

Commentary: On The Moral Bindingness of Advance Directives

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Advance directives (AD) are creatures of law, and it is perilous to write about creatures of law for any audience as international as that of the CQH. Law creates differently in different places. Indeed, one of the biggest challenges for me in reading Gianluca Vergallo's essay¹ has been for me to realize that, when I disagree with him, it is often because we are talking about different things.

Consider the very first sentence of Vergallo's abstract: "Advance directives entail a refusal expressed by a still healthy patient." First, I must register a quibble as to the modifier "still healthy." Vergallo must mean only 'still competent' here; otherwise his later claim that an AD should be binding only if created when an illness is already in progress would be self-contradictory. More importantly, though, as to an AD's necessarily entailing 'a refusal': while that definition seems to hold for an AD in (for example) England, it emphatically does not hold in the United States, where in many states an AD can as legally be a series of demands for invasive lifesaving procedures as for refusal of intubation or antibiotics. Nor does it seem to hold true in Vergallo's own Italy.² And the lesson about diversity is more broad: within the United States alone (where most bioethical issues are handled at the state level), there are several different approaches to AD. Three states have no statutory provision for AD, but instead recognize them through case law. 31 states plus Washington, D.C., have AD-specific statutes; another 13 have statutes that combine AD with a process for granting a durable power of attorney for healthcare.³ In a few states, AD are actually binding (as they are in the UK); in most they are not, but instead influence physicians by providing immunity from malpractice liability if their instructions are followed. In some states, AD are triggered by any permanent loss of capacity; in others they are triggered only by a diagnosis of irreversible loss of consciousness or by incapacity combined with a terminal illness. In Italy, the new AD law appears to differ from the American models by being much more broad; whereas United States AD statutes and forms tend to confine themselves to questions of wanting or not wanting various forms of life-saving and life-sustaining treatment (CPR, artificial nutrition and hydration, mechanical ventilation, and so on), the Italian AD seems to give patients a chance to speak broadly as to their future desires for diagnostic options and the full range of medical treatment. The Italian law provides that AD are binding on physicians unless they are incongruous with the patient's actual condition insofar as they, for example, refer to conditions the patient doesn't have, or ignore newly-developed therapies. And the Italian law is triggered by incapacity, rather than by permanent incapacity or permanent loss of consciousness.

This variety of course raises the question, which jurisdictions are getting it right? So I am happy to leave aside, as far as possible, positive-law concerns about what ADs actually are or are not in this or that jurisdiction. I will instead concentrate on what I take to be the core of Vergallo's argument, namely, the normative argument that AD should only be (let us say morally rather than legally) binding

upon physicians if they were created by a competent patient during the time in which the illness that would eventually render the patient incompetent was already in progress. The rough idea here is that AD can only be binding if patients are adequately well-informed when the AD is drawn up; the model here is the standard normative model of informed consent. Vergalla claims an AD can only be adequately well-informed if the patient who writes it is, at the moment of writing, well-informed of a particular diagnosis and its associated prognosis. An AD made in the abstract, before the onset of any particular illness, is necessarily ill-informed and should therefore not be bindingly action-guiding. The proper course for the physician is to consult it, as one piece of information among others, within the patient/physician therapeutic relationship.

Vergallo makes repeated claims that “decisions by patients before [a] disease manifests itself cannot be as well-informed as those made while the disease is still in progress.” This seems to me to be true of some kinds of decisions, but not of others. In particular, it seems to me to be true of certain broad decisions permitted in the Italian law but not in American law; and not to be true of the most typical kinds of refusals contemplated by the rather more narrow American-style AD—though such refusals are part of what is permitted within the Italian law. Consider the case of my 88-year-old mother, for example: a competent woman with limited mobility but with no particular illness. She’s certain that she does not want to be resuscitated in the event that she should code. She’s spoken with physicians about the effectiveness of these interventions, and about the burdens and suffering they can impose. She knows that only a tiny minority of people her age survive to discharge after in-hospital CPR (it’s around 15%), and she knows that CPR can cause rib and lung damage, and even brain damage. So she doesn’t want to risk it. I cannot see how her decision would be better informed if she were suddenly made aware of a terminal cancer diagnosis. Or consider someone’s decision to refuse artificial nutrition and hydration, or intubation and ventilation, if ever they are diagnosed as permanently unconscious. It is clear that, prospective though such decisions may be, they can indeed be “informed and considerate,” even in the absence of the onset of any particular fatal illness. Indeed, it is difficult to see how the onset of any particular fatal illness would better inform them, since they are value choices about whether it is appropriate to sustain unconscious life, rather than prudential choices about which treatment option might be optimal. Certainly they are not, as Vergallo seems to assert is true of all prospective decisions, “almost random, grounded on emotions and sensations, rather than sound reasons.”

