RESEARCH ARTICLE



Personhood, Dementia, and Bioethics

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Abstract

Jennifer Blumenthal-Barby (2024) has called for bioethics to end talk about personhood, asserting that such talk has the tendency to confuse and offend. It will be argued that this has only limited application for (largely) private settings. However, in other settings, theorizing about personhood leaves a gap in which there is the risk that the offending concept will get uptake elsewhere, and so the problem Blumenthal-Barby nominates may not be completely avoided. In response to this risk, an argument is presented in support of the idea that the role of philosophers and bioethicists, far from ending talk of personhood, ought to be to clarify the concept, and to do so in nuanced ways, given its application for specific kinds of impairments. The case of dementia is used to illustrate this in the context of person-centered care. Ironically, given the stigma attached to dementia, far from the need to end talk of personhood, bioethicists are needed to rescue the concept and clarify its role.

Keywords: Alzheimer's; bioethics; dementia; personhood; stigma

Introduction

Jennifer Blumenthal-Barby has argued that "it is time for bioethics to end talk about personhood." Her position is motivated by an assessment that ordinary folk find the concept of personhood "...incomprehensible, off-putting, or in direct conflict with their lived and moral experiences."2 This thought might at first appear mysterious because the word "person" is in common use, not like (say) the expression "categorical imperative," or other technical context-specific words. However, Blumenthal-Barby is concerned about a philosophically nuanced sense of "person" especially as it applies to nonnormal cases. She has in mind its application to human beings who are minimally conscious, in a vegetative state, with advanced dementia, brain death, and so forth. Such advanced impairment cases (AICs) bring to the fore a distinction between a human being, and a person, but the latter is to be understood in a sense whose genealogy traces to the philosopher Kant, though David DeGrazia seems correct that John Locke's account is at least as important, maybe more so.³ Nevertheless, the key ideas for this traditional understanding of personhood are that (1) the concept of personhood abstracts away from the material being whose matter it informs and animates, (2) this animation is constituted by certain (necessary and sufficient) personhood conditions, namely the possession of intellect, cognition, agency, and self-consciousness, and (3) these rationality-based conditions are intrinsically (nonrelationally) possessed by individuals.

It follows that, on the traditional account strictly interpreted, someone in a permanent vegetative state is no longer a person, and this has normative implications, especially for the loss of those moral rights that attach to being a person in that sense. Blumenthal-Barby is concerned with how this is expressed to those affected by the loss of such rights. A central worry is the way the traditional account—as presupposed in a theory of personhood and deployed in practical contexts—affects people with close relationships to those with AICs.

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Blumenthal-Barby's claim to end talk of personhood, given its tendency to offend and baffle, is supported by her key philosophical argument. The argument begins with the observation that theorists start with the assumption that we (human persons) matter. A theorist then goes on to identify the features of human persons which are at the core of this mattering. But this "conceptual engineering" approach, she suggests, is question-begging. It has the effect of flattening "the normative conversation," so that "...relevant normative points of debate and nuance get funneled through a very narrow conceptual lens and lost." I will not address this argument directly partly because I think Karola Kreitmair has already successfully done so.⁵ She points out two ways to interpret the position: a methodological way and a pragmatic way. The former refers to the conceptual engineering approach (mentioned above) of "identifying conceptual categories" such as "person" to read off the normative commitments that are issued from such analysis.⁶ The latter refers to the much more modest practice of identifying contexts in which the use of the term "person" will be found jarring and/or offensive. This distinction makes possible the argument that a general ban on personhood talk is not justified. As Kreitmair suggests, its wide-ranging extensions, with the accompanying risk of offending implicatures, do not provide sufficient reason to cease talk of personhood in all contexts. Rather, this fact pushes us toward what, methodologically, philosophers and bioethicists are aiming at: greater clarity.

There are many competing accounts of personhood in philosophy and bioethics, some of which are nuanced versions of the traditional account, and some which are wholly distinct. Since Blumenthal-Barby's argument is directed toward the traditional account, I will indicate this by using the expression "traditional personhood." On the other hand, philosophers, legal scholars, bioethicists, and others will often use the term "personhood" in an undefined/unqualified/intuitive way, as do people who are not philosophers, and so forth. All these groups (academic and non-academic) will at times and in a range of contexts use "personhood" in this undefined/unqualified/intuitive way. To capture this usage, I will use the expression "personhood tout court."

