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Familiar Interests and Strange Analogies: Baergen and Woodhouse on Extra-Familial Interests

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ABSTRACT

The article by Professor Baergen and Dr. Woodhouse makes a succinct and serious contribution to progress in bioethical understanding of deciding for others.¹ They begin with what is by now a familiar claim: family proxy decision makers may sometimes make decisions on behalf of incapacitated relatives that depart from what might be optimal from the patient's point of view, since the well-being of family members, or of the family as such, may be substantially affected by the direction of a patient's care. They then develop this idea, noting that others apart from family members can also be substantially affected by a patient's treatment, and arguing that the interests of strangers ought also to sometimes have a role in determining the aims and means of a patient's treatment.

Baergen and Woodhouse also devote attention to how extra-familial interests might be implemented in medical decision making. While I unearth a troubling consequence of the effort to realize their theoretical conclusion practically, my chief task is to point to some disanalogies between families and strangers, and

consider the extent to which they call into question the relevance of the interests of strangers to the treatment of patients.

Since John Hardwig's path-breaking article in 1990 in the *Hastings Center Report*, "What About the Family?"² there has been persistent attention to his thesis that, at least in some circumstances, burdens encountered by families resulting from medical treatment of relatives can be substantial enough to justify allowing family interests to count on their own behalf in deliberations about appropriate care; Baergen and Woodhouse's article continues that tradition. It is, perhaps, at least mildly ironic that nearly a quarter century ago, Hardwig motivated his view by pointing to the ways in which extra-family interests were already being used to trump conflicting patient interests. As non-patient interests that affect the wider society were increasingly regarded as morally relevant to deliberations concerning patient care, Hardwig asked how we could justifiably ignore family interests, which can be so much more immediate and individually burdensome.

Baergen and Woodhouse stand Hardwig's strategy on its head, arguing that as family interests are in principle legitimate contributors to decisions about appropriate care, so must be the interests of strangers. Relatives may indeed suffer from certain

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treatment decisions made to further a patient's best medical interests, but what is pertinent is not that they are *family* but that they are *vulnerable*; hence, medical decision making needs to be alert to the impact on everyone affected by it.

They develop this point with some delicacy. In the discussion of their arresting case study, they do not insist that extra-familial interests trump the interests of Mr. C. For example, they cite, with apparent approval, arguments concluding that patients' special place in decisions affecting them imposes limits on the degree to which their interests can be set aside by contrary family needs or desires—although just where such limits lie in extra-familial contexts is left as an exercise for the reader. However, the circumstances facing Mr. C suggest that the authors regard the scope and stringency of any special protection that patient interests enjoy to be negotiable, as extra-familial interests in Mr. C's case are presented as appropriately bearing on whether he should be denied surgery that might arrest a progressive disabling condition, substantially increase his mobility, and even extend his life.

Baergen and Woodhouse explicitly acknowledge that the harms to others posed by Mr. C's treatment remain speculative. They also allow that withholding surgery may not be the only practical safeguard against the danger he presents.³ What makes their view so striking, however, is not so much decisions as deliberation: the fact that Mr. C's treatment, given his circumstances, might make other people much worse-off, cannot be excluded as impertinent to what treatment will be offered him.

One reasonably plausible and readily available way of responding to this bold view might be by claiming that the relationship between healthcare providers and their patients remains defensibly "paternalist," although not in the "doctor knows best" sense. Rather, like parents, health professionals do not aim at what is best for humanity over all, but what is best for those to whom they are in a morally special relationship. In effect, Baergen and Woodhouse's response to this objection can be seen in their employment of consequentialism, a topic I'll turn to below. What seems more on their mind is the vexing question of how to identify a mechanism to determine when extra-patient interests are under grave enough threat to shift treatment decisions away from those that the patient favored, or that would have best promoted her own interests.

For Baergen and Woodhouse, a big challenge is guarding against the fact that Mr. C is decidedly unlikable, both because of its bearing on the instant case, and because they seem to think that many pa-

tients whose relationship to other people will put in question whether they should receive treatment that best serves their own interests are prone to be similarly unlikable.

My primary implementation concern is different. Suppose Mr. C were not a decisionally incapacitated, mobility-impaired sex offender. Suppose he were instead a politician in high office bent on manipulating intelligence data to foment a needless war. As it happens, Mr. C requires, say, a heart transplant, or a new pacemaker. (He might still be singularly unlikable, but that seems of less moment in this version of the case.) Would it be possible for healthcare professionals, or an ethics committee for that matter, to deliberate whether the threat such a man posed to tens or hundreds of thousands of people, and possibly to the entire world, made it legitimate to withhold the needed surgery?

