Introduction

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Population ageing, which has been described as one of the four global demographic "megatrends",[1] is quickly becoming a concern for many countries around the world. The growth in the size and proportion of the elderly has many implications, including the fact that there has been, and will continue to be, a significant growth in the number of individuals who are living longer, and because of that, living with chronic health conditions that often accompany advanced age. With this comes the need to make decisions about the extent to which one wishes to continue receiving treatment towards the end of life, as well as the nature of such treatment. Unsurprisingly, therefore, the development of the advance directive (AD) has been the focus of ongoing discussion in many jurisdictions. In this volume, the AD is defined as a statement in which a competent person makes an advance decision in matters concerning their health and welfare, which is to be implemented in the event that the person becomes incompetent (loses capacity) in the future. In the following, we begin with an explication of ADs in a broad, international context, laying out the origins of the concept and how this is developing over time, as well as some of the conceptual and practical challenges that arise when ADs are implemented.

I.1 Advance Directives in Context: Origins and Challenges

The fundamental idea and purpose of an AD can be usefully understood by invoking the mythical tale of Odysseus and the Sirens in Homer's epic poem *The Odyssey*.[2] Odysseus is warned that his ship will sail past the Sirens, who will attempt to incapacitate the crew and lure them to

[1] United Nations, Department of Economic and Social Affairs, Population Division, *World Population Ageing 2019: Highlights* (ST/ESA/SER.A/430) (New York: United Nations, 2019).
[2] Homer, *The Odyssey: XII Scylla and Charybdis* (Oxford: Clarendon Press, 1963).

shipwreck. The crew plug their ears so they cannot hear the Sirens' fatal song, but Odysseus opts to hear their call – yet, before they reach the Sirens, he directs the crew to bind him to the mast and to not release him if he so requests. The crew honour Odysseus' directive, binding him tighter to the mast when, under the influence of the Sirens, he urges the crew to release him. Odysseus is freed only when the danger has passed.

Odysseus' tale captures the central elements of ADs as we currently recognise them: a directive that is issued by the person to whom it will apply in the future, and who issues it in advance of losing the capacity to make the relevant decision at the critical time. Moving on from ancient mythology, the modern idea of the concept of the AD as conceived in a healthcare setting is typically traced back to the late 1960s and the work of Luis Kutner, an American human rights lawyer and co-founder of Amnesty International. Kutner acknowledged that some patients will not wish to receive life-sustaining treatment, but that they may have lost the ability to convey their wishes at the critical time. "How then can the individual patient retain the right of privacy over his body – the right to determine whether he should be permitted to die, to permit his body to be given to the undertaker?"[3]

In answer to this question, Kutner's "suggested solution is that the individual, while fully in control of his faculties and his ability to express himself, indicate to what extent he would consent to treatment".[4] He offered various labels for this solution, amongst them the "living will" and, notably, the "body trust". Regarding the latter, Kutner drew on an established legal concept, suggesting that an AD is analogous to a conditional or revocable trust, with the patient's body being the "property" that is entrusted, the patient being the beneficiary of that property, and the doctor positioned as trustee and thus acting in accordance with the patient's prior consent.[5] According to Kutner, such a trust could be revoked by the patient, presumably once they regain control of their "faculties", as Kutner puts it.

As this volume will demonstrate, Kutner's idea has increasingly gained support internationally in a variety of different ways, but notably his analogy has not: the concept of a trust is not typically said to ground the

[3] L. Kutner, "Due Process of Euthanasia: The Living Will, A Proposal" (1969) 44(1) *Indiana Law Journal* 539, 550.
[4] Ibid., p. 551.
[5] Ibid., p. 552.

legitimacy of ADs. Rather, there is a settled view within the international community of bioethicists and medical lawyers that advance statements tend to derive their authority from the idea of respect for autonomy, or self-rule, interpreted specifically through the notion of "precedent autonomy" – a specific instantiation of the broader value of autonomy that captures the idea, applicable in some limited circumstances (i.e. where the loss of one's decision-making capacity is anticipated), that it is justifiable to set a precedent for oneself in the future through the exercise of one's autonomous decisions in the present.[6] As an English judge, Munby J, suggested, ADs involve "nothing more or less than the embodiment of the patient's autonomy and right of self-determination".[7] This view is not restricted to England; it is widely invoked in laws formulated in North America and in Europe. As we will see later in this volume, the value of autonomy has been an important, though often complex, component of more recent developments in some Asian countries.

