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## "He Got His Last Wishes": Ways of Knowing a Loved One's End-of-Life Preferences and Whether those Preferences Were Honored

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### ABSTRACT

As a patient approaches death, family members often are asked about their loved one's preferences regarding treatment at the end of life. Advance care directives may provide information for families and surrogate decision makers; however, less than one-third of Americans have completed such documents. As the U.S. population continues to age, many surrogate decision makers likely will rely on other means to discern or interpret a loved one's preferences. While many surrogates indicate that they have some knowledge of their loved one's preferences, how surrogates obtain such knowledge is not well understood. Additionally, although research

indicates that the emotional burden of end-of-life decision making is diminished when surrogates have knowledge that a loved one's preferences are honored, it remains unclear how surrogates come to know these preferences were carried out. The current study examined the ways that next of kin knew veterans' end-of-life preferences, and their ways of knowing whether those preferences were honored in Veteran Affairs Medical Center (VAMC) inpatient settings.

### INTRODUCTION

Confronting end-of-life treatment decisions can be a difficult process for a dying patient's

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family. As the U.S. population ages, it is likely that a growing number of families will face the challenges of end-of-life decision making. According to a Centers for Disease Control and Prevention (CDC) report on death and dying, nearly 75 percent of all U.S. deaths in 2007 were among individuals aged 65 years or older.<sup>1</sup> Although advance care directives assist families in knowing their loved one's end-of-life preferences, a 2008 report to the U.S. Congress on advance care directives and advance care planning indicated that fewer than one-third of Americans had completed an advance directive.<sup>2</sup> As family members assume the role of surrogate decision maker, they likely will rely on other, less formal means to discern and interpret a loved one's end-of-life preferences. The purpose of the present study was to employ an epistemological framework to examine how veterans' next of kin came to know veterans' preferences for end-of-life care and how the next of kin affirmed that their loved one's wishes were honored in VAMC inpatient settings.

### **Surrogates' Knowledge and End-of-Life Decision Making**

When a gravely ill patient is unable to communicate due to advancing illness, cognitive impairment, or altered mental status, the medical community must rely on a surrogate to convey the patient's preferences for end-of-life care.<sup>3</sup> In cases when a patient has completed an advance directive, family members may rely on that document for assistance in guiding end-of-life treatment choices. Given that only 18 to 36 percent of the adult U.S. population has completed an advance directive, most surrogates must make decisions without the benefit of a patient's documented wishes. In these cases, surrogates are asked to exercise substituted judgment. The substituted judgment standard provides a framework for surrogate decision makers, in that it requires a surrogate to act on behalf of a patient, using *knowledge* of the patient's previously expressed or implied preferences regarding medical treatments.<sup>4</sup> While the substituted judgment standard has been considered the gold standard, some argue that its use is fraught with difficulties. Torke and col-

leagues delineated three problems with using substituted judgment: (1) an individual's preferences may change over time, (2) there may be a lack of concordance between patient and surrogate, and (3) patients often desire input from family members and physicians.<sup>5</sup>

Inasmuch as the exercise of substituted judgment may pose difficulties for strict adherence to a patient's expressed or implied preferences, the literature suggests a pivotal move toward recognition of the relevance of contributions from patients' family members and physicians to the decision-making process. For example, studies indicate that patients are inclined to defer to a family member's judgment for end-of-life decisions when patients become cognitively impaired,<sup>6</sup> and that patients tend to value a surrogate's decisions over their own previously expressed preferences.<sup>7</sup> In a recent systematic review of the literature on adult end-of-life decision-making goals, Kelly and colleagues found the most common reason for deferring to a surrogate is the belief that a surrogate has *knowledge* of a patient's preferences regarding medical treatment.<sup>8</sup>

Furthermore, studies also report that most patients and surrogates desire physicians' input in end-of-life decision making.<sup>9</sup> Family conferences are typically viewed as an essential vehicle for the optimal delivery of care at the end of life.<sup>10</sup> From a clinical perspective, family conferences are a way to assess family members' understandings of the patient's condition, to inform family members of changes in the patient's status, and to seek input from family members regarding the patient's preferences. Fineberg and colleagues found, however, that both the patient and family members benefited from family conferences because clinicians provided valuable information during the conferences.<sup>11</sup>

Important by-products of social interactions during family conferences are the knowledge that surrogates can acquire regarding the acuity and severity of the patient's condition, as well as knowledge of available treatment options for their loved one.<sup>12</sup> Whereas the influence of social interaction on acquiring new knowledge has been reported in studies across disciplines,<sup>13</sup> an understanding of its influence

on the surrogate decision-making process is lacking. A growing appreciation for the complexities of end-of-life decision making has broadened discourse on decision making<sup>14</sup> and has paved a path for the examination of surrogates' knowledge as a key factor in the decision-making experience and process.