Blumenthal-Barby's concerns arise because bioethicists' deployment of traditional personhood can seem jarring, or absurd (or both), to those in contexts where the concept of personhood *tout court* is in play. In particular, she worries that family members related to those with AICs, as well as clinicians, would find the idea that they do not count as persons (*tout court*) "linguistically and socially odd," "puzzling," or "offensive." And indeed, to suggest to someone that their permanently comatose mother (say) is no longer a person can seem not just uncaring and out of touch but strange or absurd. This is partly because in circumstances like these, traditional personhood abstracts away from the relational elements of (especially) those historical and emotional connections that inform the normative attributions made in the context of caring for close others who are experiencing severe mental impairments. It would seem then, from all this, that if Blumenthal-Barby is right, the best way forward for bioethics is to cease using and applying the concept of traditional personhood, all else being equal.

Retaining personhood and the gap problem

Blumenthal-Barby's article has received significant attention, some supportive, some critical, and some a mixture of both. The response here falls into the latter category, though somewhat more on the critical side. Yes, in general, using the concept of traditional personhood in clinical and certain empirical research settings can be insensitive and counterproductive; however, this is not a reason to end talk of personhood in settings where bioethicists are engaging in theoretical pursuits, or sharing their ideas with other scholars in law and politics. In these theoretical or policy-related contexts, the concept of traditional personhood plays a central role where, for example, we may be considering a range of legal protections or obligations. Now Blumenthal-Barby in fact agrees with this. In a footnote, she remarks

Political, legal, moral and historical philosophers might still have good reasons to engage with and use the concept of "persons" in some contexts (e.g., Kantian moral philosophy, responsibility theory, metaphysics).¹⁰

However, Blumenthal-Barby then goes on to express agnosticism regarding its necessity even in these contexts. Against this, I will argue that retaining, and theorizing about, the concept of personhood for specific types of AICs is desirable because doing so can lead to moral protection for those groups. The case of dementia is illustrative here because, ironically, many people think a diagnosis of dementia consigns an individual to the loss of their personhood status.

The position I defend, then, contains two basic elements: (1) Using, and giving expression to, the concept of traditional personhood in clinical, or care, settings require a degree of discretion and sensitivity, but (2) maintaining and developing analyses of personhood is needed to translate this work for applications in extra-bioethical settings, including biomedical and legal contexts.

These two elements are compatible: someone can respectfully refrain from using or presupposing the traditional personhood concept in certain practical contexts while (at other times) constructing theories of personhood to inform the norms around medicine and law. Consider the connection between traditional personhood and the concept of (legal) competence. 11 An individual who fails to reach the relevant threshold for competence loses certain rights. Although it might be disrespectful, counterproductive, or insulting to express this directly to such an individual or their families, nevertheless measures may be needed for protection in case cognitive impairments place them or others in harm's way. Take, for example, the case of someone whose Alzheimer's Dementia (AD) has severely damaged their autonomy competence thereby triggering a guardianship order. 12-13 Once again, it might be disrespectful, counterproductive, or insulting to explain the basis for this change in terms of the lost conditions we associate with traditional personhood. So, out of respect, no such explanation is presented in those terms. What typically happens is that the relevant decisions are made collectively with family, or based on an advance directive, or based on authority assigned to a proxy decision-maker such as a legal guardian, or some combination of all these. 14 The normativity depends precisely on recognizing the authority bestowed by the reason-making capacities of the earlier person who made the advance directive, or family members, or the legal guardian who meets the standards traditional personhood requires. 15

Thus, the concept of traditional personhood provides important guidance—particularly in legal domains—for decision-making in relation to AICs. Retention of this concept is compatible with Kreitmair's point about pragmatic discretion in the use of personhood talk where there are interpersonal sensitivities. Additionally, we may note that personhood tout court, a concept that is vague and broad, provides almost no guidance concerning what to do in difficult and nuanced questions involving, for example, hospital or hospice care, and financial decisions. These questions require assessments of the capacities of individuals with reference precisely to the conditions for traditional personhood painstakingly developed over a long period.

