

## **Adversaries at the Bedside: Advance Care Plans and Future Welfare**

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### **Abstract**

‘Advance care planning’ refers to the process of determining how one wants to be cared for in the event that one is no longer competent to make one’s own medical decisions. Some have argued that advance care plans often fail to be normatively binding on caretakers because those plans do not reflect the interests of patients once they enter an incompetent state. In this paper, we argue that when the core medical ethical principles of respect for patient autonomy, honest and adequate disclosure of information, institutional transparency, and concern for patient welfare are upheld, a policy that would allow for the disregard of advance care plans is self-defeating. This is because when the four principles are upheld, a patient’s willingness to undergo treatment depends critically on the willingness of her caretakers to honor the wishes she has outlined in her advance care plan. A patient who fears that her caretakers will not honor her wishes may choose to avoid medical care so as to limit the influence of her caretakers in the future, which may lead to worse medical outcomes than if she had undergone care. In order to avoid worse medical outcomes and uphold the four core principles, caregivers who are concerned about the future welfare of their patients should focus on improving advance care planning and commit to honoring their patients’ advance care plans.

## 1. INTRODUCTION

When patients are faced with diseases or medical procedures that may render them incompetent, they often have to make decisions about how they wish to be cared for in the future. This kind of advance care planning can be difficult for many reasons.<sup>1</sup> For example, without a clear sense of the specific medical decisions that are likely to arise in the future it can be difficult to determine—let alone to communicate clearly to others<sup>2</sup>—how one’s values should guide the care that one receives. As a result, some have questioned the value of advance care plans on the grounds that they are often too vague or indeterminate to represent an authoritative expression of the patient’s authentic wishes.<sup>3</sup>

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<sup>1</sup> Advance care planning can take many forms. Assigning a proxy or drafting an advance directive, such as a living will, are ways in which patients might try to ensure that the care they receive in the future reflects their considered values and goals. See L.L. Emanuel et al. Advance Care Planning as a Process: Structuring the Discussions in Practice. *J Am Geriatr Soc* 1995; 43(4): 440-446.

<sup>2</sup> For a discussion of this issue, see J.A. Tulsky. Beyond Advance Directives: Importance of Communication Skills at the End of Life. *Jama* 2005; 294(3): 359-365.

<sup>3</sup> For example, Fagerlin and Schneider have argued that living wills have failed because they are often so vague and indeterminate as to be of little value for shaping clinical care. They are clear, however, that their objections are specific to living wills and should not apply to other forms of advance care planning, such as durable powers of attorney. Even so, they do not propose to eliminate living wills

However, others have gone farther and questioned the value of advance care plans even in cases where patients have a relatively clear sense of the decisions that will need to be confronted in the future, and have expressed relatively clear preferences for how they should be cared for under various contingencies. The central concern of these critics does not focus on whether an advance care plan adequately captures the authentic wishes of the competent patient. Their concern is rather with the potential for conflict between a care plan that reflects the authentic wishes of a competent patient, and the welfare interests of that person once they are rendered incompetent and the care plan would need to be carried out.<sup>4</sup>

In this paper, we address the concerns of critics in this second group. We argue that when core values of medical ethics are upheld, a policy that permits the disregard of a patient's advance care plan out of a concern for the health interests of the incompetent patient is self-defeating. To show this, we provide a model of

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in all cases: 'We can imagine recommending them to patients whose medical situation is plain, whose crisis is imminent, whose preferences are specific, strong, and delineable, and who have special reasons to prescribe their care.' See A. Fagerlin & C.E. Schneider. Enough: The Failure of The Living Will. *Hastings Cent Rep* 2004; 34(2): 30–42.

<sup>4</sup> R.S. Dresser & J.A. Robertson. Quality of Life and Non-Treatment Decisions for Incompetent Patients: A Critique of the Orthodox Approach. *J Law Med Ethics* 1989; 17(3): 234-244; A. Buchanan. Advance Directives and the Personal Identity Problem. *Philos Public Aff* 1988: 277-302.

patient decision making that incorporates the values of respect for patient autonomy, honest and adequate disclosure of information, institutional transparency, and concern for patient welfare. We use this model to show that when these values are satisfied, a patient's willingness to explore potentially favorable treatment options depends critically on her confidence in the willingness of her family and caregivers to honor her directives. If a patient does not believe that her directives will be honored, she may effectively regard her family and caregivers as adversaries and make decisions in the present that reduce the influence of those parties in the future. As a result, such a patient would prefer to act in ways that bring about worse outcomes than would be the case if she were confident that her advance care plan would be honored.

This argument is important because it illustrates a defect in approaches that focus solely on the relative normative importance of respect for patient autonomy versus concern for the welfare of the incompetent patient. In particular, such approaches end up treating the future health states a patient is likely to occupy as largely independent of the act of contingency planning. Recognizing the dependence of the former on the latter clarifies the role of two values whose role in the debate has not been well appreciated: honesty and transparency. We show that in a context of honesty and transparency, disregard for advance care plans can create a public bad, undermining trust in health systems. Ultimately, we argue that concerns about the adequacy of advance care planning need to be addressed at the planning stage and that the best way to preserve the legitimacy of health systems and to advance patient welfare is to invest in improving the

process of advance care planning and then to honor the advance care plans that emerge from that process.

## **2. WELFARE, HONESTY, AUTONOMY, AND TRANSPARENCY**

It is widely recognized that when patients are competent, promoting honest and accessible disclosure of information in a context of transparency enables patients to exercise their autonomy and, in doing so, to advance their own welfare as they understand it. At a very general level, contemporary models of the doctor patient relationship can thus be seen as reconciling four related but distinct values.

