990); Alzheimer's Association, *Alzheimer's Disease Facts and Figures* (Washington, D.C., Alzheimer's Association, 2011).

3. Buchanan and Brock, see note 2 above; E.J. Emanuel and L.L. Emanuel, "Proxy decision making for incompetent patients: An ethical and empirical analysis," *Journal of the American Medical Association* 267, no. 15 (15 April 1992): 2067-71.

4. R. Dresser, "Precommitment: a misguided strategy for securing death with dignity," *Texas Law Review* 81, no. 7 (June 2003): 1823-47.

5. Dresser, see note 4 above; A. Fagerlin and C.E. Schneider, "Enough: The failure of the living will," *Hastings Center Report* 34, no. 2 (March-April 2004): 30-42; J.V. Welie, "Living wills and substituted judgments: a critical analysis," *Medicine, Health Care, and Philosophy* 4, no. 2 (2001): 169-83; K.B. Hirschman, J.M. Kapo, and J.H. Karlawish, "Why doesn't a family member of a person with advanced dementia use a substituted judgment when making a decision for that person?" *American Journal of Geriatric Psychiatry* 14, no. 8 (August 2006): 659-67.

6. S.H. Miles, R. Koepf, and E.P. Weber, "Advance end-of-life treatment planning: A research review," *Archives of Internal Medicine* 156, no. 10 (27 May 1996): 1062-8; J.M. Teno et al., "Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment," *Journal of the American Geriatric Society* 45, no. 4 (April 1997): 508-12.

7. D.I. Shalowitz, E. Garrett-Mayer, and D. Wendler, "The accuracy of surrogate decision makers: a systematic review," *Archives of Internal Medicine* 166, no. 5 (13 March 2006): 493-7.

8. A. Dreyer, R. Forde, and P. Nortvedt, "Autonomy at the end of life: life-prolonging treatment in nursing homes—relatives' role in the decision-making process," *Journal of Medical Ethics* 35, no. 11 (November 2009): 672-7; L.C. Kaldjian, L.A. Shinkunas, M. Bern-Klug, and S.K. Schultz, "Dementia, goals of care, and personhood: a study of surrogate decision makers' beliefs and values," *American Journal of Hospice & Palliative Care* 27, no 6 (September 2010): 387-97.

9. Dresser, see note 4 above.

10. S. Carmel and E.J. Mutran, "Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments," *Social Science & Medicine* 49, no. 3 (August 1999): 303-11; L.L. Emanuel et al., "Advance directives: Stability of patients' treat-

ment choices," *Archives of Internal Medicine* 154, no. 2 (24 January 1994): 209-17; M. Danis, J. Garrett, R. Harris, and D.L. Patrick, "Stability of choices about life-sustaining treatments," *Annals of Internal Medicine* 120, no. 7 (1 April 1994): 567-73; M.N. Wittink et al., "Stability of preferences for end-of-life treatment after 3 years of follow-up: the Johns Hopkins Precursors Study," *Archives of Internal Medicine* 168, no. 19 (27 October 2008): 2125-30; V.C. Martin and K.A. Roberto, "Assessing the stability of values and health care preferences of older adults: A long-term comparison." *Journal of Gerontological Nursing* 32, no. 11 (November 2006): 23-31, quiz 32-23; P.H. Ditto et al., "Stability of older adults' preferences for life-sustaining medical treatment," *Health Psychology* 22, no. 6 (November 2003): 605-15.

11. Dreyer, Forde, and Nortvedt, see note 9 above.

12. Hirschman, Kapo, and Karlawish, see note 6 above.

13. E.K. Vig et al., "Beyond substituted judgment: How surrogates navigate end-of-life decision-making," *Journal of the American Geriatrics Society* 54, no. 11 (November 2006): 1688-93.

14. A. Strauss and J. Corbin, *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*, 2nd ed. (Thousand Oaks, Calif.: Sage, 1998).

