

Use of a Patient Preference Predictor to Help Make Medical Decisions for Incapacitated Patients

ANNETTE RID*

*Department of Social Science, Health & Medicine, King's College London, London, UK
Institute of Biomedical Ethics, University of Zurich, Zurich, Switzerland*

DAVID WENDLER

Department of Bioethics, NIH Clinical Center, Bethesda, Maryland, USA

*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

The standard approach to treatment decision making for incapacitated patients often fails to provide treatment consistent with the patient's preferences and values and places significant stress on surrogate decision makers. These shortcomings provide compelling reason to search for methods to improve current practice. Shared decision making between surrogates and clinicians has important advantages, but it does not provide a way to determine patients' treatment preferences. Hence, shared decision making leaves families with the stressful challenge of identifying the patient's preferred treatment option. To address this concern, the present paper proposes to incorporate the use of a "Patient Preference Predictor" (PPP) into the shared decision-making process between surrogates and clinicians. A PPP would predict which treatment option a given incapacitated patient would most likely prefer, based on the individual's characteristics and information on what treatment preferences are correlated with these characteristics. Use of a PPP is likely to increase the chances that incapacitated patients are treated consistent with their preferences and values and might reduce the stress and burden on their surrogates. Including a PPP in the shared decision-making process therefore has the potential to realize important ethical goals for making treatment decisions for incapacitated patients. The present paper justifies this approach on conceptual and normative grounds.

Keywords: *advance care planning, advance directives, decisional incapacity, surrogates, treatment decision making*

I. INTRODUCTION

Patients have a right to make their own medical treatment decisions. This right is grounded in respect for patient autonomy and, in most cases, in the principle of beneficence, given that patients often are the best judges of their own interests (Dworkin, 1988). Consistent with this right, standard clinical practice allows competent patients to decide how they are treated, typically in consultation with a clinician. Although this practice respects competent patients, it poses a dilemma regarding patients who have lost the ability to make their own decisions—for example, patients who are unconscious or have severe Alzheimer's disease. This dilemma is common. In the United States, up to 40% of hospitalized adults (Raymont et al., 2004), 30% of older adults for whom treatment decisions are required (Silveira, Kim, and Langa, 2010), and approximately 95% of critically ill adults (Smedira et al., 1990; Prendergast, Claessens, and Luce, 1998) are unable to make their own treatment decisions.

Standard practice aims to extend the individual patient's right to make his or her own decisions into times of decisional incapacity (Buchanan and Brock, 1989). Clinicians encourage competent patients to complete an advance directive, prospectively documenting how they want to be treated in the event of decisional incapacity. When no clear advance directive is available, a surrogate—usually a family member or loved one—is asked to make medical decisions based on the surrogate's best estimate for how the patient would want to be treated in the circumstances. When it is unclear how the patient would want to be treated, the surrogate is asked to choose the course of treatment that best promotes the patient's clinical interests.

Patients frequently do not complete an advance directive, and they rarely discuss treatment preferences with their families or loved ones. As a result, it is often unclear which treatments the patient would want in the circumstances. Moreover, it is often unclear which course of treatment would best promote the clinical interests of incapacitated patients. In these cases, standard practice provides little guidance for how to treat incapacitated patients. A recent proposal suggests that this limitation might be addressed by incorporating the use of a "Patient Preference Predictor" (PPP) into the treatment decision-making process (Shalowitz, Garrett-Mayer, and Wendler, 2007). A PPP would predict which treatment option an incapacitated patient is most likely to prefer in the circumstances based on the patient's own characteristics. This prediction would be informed by the results of empirical research on how individual characteristics are correlated with treatment preferences in different situations involving decisional incapacity. Preliminary data suggest that a PPP is likely to predict patients' treatment preferences more accurately than surrogate decision makers (Smucker et al., 2000; Shalowitz, Garrett-Mayer, and Wendler, 2007). Available data also suggest that having confidence regarding the patient's treatment preferences reduces the negative impact on many surrogates of making treatment decisions (Wendler and Rid, 2011).

The present paper argues that the standard approach to treatment decision making for incapacitated patients should be complemented by incorporating the use of a PPP into a shared decision-making process between surrogates and clinicians. The paper provides a conceptual and normative defense of this recommendation, describes how the PPP should be used, and addresses potential objections. This defense of the PPP is based on several empirical assumptions. A critical appraisal of these assumptions, including whether the PPP would predict patients' treatment preferences more accurately than surrogates, and whether its use would reduce surrogate stress, is provided in an accompanying paper (Rid and Wendler, 2014).

II. SIX ETHICAL GOALS

There are numerous ethical, institutional, and social limits on which treatments are available to patients. For example, the fact that a patient wants "everything done" does not imply that all treatments should be provided to him or her. Numerous other factors need to be taken into account, including the cost of the treatment, its effectiveness, available alternatives, and the impact on others of providing it. The present paper brackets these considerations and focuses on how treatment decisions should be made for incapacitated patients within the limits of properly available treatments, whatever those limits might turn out to be.

To evaluate different approaches to making treatment decisions for incapacitated patients, one first needs to specify the ethical goals relevant to making these decisions. We thus begin with a brief consideration of the six ethical goals that are widely, if not always explicitly, endorsed in this regard (Rid and Wendler, 2010).¹

1) Promote the Patient's Clinical Interests

There is a long tradition in medicine according to which the clinician's first and most important obligation is to promote the well-being of the patient. "Shared decision making" between patients and clinicians is increasingly accepted as the best way to fulfill this obligation. Clinicians know the relevant medical facts, and patients are typically the best judges of their own interests. Together, they work to identify treatments that promote the patient's interests, including a plan for treatment during periods of incapacity.

2) Enable the Patient to Control How He or She Is Treated

Allowing individuals to determine the course of their lives is fundamental to respecting their autonomy, independent of whether the choices they make best promote their interests. Patients can determine the course of their lives during periods of decisional incapacity by providing oral or written advance directives. By respecting the decisions that patients make prospectively,

clinicians enable patients to control how they are treated, even during periods of incapacity.

3) Provide Treatment Consistent with the Patient's Considered Preferences and Values

Clinicians should attempt to provide treatment consistent with patients' considered preferences and values.² Given that patients' well-being is influenced by their preferences and values, this approach often helps to advance patient well-being. In addition, patients' preferences and values provide guidance regarding how the patient wants his or her life to proceed. As a result, providing treatment consistent with patients' preferences and values indirectly respects their autonomy, allowing the patients' own preferences and values to guide how they are treated.

4) Respect the Patient's Preferences for How Treatment Decisions Are Made

Many patients have preferences regarding how treatment decisions are made for them if they become incapacitated. Respecting these preferences provides another indirect way to respect patient autonomy during periods of decisional incapacity. When a patient designates a surrogate decision maker while competent, allowing the designated person to make treatment decisions when the patient is incapacitated provides a way for the patient to control his treatment indirectly.

5) Respect and Help the Patient's Family and Loved Ones

Treatment decisions can have important implications not only for patients, but also for their loved ones. Treatment decisions for incapacitated patients typically have great emotional and sometimes significant financial impact on families. While the primary obligation of clinicians is to promote the clinical interests of their patients, clinicians also should respect and help patients' families and loved ones. Moreover, because patients typically care about what happens to their loved ones, respecting and helping them frequently respects the patient's own preferences and values.

6) Promote Timely Decision Making

Making treatment decisions takes time, and during that time, some treatment must be provided to sustain the patient. Such provisional treatment can impose unwanted clinical interventions on the patient or delay wanted ones. Timely decision making is therefore central for promoting the goals of allowing patients to be in control of their treatment and providing treatment consistent with their preferences and values. Timely decision making

can also help families and loved ones by avoiding a long and often difficult decision-making process.