The first is *fidelity to patient welfare*. The commitment of physicians to promoting patient welfare and placing the interests of patients above competing interests is perhaps the oldest and most defining value of the medical profession. In fact, this was arguably the single, sovereign value of paternalistic models of the doctor-patient relationship.<sup>5</sup>

The rejection of medical paternalism ushered in a strong commitment to *respect for patient autonomy*.<sup>6</sup> To respect the status of a person as autonomous is to enable that person to exercise their powers of deliberation and choice and then

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<sup>5</sup> T.L. Beauchamp. Promise of the Beneficence Model for Medical Ethics. *J Contemp Health Law Policy* 1990; 6: 145-8.

<sup>6</sup> Ibid: 149.

to honor the decision ultimately made.<sup>7</sup> The contemporary provider-patient relationship focuses on empowering patients to make decisions, in part because this is what is required to show respect for patients as moral agents. But promoting informed, autonomous choice is also likely to be the best strategy for promoting the value of fidelity to patient welfare. Because competent patients are considered to be the best judges of their own interests and values, they are taken to be the best stewards of their own welfare. On this view, the best way to uphold fidelity to patient welfare is to promote respect for patient autonomy.<sup>8</sup> Once the relationship between health and welfare is understood, at least in part, as mediated or constructed by a person's broader goals, values, and life plans, then the clinician can no longer claim that her medical training provides special insight into how to advance patient welfare.

The elevation of respect for patient autonomy was accompanied by an explicit commitment to the third value of *honest and adequate disclosure of information*.<sup>9</sup> In order for patients to deliberate they have to have a range of

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<sup>7</sup> E.J. Emanuel & L.L. Emanuel. Four Models of the Physician-Patient Relationship. *Jama* 1992; 267(16): 2221-2226.

<sup>8</sup> A. Goldman. 1999. The Refutation of Medical Paternalism. In *Ethical Issues in Modern Medicine*. B. Steinbock & J. Arras, ed. Mountain View, CA: Mayfield Publishing: 59-67.

<sup>9</sup> R. Higgs. 2007. Truth Telling, Lying and the Doctor-Patient Relationship. In *Principles of Health Care Ethics*. R.E. Ashcroft et al., ed. Chichester, UK: John Wiley & Sons: 333-8.

relevant information regarding their current medical condition, the care plans that are available to them, what each course of care will be like, what the likely outcomes of different courses of care will be, and so on. Patients need this information to make decisions that properly reflect their individual values. Honest and adequate disclosure of information thus provides a link between the ability of a patient to exercise her autonomy and do so in a way that advances her welfare interests.

Finally, even if patients arrive at considered preferences for care in light of a robust understanding of their clinical situation, their autonomy can be thwarted if those decisions do not play a causal role in determining the care that they receive. Thus, the rejection of medical paternalism, and the elevation of respect for patient autonomy through the explicit practice of informed consent, was also accompanied by an implicit commitment to the value of *institutional transparency*. This value holds that how institutions regard patient decisions, including the role that patient decisions have in determining their care, should be generally transparent and justifiable to the people who rely on health care institutions to advance their interests.<sup>10</sup> Institutional transparency was thus part of

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<sup>10</sup> The commitment to institutional transparency is largely implicit in arguments supporting the value of respect for autonomy and informed consent. But the importance of institutional transparency is more explicit in the discussion of related issues. The first is patient confidentiality. In order to ensure patient trust and the free flow of information, patients need to understand how health care institutions will protect the privacy of their information and the conditions under

larger social movement to assure the public that the health systems on which they rely would honor in practice each individual's right to make momentous life decisions.

When patients are incompetent and lack decisional capacity, however, there is debate as to whether and how respect for autonomy can be reconciled with fidelity to patient welfare. The dominant or 'orthodox' approach seeks to use advance care planning as a way of preserving the alignment between respect for autonomy and fidelity to patient welfare in cases where patients are no longer

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which it can be shared or disclosed. The second is discussions of so-called 'do not necessitate' or DNR orders. Here, patients and families have to understand the role that such an order plays within the institution and how signing a DNR will affect the care of a patient who experiences a life-threatening event, such as cardiac arrest. Finally, the importance of institutional transparency is made salient in discussions of the limits and legitimacy of third-party influence on the patient-provider relationship. In particular, institutional transparency is a cornerstone of Daniels' procedural account of the legitimacy of the decisions of third-party payers to fund or deny payment for health services. See N. Daniels.

Accountability for Reasonableness: Establishing a Fair Process for Priority Setting is Easier than Agreeing on Principles. *BMJ* 2000; 321(7272): 1300; N. Daniels & J.E. Sabin. Accountability for Reasonableness: An Update. *BMJ* 2008; 337(7675): a1850.



capable of making their own health care decisions.<sup>11</sup> Patients, while competent, are supposed to reflect on the possible health states that might result from different courses of care, and then provide clear directions to their family and care providers about how they wish to be treated in those various circumstances should they lose capacity to make decisions for themselves.

Advance care planning is an increasingly prevalent component of medical decision making in the United States. Since the passage of the Patient Self-Determination Act (PSDA) in 1990, significant attention has been paid to the use of advance directives and other forms of advance care planning in health care settings. The PSDA requires medical practitioners working in U.S. hospitals that receive Medicare or Medicaid funding to inform their patients about their rights to execute an advance directive. While studies indicate that patients are more knowledgeable about their rights to self-determination since the passage of PSDA, only about 18-36% of Americans actually complete an advance directive.<sup>12</sup> However, among patients faced with serious, life-threatening diseases

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<sup>11</sup> M.R. Gillick. Advance Care Planning. *N Engl J Med* 2004; 350(1): 7-8; L.L. Emanuel et al. Advance Directives for Medical Care—A Case for Greater Use. *N Engl J Med* 1991; 324(13): 889-895; K.M. Detering et al. The Impact of Advance Care Planning on End of Life Care in Elderly Patients: Randomised Controlled Trial. *BMJ* 2010; 340: c1345.