The concept of traditional personhood ought to be retained by bioethicists because the ontology built into conceptualizations of personhood is what grounds normative concepts like dignity and universal rights. Since bioethicists do, and should, engage with practitioners in law and politics, as well as take part in discussions within public facing, or media-based contexts, it makes little sense to eschew dialog that drops the concept of traditional personhood, implicitly or explicitly. As Dov Greenbaum notes

...[C]ompletely discarding the employment of the personhood concept as it is currently implemented may overlook its vital role, particularly in the practical realms at the intersection of bioethics, policy, and law.¹⁶

The more limited upshot of Blumenthal-Barby's argument, then, far from ending talk of traditional personhood, is to assess the contexts in which the concept of personhood is to be deployed and adjust accordingly. Such a stance in which we coherently present two faces to a difficult situation is both familiar and necessary. This approach is one that bioethicists and theorists of personhood may (and do) adopt, and indeed, since bioethicists (*qua* bioethicists) typically are not engaged with patients and their families (in AICs), the pointy end of this difficulty is not one that looms large for them. This last point brings us to the main difficulty, as I see it, that emerges from this discussion. Should bioethicists eschew the use of the concept of traditional personhood *in their writing*, given the tendency for bioethical views to spread beyond the academy, and given the fact that bioethicists are often speaking directly to others in clinical

and public health contexts to healthcare managers, policymakers, politicians, and the wider public through various media engagements? A bioethicist might scrupulously adhere to the practice just outlined, that is, adopting respectful language for practical contexts, while presupposing the concept of traditional personhood in their writing, but that leaves a gap because views expressed in monographs, journals, and so forth tend to break through the filters of academic life to inform practice. Call the conceptual leakage that occurs here, the gap problem.

Plugging the gap

A radical response to the gap problem is that bioethics should cease talk about, and in terms of, personhood, and not just for clinical or data-gathering contexts, but for theory-making. Blumenthal-Barby seems to respond this way. The idea is that in giving analyses of traditional personhood bioethics prolongs a contested and damaging concept, and this is avoidable since there are substitute concepts, such as welfare subjectivity, and recognition respect, that provide a sufficient basis for grounding the norms that provide moral guidance.¹⁷ In a nutshell, the idea is that we can eschew the offending traditional concept while retaining the proper moral guidance we need in the full range of cases. It is this claim that can be contested.

In agreement with Kreitmair, philosophers and bioethicists posit, and fine-tune, the traditional concept to seek clarity about the nature of personhood, and especially those capacities traditional personhood embodies that ground the normative frameworks in law and politics. Now that *may* come with a cost—the conceptual leakage that Blumenthal-Barby worries about—and one position might be that we can live with the gap, and it is worth the cost, and nothing more can be done. But what bioethicists and philosophers can do (and have done) in response is to develop more sophisticated and nuanced views of personhood. In the next section, I will describe just such an account of AD cases.

I finish this section by explaining why a standard traditional account of personhood—though useful in the law—is inadequate for cases of AD, given the empirical realities of that condition. We should first note that, notwithstanding the legal practice of applying a threshold, personhood is on a continuum. Thus, for those with AD, their legal agency status cannot be determined absent some jurisdiction-relative norm. The trouble is that people who progress through phases of AD move from counting as persons under the traditional conception to not counting as (traditional) persons in the advanced stages of the disease, a period that takes 8–10 years, sometimes even, though rarely, twice that. ¹⁹ But they remain human beings and citizens with corresponding rights to proper treatment (despite losing degrees of agency) throughout. ²⁰ A conception of personhood for these cases is required that accurately captures the changing psycho-physical conditions for grounding the relevant norms of clinical treatment and ethical care. The traditional account then, though certainly useful in judging competence for legal purposes (and deserves retention for at least that reason), is simply unfit to describe what is going on here *fully* for us to infer the correct normative picture, especially as it relates to the ethics of dementia care.

