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Rethinking the Ethical Framework for Surrogate Decision Making: A Qualitative Study of Physicians

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INTRODUCTION

When patients lack decision-making capacity, physicians work together with surrogates to make decisions for patients. Standard bioethical approaches to surrogate decision making have relied on the principles of respect for autonomy and beneficence to navigate these difficult clinical situations.¹ This standard approach encourages decision makers to determine what patients would have wanted by using advance directives or substituted judgment. When decision makers do not know patients' wishes, they turn to the principle of beneficence, which aims to promote and protect patients' interests. Usually, surrogates are persons patients have previously chosen through a durable power of attorney document, or else they are patients' legal next-of-kin.

Such an approach to surrogate decision making has been advocated by the courts in cases beginning with *Karen Ann Quinlan*, in which the New Jersey Supreme Court argued that patients should not lose their right to refuse medical therapy because they can no longer speak for themselves.² In such cases, surrogates could speak for patients, basing decisions on knowledge of patients' wishes and their own assessment of patients' interests. The courts have also generally advocated that decisions be based on patients' prior wishes,³ but allow states to set their own evidentiary standards to evaluate the certainty of patients' preferences.⁴ This general approach is also supported by the federal Patient Self-Determination Act⁵ and by state laws that

include statutory documents for advance directives that allow patients to specify both their wishes for care and their preferred surrogate.⁶ Professional guidelines also direct decision makers to rely on patients' wishes and best interest.⁷

In recent years, there has been increasing criticism of these autonomy-based approaches to surrogate decision making.⁸ Major objections include the fact that most patients do not have advanced directives.⁹ Additionally, in empirical studies, surrogates are often inaccurate in predicting what patients would want in a given clinical scenario,¹⁰ even after extensive discussion with the patient or completion of advance directives.¹¹ Finally, advance care planning requires that people make decisions about life situations that they have never experienced.¹² Empirical studies report that persons with chronic illness change their minds about medical treatment over time,¹³ and we can never know what persons who lack decision-making capacity would decide if they were able to suddenly express preferences again.

While it is possible that physicians may share some of these objections to the standard legal and bioethical guidelines for surrogate decision making, it is not known to what extent physicians adhere to an autonomy-based approach in clinical practice. A few empirical studies have presented physicians with hypothetical scenarios regarding end-of-life care and suggest that physicians often override advance directives or prior preferences when making surrogate decisions.¹⁴ In addition to patients' wishes, physicians consider legal issues and the needs of patients' family members in their decisions.¹⁵ However, these hypothetical scenarios are unable to capture the interpersonal and emotional aspects of decision making that may also be important in the clinical setting.¹⁶

To study how physicians make surrogate decisions in clinical practice, we interviewed physicians within a month of their having made a major medical decision for an adult in-patient who lacked decision-making capacity. Interviews were analyzed to explore how physicians justified the decisions they made for their patients. We reasoned that our qualitative methods would be particularly helpful in allowing us to identify the concerns of physicians without imposing a particular decision-making model.

METHODS

Study Design and Population

We conducted semi-structured, in-depth interviews with physicians from an academic medical center in a large Midwestern city. Subjects were recruited from a complete list of house staff and attending physicians in the medicine, geriatrics, and intensive care unit services at this hospital. After a physician had been on service for at least two weeks, but no later than one week after the end of the rotation, we contacted the physician to request participation in an audiotaped interview about experiences with surrogate decision making. Physicians on the service lists were contacted sequentially until approximately five interviews had been completed during each month. The study was approved by the hospital's institutional review board and each physician provided written informed consent.

Data Collection

Interviews were conducted by one investigator (AMT) using a semi-structured interview guide (see table 1). For each section, physicians were asked an open-ended question about an aspect of surrogate decision making followed by optional prompts. Prompts were included in the interview guide to assure a consistent approach to questioning. However, the interviewer could ask additional questions for clarification or expand on a given topic as appropriate.

Physicians were asked about patients they had cared for within the past month who lacked decision-making capacity and required a major decision about life-sustaining therapy (such as a change in code status) or long-term disposition (such as nursing home placement) that involved discussion with surrogates. The interview explored physicians' approaches to their patients and their knowledge and understanding of bioethical guidelines for surrogate decision making. Interviews were audiotaped and transcribed verbatim. Selected audiotapes were reviewed for accuracy.