### **The Emerging Significance of Surrogates' Knowledge**

Traditional conceptions of the process of decision making at the end of life are evolving from a purely legal perspective to a broader contextual approach that takes into account the values of both patients and family members.<sup>15</sup> Several studies that used a more contextual approach emphasize that surrogates' knowledge is an operative component in the decisions they make for patients. Boyd and colleagues found that surrogates relied on multiple sources of lay knowledge to estimate the prognosis of a critically ill patient.<sup>16</sup> Only 2 percent of surrogates relied exclusively on prognostic information provided by a physician. In other studies, surrogates' knowledge of a loved one's end-of-life preferences was a key factor in surrogates' positive decision-making experiences.<sup>17</sup>

According to Meeker, having knowledge of the patient as a person is essential for knowing her or his last wishes.<sup>18</sup> Surrogates' knowledge of a patient's attributes and life history are identified as important considerations in designing improved communication practices at the end of the patient's life.<sup>19</sup> Similarly, the literature is beginning to acknowledge the value that a patient's or surrogate's subjective experience and interpretation have for informing the clinical encounter.<sup>20</sup> Such contextual approaches to the study of surrogate decision making highlight the emerging significance of surrogates' knowledge. *Knowing* a patient's end-of-life preferences is viewed as a critical factor in meeting the medical, ethical, and legal thresholds for optimal surrogate decision making,<sup>21</sup> yet the ways in which surrogates acquire knowledge is not well understood. Despite a robust discourse on surrogate decision making, there is virtually no research on the fundamental processes that facilitate knowledge of a loved one's

preferences for end-of-life care and whether those preferences were honored.

### **METHODS**

This was a qualitative study within an intervention trial that was designed to evaluate the effectiveness of an educational intervention to improve end-of-life care at VAMCs in the southeastern U.S. The Veterans Affairs (VA) Institutional Review Board granted approval for the study. Patients' next of kin were identified through electronic chart reviews of veterans' deaths at participating VAMCs. Individuals who were listed as next of kin in the patients' charts were invited to participate. A recruitment letter and participant's form were mailed to patients' next of kin three to six months after the date of death. The next of kin who returned a signed participant's form were contacted by phone to discuss the study and to schedule an interview appointment.

#### **Interview Procedures**

Between July 2005 and May 2010, face-to-face in-depth interviews were conducted with 78 next of kin by an interviewer experienced in qualitative inquiry. The interviews were conducted at the VAMC where the patient had died. The research service or chaplain service at each VA hospital provided private space for the interviews. Participants were interviewed only once, with the average interview lasting approximately two hours. Each interview was tape recorded and transcribed.

A semi-structured open-ended interview guide was utilized. Existing qualitative instruments<sup>22</sup> and the guidelines of the Center to Advance Palliative Care (CAPC)<sup>23</sup> shaped the development of the interview guide. The guide was designed to facilitate dialogue between the interviewer and the next of kin and to elicit the participant's narrative account. Topic sections in the guide included the next of kin's recollections of the following:

1. the patient's life and final days;
2. interactions with the patient, clinical staff, pastoral staff, and visitors during the patient's final hospitalization;

3. the patient's death experience;
4. the patient's end-of-life preferences and the fulfillment (honoring) of those preferences;
5. the care and treatment provided to the patient and the staff's support of the family during the patient's final hospitalization.

To ensure relevance, clarity, and readability, the guide was reviewed by an interdisciplinary research team comprised of physicians, nurses, a medical sociologist, a clinical psychologist, and a health educator. The guide was pilot tested with the next of kin recruited at the researchers' local VA medical center. Sociodemographic information was obtained by the interviewer at the conclusion of the interview.

