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Matched Preferences and Values: A New Approach to Selecting Legal Surrogates

NINA A. KOHN*

ABSTRACT

Every day, hospitals are filled with incapacitated patients whose healthcare decisions are made by other people. The law recognizes such decisions as the patients' own and, accordingly, the primary purpose of surrogate decisionmakers is to make the decisions that patients would make if able. Unfortunately, surrogate decisionmakers frequently make choices for patients that are inconsistent with patient wishes. Indeed, social psychology literature on surrogate decisionmaking finds a stronger correlation between surrogates' decisions for patients and what surrogates would want for themselves than between surrogates' decisions and what patients actually would want. Although others have treated surrogates' tendency to project their own preferences and values on patients as a barrier to appropriate decisionmaking, this Article shows how savvy patients, advocates, and policymakers can capitalize on this tendency to improve healthcare decisionmaking. Specifically, it proposes that surrogate

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decisionmakers for health care be selected based, at least in part, on the extent to which they share patients' treatment preferences. Where it is not possible to compare treatment preferences, or where an individual cares less about particular treatment decisions than about consistency with a set of values, surrogates should be selected based on shared values. Incorporating this approach into advance planning processes and the statutory law governing the selection of guardians and default surrogate decisionmakers could both increase the likelihood that decisions made are those patients would want made, and facilitate more flexible, context-appropriate treatment decisions.

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I. INTRODUCTION

Although individuals generally have a legal right to make their own healthcare decisions,¹ many are unable to exercise that right directly. Whether because of an acute medical condition or a cognitive disability, the reality for many patients is that their healthcare decisions are made by other people. Indeed, one study found that nearly a quarter of hospitalized

1. This right is well defined in the context of the refusal of treatment. *See Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 278–79 (1990) (recognizing that the Constitution protects the right to refuse medical treatment). The extent to which individuals have a constitutional right to affirmatively choose treatment, however, is less clear. *See B. Jessie Hill, The Constitutional Right to Make Medical Treatment Decisions*, 86 TEX. L. REV. 277, 313–18 (2007) (discussing constitutional jurisprudence as to the right to select treatment). Nevertheless, the right to select among treatment options is recognized both in the common law of informed consent and in state statutes setting forth the circumstances under which a person can be denied the right to make those decisions because of incapacity, including, for example, those statutes governing guardianship of incapacitated persons.

older adults facing one or more major treatment decisions had all such decisions made by a surrogate decisionmaker, and that nearly half had a surrogate decisionmaker involved in at least some treatment decisions.²

The law recognizes healthcare decisions made by surrogate decisionmakers as legally binding and constitutionally protected because the law views decisions made by surrogates as the patients' own decisions.³ Consistent with this perspective, whether the surrogate be an agent appointed by the patient, a guardian appointed by a court, or a default surrogate decisionmaker selected in accordance with state statutory law, it is generally agreed that the surrogate's primary goal should be to reach the decision the patient would have made if capable. The conventional wisdom is that such surrogate decisionmakers, therefore, should be chosen based on their relationship to the patient, trustworthiness, and willingness to follow the patient's directions.⁴

Unfortunately, as this Article shows, the extensive empirical literature on healthcare decisionmaking suggests that selecting surrogates based on such traits is often insufficient to protect patients' wishes. Even when instructed otherwise, surrogate decisionmakers frequently make treatment decisions for patients that are inconsistent with patients' preferences. Moreover, the commonly recommended strategies for improving congruence between patients' preferences and surrogates' decisions appear to have limited effect. Indeed, because surrogates tend to project their own preferences when making decisions for others, the best predictor of a surrogate's decision on behalf of a patient appears to be the surrogate's preferences for himself or herself in the same situation.

While other researchers have treated surrogates' tendency to project as a barrier to reaching appropriate treatment decisions, this Article shows that it can actually be used to improve surrogate decisionmaking. Specifically, it argues that selecting surrogates based, at least in part, on shared preferences and shared values can increase the likelihood that surrogates' treatment decisions will be consistent with patients' preferences. This Article, therefore, proposes that individuals be encouraged to consider potential surrogates' own values and treatment preferences when appointing a surrogate and

2. Alexia M. Torke et al., *Scope and Outcomes of Surrogate Decision Making Among Hospitalized Older Adults*, 174 JAMA INTERNAL MED. 370, 372–73 (2014) (reporting on the frequency of surrogate decisionmaking for older adults admitted to the hospital for at least forty-eight hours).