15. M.K. Giacomini and D.J. Cook, "Users' guides to the medical literature: XXIII. Qualitative research in health care A: Are the results of the study valid? Evidence-Based Medicine Working Group," *Journal of the American Medical Association* 284, no. 3 (19 July 2000): 357-62.

16. A.M. Torke et al., "Rethinking the Ethical Framework for Surrogate Decision Making: A Qualitative Study of Physicians," *The Journal of Clinical Ethics* 19, no. 2 (Summer 2008): 110-9; A.M. Torke et al., "Physicians' experience with surrogate decision making for hospitalized adults," *Journal of General Internal Medicine* 24, no. 9 (September 2009): 1023-8.

17. P.H. Ditto et al., "Advance directives as acts of communication: a randomized controlled trial," *Archives of Internal Medicine* 161, no. 3 (12 February 2001): 421-430; V.P. Tilden, S.W. Tolle, C.A. Nelson, and J. Fields, "Family decision-making to withdraw life-sustaining treatments from hospitalized patients," *Nursing Research* 50, no. 2 (March-April 2001): 105-15; R.L. Sudore and T.R. Fried, "Redefining the 'Planning' in Advance Care Planning: Preparing for End-of-Life Decision Making," *Annals of Internal Medicine* 153, no. 4 (August 2010): 256-61.

18. Hirschman, Kapo, and Karlawish, see note 6

above.

19. N.A. Hawkins, P.H. Ditto, J.H. Danks, and W.D. Smucker, "Micromanaging death: process preferences, values, and goals in end-of-life medical decision making," *Gerontologist* 45, no. 1 (February 2005): 107-17.

20. J.H. Karlawish, T. Quill, and D.E. Meier, "A consensus-based approach to providing palliative care to patients who lack decision-making capacity: ACP-ASIM End-of-Life Care Consensus Panel: American College of Physicians—American Society of Internal Medicine," *Annals of Internal Medicine* 130, no. 10 (18 May 1999): 835-40.

21. Dreyer, Forde, and Nortvedt, see note 9 above; Vig et al., see note 14 above.

22. A. Fagerlin et al., "Projection in surrogate decisions about life-sustaining medical treatments," *Health Psychology* 20, no. 3 (May 2001): 166-75.

23. Dreyer, Forde, and Nortvedt, see note 9 above; Vig et al., see note 14 above.

24. P.A. Singer et al., "Reconceptualizing advance care planning from the patient's perspective," *Archives of Internal Medicine* 158, no. 8 (27 April 1998): 879-84.

25. D.W. Brock, "What is the moral basis of the authority of family members to act as surrogates for incompetent patients?" *The Journal of Clinical Ethics* 3, no. 2 (Summer 1992): 121-3; J. Hardwig, "The problem of proxies with interests of their own: toward a better theory of proxy decisions," *The Journal of Clinical Ethics* 4, no. 1 (Spring 1993): 20-7.

26. J.J. Fins et al., "Contracts, covenants and advance care planning: an empirical study of the moral obligations of patient and proxy," *Journal of Pain and Symptom Management* 29, no. 1 (January 2005): 55-68.

27. C.M. Puchalski et al., "Patients who want their family and physician to make resuscitation decisions for them: observations from SUPPORT and HELP. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment: Hospitalized Elderly Longitudinal Project," *Journal of the American Geriatric Society* 48, supp. no. 5 (May 2000): S84-90; A. Sehgal et al., "How strictly do dialysis patients want their advance directives followed?" *Journal of the American Medical Association* 267, no. 1 (1 January 1992): 59-63.

28. L. Apatira et al., "Hope, truth, and preparing for death: Perspectives of surrogate decision makers," *Annals of Internal Medicine* 149, no. 12 (December 2008): 861-8; S. Diwan, G. W. Hougham, and G. A. Sachs, "Strain experienced by caregivers of dementia patients receiving palliative care: Findings from the palliative Excellence in Alzheimer care ef-

forts (PEACE) Program," *Journal of Palliative Medicine* 7, no. 6 (December 2004): 797-807.