Data Analysis

After the completion of approximately every five interviews, transcripts were read by two investigators (AMT and GCA) to identify major themes that required further exploration in subsequent interviews. This iterative process, in which data are reviewed multiple times as interviews are conducted and as new themes emerge, is a standard practice in qualitative methodology¹⁷ and allowed us to refine and test our ideas at each step of data collection. At each meeting, we also determined whether new themes were continuing to emerge with each additional interview. Interviews continued until no new themes were identified in subsequent interviews.¹⁸

At the conclusion of the interview process, each interview was read and independently coded by two investigators (AMT and MCS) using principles of grounded theory, a systematic process of developing new theory through a careful examination of raw data.¹⁹ Using these methods, segments of text in each interview (sentences or paragraphs) were identified by topic and labeled. The labels, or codes, were then organized into categories reflecting major themes. The interview text and codes were entered into Atlas.ti (Scientific Software, Berlin), a qualitative data analysis program that allows the organization of interview data. The two coders met regularly to review emerging codes and themes. Disagreements were resolved by consensus. For the current analysis, we selected all codes that addressed the physicians' reasoning about decisions for patients who lacked decision-making capacity.

Qualitative research involves several steps to ensure "credibility," a term that is conceptually similar to "validity" in quantitative studies.²⁰ In this study, we took the following steps to ensure credibility: independent coding of all data by more than one investigator; familiarity with all interviews by three researchers; analysis from two disciplinary perspectives (a doctorate-level philosopher, MCS and two practicing physi-

Table 1. Interview Guide

1. Decision-making situations

In the past month, can you think of one or more situations in which you had to make a clinical decision for a patient, and the patient could not participate in the decision-making process?

2. Target interventions

In any of these cases, did you discuss any decisions about whether to forgo medical therapy, discuss code status, or discuss whether life-sustaining therapy was appropriate for the patient?

3. General information

The most recent decision you identified was _____. Tell me about the decision.

4. Decision-making capacity

How did you decide that the patient could not make this decision?

5. Assistance with decision making

Who or what was helpful to you in making the decision?

6. Communication

Tell me about any discussions with the family or surrogate decision makers and other staff during (patient's) time in the hospital.

7. Outcomes of the decision

Regarding this decision, where did things stand when your ward/ICU month ended?

8. Conflict

Was there conflict between you and anyone else regarding the decision? Describe the conflict.

9. Ethical standards for surrogate decision making

You have described a real-life decision-making situation. Now I want to ask you about decision making in general. When a patient lacks decision-making capacity, what are the ethical standards physicians should use when they are making medical decisions?

What are the ethical standards for deciding *who* should make the decision?

What does the *law* say about how doctors should make surrogate decisions?

What does the *law* say about who should make the decisions?

cians with bioethics training, AMT and GCA); and an interview process that continued until saturation of a theme was reached. Finally, we reviewed our data and our theme structure with a group of physicians who practice in the in-patient setting to assess validity of our findings and conclusions.

RESULTS

Subjects

A total of 21 physicians were interviewed, of 33 physicians initially approached (see table 2 for the subjects' characteristics). The other 12 physicians refused or could not arrange an interview within two weeks after the end of the target month due to scheduling difficulties.

Of 21 interviewed physicians, 20 had made a major medical decision within the past month for at least one patient who lacked decision-making capacity. These 20 physicians were asked to provide an in-depth description of their most recent such a patient. From these descriptions, we identified three major themes regarding decision making:

1. Patient-centered ethical guidelines (patients' wishes and best interest),

2. Surrogate-centered ethical guidelines (surrogates' wishes and surrogates' interests), and
3. Issues of knowledge and authority (of the physician and surrogate) (see table 3).

In addition, we found physicians often concurrently relied on multiple decision-making factors for a given decision and/or sought to balance competing clinical and ethical principles.

Patient-Centered Guidelines

Physicians often appealed to patient-centered ethical guides for decision making, including patients' interests and patients' wishes.

Patients' wishes. Some physicians regarded patients' wishes as the most important consideration. One said, "Number one, your goal is to make decisions that you think the patient wants." Others balanced patients' wishes against other considerations, such as best interest. Physicians often recounted conversations in which surrogates or other family recalled specific statements by patients about preferences for care. In other cases, surrogates relied on a general understanding of patients' values or preferences. Although physicians sometimes inquired about living wills, none of the patients described in these interviews had one.

Some physicians encouraged family members to consider patients' prior wishes and to place them ahead of other considerations. One physician described his approach to a family meeting, "I always think its important that it's not a decision that the family member or the surrogate is making for themselves but it is a decision that they are making for someone else, based upon their best knowledge of what that person would want."

In some cases, patients who lacked decision-making capacity because of psychosis or mild dementia were still able to express their own preferences. In such cases, physicians expressed conflict about overriding patients' stated wishes, even while acknowledging that these patients lacked the capacity to make informed choices.

