



## Surrogate Decision-Making

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# Surrogate Decision-Making: Judgment Standard Preferences of Older Adults

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**ABSTRACT.** This qualitative study examines the judgment standard preferences of older adults related to surrogate decision-making for medical treatment. Thirty community dwelling adults over the age of 60 were presented with scenarios that depicted three decision-making standards, two of which are the predominant legal standards (substituted judgment and best interests), and a proposed third standard that allows the surrogate to consider the interests of the family in the decision-making process (best judgment). Half of the sample preferred substituted judgment,

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five preferred best interests, and ten chose best judgment. Selected cases are presented that demonstrate the themes associated with each judgment standard preference. [Article copies available for a fee from The Haworth Document Delivery Service: 1-800-HAWORTH. E-mail address: <docdelivery@haworthpress.com> Website: <<http://www.HaworthPress.com>> © 2003 by The Haworth Press, Inc. All rights reserved.]

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Autonomy and self-determination are core values of Western medicine and social work (Buchanan & Brock, 1989; Kuczewski, 1999). Conscious, competent adults have the right to make autonomous decisions about their medical care, and when patients are too ill to speak for themselves, this autonomy is often extended through the use of surrogate decision-makers (High, 1988). Frequently, patients' families are called upon to make medical decisions on behalf of incapacitated members. When deciding on behalf of a loved one, surrogates are expected to utilize judgment standards that are free from emotional and personal bias. Is this a reasonable expectation? What are potential patients' perspectives on these judgment standards? The purpose of this qualitative study was to explore and attempt to explain judgment standard preferences of a diverse sample of community dwelling older adults.

The two predominant legal standards that are employed by surrogates when making medical treatment decisions for incapacitated patients are the substituted judgment and best interests standards (Buchanan & Brock, 1989; Rhoden, 1988). Of the two, the most commonly used standard is substituted judgment. This standard mandates that medical decisions be made as that patient would have made them for herself if she were competent (Buchanan & Brock, 1989; Kuczewski, 1999; Rhoden, 1988). If the surrogate has no knowledge of the patient's medical treatment preferences, the decision is to be made using the best interests standard. This second standard weighs the burdens of the patient's life in the current state against the benefits of continuing life in that state (Arras, 1988; Buchanan & Brock, 1989; Rhoden, 1988). In order to terminate treatment under the dictates of this standard, the burdens of artificially prolonging a life must clearly and significantly outweigh its benefits (Rhoden, 1988). Both of these standards have been criticized in the literature.

In situations where there are no explicit treatment directives (a probable majority of surrogate decision-making cases), surrogates may be called upon to infer the patient's treatment predilections from their intimate and often longstanding knowledge of the patient's character and values. This process entails a certain amount of imagination and deduction on the part of the surrogate while requiring the surrogate to be objective, uninfluenced by personal emotions and biases. In his analysis of state statutes that address surrogate decision-making, Sabatino (1999) suggests that the "paradigm" for surrogate decision-making as mandated by the substituted judgment standard "is largely fiction" (p. 55). In the real world of proxy decision-making, surrogates must construe and deduce another's treatment preferences from the "complex, multi-leveled, shifting text of that person's life" (Collopy, 1999, p. 40). While the decisions that are promulgated from a substituted judgment process are not inherently flawed, they rarely meet the clear and convincing evidentiary standard required by many courts and adopted by some state legislatures (Kuczewski, 1999; Rhoden, 1988). When there is very little or no evidence from which surrogates can make such assumptions about patient preferences regarding life-sustaining medical treatment, surrogates use the best interests standard (Buchanan & Brock, 1989).

The best interests standard calls for an objective judgment as to what is in the patient's best interests. To use this standard, surrogates must focus on current and, to a lesser degree, future interests of the incapacitated patient (Buchanan & Brock, 1989). By considering only present and future interests of the incapacitated patient, the best interests standard divorces the individual from her history, values, and relationships and focuses solely on the current physiological aspects of life (Rhoden, 1988). Application of this criterion inherently involves quality of life judgments, which are inextricably related to values, preferences, and desires (Buchanan & Brock, 1989; Rhoden, 1988). Due to the complexity of the issues involved, making conclusions as to the quality of one's life entails subjective levels of extrapolation.

