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The Surrogate's Authority

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ABSTRACT

The authority of surrogates—often close family members—to make treatment decisions for previously capacitated patients is said to come from their knowledge of the patient, which they are to draw on as they exercise substituted judgment on the patient's behalf. However, proxy accuracy studies call this authority into question, hence the PPP. We identify two problems with contemporary understandings of the surrogate's role. The first is with the assumption that knowledge of the patient entails knowledge of what the patient's choice of treatment would be. The second is with the assumption that a good decision reproduces the content of that choice. If we are right, then the PPP, helpful though it might be in guiding surrogates' decisions, nevertheless would hold them to the wrong standards and in that way could add to, rather than relieve, the stress they experience as they try to do their job.

Keywords: family, surrogate, decision making

Two solidly established facts emerge from the empirical and ethical fog surrounding surrogate decision making: (1) A vast majority of patients want their family members and loved ones to make decisions for them when they can no longer do it themselves (Kelly, Rid, and Wendler, 2012), and (2) surrogates aren't particularly good at guessing what treatments the patients would have wanted (Shalowitz, Garrett-Meyer, and Wendler, 2006). The awkward position this puts surrogates in when the time comes for them to discharge their responsibilities would be eased if the patients had drawn up an advance treatment directive and discussed their preferences with their surrogates while they were still competent. However, it turns out that not only do very few people actually make advance directives—a figure hovering somewhere between 15 and 30 percent has held steady for at least twenty years—but those who do have them are very likely to find them overlooked or ignored when the time comes to use them (Support Principal Investigators, 1995; Pollack, Morhaim, and Williams, 2010). As for discussing their wishes with their surrogates, patients very rarely do this either, as they and their family members alike find these conversations quite difficult (Scott and Caughlin, 2012). In any case, there is some evidence that such conversations do not significantly increase proxy accuracy (Ditto et al., 2001; Hines et al., 2001).

No wonder so many surrogates report feeling “stress, guilt over the decisions they made, and doubt regarding whether they had made the right decisions” (Wendler and Rid, 2011). The Patient Preference Predictor (PPP) is intended to relieve that stress by giving a proxy decision maker and the professionals caring for that patient good information about the treatments other patients like her would prefer (Rid and Wendler 2014a, Rid

and Wendler 2014b).

We believe the PPP could be a valuable tool for helping family members with the sometimes desperately difficult task of caring for permanently incapacitated or dying relatives. For most families, the hi-tech biomedicine that is now the routine response to seriously injury or illness is terra incognita, a foreign country that is as unfamiliar as it is unfamiliar. Any hints, suggestions, or guideposts that show family members what they can expect and what they are supposed to do when they find themselves in that country are surely on the side of the angels.

It would be useful, though, if health professionals—and bioethicists, for that matter—had a more nuanced sense of what to expect from family members, in turn. The moral responsibilities arising from familial relationships have not been studied to anything like the same extent as those arising from provider-patient relationships. Families have traditionally been overlooked for careful ethical study, in part, perhaps, because they have been relegated to the “private” sphere, where behavior is assumed to be “natural” and motivated by love instead of duty. The resulting general ignorance about the complex character of family ethics may explain why, when professionals try to teach family members what they are to do in health care settings, they are liable to distort familial self-understandings and deform what would otherwise be valuable familial goods. And as family members themselves cannot always clearly say what those self-understandings are and what goods they are best positioned to provide to their own, they are all too apt to fall in with what health care professionals think they should do.

The leading understanding of the surrogate’s role is that she should make treatment decisions that the patient would have made were the patient not incapacitated.

This view rests on the assumption that knowledge of the patient entails knowledge of what, in a very specific and complex set of circumstances, the patient's choice of treatment would be; this is the assumption that—unsurprisingly as we see it—studies call into question. Our challenge goes to the heart of this understanding: that a proxy decision is good only insofar as it reproduces the content of that choice. If we are right, then the PPP, helpful though it might be, nevertheless could reinforce this problematic understanding and in that way might add to, rather than relieve, the stress surrogates experience as they try to do their job.

Reproducing Content

It has long been assumed that family members are presumptively in the best position to make decisions for incapacitated relatives because of their intimate knowledge of the patient. Indeed, when patients are asked why they want a family member to make those decisions, they tend to say things like, “She knows me best.” However, the many proxy accuracy studies demonstrating that surrogates are only slightly better than chance at predicting patients' choices have fueled skepticism that family members know the patient as well as they—and the patients themselves—think they do.