Let me sum up the argument so far. I have distinguished between personhood *tout court*—the ordinary sense of "person" deployed in natural language—and the traditional concept, as defined in the light of Locke and Kant. There is a third category, the nuanced sense of "person," that philosophers and bioethicists develop in the context of specific cases, for example, in care contexts for people living with dementia. Blumenthal-Barby's call for bioethicists to end talk of personhood, seen against these distinctions, puts the position into sharp relief. It makes sense when understood pragmatically that using the traditional concept in a care setting will be misunderstood and unhelpful. Nevertheless, that fact is not sufficient to ban the traditional concept when considering its applications in legal and political contexts. Yet, both personhood tout court and the traditional concept are not suitable in contexts, particularly care contexts, where an individual meets neither definition but retains elements of both. Accounts of personhood with both have been put forward and continue to be fine-tuned in ways tailored to different kinds of impairments, including dementia, as I outline below. But first, I present a strong motivation against Blumenthal-Barby's position: the need to push back against the tendency to falsely think dementia destroys personhood.

An irony: The need to keep talk of personhood for cases of dementia

Blumenthal-Barby's call to end talk of personhood for cases of dementia is motivated by her worries that bioethicists are potentially imposing on families of AIC individuals and clinicians a concept of personhood they find alien and offensive. But ironically, many people putatively hold an even more offensive view: that an individual who is diagnosed with dementia has potentially (or even actually) *lost* their personhood, when no such thing is true, even in the middle stages of the condition. As we will see, there are a variety of ways this idea is expressed—for example, that dementia leads to "social death"—and for those on the receiving end, it is highly stigmatizing and psychologically damaging. The irony is that bioethicists, gerontologists, psychiatrists, and philosophers have been, for many decades, at pains to push back against this tide and describe the ways in which people living with dementia retain personhood, and one reason for doing this has been to introduce models of *person*-centered care (PCC).²¹

To fill this out, consider that Blumenthal-Barby's position is motivated by her experience co-conducting a study involving patients with disordered consciousness, related family, and clinicians. Asking questions about personhood was found "puzzling and offensive," and "a similar point holds for the suggestion that individuals with advanced dementia are no longer persons. Be garners support from Hilde Lindemann, who notes that personhood talk is employed by "philosophers" and "educated people," and that "...if you'd asked us [her family members] whether [Carla, her sister who died at the age of 18 months] was a person, we would have pitied you for being a philosopher and said 'Of course." Now, although Lindemann seems right in this instance, where personhood *tout court* is ascribed to *a close relative*, that fact provides no reason to think either that nonphilosophers do not use or accept the traditional account, or to the claim that nonphilosophers presupposing the traditional conception wrongly fail to ascribe it to people with cognitive impairments to which they have *no close relationship*. In fact, there is evidence for both these claims.

There is an irresistible tendency among people to think of neuro-normal individuals as persons in the traditional sense.²⁵ And so, in virtue of a false understanding of the speed at which AD erodes human capacities for cognition, people then regard those diagnosed as losing their personhood, in that sense. Given that the traditional view is seen to have default application among, and toward, neuro-normal people, its effect is to fuel the stigmatizing belief that for those diagnosed with AD, a loss of personhood (traditionally understood) quickly follows. However, the evidence shows that most people with AD, even some in the moderate range, retain to a significant degree attributes that would qualify them for the traditional category.²⁶ We can say, then, that the harmful reticence by ordinary folk to ascribe personhood to those with dementia softens Lindemann's point about pitiable philosophers who misapply the concept in other contexts. Ironically, the reverse applies in this situation. Indeed, philosophers and bioethicists have put forward accounts of personhood for people living with dementia and have done so partly to respond to the harmful stereotypes and myths about dementia that are widely internalized by ordinary non-philosophers-for example, that dementia is a "living death," that with dementia "you lose your self," that it quickly turns people into zombies and so forth. Dementia stigma results in a complex interaction between cultural (including especially media) stereotypes²⁷ and the beliefs generated by interpersonal interactions.²⁸

Another argument: Too many accounts of personhood is not a reason to discard the notion

Blumenthal-Barby is not the only writer to suggest that talk of personhood is unhelpful and potentially harmful. For example, Paul Higgs and Chris Gilleard have argued for abandoning the concept of personhood in dementia. They premise this by claiming there are many incompatible and contested conceptions:

...we seek to address the use of the concept of personhood and its utility for dementia care... Differences between... positions result in multiple possible versions of personhood with the result that some have considered the very idea of personhood "logically confused and morally objectionable"...We are undertaking this task...to avoid what we identify as a potentially unhelpful gap developing between an increasingly professionalised rhetoric of "person centred care" and the everyday social realities facing those who provide such care. There is a danger, we argue, that in placing such a confused and confusing concept as personhood at the centre of any set of organisational practices of care it risks undermining the basic moral imperative of care that is central to society's responses to disabling old age...²⁹

This is an argument from risk. The idea is that because there are so many differing accounts of personhood, their uptake into practice will lack coherence; so perhaps it would be safer to avoid making this tangled web even worse, with accompanying misdirection for the practices upon which it is based.