III. SHORTCOMINGS OF THE STANDARD APPROACH

There is increasing evidence that the standard approach often fails to realize the six ethical goals for treatment decision making (Rid and Wendler, 2010). First, clinicians are often unable to determine which course of treatment would best promote the interests of incapacitated patients. For example, should a patient with moderate Alzheimer's disease be ventilated for pneumonia? When even clinical experts are unclear about which treatments are clinically indicated, it is unlikely that any approach—including current practice—will be able to determine which treatments best promote the patient's clinical interests.

Second, standard practice attempts to address this challenge by encouraging patients to document their preferences prospectively for treatment during periods of decisional incapacity. However, most patients do not complete an advance directive or otherwise document or specify their treatment preferences and values. Only about 20–30% of the US population has a living will (Perkins, 2007), despite extensive efforts for the past 20 years to encourage patients to complete an advance directive. This history suggests that we may have to accept a low rate of completion for advance directives and develop a way to treat incapacitated patients in light of this fact. Moreover, even when completed, advance directives typically do not provide clear guidance for which treatments should be provided (Lo, McLeod, and Saika, 1986; SUPPORT Principal Investigators, 1995; Hanson, Tulskey, and Danis, 1997; Perkins, 2007). Those that do provide clear guidance (e.g., the patient wants cardio-pulmonary resuscitation) may quickly become out of date, a concern that is particularly acute at the end of life when patients' preferences and circumstances can change over relatively short periods of time. And although advance care planning programs have recently achieved increased completion rates for advance directives (Detering et al., 2010; Hammes, Rooney, and Gundrum, 2010), it remains unclear whether these efforts can be generalized. In addition, the documents used in these programs document only a very small number of treatment preferences, typically regarding four or five specific treatments (e.g., cardio-pulmonary resuscitation, ventilation) and without consideration of the clinical context. For these reasons, current practice of relying on advance instructions from the patient often fails to realize the goal of allowing patients to control the treatments they receive during periods of incapacity.

Third, when it is unclear which treatments would best promote the patient's clinical interests, and the patient has left no directions for his or her treatment during periods of incapacity, the standard approach relies on surrogate

decision makers to predict which course of treatment would be most consistent with the patient's preferences and values. However, there is now robust evidence that, in cases in which it is unclear which treatment option would promote the patient's clinical interests, surrogates predict patients' treatment preferences only slightly better than chance (Shalowitz, Garrett-Mayer, and Wendler, 2006).^{3,4}

Research in social psychology and consumer behavior suggests that surrogate inaccuracy is just one example of a more general inability of individuals to predict the preferences and values of loved ones (Rid and Wendler, 2010). This research finds that we all are subject to various psychological biases in close relationships, such as projection of our own preferences. It will therefore be extremely difficult to improve surrogates' ability to predict accurately which treatments are consistent with their charges' preferences and values. This conclusion is supported by data showing that the two most widely discussed methods for improving surrogate accuracy—appointing one's own surrogate and discussing one's treatment preferences and values with this person—are largely ineffective (Ditto et al., 2001; Shalowitz, Garrett-Mayer, and Wendler, 2007). Current reliance on surrogates thus does little, to increase the chances that incapacitated patients are treated consistent with their preferences and values.

Fourth, a recent systematic review shows that the vast majority of patients want their family and loved ones to make treatment decisions for them. Only a small minority want a nonfamily member and nonclinician to make decisions, typically because they either have no family member or are in conflict with their family (Kelly, Rid, and Wendler, 2012). These data seem to suggest that the standard approach to treatment decision making promotes respect for patients' preferences regarding how decisions are made, even if it does not yield treatment consistent with their treatment-specific preferences and values. However, the available data also find that most patients want their families and loved ones to make treatment decisions for them because the patients assume that their family members know their treatment preferences (Kelly, Rid, and Wendler, 2012). Thus, patients' preferences to have family and loved ones make treatment decisions for them during periods of incapacity often traces to the questionable assumption that loved ones can identify the treatments the patient would want to receive. There are no data on how patients would want treatment decisions to be made if they knew that surrogates are, on average, unable to predict accurately their preferred treatment options.

Fifth, a further systematic review has found that making treatment decisions for an incapacitated loved one places emotional stress and burden on at least a third of surrogate decision makers. The negative impact on surrogates is often substantial and lasts months and, in some cases, years (Wendler and Rid, 2011). Some studies report stress levels consistent with posttraumatic stress disorder or a major risk thereof (Tilden et al., 2001;

Azoulay et al., 2005; Sood, Fisher, and Sulmasy, 2006; Gries et al., 2010). While some of the negative effects can be traced to having, or having lost, an ill loved one, making treatment decisions has an additional and frequently negative effect. Not surprisingly, family members and loved ones often find it extremely stressful to make treatment decisions for those they love, especially at the end of life, and especially when it is unknown which option is consistent with the patient's preferences and values (Wendler and Rid, 2011). These findings suggest that current practice often does not realize the goal of helping and benefiting patients' families and loved ones. Moreover, because reducing the burden on their families and loved ones is one of patients' three primary goals for treatment decision making (Kelly, Rid, and Wendler, 2012), the findings also press the possibility that informed patients—who recognize the extent of surrogate burden—may not want their families and loved ones to make treatment decisions for them.

Sixth, to our knowledge, there are no empirical studies that specifically investigate how long clinicians and surrogates take to make treatment decisions for incapacitated patients. However, available evidence shows that disagreements over treatment decisions are frequent, both among families and between families and clinicians, and occur in at least a third of all cases (Breen et al., 2001; Studdert et al., 2003; Meeker, 2004; Vig et al., 2007). Assuming that disagreement prolongs the decision-making process, these data suggest that current reliance on surrogates may compromise timely decision making.

IV. ALTERNATIVE APPROACHES

The shortcomings of the standard approach provide compelling reason to search for ways to improve treatment decision making for incapacitated patients. It is unlikely that any approach to treatment decision making will substantially improve the extent to which the first two ethical goals—promoting patients' clinical interests and enabling patients to control how they are treated—are realized. When even expert clinicians are uncertain about which treatments are clinically indicated, it is unlikely that any other approach will be able to do better in this regard. Moreover, the majority of patients do not exercise control over their treatment during periods of incapacity, despite extensive efforts to encourage them to do so. In addition, completed advance directives rarely provide evidence about how the patient wants to be treated in actual cases. These considerations suggest that proposed changes should be evaluated based on how well they promote the four remaining ethical goals.⁵

A number of alternative approaches to current practice have been proposed.⁶ Of the proposed alternatives, “shared decision making”—which emphasizes the joint responsibility of clinicians and surrogates for making

treatment decisions—is now becoming part of standard practice. Shared decision making has important advantages. It allows surrogates to gain the benefit of clinicians' medical expertise while being involved in decisions about the care of their loved ones and protecting them from abuse. This is likely to reduce stress and anxiety on surrogates, thereby helping patients' families and loved ones and promoting timely decision making. However, the problem remains that family members often do not know which treatments the patient would want. Shared decision making fails to increase the chance that patients are treated consistent with their preferences and values, and it still leaves families uncertain and often anxious about how to identify the patient's preferred treatment option (Wendler and Rid, 2011). This analysis suggests that more information about which treatments a patient would want in the given situation could significantly improve the shared decision-making process.