But is this skepticism warranted? We argue it is not, and for two converging reasons. The first starts with the character of the studies themselves, while the second begins with reflections on what it is to be close to someone. Both lead to the same conclusion: the notion that proxies typically have a clear and stable “target” at which to aim—the decision that the patient would have made had she been able—is confused.

Proxy accuracy studies are conducted by asking some number of patient-proxy pairs to predict, independently of each other, what the patient would want in some hypothetical future scenario in which the patient is incompetent to make a decision. What we have here is best guesses, but these are not at all the same as an actual decision. It is one thing to sit comfortably at home or in a research facility and, after no more than a few moments' thought, to answer "treat" or "do not treat" to a question like this:

You recently suffered a major stroke leaving you in a coma and unable to breathe without a machine. After a few months, the doctor determines that it is unlikely that you will come out of the coma. If your doctor had asked whether to try to revive you if your heart stopped beating in this situation, what would you have told the doctor to do? (Beland and Froman, 1995)

It is quite another thing to have lived through those months at someone's bedside, watching events unfold and knowing precisely what it is for the first wild hope of full recovery to flicker and fade until a doctor, extinguishing it altogether, asks you to decide what should be done now.

A *decision*—as distinguished from a prediction—involves carefully identifying the considerations that are salient here, in this instance, for this person, given her (and often the surrogate's shared) history, and choosing from the available options the one that seems best. Decisions about important matters do not typically spring into existence overnight, like mushrooms, but are nurtured into being by thoughtful reflection. When a patient is unable to engage in such reflection, or to have the conversation with her partner or children that would probably take place in the course of such reflection, it is simply irrational to suppose that she nevertheless will generally have a fully formed, precisely

focused decision tucked neatly away inside her skull. To suppose, further, that their knowledge of the patient should enable the partner or child to pull that decision out of her skull via “substituted judgment” is irrationality on stilts.

Second, in the ordinary sense of the phrase, “to know someone” is to know who they are. We gain a sense of who someone is by means of the stories and fragments of stories that we weave around the things about the person—her acts, experiences, characteristics, commitments, roles, and relationships—that matter most to us. If, for example, the person is your mother, some of the stories by which you constitute her identity will be the socially shared narratives about mothers that circulate widely in your culture, and others will be stories of how she reared you, how you and she get on now that you are grown, the active interest she has lately taken in politics, the way she laughs at her own jokes, and so on. Your love for her will likely soften some of those stories so that they are not perfectly accurate depictions of her, and longstanding resentments or grudges could distort some of the stories in the opposite direction. But what this narrative activity amounts to is that you know *her*, having for better or worse lived out your life entwined with hers—indeed, because your lives are intertwined, some of the stories that constitute her identity also constitute your own. That kind of knowledge naturally enough includes knowledge of some of her “values and preferences,” but there is no particular reason, unless perhaps she has been hospitalized often for the complaint that now renders her incapable, why you should have any better an idea than she would have had as to what sort of treatment is wisest here and now. She likely would have had to construct a decision; you will have to do the same. As we will go on to argue, there is reason to believe it relevant that you are in a position to construct the decision out of the same

“materials” as she would have done.

If this is right, then the role of the surrogate cannot simply be to reproduce the content of the decision the patient would have made had she been able. In at least many instances, this counterfactual will have no clear content to reproduce. There of course will be cases where a person has stable, strong, and clear preferences prior to incapacitation—not to be kept in a PVS for decades, for example. Yet even in such a clear case, a myriad of decisions go into a decade. How each decision might correspond to what the patient would have chosen for herself at that time, given the desires of those who were important to her, and possibly shifts in available information, could remain indeterminate.

Shared Agency

The richness of intimate ways of knowing others is relevant to another reason why proxy decision making cannot simply be a matter of reproducing content. What people value about making decisions is not only getting the outcome they choose, but getting the outcome *because they choose it* (Nelson, 2003). The PPP cannot help with this dimension of decision making unless perhaps its use is sanctioned by the person prior to her incapacity. The authors of the PPP have made it clear that they see this tool as an aid to a proxy decisionmaker’s deliberations, not as a device for determining what happens on its own. The importance of the distinction that we are drawing here can be better appreciated, however, if we imagine a more rabid enthusiast for the PPP saying that “most people of the patient’s education, class, gender, race and income level would

choose to be ventilated, so we'll assume that she wanted ventilation." This would be something like being told that "a person like you is most likely a Democrat, so we'll just count you as having voted for Obama." What's troubling about both assurances is that they speak only to implementing the *content* of our values; they miss the expression of our *agency* in bringing that content about.

