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

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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.

Participants—Thirty-five surrogates with a recent decision making experience for an inpatient age 65 and older.

Measurements—Key factors 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 patient to infer the patient's wishes, and (3) considering 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) The surrogate's religious beliefs and/or spirituality, (3) The surrogate's interests, (4) Family consensus and (5) Obligation and guilt.

Conclusion—These data show that surrogate decision making is more complex than the standard ethical models, which are limited to patient 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 patient preferences suggests a need for greater advance care planning.

INTRODUCTION

Approximately 40 percent of hospitalized patients lack decision making capacity due to cognitive impairment,¹ 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.²

Bioethical standards for surrogate decision making have advocated basing decisions on the patient's previous autonomous wishes as well as the patients' best interests.³ Surrogates should first honor the patient's wishes by following advance directives or relying on substituted judgment. If a patient's wishes are unknown, the 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 patients' wishes or on the patient's best interests.⁴ This emphasis on patient wishes is further supported by the federal Patient Self-Determination Act and by statutory documents for advance directives allowing patients to specify their desired care and decision makers.

There are, however, problems in the application of these standards.⁵ These include the fact that the majority of patient's do not have advance directives,⁶ and surrogates frequently make inaccurate predictions of the patients' wishes⁷ or make decisions that are not felt by the clinicians to be in the patients' best interest.⁸ Additionally, advance care planning and surrogate decision making both require decisions to be made about life situations that the decision makers themselves have not experienced.⁹ Studies show that despite advance care planning, chronically ill patients change their mind about their medical treatment over time and as their health status dissipates.¹⁰ This instability in patients' wishes adds to surrogates' challenge of respecting the patients' autonomy.

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

Hospitalized older adults often face life-threatening decisions and sometimes must make them with significant time pressures. However, we have little information about surrogates' approach to decision making in this setting. To gain better insight into the ethical factors considered by surrogates during the decision making process, we interviewed surrogates of hospitalized older adults during or soon after they 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 age 65 and older admitted to the 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 the patient during their 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, etc; 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 Table 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 between interviews. Surrogates were interviewed within one month of having made a major medical decision for the inpatient. This was done in order to minimize recall bias. In the case of a patients' death, surrogates were interviewed between 2 and 5 months in order 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, three investigators (AMT, SP and CP) 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. These investigators continued to meet after approximately every 5 interviews to discuss emerging themes and determine if theme saturation had been achieved. For the current analysis, all interviews were read and coded independently by two researchers (AMT and JF) using methods of grounded theory.¹⁴ Segments of the transcripts pertaining to 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 describing the factors surrogates relied upon to make decisions. Discrepancies in coding were discussed and a consensus 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.¹⁵ 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 credibility or trustworthiness of the data. Three researchers were familiar with all of the interviews, each of which 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. 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 (Table 2). At the public hospital, 87 surrogates were enrolled in the larger observational study, of whom 30 consented to an interview. At the tertiary referral center, 13 surrogates were enrolled in the observational study and 5 completed an interview. We found 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 surrogates except one were relatives of the patient (Table 2). 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 decision outcomes.

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.

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

Patient's Input: These data found two ways that surrogates respected the patients' wishes through the use of the patients' input. First, surrogates often actively shared in the 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 surrogate 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, surrogates acknowledged that the patient may have been unable to fully understand the decision but still honored the patient's decision.

Knowledge of patient's prior wishes: Some surrogates based their decisions on statements of preference made by the patient sometime 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 advance directives.

On many occasions, surrogates who lacked knowledge of the patients' preferences often expressed their desire to have more information so they could better decide in accordance with the patient's wishes. This lack of this 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.

Patient’s best interests: Surrogates often considered what was in the patients’ best interest when making decisions. Their emphasis on the patients’ best interests was displayed in four different ways. First, surrogates often considered what decision would most help to improve the patients’ health. When asked, “When looking back on [the patient’s] time in the hospital, what seems most important to you?” surrogates frequently answered with a response such as the patient receiving the best possible care or the patient getting healthy. Sometimes surrogates viewed specific procedures or undertakings as necessary or as the only option for improving the patient’s health and thus 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 patients’ best interest in terms of the patients’ suffering or 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 code status.

Third, some surrogates would weigh the risks and benefits of procedures when trying to make a decision in the patients’ best interests. This often included gathering information from the clinicians or other resources such as the internet. In fact, some surrogates reported feeling more uneasy about making decisions when they felt they did not have adequate information.

Finally, surrogates often sought the advice of the physician or other professionals when making decisions. Surrogates reported that they valued the clinician’s opinion because they trusted the clinician to place the patients’ best interest first and foremost. However, surrogates seemed to only consider clinician 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 the clinician’s opinion tended to be mentioned hand-in-hand.