The notion of denying healthcare to a Strangelovian version of Mr. C might strike some as a *reductio* of the Baergen-Woodhouse view, but that's not how I intend it. The point, rather, is to raise the worry that among the challenges their view faces is how to administer it in ways that will not be significantly biased against the relatively poor and powerless. That our authors are concerned that the conflicts between patient and extra-familial interests are likely to grow "if political or economic factors lead to reductions in healthcare facilities and programs" suggests that their paradigm for the socially problematic patient is someone much more like their Mr. C than like my highly placed political version.⁴ If the extent to which a patient's interests are taken as central in determining treatment is influenced by his social and economic standing—and it seems highly plausible that the threats posed by the poor would be much more under discussion than those posed by the wealthy—whatever mechanisms determine the impact of extra-familial interest would have to be carefully tailored to avoid rampant unfairness.

If the concern about the justice of implementing decision-making policies and practices that are sensitive to extra-family interests raises serious issues for Baergen and Woodhouse, why should not they also trouble Hardwig and those influenced by his thinking? After all, their Mr. C is, in part, facing this problem because neither his society nor his family seems willing to make secure provisions for his subsequent health and social care. If Mr. C had extensive private means, he would not need his sister to provide him with the situation he needs. Once again, it seems, it is patient-centeredness for the rich and powerful, trade-offs with families and

strangers for those without money or might.

Is there, then, any ground for thinking that the interests of family members have a special importance that extra-familial interests lack? Baergen and Woodhouse themselves suggest one interesting candidate. They hold that the relevance of extra-familial interests is revealed by consequentialist moral reasoning, “whereas a focus on respect for autonomy and the right to self-determination would tend to allow a (limited) consideration only of family (because of the role of family in the function and formation of the individual).”⁵ This pregnant parenthetical phrase deserves greater attention than they give it. Just what is it about “the role of the family in the function and formation of the individual” that makes family needs and desires—even if they run counter to a patient’s medical interests—relevant to the exercise of the patient’s autonomy or right to self-determination? If these considerations turn out to be at all robust, they would seem to spell trouble for their argument, which is that the motivation for taking family interests into account has to do with how treatment decisions effect others *as such*, without regard for any more complicated ways in which those interests might or might not relate to those of the patient.⁶

Rather than pursue this line of thought, their strategy is to maintain that consequentialist moral approaches—by which I take them to mean impartialist, “each counting for one, no one for more than one,” utilitarian-style consequentialism—support the extra-familial interests claim, and that such an impartialist perspective is appropriate to clinical decision making. If so, this would undermine the objection that the professional-patient relationship, like the parent-child relationship, is morally special, and hence deflects the claims of the overall good impartially considered. In defense of the appropriateness of consequentialism to clinical decision making, Baergen and Woodhouse remind us of its predominant role in decision making around the allocation of organs, or in public health. If we can defensibly base decisions on consequences there, the suggestion seems to be, there are no in-principle barriers against doing so in other healthcare contexts.

Once impartially considered consequences are acknowledged as belonging squarely in the decision-making picture, the relevance of both familial and extra-familial interests seems natural. This is so even if we think of the claim of extra-familial interests as based in distributive justice, *à la* Hardwig’s initial defense of familial interests, since, as Baergen and Woodhouse see it, distributive justice is a moral notion more closely allied to consequentialism than

to respect for autonomy and self-determination, which seem to be the going alternatives.

Yet the situation here is less straightforward than they suggest. Portraying public health ethics as a paradigm for the ethics of clinical encounters is at least a conspicuous enough position to need some argument. Further, the way in which Baergen and Woodhouse deploy the organ procurement analogy seems a bit tendentious. For one thing, when there is simply not enough of a resource to go around, making decisions on grounds other than patient need or desires seems inescapable. Further, the criteria used to assign transplant candidates’ places on waiting lists are construed typically as emerging from efforts to balance consequential and deontic concerns, to promote optimal efficiency *within* the constraints of equity. This explains why urgency of need—how soon one is likely to die for the want of a transplant—is such a significant factor in the allocation of vital organs. Impartialist consequentialism would presumably direct decision makers to put a premium on how likely a candidate was to live a long and healthy life with a transplant, rather than how likely she was to die soon without one. The treatment of Mr. C’s case is, in fact, reminiscent of earlier and now unpopular efforts to allocate life-sustaining therapies via notions of the “social worth” of the recipient. If, as George Annas memorably quoted in a reference to the days of the “God Committee” that determined access to early dialysis in Seattle, “the Pacific Northwest was no place for a Henry David Thoreau with bad kidneys,” a renally impaired, decisionally incapacitated pederast would likely have an even worse lookout.⁷

Of course, Baergen and Woodhouse might not be at all disconcerted by such an implication. Taking social worth into account—at least in some dimensions of that commodious notion—is just what they advocate, and expanding the remit of ethics committees (although not perhaps to a Divine pitch), just what they call for. Further, they might point out, even if considerations other than maximizing good consequences are at work in organ allocation as currently practiced, it is not at all clear that they have anything to do with any “special” moral relationship between providers and recipients of healthcare, nor even that those considerations involve respect for patient autonomy or self-determination.