### Analytical Procedures

As part of the analytical procedure, data coding was an interactive, iterative process. Two coder-analysts simultaneously listened to the taped interviews, and each made notations and wrote memos on the transcriptions.<sup>24</sup> The transcriptions of the interviews were reviewed continuously to confirm, compare, and contrast emerging themes, patterns, and interrelationships. The code book initially was comprised of items specific to the interview guide. As

themes emerged, new codes were discussed, negotiated, and added to the code book. Upon thematic saturation, 56 codes had been identified, and 25 codes with relevance to this analysis were employed (see table 1). We constructed a matrix to identify patterns and interrelationships within and between the codes<sup>25</sup> to facilitate regrouping the themes into four categories:

1. factors concerning patients,
2. factors concerning next of kin,
3. factors related to staff, and
4. factors related to the institution (table 1).

The interpretive process for the analysis was guided by an epistemological perspective that explored the nature of knowledge and the ways that individuals acquire knowledge. The following questions were instrumental in informing the process:

1. What do next of kin know about a loved one's end-of-life preferences?
2. How do next of kin come to know their loved one's end-of-life preferences?
3. How do next of kin obtain knowledge about loved one's preferences being honored?

This form of inquiry draws upon the theoretical propositions that social conditions, cultural

**TABLE 1.** Codes categorized by individual and institutional factors

Patients	Next of kin	Staff	Institution
Medical history	Caregiver role	Physician visits	Location of care and death
Length of final hospital stay	Expectedness of death	Pastoral care visits	Death pronouncement
			Suggestions for improvement in end-of-life care
Cause of death	Presence at time of death	Nursing care to the veteran	--
Mode of death	Presence after death	Staff communication	--
Events surrounding death	Experience of loved one's death	--	--
Interactions with the patient and the family	--	--	--
Pain at time of death	Regrets	--	--
Biography	Bereavement concerns	--	--
Final requests	--	--	--
Expressed last goodbyes	--	--	--
Peace at time of death	--	--	--

practices, and communication are integral to the formation of knowledge.<sup>26</sup> To systematically document the interpretive process, memos were logged regularly and incorporated into the thematic data base. A negotiated approach was used throughout the process to achieve coder agreement and ensure the methodological rigor of the data analysis.

## RESULTS

### Participants' Characteristics

Next of kin were predominately female (78 percent) and white (60 percent) with a mean age of 61 years (standard deviation=11.4). Relationship status of next of kin included surviving spouse (40 percent), adult child (32 percent), sibling (17 percent), ex-spouse, other relative or significant other (9 percent), and unrelated named caregiver (2 percent).

### The Process of Knowing

The process of knowing a loved one's preferences regarding end-of-life care appeared to unfold over time and to be facilitated by hearing about the patient's preferences, seeing the care provided to the patient, and interacting with the patient and the clinical staff. Although prior illness conditions may have precipitated informal discussion of end-of-life issues, at the time of a patient's final hospitalization, the next of kin's need to know their loved one's end-of-life preferences was not their foremost concern. Rather, what took precedence was their need to know their loved one's medical status and life-saving treatment options. As awareness of the patient's dying emerged, the need to know the patient's preferences regarding care at the end of life became more salient. This was comprised of two phases:

1. the patient is sick, and
2. the patient is dying.

*Phase 1: the patient is sick.* This phase involved seeking information about the patient's current medical condition and obtaining information about treatment options. It was during this phase that the patient entered the hospital. The concerns of the next of kin often focused

on what was wrong with the patient and securing the tests that were necessary to determine what plan of care to pursue; 47 percent of patients' next of kin cited the patient's acute illness and treatment options as their primary concerns during the patient's early hospitalization. At this point, awareness of the patient's end-of-life preferences was not at the forefront of the next of kin's consciousness because they did not expect that death might occur during hospitalization: a majority (53 percent) indicated they did not expect the patient would die. Moreover, although 59 percent indicated their loved one had an advance directive, only 6 percent mentioned end-of-life preferences when they described the patient's early days of hospitalization. This does not mean that the next of kin did not have knowledge of their loved one's end-of-life preferences, but only that such knowledge did not appear to be salient at that time.