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

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 the primary means for reaching a decision while in other instances, the surrogates used their own wishes as a backup guide when the 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."

Surrogate's Religious Beliefs/Spirituality: At times surrogates based their decisions on their own religious beliefs and/or spirituality. Several surrogates explained that the patients' situation was part of God's plan. In some cases, this deterred the surrogate from making decisions which may interfere with God's plan, and in other instances, the surrogate still made decisions 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."

Surrogate's Interests—Beyond the surrogates' wishes, the surrogates' interests played a role in decision making. The surrogates' interests include considerations of how decisions may affect the surrogates' lifestyle and the impact of a decision or outcome on the surrogate and/or family. In several cases, the 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 the 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, he still made the decision to put him in a nursing home following discharge. He explains: "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 facility was to the surrogate's family. Many surrogates discussed trying to find an institution in a specific region or radius of the patient's family. Convenience appeared to play little role in other major medical decisions made by the surrogates.

Family Consensus: Surrogates often felt compelled to reach a family consensus on decisions or have the support of their family behind the decisions they made. Surrogates used a family consensus as a means of reaching what they considered 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 surrogate approaches to decision making found that, in addition to the patients' wishes and best interests, surrogates consider 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 have also found that physicians consider surrogate-centered and other ethical factors when making decisions for hospitalized patients¹⁶ 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 factors in decision making.

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

Our study highlights the value surrogates place on family consensus in decision making. Many surrogates favor consensus because it distributes the responsibility of the decision among several individuals, or may lessen the guilt felt by the surrogate when making decisions such as ending life-support. However, there are other potential benefits to consensus. Consensus helps to maintain family cohesion through the distress, and makes surrogates more comfortable in their role. Most important, family consensus may actually align with the patient's wishes for the decision making process.¹⁸ Not only do patients want family and caregivers to reach consensus regarding their care¹⁹, guidelines also advocate for working towards consensus in surrogate decision making.²⁰

We found that when surrogates lacked information about patient preferences, some employed other means for making their decisions in addition to considerations of what is in the patient's best interest. Specifically, some 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.²¹ Two additional studies using hypothetical cases found that surrogates' decisions for a patient were more closely aligned with preferences for themselves than with the patients' own preferences. The authors regarded this finding as an example of the surrogate's "projection" and noted that it is conceptually different from substituted judgment, in which a surrogate might imagine what the patient would want rather than themselves.²² 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 of Judeo-Christian ethics. The normative role of this "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,²³ we found surrogates consider their own needs and preferences when making decisions. This raises the question of whether it is ethically acceptable for a surrogate to base a decision on their own needs or whether the traditional model that relies entirely on patient factors should be maintained. Studies have shown that the patient's themselves are concerned with burdening their loved ones²⁴, recognize that surrogates must live with the decisions they make²⁵, and do not perceive deviations from their preferences as infractions of their autonomy.²⁶ Patients therefore give surrogates some leeway when making decisions.²⁷

The emotional needs of the surrogate, particularly the understandable drive to avoid guilt, also swayed their decisions. Surrogates often made decisions which gave the patient 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 patient. This highlights the need for surrogate reassurance that decisions to refuse life-sustaining therapy does not mean that

the surrogate has given up on or is personally responsible for negative outcomes or the patient's death.

Our paper had several weaknesses. First, we had a low response rate of 35%. This could introduce bias into our results. Our largely female sample may have underrepresented 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% female.²⁸ Additionally, we chose to delay interviews when the patient had recently died to allow time for acute grieving; responses of the subjects whose interviews were delayed due to patient death may have differed from those interviewed sooner and may be a source of bias in the sample.

In conclusion, surrogate decision makers for hospitalized older adults rely heavily on the standard ethical concepts of patient preferences and best interests, but also consider other factors such as their own preferences, interests, emotions, experiences and religious beliefs, factors which 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 wishes for themselves as a decision making guide, but may also consider their own beliefs and interests. More work is needed to understand the implications of expansion of 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.

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Table 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 7–14 for up to 3 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?
10	Additional surrogate information Race: How would you describe your race?

Table 2Subject's Characteristics ($N = 35$)

Characteristic	Number of surrogates	Percent (%)
Race:		
African-American	18	51.4
White	17	48.6
Gender		
Female	28	80.0
Education		
9–12 years	20	57.1
13–16 years	11	31.4
17+ years	4	11.4
Religion		
Protestant	29	82.9
Catholic	3	8.6
Spiritual	1	2.9
None	2	5.7
Relationship of surrogate to patient		
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)