It may be that Vergalla and I have no real disagreement here. Late in his paper he seems primarily to be opposed to AD as a mechanism for advance consent to, or dissent from, particular treatment plans. He seems to admit, his early rather broad argument against all prospective consent notwithstanding, that AD are best suited to situations in which patients “are determined to refuse, rather than accept” various life-sustaining procedures such as CPR, artificial nutrition and hydration and mechanical ventilation. In other words, many of his objections to the bindingness of AD might evaporate if Italian AD were as narrow as American.

Vergalla is troubled by the fact that a patient, once incompetent, may not be able to revoke her earlier AD choices. The choices made when healthy, he worries, may not be the ones the patient would make when sick. Disturbingly, he assumes that terminally ill patients “would want to try any possible kind of treatment available, no matter how invasive, in order to stave off or slow down their demise.”

This assumption flies in the face of history; AD have been developed precisely because many terminally ill patients have not wanted the invasive treatments pressed on them in the post-war years by the new high-tech medicine. The fact that AD allow patients to determine the course of their future care after they've lost competence was supposed to be the most desirable feature of AD, but Vergalla treats this feature as a bug.

How much of a bug it might be will again depend upon the exact legal structure of the AD. If we are dealing with an AD that goes into effect whenever a patient loses capacity, even temporarily (which seems to be the case with Italy's new law), Vergalla's worry seems better justified. We can think of the healthy, young 25-year-old who writes an AD specifying that he does not want his life saved if he will not be able to walk. It is easy to imagine the patient (eventually) being grateful that treatment had been supplied against the instructions in his AD. We know that many people accommodate themselves to disabilities that they might previously have thought intolerable. If, on the other hand, we are dealing with an AD like those common in the US—which are triggered only by permanent loss of capacity or consciousness—then the possibilities of preference-change and accommodation will often (not always—see below!) seem irrelevant. And in addition, changes in medical technology that could cure the previously incurable, or restore to consciousness the previously un-restore-able, would also change the applicability of AD to patients in those circumstances. If technology changes in such a way as to make you no longer permanently unconscious, then your AD does not apply. This is perhaps why, in the second section of his article, Vergalla speculates that living wills may be most valuable in cases of permanent unconsciousness or incapacity.

Toward the end of his article, Vergalla contrasts advance treatment planning with advance directives, and determines that advance treatment planning—a kind of shared-decisionmaking around the treatment plan of a patient who faces a reasonably well-charted illness trajectory—is the preferable option. This seems to me like a false choice, at least with regard to some aspects of AD. Yes, advance treatment planning is probably preferable to a broad AD in which the patient holds forth about what treatments he wants if he gets Parkinson's and what treatments he does not want if he has brain cancer. And indeed, on the whole, advance treatment planning sounds like an excellent idea. But it cannot be thought of as a substitute for AD that address desires specifically related to life-support and life-saving interventions. AD can give voice to patient preferences given sudden, unanticipated and devastating events—the stroke, the automobile accident, the unexpected heart attack—that are never going to be subjects of advance treatment planning.

I will end this commentary by raising a circumstance in which I am, personally, not clear on the question whether AD should be considered morally binding. I am thinking here of the case of the happy demented patient. Suppose that, when competent, a patient fills out an AD that specifies that, in the event of dementia, he wants to receive no antibiotics. He has no desire to continue avoiding death once he is demented; in fact, the idea of living with dementia, and of being seen by others in a demented state, fills him with fear and disgust. And now suppose he becomes demented, and—his earlier views notwithstanding—he seems to be enjoying life in his demented state. He socializes with others, enjoys meals, enjoys walks in the garden. (This was my own father's experience with Alzhiemer's.) Now suppose he becomes sick (as my own father did not) with an infection that

would easily be cured with antibiotics. Suppose, also, that the patient, who does not like feeling sick, is in fact asking for treatment, or at least readily assents to it when proposed.