It can also be argued that the distinction between the best interests and substituted judgment standards is not as clear as the courts would lead one to believe (Rhoden, 1988). Use of the substituted judgment standard calls for a consideration of the patient's character, past preferences, and history in order to make a decision that is consonant with what the patient would have decided herself; the best interests standard asks the surrogate to consider only the patient's current state in order to arrive at a decision that best serves the patient's current interests. How can one make a decision that promotes a patient's current interests with-

out considering a patient's past? It can be argued that making judgments about a patient's interests would involve some consideration of the patient's prior preferences (Rhoden, 1988). Similarly, how can a responsible surrogate base a decision on prior preferences of the patient without considering the patient's current interests? Indeed, the line between the two legal standards is blurred. Add the familial context in which end-of-life decisions are made, and the decision-making situation becomes even more complicated.

The surrogate decision-making process is dynamic and cannot be divorced from the influence of the surrogate's own interests, including the interests of the family to which the patient and surrogate belong. Not recognizing this fact distorts the true nature of surrogate decision-making and ignores the importance of the family in this process. Families have the presumptive authority to make decisions on behalf of ill members, and this authority is based in legal and moral principles (Buchanan & Brock, 1989). Legally, patients can formally appoint family members to make decisions on their behalf through the execution of a Durable Power of Attorney for Health Care (DPAHC). In addition, 28 states have enacted legislation that allows family members, often in a stated order of priority, to make medical decisions for a decisionally incapacitated member in the absence of a DPAHC (Partnership for Caring, personal communication, November 1, 2001). There are also ethical arguments indicating that the family has the moral authority to act as a surrogate. These include the family's familiarity with the patient, their care and concern for fellow family members, their motivation to ensure members' well being, and the fact that families are deeply affected by decisions made on behalf of incapacitated members (Brock, 1996; Buchanan & Brock, 1989; Hardwig, 1990; Jecker, 1990; Nelson, 1992; Nelson & Nelson, 1995; Rhoden, 1988).

Some negative perceptions of family members in the context of the medical system appears to be pervasive, yet there is little empirical evidence to support those views. There is fear that family members acting as surrogates will honor their own self-interests at the expense of the patient's well being and will make treatment decisions that are either discordant with patient preferences or that ignore the patient's best interests (Collopy, 1999; Levine & Zuckerman, 2000; Rothchild, 1994). For example, in his article about family dynamics in end-of-life treatment decisions, Rothchild (1994) indicates, "[D]ecision-making is a heavy responsibility for the family . . . Conflicts of interest may arise because of an inheritance or the stress of caring for an elderly patient. Family members may make decisions based on their own best interests rather than the patient's" (p. 252). These suspicions around the family's motivation

can influence the relationship that the family has with the health care provider. Collopy (1999) indicates that health care professionals may view the surrogate as “an interloper whose improper, misguided, or self-interested decisions will work against the patient’s best interests” (p. 37). Certainly there are families that can be described in this manner, but representing all families in such a negative way does not do justice to those who are able to make appropriate decisions for their incapacitated loved ones. Families may be far from perfect surrogate decision-makers, but based upon practical and moral considerations, they appear to be the best available alternative in most situations (Nelson & Nelson, 1995).

Given the aforementioned problems with the current decision-making standards and the growing awareness of the family’s role in the medical decision-making process, alternative decision-making standards need to be explored. If families do have the presumptive authority to make medical decisions for decisionally incapacitated members and the current standards as reflected in court rulings are unattainable, an alternative decision-making standard could incorporate tenets of both substituted judgment and best interests while acknowledging the family’s integral role in the decision-making process. It can be argued that many surrogates attempt to do their best to make decisions in accord with the patient’s previously stated wishes while simultaneously considering the patient’s current interests and the family’s needs. This conceptualization is a melding of the two judgment standards in which the family’s roles and interests in such a decisional process are explicitly acknowledged. For purposes of this research, this criterion can be thought of as the “best judgment” standard. It is the authors’ attempt to formulate a practical alternative to the current predominant legal standards which allows surrogates to consider the interest of the patient in the context of the family’s broader needs and interests.