At the time of intake and during the early hours and days of hospitalization, 35 percent of the next of kin expressed a belief that the patient would be treated and released from the hospital. Among these next of kin, 78 percent had no expectation the patient would die during the hospitalization. If the next of kin believed that the patient would be treated and released, they tended to focus on the patient's illness and recovery rather than on details pertinent to life-sustaining decisions. The following quote exemplifies this thinking: "And I said, 'but he was here to have um, a urinary tract infection and has gone downhill since then.' . . . When they called me and said they were taking him to the hospital with a fever of 104, I never gave up, I kept thinking, 'well they'll get this cured and then we'll go back to the nursing home' " [the patient's wife].

*Phase 2: the patient is dying.* During hospitalization, patients reached a point that continued pursuit of life-sustaining treatment was not medically indicated. During this second phase, the next of kin became aware that the patient was dying. A majority (78 percent) said they had a discussion with a physician regarding the patient's impending death. At this point, knowl-

edge of a loved one's preferences had salience; 54 percent of the next of kin reported that end-of-life treatment options were part of the discussion. During discussions with medical staff, the next of kin often recalled prior conversations with the patient regarding end-of-life preferences: ". . . I mean there are just so many issues . . . but as far as we know that he was dying, at the end . . . the doctor came and sat down with us and told us that 'look here's, here's where we are, the medicine that he's on right now is pretty much the only thing that's keeping him alive' . . . [the patient] had mentioned to me that he did not want to be on any type of life support" [the patient's brother].

Transition to the "patient is dying" phase also occurred when medical staff discussed a referral to hospice; 19 percent of next of kin indicated having a discussion about hospice with a clinician during the patient's final hospitalization. As the following quote illustrates, these discussions brought to light end-of-life preferences by addressing the patient's end-of-life status: "Then [the doctor] told me, that's the first time I knew that he was in a dying condition. . . . that's when the doctor shared with me that when his muscles wouldn't work with him breathing, his heart would quit. And they were sending him home to hospice on Monday and, so the next day everybody was coming around to talk about hospice, social worker, psychologist . . ." [the patient's wife].

### Ways of Knowing

Several ways of knowing a loved one's end-of-life preferences and ways of knowing whether those preferences were honored emerged from our data analysis and interpretation:

1. hearing is knowing,
2. seeing is knowing, and
3. interacting is knowing.

*Hearing is knowing* involves obtaining knowledge by listening to a loved one as he or she expresses end-of-life preferences or listening to end-of-life conversations between clinical staff and the loved one. *Seeing is knowing* refers to acquiring knowledge via observations

of medical staff performing clinical end-of-life medical and nonmedical comfort care activities. The third way of knowing, *interacting is knowing*, refers to knowledge acquired through interactions with clinical staff.

1. *Hearing is knowing.* Hearing from a loved one about his or her end-of-life preferences takes place via informal discussions and formal advance care planning deliberations. A majority of patient's next of kin (81 percent) recalled conversations in which the patient conveyed both implicit and explicit end-of-life care preferences. The following quotes illustrate both informal and formal discussions between next of kin and a loved one: ". . . he had already told me, and we did talk some about, we discussed it. He said, 'you know what I want done.' 'You know this and this,' you know. And so I knew what everything, what he wanted done. I mean we knew too, down to the last detail how he wanted things . . ." [the patient's ex-wife]. "And [my husband] and I had talked a long time before when we made our living wills and our DNRs and all that we said we did not want, if things happen to get so bad, we didn't want our lives prolonged" [the patient's wife]. "I remember him saying . . . that he did not want to be on, put on a life respirator; you know, stuff like that trying to save him" [the patient's brother].

When patients lost the capacity to participate in making medical decisions or did not have a documented advance directive, the next of kin described conversations in which patients expressed end-of-life care preferences. A majority (59 percent) indicated that their loved one suffered cognitive impairment that included dementia, Alzheimer's disease, posttraumatic stress disorder, delirium, mental illness, or an undefined impairment. Among the 46 cases of cognitive impairment, 80 percent ( $n=37$ ) of the next of kin claimed they had an informal discussion with their loved one regarding end-of-life preferences: ". . . the Alzheimer's . . . I don't know really how much he really understood, you know, but we talked with him . . . he had already done told us before his mind had ever started going bad. He had already told us he did not want to be on any machines, and he did

not want to be resuscitated. If anything happened to him, he did not want that, and he did not want us to do it” [the patient’s son].