V. SHARED DECISION MAKING COMBINED WITH A PPP

One option for obtaining more information regarding patients' treatment preferences begins with data suggesting that patients' preferences regarding medical treatment are correlated with individual characteristics. Empirical studies show that many factors influence how patients want to be treated during periods of decisional incapacity, including age (Covinsky et al., 1996; Phillips et al., 1996; Rosenfeld et al., 1996; Pearlman et al., 2000), gender (Garrett et al., 1993; Phillips et al., 1996; Rosenfeld et al., 1996; Pearlman et al., 2000; Bookwala et al., 2001; Fried et al., 2007; Barnato et al., 2009), race (Garrett et al., 1993; Covinsky et al., 1996; Phillips et al., 1996; Cicirelli, 1997; Fried et al., 2007; Barnato et al., 2009), marital status (Fried et al., 2007), geographical location (Phillips et al., 1996), education (Garrett et al., 1993; Cicirelli, 1997; Pruchno et al., 2006), occupational status (Cicirelli, 1997), income (Fried et al., 2007), religiousness (Pruchno et al., 2006; Balboni et al., 2007), and fear of end-of-life suffering or the dying process (Cicirelli, 1997; Pruchno et al., 2006). Similarly, various aspects of the available treatment options—the burden of treatment (Pearlman et al., 2000; Bookwala et al., 2001; Fried et al., 2002), the expected health state after treatment (Ditto et al., 1996; Patrick et al., 1997; Fried, Bradley, and Towle, 2002, 2003), as well as the likelihood (Murphy et al., 1994; Weeks et al., 1998; Coppola et al., 1999) and the expected duration of that health state (Cohen-Mansfield, Droge, and Billig, 1992; Weeks et al., 1998)—influence how patients want to be treated. These data point to the possibility of “predicting”⁷ how a given incapacitated patient would want to be treated based on his or her individual characteristics and the situation in question. We call the tool for predicting incapacitated patients' treatment preferences in this way a “Patient Preference Predictor” (PPP).⁸

To create a PPP, it would be necessary to gather extensive empirical data on how individuals want to be treated in various situations involving decisional incapacity. Ideally, this would involve conducting a representative survey of competent adults living in a given region or country—for example, in the United States.⁹ The survey would collect information on sociodemographic factors (e.g., age, gender, education, religiousness), current physical, psychological and social functioning (e.g., perceived quality of life, social support), attitudes and values (e.g., valued life activities), and relevant personal experience (e.g., with medical care or incapacitated patients). It would also present common treatment dilemmas regarding the care of incapacitated patients and elicit respondents' considered treatment preferences in those situations. For example, respondents might be asked whether they would want to undergo various diagnostic and/or therapeutic interventions if they became incapacitated in the near future, and their chance of regaining the ability to reason, remember, and communicate was less than 1%. Respondents would also be asked to indicate the strength of their reported treatment preferences. The scenarios would be described to represent treatment dilemmas that are likely to occur in practice, without providing more information about the chances of recovery and the nature of the predicted postintervention health states than clinicians realistically possess.

Based on these data, statistical analysis would be used to identify which factors predict patients' treatment preferences during periods of decisional incapacity. The identified predictors, including their weight and possible interaction with other predictors, would then be modeled statistically for predicting the treatment preferences of individual patients. For example, if a 57-year-old married female with a college degree loses consciousness after head trauma, and her chance of recovery with the ability to reason, remember, and communicate is less than 1%, the model could be used to predict how the patient would want to be treated based on her individual characteristics and the given clinical situation. Imagine the model indicates an 80% likelihood that the patient would want to be intubated. Our hypothesis is that this type of information would be useful to surrogates and clinicians as they determine how to treat the patient.¹⁰

Limited evidence supports this approach. Available data—discussed in detail in an accompanying paper (Rid and Wendler, 2014)—suggest that the treatment preferences of the *average* person predict patients' preferred treatment options just as accurately as surrogates (Smucker et al., 2000; Houts et al., 2002; Shalowitz, Garrett-Mayer, and Wendler, 2007). This finding is consistent with extensive empirical data showing that the predictive accuracy of mechanical predictions is at least as good, and often superior to, the accuracy of expert or “clinical” judgment in a broad range of contexts (Dawes, Faust, and Meehl, 1989; Grove et al., 2000). These data suggest that making *individualized* predictions of patients' treatment preferences will, on average, be more accurate than the predictions of their surrogate decision makers.

Advantages

Predictions regarding patients' considered treatment preferences have the potential to improve the shared decision-making process for incapacitated patients in at least four ways. First, providing surrogate decision makers with predictions about the patient's treatment preferences is likely to correct some of the biases that distort surrogates' predictions regarding the preferences of their loved ones.¹¹ For example, introducing predictions of the patient's preferred treatment option may reduce family members' tendency to be overconfident regarding their substituted judgment or prevent them from assuming prematurely that their loved one shared their own treatment preferences. Moderating these biases should improve surrogates' ability to predict their loved ones' treatment preferences and hence promote the goal of providing treatment consistent with the patient's preferences and values.

Second, providing the surrogate with a prediction of the patient's treatment preference has the potential to reduce the stress and anxiety associated with trying to predict a loved one's preferred treatment option. Many studies show that the level of anxiety surrogates experience in the decision-making process is ameliorated when they are confident that they know which treatment the patient would have wanted (Wendler and Rid, 2011). These findings suggest that surrogates might be reassured by information on which treatment their loved one would likely have chosen. The resulting relief of stress and anxiety would complement the reassurance and comfort offered by the shared decision-making approach and thus further promote the goal of respecting and helping patients' families and loved ones.

Third, knowing which treatments the patient is likely to want may help to reduce conflict, both among family and loved ones, and between families and clinicians. Having information that a particular course of treatment is likely consistent with the patient's preferences also might facilitate the surrogate's allowing a loved one to die, or conversely, choosing painful treatment for him or her. Predictions of the patient's treatment preferences therefore have the potential to promote the goal of making timely treatment decisions.

Fourth, patients might prefer incorporating predictions about their treatment preferences over the standard approach to treatment decision making if this increases the chances that they will receive treatment consistent with their preferences and values, and it helps their loved ones make difficult treatment decisions for them. If this is right, incorporating a PPP into the shared decision-making process would also promote the goal of respecting patients' preferences for how treatment decisions are made for them.

The extent to which these four considerations ultimately support use of the PPP depends on the plausibility of the included empirical assumptions. The task of evaluating these assumptions in light of the available empirical data is undertaken in an accompanying paper (Rid and Wendler, 2014). The

rest of the present paper focuses on the conceptual and normative questions related to including a PPP in the shared decision-making process.

VI. CONCEPTUAL UNDERPINNINGS

Like the standard approach, the PPP assumes that patients' "last competent" preferences and values—the considered preferences and values the patient endorsed prior to losing decisional capacity—should guide how they are treated. Picture again the 57-year-old married female with a college degree who loses consciousness after head trauma. Standard practice assumes that the preferences and values of this person when she was last competent—in the present case, when she was a 57-year-old married female with a college degree—are the material preferences and values for determining how she should be treated now. Her preferences and values when she was a 20-year-old undergraduate, or a 30-year-old single professional, are relevant now only to the extent that they predict or influence her preferences and values at the time she was last competent. While an in-depth defense of relying on patients' considered "last competent" preferences and values goes beyond the scope of this paper, we offer a brief response to the three most important objections to this approach.¹²

The Relevance of Considered "Last Competent" Preferences and Values

Some argue that a patient's considered "last competent" preferences and values are no longer relevant for determining how the patient should be treated. Proponents of this view often claim that the processes that lead to decisional incapacity cause such drastic psychological change that the person who exists after these changes is literally a different person than before (Dresser, 1986). Although cases involving a change in personal identity are of theoretical interest, they are of limited practical relevance. It is exceptionally rare that incapacitating injury or disease damage the brain enough to destroy one person but leave sufficient functioning for a literally different, functioning person to emerge. Moreover, there often is no way to determine the preferences and values of currently incapacitated patients. For example, it is not possible to scan the brain of an incapacitated patient to determine his or her current preferences and values. Hence, it is typically impossible to evaluate the extent to which a patient's preferences might have changed since his or her last period of competence. Patients' considered "last competent" preferences and values thus provide the best estimate for what the patient currently wants.¹³

Second, critics might grant that the considered preferences and values patients had while competent are relevant for determining how they should be treated during periods of decisional incapacity but argue that it is not necessarily their "last competent" preferences and values that should count.