3. See *Cruzan*, 497 U.S. at 277–80 (treating the right to refuse treatment as including the right to have a legal surrogate refuse treatment on one's behalf).

4. See *infra* note 16.

that states require that guardians and default surrogate decisionmakers be selected based in part on their personal preferences and values.

This Article proceeds in four parts. Part II describes how surrogate decisionmaking currently occurs in the healthcare context, including the legal processes by which surrogates are selected. Part III reviews the social science literature examining the extent to which surrogates make decisions that patients would make if able and the reasons why they often fail to do so. Part IV reviews existing strategies for improving the rate at which surrogates make the decisions patients would want made on their behalf. Finally, Part V proposes a shared preferences and values approach to surrogate selection as a mechanism for increasing the likelihood that surrogates will make the decisions patients would want made, and explores how and why such an approach should be operationalized.

II. OVERVIEW OF SURROGATE DECISIONMAKING IN THE HEALTH CARE CONTEXT

When patients lack capacity to make a healthcare decision for themselves, the law allows a third party to be authorized to make that decision on behalf of those individuals. Legally recognized surrogates for healthcare decisionmaking fall into three broad categories.

First, there are health care agents appointed by patients prior to the onset of cognitive incapacity. Patients can appoint their own surrogate by executing a type of advance directive known alternatively as a “health care proxy” or a “power of attorney for health care.”⁵ These documents authorize another person to make decisions for the person executing the document (the “principal”) if the principal cannot make or communicate medical choices. As part of a health care proxy, principals can also include instructions as to particular decisions they want made, including instructions related to the use of life-sustaining technology.⁶

Second, surrogates can be appointed by a court, most commonly through a guardianship proceeding. Such surrogates are typically called “guardians.”⁷

5. This Article uses the term *health care proxy* because it is less confusing to the general public than the term *power of attorney for health care*, which tends to be confused with power of attorney for financial decisions.

6. See, e.g., UNIF. HEALTH-CARE DECISIONS ACT § 4 (1994) (including a standardized form providing for such instructions).

7. Most states use the term *guardian* to refer to someone appointed to make personal and health care decisions for an incapacitated person, as does the Uniform Adult Guardianship and Protective Proceedings Act. See UNIF. ADULT GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 102(4) (1997). Many states also use the term *guardian* to refer to someone appointed to make financial decisions for a person who has been adjudicated to lack capacity to make such decisions. See, e.g., N.Y. MENTAL HYG. LAW § 81.03(a) (McKinney 2004). The term *conservator*, by contrast, is used by many states to refer to

A guardian may be appointed only after a court determines that an individual is incapacitated and in need of a guardian.⁸ An incapacitated individual who previously engaged in adequate advance planning should generally not need a guardian because the individual will already have an appointed healthcare agent available to make needed decisions.⁹

Third, surrogates can be authorized to act by state statutory law even though they have neither been appointed by the patient nor by a court of law. Despite continued efforts by the medical community, legal community, and even the federal government¹⁰ to encourage the use of health care proxies, most adults do not have one.¹¹ A substantial majority of states have addressed this situation by enacting statutes that authorize default decisionmakers for incapacitated persons who lack a valid health care

someone appointed to make financial decisions, and the Uniform Adult Guardianship and Protective Proceedings Act also takes this approach. *See* UNIF. ADULT GUARDIANSHIP AND PROTECTIVE PROCEEDINGS ACT § 102(2) (1997). However, there are a few states that use the term *conservator* to refer to someone appointed to make both financial and personal decisions, and Louisiana uses the term *interdiction*. *See* LA. CIV. CODE ANN. art. 389 (2000).

8. A person can have significantly diminished capacity without being incapacitated. States have different standards for what constitutes incapacity for the purpose of guardianship. The modern approach is to consider individuals' functional limitations, not simply their medical diagnosis when determining capacity. For further discussion of different approaches, see NINA A. KOHN, ELDER LAW: POLICY, PRACTICE, AND PROBLEMS 152 (2014).