Although the literature argues that consideration of the needs of the patient’s family has a place in the decision-making process (e.g., Hardwig, 1990; Nelson & Nelson, 1995), preferences for this type of judgment standard have not been measured. Which of the judgment standards discussed in this paper, substituted judgment, best interests, and best judgment, do older adults prefer their surrogate decision-makers employ? It is the purpose of this research to explore judgment standard preferences among a diverse sample of 30 community dwelling adults age 60 and above. Results from semi-structured qualitative interviews will be presented to help explain these preferences.

## METHOD

### Sample

Thirty community dwelling adults age 60 and over participated in semi-structured qualitative interviews in their homes. Participants were recruited via flyers placed in congregate senior housing, social worker referrals, presentations at churches and congregate meal sites, and direct requests from the researcher for an interview. Attempts were made to recruit an ethnically and religiously diverse sample, because those two variables have been demonstrated to be related to attitudes regarding end-of-life decision-making (Eleazer et al., 1996; Fung, 1994; Moore & Sherman, 1999). During the first phase of the data collection (22 interviews), all persons who expressed interest in the research and consented to be interviewed were included in the data collection process. The demographic breakdown of these 22 interviewees showed little ethnic and religious diversity (participants were predominantly White and Catholic). Therefore, theoretical sampling was employed and recruitment was focused on members of minority groups and older persons affiliated with Protestant church denominations in order to capture a wider range of end-of-life attitudes. Subsequently, data from seven Black and one White Protestant persons were collected. Initially, participants were given \$10 for the interview. As data collection progressed and members of minority groups were targeted for interviews, potential participants were offered \$20 to increase the likelihood that minority participants would be willing to participate.

Nineteen participants were women and eleven were men. Thirteen were between the ages of 60 and 69, eight were between the ages of 70 and 78, eight between the ages of 80 and 85, and one participant was 91 years old. For the entire sample, the mean age was 72.53 ( $SD = 8.61$ ). Twenty-two participants were White, seven were Black, and one was Native American. All of the participants had a household income of less than \$29,999 per year, except one participant whose income was between \$40,000 and \$49,999. One participant had less than an eighth grade education, four had some high school, thirteen were high school graduates, eight had some college, two were college graduates, and two held a graduate degree. Ten participants were Catholic, four were Jewish, thirteen were affiliated with various Protestant denominations, and three participants indicated that they were atheists.

Five participants were married, seven were divorced, nine were widowed, four were never married, four were separated, and one participant



was estranged from his common-law wife. Twenty-four of the interviewees had living children and six never had children. Five described their health as excellent, thirteen said that their health was good, nine indicated their health was fair, two reported that their health was poor, and one participant described his health as very poor.

The majority of the sample, nineteen participants, had completed an advance directive (AD) of some type, whereas ten participants had not, and one interviewee was unsure as to whether or not he had executed an AD. This completion rate of AD is higher than is reported in the literature and could be due to the self-selected nature of the sample.

### *Interview Schedule*

The interview schedule consisted primarily of open-ended questions addressing participants' preferences regarding the surrogate decision-making processes. The interview included questions pertaining to the participants' personal experiences with surrogate decision-making, factors important in the surrogates' decision-making process, and preferred judgment standard to be used by their surrogates when arriving at a decision relative to life support. Interviews were audio taped and lasted between one and two hours. In order to assess judgment standard preferences, participants were read the text below:

