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Understanding Advance Directives as a Component of Advance Care Planning

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Walsh (2020) presents an argument against what she calls the received view of advance directives in the philosophical literature, suggesting instead a view that she believes is supported by “real clinical practice.” However, the argument she presents has radically disruptive implications for clinical practice and is greatly at odds with current expert clinical recommendations. For example, Walsh argues for more stringent regulation of advance directives, and goes so far as to suggest that websites that facilitate advance directive completion should be banned. Yet clinicians have argued that onerous legal requirements for advance directives have adverse consequences, particularly for vulnerable patients without access to the legal consultation that Walsh treats as essential (Castillo et al. 2011; Rolnick et al. 2017), and have designed large-scale clinical trials to validate the efficacy of advance directive completion websites in diverse populations (Sudore et al. 2018). Walsh also extends her argument in passing to object to advance directives that designate surrogates or powers-of-attorney to decide on patients’ behalf, where expert clinical groups have advocated for such documents as essential components of patients’ care plans (Nuffield Council on Bioethics 2009; Institute of Medicine 2015). While Walsh presents her position as a defense of clinical common sense, there is a chasm between her proposals and clinical best practices (as well as the clinical practice of the second author of this commentary).

What accounts for the divergence between Walsh’s skepticism about advance directives and the importance placed on advance directives by clinicians? One problem appears to be Walsh’s antiquated and narrow conception of the role of advance directives in clinical decision-making. Crucially, Walsh does not address

the broader concept of *advance care planning*, of which advance directives are in most cases a critical component (Sudore et al. 2017). Advance care planning, understood as a process, has well-established clinical benefits for patients and families, including: improved communication between family members and clinicians, increased patient and family satisfaction, reduced family member stress and anxiety, and increased use of hospice care (Teno et al. 2007; Silveira et al. 2010; Detering et al. 2010). It is unfortunate that Walsh does not engage with this clinical literature.

Several of Walsh’s arguments echo well-known limitations of advance directives in medical decision-making. It can be difficult to prognosticate a patient’s course and make advance decisions for predicted clinical states, and directives that refer too narrowly to specific treatments can fail to leave room for interpretation or to offer guidance about decisions beyond those envisioned. However, clinicians caring for patients with dementia have responded not by discounting the moral weight of advance directives or advocating legal barriers to advance directive completion. Rather, clinicians have adopted a conception of advance care planning focused on better understanding patients’ values and goals of care, to safeguard autonomy and ensure that patients’ wishes are respected in the event that they are unable to make their own care decisions. The goal of such planning is not to rigidly specify care decisions in advance, without regard for how patients’ preferences may be changed in the course of illness. Instead, clinicians have argued for a more inclusive conception that prepares for flexibility and shared decision-making, providing patients with the opportunity to explore their personal

values and discuss their thoughts about future care with others (Sudore et al. 2017).

Within this broader conception of advance care planning, advance directives are not seen as a goal or endpoint of planning—some patients may undergo planning without completing an advance directive, and unfortunately many patients who have advance directives have not done effective planning. Still, advance directives continue to serve several important purposes in advance care planning. First, these documents are tools to begin important discussions about end-of-life care, related goals and values, and, if desired, medical orders on particular treatment interventions. Second (though perhaps first in importance for patients with dementia), advance directives are used to identify surrogates capable of making decisions for the patient according to his or her values. Here it is not sufficient to merely designate a surrogate, as in Walsh's case of Mr. White. The designation of a surrogate must be supplemented by conversations preparing the surrogate for the important role of decision-making on behalf of the patient in light of the patient's values (which for most patients will include regard for the patient's current well-being). Patients who have not identified a surrogate decision-maker, or have ill-prepared surrogates (as in Mr. White's case), are more likely to be subjected to unnecessary interventions that are burdensome and inconsistent with their goals of care. Parenthetically, it is curious that one of Walsh's cases involves the insertion of a feeding tube contrary to a patient's advance directive, as tube feeding is associated with medical complications including pressure ulcers, often necessitates the use of physical or chemical restraints, has not been shown to promote survival or quality of life in dementia, and is considered a marker of low-quality dementia care (Mitchell 2015). Finally, advance directives confer appropriate legal authority to selected surrogates to make decisions on patients' behalf when patients lose capacity, as all patients with dementia should prepare for the likelihood that they will lose decisional capacity in the course of illness. Without an authorized decision-maker, a court-appointed conservator or deputy (who may not know anything about a patient's values or wishes) may be charged with making decisions for incapacitated patients; or family members may need to petition the court in order to make these decisions on behalf of patients, a costly and burdensome process that may do little to promote the patient's interests or autonomy.

The overall aim of advance care planning is to prepare patients, caregivers, and clinicians to navigate

complex treatment decisions when patients are unable to do so themselves, while also ensuring that they have an adequate understanding of the values and goals that guide decision-making. While the goals of advance care planning have shifted with recognition of the limitations of advance directives, such directives remain important to appropriate end-of-life decision-making and advance care planning.

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

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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.

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