One-third (33 percent) of the next of kin stated that the patient did not have an advance directive. Among those patients who did not have an advance directive, however, 77 percent of the next of kin described informal conversations with the patient concerning end-of-life care preferences: “I had already signed my stuff, but I could never get him to sign it. . . . But he didn’t want life support, he said ‘don’t ever put me on life support.’ . . . He did not want to be put on life support” [the patient’s wife].

Being present during doctor-patient encounters and hearing conversations between a physician and the patient regarding end-of-life treatment decisions provided another way for the next of kin to know their loved one’s expressed end-of-life care preferences: “. . . another thing the doctor asked him not only one time but three different times, if his heart stopped if he wanted them to start it back, and he told him, ‘No.’ And if he stopped breathing, did he want that started back, and he told him, ‘No.’ ’Cause, I think he had made up his mind that he was ready to go” [the patient’s wife]. “He didn’t want to be on a respirator . . . the doctor asked him, you know, ‘if you have difficulty breathing,’ ’cause he was having the lung problems and having to have the oxygen, and he said, ‘No,’ he did not want to be on a respirator. So I was glad that he was able to talk to the doctor and tell him what he wanted” [the patient’s wife].

Nine of the next of kin (11 percent) characterized the conversations they had with physicians as “explaining” the end-of-life process and procedures. Hearing such explanations expanded the knowledge of the next of kin about end-of-life scenarios and the physician’s clinical position. The explanations also helped the next of kin to integrate their knowledge of advance directives with their interpretations of a loved one’s expressed end-of-life preferences: “. . . when the doctor came . . . I asked, ‘what if I’m here and my dad has a heart attack or appears to be having a heart attack, do we try and resuscitate him or is that when you don’t?’ What I wanted to know is when do you refuse ex-

actly . . . I just wanted him to be really clear with it . . . and [the physician] told me . . . and she also explained to me that because I wasn’t sure how he would die. I said, ‘what will it be like what should I expect.’ . . . You know he didn’t want any extreme measures taken. . . . So in that regard he wouldn’t have wanted them to pound on his chest and try and revive him” [the patient’s daughter].

In four (5 percent) cases, the next of kin perceived end-of-life discussions with clinical staff as lacking. The wife of one patient, for example, said that poor communication with clinical staff compromised her understanding of end-of-life treatment and limited her knowledge of what to expect: “. . . [the patient] did not wish to live in a state of vegetation. . . . I think had he been anywhere else except here a doctor would have sat down and explained things to me . . . and would have quit giving me false hope, ’cause see every time they told me they was gonna try in a day or two to bring him out . . . I looked forward to being able to talk with my husband. . . . All I could see was the hope at the end. . . . I just never expected him to die . . . didn’t even entertain the thought of him dying . . . I just don’t understand it.”

*2. Seeing is knowing.* When asked if the loved one’s end-of-life wishes were honored, 79 percent of the next of kin answered in the affirmative; 73 percent referenced their observations of either medical care comfort care procedures or nonmedical comfort care activities. Of the next of kin who referenced their observations of comfort care, 47 percent ( $n=27$ ) described witnessing medical procedures such as the delivery of pain medication or removal of intravenous lines, and 46 percent ( $n=26$ ) described observing staff attending to the nonmedical comfort needs of the patient. The following quotes indicate that observations of the delivery of comfort care seemed to give the next of kin the knowledge that their loved one’s wishes were honored at the end of life: “. . . they stopped all of her medicines and were just giving her pain medicines, just making her comfortable . . . I really felt like, you know, they did take good care of her and they made her

comfortable and she didn't suffer . . ." [the patient's daughter]. ". . . I understood what they were going to do and why . . . it seemed like the humane thing to do. . . . So I understood it, very hard to watch them undoing this or undoing that" [the patient's wife]. "All he wanted was to be kept comfortable and out of pain . . . that last day that he lived, the nurse came in . . . she tried to get him to drink. . . . But the only thing that he wanted was Coca-Cola . . . gave that to him every time he wanted it . . . the thing that impressed me so was them keeping him so clean and doing everything to make him comfortable" [the patient's wife].