Now I would like to describe to you three different ways that a person can arrive at a decision about someone else's medical care and then ask you which of the three you would want the person deciding for you to use. The first way of deciding is when the person who has to make the medical treatment decision tries as best as he or she can to make that decision in the exact same way that the sick person would if the sick person were able. The person deciding is supposed to put his or her own feelings and biases aside and make the decision as much like the sick person would as possible. For example, Mrs. Smith has been very ill and is now in a coma. There is little chance that Mrs. Smith will recover from the coma. Let's say that her doctor asks Mrs. Smith's daughter to make the decisions about her mother's medical treatment since Mrs. Smith can't speak for herself. Using the first way of deciding, the daughter would recall what her mother had told her about the mother's medical treatment wishes. Regardless of the daughter's feelings about the treatment wishes, this way of deciding requires that the daughter decide about her mother's care based upon what her mother had



told her when her mother was able to talk. The daughter is supposed to make the decision just like she believes her mother would.

The second way of deciding is to make the decision for the sick person based on what is seen as best for that sick person at the present time. Again using Mrs. Smith as an example, her daughter would make the decision about medical treatment by looking at the situation and asking herself questions such as: Is my mother currently in pain? Would the treatment cause her pain or help her feel better? Would giving her a certain treatment increase the chance that she may survive? What are the advantages to the treatment? What are the disadvantages? The daughter is supposed to make the decision based upon what is best for the mother right now in that situation, not relying on past information about her mother's treatment wishes.

The third way of deciding combines the first two ways and also allows the daughter to consider Mrs. Smith's family in the decision. Using this third way of deciding, the daughter would consider what her mother's treatment wishes were and would also think about what is best for her mother in the current situation. In addition, the daughter may consider how the decision would affect Mrs. Smith's family. Does the family feel that it is best for the doctor to give Mrs. Smith the suggested treatment? How does the daughter feel about making this decision for her mother? Using this way of deciding, the daughter uses her judgment to make the decision given her mother's wishes, her mother's current medical state, and the family's needs and feelings.

Once these scenarios were read, the participant was given a visual that briefly summarized the three standards.

### ***Data Analysis***

The data were analyzed using template analysis (Crabtree & Miller, 1992), which involves the creation of a set of a priori coding categories based upon the main research questions. The coding categories are then used to categorize the data into meaningful groupings for the purpose of data management (Crabtree & Miller, 1992; Miles & Huberman, 1994). In this research, interview transcripts were analyzed and the first-level coding categories were used to organize the qualitative data. Next, the

quotations associated with the first-level coding categories were further analyzed for themes (i.e., second-level interpretive analysis). Finally, selected themes were examined via matrix analysis (i.e., row by column visual display) in an attempt to develop a theory to explain judgment standard preferences (Miles & Huberman, 1996).

In order to establish the trustworthiness of the first level coding process, an independent peer reader was utilized to confirm the reliability and validity of the first-level coding scheme as well as the resulting interpretations. Member checking was also employed to demonstrate the accuracy of the first-level and interpretive (second-level) coding processes. Five participants representing the three judgment standard preference groups were chosen to be part of the member checking process. These participants were given opportunities via telephone to comment on the summaries of their own interviews and the summary of thematic interpretations across interviews. One participant had a minor correction for her own summary. All participants indicated that the theoretical generalizations made about the judgment standard preference they chose made sense and were appropriate.

## ***RESULTS AND DISCUSSION***

Results from the thematic analysis indicated that those participants who chose the substituted judgment standard were most concerned with maintaining their independence and autonomy and avoiding prolonged life support. Fifteen participants (8 men and 7 women) chose this judgment standard. Eleven of the fifteen had completed an advanced directive and only one of the fifteen had been involved in surrogate decision-making for a family member. Five participants (1 man and 4 women) chose the best interests standard and were most concerned with medical realities and the medical soundness of their surrogates' decision-making process. They trusted their surrogates to make medical decisions that minimized costs and maximized benefits to the older person. Three of the five participants who chose the best interests standard had completed an advance directive, and one had been directly involved in surrogate decision-making for an ill family member. Finally, the ten participants (2 men and 8 women) who chose the best judgment standard were concerned with quality and quantity of life and avoidance of family burden. Five of ten had an advance directive and a majority (6 of 10) had been involved in surrogate decision-making for an ill family member. Table 1 summarizes the broad themes associated with prefer-