<sup>12</sup> United States Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation (ASPE). 2008. *Advance Directives and Advance Care Planning: Report to Congress*. Washington, D.C.:

or treatments, advance directives and other forms of self-determining health plans are more prevalent.<sup>13</sup>

While the promotion of certain kinds of advance care planning is federal policy, there remains a debate in the medical ethics community over the normative status of advance care plans when they direct care givers to act in ways that may conflict with the current, best interests of the incompetent patient. Debates of this kind have centered around the following sort of case.

A patient learns that she has a rapidly advancing brain tumor and the only treatment that might prolong her life is invasive surgery. There is a significant probability that removing the tumor will also damage structures in her brain that will leave her conscious but incompetent. Suppose further that this patient has very specific values that shape her current interests: she values a life of intellectual engagement, both in her reading and writing, but also as it pervades her relationships with her friends and her community. In fact, she values having a life of intellectual engagement so much that she regards her interest in maintaining this kind of activity as more important than her interest in remaining

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ASPE. Available at:

<https://aspe.hhs.gov/sites/default/files/pdf/75811/ADCongRpt.pdf> [Accessed 28 Jan 2016].

<sup>13</sup> A. Jones, A.J. Moss, & L.D. Harris-Kojetin. Use of Advance Directives in Long-Term Care Populations. *NCHS Data Brief* 2011; 54: 1-8; J.K. Rao et al. Completion of Advance Directives Among U.S. Consumers. *Am J Prev Med* 2014; 46(1): 65-70.

alive if she were to be incapable of such engagement. She believes that without the cognitive capacities necessary for intellectual engagement, her life would not be worth living.

This patient feels strongly enough about how she wants to be treated in the future that she formulates an advance care plan that reflects her values and expresses it in an advance directive. Because surgery is the option with the highest likelihood of preserving her cognitive abilities, she wants to pursue that option. However, because surgery also has a significant probability of leaving her with a cognitive deficit if it is not successful, she is only willing to undergo surgery if she is confident that her agents—her family and her care team—will not take steps to preserve her life if surgery leaves her severely cognitively impaired.

If the patient in our example were to enter an incompetent but pleasantly demented state following surgery, proponents of the orthodox approach would argue that the patient's prior plan provides clear evidence of what the patient wants to have happen to her in this situation and, therefore, that her plan ought to be followed.<sup>14</sup>

Critics of the orthodox approach argue, in effect, that it may not be possible to reconcile respect for patient autonomy and fidelity to patient welfare in this case. At the heart of their argument is a concern that the interests of patients can change over time or because of the ravages of sickness or injury, and that it is the physician's duty to safeguard the interests of the patient before

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<sup>14</sup> N.K. Rhoden. The Limits of Legal Objectivity. *NCL Rev* 1989; 68: 845.

them.<sup>15</sup> If incompetent patients no longer have the interests that animated their decision making when they were competent—interests that structured their conception of welfare when they made their advance care plan—then the link between respect for autonomy and fidelity to patient welfare is severed. To honor the patient’s advance care plan, thereby showing respect for the autonomy of the once-competent patient, requires the patient’s agents to act in ways that critics view as compromising fidelity to the now-incompetent patient’s welfare. In these cases, physicians must make a choice between honoring precedent autonomy--the act of treating the patient according to the wishes outlined in the advance directive--which is based on interests the patient no longer possesses, or treating the incompetent patient according to the interests she has currently, violating the patient’s expressed wishes. As a result, some have argued that it is a mistake to seek to honor precedent autonomy in such cases and that decisions about how to care for incompetent patients should be grounded solely in the value of fidelity to the patient’s welfare.<sup>16</sup> In other words, caretakers should treat the incompetent patient according to her current best interests, and not according to any advance care plan she may have formulated before her medical condition, and her attending interests, changed.

Skepticism about whether to honor an advance care plan can come from two sources. First, even if a patient can formulate an advance care plan that is

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<sup>15</sup> For example, see R. Dresser. Dworkin on Dementia: Elegant Theory, Questionable Policy. *Hastings Cent Rep* 1995; 25(6): 32-38.

<sup>16</sup> Dresser & Robertson, *op. cit.* note 4, p. 240-1.

specific enough to address the particular situation that arises, we might worry about the extent to which the patient was able to understand, when competent, what her life would be like in this new state of diminished capacity.<sup>17</sup> To construct an advance care plan, the patient has to consider: how the course of disease or illness is likely to affect her health in the future; what kind of treatment or care options are likely to be available in the future; what her physical, intellectual and emotional capacities will be like in the various health states she might occupy; how this might affect the interests she will have in the future, and what circumstances or conditions she would like their care plan to promote or to avoid. Each of these considerations can pose a daunting intellectual and emotional challenge.<sup>18</sup> If the patient's ability to comprehend what her condition will be like was hampered by well-known difficulties in affective forecasting, then even if her directive is specific enough to address the particular situation that has arisen, the decision in that directive may reflect a faulty assessment of what it is like to occupy that incapacitated state. If the assessment of what it is like to be in a state of diminished capacity is predicated on misunderstanding, then the choice

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<sup>17</sup> R.E. Lawrence & D.J. Brauner. Deciding for Others: Limitations of Advance Directives, Substituted Judgment, and Best Interest. *Virtual Mentor* 2009; 11(8): 571; N. Thorevska et al. Patients' Understanding of Advance Directives and Cardiopulmonary Resuscitation. *J Crit Care* 2005; 20(1): 26-34.