9. *See, e.g., In re Maher*, 621 N.Y.S.2d 617, 622–24 (App. Div. 1994) (refusing to impose a guardianship where the allegedly incapacitated person had successfully engaged in advance planning).

10. The federal government imposes requirements on health care institutions to inform patients about advance directives and related rights. *See* 42 C.F.R. § 489.102 (2013).

11. *See* U.S. DEP'T OF HEALTH & HUMAN SERVS., ADVANCE DIRECTIVES AND ADVANCE CARE PLANNING: REPORT TO CONGRESS 13 (2008) (reviewing studies on the frequency of advance directives and concluding that “studies find that only 18–36 percent of Americans have completed an advance directive” and that there was a low rate of advance directive completion even among high-need populations such that “[f]ewer than half of severely or terminally ill patients had an advance directive in their medical record, and among individuals with chronic illnesses, only one in three completed an advance directive”); Anil Kumar et al., *Prevalence of Use of Advance Directives, Health Care Proxy, Legal Guardian, and Living Will in 512 Patients Hospitalized in a Cardiac Care Unit/Intensive Care Unit in Two Community Hospitals*, 6 ARCHIVES MED. SCI. 188, 189 (2010) (finding that only 22% of cardiac patients in two community hospitals had an advance directive and only 19% had a health care proxy); Bernard Lo & Robert Steinbrook, *Resuscitating Advance Directives*, 164 ARCHIVES INTERNAL MED. 1501, 1502 (2004) (reporting that approximately 25% of patients have advance directives); Christopher B. Rosnick & Sandra L. Reynolds, *Thinking Ahead: Factors Associated with Executing Advance Directives*, 15 J. AGING & HEALTH 409, 411 (2003) (surveying studies on advance directive frequency).

proxy. Such statutes typically create a priority list indicating which persons will be selected as surrogates for patients who lack capacity but who do not otherwise have an appointed surrogate.¹² Individuals appointed under such statutes are referred to as “default” surrogate decisionmakers.¹³

Although the process by which surrogates are chosen varies depending on the type of surrogate, there is considerable overlap in the identity of those chosen to serve as surrogates. Across all three categories, close relatives, specifically spouses and adult children, are most commonly selected as surrogates.¹⁴

Although persons executing a health care proxy are free, with only minor statutory exceptions, to appoint anyone they choose, they typically appoint someone who is closely related to them. Indeed, research suggests that the vast majority, perhaps as many as nine out of ten individuals, select either their spouse or an adult child as their healthcare agent.¹⁵ This approach is consistent with the advice typically offered by attorneys, medical professionals, and others who help patients execute advance directives;

12. See Nina A. Kohn & Jeremy A. Blumenthal, *Designating Health Care Decisionmakers for Patients Without Advance Directives: A Psychological Critique*, 42 GA. L. REV. 979, 984–86 (2008) (outlining the range of such statutes).

13. *Id.* at 984.

14. See *infra* notes 15, 27, 18, & 20 and accompanying text.

15. See William D. Smucker et al., *Modal Preferences Predict Elderly Patients' Life-Sustaining Treatment Choices as Well as Patients' Chosen Surrogates Do*, 20 MED. DECISION MAKING 271, 273 (2000) (reporting that 91% of patients chose a spouse or child as their surrogate). Studies in which subjects are asked to name or choose their surrogates show similar patterns. See, e.g., Angela Fagerlin et al., *Projection in Surrogate Decisions About Life-Sustaining Medical Treatments*, 20 HEALTH PSYCHOL. 166, 171 (2001) (finding that 60% selected spouses and 31% selected adult children when asked to select a surrogate); Jan Hare et al., *Agreement Between Patients and Their Self-Selected Surrogates on Difficult Medical Decisions*, 152 ARCHIVES INTERNAL MED. 1049, 1050 (1992) (finding that 72% selected spouses and 10% selected adult children when asked to select a surrogate); Dallas M. High, *Standards for Surrogate Decision Making: What the Elderly Want*, 17 J. LONG-TERM CARE ADMIN. 8, 9 (1989) (indicating a strong patient preference for spouses and adult children as surrogates); M. Kay Libbus & Cynthia Russell, *Congruence of Decisions Between Patients & Their Potential Surrogates About Life-Sustaining Therapies*, 27 J. NURSING SCHOLARSHIP 135, 137 (1995) (finding, that all selected surrogates were relatives of the patient and that 53% were spouses in a study where patients were asked to choose a surrogate); Karem Principe-Rodríguez et al., *Substituted Judgment: Should Life-Support Decisions Be Made by a Surrogate?*, 18 P.R. HEALTH SCI. J. 405, 406 (1999) (in a small study of terminally-ill patients at a medical center for veterans, finding that 45% selected wives and 20% selected adult children as surrogates); Jeremiah Suhl et al., *Myth of Substituted Judgment: Surrogate Decision Making Regarding Life Support Is Unreliable*, 154 ARCHIVES INTERNAL MED. 90, 93 tbl.4 (1994) (reporting that the majority of surrogates who had been selected by patients being studied were spouses).