If respect for autonomy is a matter of patients getting what they want, this is so. Yet considerations of justice in distribution are quite typically understood to reflect an appreciation of the special moral status of persons that also is expressed in terms of respect for their autonomy. Morality, commonly

understood, frowns on treating others solely as means to ends that they have not themselves elected, even if those ends would maximize the overall utility; presumably, that has something to do with honoring our status as beings that can choose for ourselves what we value.

Further, it is just this sort of nonconsequential conception of distributive justice that may help us understand how family interests might be relevant to medical decision making in ways that extra-familial interests are not—how they might count, that is, even if there is something morally privileged about a patient's relationship to his professional caregivers. Let's return to the point of distinction between families and strangers that Baergen and Woodhouse themselves note—"the role of family in the function and formation of the individual"—and try to sort out its connection to respect for autonomy. Families are characteristically the crucibles of our autonomy, providing both the "self" of self-determination and the stuff of which many of our values are made, either directly (we "inherit" them) or in reaction (we individuate ourselves by developing some values and ways of valuing that stand out against those prevalent in our families). Because of their proximity to the development or exercise of a patient's values, close family members are often taken to be generally in the best position to know or accurately reconstruct what decisions an incapacitated patient would make. How true this is (and how true it needs to be) is actively disputed.⁸ But the presumptive appropriateness of families as proxies may not be solely a matter of their ability to accurately reproduce (or reconstruct) the decisions a patient would have made on her own. Surely, in at least some cases, incapacitated patients will have no determinate preference about treatment at which the family can aim, accurately or not; in other cases, the very reaction of the family to the kind of situation in which the patient finds herself would be among the circumstances that a patient would have taken into account had she been able to do so.

But if those most closely bonded to us cannot always convey the content of our choices, they may still choose in ways that reflect who we are more closely than others could. To issue in decisions, the various things that matter to us have to assume a certain pattern of salience, in light of our understanding of particular sets of presenting circumstances, possibilities of response, and the odds of various outcomes. It is their relation to *that* dimension of decision making—a dimension pertaining more to the distinctive ways we exercise our agency than to the specific choices we make—that family members

may share with their familial intimates. The sense that we may share not just *what* we value, but *how* we value, may make intelligible the fact that some people seem as interested in who makes decisions for them as in what is decided.

These considerations do not at all imply that various family members cannot have sharply opposed interests. They are, however, meant to indicate how the role of families in the function and formation of individuals may make deliberation leading to decisions that differ from those a patient might have made for himself, yet emerge from a process that the patient would recognize as "familiar"—and therefore as less heteronomous than the decisionally effective interests of strangers.⁹

There are other potentially distinguishing points that could be explored. If notions of "shared agency" seem a reach too far, family members may sometimes have a certain sympathy for each other's values, needs, and desires, even if their own are different; if my interests as a patient have to lose out, it may still make a difference to me to whom I lose. Further, a patient's best medical interests are sometimes achievable only by decisions that in effect draft family members into prolonged, exacting service; while at least in principle they could simply "opt out," it seems very plausible to think that everyone's interest might be better served by trying to craft compromises that take seriously not only a patient's medical interests, but also preserve connections among family members without exploitation. And so forth.

Even if, however, these or related considerations do constitute disanalogies between families and strangers relevant to proxy decision making, they do not show that extra-familial interests are irrelevant to medical decisions outside of scarcity or public health threats; rather, they contribute to appreciating part of what needs to be done before that provocative view can be assessed with any determinateness. Baergen and Woodhouse have left bioethicists with another intricate and important complication to consider in understanding how to decide for others—for which they ought to be thanked.

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NOTES

1. R. Baergen and W. Woodhouse, "Surrogates and Extra-Familial Interests," in this issue of *The Journal of Clinical Ethics*.

2. J. Hardwig, "What About the Family?" *Hastings Center Report* 20, no. 2 (1990): 5-10.

3. Berger and Woodhouse, see note 1 above.

4. *Ibid.*

5. *Ibid.*

6. Hilde Lindemann and I have explored this idea in some detail, both jointly and severally, in a variety of places. See, for instance, chapter two of H.L. Nelson and J.L. Nelson, *The Patient in the Family* (New York: Routledge, 1995), and, more recently, J.L. Nelson, "Trusting Families: Responding to Mary Ann Meeker, 'Responsive Care Management: Family Decision Makers in Advanced Cancer,'" *The Journal of Clinical Ethics* 22, no. 2 (Summer 2011): 123-7.

7. G. Annas, "The Prostitute, the Playboy, and the Poet: Rationing Schemes for Organ Transplantation," *American Journal of Public Health* 75, no. 2 (1985): 187-9.

8. On these disputes, see D.I. Shalowitz et al., "The Accuracy of Surrogate Decisionmakers—A Systematic Review," *Archives of Internal Medicine* 166, no. 5 (2006): 493-7, and the classic paper by A. Seghel et al., "How Strictly Do Dialysis Patients Want their Advance Directives Followed?" *Journal of the American Medical Association* 267 (1992): 59-63.

9. H. Lindemann and J.L. Nelson, "The Surrogate's Authority," *Journal of Medicine and Philosophy* (forthcoming, 2014).