<sup>18</sup> T.D. Wilson & D.T. Gilbert. Affective Forecasting: Knowing What to Want. *Curr Dir Psychol Sci* 2005; 14(3): 131-134.

reflected in the advance care plan may not have been adequately informed to be morally binding.<sup>19</sup>

A related but nevertheless distinct claim is that even if the patient's prior directive accurately expressed the competent patient's wishes, given her values and life plan, the patient's interests have now changed. Critics of precedent autonomy worry that the patient's advance care plan conflicts with the current interests of the patient, and that honoring her directive would result in the under-treatment of a vulnerable person who is capable of leading a life that is of value to her. This is because after the point of incompetency, the patient may have a 'significant interest in continued life',<sup>20</sup> an interest that would be violated if the care team were to abide by the patient's plan. Severe cognitive impairment may damage the physical and mental structures that enable the patient to have a range of higher-order preferences and beliefs. She may no longer be able to entertain the belief that a life of intellectual engagement is preferable to a life of modest perceptual activity and pleasant physical stimulation. She may not be able to perceive that she is being maintained in such a state. Nor would her living in such a state be perceived, from her own point of view, as painful or disrespectful. Moreover, caregivers have seen other patients in a pleasantly demented state and know that those patients can respond positively to tender care, enjoyable food, and can be kept in a comfortable state with proper attention and interaction.

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<sup>19</sup> J. Halpern & R.M. Arnold. Affective Forecasting: An Unrecognized Challenge in Making Serious Health Decisions. *J Gen Intern Med* 2008; 23(10): 1708-1712.

<sup>20</sup> Dresser & Robertson, *op. cit.* note 16, p. 237.

In light of these concerns, Dresser and Robertson argue that ignoring the patient's prior wishes and responding directly to the interests of the now-incompetent patient avoids the pitfalls of overtreatment, undertreatment, and has 'the best chance of respecting incompetent patients'.<sup>21</sup>

### **3. MODELING DECISION MAKING WITH ADVANCE CARE PLANS**

We are concerned that the debate over the normative status of advance care planning in situations like the one described above is framed in a way that is fundamentally flawed. It treats patients' beliefs about how their agents will treat them in the future as independent of the act of creating an advance care plan. The debate ignores the direct connection between patients' beliefs about how their agents will act in the future and how they exercise their autonomy in the present. In particular, a patient's choice to undergo treatment may hinge on beliefs about the reliability of the patient's agents in the future. In the case we described above, the patient is willing to undergo surgery—the option that both she and her care giver recognize as holding the best prospect to advance her medical interests—only on the condition that her agents will faithfully act so as to prevent her from winding up in what she regards as the worst state, namely, lingering on with severely diminished cognitive capacity. If the patient believes that her agents will not reliably honor her wishes and her values are as we have described them, then she may prefer not to undertake surgery in the first place. The reason is that, without confidence in the fidelity of her agents, the patient may believe that she

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<sup>21</sup> Ibid: 234.

must exercise her autonomy while she can to choose the option that is most likely to bring about the best option that is available to her without relying on her agents. The patient may, in effect, view her providers and her proxy not as agents, but as adversaries.

We can provide a more explicit model of the patient's choice situation using some basic tools from game theory. Game theoretic modeling allows us to represent more precisely the structure of a choice situation that involves the interaction of multiple parties. In the parlance of game theory this is a 'strategic interaction', in the sense that the patient's actions depend on her beliefs about what her agents are likely to do in the future, and in particular whether the patient believes that her agents will respect her advance care plan or not.

The decision problem facing the patient in our example can be represented by the following game tree. Every node in the tree represents a point at which the 'player' labeled next to the node makes a decision. At the top of the tree, for example, the patient has to decide whether to seek care and draft a future plan for her medical needs (represented by branches on the left side of the tree), or to not seek care (represented by branches on the right side of the tree).<sup>22</sup> The player 'Nature' refers to the variety of influences present in the patient's environment that determine whether the patient is likely to enter an incompetent state, a competent state, or a state in which the patient is no longer living. These

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<sup>22</sup> For the purposes of this paper we assume that if a patient creates an advance care plan, that plan is made explicit to her care team.



influences can include treatment options (in our example, brain surgery), or even the influence of luck.

Outcomes in the diagram are labeled  $o_1, o_2, o_3, \dots$  while the probabilities that such outcomes will occur are labeled with the letters  $p, q, r, s$ , and  $v$ .

### [TREE DIAGRAM]

Within this model, the patient's decision of whether or not to seek treatment is determined by the way she values the possible outcomes of her choices (represented as a utility) and how likely each of those outcomes is if she makes a particular choice (represented as a probability distribution).<sup>23</sup> The patient in our model is faced with two possible actions. She can either choose to undergo surgery with an advance care plan that expresses her preference to not receive treatment if she becomes incompetent, or she can choose not to undergo surgery. We refer to these possible actions as the 'options' available to the patient. Importantly, neither option leads to any particular outcome with complete

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<sup>23</sup> For any outcome  $o_i$  that is likely to occur with probability  $x$ , the expected payoff of that outcome is the amount that outcome is worth to the agent (called the outcome's 'utility', represented as  $u(o_i)$ ) multiplied by the probability that the outcome will be achieved. We can therefore represent the expected payoff or utility of seeking care and not seeking care as follows:

$$EU(\text{NoCare}) = ((pu(o_5)) + vu(o_6) + ((1-p-v)u(o_7)))$$

$$EU(\text{Care+Plan}) = ((1-q-s)u(o_4) + (s((1-r)u(o_2) + ru(o_1))) + qu(o_3))$$

certainty.<sup>24</sup> Here, outcomes refer to possible future medical states that the patient might experience. For example, if the patient chooses to undergo surgery, that option could lead to outcomes  $o_1$ ,  $o_2$ ,  $o_3$ , or  $o_4$ . Outcome  $o_3$  is the patient's most preferred outcome given her values, as the patient would most prefer to have a successful surgery (a surgery that leaves her in a state of competency). The *outcome* of successful surgery ( $o_3$ ) is only available to the patient if she chooses the *option* to undergo surgery. However, choosing the option of surgery might also lead to the patient's least-preferred outcome ( $o_2$ ). In outcome  $o_2$ , the surgery is not successful, and the patient's physician elects to continue treating the patient, thus disregarding the patient's advance care plan.

