




The Irrelevance of Origins: Dementia, Advance Directives, and the Capacity for Preferences


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Account in order to render the alternatives the only live options. We know of no such argument.

CONCLUSION

The current accounts of personal identity do not merit a high level of confidence. Thus, regardless of one's view of personal identity, one cannot be highly confident that a patient maintains identity from the time she signs an AD through the onset of severe dementia. If we lack high confidence about this, then we cannot be highly confident that an AD is being applied to the person who signed it. This lends support to Walsh's (2020) advice that "one ought to be cautious about projecting current preferences onto a future self," (61) not only because the transformative experience of having severe dementia might result in unexpected emerging preferences, but also because personal identity may not persist into late-stage dementia. Therefore, we suggest that we should give greater weight to the preferences of patients with severe dementia.

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OPEN PEER COMMENTARIES



The Irrelevance of Origins: Dementia, Advance Directives, and the Capacity for Preferences



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We agree with Emily Walsh (2020) that the current preferences of patients with dementia should sometimes supersede those patients' advance directives. We also agree that consensus clinical ethics guidance does a poor job of explaining the moral value of such patients' preferences (Wasserman and Navin 2018). Furthermore, Walsh correctly notes that clinicians are

often averse to treating patients with dementia over their objections, and that this aversion reflects clinical wisdom that can inform revisions to clinical ethics guidance (Navin et al. 2019).

But Walsh's account of the moral value of the preferences of patients with dementia suffers from three major problems: (1) it does not engage the actual

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practices of clinical ethics; (2) it provides an inadequate account of why these patients' preferences matter; and (3) it offers a poor explanation of clinicians' intuitions in these cases. Her arguments engage a philosophical debate that is largely irrelevant to clinical practice and she therefore leaves pressing real-world clinical ethics questions unaddressed. After underscoring some of Walsh's main points, we will discuss each of these shortcomings.

Walsh's target is Ronald Dworkin (1994), who argued that, in conflicts between an advance directive and a demented person's new preferences, the advance directive should have priority. She draws on work from L.A. Paul (2014) to argue that dementia can be a cognitive "transformative experience" (TE) that changes the ways in which patients appreciate their lives. While Dworkin envisions dementia as an attack on patients' capacity for autonomous life, Walsh argues that some (early) dementia patients appreciate their new lives in ways they could not have predicted, and that this appreciation for a life with dementia is not an irrational expression of neurodegeneration. It follows that such preferences matter morally. Walsh acknowledges that changes in a demented patient's preferences *could* also be caused by neurodegeneration, rather than by judgments informed by TEs, but she notes that we cannot be certain about the cause of an individual demented patient's new preferences. She concludes that we should respond to this uncertainty by always treating demented patients' new preferences as if they were caused by post-TE rational reflection, which means that such preferences should always have moral weight. Walsh does not provide support for this conclusion, but it is worth noting that her radical intolerance of one kind of error (failure to recognize post-TE rational preferences) implies a radical tolerance of another kind of error (false attribution of post-TE rationality to preferences formed by neurodegeneration), which is an oddly all-or-nothing approach to the problem of inductive risk (Douglas 2000). Finally, Walsh argues that her theory explains why clinicians are often resistant to treating demented patients over their objections, even when doing so would accord with their prior wishes.

Our first major concern is that Walsh relies on philosophical claims about mental causation and personal identity that are both widely contested and largely irrelevant to clinical bioethics practice. Her narrow target is Dworkin—which explains why she has adopted his idiosyncratic philosophical framework—but she mistakes Dworkin's background assumptions and conclusions as representative of, or