patients are generally advised to select a surrogate who knows them well, who is familiar with their wishes, and whom they trust.¹⁶

Courts appointing guardians also typically appoint relatives of the incapacitated person. State statutory law governing the guardianship

16. This conventional wisdom can be seen in the advice offered by a wide array of governmental and nongovernmental organizations offering advice to the public about advance directives. See, e.g., CTR. FOR PRACTICAL BIOETHICS, CARING CONVERSATIONS: MAKING YOUR HEALTHCARE WISHES KNOWN 8 (2013), <http://www.practicalbioethics.org/files/caring-conversations/Caring-Conversations.pdf> [<http://perma.cc/RC2E-3K5U>] (stating in its advice to those executing a health care directive that, “A simple question to consider is, ‘Who can I trust to make the decision I would make for myself?’” and recommending that, “Honest and frequent communication is the most important thing you can do to help your Agent make decisions for you that you would make for yourself”); COMPASSION & CHOICES, THE GOOD TO GO RESOURCE GUIDE 6 (2012), <https://www.compassionandchoices.org/userfiles/Good-To-Go-Resource-Guide.pdf> [<https://perma.cc/YRZ6-E79C>] (“As you consider potential agents, ask yourself, ‘Are they assertive? Do they live nearby? Are they comfortable talking about death? Will they respect my values?’”); U.S. Dep’t of Health and Human Servs., *Advance Care Plan Considerations*, LONGTERM CARE.GOV, <http://longtermcare.gov/how-to-decide/advance-care-plan-considerations/> [<http://perma.cc/3RA2-5XMD>] (last visited Apr. 20, 2015) (instructing individuals selecting decision makers for health care to “[c]hoose someone who will understand and be able to carry out your wishes even if they include stopping life-sustaining treatment”); *End-of-Life Care Decision Making*, ELDER L. ANSWERS, <http://www.elderlawanswers.com/end-of-life-care-decision-making-12045> [<http://perma.cc/46HK-YYFA>] (last updated Apr. 20, 2015) (“Since the agent will have the authority to make medical decisions in the event the principal is unable to make such decisions for him- or herself, the agent should be a family member or friend that the principal trusts to follow his or her instructions.”).

Likewise, the American Bar Association’s Commission on Law and Aging, a leader in elder law policy, has recommended that individuals choose their surrogate based on the following criteria:

1. Meets the legal criteria in your state for acting as agent or proxy or representative. . . .
2. Would be willing to speak on your behalf.
3. Would be able to act on your wishes and separate his/her own feelings from yours.
4. Lives close by or could travel to be at your side if needed.
5. Knows you well and understands what’s important to you.
6. Is someone you trust with your life.
7. Will talk with you now about sensitive issues and will listen to your wishes.
8. Will likely be available long into the future.
9. Would be able to handle conflicting opinions between family members, friends, and medical personnel.
10. Can be a strong advocate in the face of an unresponsive doctor or institution.