This model is important because it demonstrates how the patient's choice to undergo surgery can lead to either her most-preferred outcome  $o_3$  or the patient's least-preferred outcome  $o_2$ . If the patient fears that her physician and family are likely to disregard her advance care plan if she opts for surgery and survives in an impaired state, then avoiding surgery altogether may represent her best option. In particular, avoiding surgery is the patient's best option when its

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<sup>24</sup>For simplicity, we assume that the patient is considering whether to seek care in conjunction with creating an advance care plan or to avoid care altogether. We do not include the option that the patient will undergo medical treatments without a contingency plan. It should be noted, however, that the model can be expanded to include this alternative.

expected payoff is greater than the expected payoff from the choice to undergo surgery.<sup>25</sup>

This model highlights the critical role of the patient's beliefs about how her agents will act in the future for her decision to pursue or avoid care. In particular, when a patient with the values that we describe is confident that her care givers and family will act so as to prevent her from living in a cognitively debilitated state ( $o_2$ ), then she will opt to undergo surgery. Alternately, when the patient does not trust that her agents will respect her autonomous choice by following her plan in the future (i.e. when she believes that  $1-r > r$ ), then the decision that best advances her interests, from the standpoint of the patient's own values, is to refuse surgery. In effect, she views those who are supposed to act as her agents (her care team and close family, for example) as analogous to adversaries. In other words, because she believes that if she winds up in an incompetent state, her agents are likely to take a course of action that will lead to outcome  $o_2$ , which she strictly disprefers to  $o_1$ , her best option is to act now in a way that reduces the prospect of winding up in an incompetent state.<sup>26</sup>

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<sup>25</sup> The patient chooses to avoid care when (when  $EU(\text{Care}+\text{Plan})$  is less than  $EU(\text{NoCare})$ ).

<sup>26</sup> For example, suppose that the patient values a competent life (outcomes  $o_3$  and  $o_6$ ) with five utiles, death (outcomes  $o_1$ ,  $o_7$ , and  $o_4$ ) with one utile, incompetency without care (outcome  $o_5$ ) with zero utiles, and incompetency with continued care (outcome  $o_2$ ) with negative two utiles. Further, suppose that if the patient does not pursue care, death is very likely ( $1-p-v = 0.8$ ), and competent and incompetent life

This formal representation of the patient's choice situation reveals what is wrong with the debate between proponents and critics of precedent autonomy. In order to make an informed decision in the present, the patient needs to understand whether or not her agents are likely to carry out her wishes in the future. If the patient believes that her physician will show fidelity to her welfare as an incompetent patient rather than honor her autonomous choice as outlined in the advance care plan, her best option may be to act on her values while she still can and forgo treatment altogether.

It may be objected that the model we present here is so idealized or stylized that it is not relevant to real world cases. After all, real people often do not act as utility maximizers, they almost certainly do not formulate their own choices in these terms and they probably do not view themselves as playing a game against their clinician or their families.

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are equally unlikely ( $p = v = 0.1$ ). Finally, suppose that incompetency following surgery is likely ( $s = 0.6$ ), competency is somewhat likely ( $q=0.5$ ), and death is least likely ( $1-q-s = 0.1$ ). Then the patient's level of trust in her physician will play a determining role in her decision making. If the patient is entirely confident that her physician will follow her advance care plan ( $r = 1$ ), then a simple expected utility calculation demonstrates that it is rational for the patient to pursue care ( $EU(\text{Care}) > EU(\text{No Care})$ ). On the other hand, if the patient is confident that her physician will not follow her advance care plan ( $r = 0$ ), then the patient will elect to forego care. The patient is indifferent between her two options when  $r = 0.5$ .

These objections misunderstand the value of the analysis provided here. In particular, our analysis is not presented as a descriptive claim about how real patients *represent* such decisions to themselves. Rather, it is presented as a normative model that illustrates how key variables ought to affect patient choice, given several morally important assumptions.

One assumption is that the patient has particular values that shape her preferences over the possible medical states she might enter. The model represents these values as utilities and represents these states as outcomes.

Another assumption of the model is that the patient understands (a) what choices are open to her and (b) how likely various outcomes are if she makes those choices. But this is all information that should be conveyed to patients during the informed consent process. Even if actual patients don't frame their decision in our terms, their decision needs to be informed by the information included in our model if it is to represent a morally transformative choice.<sup>27</sup>

Similarly, the model assumes that the patient understands (c) how her agents are likely to behave if she makes various choices. But, as we indicated above, this is a necessary requirement of transparency. In particular, because the patient must rely on her agents to carry out her wishes, she needs to understand in advance how her agents will respond to the various choices she might make.

The model also assumes that the patient is rational in a very weak sense, namely, that she will select the option that she predicts will be best according to

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<sup>27</sup> A.E. Buchanan & D.W. Brock. 1989. *Deciding for Others: the Ethics of Surrogate Decision Making*. Cambridge, UK: Cambridge University Press.

her values.<sup>28</sup> This assumption embodies a normative commitment to the importance of rational decision making. If the patient is rational, the model states that she ought to pursue the alternative with the greatest predicted benefit, given her own preferences and values, and given an honest and transparent conveyance of information between the patient and her doctor about the likelihood that she will end up in any of the possible outcomes. This assumption also presupposes the empirical claim that most people, perhaps with the assistance of others, are generally capable of making decisions that are weakly rational. Hence, we claim that our model is normative in the sense that patients ought to choose as our model indicates if their values are as we stipulate them to be and if the principles of honesty and transparency have been satisfied. Whether any particular patient does so is an empirical question.