Patients' interests. Physicians often used the precise term "best interest" to describe this aspect of decision making. In addition, physicians often appealed to related concepts such as quality of life, and pain and suffering (see table 3).

Sometimes physicians offered their own assess-

Table 2. Subjects' Characteristics (N = 21)

Characteristic	n
Gender	
Female	8
Male	13
Status	
Intern	6
Resident	8
Fellow	1
Attending	6
Race	
African-American	1
White	15
Asian	5
Religion	
Protestant	2
Catholic	6
Jewish	4
Muslim	4
Other	5

Table 3. Major Themes, Codes, and Quotations

Themes	Codes	Examples of Quotations
Patient-centered ethical guidelines		
Patients' wishes	Respect for autonomy Advance directives Substituted judgment Patients' preferences	<p>I always think it's important to get at that it's not a decision that the family member or the surrogate is making for themselves but it is a decision that they are making for someone else, based upon their best knowledge of what that person would want.</p> <p>...the niece then said, "I spoke with her three days ago, and I know that she was coherent because she was saying things that only she would have said... I asked her if she would want a colostomy and she said no." So it was actually a very good conversation because the niece felt very confident about what the patient would have wanted.</p> <p>(The patient) made it clear that what she really valued was her functional status and that without it she wouldn't really want to be around.</p>
Patients' interests	Best interest Quality of life Pain and suffering Risks Benefits	<p>Treating everything that the patient had, aggressively, would probably not be in the best interest of the patient.</p> <p>Survival at one year was very minimal, let alone the next six months. You know with risks of aspiration, rebleeding, inability to anticoagulate ...it was mutually agreed upon that what would be in his best interest was a palliative approach.</p> <p>To subject them to invasive tests and invasive procedures are, is this really going to benefit their quality of life?</p>
Surrogate-centered ethical guidelines		
Surrogates' wishes	Surrogates' wishes Belief and religion	<p>We talked about what (the daughter's) goals were, and she wanted (her mother) to be home, she didn't want her to be in a nursing home, which was great that we established that right away. And then... what she wanted was for her to be comfortable.</p> <p>Yet her daughter was extremely religious and...felt that God would make her heart stop beating when the time was ready and so she didn't want hospice care and so I think it was sort of a struggle to get her even to agree to a DNR/DNI type of status.</p>
Surrogates' interests	Emotions Family burden	<p>I think when it came down to the question of should he stay in the hospital or should he be allowed to go home...the feeling of the patient's daughters and his wife were that it would be too hard emotionally for them to take care of him and let him lapse, you know, let him pass at home.</p>
Knowledge and Authority		
Physicians	Clinical judgment Physicians' judgment Appropriate care Futility	<p>Having good clinical sense was probably the most helpful thing.</p> <p>I do try to guide (the family) toward one thing. I don't think I'm unbiased when I suggest one thing or another. <i>(continued next page)</i></p>

ment of patients' interests and relied on this to guide family members. As one physician said, "When I feel strongly that the patient's quality of life is really poor then I do feel that it is appropriate for the physician to try and guide the family member towards a decision."

In other cases, physicians relied on surrogates' assessments of patients' interests as they made decisions about therapy. In many cases, there was general agreement on what was in patients' interests.

Although physicians varied in whether they relied on their own assessment of best interest or surrogates' assessments, they often did not acknowledge this distinction. On one occasion, a physician commented on the agreement between her assessment and that of the surrogate, stating, "In that instance, I think the best thing for the patient was also the thing that the daughter thought was best."

Surrogate-Centered Guidelines

In addition to patient-centered factors, physicians often referred directly to the wishes and interests of surrogates.

Surrogates' wishes. Physicians often contacted family members to ascertain surrogates' own preferences for care. In these cases, physicians did not explore the reasoning behind surrogates' preferences or ask them to reason based on patients' interests or wishes, but rather the physicians accepted the surrogates' preferences for care at face value. In such cases, surrogates' wishes were generally respected as a key element of decision making.

In one example, an attending physician described her advice to her resident and intern regarding a decision to perform an endoscopy to diagnose a suspected gastrointestinal bleed, "I recommended that they discuss this with the family. . . . And if the family said oh, we really want you to go and look and make sure it isn't a bleeding ulcer, then we would go ahead and do it." In this case, the family refused the intervention on behalf of the patient. The medical team did not inquire further about the basis for the surrogate's decision.

At times surrogates explicitly based their decisions on their own values or religious beliefs. Physicians expressed discomfort with this, especially when surrogates' decisions were in conflict with physicians' beliefs about appropriate care.

