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Patients' Interests in their Family Members' Well-Being: An Overlooked, Fundamental Consideration within Substituted Judgments

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INTRODUCTION

Patients' expectations for decision making by their health surrogates are often discordant with commonly accepted standards for substituted judgments, and actual decisions by surrogates are similarly discordant. This descriptive-normative divide stems, in part, from a narrow view of the personhood of patients that is predominant in medicine and also in biomedical ethics. This limited view of patients leads to an incomplete mapping of their important concerns, particularly concerns based on patients' social sense of self. One particular concern that is typically overlooked within substituted judgments is patients' interests in how treatment choices affect the well-being of their family members. Academic discourse tends to portray the interests of patients and their intimates as distinct and competitive; for example: *Should patients choose without regard to the consequent burdens on their family? What family interests, if any, ought to limit a patient's decisions?*

In fact, these interests are often indistinct, mutual, and reciprocal. The effect of a patient's decision on the family is not only a concern of the family. Often, it is a serious, if not critically important, interest of the patient. An examination of patients' interests in family well-being may illuminate and perhaps narrow the rift between normative and descriptive aspects of substituted judgment. For this discussion, the term "surrogate" may include other intimates whose welfare the patient includes among his or her personal interests and who are substantively affected by treatment decisions.

BACKGROUND

Capacitated patients make choices about healthcare by integrating a host of values and interests, such as emotional and financial concerns, spiritual needs and religious obligations, and concern for family. Patients often involve family members in these deliberations, and when patients have lost decision-making capacity, family members must extrapolate or construct a decision for the patient while they wrestle with their own interests. Although surrogacy is imperfect, it serves a vital role in clinical care.

Dan Brock offers the following justification for surrogacy: (1) surrogacy has been endorsed by our democratic political process; (2) it promotes self-determination of the incapacitated person; (3) family members will perform best in this role; (4) family members will be most affected by decisions, the patient accepted; (5) justice requires consideration of the effects on family; and (6) the family is a moral unit with responsibility for its members.¹ Half of these involve family interests.

Of the widely accepted standards for decision making, namely, known wishes, substituted judgments, and best interests, the substituted-judgment standard is perhaps the most widely employed in decision making for incapacitated patients.² Standards for substituted judgments require that decisions reference patients' important values, beliefs, and specific preferences for care.³ Under the standard, surrogates should strive to make decisions that patients would most likely have made.⁴

Despite the broad application of the substituted-judgment standard, a number of unresolved issues exist.⁵ I will discuss two issues in particular that are closely related to one another. First, surrogates often fail to replicate and fail to strive to replicate the patient's decision. Second, results of studies examining attitudes and preferences of patients and surrogates seem to challenge the normative assumptions on which the standard is based.

First, the literature clearly documents that surrogates fail to accurately represent patients' wishes in one-third to nearly one-half of decisions.⁶ Although surrogates tend to choose overtreatment, some studies also find undertreatment relative to patients' preferences.⁷ Other studies find that some surrogate decisions more closely reflect surrogates' preferences for their own treatment, than they do the preferences of the patient.⁸ Therefore, some surrogates use decision-making processes other than the identifying patients' choices. These surrogates engage in an ethically disconcerting abrogation of the substituted-judgment standard and patients' autonomy. Do surrogates simply ignore the substituted-judgment standard, or attempt, but fail to achieve, this perhaps too-rigorous a standard? Clinicians, by and large, appear to overlook these lapses.

It is interesting that patients also appear, for the most part, unalarmed by the flaws of their surrogates. This leads to the second concern regarding disparities between empiric studies, which are concerned with the sociological and cultural dimensions of substituted judgments, and the preconceptions underlying the standard. These studies suggest that patients may care less about decisional accuracy and may be more concerned with issues of trust in, and fidelity by, their surrogates.⁹ For example, patients maintain their selection of health agent even when they are informed that their agent is not likely to replicate their treatment choices.¹⁰ One interesting study suggests that many patients do not expect or even want their surrogates to follow their explicit wishes.¹¹ Another study reports that patients are likely to modify their preferences to accommodate family concerns.¹² Therefore, the core element of the standard, striving to replicate patients' decisions, may not be essential for many patients.