AM. BAR ASS’N COMM’N ON LAW AND AGING, CONSUMER’S TOOL KIT FOR HEALTH CARE ADVANCE PLANNING 1 (2d ed. 2005), http://www.americanbar.org/content/dam/aba/un-categorized/2011/2011_aging_bk_consumer_tool_kit_bk.authcheckdam.pdf [<http://perma.cc/U2S2-R75H>].

process generally requires courts to consider a hierarchy of persons—commonly any person or entity nominated by the individual, followed by the person’s spouse, adult child, parent, and other relatives or friends.¹⁷ While a court may appoint a nonrelative, including a professional guardian, such appointments are the exception not the rule.¹⁸

Similarly, default surrogate statutes also give preference to close family members. Most states with default surrogate laws have created a statutory “priority list” indicating which persons may serve as surrogates in the absence of an advance directive.¹⁹ Typically, the priority list is composed of members of the immediate family, starting with the spouse. Some states make allowances for nontraditional families by including domestic partners or “close friends.”²⁰ A number of states also allow a physician to make a decision where no surrogate is available.²¹ Other states give physicians a role in selecting the surrogate.²² States generally require healthcare providers to adhere strictly to the state’s priority list in identifying default surrogate decisionmakers for incapacitated patients.²³ This rigid priority list approach is consistent with the Uniform Health Care Decisions Act (UHCDA). Under the UHCDA, if a patient does not have a designated surrogate or if that surrogate is not “reasonably available,” a health care provider can obtain consent to medical treatment (or refusal of consent) from “any member of the following classes of the patient’s family who is

17. See KOHN, *supra* note 8, at 145.

18. There is a remarkable dearth of data on adult guardianship; however, all indications are that the vast majority of guardians are family members of the ward. In 2009, the National Center for State Courts’ Center for Elders and the Courts surveyed court personnel—including judges—working in the guardianship arena. Based on the responses to the survey, respondents reported that 72% of guardians were family members in jurisdictions where public guardians are available and 81% of guardians were family members in jurisdictions lacking a public guardian. See BRENDA K. UEKERT, NAT’L CTR. FOR STATE COURTS, ADULT GUARDIANSHIP COURT DATA AND ISSUES: RESULTS FROM AN ONLINE SURVEY 19 (2010), http://www.guardianship.org/reports/Guardianship_Survey_Report.pdf. The report cautioned, however, that the sample was not representative of court personnel nationwide. *Id.* at 4.

19. See Kohn & Blumenthal, *supra* note 12, at 983.

20. *Id.* at 984–85.

21. *Id.* at 985.

22. *Id.*

23. *Id.* There are some exceptions. For example, in Tennessee, the priority list is merely to be given “consideration” when selecting a surrogate “who has exhibited special care and concern for the patient, who is familiar with the patient’s personal values, who is reasonably available, and who is willing to serve.” TENN. CODE ANN. § 68-11-1806(c)(2)–(3) (2004). Similarly, in Colorado and Hawaii, specified interested persons are called upon to decide amongst themselves who will serve as the surrogate based on who among them is close to the patient and is most likely to be familiar with the patient’s wishes. COLO. REV. STAT. ANN. § 15-18.5-103(4)(a) (West 2011); HAW. REV. STAT. § 327E-5(d) (1999 & Supp. 2007).

reasonably available, in descending order of priority . . . : (1) the spouse, unless legally separated; (2) an adult child; (3) a parent; or (4) an adult brother or sister.”²⁴ If none of these individuals are reasonably available, any other adult “who has exhibited special care and concern for the patient, who is familiar with the patient’s personal values, and who is reasonably available may act as surrogate.”²⁵

There is also considerable overlap among the systems as to how a surrogate is instructed to make decisions. Where the law articulates a decisionmaking standard for surrogate decisionmakers for health care, state statutes generally require surrogates to make decisions using substituted judgment,²⁶ at least where the patient’s wishes are actually known and often where they are reasonably ascertainable; that is, they should make the decision they believe the patient would make if able to do so. This approach requires the surrogate to adhere to the patient’s preferences, which may not be feasible where there is insufficient information about those preferences, and requires a degree of speculation even when prior discussions have occurred. Thus, the UHCDA instructs surrogates to make health care decisions “in accordance with the principal’s individual instructions, if any, and other wishes to the extent known to the agent. Otherwise, the agent shall make the decision in accordance with the agent’s determination of the principal’s best interest.”²⁷ This is the majority approach to decisionmaking by appointed health care agents.²⁸