TABLE 1. Themes Associated with Judgement Standard Preferences

Standard Choice	Involvement in Surrogate Decision-Making for an Ill Family Member	Factors Important in Decision-Making Process	Reason for Choosing Standard
Substituted Judgment (n = 15; 8 men and 7 women)	One participant had been involved in surrogate decision making for an ill family member	Important that surrogate considers the older person's ability to maintain independence and the older person's aversion to being on life support	Substituted judgment standard chosen because of older person's desire to have medical treatment wishes followed; avoidance of life support important; autonomy in current and future medical decision-making valued independence a recurrent theme
Best Interests (n = 5; 1 man and 4 women)	One participant had been involved in surrogate decision-making for an ill family member	Important that the surrogate consider the medical soundness of various options during the decision-making process	Best interests standard chosen because it is most important that the surrogate consider the medical realities of the older person's condition; decisions made by surrogates should be medically sound; family trusted to make a medical decision that minimizes costs and maximizes the benefits to the older person
Best Judgment (n = 10; 2 men and 8 women)	Six participants had been involved in surrogate decision-making for an ill family member	Important that the surrogate consider the quality and quantity of the older person's life and the avoidance of family burden	Best judgment standard chosen due to its inclusiveness; consideration of family's interests in decision-making process important; holistic factors such as quality and quantity of life important; participants explicitly acknowledged the complexity of surrogate decision-making

ences for the three judgment standards. Identified factors that were important in the decision-making process and the reasons given by participants for choosing the standards thematically differentiated the three groups. The following paragraphs further elucidate these themes and provide quotes from specific cases to demonstrate the concepts.

Mr. B., a 60-year-old Italian-American who is twice divorced, chose the substituted judgment standard. His choice for decision-making surrogate was his adopted son. He indicated, "I would ask him to speak for me. But I would also leave a DNR, you know. I just don't want to go through the agony of having my life prolonged with artificial means.

And I'm not that certain that there are many people around today who would think anything opposite of that." Mr. B. expressed a strong aversion throughout the interview to having his life sustained through the use of medical technology.

When asked what he would want his son to consider if his son had to make medical decisions on his behalf, he said, "... that he would just use common sense, not to keep me alive on artificial means." These considerations were directly related to the reasoning he offered for choosing the substituted judgment standard. "I would go with number 1 [substituted judgment standard]. I just can't envision myself changing my way of thinking. It serves no purpose really to be kept alive. What's the gamble? You're not going to gain anything by it." At this point in time, Mr. B. appears to have made a firm decision regarding no life support at the end of his life. Choosing the substituted judgment standard provides Mr. B. extended autonomy, even in the face of decisional incapacity (Buchanan & Brock, 1989; High, 1988; Rhoden, 1988). Mr. B. had not formally indicated his wishes through an advance directive, although he did mention that he thought such documents were a good idea.

Mrs. D., an 80-year-old White divorced woman who lives alone in congregate senior housing, also chose the substituted judgment standard. Well into her seventies, Mrs. D. completed her bachelor's degree and places considerable importance on her activities outside of the home. Like Mr. B., she expressed a strong aversion to being kept alive on machines. Discussing this issue, she remarked, "Well, I'm going to have to die someday. I'd rather do it in a hurry than to prolong it . . . I don't think any of us care that much about being in pain. And I also would not want to be incompetent and hang around useless for any length of time. Let me go." To Mrs. D., life support is equated with suffering and a lack of autonomy, two states that she wants to avoid at the end of her life. She has completed a living will that reflects her end-of-life treatment wishes and she is confident that her proxy (youngest daughter) would honor her wishes.