What the standard requires of patients (identifying and communicating health preferences) and what it requires of surrogates (extrapolating a patient's decision) differs from what many patients and their surrogates expect of each other. Patients may not require that surrogates follow expressed wishes, and surrogates may not require that patients leave preferences for treatment. Thus, the standard often fails patients, and surrogates often fail to meet the standard.

This apparent normative-descriptive uncoupling stems in part from a sociologically impoverished, but widely held, view of the prototypical patient.¹³ This view is evidenced by many physicians who, while eliciting their patients' treatment preferences, limit their conversations to concerns of direct medical benefits and burdens, overlooking patients' broader socially based interests. Typical templates for living wills concretize this medical approach by linking treatment preferences largely to condition and prognosis.¹⁴ Patients' decisions are often thought of as more "authentic" if they narrowly focus on immediate self-interests, and are somehow thought to be "tainted" by considerations that are less atomistic. As Nancy Jecker notes, "our tendency is to discredit decisions to forgo treatment that are made on the basis of the . . . burden treatment places on family members."¹⁵ Therefore, abbreviated views of the personhood of patients in academic discussions and in clinical practice¹⁶ tend to limit the integration of patients' family-centered concerns in both the preferences identified and left by patients and the deliberations of surrogates.¹⁷ This occurs despite ample

evidence that patients are deeply concerned with the effects of their illness and treatment choices on their family members.¹⁸ Parenthetically, the literature is peppered with discussions of broader notions of "self," but these have not been widely integrated.¹⁹ These still-underacknowledged concerns of patients may well account for both the apparent inaccuracy in surrogates' decisions and patients' acceptance of this inaccuracy.

RELEVANCE OF PATIENTS' CONCERNS FOR THEIR FAMILY'S WELL-BEING

Paradigms of the personhood of patients in which the patients' interests and their families' interests are less discrete are certainly morally valid. Mappes and Zembaty contend, "if one wants to be the kind of person who performs actions that further the interests of other family members and perhaps even identified those interests as one's own, one acts autonomously. . . . When one identifies with the interests of others and acts accordingly, one is *also* acting in one's self-interest."²⁰

For many patients, particularly those of some minority cultures, distinguishing a patient's self-interests from a patient's family's interests may be artificial and unnecessary. To illustrate, one writer notes of his Pakistani culture, "you *are* your family and your family is you."²¹ Blackhall and colleagues found differences between Whites, African-Americans, Korean-Americans, and Mexican-Americans, with the Hispanic group most strongly considering the impact of illness on the family.²² In Buddhist thought, patients who forego life-sustaining treatments so the family does not suffer, emotionally or financially, perform a valued act of compassion.²³ Family-centered interests should be better recognized among the more commonly addressed interests that underlie substituted judgments.

Patients' interests in the well-being of their family ought to be a routinely explored content area in substituted judgments for the following reasons. (1) It is an important concern of patients. (2) Family members commonly sacrifice for each other in various aspects of life, including financial, emotional, and health-related ones, and this mutual sacrifice is generally sociologically and anthropologically functional. For example, parents often hold their children's welfare over their own, siblings donate and accept organs amongst themselves, and adult sons and daughters assume caretaking and financial responsibilities for aging parents. (3) It can promote greater cross-cultural sensitivity among clinicians of patients who, for cultural reasons, fundamentally define themselves in terms of family. (4) Surrogates' self-interests already influence substituted decisions, but this influence is unopposed by an assessment of surrogates' interests from the patient's perspective.²⁴

PATIENTS' INTERESTS IN FAMILY TO BOLSTER THE ETHICS OF THE SUBSTITUTED-JUDGMENT STANDARD

Studies of patient-surrogate pairs report nonconcordance by surrogates in a third or more of surrogate decisions.²⁵ Before concluding that the substituted-judgment standard is untenable, it is useful to examine research designs common to these studies. Typically, these studies compare the preferences of patients with the choices of surrogates. Each of these are elicited using the limited models that focus narrowly on the triad of condition-treatment-medical outcome. Therefore, preferences that are generated and then analyzed are oversimplified, inexpansive, and perhaps not terribly robust in authenticity. Could this account for a portion of the apparent discordance between the choices of patients and surrogates?