Table 3. Continued from previous page

Themes	Codes	Examples of Quotations
Surrogates	Appropriate surrogate Legal next-of-kin Surrogates' motivations Surrogates' knowledge and understanding	If there is no spouse involved then we try to find the next closest family members. So if there's children we involve them. If there's no children we start going to siblings or whoever seems to be the next in line. The first thing is to try to identify someone that the patient would want to make decisions for them. Some of her motivations were probably a little bit self-serving to...do all this for her mother, if she wanted her mother to be around to be with her, et cetera. But still... I think she did care for her mother....she wanted to do well by her mother.

Multiple Principles

But at the same time...you want to have hopefully discussed these issues and do what that individual would want, what's best for them.

In the end, you have to do what the family wants, because if you don't do what the family wants, then there's a huge conference and then everyone leaves unhappy...I wish that what I think is best for the patient was able to trump what the family wants.

Surrogates' interests. Physicians were concerned with surrogates' well-being, including their emotions and experience of burden. However, physicians generally said that surrogates' needs were less important than patient-centered concerns: "I think family burden is an issue. I don't think it should govern what the final decision is, but I do think it should be addressed."

However, another physician described the in-hospital death of a patient who had expressed a previous desire to die at home. In this case, the patient's family members felt that they could not cope with caring for the patient (see table 3). This physician expressed discomfort with the decision, while acknowledging the complexity of balancing patients' and families' needs.

Knowledge and Authority

Physicians' authority. Physicians justified their own role in decision making based on two sources of authority: clinical knowledge and duty toward patients. Physicians who made complex surrogate decisions often appealed to clinical considerations to guide their decisions. These considerations included the individual physician's clinical judgment, providing care that was "appropriate" for the patient's medical condition, and meeting an external "standard of care."

Although such clinical decision making may implicitly be built on considerations of the patients' good (that is, on the principle of beneficence), physicians often justified choices that had an ethical dimension using only such clinical considerations. For example, a physician justified a decision to pursue palliative care based on his observation that ". . . clearly the prognosis was poor, and going further with treatment like, you know, trach and G-tube and these sorts of things, and likely ventilator dependence, was just futile . . . just inappropriate, just not right for the patient."

Another physician reviewed the process of making a difficult surrogate decision and concluded that "having good clinical sense was probably the most helpful thing."

Secondly, physicians expressed a belief that their sense of authority as a decision maker was based on their duty toward patients. In some cases, this duty included guiding the family members toward the correct decision: "If the patient can't make the decision then I discuss it with the family, I sometimes will push the family, to do what I think is best for the patient."

At other times physicians guided surrogates toward specific therapies based on surrogates' own preferences: "If you guys are really leaning toward comfort, and making pain control the goal here, then we should talk about code status and what we would do in the event that something would happen."

Surrogates' authority. Physicians attributed authority to surrogates based in part on surrogates' social and legal status as durable power of attorney or next-of-kin. Some physicians sought to identify the persons patients would have chosen as surrogates. However, physicians also appealed to the knowledge and motivations of surrogates as justifications for their authority. For example, physicians described surrogates' level of caring and concern for patients as they justified honoring surrogates' preferences for care (see table 3).

Balancing Multiple Principles

Physicians often considered several principles simultaneously and at times seemed to give each equal consideration. Some physicians clearly identified a single principle as most important. At other times they described how they resolved conflict among several competing decision-making factors or among individuals who were reasoning from different principles. Physicians struggled when the concerns of family members appeared to conflict with concerns centered on patients.

DISCUSSION

In this qualitative study of physicians' framework for surrogate decision making, we found that physicians' moral reasoning extended beyond the principles of patients' autonomy and beneficence that dominate most ethical discourse. First of all, physicians reported considering the wishes and needs of surrogates in addition to those of patients. Second, physicians expressed a sense of shared authority with surrogates.

Physicians considered both clinical judgment and their duty toward patients as sources of their own authority in decision making. However, we found that ethical and clinical reasoning were not separate processes, but were often combined in complex ways. These findings suggest that ethical models based entirely on patient-centered guidelines²¹ do not adequately capture how physicians make surrogate decisions.

The Impact of Concerns Around Surrogates

We found preliminary evidence that although physicians are aware of the traditional, autonomy-based approaches to surrogate decision making, concerns regarding surrogates often affected decisions in the hospital setting. We propose that the interpersonal interactions between the physicians and surrogates, as well as the practical considerations around the role of family members in providing care make surrogates' concerns much more salient in the clinical setting than they are in theoretical models. For example, the wishes of a caring family member may be given great authority in actual clinical decision making, regardless of whether the surrogate provides a justification that is based on a particular ethical principle.