Thus our argument is not an empirical argument about what real world patients will do. Patients can fail to follow the normative claims of the model for several reasons. For example, patients may be unable to accurately understand their own values, or may have difficulty determining the relative likelihoods of the medical states they might enter. This sort of difficulty can arise because the patient does not receive sufficient information from her care team, or because the

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<sup>28</sup> Our model is based on traditional Von Neumann-Morgenstern game theory, but it should be noted that weaker theories of rationality are also applicable. We use this model in particular because it makes clear the relationship between the patient's values and preferences and her reliance on her care giver and health care system for honest and transparent information.

decision scenario is too complex for the patient to comprehend. In any case, these potential failures of real individuals to act rationally only make clearer the significance of the principles of honesty and transparency. Without the honest and transparent disclosure of information, the patient will not be equipped to make the decisions she faces in light of her own values. That is, honest and transparent information is essential to the patient's ability to make decisions regarding her care, and her care giver's failure to disclose necessary information will hinder the patient's ability to make a decision in light of her values.

It might also be objected that we do not take seriously the distinction between the competent patient when she creates an advance care plan and her future incompetent self. As critics of the orthodox approach might argue, the patient is so different at these two times, with such different interests, that it would not be unreasonable to regard them as distinct persons.<sup>29</sup> Moreover, because a choice must be informed if it is to be morally transformative, and because the competent patient may not understand the degree to which her future, incompetent self may have a stake in living under conditions the competent person finds intolerable, care givers can rightly question whether the patient's

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<sup>29</sup> R. Dresser. Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values under the Law. *Ariz. L. Rev* 1986; 28: 373.

choices as outlined in an advance care plan have the requisite force when the patient is incompetent.<sup>30</sup>

We regard this objection as an attempt to have one's cake and to eat it too in such cases. That is, the physician might reason that he can honestly tell the competent patient that he will honor her future wishes, thereby inducing her to opt for surgery. If surgery turns out well, then the patient survives 'as the same person' and the physician has honored his commitment. If surgery turns out badly, then the patient's old interests do not survive and the physician is not bound to honor those prior preferences. He is morally free to attend to the present welfare interests of this 'new person'. Given the change in fundamental interests—or, if you prefer, the more metaphysically loaded idea that there has been a literal change in the 'person' with whom the physician is dealing—it is not dishonest to commit to following the wishes of the competent patient, knowing that if the competent patient does not 'survive', the care team will assiduously advance the new interests of the numerically distinct surviving patient.

The problem with this objection, however, is that even if we grant the substantive claims in it about the change in interests/persons, it still treats the state of affairs that a patient is likely to occupy in the future as largely independent of the act of advance care planning and overlooks the role of honesty and transparency in this process. To comply with the principle of honesty, caregivers

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<sup>30</sup> J.A. Robertson. Second Thoughts on Living Wills. *Hastings Cent Rep* 1991; 21(6): 6-9; M.R. Tonelli. Pulling the Plug on Living Wills: A Critical Analysis of Advance Directives. *Chest* 1996; 110(3): 816-822.



would have to inform that competent patient that there are several senses in which she might not survive surgery. One sense is that the organism that she currently occupies could die. Another sense is that her organism could survive, but that her brain could be so badly damaged that the *person that she is now* ceases to exist. In that case, her organism would be occupied by a new, numerically distinct, person with distinct welfare interests.

To comply with the principle of transparency, care givers would also have to inform the competent patient that in the event that her organism survives but that the *person she is now* does not survive, they will not follow the directive that she makes now if it conflicts with the interests of that new person.

It is possible that a consent process that respects the principles of honesty and transparency in this way might lead the patient that we describe here to opt for surgery. This might occur if she became convinced that there is a real sense that *she* has nothing to lose: either the *person that she is now* survives in good health or the *person that she is now* does not survive (either because or organism dies or because the *person that she is ceases to exist*). In neither case will *she* face the option of living in a state of diminished mental capacity. If the patient accepts this reasoning, however, there would be no need to violate the patient's advance care plan, because her plan would reflect this new attitude toward the patient's own future.

Alternatively, the patient may resist that idea that she is not identical to the self that would survive in an incapacitated state, or the patient may prefer not to have any future person that occupies her organism survive in a state of

diminished cognitive capacity. In either case, a process of honest and transparent consent will lead such a patient to opt not to have surgery. In this case, the patient avoids what all parties agree is the option with the best prospect for improving her medical condition: surgery. Notice, again, that care givers would not be faced with the choice between honoring the present interests of the incompetent patient and following the patient's prior directive. That dilemma would not arise because the patient has chosen to exercise her autonomy while she can to avoid the option that may result in an outcome in which her care team may disregard her advance care plan after the patient becomes incompetent.

An alternate reading of the objection is that it involves a violation of either honesty or transparency. It violates honesty if, in this scenario, the physician agrees to uphold the patient's advance care plan without informing the patient that there is a relevant sense in which she might not 'survive' the surgery. It violates transparency if the physician fails to disclose that the care team will not follow her directive if the *person that she is now* does not survive because it will not be applicable to this 'new' person.

Neither of these violations could be justified by concern for the interests of the future incompetent person.<sup>31</sup> The reason is that these violations are perpetrated against a competent person who has a right, well established in both ethics and law, to make free and informed decisions about her person. Because the decision to decline or undertake surgery is a decision that the patient makes while competent, these violations would undermine the ability of the competent

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<sup>31</sup> We thank an anonymous referee for posing this question.

person to determine the course of her own care in the present. At the same time, these violations would be carried out in the name of a person who does not yet exist and who, if the principles of honesty and transparency are not violated, likely will never exist.