24. See UNIF. HEALTH-CARE DECISIONS ACT § 5 (1993). If more than one member of a class assumes surrogate decisionmaking authority, the will of the majority of the members of that class governs. *Id.*

25. *Id.*

26. Notably, the law is often unclear about such decisionmaking standards. *Cf.* Lawrence A. Frolik & Linda S. Whitton, *The UPC Substituted Judgment/Best Interest Standard for Guardian Decisions: A Proposal for Reform*, 45 U. MICH. J.L. REFORM 739, 742–43 (2012) (finding that a majority of the states do not articulate a decisionmaking standard for guardians, at least with regard to decisions other than healthcare decisions, and indicating that a number of states do not articulate a standard even for guardians’ health care related decisions).

27. UNIF. HEALTH-CARE DECISIONS ACT § 2(e) (1993).

28. This conclusion is reached based on the Author’s examination of the relevant state laws. Some states, notably, provide that if the patient’s wishes are not known, the surrogate should make the decision based on the patient’s values—a departure from a more generalized “best interests” approach. See, e.g., ARIZ. REV. STAT. ANN. § 36-3203(C) (2009).

III. THE CONGRUENCE PROBLEM

A primary goal of appointing surrogate decisionmakers is to ensure the treatment decisions made for individuals are those the individuals would have made for themselves if able to do so. Where a surrogate's decision matches the decision the patient would have made, the decisions are said to be "congruent." Where the two diverge, they are said to be "incongruent."

This Part reviews the social science literature on both the incidence of incongruency and causal explanations for it. At the outset, however, it is important to note that this literature, although extensive and very informative, has significant limitations. After all, it is not possible to conclusively determine whether or not surrogate decisionmakers make the decisions incapacitated patients would make for themselves. Such determinations require speculation and counterfactual reasoning because, by definition, incapacitated persons cannot make the relevant decisions. To understand the extent and causes of incongruency, social scientists must therefore compare surrogates' decisions to those that patients with capacity believe they would make for their future, incapacitated selves. Thus, researchers generally examine issues of congruence by asking an individual with capacity to predict his or her own future health care treatment choices and simultaneously asking the individual's surrogate to indicate the treatment decision that the surrogate would make under the same conditions. Naturally, such studies have limitations. Most fundamentally, these studies are based on the assumption that surrogates and patients have similar decisionmaking patterns in hypothetical and actual treatment situations. In addition, they generally evaluate congruence based solely on a patient's pre-incapacity wishes even though people have difficulty with "affective forecasting," that is, predicting future emotional states and reactions.²⁹ Despite these limitations, such studies provide valuable—albeit somewhat discouraging—insight into how surrogate decisionmakers make decisions on behalf of patients.

First and foremost, the extensive literature on surrogate decisionmaking in the health care context suggests that surrogate decisionmakers frequently make choices for patients that are inconsistent with what the patients would have done. A systematic review by Shalowitz et al. surveyed forty years of research on surrogate decisionmaking to identify sixteen studies that provided quantitative data on surrogates' ability to accurately predict patients' choices.³⁰ These studies typically presented patients and their

29. See Jeremy A. Blumenthal, *Law and the Emotions: The Problems of Affective Forecasting*, 80 IND. L.J. 155, 219–21 (2005).

30. David I. Shalowitz et al., *The Accuracy of Surrogate Decision Makers: A Systematic Review*, 166 ARCHIVES INTERNAL MED. 493, 494 (2006).

surrogates with hypothetical scenarios requiring a decision about medical treatment, and then compared the decision the patient would have made with that made by the surrogate for the patient.³¹ Looking across the sixteen studies—representing a total of nearly 20,000 patient-surrogate paired responses—the study found that surrogates predicted patients’ treatment preferences with on average only 68% accuracy.³² Notably, the level of congruence did not appear to vary based on whether the surrogate was chosen by the patient or assigned according to a statutory hierarchy of default surrogate decisionmakers.³³ Subsequent studies, including those seeking to explain this lack of congruence, have further documented the failure of surrogates to accurately predict patients’ treatment preferences.³⁴