However, this problem may be addressed on other grounds, in so far as we delineate with greater clarity the different uses of personhood. As Paula Boddington and colleagues remark

We argue against abandoning the use of the term "person" in relation to people living with dementia, not in spite of, but precisely because of its varied meanings and usage. The contradictions and tensions between different accounts of what it is to be a person can function as a valuable clue to important philosophical and ethical issues, and are not a reason to discard the notion of the person or to replace with an alternative concept.³⁰

The views of Higgs and Gilleard and Boddington et al need not be thought wholly incompatible, and there is something correct about both of them: there is indeed a lacuna between the rhetoric of personcentered care and its application, but like Boddington et al, I take this situation to motivate the development of better and more relevant conceptualizations of personhood so that we may ameliorate the risk of harms to people living with dementia and their families, something all sides of the debate agree on. This motivation should be seen in the context of the stigmatization of dementia mentioned earlier.

A desideratum for providing a theory of personhood suitable to the care of those living with dementia is that it should be based on the most accurate biomedical and neuro-psychiatric science to account for and accommodate the changes in cognition that accompany progressive losses in function. It should make no other accommodations: our default assumption should be that individuals living with dementia are no different from neuro-typical people except for the cognitive impairments wrought by the relevant disease. (As noted above, Alzheimer's impairs an individual almost imperceptibly slowly.) Viewed any other way would be to covertly—and no doubt inadvertently—import prejudices against people with dementia sourced from the very stigmatizing beliefs an account is designed to push back against. This morally inclusive position acknowledges that a person newly diagnosed with dementia remains a person. Early signs and symptoms in AD are typically subtle and vague and include some difficulty remembering recent events, reduced concentration, a sense of apathy, and challenges in completing everyday tasks. However, the basic conditions for the traditional account of personhood remain almost wholly intact in the early stages. The challenge for a theorist of personhood and dementia is to account for its middle and later stages when the conditions for the traditional conception are threatened, namely those processes that underlie thinking, rational agency, self-awareness, and perception.

Retaining personhood for PCC

In AD, the capacities for personhood erode over many years. Diagnoses take time and progression of symptoms varies. In the critical middle stages of AD, some elements of traditional personhood remain, and some are permanently lost, and the changes do not occur in a linear fashion.³¹ Thus, people with middle-stage Alzheimer's find themselves liminally positioned—between personhood (in the traditional understanding) and its absence—and this is a morally vulnerable place to be.

The capacities we associate with traditional personhood do not simply switch off. Importantly, people commonly report that their sense of being the same self as they were prior to illness is retained.³² Given this, it would be unwise to think that those with AD at this point are not persons, at least in some robust

sense, and it would also be unwise to give up on the language of personhood that presupposes it. Perhaps the most famous theorist on these questions—Tom Kitwood—certainly thought so, developing a model of *person*-centered care. As Sam Fazio et al describe it as follows:

Kitwood and Bredin (1992)³³ shared evidence from studies of different care practices, suggesting that dementia does not universally progress in a linear fashion, and most importantly, it varies from person to person. They concluded that the person with dementia is in a state of relative well-being or ill-being, and that indicators can be observed through detailed observation. They found a need for high-quality interpersonal care that affirms personhood; one that implies recognition, respect, and trust. The approach that Kitwood and Bredin developed to fill this need was person-centered care.³⁴

Tieu and Matthews have put forward an account of personhood in dementia that recapitulates the work of Kitwood. Kitwood's "enriched model of dementia," described it not only as a biological or neurological condition but also as a psychological and social one. ³⁵ In agreement with Kitwood, they highlight the fact that dementia symptoms stem from various factors, including physical health, personal history, personality, and social surroundings. The ethical basis of PCC lies in recognizing individuals with dementia as persons, interpreted, they argue, as being in possession of an *overarching sense of continued selfhood*. This way of conceptualizing PCC privileges their perspective and views the individual as having an ongoing identity forged relationally and historically.