#### **4. TRANSPARENCY, LEGITIMACY, AND SOCIAL TRUST**

Philosophical debate about whether to honor prior directives when they conflict with the present interests of incompetent patients often begin with a scenario in which we are faced with an incompetent patient who has an advance care plan that conflicts with her present interests. The argument is then made that if we violate a patient's advance care plan out of our commitment to advance the genuine interests of the incompetent patient before us, no one is harmed. The patient before us no longer has the interests that once animated her advance care plan, but she does have a stake in a continued pleasurable existence. If her agents honor her plan, it results in significant harm to a patient who no longer has the interests that motivated the care plan in the first place. It thus appears that honoring the patient's advance care plan past the point of incompetency makes no one better off and at least one person worse off. This policy is thus Pareto inferior, while the policy of violating advance care plans, where appropriate, is Pareto superior.<sup>32</sup>

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<sup>32</sup> A.I. Applbaum. 2000. *Ethics for Adversaries: The Morality of Roles in Public and Professional Life*. Princeton: Princeton University Press.

As we have argued, focusing on a time point when caregivers are faced with an incompetent patient creates an artificial independence between the state the patient occupies and the process of advance care planning. The patient's advance care planning process is disregarded and the role of honesty, transparency, and the patient's belief about how her care givers would respond to her advance care plan in the future is removed from debate. The analysis we have presented to this point is intended to correct this error and to highlight the close connection between honesty, transparency, a patient's trust or lack of trust in her agents, and her willingness to elect certain treatment options.

Nevertheless, the idea that no one is harmed by disregarding the advance care plan of a now incompetent patient exerts powerful force on this debate. We want to challenge this claim and, in doing so, highlight how philosophical debate usually frames this issue in a way that obscures a set of larger social issues.

In particular, the claim that nobody is harmed by ignoring an incompetent patient's advance care plan is usually framed as a response to a single, isolated case. The tacit presumption is that health care providers always engage in single-shot interactions with their patients. In game theory, a single-shot game involves only one round of interaction between a specific set of players who do not interact again in the future, and whose play is not observed or known to others who will interact with one of these parties in the future. The presumption of this way of framing the problem is not just that each patient and care team only face this set of decisions (play this game) one time, but that the way that a care team behaves

with a particular patient will not be known by any other party, including patients who will have to have similar interactions with their care team in the future.

However, if health care institutions embody the value of institutional transparency, then health care providers are not playing a series of disconnected, single-shot games. In transparent institutions, information about how care teams deal with particular kinds of cases should be available to patients. But, as we now argue, if this information is available to patients, the policy of disregarding advance care plans will produce a public bad. The reason is that the knowledge of how care teams have treated the advance care plans of patients is centrally relevant to the willingness of other patients to formulate such plans and to trust their care providers to carry them out.

When information about how care teams treat advance care plans is available to other, similarly situated patients, then the interaction turns into an instance of the ‘indirect reciprocity game’. In behavioral economics and game theory, indirect reciprocity refers to a game involving three (or more) parties, A, B, and C in which A and B play a game while C observes and then, in a second round of play, C plays the same game with B.<sup>33</sup> Let person A be our patient from the example above and party B her care team. Person C is another patient who, like A, has strong personal preferences about how she would like to be treated in a future health state and who faces similar decisions regarding their future care.

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<sup>33</sup> For a full theoretical framework for indirect reciprocity, see M.A. Nowak & K. Sigmund. Evolution of Indirect Reciprocity by Image Scoring. *Nature* 1998; 393(6685): 573-577.

Importantly, both persons A and C are willing to undergo care only if they are confident that their advance care plans will be respected by their care teams in the future. In the first round of the indirect reciprocity game, patient A interacts with her care team B and faces the choices modeled in the game tree presented above. In the indirect reciprocity game, however, person C knows how A and B play the game—the choices they make in interacting with one another. When it is C's turn to play the game, she uses this information to decide whether or not to trust B.

If person A makes an advance care plan and chooses to undergo care (person A cooperates) and the care team B upholds their agreement to honor person A's advance care plan (party B cooperates) in round one, then person C will be confident that the care team will treat her similarly and abide by her advance care plan. In this case, person C will be willing to cooperate with care team B and submit to care with an advance care plan when she plays in round two.

If the care team B chooses to not cooperate and disregards patient A's advance care plan, then party C will not trust the care team B to follow her contingency plan and thus will opt not to cooperate with the care team. In other words, patient C will opt to avoid a treatment plan that represents her best option for care because it requires her to rely on a care team that she cannot trust to help her avoid a state of affairs that she regards as worse than an early death. This option produces a public bad; patient C, and any other patient in C's position, will lack trust in their providers and forego care options that represent their best prospect for treatment. As a result, some of these patients forego care that could

have provided them with significant health benefits. This constitutes a public bad because it makes people with preferences like the patient in our example worse off than they would be if they were willing to formulate and act on an advance care plan.

The indirect reciprocity game is an accurate model of the interactions of patients and their care givers because the question of whether or not to honor a certain class of advance care plans is a matter of policy. It is not simply a question of how to deal with a single isolated case. This game simply models the consequences of patients understanding the policies that will govern their care and treatment.<sup>34</sup> Hiding this policy from patient A may make it possible for A to undertake surgery and for her agents to disregard her advance care plan if they think that is the best way to advance her welfare once she is incompetent. But to avoid a public bad, care providers would have to hide this policy not just from A, but from patient C and every other person with strong preferences about their future health states.

The claim that no one is harmed by ignoring an advance care plan that conflicts with the best interests of an incompetent person ignores the fact that the question at hand is not how to deal with an isolated case, but what our stated

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<sup>34</sup> As a result, it is not necessary that C actually observe the play of A and B, or that C must interact in round two with party B. All that matters is whether C believes that her interaction with her care givers will be sufficiently similar to that of A and B that it should effect her willingness to formulate and act on an advance care plan.

policy should be. To avoid producing a public bad, health care providers would have to violate the principles of honesty and transparency and keep patients in the dark about how care teams will respond to the decisions they make.

