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Law, Ethics, and the *Patient Preference Predictor*

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Abstract

The Patient Preference Predictor (PPP) is intended to improve treatment decision-making for incapacitated patients. The PPP would collect information about the treatment preferences of people with different demographic and other characteristics. It could be used to indicate which treatment option an individual patient would be most likely to prefer, based on data about the preferences of people who resemble the patient. The PPP could be incorporated into existing U.S. law governing treatment for incapacitated patients, although it is unclear whether it would be classified as evidence of a specific patient's preferences or those of a reasonable person sharing certain characteristics with the patient. Ethical concerns about the quality and significance of PPP choices could influence legal decision-makers' views of the PPP.

Annette Rid and David Wendler present a rich and thoughtful proposal to improve treatment decision-making for incapacitated patients (Rid and Wendler, 2013a; Rid and Wendler,

2013b). They argue that a patient preference predictor (PPP) should be incorporated into this form of decision-making. I appreciate their contribution and welcome the debate it will undoubtedly provoke. In this commentary, I describe ethical and policy issues raised by Rid and Wendler’s proposal. Because the PPP proposal originated in the United States, I examine it in light of U.S. legal and ethical standards.

### **The PPP and Existing Legal Standards**

Rid and Wendler suggest that the PPP could be easily incorporated into the existing legal framework governing decisions on life-sustaining treatment for incapacitated patients. It is not entirely clear what role the PPP would play in that framework, however. Would legal decision-makers regard it as evidence of a specific incapacitated patient’s former preferences? Or would they see it as evidence of the preferences of a reasonable person sharing certain characteristics with the patient?

Although there is some variation among states, U.S. courts and legislatures have adopted three general standards to resolve treatment questions when patients are unable to decide for themselves. In its influential *In re Conroy*<sup>1</sup> decision, which addressed withdrawal of a feeding tube from an advanced dementia patient, the New Jersey Supreme Court described these legal standards. First is the “subjective” standard. This standard asks “not what a reasonable or average person would have chosen to do under the circumstances but what the particular patient would have done if able to choose for himself” (1229). To apply this standard, there must be evidence of the patient’s expressed treatment preferences as a competent individual.

I am unsure whether courts would classify PPP information as evidence of a specific patient’s preferences. According to Rid and Wendler, the PPP “would yield a prediction of

which treatments are most likely to be consistent with the preferences and values of a currently incapacitated patient” (Rid and Wendler 2013a, 17). This suggests that PPP data could substitute for evidence of the patient’s expressed preferences as a competent individual. But as the *Conroy* excerpt indicates, subjective standards require explicit evidence that a particular patient, not a representative sample of individuals who are in some ways similar to the patient, expressed preferences for a certain treatment choice. The law’s emphasis on protecting the individual’s freedom to decide in idiosyncratic ways suggests that judges and other legal decision-makers might not see the PPP as relevant to the subjective standard.

Most cases involving incapacitated patients cannot be resolved using a purely subjective standard. In these cases, courts rely on an objective assessment of the situation. Courts typically call this approach the best interest standard; Rid and Wendler refer to it as the approach that “best promotes the patient’s clinical interests” (Rid and Wendler 2013a, 3). Objective standards focus on the incapacitated patient’s current condition, seeking to ascertain the choice that would best protect the patient’s welfare. The patient’s beliefs and values as a competent person may be relevant to the extent that they affect the patient’s well-being, but the emphasis is on pain, pleasure, and other experiences that are likely to affect a mentally impaired patient’s existing quality of life. Judges developed the objective approach in the course of exercising the state’s *parens patriae* responsibility to protect the welfare of vulnerable persons, both children and mentally incapable adults.