I.1.1 Conceptual Challenges

However, here a first complication arises, because we should not assume that autonomy is a single, straightforward concept. A glance at the international bioethics literature reveals considerable debate over the precise nature of autonomy, with multiple accounts of autonomy being contested. This presents a challenge to advance decision-making: which version of autonomy does and should underpin, inform and constrain decisions made in advance?

There are many accounts of autonomy to choose from.[8,9] Some, taking their lead from Immanuel Kant, view autonomy in principled, objective terms: truly autonomous decisions are (only) those that align with what is objectively "right".[10] Others depict autonomy in fundamentally relational terms, where an individual's decision can be best understood in the context of their relationships. Even relational autonomy is not reducible

[6] J.K. Davis, "The Concept of Precedent Autonomy" (2002) 16(2) *Bioethics* 114.
[7] *HE* v. *A Hospital NHS Trust* [2003] 2 F.L.R. 408, per Munby J, [37].
[8] J. Coggon, "Varied and Principled Understandings of Autonomy in English Law: Justifiable Inconsistency or Blinkered Moralism?" (2007) 15(3) *Health Care Analysis* 235.
[9] J. Christman, "Autonomy in Moral and Political Philosophy", in E.N. Zalta (ed.), *The Stanford Encyclopedia of Philosophy* (2020), https://plato.stanford.edu/archives/fall2020/entries/autonomy-moral/.
[10] C.M. Korsgaard, *The Sources of Normativity* (Cambridge: Cambridge University Press, 1996).

to a single account, since it is "an 'umbrella term', covering a range of diverse perspectives".[11]

Generally, however, ADs tend not to be associated with relational or principled understandings of autonomy. Rather, ADs usually find their authority in more individualistic, liberal and subjective understandings of autonomy, as emphasised in Munby J's suggested synonym, "self-determination". According to such accounts, an AD expresses – and gains its normative force from – an individual's sincerely and strongly held beliefs and values. Viewed as such, an AD is an expression of different aspects of an individual's personal identity: their preferences, value commitments, desires and beliefs.

This view, of course, involves making a number of assumptions. First, it assumes both that individuals know and can articulate their beliefs and values, and that a person's preferences or desires in the moment will be aligned with more considered values that capture the person's "authentic" commitments over a longer period of time. Second, it assumes that an individual's wishes *should* govern decision-making, irrespective of any other countervailing ethical considerations. Once again, a glance at the extensive bioethics literature on ADs and the value of autonomy reveal that these assumptions are problematic if not interrogated closely. Notwithstanding this point, the role that the principle of "respect for autonomy" plays in grounding and justifying ADs remains largely solid.

But this is not the end of the conceptual story. Beneath this widely supported account lurks another problem. Philosophers have long pondered the nature of personal identity, asking such questions as: what makes me *me*? As with autonomy itself, there are a range of accounts available, at one end locating identity in *bodily* continuity, at the other end locating identity in *psychological* continuity, with others occupying the middle ground in which body and mind interact to constitute identity.[12] If we focus here on the two poles, however, they present problems for ADs. Bodily accounts inevitably underplay the importance of the mind (and brain) and with them the assumed ethical importance of autonomy. Psychological accounts, which arguably command greater

[11] C. Gómez-Vírseda et al., "Relational Autonomy: What Does It Mean and How Is It Used in End-of-Life Care? A Systematic Review of Argument-based Ethics Literature" (2019) 20(1) *BMC Medical Ethics* 76.

