

Will a Patient Preference Predictor Improve Treatment Decision Making for Incapacitated Patients?

ANNETTE RID*

*King's College London, London, UK
University of Zurich, Zurich, Switzerland*

*Address correspondence to: Annette Rid, MD, PhD, Department of Social Science, Health & Medicine, King's College London, Strand, London WC2R 2LS, UK.
E-mail: annette.rid@kcl.ac.uk

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One of the cornerstones of contemporary medicine is the patient's right to decide about his or her medical treatment. Clinicians respect this right by obtaining the informed consent of competent patients, but face a dilemma in the many cases in which patients lack decisional capacity—for example, due to sudden events like stroke or head trauma or as a result of a gradual decline in cognitive function. A series of high-profile court cases in the United States, most notably the cases of Karen Quinlan in 1976 and Nancy Cruzan in 1990, spurred the development of the current ethical and legal framework for making treatment decisions for incapacitated patients. The framework primarily aims to extend the patient's right to decide about his or her medical treatment into times of decisional incapacity. It encourages patients to discuss and document prospectively how they want to be treated in the event of incapacity. If patients lose the ability to make their own decisions, they will then be treated according to their previously stated preferences and values. When no clear advance directive is available, clinicians ask a surrogate decision maker—usually a member of the patient's family or a loved one—to make medical decisions based on the surrogate's best estimate for how the patient would want to be treated in the given situation (the “substituted judgment” standard). When it is unclear how the patient would want to be treated, clinicians and surrogates choose the course of treatment that best promotes the patient's clinical interests.

This framework for respecting the rights of incapacitated patients is widely endorsed, and it has been adopted not only in the United States, but in

many other countries. However, more than two decades of experience have revealed numerous challenges for the framework. Completion rates of instructional advance directives (ADs), which allow patients to document preferences for or against specific treatments or their general goals of care, have been stubbornly low. Furthermore, completed ADs are not always available when they are needed, and oftentimes they are too vague to guide treatment decisions in the given circumstances (Fagerlin and Schneider, 2004). Recent studies have demonstrated higher completion rates and better implementation of ADs (Detering et al., 2010; Hammes, Rooney, and Gundrum, 2010), but these successes are typically based on extensive programs of clinician training and patient counseling that may not be feasible on a larger scale. In addition, surrogate decision makers struggle to predict their loved one's treatment preferences or goals of care (Shalowitz, Garrett-Mayer, and Wendler, 2006), while efforts to improve surrogate accuracy have had mixed results (Ditto et al., 2001; Kirchhoff et al., 2010).

These findings might not be regarded as a challenge if being treated consistent with their preferences and values is not patients' primary goal for treatment decision making during periods of incapacity. The available evidence suggests that this may indeed be the case, given that the vast majority of patients want their families and loved ones to make treatment decisions for them, and many are willing to grant their surrogates considerable leeway in decision making (Kelly, Rid, and Wendler, 2012). Yet the available data also indicate that patients typically want their family to make decisions for them because they believe their loved ones know which treatments they want (Kelly, Rid, and Wendler, 2012). In addition, patients frequently worry about burdening their families in the event of incapacity, and many wish to reduce stress on their loved ones (Kelly, Rid, and Wendler, 2012). Helping to make treatment decisions for an incapacitated loved one, however, causes significant stress and anxiety in surrogate decision makers—especially when surrogates are uncertain about the patient's preferred treatment option (Wendler and Rid, 2011). These considerations raise questions about the extent to which patients want their loved ones to be involved in decision making when they learn that surrogates often have difficulty determining their preferred treatment option and frequently experience significant stress from helping to make treatment decisions.