When asked what factors were important for her daughter to consider if she ever did have to make such decisions on her mother's behalf, Mrs. D. said, "My comfort and the rapidity with which we could get through this mess. Don't try to keep me alive, I'm ready to go." Again, aversion to life support and the desire to have her preferences respected is a strong theme for Mrs. D. This is echoed in the reasoning that she gave for choosing the substituted judgment standard, "... like I said, when my job is done and it is time for me to go home, I want to go. I don't

want to hang around . . . since I am going to be the one to make the decisions [in advance], that is what I think I have decided.”

As these cases demonstrate, those who chose the substituted judgment standard thoroughly embraced the notions of independence and autonomy in medical decision-making and felt strongly about avoiding artificial means for prolonging their lives. Seemingly, they chose the substituted judgment standard because of their desires to have these wishes honored regarding no life support. Next, the themes associated with a preference for the best interests standard and one representative case are presented.

Mrs. O., a married 81-year-old Jewish woman, chose the best interests standard and indicated that she would want her husband and her only child (a son) to speak on her behalf if she were too ill to make decisions for herself. Mrs. O does not want her life prolonged via medical technology if there is no chance for recovery, “If I were terminally ill and was suffering, do not do anything to prolong life.” This desire not to have life prolonged if recovery is not possible is balanced with the desire for her surrogates to consider the medical realities of the situation. When asked why she chose the best interests standard, Mrs. O. indicated, “I say that because if I were unable to speak for myself, they [husband and son] would know better what my condition was. My son is completely thorough. If he does not know about a subject, he’ll read. . . . They’d know better at that moment, circumstances at that moment.” Later in the interview, she went on to say, “His [son’s] approach is such that if there was the slightest chance of some recovery . . . he would take that chance. I suppose . . . that if I got worse and worse, his decision might change. When I answer these questions, I take into consideration the character and the makeup of my husband and son. My trust is so complete in either one, or both.” This theme of complete trust in the judgment of one’s appointed surrogate was a theme that reverberated through the interviews of those who chose the best interest standard.

Mrs. O. expressed considerable confidence that her decision-making surrogates would make the correct decision for her, a decision that would reflect the medical realities of her condition balanced against the probable outcomes of such a decision. From her comments it appears that she does not think that her family’s needs, if they were to be considered in such a decision, would ever conflict with her own needs. Her trust and confidence in her husband and son regarding medical decision-making is not a trust based solely on the family’s closeness or her perceptions of their care for her. She has spoken in depth with both of them about her wishes and has executed both a living will and a health

care proxy. In describing this process she said, "My son sat down with me and the two of us sat down with my husband and went over it. They give you a questionnaire, we went over each of the questions and were in agreement that this is the way it should be. . . . Only by letting them know ahead of time they should feel no guilt . . . you take it out of their hands."

For those five participants who chose the best interests standard, including Mrs. O., the most important factor to be considered in decisions made on their behalf is the medical soundness of that decision. These participants want their surrogates to weigh the advantages and disadvantages of any proposed treatment in the context of the medical realities of their physical condition. They implicitly trust the family to make a decision that is in the older person's best interests. The participants impart to their surrogates the decisional latitude to make a decision that is based on medical realities, and not all of them wanted their surrogates and families to make decisions that take into account the needs of the family as a whole. This is contrasted with the 10 participants who chose the best judgment standard, all of whom felt it was appropriate for their family's needs to be considered in the decision-making process. This is the component of the best judgment standard that sets it apart from the other ways of deciding.

The best judgment standard is a melding of the substituted judgment and best interest standards that also allows for the surrogate to consider the needs of the family in the decision-making process. Although participants in this study were not asked to define family need, some spontaneously offered examples. For the most part, these conceptualizations of family need offered by the participants were related to emotional needs of the family, most around the potential emotional costs associated with having a family member linger on life support. Additional family needs mentioned included financial demands and overall family burden. As compared with the substituted judgment standard which underscores the ethical values of self-determination and autonomy and the best interests standard which emphasizes patient welfare (Buchanan & Brock, 1989; Rhoden, 1988), the best judgment standard attempts to balance these aforementioned ethical tenets against the value of distributive justice whereby it is acknowledged that others have interests and rights in the decision-making process (Hardwig, 1990; Nelson, 1992; Nelson & Nelson, 1996). Of the 10 participants who chose the best judgment standard, six had been involved in surrogate decision-making for an ill family member and many of them related that experience to their belief that the family's needs should be represented in the medical

decision-making process related to end-of-life care. In addition, women were over-represented among those who chose the best judgment standard. Many of those who chose the best judgment standard acknowledged how difficult such a decision-making process can be on the chosen surrogate and the extended family. They discussed how complex such a decision-making process actually is, particularly when there is no advance directive or previous discussions about the loved one's treatment wishes.