[12] A.V. Campbell, "Why the Body Matters: Reflections on John Harris's Account of Organ Procurement", in J. Coggon et al. (eds.), *From Reason to Practice in Bioethics: An Anthology Dedicated to the Works of John Harris* (Manchester: Manchester University Press, 2015), pp. 131–41.

respect, do attend to autonomy, but they present a new challenge: whose autonomy is being respected when an AD is honoured?

According to Davis, invoking the value of "precedent autonomy" can give rise to "cases where the patient decided his or her future treatment, is later treated in accord with that earlier decision, but seems somehow estranged from that decision when treatment is provided".[13] The "estrangement" is typically described in terms of the individual's mental capacity or competence: the individual making the directive has the capacity to do so, which they lack at the time that the directive is to be applied. And this sort of estrangement potentially presents a problem for ADs, as Buchanan has suggested:

> Presumably a point is eventually reached at which the degree of psychological continuity between the author of the AD and the incompetent individual is so small that the AD of the former has no authority at all over the latter.[14]

As such, there are some substantial philosophical questions attending the very idea of ADs. Should they be understood in terms of trust or autonomy? If, as is usually assumed, they are anchored in respect for autonomy, then what account of autonomy is being invoked to justify the AD and its implementation, and why should this be determinative of what should happen? And on what basis can the autonomous individual, such as Odysseus, bind the future non-autonomous individual – are these even the same person? The increasing adoption of ADs worldwide nevertheless suggests that, while some philosophers may be vexed, their concerns do not overly trouble or inhibit lawmakers, policymakers, clinicians and patients – at least in those countries, largely in the West, where regulatory frameworks have gained traction over some years, if not decades. But even if we assume there is some stable basis for honouring ADs across countries, questions remain about what follows for the local implementation of ADs.

I.1.2 Practical Challenges

The real-world adoption of ADs has presented several distinct challenges, "as they can be non-existent, uninformed, imprecise, unavailable,

[13] See note 6, p. 115.
[14] A. Buchanan, "Advance Directives and the Personal Identity Problem" (1988) 17(4) *Philosophy and Public Affairs* 277, 298.

inadequate, [and] unpredictable".[15] These sorts of problems appear to have been detected wherever efforts have been made to adopt ADs, and so it is reasonable to think that the increasing tendency for ADs to gain a foothold in different parts of the world will give rise to similar trends. Here we summarise how designing and implementing ADs in practice in those places where ADs have been examined in some detail has been a far from straightforward journey.

I.1.2.1 Which Model or Form of AD?

"Not every attempted directive will be worth the paper it is written on. And not every attempted directive will be written on paper at all".[16] An AD can take various forms. As in Odysseus' case, the directive might be issued verbally, perhaps also being captured in an audio or video recording. Alternatively, patients might set down their wishes in writing, whether in a bespoke document or in a pro forma, and either on paper or electronically. They might also (or instead) convey the information on a tag that is worn about their person – or even on a bodily tattoo.[17] Questions accordingly arise about the form an AD should take and which mechanism or model of advance decision-making is to be adopted. Not only might the precise form vary, but – to add further complexity – so too do the terms used to capture the phenomenon. Sometimes different labels are used to refer to the same essential idea – for example, the "living will" to which Kutner referred, which is still in use in some contexts,[18] may be synonymous with the "advance directive". On other occasions, apparently neighbouring terms, which deploy the same or similar words, nevertheless refer to somewhat different phenomena.

The situation in England provides a pertinent example of the terminological steps that can be deployed to specify the scope and application of an AD, and to differentiate the AD from other decision-making tools or interventions in healthcare, and in end-of-life care in particular. Fleshing out the English context also helps to demonstrate the complexity that may arise in practice more widely. In that country, the Mental Capacity Act 2005 governs advance decision-making. The Act refers specifically to

[15] R. Huxtable, "Advance Decisions: Worth the Paper They Are (Not) Written On?" (2015) 5 *BMJ End of Life Care* 1, 5.
[16] Ibid., p. 3.
[17] C. Polack, "Is a Tattoo the Answer?" (2001) 323(7320) *BMJ* 1063.
[18] T. Higel et al., "Effect of Living Wills on End-of-Life Care: A Systematic Review" (2019) 67(1) *Journal of the American Geriatrics Society* 164.

the "advance decision to refuse treatment" (ADRT) and sets out the conditions governing their validity and applicability,[19] separate from an advance statement of the person's wishes that are to be drawn upon in making a decision in the person's "best interests".[20] Here we see an immediate qualification to the scope of the AD: it is to be restricted to a decision to *refuse* a treatment or care intervention, essentially on the grounds that a person's positive requests for particular interventions (whether made in the present or in advance) can only be indicative, but not determinative.