Ronald Dworkin, for example, holds that incapacitated patients should be treated consistent with their critical interests, which are taken to reflect a comprehensive view of what makes their life good on the whole (Dworkin, 1993, 205). However, most people change their considered views about what makes their lives go well over time. It is therefore unclear which set of critical interests should be decisive. In addition, declaring any set of critical interests as the primary one is incompatible with individuals' fundamental interest in being able to develop *and revise* their conception of the good. This fundamental interest supports treating incapacitated patients based on their considered "last competent" preferences and values.

Third, considered "last competent" preferences and values might be deemed irrelevant because patients, while competent, cannot fully anticipate their future treatment preferences (Ditto, Hawkins, and Pizarro, 2005). Patients might therefore have very different views once the given situation actually arises. However, as discussed previously, this concern is often impossible to verify once a patient becomes incapacitated—and in most cases, the patient's "last competent" preferences and values provide the best estimate for what the patient currently wants in this situation.¹⁴ Moreover, the fact that a person's considered preferences were or might have been biased does not necessarily imply that they should be overridden. Preferences and values should be respected if they reflect the person's informed and considered judgments, even if there is reason to believe that biases are at work.

VII. IMPLEMENTATION

Incorporating the PPP into the Shared Decision-Making Process

A fully developed PPP would yield a prediction about which treatments are most likely to be consistent with the preferences and values of a currently incapacitated patient, along with associated probabilities for the strength of his or her preferences. Surrogates and clinicians would use this information in situations in which the patient's treatment preferences are unclear and in which it is not clear what treatments would promote the patient's clinical interests.¹⁵ There are three primary ways in which the PPP could be incorporated into the shared decision-making process: first, the predictions of the PPP could be provided to surrogates and clinicians for their consideration in the decision-making process; second, the patient's predicted treatment preferences could be treated as a weak default, which is followed unless the family or loved ones object; or third, the prediction could be treated as a strong default, to be followed unless surrogates have compelling reason to believe that the identified course of treatment is not consistent with the patient's preferences and values.

Which of these three options is adopted will influence the extent to which the process of shared decision making between surrogates and clinicians

realizes the ethical goals for treatment decision making for incapacitated patients. Assuming the PPP predicts patients' treatment preferences more accurately than surrogates, the strong default approach likely would best promote the goal of providing treatment consistent with patients' values and preferences. At the same time, this approach might increase the emotional burden on patients' families and loved ones compared to using the PPP prediction as a weak default or merely as additional information to consider. For example, a strong default might result in families feeling excluded from the decision-making process.

Determining which of the three options should be adopted will require evaluation of the appropriate trade-offs between the primary goals for treatment decision making. For example, is it more important to provide treatment that is consistent with the patient's preferences and values or to ensure that the family is helped in the decision-making process? How these trade-offs should be made will depend, in part, on how patients—and, to a lesser extent, surrogates—view these trade-offs. Empirical data on which goals for treatment decision-making patients and surrogates value most, how they prioritize or balance the competing goals, and which approach best realizes the prioritized goals are therefore needed. The best way to incorporate a PPP into the shared decision-making process should be determined based on such data.

Individualizing the Use of a PPP

Which approach is adopted for implementing the PPP should depend, in part, on the ethical goals for treatment decision making as they are prioritized by the majority of patients. Some patients, however, will not agree with the priorities of the majority. For example, while the majority of patients might prioritize the goal of respecting and helping families, some patients might care most about being treated consistent with their own preferences and values. Other patients might want to opt out of using the PPP altogether.

To promote the goal of respecting patients' preferences for how treatment decisions are made, some mechanism will be needed that allows patients to determine whether and/or how the PPP is used. The clearest way would be to ask patients to document their preferences regarding the possible use of a PPP in an advance directive. However, the majority of patients do not complete an advance directive (Perkins, 2007)—and the PPP aims to improve treatment decision making in precisely that situation. It therefore seems sensible to use the PPP by default, unless there is evidence that the patient disagreed with this approach. Patients who disagree could opt out of the PPP by including this information in an advance directive. Surrogates could also opt out on the patient's behalf. For the opt-out system to work, information about the PPP must be widely disseminated. Moreover, the PPP itself should be accessible to the public. For example, an online version

would allow individuals to enter their personal characteristics and see what the PPP would predict for them in different treatment scenarios. This process might encourage people to think not only about the PPP and its implications for their care, were it to be used, but also about their treatment preferences more generally.

Surrogates also might have reasons for why they do not want a PPP used as part of the decision-making process. For example, some surrogates might regard use of the PPP as taking decision-making authority away from them. To promote the goal of respecting and helping the patient's loved ones, surrogates also should be allowed to opt out of using the PPP. However, in this situation, clinicians should verify that the independent judgment of surrogates does not contradict compelling PPP predictions indicating a significant chance that the identified treatment option is not consistent with the patient's preferences and values. For example, if there were a very high likelihood that a patient would have strongly preferred a particular treatment option and the patient's surrogates decide against this treatment, surrogates could be provided with this information, even though they opted out of using the PPP. Moreover, surrogates should not be allowed to opt out of using the PPP if the patient has made an explicit statement that information from the PPP should be incorporated into the shared decision-making process.

Interpreting PPP Results

It is highly unlikely that the PPP will predict a given incapacitated patient's treatment preferences with a likelihood of 100%, or absolute certainty. In the vast majority of cases, the PPP's predictions will therefore be more or less certain. Between absolute certainty and absolute uncertainty, when should PPP predictions be seen as indicative of the patient's treatment preferences? Is a "preponderance of evidence"—which equals a likelihood of more than 50%—sufficient to claim that the patient preferred a particular treatment option? Or should a higher degree of certainty be required—for example, a likelihood nearing 70%, which might indicate "clear and convincing" evidence for the patient's treatment preferences? Or a likelihood of almost 100%, offering evidence "beyond a reasonable doubt"? To be practically useful, some threshold percentage needs to be set that determines when the PPP's predictions should be seen as indicative of the patient's preferences. Predictions that fall below this threshold should not be considered in the decision-making process.¹⁶

It is important not to confound the chosen threshold percentage for when the PPP would be used with the predictive accuracy of the PPP when used. The threshold percentage determines how likely it must be that the PPP's predictions reflect the patient's preferences before the PPP is incorporated into the decision-making process. By contrast, the PPP's predictive accuracy indicates how accurately the PPP predicts patients' treatment preferences *given*

the chosen threshold percentage. A high threshold would imply that the PPP is rarely used—but when it is used, the PPP’s predictive accuracy would be very high (although not necessarily nearing 100%). A lower threshold percentage would result in less accurate predictions, although likely still more accurate than predictions made by surrogate decision makers, on average, given the available evidence on surrogate accuracy (Rid and Wendler, 2014).

The chosen threshold percentage determines the degree of certainty that is required before the PPP is used to predict which treatment the patient preferred in the situation. Because a PPP makes predictions about patients’ treatment preferences based on statistical inference, mistakes—defined as pursuing a course of treatment that is inconsistent with the patient’s preferences and values—are unavoidable (though presumably less frequent than in current practice). A high threshold requiring, for example, a likelihood of 90% or higher to favor a particular course of treatment would provide considerable certainty that the patient preferred the identified treatment option prior to becoming incapacitated. There would be significantly less certainty if the adopted threshold required a likelihood of 51%. In setting the threshold for PPP predictions, it is therefore important to consider the relative disvalue of the different types of possible mistakes.

Two types of mistakes can be made: (1) providing unwanted treatment and (2) withholding or withdrawing wanted treatment. A high degree of certainty for PPP predictions is justified if one type of mistake is morally worse than the other in the vast majority of cases. For example, one could argue that withholding or withdrawing wanted treatment—which typically leads to deterioration of patient health from disease and sometimes death—is worse than providing unwanted treatment because clinicians’ first and primary obligation is to protect and prolong life. However, one could equally argue that providing unwanted treatment is worse because it involves violating the patient’s right to bodily integrity or control. Both types of mistakes involve contradicting a fundamental value—and at the level of abstract principles, neither consideration seems to trump the other consistently. Whether it is better to have some chance for an extension of life or a particular instance of respecting one’s bodily integrity and autonomy depends on the circumstances. Moreover, there currently are no data or reasons to think that a clear majority of patients consistently prioritizes one of these values over the other.