This special issue presents and discusses a proposal to address these challenges by supplementing current practice with the use of a "Patient Preference Predictor" (PPP) (Rid and Wendler 2014a, 2014b). A PPP would predict which treatment course an incapacitated patient would want, based on representative data on similar individuals' treatment preferences in common situations involving decisional incapacity. The underlying idea is that use of a PPP would reduce stress on surrogate decision makers by offering predictions of the patient's preferred treatment option. In addition, limited data suggest that evidence-based predictions of an incapacitated patient's

treatment preferences might be more accurate than predictions of surrogates. If these data can be confirmed, PPP predictions might also help to ensure that patients are treated consistent with their own preferences and values. Two papers in this issue advance the PPP proposal and discuss some of the interesting conceptual, normative, and practical issues it raises (Rid and Wendler 2014a, 2014b). In particular, are incapacitated patients' "last competent" preferences and values relevant for how they should be treated? Is it possible to ensure that the PPP reflects individuals' informed and considered preferences? How should PPP predictions be incorporated into the treatment decision-making process between surrogates and clinicians? Do PPP predictions stereotype patients? Might use of a PPP actually have harmful effects on surrogate decision makers? And how costly would it be to develop a PPP?

Six astute commentaries on the PPP proposal reveal many additional important questions. Commentators raise further concerns about the feasibility of developing a PPP. For example, the clinician-philosopher Scott Kim argues that it is impossible to validate a PPP because many patients change their treatment preferences over relatively short periods of time (Kim, 2014). Kim also contends that the PPP would not be able to make predictions for patients who simply do not have considered treatment preferences, although it is precisely for these patients that use of the PPP is intended. Psychologists Peter Ditto and Cory Clark equally emphasize that individuals may not have considered preferences for how they are treated in the event of incapacity. However, Ditto and Clark (2014) are cautiously optimistic that PPPs for specific health conditions—instead of one general PPP—might be able to address this concern. Lawyer Rebecca Dresser, by contrast, is skeptical that a PPP survey would gather robust data on individuals' treatment preferences or goals of care, and therefore cautions against its use. She also points to the uncertain legal status of PPP predictions (Dresser, 2014). Philosopher Stephen John shows that classifying individuals for the purposes of predicting their treatment preferences raise both epistemological and moral questions. He argues that a PPP could be justifiable, provided that efforts to maximize its predictive accuracy are constrained by moral considerations, such as the possibility that PPP predictions perpetuate social injustices (John, 2014). Several commentators also raise concerns that the benefits of the PPP may not justify the costs of its development and use (Ditto and Clark, 2014; Kim, 2014).

Furthermore, commentators question the fundamental conceptual and normative assumptions on which the PPP proposal rests. Philosophers Hilde Lindemann and James Lindemann Nelson argue that the PPP is based on the traditional, but flawed conception of the surrogate's role in treatment decision making. In their view, good surrogate decisions should not only implement the content of the patient's preferences and values, but should also express the patient's agency through how the surrogate deliberates and eventually makes a decision (Lindemann and Nelson, 2014). Stephen John

makes a related point when he argues that the reasons surrogates give for their decisions should be reasons that the patient himself would endorse (John, 2014). In his view, PPP predictions are unlikely to meet this condition. Philosopher Dan Brock submits that the surrogates' ability to predict their loved one's treatment preferences is not the most important reason for why patients choose a surrogate. He claims that other reasons, such as trust and mutual responsibility, matter more to patients than surrogates' predictive accuracy (Brock, 2014). Scott Kim reasons along similar lines and argues that surrogate decision makers offer a "thread of authorization" which the PPP lacks (Kim, 2014). Finally, commentators raise the concern that the PPP overemphasizes respect for those preferences and values a patient had before losing decisional incapacity, and thereby may weaken respect for his or her current preferences (if any) or consideration of his or her clinical interests (Brock, 2014; Dresser, 2014).

The survey of these arguments shows that the papers in this issue address many questions that lie at the heart of the current debate about treatment decision making for incapacitated patients. As the issue's editor, my hope is that the PPP proposal and its incisive criticism will help readers not only to understand, but also to address the challenges of developing a sound approach to respecting the rights of incapacitated patients while reducing the burden on their families and loved ones.

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