The English picture becomes even more complex, bringing with it the potential to confuse patients and professionals alike. A patient in England can make an ADRT, which may be verbal or written. They might also, separately, confer a "lasting power of attorney" – essentially appointing a proxy or surrogate decisionmaker, who is empowered to make decisions on the patient's behalf when they have lost mental capacity.[21] Patients might also be involved in (or subject to) a more specific decision, such as a DNACPR decision (do not attempt cardiopulmonary resuscitation). While DNACPR decisions are made by practitioners on the grounds of medical futility, in consultation with the patient or those interested in the patient's welfare where possible, they can also be captured in various ways, including – following a recent initiative – in a ReSPECT form.[22] Provided that they meet the relevant conditions, some such forms might amount to legally recognisable ADRTs. But forms like ReSPECT can also be described differently, as an instance of "advance care planning" (ACP). ACP overlaps with, but is distinct from, the ADRT or DNACPR decision. ACP involves a more general reflection, not merely on any specific treatment to which a patient does not consent, but also about the patient's general views, values and wishes regarding their treatment and care.[23] And, in turn, ACP may include some sort of "values history" – and these might also,

[19] Mental Capacity Act 2005, sections 24–6.
[20] Mental Capacity Act 2005, section 4(6)(a).
[21] Mental Capacity Act 2005, sections 9–14. Note, however, that a discussion of proxy decision-making is beyond the scope of this volume.
[22] C.A. Hawkes et al., "Development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)" (2020) 148 *Resuscitation* 98.
[23] A. Mullick et al., "An Introduction to Advance Care Planning in Practice" (2013) 347 *BMJ* f6064.

on occasion, be appended to a patient's ADRT.[24] Indeed, increasingly, we see a trend internationally to encourage those involved in ACP to make an AD (where one has not been made previously) as part of good practice in planning future care of someone close to the end of life.

Thus, the variety of terms and tools available in England surely complicates efforts there to make provision for a future in which one has lost capacity. Neither patients nor professionals might be sure about where and how the patient's wishes regarding their future care should be captured. Even once this is settled, there then arises the question of what information should be captured within the relevant tool, and what protections should be added if endorsing the AD will have life-changing, even life-ending, implications? A detailed statement, which is sensitive to the patient's particular medical condition, might seem advisable,[25] and it might be judged appropriate for this to be witnessed or signed as part of a formal legal procedure. Yet, choosing a form that is too precise, detailed and voluminous might make it difficult to apply in practice – even more so if legal protections impose time or financial burdens on the person wishing to make it. And even a detailed directive might fail to speak to the situation which later arises – a risk that obviously also presents if the directive is too brief, general or imprecise. In short, there may be risks associated both with over- and under-specification, as subsequent chapters in this volume will demonstrate.

I.1.2.2 Will People Make ADs?

The accommodation of ADs in law, policy and practice will not automatically translate into their uptake. A review of the operation of the law in England suggested that public awareness of advance decisions there remains low, with research showing that only 3% of the public have made an advance decision, even though 82% have "clear views about their end-of-life care preferences".[26]

Similar findings about uptake of ADs have been reported elsewhere. Evans et al.'s systematic review of practice in Germany, published in

[24] D.J. Doukas and L.B. McCullough, "The Values History: The Evaluation of the Patient's Values and Advance Directives" (1991) 32(2) *Journal of Family Practice* 145.

[25] N. Evans et al., "A Critical Review of Advance Directives in Germany: Attitudes, Use and Healthcare Professionals' Compliance" (2012) 87(3) *Patient Education and Counseling* 277.

