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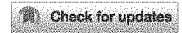
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The Moral Weight of Preferences: Death, Sex, and Dementia

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Ana is a 73-year-old woman experiencing the early phases of mid-stage dementia. Before dementia symptoms onset, Ana lived alone for twenty years, following a divorce in her late forties. Three years ago, when Ana first displayed signs of early dementia, she went to live with her adult son and his family.

Six months ago, Ana, her son, and her daughter made the shared decision for Ana to move into an assisted living residence for dementia patients. Ana regained a sense of independence from her adult children and has professional, supportive caregivers helping with her progressive needs. Ana lives in her own room, gets herself dressed daily, and eats strawberry ice cream whenever available. She also has developed a romantic, and sometimes sexual, relationship with her neighbor down the hall.

In “Cognitive Transformation, Dementia, and the Moral Weight of Advance Directives,” Emily Walsh raises pertinent questions regarding the stability of preferences, and interests, across time, particularly in the setting of dementia diagnosis (Walsh 2020). Advance directive policy and practice rely on an at least somewhat coherent account of personal identity, and we largely agree with Walsh that dementia raises complex issues for philosophical accounts of personal identity.

What does it mean for Ana’s personal identity if she develops different preferences as her dementia progresses? She now eats ice cream although she never liked sweets before, and thought them unwise dietary choices. Ana dresses in clothing her pre-dementia-self purchased. But if she prefers to wear her clothes in new ways, or no longer cares (or notices) that the

prints clash, does this change something about who she is?

If relatively inconsequential preferences shift as dementia progresses, perhaps more weighty preferences also change, such as medical treatment preferences in an advance directive. It seems the moral weight of Ana’s newfound preferences to eat strawberry ice cream and wear checks with stripes are not weighty enough to warrant anyone overriding her choices in favor of her prior preferences, nor do they suggest that she has become an entirely new person.

But preferences and choices related to ice cream and advance medical directives are neither morally nor legally equivalent. Presumably Ana never established a legal document stating strawberry ice cream should be withheld from her in the future. We disagree with Walsh’s conclusion that surrogates, whether clinicians or family, may be either legally or morally justified in overriding an advance directive for a dementia patient, based on a surrogate’s perception of the patient’s best interest.

Whether or not Ana’s current self is continuous with her prior self is presumably at the crux of why Walsh employs L.A. Paul’s concept of “transformative experience.” Though many experiences are transformative, we are skeptical that Paul’s concept of “transformative experience” as a *technical* term applies, let alone cashes out in useful ways in this context.

For Paul, because we cannot know how a “transformative experience” will change us, the *choice* to undergo a “transformative experience” is irrational (Paul 2016). We can make a choice, but we cannot soundly reason our way into it. Paul’s theory is about

the *choosing* of a “transformative experience.” Yet many experiences that transform us are unchosen, such as medical diagnoses, and not all transforming experiences are “transformative experiences” as defined by Paul.

Walsh’s deployment of “transformative experience” suggests that even if a transforming experience is unchosen, Paul’s theory could still apply when making choices for our future selves. We agree that choosing for future selves is epistemically complicated. However, we aren’t convinced that Paul’s theory applies to the transformative effects of any (unchosen) experiences. Walsh’s analysis suggests the very concept of dictating preferences for your future self is unsound. This argument yields ethically and practically unsavory conclusions.

Ana might prefer strawberry ice cream, but still accept chocolate, if given a choice. This is different from a preference to not receive artificial nutrition or hydration if Ana’s dementia progresses to the point where she can no longer feed herself by mouth. If Ana has clearly indicated this preference in a valid advance directive, the preference takes on a different status. It is arguably inappropriate to even *ask* Ana, as she suffers from dementia such that she cannot feed herself, if she still wishes to decline artificial nutrition or hydration. Her prior, legally competent, self already made a decision, anticipating this very moment when she would lack capacity to make an informed choice.

Advance directives have, as the author rightly identifies, particular *legal* weight. They translate preferences into actionable choices that a capacitated person makes prior to the moment in which she lacks capacity to make choices. Accordingly, even if we accept the author’s challenge of the *moral* weight of advance directives (and we do not), it at best shows that the legal scheme surrounding advance directives should be modified, not that we should permit countervailing bedside judgments of clinicians and surrogates (see Hart 1994).