On the one hand, respect for the wishes of the formerly-competent patient would seem to demand that the antibiotics be withheld. But the mind which formulated those wishes has been permanently altered, the patient is currently enjoying life, antibiotic therapy would be noninvasive and likely effective, and the patient wants treatment. The wishes formerly expressed by the patient when competent are in clear conflict with the best interests of the patient as he is now.

One kind of argument advanced in this case (by Ronald Dworkin⁴) is that the 'critical' interests of the competent patient in shaping his life and the ways in which he will be remembered should morally be allowed to trump his current 'experiential' interests in walking around the garden and eating lunch. (Roughly speaking, 'critical' interests are deeply-held views about what makes a life worthwhile and successful, while 'experiential' interests relate to what is pleasurable. I have a critical interest in maintaining a good relationship with my children, and an experiential interest in going out to see a good film.) In our case, the patient has lost his autonomy, but the integrity of his life can be preserved by advancing the critical interests of his earlier, competent self.

Rebecca Dresser⁵ has famously responded to Dworkin by arguing that the patient's dementia has made him a different person. The person with the critical interests is gone, and for that reason those interests need no longer guide us. I am loathe, however, to accept the idea that the current patient is morally a different person from his earlier competent self. In addition to philosophical questions about whether persons are minds or bodies or both, the idea that Alzheimer's changes one person into another raises many more practical questions than it can possibly answer. For example, we might enquire whether, if the patient walking in the garden is not the patient referenced in the AD, is he also not the patient referenced in the health-insurance policy he signed when competent?

I have a great deal more sympathy for the response of Jennifer Hawkins⁶ to Dworkin's (and others') arguments about the critical interest in shaping the trajectory of one's life. It seems to Hawkins, as it does to me, that there is no place from which to value the trajectory of a life taken as a whole, independently of its value to the person living it. In the case before us, a human being is enjoying a life, and can be kept enjoying that life for a while longer with just a few antibiotic pills. Against this consideration is placed the AD, which (on Dworkin's view) was designed to advance a life-trajectory that was once of critical interest to this same human being. But it is of critical interest to him no more—and that vision of the 'trajectory' of a worthwhile 'life-as-a-whole' will not now be enjoyed by anyone even if it is fulfilled. Promotion of this life-trajectory seems an abstract and thin reason to let a contented person die.

I am less worried about the bindingness of AD when the demented patient is miserable, or where the proposed interventions are physically burdensome or have low odds at success. In these cases it is more likely that the patient's current interests are not in conflict with his earlier-expressed preferences.

And it may yet be true that there is reason for us to decide, even in the case of the happy demented patient, that AD should be binding. Even if we think that making the AD binding is not what is best for the patient—even if we follow Hawkins in discounting the value of an abstract life-taken-as-a-whole—we may

have other reasons, not rooted in the patient's best interests, for making AD binding. We may, as a matter of prudence, be less worried about mistakes that might flow from a routine custom of enforcing AD than we are about mistakes that might flow from routinely empowering alternative decisionmakers in such cases. We may be more afraid of paternalistic physicians, greedy insurers, or burdened and impatient family-members than we are of ourselves. We might think that a bright-line rule in favor of enforcing AD is the simplest to implement—that it will avoid our having to make messy decisions about which of the demented are sufficiently happy to have their AD overridden, will facilitate planning, and will minimize conflict among and between family members and caregivers. Clear, enforceable rules, it turns out, have a number of structural virtues that in many cases make them a reasonable alternative even to the exercise of careful professional judgment.

Notes

1. Vergallo G. Advance health care directives: Binding or informational value? *Cambridge Quarterly of Healthcare Ethics* 2020;29(1).
2. I use hedging language about what “appears” or “seems” to be true of the December, 2017 Italian law because I am wholly reliant on English-language summaries of it, e.g., Ciliberti R, Gorini I, Gazzaniga F, De Stefano F, Gulino M. The Italian law on informed consent and advance directives: New rules of conduct for the autonomy of doctors and patients in end-of-life care. *Journal of Critical Care* 2018;48:178–82.
3. Gunter-Hunt G, Mahoney JE, Sieger CE. A comparison of state advance directive documents. *The Gerontologist* 2002;42(1):51–60.
4. Dworkin R. *Life's Dominion: An Argument About Abortion, Euthanasia and Individual Freedom*. New York: Vintage Books; 1994.
5. Dresser R. Dworkin on dementia: Elegant theory, questionable policy. *The Hastings Center Report* 1995;25(6):32–8.
6. Hawkins J. Well-being, time, and dementia. *Ethics* 2014;124(3):507–42.