Assuming, then, that preserving life and respecting bodily integrity and autonomy are both very important, “preponderance of evidence” should be sufficient to guide treatment. For example, if the PPP predicts a 55% likelihood that the 57-year-old female head trauma patient wants to receive even burdensome clinical interventions, providing these interventions is more likely to be consistent with the patient’s preferences and values than not (this assumes that there is no compelling direct evidence of what the patient

prefers, such as a clearly pertinent advance directive, and that there is no reason to think that surrogates will be more accurate in the particular case).

The degree of certainty for PPP predictions must be qualified for situations in which the goal of providing treatment consistent with patients' preferences and values conflicts with other goals for treatment decision making. In these situations, a sliding threshold—which requires stronger evidence about patients' treatment preferences as competing goals gain in weight—might be necessary. For example, if one course of treatment would clearly protect the patient's clinical interests, surrogates and clinicians might wish to exclude the possibility that the patient had a strong preference against this treatment. They should consider denying the clinically indicated treatment only if there is considerable certainty—such as a likelihood of 90% or more—that the patient would not want this course to be followed, and the PPP also indicates the patient likely would give important weight to this preference. If another course of treatment is in the patient's clinical interests, but the case for treatment is less compelling than above, clear and convincing evidence for the patient's preferences against this treatment might be required to override the patient's clinical interests—for example, a likelihood of at least 70% that the patient did not want this treatment in the given situation.

Establishing the PPP

Patients' treatment preferences are at least partially determined by how they evaluate their predicted postintervention health state (Rosenfeld, Wenger, and Kagawa-Singer, 2000; Fried, Bradley, and Towle, 2003). The evaluation of health states, however, is subject to systematic biases. Healthy individuals overestimate the negative impact of disease on their lives, while underestimating their ability to adapt to life with disease. As a result, the healthy typically give lower evaluations of health states than people who have experienced them (Ubel, Loewenstein, and Jepson, 2003).

Creating a PPP based solely on the preferences and values of healthy individuals would thus effectively impose the views of the healthy on the ill and disabled. Conversely, if the PPP was based on the preferences and values of individuals living with disease, the views of the ill and disabled would be imposed on individuals who were healthy prior to losing decisional capacity. Given that the PPP aims to predict the treatment preferences of a wide range of incapacitated patients—spanning from young accident victims to older patients with dementia—either approach would undermine the goal of providing treatment consistent with the patient's own competent preferences and values. The PPP should therefore be modeled based on the treatment preferences of a representative sample of the population, including the healthy, the ill, and the disabled. The only precondition for participating in the survey that gathers the data on treatment preferences is that respondents are competent to participate. Because the PPP predicts patients' treatment

preferences based on their individual characteristics, the PPP algorithm would apply the preferences of competent healthy people to patients who were healthy immediately prior to incapacity. Conversely, the preferences of individuals living with disease or disability would be applied to patients who suffered from disease or disability before they became incapacitated (on the assumption that this approach results in more accurate predictions).

Ensuring the PPP's Validity

Advance directives have been criticized for, among other things, sanctioning instructions whose validity can be difficult to establish (Fagerlin and Schneider, 2004). Clinicians typically do not know whether the patient had adequate information or was under the influence of distorting psychological biases when the advance directive was completed. The patient might have underestimated his ability to adapt to disease or disability, or he might have focused disproportionately on—and thus exaggerated the importance of—things that would change in the future while ignoring things that would remain the same. It is also possible that the patient was depressed when she completed her advance directive. Moreover, the advance directive could be outdated when needed because many patients change their treatment preferences and values over time, especially as their disease progresses. To what extent do these concerns apply to a PPP?

A PPP predicts incapacitated patients' treatment preferences based on their individual characteristics and known statistical correlations regarding how these characteristics influence preferences toward treatment during periods of decisional incapacity. The statistical correlations are derived from data gathered in a large and representative survey of the population. Not surprisingly, measures to obtain authentic reports of individuals' treatment preferences are much easier to implement during a survey of several thousand adults than in the clinical setting, where millions of people engage in advance care planning every year. For example, before taking the survey, respondents could be provided with material and up-to-date information about common medical treatments and their clinical outcomes. Respondents could also be informed about widespread psychological biases that influence health state evaluations. "Debiasing" methods, such as encouraging survey participants to consider the variety of factors that contribute to their life satisfaction, as well as how they have adapted to adversity in the past, could be used to reduce the impact of these biases (Ditto, Hawkins, and Pizarro, 2005). Similarly, "false consciousness" preferences due to internalized social discrimination could be reduced by emphasizing patients' equal rights to treatment. While all these measures can be taken in the clinical setting, their rigorous administration is more likely in the setting of a survey that is both more controlled and more flexible. Assuming sufficient financial resources, participants in the PPP survey could undergo a comprehensive

and carefully designed information session prior to the survey. Time constraints also are less pressing in the context of a survey when compared to the clinical setting. In addition, the PPP survey could be conducted regularly to ensure respondents' treatment preferences are based on up-to-date information about medical treatments.

One might argue that the survey situation introduces its own biases, such as a social desirability bias. However, these biases can be at least partially addressed by emphasizing to the participants that the survey aims to record their authentic, considered preferences and values for treatment. Through careful design, the PPP survey appears to be in an overall better position to ensure the validity of recorded treatment preferences than most advance care planning programs. However, efforts to inform and "debias" survey participants should not be misunderstood as excluding or disallowing biased treatment preferences. For example, if a respondent is convinced that she could not adapt to a given health condition and indicates her treatment preferences accordingly, this must be respected. The goal is to provide survey respondents with enough information to think clearly about how they want to be treated and thus ensure that their preferences are considered and the PPP's predictions accurate. The goal is to determine as accurately as possible individuals' considered preferences, not the preferences that they ought to have.

Finally, the possibility that patients' preferences might change in light of disease is less relevant for the PPP than for advance directives. During the PPP survey, respondents will be asked about their treatment preferences in case they become incapacitated in the near future, not in 10 or 20 years. Respondents will also provide information about their current health and quality of life, including the activities of daily of life in which they are able to engage. The PPP would thus predict the considered "last competent" preferences that patients endorsed prior to becoming incapacitated, not the preferences they might have projected for the given situation in the distant past. This decreases concerns that the PPP's predictions might pertain to preferences the patient no longer endorses.

VIII. ADDRESSING CONCEPTUAL AND NORMATIVE CONCERNS

No Way of Evaluating the Accuracy of Predicted Preferences

One might object that it is impossible to verify that the PPP's predictions accurately reflect the now-incapacitated patient's preferences and values. There is currently no method to determine which treatments most incapacitated patients prefer. Therefore, when a patient never regains competence, it is impossible to know whether the PPP's predictions were accurate. However, it is also difficult to evaluate the PPP's accuracy when a patient regains competence, given that recovered patients are likely to be influenced by hindsight bias when they consider whether the chosen course of treatment was

consistent with their preferences and values. If it is unclear whether the PPP offers any improvements over current practice, why should it be pursued?

The proposal to incorporate the use of a PPP into the shared decision-making process is a pragmatic approach to a problem that cannot be “solved” at this point. There is currently no diagnostic method for identifying the actual treatment preferences of most incapacitated patients. As argued above, patients’ considered “last competent” preferences provide the best estimate for which treatments they would want in this situation. With regard to treating patients consistent with their preferences and values, any approach to treatment decision making must therefore currently be evaluated based on how well it treats patients according to their considered “last competent” treatment preferences. One way of making this evaluation is to compare how well a given approach predicts the treatment preferences of competent patients. Available data suggest that surrogate decision makers are quite inaccurate on this measure (Shalowitz, Garrett-Mayer, and Wendler, 2006), and that use of a PPP is likely to be more accurate (Smucker et al., 2000; Houts et al., 2002; Shalowitz, Garrett-Mayer, and Wendler, 2007). Thus, although there is no direct way of evaluating the PPP’s predictive accuracy—as well as the predictive accuracy of alternative approaches to treatment decision making—the available evidence suggests that incorporating a PPP into the shared decision-making process offers an improvement over current practice.