In support, recent studies highlight a shift toward preserving or enhancing continuity of selfhood as the central aspect of PCC.³⁶ This involves maintaining a sense of identity based on past, present, and future experiences, preferences, goals, relationships, and well-being. Reflexivity, or self-awareness, plays a crucial role in this conception of personhood, alongside a temporal dimension reflecting one's roles and relationships over time. Importantly, people living with dementia, even advanced dementia, maintain their agency, albeit in limited ways, and they do so when they are enabled to make sense of their situation. Respect for agency requires thinking of people as sense-making beings, not merely recipients of welfare ("welfare subjects" in Blumenthal-Barby's gloss), this latter concept tending more toward a pacifying or infantilizing treatment.³⁷

Although PCC is widely seen as the gold standard in aged care, as Boddington et al acknowledge there is a lack of consensus on its precise definition. This ambiguity arises from the varied interpretations of what it means to be a person within the context of PCC. Some interpretations overly prioritize individualization, neglecting the social aspect emphasized by Kitwood. In many Western societies, PCC has been shaped by an ideology that emphasizes independence, self-management, and consumerism. These qualities do not reflect how traditional personhood ought to be understood even for neurotypical people, given the social conditions that undergird personal interactions, let alone what is required for people living with dementia. A more balanced approach is both required and possible, stressing the importance of interdependence, shared decision-making, and strong relationships between caregivers and clients, aligned with broader social networks. The research that supports this view (see note 36) indicates that meaningful relationships significantly impact the quality of life for people with dementia, aligning with Kitwood's original principles.

PCC for people living with dementia was put in place precisely in opposition to heavily medicalized models of care with their presuppositions of "loss of personhood." If we end talk of personhood, the use of a substitute concept for the treatment of people living with dementia, for example, as mere subjects whose welfare must be attended to, we will lose sight of the fact that personhood provides the normative grounding for the respect that is due to people who are at the most vulnerable point in their lives.

Conclusion

The position presented here in response to the call "to end talk of personhood" has several strands. First, in agreement with Kreitmair, I offer limited support for Blumenthal-Barby under its pragmatic

interpretation. Second, I suggest that the gap problem—in which writing and theorizing about person-hood inevitably feeds into policy and practice—is arguably worth the cost, given the important role the traditional concept of personhood in fact plays in our extra-bioethical practices that are governed by legal or policy norms. Third, again in support of Kreitmair's idea that the role of philosophers and bioethicists is to gain conceptual clarity in relation to a concept of personhood, I have provided an illustration in the form of the right concept of personhood as this may be applied in PCC for people with dementia. I have emphasized the need for this—as I say ironically—given the broader cultural context in which ordinary folk all too quickly apply depersonalizing and stigmatizing labels to those living with dementia, labels that deny their agency and their moral status as persons.

Competing interest. The author declares none.