31. *Id.* Because nine of the sixteen studies assessed congruence based on a scale of how likely the patient and surrogate were to make particular treatment decisions, the reviewers “collapsed” surrogates’ treatment decisions into two categories: those that would result in treatment and those that would not. *Id.* The reviewers treated “uncertain” responses as falling within the treatment category “based on recommendations that physicians treat patients under conditions of uncertainty.” *Id.*

32. *Id.* Notably, this rate of agreement is most likely significantly higher than the rate of actual, conscious agreement, because it fails to account for chance agreement. A better measure of actual agreement would be Cohen’s kappa, which measures the difference between the observed and expected levels agreement. *See* Kohn & Blumenthal, *supra* note 12, at 998 n.85.

33. *See* Shalowitz et al., *supra* note 30, at 495–96 (finding that, across the sixteen studies examined, patient-selected surrogates had an approximately 69% accuracy rate whereas legally-assigned surrogates had an approximately 68% accuracy rate); *accord* Daniel P. Sulmasy et al., *More Talk, Less Paper: Predicting the Accuracy of Substituted Judgments*, 96 AM. J. MED. 432, 435 tbl.V (1994) (finding no relationship between a surrogate’s predictive accuracy and whether the surrogate was patient-selected or chosen by state law).

34. *See* Jessica Bryant et al., *The Accuracy of Surrogate Decision Makers: Informed Consent in Hypothetical Acute Stroke Scenarios*, 13 BIOMED CENT. EMERGENCY MED. 1, 3 (2013) (reporting in a study of surrogate decisionmaking for stroke-related care that “surrogates predicted patients’ treatment preferences with 76.5% crude agreement; however, the kappa statistics for each scenario indicated poor agreement”); Magali Ciroidi et al., *Ability of Family Members to Predict Patient’s Consent to Critical Care Research*, 33 INTENSIVE CARE MED. 807, 809 (2007) (examining congruency of French patients and their surrogates in two scenarios and finding 32% discrepancy in one and 42% discrepancy in the other); Anand V. Mantravadi, *Accuracy of Surrogate Decision Making in Elective Surgery*, 33 J. CATARACT & REFRACTIVE SURGERY 2091, 2093–94 (2007) (finding that patients’ self-selected surrogates predicted patients’ preferences for cataract surgery in the hypothetical event the patient had dementia with a rate of accuracy 34%; however, 97% of proxies were confident in their predictions in that scenario); Melissa A.Z. Marks & Hal R. Arkes, *Patient and Surrogate Disagreement in End-of-Life Decisions: Can Surrogates Accurately Predict Patients’ Preferences?*, 28 MED. DECISION MAKING 524, 528 (2008) (finding that surrogates incorrectly predicted patients’ preferences for cardiopulmonary

The lack of congruence between decisions made by healthcare surrogates and those made directly by patients may be attributable to a variety of factors. Some of these factors may seem relatively benign. Surrogates may simply be unaware of patients' treatment preferences or even their underlying values. For example, Reamy et al. studied 266 dyads composed of "an individual with mild to moderate dementia and his or her family caregiver."³⁵ They found that caregivers consistently reported that patients cared less about five key values—autonomy, burden on others, control, family, and safety—than patients actually did.³⁶ Such lack of familiarity may be attributable to a variety of factors, including patients failing to discuss their wishes with surrogates, surrogates forgetting the content of discussions that occurred, or surrogates believing patients' wishes at the time of incapacity would be different than their wishes at the time discussed.

Another factor that may contribute to high levels of incongruence is that surrogates may not be aware of the limits of their knowledge, instead misjudging their degree of familiarity with and understanding of patients' preferences. Research indicates that surrogates often have a false sense of confidence in their ability to predict patients' preferences accurately.³⁷ For example, a study examining spouses' predictions of whether patients would want cardiopulmonary resuscitation (CPR) found that spouses who expressed confidence that they knew what their partner would want were not more accurate than those who lacked such confidence.³⁸ Indeed, both surrogates and patients may be overconfident as to surrogates' ability to predict patients' wishes. In another study in which surrogates predicted patients' treatment preferences at a rate no better than chance, both surrogates and patients believed that the surrogate knew the patients' wishes.³⁹

resuscitation 26% of the time and patients' preferences related to balancing extended life versus relief from pain 35% of the time); Julia T. Newman et al., *Surrogate and Patient Discrepancy Regarding Consent for Critical Care Research*, 40 CRITICAL CARE MED. 2590 (2012) (finding in a study of patients in a medical intensive care unit and their surrogate decisionmakers' willingness to consent to seven hypothetical research scenarios that the kappa "values for all seven scenarios demonstrated less than moderate agreement" and that agreement decreased as the risk associated with the proposed research increased).