Regardless, decisional concordance, although it nearly monopolizes this area of research, should not be the only valid outcomes measure. The literature suggests other ethically relevant measures of appropriate surrogate behavior. One alternative outcomes measure is surrogate decisions that are acceptable to patients, based on patients' trust in their surrogates, rather than on the accuracy of the decision. Another alternative outcomes measure is surrogate decisions that are acceptable to patients because their primary concern is that their surrogates are comfortable with the decisions they make. Here, an overriding interest of the patient is their surrogate's well-being. Current norms for good surrogate decisions are most appropriate for patients who live largely in social vacuums. A more expansive view of decisions by and for patients is warranted. If,

according to the substituted-judgment standard, surrogates must strive to make the patient's decision, and many patients strongly consider the burden on family in their preferences, then the standard does support some surrogate decisions that attend to the well-being of surrogates. Perhaps good substituted judgments are better described as those that the patient would find highly acceptable for a range of reasons and concerns. Under this interpretation, I suspect the majority of "problematic" surrogate decisions are, in fact, appropriate.

A more robust interpretation of the substituted-judgment standard would require patients, as before, to communicate their health values and preferences. Patients would identify those whose well-being they consider to be a self-interest, and what approaches to surrogate decision making are acceptable and unacceptable. For example, a patient may want the surrogate to focus primarily or exclusively on achieving concordance with the patient's direct medical preferences. Alternatively, a patient's primary concern may be the surrogate's comfort with a decision. Some patients may prefer that the surrogate make decisions that best relieve the burden on the surrogate. Patients may include or exclude one or more of these considerations, and may choose to combine or to rank them.

A re-implemented standard would require surrogates to attend to these concerns and priorities of the patient. In doing so, surrogates may be more likely to confront their own nonpatient-centered agendas and biases and to discern the differences, if any, between their own interests and patients' concerns for their interests.

The major thrust here is to operationally expand the substituted-judgment standard to more explicitly allow for, if not embrace, a social dimension of patients that has been relatively neglected, despite its centrality in human life.

CONCERNS

An obvious related concern is the group of surrogates who exert their own interests while they are deciding for others. John Hardwig identifies several issues.²⁶ These include protecting patients from undue interests of surrogates, deciding whose interests among various family members should be considered, and that surrogates who act on their own interests unfairly treat incompetent patients who, if competent, would choose to ignore the interests of family members. These concerns are most troubling within a construct that views the interests of patients and surrogates as separate and competitive, but are less problematic within a patient-centered construct that can also account for surrogates' interests. In the latter model, the patient (contemporaneously or prospectively) determines whose interests and what interests are germane. Therefore, it promotes fair treatment of the patient, in that the patient's concerns for family would similarly affect the decisions that are made, whether the patient has or has not lost decision-making capacity. Furthermore, to completely neglect such an important interest of patients because of concern about possible inappropriate behavior by family distorts the likelihood of harm and conflicts with a basic assumption underlying all of health-related surrogacy (clinical care, clinical research, organ harvesting), namely, the trustworthiness of the family.

Still, numerous concerns exist. For one, patients may wish to identify their family-related interests and may wish to address whether and how these should be accounted for in health decisions. However, there are neither well-developed mechanisms with which patients can communicate and record these concerns, nor clear methods by which surrogates and health professionals can integrate these concerns into substituted decisions. Furthermore, problems similar to those with conventional directives—their limited influence on decisions—would be likely.

A great challenge for surrogates is to integrate patients' concerns for the well-being of family into decisions when patients are not likely to have left serviceable preferences in this regard, and neither physicians nor advance directive documents are likely to have stimulated such discussions. Surrogates will likely need to determine whether and how deeply the patient held a particular family-related interest (for example, relief of a spouse's emotional distress), and how the patient would have wanted this concern to affect decisions. Of

course, it is not known how surrogates might perform in the task of separating their own interests from the patient's concerns of the surrogates' interests.