Stereotyping of Patients

One might be concerned that treating incapacitated patients based on statistical correlations between their individual characteristics—such as age, gender, and education—and their treatment preferences involves inappropriate stereotyping. When someone is regarded as embodying or conforming to a set image or type, he or she is being “stereotyped.” Stereotypes are based on generalizations that often, but not necessarily, have a negative connotation. For example, people sometimes believe that the “Gothic” style—wearing dark clothes and makeup—indicates depression and suicidality. There are various concerns about stereotyping.¹⁷ The most important concern to address here is that the use of stereotypes fails to pay adequate respect to individuals and their particular characteristics and circumstances. If the PPP failed to respect individuals, it would undermine the goal of treating patients consistent with their preferences and values and, consequently, patients’ families and loved ones would not be helped in the decision-making process.

However, the way in which we propose that the PPP be used respects individuals and their particular characteristics and circumstances. Surrogates and clinicians would use the PPP only if a patient were incapacitated, and it is not otherwise clear which treatment they would prefer in the circumstances. If the patient clearly conveyed his or her treatment preferences in conversation or in a written advance directive, these preferences would

be followed. Moreover, the PPP would be used only if the patient did not oppose, while competent, its incorporation into the decision-making process. Surrogates would scrutinize the patient's predicted treatment preferences based on what they know about their loved one, and they could object to and override the PPP's predictions. The clear priority of advance directives and surrogates' judgment over PPP predictions thus ensures respect for the individuality of each individual patient. Furthermore, a PPP would not be used to make a general judgment of the patient, such as how reasonable his or her treatment choices are. It would be used only to predict the patient's considered treatment preference under the given circumstances.

Importantly, the PPP would provide highly individualized predictions of the given patient's treatment preferences rather than rough generalizations. PPP predictions would be based on numerous individual characteristics, all of which are factored into the prediction. For example, older age is correlated with a decreased willingness to undergo highly burdensome interventions to avoid death. However, there is considerable diversity among older persons regarding their treatment preferences (Fried et al., 2007). Similarly, being African-American is consistently associated with wanting more treatment (Garrett et al., 1993; Covinsky et al., 1996; Phillips et al., 1996; Cicirelli, 1997; Barnato et al., 2009), but not all African-Americans prefer to be treated when treatment is available. The PPP would reflect this diversity by factoring numerous predictors of patients' treatment preferences, including their importance and potential interaction with other predictors.

Stereotyping would be a concern if PPP predictions were based on only a few, easily identifiable individual characteristics. For example, the PPP would unduly generalize if it predicted patients' treatment preferences based solely on age and race. However, this problem can be avoided by requiring that as much relevant information about the patient's individual characteristics as possible is entered into the PPP algorithm. Exceptions from this requirement should be allowed only when there is no feasible way of obtaining the relevant information, for example when patients have no surrogates (Varma and Wendler, 2007) or in emergency situations.

Finally, it should be noted that a PPP might actually help to prevent stereotyping of patients. For example, families and clinicians might assume prematurely that someone who is 82 years old would not want to receive treatment. The PPP's predictions might help to correct this misperception.

Excessive Emphasis on Patient Autonomy

The PPP primarily promotes the goal of providing treatment consistent with the patient's considered preferences and values. All other improvements of current practice, including helping and respecting patients' families and loved ones, are taken to be largely derivative of realizing that goal. One might be concerned that this approach puts too much emphasis on patient autonomy.

It is important to recognize, however, that providing treatment consistent with patients' preferences and values typically promotes both patient autonomy and patient well-being. Moreover, a PPP itself does not provide a normative framework for prioritizing any of the goals for treatment decision making, including those related to patient autonomy. The PPP is simply intended to implement some of the goals for treatment decision making better than current practice allows. For empirical reasons, the implementation of these goals often depends on providing treatment consistent with the patient's preferences and values, which is often instrumental to realizing several goals for treatment decision making. For example, data suggest that identifying which treatment the patient is likely to prefer will reduce the burden on the family and loved ones (Wendler and Rid, 2011). In this way, a method that increases the extent to which treatment is consistent with patient preferences is likely to benefit patients' families and loved ones, in addition to respecting the patient.

IX. CONCLUSION

Treatment decision making for incapacitated patients should promote six ethical goals. Yet, in practice, it is often difficult to realize any of these goals. The combination of shared decision making with a PPP—a tool that provides surrogate decision makers and clinicians with individualized predictions of the patient's preferred treatment option—has the potential to improve current practice considerably. This approach might be more likely to provide treatment consistent with the patients' considered preferences and values than current practice, and it might help patients' families and loved ones in a difficult time. Assuming this is the case, patients may well prefer use of the PPP approach over current practice or shared decision making alone. Promotion of the goals for treatment decision making could thus be significantly advanced by incorporating the PPP into the shared decision-making process between surrogates and clinicians. The present paper has argued that this approach can be justified both conceptually and normatively. Future research will have to evaluate whether patients endorse the use of a PPP in the decision-making process, whether it is possible to develop a reliable and valid PPP database and model, and whether, in practice, the use of a PPP promotes the goals of treating patients consistent with their preferences and values and helping patients' surrogates.¹⁸

NOTES

1. Much of the following discussion is shaped by Allen Buchanan and Dan Brock's *Deciding for Others* (Buchanan and Brock, 1989).

2. This expression is meant to convey that patients should be treated consistent with *how they want their lives to go*. In our view, treating patients consistent with their "preferences and values" captures this idea best. However, for present purposes, other expressions could convey the intended point—for example, treating patients consistent with their "goals," "ends," or their idea of a "flourishing life."

3. A systematic review of the existing data on surrogate accuracy, involving 19,526 paired patient-surrogate responses to hypothetical treatment scenarios, found that patient-designated and next-of-kin surrogates correctly predicted patients' treatment choices only 68% of the time (Shalowitz, Garrett-Mayer, and Wendler, 2006). However, the treatment offered in many of the scenarios clearly was in the patient's clinical interests. Given that most of the scenarios offered binary choices, these data suggest that surrogates' predictions are only slightly better than chance in cases where it is *unclear* which treatment option would best promote the patient's clinical interests. These are precisely the cases—cases in which it is unclear which treatments the patient would have preferred and no treatment option is clearly in the patient's best clinical interests—with which the present paper is concerned.

4. Some commentators have recently argued that the available data on surrogate (in)accuracy are too flawed methodologically to support this conclusion (Johansson and Brostrom, 2008; Brostrom and Johansson, 2009). We agree with some of the methodological criticisms raised by these commentators. However, we believe that the available studies still provide robust—although imperfect—evidence that surrogates inaccurately predict patients' treatment preferences. This conclusion is also supported by research from other fields, which shows that people in close relationships often poorly predict what their loved ones want or value (Rid and Wendler, 2010).

5. Much academic discussion focuses on cases that pose a conflict between two or more of the goals for treatment decision making. For example, what should be done when the patient's treatment preferences conflict with his or her clinical interests? What should be done when patient's treatment preferences conflict with his or her family's financial interests? Such conflicts raise important questions regarding how we should prioritize or balance the different goals for treatment decision making. Although these questions have substantial theoretical interest, they are of limited practical relevance. In practice, most of the difficult cases are ones in which it is difficult to realize any of the six goals for treatment decision making.

6. For a more comprehensive review of proposed modifications of treatment decision making for incapacitated patients, including an analysis of how well these proposals promote the six ethical goals for treatment decision making, see Rid and Wendler (2010).