at least practically aligned with, the received view in clinical ethics. She notes that "the received view in the philosophical literature, put forward by Dworkin," (54) gives decisive weight to advance directives, and she suggests that Dworkin's view is inconsistent with clinical practice (which is true). However, she ignores the vast bioethics literature that connects moral philosophy to clinical practice. This is a regrettable misstep. In the dominant clinical ethics schema, it is not the origin story of a preference that gives it moral weight, but whether decision-making capacity (DMC)—in the form of understanding, appreciation, and rationale—can be demonstrated by the patient who expresses a preference (Berlinger et al. 2013; Karlawish 2020). Clinical ethicists warn *ad nauseum* that a patient's diagnosis, such as dementia, does not determine whether they possess DMC, but that DMC must be directly assessed. Furthermore, consensus guidelines reject the idea of a *global* DMC determination for a patient, but insist that DMC must be assessed separately for individual decisions, and that the thresholds for DMC may be lower for some decisions than for others.

As a result, Walsh's complicated story about the TEs associated with dementia is irrelevant to real-world clinical decision making. In the clinic, whether a patient gets what they want depends not on what *caused* their preferences, but whether a patient possesses DMC relative to that preference. Walsh discusses the preferences of patients with an "altered sense of appreciation" (60) who achieve a "different stage of agency" (61) through dementia. She therefore seems focused on cases in which patients likely retain DMC (at least during some intervals and for some decisions). But, giving substantial weight to the current preferences of dementia patients who retain DMC would be unproblematic from the point of view of contemporary clinical ethics practice.

Second, Walsh provides an inadequate account of why demented patients' preferences matter. On her view, it is our uncertainty about the origins of demented patients' new preferences—that they *could* have come from cognitive transformative experiences—that explains why we should take such patients' new preferences seriously. But we do not need this complicated and speculative origin story, rooted in particular accounts of mind, body, and self—one which is epistemically inaccessible in the clinical moment—to defend the moral value of DMC-lacking patients' preferences. Instead, we have argued that clinicians ought to give at least some weight to *all patients'* preferences, because doing so is a requirement of respecting

them as persons and taking their claims to liberty seriously (Wasserman and Navin 2018). The fact that a patient reasons well counts in favor of granting *additional* weight to their preferences, but the fact that a patient reasons poorly does not mean that their preferences count for nothing. This idea is widely recognized in pediatrics, where the notion of *pediatric assent* highlights the value of even very young's children's participation in decision making about their care, though the American Academy of Pediatrics has not always well expressed the moral bases and practical consequences of pediatric assent (Navin and Wasserman 2019; Wasserman et al. 2019).

Finally, Walsh's account has poor fit as an explanation of clinicians' intuitions about the preferences of patients with dementia. Clinicians often do take such preferences seriously, but not for the reasons Walsh articulates. In our clinical ethics consultation work, whether or not patients *previously* possessed DMC seems to make little difference in clinicians' reluctance to treat over objection. For example, clinicians have been just as unwilling to forcibly dialyze a patient with trisomy 21 (Down syndrome) as they have been to perform coercive surgeries on patients with dementia. This is inconsistent with Walsh's theory, according to which a DMC-lacking patient's preferences matter if they *previously* possessed DMC, such that their preference shift could theoretically be the result of a transformative experience. A patient who has never possessed DMC cannot have formed new preferences based on the kind of transformative experience that Walsh discusses, and Walsh therefore cannot account for why their preferences matter.

While there are many possible reasons for clinicians' hesitancy to treat over objection—including worries about litigation—their moral reasons for reluctance often seem to be grounded in a more direct aversion to coercive treatments (Navin et al. 2019). Clinicians seem to have a basic intuition that forcible treatment violates a patient's bodily integrity and that it is wrong to coercively intrude on their bodies, save for especially compelling reasons. Therefore, a better explanation for clinicians' aversion to treatment over objection is that they have a sense that patients' preferences matter morally, *regardless* of how well a patient reasons or whether they underwent 'cognitive transformative experiences'.

Walsh asks many of the right questions, but answers them in the wrong way. Her arguments would be more relevant if they had engaged with the practical realities of clinical ethics, and they would have been stronger if they had engaged with the expansive bioethics literature on the topic she addresses (see especially Dresser 1995).

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