The most vexing clinical cases for physicians may involve direct conflict between the wishes and needs of family members and those of patients. In our study, physicians were ambivalent about honoring the requests of family members in such cases but recognized practical constraints. For example, a family who was unwilling to take a patient home could not be forced to do so, even though the patient had previously expressed a wish to die at home. Some physicians described how they coped with such conflict, and some expressed acceptance of differences and recognition of the validity of the family's point of view even if it conflicted with their own.

Shared Decision-Making Authority

Although most of the ethical literature has focused on the nature of the surrogates' authority as decision makers,²² physicians in this study described a sense of shared authority. They respected surrogates' authority based on legal standards, through durable power of attorney documents or through guidelines for assigning authority to the next-of-kin. However, physicians often considered the motivations of the surrogates when justifying their role as decision makers. Physicians often made comments about the level of care provided by surrogates or about surrogates' goodwill toward patients. This information was used to justify giving surrogates greater leeway in decision making. Although it is rare to disqualify surrogates in the clinical setting, surrogates may have more of an impact on decision making if they are judged by the physician to have goodwill toward the patient.

Physicians also exerted authority in surrogates' decisions. Physicians often expressed a belief that they should guide the family toward a clinical decision, based either on patients' preferences, surrogates' goals, or even on physicians' own assessment of best interest. The amount of authority physicians ought to exert in surrogate decision making is still a matter of debate among bioethicists.²³ Regarding the patient-physician relationship,²⁴ several authors have argued that physicians' duties to patients include advice and guidance. In cases when patients cannot make decisions, physicians may have a similar obligation to guide surrogates in their decision making.

Physicians' own sense of decision-making authority derived from two sources: their clinical knowledge and their duties to patients. However, clinical and ethical reasoning were often combined or overlapped in complex ways. In some cases, physicians justified surrogates' decisions entirely in clinical terms without reference to ethical concerns or moral values. We recognize that clinical standards may be implicitly based on ethical principles, such as beneficence. However, in these cases, physicians' level of reasoning did not include consideration of ethical concepts that may have impacted their decisions in important ways. More commonly, physicians' reasoning combined clinical concerns about diagnosis and prognosis with ethical concerns about best interest and individuals' preferences.

Although clinical medicine and bioethics may often be regarded as separate disciplines, they require a similar approach: the application of general principles and rules to unique individual circumstances. This "practical reasoning," or *phronesis*, was first described by Aristotle in regard to the practice of ethics. Such

a practice requires knowledge of both the discipline and also of how rules of the discipline apply to an individual case. Clinical medicine is an example of this type of thinking.²⁵ In this study, we found that physicians often combined elements of clinical and ethical reasoning as they made complex choices for patients. Physicians considered how concepts such as patients' preferences or best interests apply to particular patients. Simultaneously, physicians considered issues of diagnosis, clinical status, and prognosis in making decisions. The application of practical wisdom was an important similarity in clinical and ethical reasoning in patient care.

We also found evidence that physicians sometimes drew upon both clinical and ethical knowledge without making clear distinctions between them. In some cases, physicians answered questions that had an ethical dimension through appeals to clinical knowledge, with the tacit assumption that clinical findings could guide them to make the "right" choice for patients. We conclude that there are important similarities between the "practical reasoning" of ethical and clinical decision making, but that physicians may not be able to identify whether their basis for decision making arises from the discipline of biomedical science or ethics.

This study has several limitations. Because it involved interviews with physicians in a single medical center, findings may not generalize to other healthcare settings. Additionally, there may be differences in the culture of a medicine service compared to other specialties. This study explored physicians' own explanations for their decision making. It may be the case that individuals have incomplete insight into the true underlying factors that motivate their own behavior. However, the field of applied biomedical ethics rests upon the assumption that examining the moral principles that underlie clinical decisions is a valuable enterprise that can improve the quality of patient care. Finally, this qualitative study identified decision-making factors important to physicians, but could not quantify the relative importance of each factor or determine how frequently each consideration affected decision making.

CONCLUSIONS

We conclude that although physicians who are engaged in surrogate decision making often rely on the traditional, patient-centered ethical principles of respect for autonomy and best interest, they also consider the surrogates' interests and wishes. Physicians' sense of authority in surrogate decision making came from both their clinical knowledge and their own duties toward patients. Physicians respected surrogates' authority based on the law and the nature of their relationship with patients, but also based on surrogates' good intentions toward patients. These findings suggest that physicians' decision-making framework was broader and more complex than previously thought, and may rely on factors that have been ignored in traditional ethical models. In order to be useful for practicing physicians, future guidelines for surrogate decision making should take account of actual clinical practices, and should be expanded to explicitly address these additional considerations.

NOTES

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