7. We realize that the term “predicting” is not ideal because predictions typically concern states of affairs that have yet to occur. In the case of incapacitated patients, however, we are predicting what the patient's preferences are now and whether giving a particular treatment will be consistent with his or her preferences.

8. The proposed approach was first developed with the idea of creating a database that stores and retrieves information about individuals' treatment preferences in common treatment scenarios involving decisional incapacity, rather than predicting patients' treatment preferences based on their individual characteristics and information on how these characteristics influence people's preferences for treatment during periods of decisional incapacity. We therefore replaced the original name of the predictive model, a “population-based treatment indicator” (Shalowitz, Garrett-Mayer, and Wendler, 2007), with what seems to be a more accurate description: “Patient Preference Predictor” (PPP). We are grateful to Bob Wesley for suggesting this name.

9. Competent here means able to understand a situation and convey one's preferences regarding it. This sense of competence may not be coextensive with competence to make one's own decisions. For example, one may be able to understand and convey one's preferences but unable to make a voluntary decision regarding the issue at hand.

10. Some commentators have endorsed basing treatment decisions for incapacitated patients on the preferences of patients in the same community (Emanuel and Emanuel, 1993). However, this approach should not be confused with the present proposal. The PPP is intended to make highly individualized predictions of how the given incapacitated patient wants to be treated, rather than give communities of patients a say in how limited resources for care should be used.

11. For a summary of the most relevant biases, see Rid and Wendler (2010).

12. Note that the PPP is not committed to any particular account of which preferences and values should guide the treatment of incapacitated patients. In fact, the PPP can be based on any type of considered preferences and values recordable in a survey. For example, if it turns out that treatment decisions should be based on the preferences and values we endorse during a particular stage in life, the PPP survey could admit only individuals who are in that stage.

13. Methods to determine the treatment preferences of incapacitated patients may be developed in the future. Moreover, other newly developed methods might change our understanding of which patients are decisionally incapacitated. For example, functional magnetic resonance imaging might someday allow

clinicians to elicit the treatment preferences of a subset of patients who we consider today to be in a “persistent vegetative state.”

14. Note that the same conundrum applies to the standard approach to treatment decision making for incapacitated patients. Surrogates typically base their substituted judgment on prior discussions or experiences with their loved one and thus assume that she would still endorse and act upon her prior considered preferences and values. The use of advance directives is based on the same assumption.

15. When some treatment clearly promotes the patient’s clinical interests, but the patient’s treatment preferences are unclear, the PPP might be used to exclude that the patient would *not* have wanted this particular treatment. In this situation, the patient’s clinical interests should only be overridden if the PPP provides compelling evidence that the patient strongly rejected the given treatment. We discuss this situation in more detail below.

16. Note that this threshold does not determine how the PPP’s predictions should be used; it can be used, for example, as mere information to consider, or a weak or strong default recommendation for treatment. As discussed, other considerations are relevant for this decision.

17. For a thorough analysis of stereotyping, in particular when statistically sound and material, but nonuniversal generalizations are problematic, see Frederick Schauer’s *Profiles, Probabilities and Stereotypes* (Schauer, 2003).

18. These questions and a roadmap to future research are discussed in detail in an accompanying paper (Rid and Wendler, 2014).

ACKNOWLEDGMENTS

The authors thank Marion Danis, Frank Miller, Alan Werthheimer, and Bob Wesley for helpful comments on previous versions of this paper. This work was completed as part of the authors’ official duties as employees of the NIH Clinical Center. However, the opinions expressed are the authors’ own. They do not represent any position or policy of the National Institutes of Health, Public Health Service, or Department of Health and Human Services. Annette Rid received financial support from the Swiss National Science Foundation (PA00B-117505/1 and PA0033-117505/2) to work on this project.

REFERENCES

- Azoulay, E., F. Pochard, N. Kentish-Barnes, S. Chevret, J. Aboab, C. Adrie, D. Annane, et al. 2005. Risk of post-traumatic stress symptoms in family members of intensive care unit patients. *American Journal of Respiratory Critical Care Medicine* 171:987–94.
- Balboni, T., L. Vanderwerker, S. Block, M. Paulk, C. Lathan, J. Peteet, and H. Prigerson. 2007. Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology* 25:555–60.
- Barnato, A., D. Anthony, J. Skinner, P. Gallagher, and E. Fisher. 2009. Racial and ethnic differences in preferences for end-of-life treatment. *Journal of General Internal Medicine* 24:695–701.
- Bookwala, J., K. Coppola, A. Fagerlin, P. Ditto, J. Danks, and W. Smucker. 2001. Gender differences in older adults’ preferences for life-sustaining medical treatments and end-of-life values. *Death Studies* 25:127–49.
- Breen, C., A. Abernethy, K. Abbott, and J. Tulsky. 2001. Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *Journal of General Internal Medicine* 16:283–89.
- Brostrom, L. and M. Johansson. 2009. Surrogates have not been shown to make inaccurate substituted judgments. *Journal of Clinical Ethics* 20:266–73.

- Buchanan, A. and D. Brock. 1989. *Deciding for Others: The Ethics of Surrogate Decision Making*. Cambridge, UK: Cambridge University Press.
- Cicirelli, V. 1997. Relationship of psychosocial and background variables to older adults' end-of-life decisions. *Psychology Aging* 12:72–83.
- Cohen-Mansfield, J., J. Droge, and N. Billig. 1992. Factors influencing hospital patients' preferences in the utilization of life-sustaining treatments. *Gerontologist* 32:89–95.
- Coppola, K., J. Bookwala, P. Ditto, L. Lockhart, J. Danks, and W. Smucker. 1999. Elderly adults' preferences for life-sustaining treatments: The role of impairment, prognosis, and pain. *Death Studies* 23:617–34.
- Covinsky, K., C. Landefeld, J. Teno, A. Connors, Jr., N. Dawson, S. Youngner, N. Desbiens, et al. 1996. Is economic hardship on the families of the seriously ill associated with patient and surrogate care preferences? SUPPORT Investigators. *Archives of Internal Medicine* 156:1737–41.
- Dawes, R., D. Faust, and P. Meehl. 1989. Clinical versus actuarial judgment. *Science* 243:1668–74.
- Detering, K., A. Hancock, M. Reade, and W. Silvester. 2010. The impact of advance care planning on end-of-life care in elderly patients: Randomised controlled trial. *British Medical Journal* 340:c1345.
- Ditto, P., J. Danks, W. Smucker, J. Bookwala, K. Coppola, R. Dresser, A. Fagerlin, et al. 2001. Advance directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine* 161:421–30.
- Ditto, P., J. Druley, K. Moore, J. Danks, and W. Smucker. 1996. Fates worse than death: The role of valued life activities in health-state evaluations. *Health Psychology* 15:332–43.
- Ditto, P., N. Hawkins, and D. Pizarro. 2005. Imagining the end of life: On the psychology of advance medical decision-making. *Motivation and Emotion* 29:481–502.
- Dresser, R. 1986. Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law. *Arizona Law Review* 28:373–405.
- Dworkin, G. 1988. *The Theory and Practice of Autonomy*, *Cambridge Studies in Philosophy*. Cambridge, UK: Cambridge University Press.
- Dworkin, R. 1993. *Life's Dominion: An Argument about Abortion, Euthanasia, and Individual Freedom*. New York: Knopf.
- Emanuel, L. and E. Emanuel. 1993. Decisions at the end of life. Guided by communities of patients. *Hastings Center Report* 23:6–14.
- Fagerlin, A. and C. Schneider. 2004. Enough. The failure of the living will. *Hastings Center Report* 34:30–42.
- Fried, T., E. Bradley, and V. Towle. 2002. Assessment of patient preferences: Integrating treatments and outcomes. *Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 57:S348–54.
- . 2003. Valuing the outcomes of treatment: Do patients and their caregivers agree? *Archives of Internal Medicine* 163:2073–78.
- Fried, T., E. Bradley, V. Towle, and H. Allore. 2002. Understanding the treatment preferences of seriously ill patients. *New England Journal of Medicine* 346:1061–66.
- Fried, T., P. Van Ness, A. Byers, V. Towle, J. O'Leary, and J. Dubin. 2007. Changes in preferences for life-sustaining treatment among older persons with advanced illness. *Journal of General Internal Medicine* 22:495–501.
- Garrett, J., R. Harris, J. Norburn, D. Patrick, and M. Danis. 1993. Life-sustaining treatments during terminal illness: Who wants what? *Journal of General Internal Medicine* 8:361–68.