Notes

- 1. Blementhal-Barby J. The end of personhood. American Journal of Bioethics 2024;24(1):3-12, at 3.
- 2. See note 1, Blumenthal-Barby 2024, at 7.
- 3. DeGrazia D. Putting a pronouncement about personhood into perspective. American Journal of Bioethics 2024;24(1):13–5, at 13. John Locke famously—in book 2, chapter 27 of An Essay Concerning Human Understanding—offers a developed metaphysic of the person, explicitly distinguishing the conditions for person and human being, such that one's accountability tracks the continuity of consciousness that is potentially separable from the human being that contingently hosts that consciousness. Kant is more concerned directly with autonomy and rights: rational agents acting in concert with other rational agents see them as ends-in-themselves (generating rights) while doing so autonomously by internalizing a universal moral law. The thought, then, is that an individual with severe cognitive impairments continues to survive as a human biological subject, but not a person (Locke), and in so far as that is true the individual thereby lacks the capacity for autonomy and loses those rights tied to such capacity (Kant).
- 4. See note 1, Blumenthal-Barby 2024, at 5.
- Kreitmair KV. Personhood and the importance of philosophical clarity. American Journal of Bioethics 2024;24(1):35–8.
- 6. See note 5, Kreitmair 2024, at 35.
- 7. See note 1, Blumenthal-Barby 2024, at 6.
- 8. Blumenthal-Barby's paper appears in the *American Journal of Bioethics* and it received 25 open peer commentaries.
- 9. Greenbaum D. Reconceptualizing personhood in bioethics and law: A spectrum-based approach. *American Journal of Bioethics* 2024;24(1):38–40.
- 10. See note 1, Blumenthal-Barby 2024, at 11.
- 11. Young, R. Medically Assisted Death. Cambridge: CUP; 2007, at 137.
- 12. Unless otherwise specified I will be discussing Alzheimer's dementia. According to the most recent Alzheimer's Association report Alzheimer's represents between 60 and 80 percent of total dementia cases.
- 13. Alzheimer's Association Report. Alzheimer's disease: Facts and figures. *Alzheimer's & Dementia* 2023;**19**(4):1598–695. doi:10.1002/alz.13016, at 1601.
- 14. A wrinkle here is that in acting for the sake of the earlier decision, it seems to be a question of *personal identity over time* that is raised, rather than personhood. Nevertheless, on a nonreductionist account of personal identity, although the later self loses legal personhood status, the *authority* to give effect to the earlier decision through an advance directive (and other means) presupposes legal personhood status of the earlier self. Thanks to an anonymous referee for seeking clarification on this point.
- 15. Like competence, use of "personhood" in medicine and law is typically threshold-setting: the presence of personhood capacities to a specified level provides the ontological ground for the norms that operate in those spheres. In law, particularly, the application of rights and protections (that

- accrue to patients), and obligations (that apply to professionals), requires those levels to be nominated and acknowledged.
- 16. See note 9, Greenbaum 2024, at 38.
- 17. See note 1, Blumenthal-Barby 2024, at 8-10.
- 18. See note 5, Kreitmair 2024, at 37.
- 19. See note 13, Alzheimer's Association Report 2023 for a thorough treatment of the empirical realities of AD.
- 20. This point would appear to support, rather than deny, Blumenthal-Barby's concerns that the personhood concept imports unnecessary norms and potential offensiveness. But to clarify, though I agree that the traditional account is misplaced here, our response ought not jettison either the traditional account (given its place elsewhere in legal and policy contexts), or to balk at the work needed to develop nuanced accounts of personhood, as sketched below for the case of dementia. Thanks to an anonymous referee for prompting the need for clarification here.
- 21. Some well-known writers who have pushed back include Tom Kitwood, Steven Sabat, and Julian Hughes. See Kitwood TM. Dementia Reconsidered: The Person Comes First. Ann Arbor, MI: Open University Press; 1997; Sabat SR. Alzheimer's Disease and Dementia: What Everyone Needs to Know. New York: Oxford University Press; 2018. Hughes J. Dementia and Ethics Reconsidered. Maidenhead: Open University Press; 2023.
- 22. Kostick KM, Halm A, O'Brien K, Kothari S, Blumenthal-Barby JS. Conceptualizations of consciousness and continuation of care among family members and health professionals caring for patients in a minimally conscious state. *Disability and Rehabilitation* 2021;43(16):2285–94.
- 23. See note 1, Blumenthal-Barby 2024, at 6.
- 24. Lindemann H. *Holding and Letting Go: The Social Practice of Personal Identities.* Oxford: Oxford University Press; 2014, at 10.
- 25. This assumption is so deep-seated I know of no clear social science that seeks to test it. However, a neat way of indirectly establishing the idea is to consider the ubiquity of folk psychology (or theory of mind), in which the capacities we have for understanding behavior involve meta-representing the attitudes, and contents of, (typically) beliefs and desires of others. This implied attribution of rational competence to others brings with it an attribution of personhood, precisely because attributing rational competence can be re-described as attributing to another the conditions for their personhood. Indeed, as Hutto and Ravenscroft note, folk psychology sometimes goes under the name 'the person theory of humans'. See Hutto D, Ravenscroft I. Folk psychology as a theory. In: Zalta EN, ed. *The Stanford Encyclopedia of Philosophy* (Fall 2021 Edition); available at https://plato.stanford.edu/archives/fall2021/entries/folkpsych-theory/ (last accessed 23 Aug 2024).
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