[26] House of Lords, Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: Post-legislative Scrutiny* (HL Paper 139) (London: The Stationery Office Limited, 2014), p. 75, [193].

2012, found studies revealing 2.5%–10% of the population had ADs.[27] Citing other studies, the authors saw this range as comparable to uptake in Spain (2%) and the Netherlands (7%), but substantially lower than uptake in the United States (around 20%).[28]

Uptake may, of course, have risen in the intervening years since these studies. Yet, more recent research also points to the low incidence of ADs, at least among some patients. Sutter et al., for example, systematically reviewed studies exploring ADs amongst neurocritically ill patients.[29] They expressed concern about the "limited number of neurocritically ill patients having ADs or defined healthcare agents", given (inter alia) the high burdens imposed by such conditions.[30]

Perhaps there is a fairly straightforward way of enhancing uptake: invest in informing and educating citizens and patients about ADs, so that they can be empowered to set down their wishes. Certainly, such initiatives are underway worldwide, but there are reasons to be sceptical about the likelihood of success. Fagerlin and Schneider, in their forcefully entitled 2004 article "Enough: The Failure of the Living Will", reviewed various attempts in the United States at enhancing uptake and found them wanting:

> If after so much propaganda so few of us have living wills, do we really want them, or are we just saying what we think we ought to think and what investigators want to hear?[31]

I.1.2.3 Can People Make ADs?

The low uptake of ADs might be better understood once one considers the magnitude of the task of making an AD. How easy is it, ask Fagerlin and Schneider, for a patient to "conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable

[27] See note 25, p. 286. Although, interestingly, Horn cites data showing that in Germany, there are statistics demonstrating that 93% of the German population are in fact aware of ADs. See further R. Horn, "'Why Should I Question a Patient's Wish?' A Comparative Study on Physicians' Perspectives on Their Duties to Respect Advance Directives" (2017) 24 *European Journal of Health Law* 523.

[28] See note 25, p. 286.

[29] R. Sutter et al., "Advance Directives in the Neurocritically Ill: A Systematic Review" (2020) 48(8) *Critical Care Medicine* 1188.

[30] Ibid., p. 1193.

[31] A. Fagerlin and C.E. Schneider, "Enough: The Failure of the Living Will" (2004) 34(2) *The Hastings Center Report* 30, 33.

treatments?"[32] In response, approaches to making ADs that are disease specific have been proposed,[33] alongside a critical role for specialist clinical input that focuses on discussing treatments that are more predictable.[34] This approach, of course, requires the specialist clinician to be familiar with the provision that has been made for advance decision-making. Unfortunately, research has shown that professional understanding of ADs, alongside a more general awareness of this tool, remains low.[35]

Educational campaigns to better inform professionals and the public about ADs look to be an important intervention, but perhaps only as part of a general attempt to change public and professional attitudes that stress the importance of enabling and empowering people to take control of the future direction of their lives, in light of expected (or unexpected) health crises.

I.1.2.4 Will the AD Be Available When Needed?

Let us assume that an informed patient has been able to set down their wishes in the relevant way, with the relevant support. Will their statement be available to the clinicians at the point that it is needed? Here, too, there is reason to suspect that this cannot be guaranteed. Fagerlin and Schneider, again, put the point pithily: "long can be the road from the drafter's chair to the ICU bed".[36]

Suggestions to close the informational gap have looked to a role for patients' electronic medical records,[37] national registries or new storage systems to enable rapid access to information about the existence of ADs. We might think that this is particularly likely to be important in professional settings, like emergency paramedic response, where time is limited but important decisions about life-saving interventions frequently need to be made. Practices may vary, but it seems fair to suggest that systemic approaches to quickly access information about the existence of an AD will be required.

[32] Ibid.
[33] See note 25, p. 286.
[34] Cf. R. Nowland et al., "Management of Patients with an Advance Decision and Suicidal Behaviour: A Systematic Review" (2019) 9(3) *BMJ Open* e023978.
[35] See note 25, p. 284.
[36] See note 31.
[37] See note 26, p. 77, [200].