It might be thought that there is just no help for that—reproducing content is the best that can be done for people who have lost decision making power. But we believe that something better is available. Carol Rovane has argued (1998) that persons are fundamentally agents who are responsive to reasons, and that the endurance of a person's identity over time and change lies in the coherence of their reasons. The authority and importance imparted by the agentic dimension of our choices is a matter of where those choices come from—their relation to a set of beliefs and values, projects and processes whose harmonious interaction contributes to maintaining our unity as selves. People in bonded relationships have something more than a rich and detailed knowledge of the other: they may also have a sense of common purpose, a tacit awareness of being in this together, a mutual upholding of each other's lives and selves in one way or another. At least at the ideal limit and sometimes, perhaps, even in practice, close family members may come to share what Rovane has called a "deliberative perspective"—a view of what is true and what is of what kind of value, and of how those values are ordered—that has been generated and preserved by shared experience over time, and on which they draw in reflection and in choice.

Even when that deliberative perspective is not shared so completely as to allow the surrogate to fully express the patient's agency in her own deliberations and decisions,

family members may have a kind of access to the patient's perspective that others are unlikely to enjoy. Their own deliberative strategies and view of the world may overlap in important ways with those of the patient. Alternatively, they may be able to bring the patient's characteristic ways of thinking and choosing to bear on the decisions at hand, because they know those strategies and are familiar with the details of the worldview even if they do not use them in their own lives. When a person shares the kind of bonds with others that allows her intimates to express something of her own agency, what might have mattered most to her is not so much what is decided as who does the deciding.

What we have done here, of course, is simply to rough out a possible source of proxy authority, one that is not distressed by inaccuracy nor reproducible via PPPs. It might well be maintained in response that this "possible source" remains pretty rare: if such sharing of deliberative perspective were at all common, then we ought to see greater concordance among family members in test conditions. Further, the common incidence of shattered families, and of serious discord even within families that are intact, suggests that the kind of closeness that Rovane discusses remains at best the exception rather than the rule.

We are not much troubled by the first point, on the conceptual and contextual grounds we've already outlined: predictions simply aren't decisions. The importance of this point might be more evident if we could determine the concordance of predictions and decisions about matters of this kind *in the first person case*. Surely, people's own responses surprise themselves often enough when they encounter in reality a choice they had only speculated about before.

The second point we must allow—how could it be denied? Indeed, it is largely for

this reason that we acknowledged that approximations to a shared deliberative perspective might be all that one would usually come across. Again, however, we find comparison with first-person perspectives useful: a fully rationally unified deliberative perspective within one person is not something you come across every day. Disharmony within oneself is hardly a rare phenomenon; we are not always of one mind about what we think best to do, even when we focus solely on advancing our own interests. Nor do we always get along all that well with ourselves.

Yet even if our Rovane-inspired account were to be admitted strictly on theoretical grounds, it could well be argued that the evidence is against us. The existing data indicate that the strong preference for family surrogates revealed in the literature is, contrary to our suggestion, largely based on the belief that family surrogates will decide as the patient would (Kelly, Rid, and Wendler 2012). Reproducing content, it seems, matters more to people than sharing agency.

We are not altogether convinced. We have no reason to think that any of the studies Kelly, Rid, and Wendler draw on explicitly present an accessible description of the concept of shared agency to their respondents. Further, the significant sympathy several studies reveal for the idea that family proxies ought to have some degree of latitude in their choices suggests that the preference for intimates may have more complex sources than the studies can reflect. Finally, while some of the studies seem pretty explicit about the importance of reproducing content (Elliot and Olver, 2007: “families best qualified to know patients wishes,” and Waters 2000 and 2001: “family knows preferences”), their characterization of other studies seem more open to interpretation. The reason for family preference in Terry et al. 1999, for example, is

summarized as “trust in relationship,” and several studies by High (1987, 1988, 1990) are summarized as “trust family.”

It would be interesting see whether presenting respondents with data about proxy accuracy levels significantly reduces or even completely extinguishes their preferences for family proxies. If it does not, and especially if respondents are also offered possible alternative reasons for choosing family members that strike them as more apt, that may provide some grounded reason for believing that when people envisage themselves as helpless patients, their thoughts turn to their families for reasons that go far beyond how good they are at matching a guess.¹

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