Legal decision-makers turn to the objective approach when clear evidence of individual patient preferences is absent. In some cases, they adopt a mixed subjective-objective approach. For example, *Conroy*’s “limited-objective” standard allows nontreatment when there is “some trustworthy evidence” that the individual patient would refuse treatment and “it is clear that the

burdens of the patient's continued life with the treatment outweigh the benefits of that life for him" (New Jersey Supreme Court 1985, 1232). In *Conroy*, the court considered pain, suffering, humiliation, dependence, and loss of dignity as relevant burdens and "physical pleasure, emotional enjoyment, or intellectual satisfaction" as relevant benefits. Courts applying what is known as the substituted judgment standard often consider a similar mix of subjective and objective evidence.

The best interest standard, or as *Conroy* called it, the "pure-objective" standard, applies when there is no evidence of the individual's previous treatment preferences. In this situation, the *Conroy* court determined, treatment could be withheld or withdrawn "if the recurring, unavoidable and severe pain of the patient's life with the treatment [are] such that the effect of administering life-sustaining treatment would be inhumane" (New Jersey Supreme Court 1985, 1232). Other courts have applied this standard to allow nontreatment in less dire circumstances, including cases involving permanently unconscious patients.

My guess is that legal decision-makers would regard the PPP as a tool for adding precision to decisions for patients who left no clear indication of their prior preferences. Objective standards are grounded in community norms and the commonsense judgments of ordinary people. Such standards "reflect a societal consensus, or the perspective of a 'reasonable person,' choosing as most people would choose for themselves" (NY State Task Force 1992, 55). The PPP would supply empirical data on the treatment preferences of a representative sample of people who have much in common with a specific patient. Responses to the PPP survey would convey information about what a reasonable person with characteristics similar to the patient would prefer, thus allowing decision-makers to fine-tune an objective judgment about the appropriate treatment for an incapacitated patient.

It remains to be seen how courts and legislators would classify PPP evidence. Whether they see it as relevant to the subjective or the objective approach to treatment decision-making, they are likely to insist that its use be optional. From a legal perspective, Rid and Wendler are wise to present the PPP as a potentially helpful supplement, rather than a requirement, for treatment decision-making. Any attempt to mandate the PPP would create problems, for courts and legislatures would reject any effort to deprive individuals and surrogates of their existing decisional authority over the care incompetent patients receive. The U.S. Constitution, as well as state and federal antidiscrimination statutes, would probably prohibit the mandatory use of classifications like race, gender, national origin, disability, and age to determine the medical care an individual patient receives.

A full policy evaluation of the PPP is impossible at this time, however. Such an evaluation can come only after experts develop the survey and begin putting the PPP in practice. Rid and Wendler attempt to address some of the problems that could materialize in the implementation process, but others will undoubtedly emerge. Appealing policy proposals often lose their luster once they enter the real world. Indeed, as Rid and Wendler point out, enthusiasm for advance directives and surrogate decision-making dissipated after years of implementation and study revealed deficiencies in those approaches. A similar learning curve can be expected for the PPP.

Research will also be necessary to determine whether the PPP will meet its objectives, such as increased accuracy about patients' treatment preferences and reduced family distress. And as Rid and Wendler acknowledge, developing and maintaining a PPP will be costly. Will the PPP offer a substantial enough benefit to justify its cost? How often will surrogates and clinicians actually use it? When the PPP is used, how much benefit will it provide? Could

similar or greater benefit be achieved through devoting resources to other reforms, such as the creation of hospital and nursing home teams to support and assist surrogates in the decision-making process? The answers to these questions are unknowable at this point. Moreover, ethical questions about the quality and proper weight of PPP choices could influence legal decision-makers' views of the PPP.

### **Two Questionable Assumptions**

The PPP rests on two assumptions that merit further examination. One is the assumption that competent individuals have adequate information to make valid choices about their treatment as incapacitated patients. The other is the assumption that the preferences of competent individuals should govern decisions on behalf of incapacitated patients. The PPP is not alone in relying on these problematic assumptions; advance directives and other subjective treatment standards rely on them as well. In the remainder of my commentary, I discuss ethical concerns related to these assumptions.

