

# It's Not How Surrogates “Decide” that Matters: Appreciating the Role Surrogates Play

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On what basis should a surrogate contribute to decision-making regarding a patient's treatment? As Devnani et al. imply in the current issue of *JGIM* by referencing the work of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research from 1983, this question seems to have been settled for over 30 years: surrogates should rely on patients' preferences.<sup>1</sup> Only when such preference are unknown, Devnani and colleagues continue, should surrogates “act upon the ethical principle of beneficence by making decisions in order to maximize patient well-being.”<sup>1</sup> It is against this background that the authors set out to explore whether, in fact, surrogates actually follow this theoretically oriented set of rules. Given the preponderance of ethical discussion within both the medical and bioethics literature that relies on the seemingly a priori acceptance of this theoretical frame, turning attention to how real people in actual medical circumstances participate in decision-making for a loved one is of major importance, and for that reason alone, Devnani et al.'s contribution is worthwhile.

There is, however, something much deeper at stake—and more deeply troubling—that these authors fail to address.

Embedded within the primal question of what ought to serve as the basis for surrogates' contributions to decision-making is a more fundamental issue: what, exactly, is a surrogate's role? Surprising, this issue receives little attention in the medical or bioethics literature nowadays (there have been a few exceptions over the past 5 years; see, for example, recent studies by Lilley and colleagues and by Eves and Esplin).<sup>2,3</sup> The reason so little attention has been directed toward this issue may actually be extrapolated from the very title of Devnani and colleagues' article: “How Surrogates Decide: A Secondary Analysis of Decision-Making Principles Used by Surrogates of Hospitalized Older Adults.” Specifically, like most who write about or are engaged in studying surrogates—see, for example, several studies published in the first 6 months of 2017<sup>4–7</sup>—Devnani et al. start with the presumption that surrogates *decide*, i.e., that the role of the

surrogate is primarily that of a decision-maker. Indeed, throughout Devnani et al.'s article, as is similarly found in almost all literature concerning surrogates, one can find that now familiar term, “surrogate decision-maker.” But the question here is what, exactly, are surrogates supposed to be *deciding*? Or put somewhat more directly, is “surrogate decision-maker” the best way to describe what surrogates do and the reason for which physicians turn to surrogates in the first place?

In the most basic sense, good medical decision-making—“good” being taken in both the medical and ethical sense of the term—relies on clarity and accuracy regarding two fundamental elements: pathophysiological considerations and so-called personhood considerations, i.e., information regarding a patient's goals, values, and preferences.<sup>8</sup> This is what serves as the root of the idea that decision-making is a shared undertaking. But what, exactly, is it that a patient—or when a patient lacks the capacity to participate in decision-making, the patient's surrogate, i.e., the individual who will *speak on behalf of the patient*—is tasked with *deciding* such that, as the President's Commission concluded all those years ago, the individual may be properly respected and honored?

The short answer is that patients have the authority to accept or refuse what a physician, nurse practitioner, or other healthcare provider recommends; in other words, in typical circumstances, patients cannot be forced against their will to accept medical interventions. But the recommendation that is offered to a patient is to be grounded in both the provider's expertise regarding anatomy, physiology, pathology, etc., *and* the provider having an appropriate understanding of who that patient is as a person, typically articulated in terms of goals, values, and preferences. The patient, or the surrogate on the patient's behalf, thus helps the healthcare provider come to understand something valuable about the patient, and then accepts or rejects what the provider offers.

In the most simplistic way of stating it, and also as an ideal, physicians are responsible for winnowing down options (if there are various legitimate means for responding to a particular pathological state) to that which most closely conforms with the patient's sense of value and worth; in this set-up, the only “decision” that a patient or surrogate makes is whether to accept or reject the provider's recommendation. Of course, in the real world of everyday practice, it is uncommon to whittle all pathologically responsive potential options down to a single recommendation; two or three options may be, all things

pathologically and “personhood”-wise considered, equivalent. In such situations, a patient is offered the choice among options A, B, or C—and then decides on A or B or C over the other two. But that choosing, that decision, is itself to be framed by what matters most for the patient, since those medical options offered (and hence recommended as equally legitimate) are to have been selected by the physician in recognition of an understanding of the patient’s goals, values, and preferences.

The reason to be so explicit about all this is that the kind of inquiry that Devnani et al. undertook in their study of surrogates seems to blend together the acts of presenting (or representing) a patient’s goals, values, and preferences and the act of accepting or rejecting the physician’s recommendations. And they are not alone, as evidenced by the simple fact that throughout both the medical and bioethics literature for decades now, as well as in everyday clinical practice and as part of medical and nursing education, we uncritically accept and utilize the term “surrogate decision-maker” as a way of referencing the surrogate role. In doing so, however, we over-emphasize what may actually be the lesser of the two roles a surrogate has, namely to accept or reject. That this is lesser of the two is based on the fact that what the provider offers must take into consideration what the surrogate can present about who the patient is as a person, e.g., what kind of life the patient has been living, along with what may serve for the patient as the minimum acceptable outcome given the current medical situation, and how much burden of intervention the patient would be willing to undertake in order to attempt to achieve that outcome. In other words, the provider intimately depends upon the surrogate’s ability to speak on behalf of and to represent the patient in order to put together a potential plan of care.

And just here, then, the self-acknowledged limitation of Devnani et al.’s work demands greater attention. As they state toward the end of their discussion, “dividing our cohort of surrogates into patient *preferences* and *patient well-being* groups may be an artificial dichotomization.”<sup>1</sup> Within the frame of how a surrogate can convey to a patient’s physician the personhood issues for that patient, such a dichotomy is clearly nonsensical; expressing what a person may have previously stated about all sorts of preferences—some medical, some not—is clearly important for the physician when developing a recommended plan of care, but so is offering insight into how the person who is now patient might view different outcomes, interventions, likelihood of interventions resulting in said outcomes, and so forth, i.e., what “best” or “valuable” or “worthwhile” actually means for this patient given the actual circumstances in which the patient now resides. And in presenting all of this, the surrogate represents—or re-presents—the patient; the surrogate also presents him- or herself as an active participant in the decision-making process, thereby taking on moral weight and responsibility (hence, the idea that a surrogate can somehow be morally neutral is also nonsensical).

Despite skirting these matters, the work that Devnani and colleagues offer us is nonetheless important, because it helps highlight the fact that in practice, people do not follow the simplistic frames of bioethics theory and principles. Rather, they participate in the decision-making process in complex, muddled ways. Future research must, therefore, approach the question of how surrogates contribute to the care of their loved ones by similarly framing that question in terms of such complexity and muddiness. What is clear is that the kind of research that Devnani et al. offer us should not be pursued in the service of bioethics theory, but rather directed toward how to develop a better appreciation of the struggles and difficulties people actually experience when serving in the surrogate role—that is, of speaking on behalf of a loved one and trying to represent another, an act which also brings oneself directly into the fore, since speaking for another is itself to participate within the process, and hence to share in the moral weight of decision-making.

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**Compliance with Ethical Standards:**

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