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Govind C. Persad

To cite this article: Govind C. Persad (2020) Advance Directives and Transformative Experience: Resilience in the Face of Change, *The American Journal of Bioethics*, 20:8, 69-71, DOI: [10.1080/15265161.2020.1781975](https://doi.org/10.1080/15265161.2020.1781975)

To link to this article: <https://doi.org/10.1080/15265161.2020.1781975>



Published online: 06 Aug 2020.



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Walsh, E. 2020. Cognitive transformation, dementia, and the moral weight of advance directives. *The American Journal of Bioethics* 20(8): 54–64.

THE AMERICAN JOURNAL OF BIOETHICS
2020, VOL. 20, NO. 8, 69–71
<https://doi.org/10.1080/15265161.2020.1781975>



OPEN PEER COMMENTARIES

Advance Directives and Transformative Experience: Resilience in the Face of Change

Govind C. Persad

University of Denver

Walsh valuably deploys L.A. Paul’s “transformative experience” framework (2016) to challenge Ronald Dworkin’s defense of following advance directives prepared in advance of dementia (1994). In this commentary, I critique three aspects of Walsh’s paper: (1) the ambiguity of its initial thesis, (2) its views about the ethics and legality of clinical practice, and (3) its interpretation and application of Dworkin’s and Paul’s views. I also consider what Walsh’s proposal would mean for people facing the prospect of dementia. I conclude that our reasons to honor many advance directives survive the move to a transformative experience framework.

INITIAL AMBIGUITIES

Walsh claims that endorsing “the strongest legal status of advance directives” is “philosophically inadequate,” and then continues by claiming that post-dementia preferences “ought to be given moral weight in medical decisionmaking” (55). This left me uncertain whether Walsh’s thesis should be understood as legal or moral, and as about moral overridingness or only moral weight. Regarding the former, many documents, such as ordinary wills that transfer property in morally unfair ways, should be legally enforced despite their moral shortcomings. Regarding the latter, giving post-dementia preferences some moral weight is compatible with giving *more* weight to pre-dementia

directives. Similarly, the paper claims that we should reduce our “confidence in the effectiveness of advance directives” (55), but doesn’t explain for whom the advance directives would be effective or ineffective.

THE ETHICAL AND LEGAL STATUS OF CLINICAL PRACTICE

Walsh argues that Dworkin’s view is “out of touch with clinical practice” (55). I am doubtful this criticism bears much ethical weight. Many aspects of clinical practice are normatively unjustified, including widespread failure to discuss costs with patients (Jagsi et al. 2018; Schrag and Hanger 2007); “cherry-picking” patients who are less likely to have complications (Humbyrd 2018); and biased treatment of overweight, minority, or disabled patients (Rubin 2019; Hoffman et al. 2016). The fact that some, or even most, clinicians distrust advance directives does not provide a particularly compelling reason to reject advance directives. Medical ethics is better understood as an effort to improve medical practice than as a justification of existing practice.

Relatedly, Walsh is perhaps too charitable in attributing clinicians’ skepticism about advance directives to philosophical concerns, rather than a broader and potentially self-interested preference for physician-driven rather than patient-driven decision making. The turn toward shared or patient-centered decision-making has been recent and not entirely uniform.

CONTACT Govind C. Persad ✉ gpersad@law.du.edu 📍 Sturm College of Law, University of Denver, Denver 80210, USA.

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Japanese medical practice, for instance, remains much more physician-driven than American practice (Sullivan 2017), which makes it unsurprising that advance directives lack legal force in Japan. Meanwhile, some countries have moved toward advance directives; while they once lacked legal force in France and Italy (de Boer et al. 2010), this is no longer true. Advance directives are legally binding in Italy (Ciliberti et al. 2018). They also acquired legal force in 2016 in France, except in emergencies or if “manifestly inappropriate or inconsistent with the patient’s medical condition” (Trarieux-Signol et al. 2018).

Walsh also assigns more weight to a patient’s “best interests” than American law or medical ethics standards permit. Best interests are typically only invoked in the absence of information about the patient’s values (Matter of Conroy 1985). Normally—as Walsh recognizes—we respect patients’ decisions not because patients best know their own interests, but because their chosen commitments have primacy over their interests. Later, Walsh suggests that clinicians must “balance the considerations stipulated in an advance directive with the well-being of the patient before them” (63). But this needs to be argued for, not assumed. Clinicians are not permitted to “balance” the wrong of forcing a refusing patient to eat, or of resuscitating a person with a do-not-resuscitate (DNR) order, against their judgment about that patient’s well-being. We need an explanation of why they may do so when the refusal comes via a proxy decisionmaker or advance directive. An explicit request for food or a disavowal of the DNR by the “patient before them” could make things different, but clinicians’ belief that a patient’s advance directive does not promote their well-being should not, without more, permit overriding that directive.