There are reasons to worry about the quality of PPP choices, for they will address health situations that survey participants have never experienced. In contemporaneous medical decision-making, patients make informed choices when they understand the nature, risks, and potential benefits of the relevant treatment options. Informed patients evaluate how different options could affect their quality of life during and after treatment is administered or forgone. It is doubtful that PPP survey participants will have anything like this level of understanding about the multiple choices they will make about the treatment they would prefer as individuals with dementia or other incapacitating conditions (Dresser 2003a; Fagerlin and Schneider 2004). I also wonder whether survey respondents will take their task as seriously as they should. They might

devote less thought and effort to the PPP survey than they would to their personal advance treatment directives.

Rid and Wendler suggest “a comprehensive and carefully designed information session” to educate survey-takers and to mitigate the psychological biases that influence how people rate the value of life in different health states (Rid and Wendler 2013a, 25). This is a tall order for one session; I think they are underestimating the time and effort that would be needed to teach survey respondents what they need to know. For many years, I have asked my law and medical students to complete the Advance Medical Directive (Emanuel and Emanuel 1989) in preparation for a class on advance directives. In class discussions, almost everyone in this relatively educated group voices confusion and uncertainty about how to complete the Directive. I expect that many people would need more than one session to develop an adequately informed understanding of the treatment situations presented in the PPP.

Participants’ PPP survey choices could also be significantly influenced by the way information is presented. As three psychology researchers have reported, “for choices among options that are important, complex, and unfamiliar, like those consumers face in the current health care environment ... preferences do not preexist but are constructed on the spot by the decision maker through a process that is heavily influenced by framing and contextual factors” (Hibbard et al. 1997, 402). Any educational material would have to be thoroughly tested to ensure that it did not unduly influence survey participants’ substantive responses.

Moreover, even well-educated PPP survey-takers might not be qualified to determine their treatment preferences about hypothetical medical situations (Gilbert and Wilson 2007; Quoidbach, Gilbert, and Wilson 2013). Competent patients are known to change their earlier treatment preferences as death approaches, “because they cannot accurately imagine what they

will want and how much they can endure in a condition they have not experienced” (Groopman and Hartzband 2012). Before the onset of serious illness, people may fail to appreciate their ability to adjust to physical decline and to find pleasure and meaning in the life that remains. The opposite may occur as well—they may underestimate the burdens that illness and medical interventions will impose. Findings from studies of future-oriented decision-making show that many people don’t know how they will experience a future health condition and don’t know what their preferences will be in that situation (Hibbard et al. 1997).

Of course, competent patients remain able to make treatment choices that align with their changing preferences. But there is no such opportunity to alter an earlier treatment preference once incapacity sets in. A PPP that locks in the preferences of individuals with capacity could impose harm on vulnerable patients with interests that differ from those of capable decision-makers.

This brings me to the PPP’s second questionable assumption. Rid and Wendler assume that PPP preferences will supply a morally acceptable basis for determining the medical care incapacitated patients receive. The PPP omits an important moral element, however. The PPP will collect information about what competent individuals think they would prefer in various hypothetical treatment situations. It will supply information about the preferences of competent persons in different demographic and health groups. But it will collect information from competent individuals whose mental abilities shape their views about what constitutes an acceptable quality of life. The PPP will not supply information about quality of life from the perspective of conscious mentally impaired individuals.

Because conscious incompetent patients have the capacity to experience benefits and burdens, they have interests that ought to influence the treatment they receive. Anyone who has

spent time around dementia patients knows that most of them are capable of thought, emotion, and interaction with the people and environment around them. Most also have desires about how their lives should go. Like many other cognitively impaired individuals, most dementia patients are far from experiential ciphers. Yet their interests are excluded from the PPP.