- Gries, C., R. Engelberg, E. Kross, D. Zatzick, E. Nielsen, L. Downey, and J. Curtis. 2010. Predictors of symptoms of posttraumatic stress and depression in family members after patient death in the ICU. *Chest* 137:280–87.
- Grove, W., D. Zald, B. Lebow, B. Snitz, and C. Nelson. 2000. Clinical versus mechanical prediction: A meta-analysis. *Psychological Assessment* 12:19–30.
- Hammes, B., B. Rooney, and J. Gundrum. 2010. A comparative, retrospective, observational study of the prevalence, availability, and specificity of advance care plans in a county that implemented an advance care planning microsystem. *Journal of the American Geriatrics Society* 58:1249–55.
- Hanson, L., J. Tulsky, and M. Danis. 1997. Can clinical interventions change care at the end of life? *Annals of Internal Medicine* 126:381–88.
- Houts, R., W. Smucker, J. Jacobson, P. Ditto, and J. Danks. 2002. Predicting elderly outpatients' life-sustaining treatment preferences over time: The majority rules. *Medical Decision Making* 22:39–52.
- Johansson, M. and L. Brostrom. 2008. Turning failures into successes: A methodological shortcoming in empirical research on surrogate accuracy. *Theoretical Medicine and Bioethics* 29:17–26.
- Kelly, B., A. Rid, and D. Wendler. 2012. Systematic review: Individuals' goals for surrogate decision-making. *Journal of the American Geriatrics Society* 60:884–95.
- Lo, B., G. McLeod, and G. Saika. 1986. Patient attitudes to discussing life-sustaining treatment. *Archives of Internal Medicine* 146:1613–15.
- Meeker, M. 2004. Family surrogate decision-making at the end of life: Seeing them through with care and respect. *Qualitative Health Research* 14:204–25.
- Murphy, D., D. Burrows, S. Santilli, A. Kemp, S. Tenner, B. Kreling, and J. Teno. 1994. The influence of the probability of survival on patients' preferences regarding cardiopulmonary resuscitation. *New England Journal of Medicine* 330:545–49.
- Patrick, D., R. Pearlman, H. Starks, K. Cain, W. Cole, and R. Uhlmann. 1997. Validation of preferences for life-sustaining treatment: Implications for advance care planning. *Annals of Internal Medicine* 127:509–17.
- Pearlman, R., K. Cain, H. Starks, W. Cole, R. Uhlmann, and D. Patrick. 2000. Preferences for life-sustaining treatments in advance care planning and surrogate decision making. *Journal of Palliative Medicine* 3:37–48.
- Perkins, H. 2007. Controlling death: The false promise of advance directives. *Annals of Internal Medicine* 147:51–57.
- Phillips, R., N. Wenger, J. Teno, R. Oye, S. Youngner, R. Califf, P. Layde, N. Desbiens, A. Connors, Jr., and J. Lynn. 1996. Choices of seriously ill patients about cardiopulmonary resuscitation: Correlates and outcomes. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *American Journal of Medicine* 100:128–37.
- Prendergast, T., M. Claessens, and J. Luce. 1998. A national survey of end-of-life care for critically ill patients. *American Journal of Respiratory and Critical Care Medicine* 158:1163–67.
- Pruchno, R., E. Lemay, Jr., L. Feild, and N. Levinsky. 2006. Predictors of patient treatment preferences and spouse substituted judgments: The case of dialysis continuation. *Medical Decision Making* 26:112–21.
- Raymont, V., W. Bingley, A. Buchanan, A. David, P. Hayward, S. Wessely, and M. Hotopf. 2004. Prevalence of mental incapacity in medical inpatients and associated risk factors: Cross-sectional study. *Lancet* 364:1421–27.

- Rid, A. and D. Wendler. 2010. Can we improve treatment decision-making for incapacitated patients? *Hastings Center Report* 40:6–45.
- . 2014. Treatment decision-making for incapacitated patients: Is development and use of a Patient Preference Predictor feasible? *Journal of Medicine and Philosophy* 39:130–52.
- Rosenfeld, K., N. Wenger, and M. Kagawa-Singer. 2000. End-of-life decision making: A qualitative study of elderly individuals. *Journal of General Internal Medicine* 15:620–25.
- Rosenfeld, K., N. Wenger, R. Phillips, A. Connors, N. Dawson, P. Layde, R. Califf, et al. 1996. Factors associated with change in resuscitation preference of seriously ill patients. The SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Archives of Internal Medicine* 156:1558–64.
- Schauer, F. 2003. *Profiles, Probabilities, and Stereotypes*. Cambridge, MA: Belknap Press.
- Shalowitz, D., E. Garrett-Mayer, and D. Wendler. 2006. The accuracy of surrogate decision-makers: A systematic review. *Archives of Internal Medicine* 166:493–97.
- . 2007. How should treatment decisions be made for incapacitated patients, and why? *PLoS Medicine* 4:e35.
- Silveira, M., S. Kim, and K. Langa. 2010. Advance directives and outcomes of surrogate decision-making before death. *New England Journal of Medicine* 362:1211–18.
- Smedira, N., B. Evans, L. Grais, N. Cohen, B. Lo, M. Cooke, W. Schechter, et al. 1990. Withholding and withdrawal of life support from the critically ill. *New England Journal of Medicine* 322:309–15.
- Smucker, W., R. Houts, J. Danks, P. Ditto, A. Fagerlin, and K. Coppola. 2000. Modal preferences predict elderly patients' life-sustaining treatment choices as well as patients' chosen surrogates do. *Medical Decision Making* 20:271–80.
- Sood, J., C. Fisher, and D. Sulmasy. 2006. Religious coping and mental health outcomes in family members making DNR decisions. In *Research in the Social Scientific Study of Religion*, vol. 16, ed. R. Piedmont, 221–43. Boston: Brill Publisher.
- Studdert, D., M. Mello, J. Burns, A. Puopolo, B. Galper, R. Truog, and T. Brennan. 2003. Conflict in the care of patients with prolonged stay in the ICU: Types, sources, and predictors. *Intensive Care Medicine* 29:1489–97.
- SUPPORT Principal Investigators. 1995. A controlled trial to improve care for seriously ill hospitalized patients. The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *The Journal of the American Medical Association* 274:1591–98.
- Tilden, V., S. Tolle, C. Nelson, and J. Fields. 2001. Family decision-making to withdraw life-sustaining treatments from hospitalized patients. *Nursing Research* 50:105–15.
- Ubel, P., G. Loewenstein, and C. Jepson. 2003. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Quality of Life Research* 12:599–607.
- Varma, S. and D. Wendler. 2007. Medical decision-making for patients without surrogates. *Archives of Internal Medicine* 167:1711–15.
- Vig, E., H. Starks, J. Taylor, E. Hopley, and K. Fryer-Edwards. 2007. Surviving surrogate decision-making: What helps and hampers the experience of making medical decisions for others. *Journal of General Internal Medicine* 22:1274–79.
- Weeks, J., E. Cook, S. O'Day, L. Peterson, N. Wenger, D. Reding, F. Harrell, et al. 1998. Relationship between cancer patients' predictions of prognosis and their treatment preferences. *The Journal of the American Medical Association* 279:1709–14.
- Wendler, D. and A. Rid. 2011. Systematic review: The effect on surrogates of making treatment decisions for others. *Annals of Internal Medicine* 154:336–46.