For the most part, participants chose the best judgment standard because of its inclusiveness: the standard takes into account previous treatment wishes, the costs and benefits of the treatment, and the needs and wishes of the family. In addition, these participants described more holistic factors that they deemed important in the surrogate decision-making process than did the other two judgment standard groups. Even though one of the other judgment standards, best interests, requires one's surrogate to make quality of life judgments on behalf of the patient, those who chose the best interests standard in this study did not explicitly discuss such factors as important in their surrogates' decision-making process. On the other hand, those who chose the best judgment standard felt that it was important for their surrogates to consider the quality and quantity of the patient's life and the avoidance of family burden. These considerations are broader and more open to interpretation than the factors that the other groups indicated were important for surrogate consideration: aversion to life support, maintenance of independence, and medical soundness of the decision. For these participants, the far-reaching nature of the factors that are important in the decision-making process seems to be related to the preference for an inclusive standard that allows surrogates the freedom to make decisions that consider such factors.

These findings have numerous social work implications. Of particular interest are the implications associated with the implementation of the best judgment standard. Given that families are collections of individuals, albeit individuals whose lives are intertwined, multiple perspectives regarding the definition of family interest may be represented. Thus "family interest" may be differentially defined depending upon whose perspective is assessed. Given this possibility, it is important that social workers facilitate communication among all of the involved family members so that individual members' voices can be heard and multiple perspectives can be shared. Social workers can utilize their mediation skills to help family members better understand one another's perspectives and to hopefully assist the family in developing a consensus regarding decisions made on behalf of a loved one. Ideally, open communication around advance



care planning, goals, and values should be an ongoing process among family members prior to the crisis of a loved one's inability to make important medical decisions. Social workers are uniquely suited to facilitate this communication given their education, training, practice arenas. With ongoing communication between the patient and family, both the family's and patient's interests can be better elucidated and defined. Patients belong to families, and families belong to patients. The patient's interests help define the family's interests, and vice versa. Regardless of the preferred judgment standard, family members and patients need to communicate openly, and social workers can facilitate this process.

Social workers are trained to "begin where the client is." This research indicates that an understanding of persons' lived experiences related to end-of-life decision-making is important in understanding their current preferences. Social workers have the skills and knowledge base necessary to help patients and families grapple with the complex medical, emotional, ethical, moral, and spiritual issues that arise in the surrogate decision-making process. In addition, social workers can assist health care professionals to understand and appropriately respond to patient and family feelings and needs in a sensitive manner as a member of a treatment team (Pilssecker, 1979). The social worker can collaborate and consult with the various parties involved in the decision-making process, facilitating communication and working to facilitate patient self-determination. Indeed, the profession of social work can be the catalyst that unites the ethics of medicine and the morality of the family.

Implications for further research are also suggested by this study. Specifically, research should be conducted to address how surrogates make decisions for decisionally incapacitated family members in actual decision-making situations. In order to make positive changes for patients and families, a thorough understanding of the current factors involved in the surrogate decision-making process is needed not only from the perspective of older adults themselves, but from the perspective of the family members charged with making such decisions. As the population continues to age, research addressing end-of-life decision-making from multidimensional perspectives becomes increasingly important, particularly given the influence of lived experience on end-of-life decision making. It is important to fully study, with diverse samples, such questions and dilemmas that arise during the last moments of life so that critical decisions can be based on knowledge and understanding rather than ignorance and fear.

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