*3. Interacting is knowing.* In 11 cases (14 percent), the next of kin learned of a loved one's end-of-life preferences through interacting with clinical staff. The next of kin said they came to know their loved one's wishes were honored during such encounters: "My brother was in that room on the floor . . . he was all out of it. And then that Friday I went to consult with doctor. She told me my brother had requested that he didn't want no machine or nothing . . . the doctor and my brother had talked and then the doctor talked with me about my brother's request. So the doctor and my brother kind of, you know, lift the weight off of me . . . the doctor was in the room when I came and that's when she told me that everything was near the end. So, the request that he didn't want the machine on him . . . a little after 10 . . . my brother had gone" [the patient's sister].

Interactions with staff in the palliative care setting had particular relevance for the next of kin who did not have a long history with the patient (for example, significant others.) Of these, five were not connected to the patient by blood or marriage. The next of kin valued interactions with clinical staff because they were a way to acquire information about the patient's preferences: "The doctors probably told him about his terminal illness, but he didn't mention it to me . . . he came in that Wednesday night and he died the next morning. . . . Now I don't know about the life-support machines because he never talked about that. . . . If they can have a meeting with the patient and the

family, especially if they know someone is passing away . . . and sit them down you know and just talk to them and probably that would make the patient open up more . . . 'cause you can come in the hospital and you don't know if you're leaving. . . . So if they could just have a talk with the family together and probably the patient could open up and tell the family members different things that need to be done. . . . 'Cause you don't know, you can come in for one thing and just like him be gone just like that . . . on a quick death like that . . ." [the patient's girlfriend].

In two cases the next of kin characterized their social interactions with clinical staff as a negative. Nonetheless, they acquired knowledge of their loved one's preferences during these encounters. Additionally, despite a negative perception of the interaction, as exemplified in the quote below, the next of kin became aware that their loved one's expressed end-of-life preferences were being honored by clinical staff: ". . . the doctors considered him in sound mind, able to make these decisions . . . I don't know what may have been said between my father and the doctors before hospice was ever brought up to me . . . the doctor brought that up because my father was refusing to eat. . . . It became very ugly between the doctor and I because my father wants to die [that is, to stop dialysis] and the doctor said, 'why would you be trying to keep him alive? This is the man's will' . . . at that board meeting [family conference] . . . they voiced my father's opinion like they're standing up for him and his will" [the patient's son].

In the four instances of interfamily strife, we found that the interactions between family members and clinicians informed surrogates and family members about the medical, legal, and ethical aspects of the patient's preferences. These interactions helped the next of kin to know that the patient's wishes had been honored: "We probably could have pulled the plug sooner . . . a lot of animosity between me and his children from his first marriage . . . when they called us in on Thursday morning, the doctor told them that there was absolutely nothing there, she told them that I would have the final say that that was their father's last wishes.

... I was glad we got the living will because he got his last wishes and that's what I told his kids. I said, 'we're doing what he wants, not what I want, not what you all want, we're doing what he wants' " [the patient's fiancée].

## DISCUSSION

The findings of this study suggest that surrogates undergo a process of formulating knowledge, wherein they utilize hearing, seeing, and interacting as ways of knowing a loved one's end-of-life preferences and knowing that those preferences were honored. Our analysis revealed two phases in the process of formulating this knowledge. During the first phase, *the patient is sick*, the next of kin focused on the acute illness that necessitated their loved one's hospital admission. Because many next of kin believed their loved one was not seriously ill and would recover, knowledge of the patient's end-of-life preferences was not then their primary concern. Even though a majority of the next of kin said their loved one had an advance directive, very few made mention of the patient's stated preferences when they described the early days of the patient's hospitalization. It was during the second phase, *the patient is dying*, that their knowledge of a loved one's end-of-life preferences became salient to make treatment decisions.

Discussions with physicians regarding a loved one's impending death appeared to play an important role in the transition from the *patient is sick* phase to the *patient is dying* phase. When clinicians raised topics of treatment options and hospice placement, knowledge of a loved one's preferences began to have operative relevance to the next of kin. During this phase, the next of kin articulated recollections of prior conversations when the patient either implicitly or explicitly conveyed her or his end-of-life preferences. Our findings suggest that end-of-life discussions with a clinician were key for the next of kin to transition from the *patient is sick* to the *patient is dying*.