The widely accepted moral principle of respect for persons obligates us to protect incapacitated patients from harm. When competent persons make judgments about the treatment an impaired patient should receive, they make judgments about that patient's quality of life. To protect the lives of individuals with compromised capacities, quality-of-life judgments should focus on the value life has to the patient herself. In their book on surrogate decision-making, Buchanan and Brock said it well:

The question is not whether the patient's quality of life is below average, or worse than it used to be, or anything of the sort. Instead, the proper quality of life judgment is only whether the quality of life with the life-sustaining treatment will be so poor as to be not worth living or worse than no life at all (Buchanan and Brock 1989, 124).

At this point, we don't know how PPP survey participants would factor quality of life into their preferences for or against treatment as conscious patients with dementia or similar mental impairments. But in light of the fears that many people have about aging and mental decline, it is certainly possible that a large portion of PPP respondents would regard life with even moderate dementia as not worth living (Brock 1988). It is possible that many would choose to decline even minor treatment interventions such as oral antibiotics in those circumstances.

If the PPP yielded preferences like these, should it be invoked to authorize nontreatment of a dementia patient who appears to enjoy her limited life? According to the current legal and ethical consensus, it would be impermissible to forgo a low-burden life-sustaining treatment

from someone born with an intellectual disability such as Down syndrome who appears to enjoy a quality of life similar to a dementia patient like this. But the PPP could support forgoing treatment for the dementia patient if survey data showed that mentally capable adults from the patient's demographic group would prefer that decision.

Rid and Wendler suggest that the PPP would rarely support a decision that conflicts with the incapacitated patient's clear clinical interests (Rid and Wendler 2013a, 22). But the existing proposal omits the details and examples that would clarify how the PPP could be applied in a way that is consistent with our duty to protect incompetent patients' experiential interests. A California court described the basic responsibility owed to incompetent patients in the following passage:

In the years since the *Quinlan* decision, most courts have adopted the formula that a patient's right to choose" or "right to refuse" medical treatment survives incompetence. It would be more correct to say that incompetent patients retain the right to have appropriate decisions made on their behalf. An appropriate medical decision is one that is made in the patient's best interests, as opposed to the interests of the hospital, the physicians, the legal system, or anyone else.<sup>2</sup>

As Rid and Wendler point out, "clinicians are often unable to determine which course of treatment would best promote the interests of incapacitated patients" (Rid and Wendler 2013a, 7). I don't deny that the best interest standard can be difficult to apply, but that is not the end of the story. First, there *are* cases in which clinicians and surrogates can determine that a certain treatment option would be best for an incapacitated patient in her current condition. Thousands of such decisions are made every day, but they are not the ones that come to the attention of ethics committees and judges.

Second, neither ethics nor law has invested much time and energy in fine-tuning the best interest standard. The focus on promoting the treatment preferences of competent individuals has deterred clinicians and legal decision-makers from developing a more robust approach to this standard. Applying the best interest standard requires observers to understand how a cognitively impaired individual experiences her life and to predict how various treatment options could affect that individual's well-being. Various assessment techniques enable clinicians to investigate these questions, and patients themselves can often communicate information about their subjective states (Mead 2013). More work is needed to develop an adequate knowledge base about the experiential welfare of conscious incompetent patients. Such an inquiry would allow observers to improve their ability to determine the treatment decision that would be preferable from the incapacitated patient's perspective (Dresser 1994a; Dresser 2003b; Dresser and Whitehouse 1994).

The contours of the best interest standard may be fuzzy, but the core duty of protection is clear. The PPP should incorporate this protective element. Survey data about competent people's preferences is not the same as data about the contemporaneous interests of conscious incapacitated patients. Whether or not professionals and the public embrace the PPP as an aid to decision-making, our society needs a morally robust debate over what we owe to the growing population of dementia and other incapacitated patients who depend on others to protect their interests in receiving humane care. My hope is that Rid and Wendler's proposal will highlight the need for this essential debate.

## **Notes**

1. *In re Conroy*, 486 A.2d 1209 (N.J. 1985).
2. *In re Drabick*, 245 Cal. Rptr. 840, at 852 (1988).

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