Earlier, I noted that patients' identified preferences may be of limited authenticity when they have been elicited when broader interpersonal interests have been excluded. Concerns of authenticity must be raised when patients' preferences form a basis for apparent sacrifice by the patient for the benefit of the family. The authenticity of capacitated patients' stated interests in the well-being of the family may be obscured or diminished by controlling influences such as the patient's illness itself, dysfunctional family dynamics, or depression—which is highly prevalent and underdiagnosed in the setting of major disease. What protections should patients have?

The integration of patients' authentic family-related interests into decision making is made far more complex by the onset of decision-making incapacity. Family members become the best source of this information, but, in dysfunctional families, they are likely participants in the controlling relationship, or have wielded other undue influences over the patient. Reliance on family members to identify these interests may be further confounded by the considerable prevalence of psychiatric illness among caregivers of chronically and critically ill patients. These surrogates may unknowingly bias their decisions with concerns of their own well-being. Perhaps the added stress of serving as health surrogate could be attenuated through discussions in which the conflicting and harmonizing interests of surrogates are clarified.

Arguably, integrating patients' family-related concerns into substituted judgments introduces yet another order of ambiguity into these decisions, making many surrogate decisions more unsettling to clinicians. Can clinicians and surrogates construct useful information about incapacitated patients' family-related interests? Is this article pragmatically disconnected? The alternative of ignoring this interest of patients poorly serves them and their family members. Moreover, greater attention to patients' interests in family well-being can have valuable consequences. The first is the broadening of medicalized views of the personhood of patients. Second, since surrogates' interests inevitably affect surrogates' deliberations, to explicitly consider family well-being from the *patient's perspective*, however challenging, is likely to improve the status quo. Third, additional considerations are added for surrogate decisions to enter incapacitated patients into clinical research. Fourth, a research agenda in this area of patient care is stimulated.

RESEARCHAGENDA

There is much to be studied. First, we need clearer empiric evidence that a core consideration of patients is their interests in family well-being, and that patients want this consideration integrated by their surrogate decision makers.

Second, greater study is needed of interfacing interests within families as they pertain to health. In particular, this work must account for various ethno-culturally based requirements for self-effacement and self-advocacy within families. We need to better understand the authenticity of health choices in and across these systems. How are competing health-related interests negotiated within families, and how they are weighted and acted upon?

Third, conceptual and policy work is needed regarding what limits, if any, should apply to the type of interests considered, the magnitude of the patient's sacrifice or trade-off, and the degree to which these should direct treatment. There are also implications for social policy. For example, what are societal responsibilities to uninsured or underinsured families whose ill members choose a shorter and less expensive trajectory of serious illness to spare the family?

Fourth, we need validated measures to identify these concerns of patients, and methods to document their preferences and to guide surrogates. Although I have significant ambivalence about advance directives, perhaps modified directives could at least help stimulate an assessment of these issues. Domains for assessment could include whether family burden is relevant, the valence of sacrifice (that is, refusal of an otherwise desired treatment or acceptance of an otherwise undesired treatment), the type of sacrifice (such as physical or emotional), and the magnitude of the sacrifice (minor or major).

Fifth, does a reinterpreted substituted-judgment standard result in greater or less patients' satisfaction, families' ability to cope, and clinical confidence?

Other issues to examine are the degree to which patients consider family burden and the manner in which they integrate these concerns into decisions. Which patients are more or less likely to do so and why? How do patients respond to surrogates who plan to exert their own interests? How do clinicians currently address and respond to patients' family-related concerns? These are just some of the many questions to be asked.

CONCLUSION

The substituted-judgment standard is problematic in that surrogates often fail to achieve it, and patients often dismiss it. A shift in emphasis from the narrow accuracy of substituted judgments to the quality of these judgments may bridge this normative-descriptive chasm. This latter approach focuses on decisions that patients are most likely to find acceptable, based on an array of essential patients' concerns, including the well-being of people for whom they care deeply. Standards for decision making should better account for the diversity of patients' personal needs and requirements, the varied processes they use for health deliberations, and the multidimensional content of their decisions.

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