Three ways of knowing a loved one's end-of-life preferences emerged from our analysis: hearing, seeing, and interacting. *Hearing* ap-

peared to be the most prevalent way of knowing, with 81 percent of the next of kin reporting conversations with their loved one about end-of-life preferences. The importance of hearing as a way of knowing about a loved one's preferences was supported by the fact that even when a patient was cognitively impaired, the next of kin indicated they had acquired knowledge of their loved one's preferences during prior conversations. The value of casual or informal conversations about end-of-life preferences is twofold. First, end-of-life conversations impart knowledge of a loved one's preferences. Second, this acquired knowledge was used in a practical way by the next of kin during the difficult process of making decisions at the end of life.

Our analysis further revealed that hearing conversations between the patient and a physician was a way to learn about a loved one's preferences. Obtaining knowledge in this way highlights the significance of end-of-life discussions, even when surrogates were merely observers. Conversations between the next of kin and clinicians were also instrumental for acquiring knowledge, particularly when the next of kin perceived a physician to be "explaining" end-of-life processes. Conversely, our findings indicate that perceptions of poor communication as the patient approached death compromised the next of kin's understanding of end-of-life options.

*Seeing* as a way of knowing had relevance for affirming that a loved one's wishes were honored. Observing the delivery of medical and nonmedical comfort care provided evidence for the next of kin that their loved one's wishes were being honored. This is important because honoring a loved one's wishes diminishes the stress associated with end-of-life decision making, and so has the potential to reduce the negative impact of making difficult end-of-life decisions on behalf of a loved one.<sup>27</sup>

*Social interaction* at the end of life informed the next of kin in various ways. For the next of kin who did not have a long history with the patient, interactions with clinicians were an important way to learn about their loved one's preferences. Typically, next of kin who had been in

a long-term relationship with the patient had multiple opportunities to hear the patient discuss end-of-life preferences during visits with a physician or with clinical staff during a hospitalization; but the interactions between clinicians and next of kin who had a limited history with a patient appeared to be uniquely valuable for the next of kin to acquire knowledge about their loved one's end-of-life preferences.

In cases of family strife, interactions with clinicians helped inform the next of kin and other family members of the patient's options. Furthermore, interactions with clinicians afforded the next of kin who had complicated family circumstances the opportunity to know that their loved one's wishes were honored. We found that even negatively perceived interactions with clinicians served as a way to learn about a loved one's preferences and as a way to know whether those preferences were honored, which underscores the significance of social interaction as a way to acquire knowledge.

The formation of knowledge in surrogates at the patient's end of life is not well understood. Employing an epistemological approach, our data described how surrogates in our study came to know their loved one's end-of-life preferences and know whether those preferences were honored. These results extend the literature on ways of knowing. A post-analysis review of the literature indicated similar findings among educational studies. Researchers examining learning strategies found university students and individuals living in communities utilized "speaking," "looking," "hearing," and "seeing" as ways of knowing.<sup>28</sup> Results from these earlier studies provide support for our findings that independently emerged from qualitative analysis.

## CONCLUSION

Our study explored how patients' next of kin came to know their loved one's preferences regarding end-of-life treatment and how the next of kin affirmed the honoring of those preferences. As our findings reveal, learning is not a linear process. The next of kin in our study uti-

lized multiple ways of knowing. A broader understanding of how the next of kin come to know about the patient's end-of-life preferences may provide new ways for physicians to initiate conversations about end-of-life care.

Contextualizing the acquisition of knowledge by surrogates as a process can inform the broader discourse on end-of-life decision making. Even though clinicians may determine that a patient's prognosis at the time of hospitalization is dire, it is important to recognize that the patient's next of kin may not have an expectation of death during the early days of a hospitalization. The next of kin may have prior knowledge of a loved one's preferences; however, it is communication at the end of life that may serve as a pivotal juncture in the process of acquiring knowledge for the next of kin. A more informed understanding of how family members acquire and process knowledge may prove helpful to clinicians as they confront difficult encounters around making decisions at the end of a patient's life.

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