Here again, our point is not that the consequences that we describe necessarily will come about. In fact, we are concerned that these consequences might not come about precisely because care givers and health institutions do not adequately discharge their duties to patients under full transparency. Our claim, instead, is that the model we present illustrates the consequences of adopting a policy in a context in which patients have the values that we describe and patients participate in healthcare institutions that uphold honesty and transparency.

Honesty and transparency have not figured prominently in a debate that is usually framed as a conflict between patient autonomy and patient welfare. But the principles of honesty and transparency are not only critical to the individual relationships of health care providers and patients. They are critical to the proper functioning and legitimacy of health care institutions.

First, health care interactions are not arms-length transactions in which the guiding principle is that the buyer should beware. Rather, healthcare providers have a fiduciary relationship to patients. Patients lack relevant knowledge and information about their health status, the means available to them to protect or advance their health interests, the consequences of taking various courses of action, and so on. Patients thus rely on providers to provide this information. When institutional policy is relevant to patient medical decision making (as it is in



the case at hand) then the provider's fiduciary duty to patients cannot be discharged without disclosing this information.

Secondly, honesty and transparency about such policies are minimal, necessary conditions for the legitimacy of health institutions. A social or political institution is legitimate if it is 'acceptable or justifiable or desirable'<sup>35</sup> in the eyes of the people who participate in that institution. The general idea is that when an institution is legitimate, those who interact with it can accept or endorse the way that the institution treats them. When an institution is legitimate, its participants can view outcomes that they experience as a result of their interactions with the institution as acceptable or fair, even if those outcomes are not what those individuals would regard as most desirable.

Legitimacy is particularly important for institutions that have a profound impact on the rights, welfare, or life prospect of the people they interact with, and for institutions that people either cannot avoid (such as governments or states), or cannot avoid without being deprived of access to an important good.<sup>36</sup> Health care institutions fall into this latter category; patients with severe injury, sickness, or disease are constrained to seek medical care from health care institutions whose

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<sup>35</sup> P. Pettit. Legitimacy and Justice in Republican Perspective. *Curr Leg Probl* 2012; 65: 59-82.

<sup>36</sup> For example, Daniels argues that within Rawls' theory of justice as fairness, we can understand health care institutions as among the basic social institutions tasked with providing equality of opportunity for citizens. See N. Daniels. 1985. *Just Health Care*. Cambridge, UK: Cambridge University Press.

configuration and operation can have profound impact on their rights, health and welfare. This is because health care institutions are uniquely capable of providing the care patients require in order to meet their medical needs.

Transparency is a minimal, necessary condition for the legitimacy of health care institutions. This means that although transparency alone does not guarantee legitimacy, institutions that are not transparent, in some meaningful sense, cannot be legitimate. Transparency plays this role for several reasons. First, it is often regarded as a hallmark of fair processes.<sup>37,38</sup> Transparency promotes fairness by giving stakeholders the information they need to assess whether their interests are valued, safeguarded and advanced or neglected or denigrated. Second, and relatedly, transparency is a prerequisite for endorsement.<sup>39</sup> To accept or endorse an institution, those whose interests are directly affected by it have to be able to understand how the institution operates in its dealings with stakeholders. Finally, transparency promotes trust. It does this in a negative way when it provides assurance that institutions function in ways that are fair and not proxy for some special interest. It does this in a positive way when it promotes the

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<sup>37</sup> D.K. Martin, M. Giacomini, & P.A. Singer. Fairness, Accountability for Reasonableness, and the Views of Priority Setting Decision-Makers. *Health Policy* 2002; 61(3): 279-290.

<sup>38</sup> A. Gutmann & D. Thompson. 1996. *Democracy and Disagreement*. Cambridge, MA: Harvard University Press.

<sup>39</sup> For a discussion, see M. Turilli & L. Floridi. The Ethics of Information Transparency. *Ethics Inf Technol* 2009; 11(2): 105-112.

active identification and support of stakeholders with the mission of the institution.

It is not a stretch, therefore, to say that transparency is the political equivalent of the informational requirement for informed consent. For communities to accept or endorse (or to reject and press for reform of) the operation of the institutions that profoundly affect their rights, welfare or life prospects, their members must be able to understand and evaluate how those institutions operate.

Health systems could avoid producing a public bad by keeping patients and the public in the dark about their policies for disregarding advance care plans. But this would come at the cost of flouting providers' fiduciary duties to patients and undermining the legitimacy of those social institutions.

## **5 CONCLUSION**

It is perhaps paradoxical, but the upshot of the analysis presented here is that care teams who are committed to promoting the welfare of their patients across time, and to upholding the values of honesty and transparency, should be firmly committed to helping patients make the best advance care plans they can and then to respecting the decisions reflected in those plans. Critics of advance directives are right to be concerned about deficiencies in advance care planning that might lead patients to make choices that are, in some sense, not as good as they might be. But the upshot of the analysis here is that those concerns need to be addressed with the patient, while competent, during the advance care planning

process. In particular, patients should be made aware that their interests may change over time, and that their evaluation of future health states may be colored by present values that they may not retain in that future state. This has the advantages of strengthening trust in individual care teams and ensures that they are viewed as agents and not adversaries. It also promotes respect for patients and enhances the legitimacy of the institutions on which we rely to safeguard and advance our health and wellbeing.

In contrast, attempting to promote the medical best interests of the patient at every point in time, regardless of patient choice, can result in patient outcomes that are worse than those that result from the strategy of respecting patient choice—even patient choices that are inconsistent with what others regard as her best medical interests once she is no longer competent. This approach threatens trust in providers and, in doing so, threatens to either undermine the legitimacy of health care institutions or to produce a public bad.