Last, Walsh’s proposal to ban websites that offer “easy” advance directives seems overbroad. It would be hard to legally justify such a ban, at least in the United States. And ethically, I worry that a ban would produce even worse decisions. Just as online will-preparation websites are nonideal but typically justifiable, so too are online tools for developing advance directives.

DWORKIN’S APPROACH

Dworkin is clear that his proposal applies to cases of *severe* dementia. But many of the cases Walsh discusses do not involve severe or late-stage dementia, presenting the problem of talking past, rather than engaging, Dworkin’s view. Ms. Black is a patient with “mid-stage dementia” and Mr. White has “early-stage dementia,” although fast-progressing. Both these patients can still

communicate understandable preferences, as can Wendy Mitchell. It is very plausible that, even on Dworkin’s view, we should honor such patients’ contemporaneous requests for pain relief rather than their earlier directives. But such express requests are typically absent in severe dementia, leaving us with the choice between following an advance directive and deferring to others’ judgments about a patient’s best interests.

My view (Persad 2019) differs importantly from Dworkin’s, because it focuses on situations where dementia is described as producing a “new person.” I argue that in these cases, the pre-dementia individual retains rights over the body they historically occupied, even after the body is occupied by the post-dementia individual. Whether the post-dementia individual has undergone a transformative experience is irrelevant to my argument, which grounds the advance directive’s authority in the pre-dementia individual’s connection to the body, not in psychological links between the post- and pre-dementia individuals. On my view, if dementia, understood as transformative experience, produces a new individual, this would undermine—not strengthen—the transformed individual’s rights over the body she occupies, if those rights conflict with the claims of the pre-dementia individual.

PAUL’S FRAMEWORK

Paul (2016) believes we should select or reject transformative experiences by considering our feelings about their *revelatory value*: whether we value the experience of discovering life as a vampire, or a parent, or a citizen of a different country. Walsh suggests that on Paul’s view “the rational action to take,” in response to dementia, “is to allow yourself to experience ‘preference revelations’ as the disease itself unfolds” (62). But Paul doesn’t believe we should always allow ourselves to experience revelation. Rather, she suggests that someone who does not value experiences of revelation has good reason to avoid revelation.

Agnes Callard (2018) persuasively challenges Paul’s approach. Callard observes that Paul’s approach provides no resources for choosing among experiences that involve revelation, since it disallows any examination of the content of the revelation. As Callard observes, one can value the transformative experience of motherhood without desiring other transformative experiences, like emigration, dementia, or career change.

Related to Callard’s point, Walsh’s conclusion that we “are not in a position to adequately imagine” (61) life with dementia seems too hasty. Consider Nir Eyal’s proposal (2020) to assess the effects of various medical conditions via the judgments of people who previously had

those conditions. Although most dementias are irreversible, some are reversible (Muangpaisan et al. 2012). Reports from people who recovered from reversible dementia could tell us more about life with dementia.

Ultimately, some people are right to fear or avoid the transformative experience of dementia, either because they do not value being transformed (Paul's view), or because they do not value being transformed *in that way* (Callard, perhaps supplemented by Eyal). But, unlike optional transformative experiences like motherhood or emigration, people facing dementia cannot choose continued life without dementia. Rather, their only alternative is to not continue living, through physician-assisted death or in some other way (Menzel and Steinbock 2013). Given this, enforceable advance directives are valuable because they reduce the burdens of revelation and weaken the reasons we have to choose death over dementia.

The option, however unappealing, of choosing death over dementia also complicates Walsh's claim that dementia is distinctive in being wholly unchosen. Many transformative experiences—like “love at first sight” or serious injury—are unchosen. Others, like continuing a pregnancy in a setting where termination is illegal or stigmatized, are chosen against a backdrop of bad options. The latter situation often also describes dementia.

SELF-BINDING WITHOUT ADVANCE DIRECTIVES

Say that we ceased to honor advance directives whenever clinicians believed honoring those directives would wrong a future, transformed self. People would still have ways of *self-binding*—of protecting their decisions against being undone. They could transfer their possessions to their family members in advance, or devise more elaborate measures like a “delayed-onset euthanatic implant” (Battin 1994).

A practical problem with Walsh's proposal and other suggestions that advance directives be weakened or ignored is that they incentivize pursuing these self-binding measures, even at high cost to oneself. For instance, a person facing the prospect of dementia without the option of an advance directive may elect to choose physician assisted suicide sooner than they otherwise would (Steinbock and Menzel 2018), in order to avoid a situation where an undesired transformation undermines their commitments.

FUNDING

This work was supported by the Greenwall Foundation Faculty Scholars Program.

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