Either the author accepts that advance directives should be legally permissible, and therefore given legal force, or thinks the moral risk of changed preferences should render the legal scheme impermissible. The middle ground we suspect Walsh hopes to inhabit is untenable, as any introduction of extra-legal decision-making, even if supposedly in service of the best interests of people like Ana, renders the legal force of advance directives moot (for any advance directive, not only those of dementia patients).

The more salient, and sticky, parts of Walsh’s analysis are moral implications of modified preferences in

areas that fall outside the scope of advance directives. We take it that we and the author would agree that contemporaneously expressed preferences about many features of daily life by persons with dementia can and should be respected. If Ana did not eat strawberry ice cream pre-dementia, she can still reasonably decide to eat it during her dementia progression. But what about decisions that depart from apparently prior-held preferences, and which have more serious implications? What about, for example, her new sexual relationship?

There are at least two potentially fraught elements of this relationship. The first is whether Ana is in a position to consent to sex, and the other is whether an assessment of her consent ought to be informed by her previously held preferences, or external perceptions of best-interest. We have argued elsewhere that although there is a relatively bright line in the law according to which consent demarcates between sex and rape, in moral terms this line is frequently much dimmer (Fyfe and Lanphier 2020).

We might not always be able to offer valid legal consent to sexual encounters if they occur when our capacity to consent is compromised. Engaging in sex under the influence of drugs or alcohol is a prime example, but compromised consent could also occur when individuals face other temporary or permanent limitations (intellectual disability, dementia, being under the age of majority), rendering them outside a legal competency threshold (McGuire and Bayley 2011; Oberman 2000).

This is where things get uncomfortable. People who have diminished capacity are often more vulnerable, particularly to sexual and other forms of abuse (Stavis 1991). Yet individuals with diminished capacity can also engage in satisfying, chosen, sexual experiences (Stavis 1991). For Ana, the moral and legal stakes of her perceived capacity to consent to sex, and her perceived best-interest, are high.

What if Ana’s children learn of her relationship and are outraged that the residence has allowed their mom—who never to their knowledge had romantic relationships since her divorce—to engage in sex now? Does her known past behavior reflect something about who she was or is that ought to be part of her durable personal identity, and “preserved” by her caretakers? It is also likely that Ana’s children are not privy to every aspect of their mother’s sexual choices, before or after her dementia onset. To let them substitute their own judgment of her prior preferences for her current preferences seems wrong.



Alternately, do caregiver perceptions of Ana’s current quality of life matter in assessing her sexual

choices? If residence caregivers notice Ana's euphoria within her romantic relationship, and how tender she and her partner are toward each other, is this assessment of well-being and safety sufficient to assess her best interest? How does or should this assessment interface with the law that might suggest Ana is not capacitated to give meaningful consent to sex? (Her partner living in a residence for dementia patients presumably also lacks capacity to legally consent, which may change perceptions of vulnerability in this instance.) Should caregiver perceptions override the legal standard of capacitated consent? Is this an appropriate form of bedside adjudication?

Though we disagree with Walsh's conclusions regarding the durability of advance directives, we agree that taking seriously current choices and contemporary preferences of persons with dementia is morally important. Honoring Ana's sexual preferences could be a permissible, though nonideal, form of ethically justifiable non-consent (Fyfe and Lanphier 2020). However, the moral weight of these preferences does not raise her sexual encounters to meet a legal threshold of consent; the legal problem is distinct, and unresolved.

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“Why Should Adamancy of an Uninformed View Give Moral Weight?”

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Emily Walsh's (2020) argument does an excellent job of identifying key problems with the philosophical emphasis on precedent autonomy and the corresponding discounting of the current expressed desires of people living with dementia. In my view, Walsh's piece expands and updates the powerful arguments previously made by Rebecca Dresser and Peter Whitehouse (1994). The worry is that competent people who write advance directives (ADs) are not in the kind of privileged position philosophers and others often presume, and that their future, demented selves

may be inappropriately and unfairly controlled by their prior, epistemically and personally distant selves. In other words, people who make ADs to guide their medical care in the event of loss of decisional capacity often do not recognize what life might in fact be like for them once they experience the transformative effects of progressive dementia. Indeed, on the transformative experience view (Paul 2014), if the experience transforms them personally, they *cannot* know (at least not how it will affect them personally, in terms of knowledge and values or preferences).

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