

## OPEN PEER COMMENTARIES



## Decisional Humility and the Marginally Represented Patient

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There was a cartoon circulating during the national debate about Terri Schiavo (Davies for the *Journal News* 2003). A couple is seated in a lawyer's office with their attorney seated behind a desk. On the wall next to a diploma is a sign advertising living wills. The caption from one of the clients is "... & in the event that either of us is being kept alive by artificial means, we don't want Jeb Bush to get involved." The couple clearly do not want the state or bureaucrats stepping in and imposing their judgment in this private realm when they have lost decisional capacity. And yet that seems to be the default position offered by Dr. Berger (2020) in his argument about what he terms representedness. As we see the argument, he wants to deny non-intimate surrogates, family members of standing the opportunity to engage in surrogate decision making and seemingly substitute a cadre of well-meaning, well-intended bureaucrats.

Citing scholarly papers, many of which date to the 1980s and 90's during the heyday of bioethics scholarship on surrogate decision making and advance directive literature, Berger places his faith in the ethics committee, chaplains, and social workers over family members who have become distanced from the patient. Clearly, there is a role for clinical ethicists to step into the fray when the patient is truly isolated and incapacitated, that is when he/she has no relatives or friends to represent them. But the same cannot be said when there are available surrogates. Does Berger really think we—the professional class—is better positioned for this role than family members, even when they have lost contact from the patient?

Berger offers a vignette of a nephew who hasn't seen his uncle for six years. In his formulation, he opts for salvation from a bioethical bureaucracy. We find this troubling. On the basis of a very thin narrative reed—on a hypothetical which virtually has no content whatsoever—the nephew is excluded. How do

we know that this is justified, that he should be excised from the decision-making process? The story, as told is incomplete, more a parable than a case report (Fins 1998). Maybe the nephew was close to the patient as a child. Maybe the patient was a favorite uncle long ago. Or he might have been especially close to the nephew's parent.

We don't know what the reservoir of available narrative might be. This information might provide insight into the patient's preferences and predilections, religious beliefs or philosophy of life. This can be pivotal information. We just don't know until we ask and query the situation.

The narrative that lies within the case is unexplored and unexamined. To categorically exclude this surrogate, and thus discount his potential knowledge and contributions, is problematic and counter-productive. As the well-worn adage, we believe attributed to the great Al Jonsen goes: good facts lead to good ethics. And absent meaningful and respectful engagement with families, distanced or otherwise, we are deprived of important information and operating without available facts.

Berger's position seems to be one of the extremes. Patients are cast as completely incapacitated and surrogates are presumed to be devoid of any useful knowledge. While both scenarios can certainly exist, both patients and potential surrogates need to be assessed for their capacity and their knowledge base. As is increasingly appreciated, there are states of liminal consciousness and capacity (Fins and Bernat 2018) and patients who seem beyond the reach of communication may have residual or reemergent agency (Fins 2018) and be able to express preferences that may be in part dispositive (Fins 2019). This can help mitigate the challenges of surrogate decision-making (Fins and Hersh 2011).

But even when the surrogate is as Berger describes a non-intimate relational one it is important to counter Berger's exclusion with the potential that remains to work with the surrogate, not only to find available evidence that would guide decision making but also—if that information is unavailable—to work with the relative together to make good and prudential choices. Why would we simply discount someone who had more of a connection to the patient than some nameless clinician or bureaucrat? That just doesn't make sense.

A surrogate may come to the discussion with a tangential connection to the patient, but the ethicist can guide him or her. So instead of the ethicist or a guardian assuming the role in isolation, a *guided* surrogate and ethicist can collaborate—that is labor together—work to find a right set of actions (Fins 2018). This collaboration can temper the potential for ignorance or excess by either the surrogate or the non-related “expert”. It also helps to spread the moral responsibility around.

We don't understand why Berger jumps so easily to the exclusion of the surrogate and skips this key collaborative step. Even when surrogates are well-positioned to represent incapacitated loved ones, clinical ethicists provide them with guidance and information. It seems even more critical in this context. The point is short of accepting the views of a distant surrogate, there is a good alternative to work with them and help craft a care plan for the incapacitated patient. But of course, that sort of mediation becomes impossible if that surrogate—who may yet retain legal authority to make decisions whether Dr. Berger likes it or not—feels excluded (Meltzer et al. 2017).

The argument as cast is framed as a choice between the well-informed intimate surrogate against those who are less well-positioned and that is really not the choice at hand. The real question is whether to include the distant surrogate or seek a remedy vesting authority in an ethics committee or a guardian. To be clear working with a distant surrogate neither requires committee input nor oversight. But usurping the role of the surrogate does.

And this brings us to guardians. Why does Berger think that this is the better remedy? Not only does it preclude the identification of preexisting knowledge which could be gained from the surrogate, it also precludes moderating a surrogate's views with additional professional guidance. What is left are guardians, so unflatteringly profiled recently by Rachel Aviv in *The New Yorker* (Aviv 2017), who step up for proprietary reward and who often abdicate on the hard decisions.

In our experience, we have encountered guardians who represented hundreds of “clients” and who were often unavailable and unresponsive. Many were unwilling or “unauthorized” by their agencies to make decisions to withhold or withdraw LST because they do not want to take that risk, even though they were authorized by the courts to make all medical decisions. We have encountered guardians who acknowledge that they make medical decisions according to their own religious values or those of the agency owner, regardless of whether there is any indication that “their ward” shares those values. And, we find that some independent and well-meaning guardians recognize that they have no basis upon which to make sound decisions for the stranger in their care, and then simply consent to all clinical recommendations assuming that all are in the incapacitated patient's best interest. These failures leave isolated and incapacitated patients truly trapped and unrepresented by guardianships that preclude alternative representation.

Finally, there is the question of what we will call “decisional humility.” In our state, there is a statutory mechanism for an ethics review committee to make decisions on behalf of isolated and incapacitated patients. We have to assemble a stipulated minimum number of members of the committee to ensure an interdisciplinary mix and community representation, hear the clinical facts, deliberate, and keep special records. It is a robust process in which procedural caution becomes a means to compensate for the fact that none of us are connected to the patient by blood or friendship. Nonetheless each of these deliberations, which both of us have chaired since the law went into effect nearly a decade ago, leaves us with a sense of dis-ease, a feeling of overstepping into a realm that ideally should not be our purview. We step in because we have to do so, but we do so reluctantly and with a sense of humility and disinclination, fearful that we may abuse power vested in us in the face of the patient's vulnerability.

Why Dr. Berger would seek to create more of these uncomfortable scenarios by excluding available surrogates befuddles us. Although he is well-intentioned, we worry that his confidence in the institutions of clinical ethics is misplaced and that he is too quick to deny surrogates of their rightful representation. In all of this, we are reminded of Justice Brandeis's admonition about institutional authority, notably quoted by Justice Stevens in his dissent in *Cruzan*, a case about evidentiary standards and the place of surrogate decision making (*Cruzan v. Dir., Mo. Dep't of Health* 1990). Justice Brandeis warned, “Experience should teach us to be most on our guard to protect liberty

when the government's purposes are beneficent ... The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding," (Olmstead v. United States 1928).

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# From Solo Decision Maker to Multi-Stakeholder Process: A Defense and Recommendations

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Berger (2020) argues effectively that “representativeness is more aptly understood as a variable that is multidimensional and continuous based on relational moral authority,” and also makes some useful suggestions about how taking this observation seriously might require changes in current patterns of practice regarding surrogates. But the essay raises additional important questions about how the Best Interest Standard (BIS) should be used among unrepresented patients and other patients as well because many surrogates besides those who “have no actionable knowledge of a patient’s preferences” find themselves in positions in which they need to determine, with the physician, what is in the patient’s best interests.

First of all, consider that much of the author’s argument is based on Pope’s recommendation that, for unrepresented patients, BIS decisions should not be

made by any one person solo, but by “a robust and transparent multi-stakeholder process involving other institution-based health care professionals and extra-institutional parties” (citing Pope 2013). Despite this recommendation being foundational to Berger’s argument, however, Berger does not provide an argument—neither Pope’s nor the author’s own—for the ethical correctness of this method for reaching a BIS judgment about an unrepresented patient, or about any other patient who is incapable of relevant decision making. This omission is internally problematic for the author’s argument since the author’s criticism of permitting “self-identified surrogates” who “have no actionable knowledge of a patient’s preferences” depends on the assumption that the multi-stakeholder process is superior.

This omission, moreover, is also problematic when considered with regards to other aspects of current

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