35. Allison M. Reamy et al., *Understanding Discrepancy in Perceptions of Values: Individuals with Mild to Moderate Dementia and Their Family Caregivers*, 51 GERONTOLOGIST 473, 475 (2011).

36. *Id.* at 478–79.

37. See VICTOR G. CIRELLI, FAMILY CAREGIVING: AUTONOMOUS AND PATERNALISTIC DECISION MAKING 104 (1992); Suhl et al., *supra* note 15, at 94–95.

38. Richard F. Uhlmann et al., *Physicians' and Spouses' Predictions of Elderly Patients' Resuscitation Preferences*, 43 J. GERONTOLOGY M115, M117 (1988).

39. Suhl et al., *supra* note 15, at 93.

The lack of congruence may also stem from surrogates' susceptibility to another form of "wishful thinking," that is, surrogates may assume that patients want what surrogates want for them. Marks and Arkes examined 144 patient-surrogate dyads in which the surrogate and patient disagreed as to preferences for CPR, and 294 such dyads where there was disagreement as to whether palliative treatment should be provided even if it would result in an earlier death.⁴⁰ The researchers found that in both scenarios, what surrogates wanted for patients was a statistically significant predictor of what they had predicted patients wanted for themselves.⁴¹

Less benignly, surrogates may deliberately deviate from patients' wishes because they believe that complying with them would cause an immoral or otherwise undesirable result. Numerous studies have shown that surrogates sometimes choose to ignore or override known patient preferences.⁴² Moreover, they may do so even when overriding the patient's wishes does not benefit the patient. For example, in one study, nearly one-third of surrogate decisionmakers for nursing home residents surveyed consented to the resident's participation in a medical study even though they believed the resident would not have done so and the research would not personally benefit the resident.⁴³

Still other research demonstrates that surrogates often plan to make decisions about treatment based at least partly on their own values.⁴⁴ These values may differ from patients' values and preferences, thus leading to incongruent decisions.⁴⁵ Such differences in values may be inherent to

40. Marks & Arkes, *supra* note 34, at 527.

41. *Id.* at 529. Given the limitations of the study design, the researchers were unable to determine whether this effect was conscious. *Id.*

42. See, e.g., Elizabeth K. Vig et al., *Beyond Substituted Judgment: How Surrogates Navigate End-of-Life Decision-Making*, 54 J. AM. GERIATRICS SOC'Y 1688, 1690–91 (2006) (reporting that a subset of surrogate decisionmakers for chronically ill veterans would make decisions contrary to the veterans' known wishes).

43. See John W. Warren et al., *Informed Consent by Proxy: An Issue in Research with Elderly Patients*, 315 NEW ENG. J. MED. 1124, 1127 (1986).

44. Vig et al., *supra* note 42, at 1690–91.

45. See Laraine Winter & Susan M. Parks, *Elders' Preferences for Life-Prolonging Treatment and Their Proxies' Substituted Judgment: Influence of the Elders' Current Health*, 24 J. AGING & HEALTH 1157, 1170 (2012) [hereinafter Winter & Parks, *Elders' Preferences*]. In another study, Winter and Parks found that "reluctance to burden others" predicted older adults' preferences for end-of-life treatment. Laraine Winter & Susan M. Parks, *The Reluctance to Burden Others as a Value in End-of-Life Decision Making: A Source of Inaccuracy in Substituted Judgment*, 17 J. HEALTH PSYCHOL. 179, 183 (2011). Proxies' tendency to put less weight on this factor relative to principals thus may result in incongruent treatment decisions. *Id.* at 184.

the individuals making them. Alternatively, they may reflect the fact that individuals' priorities can vary depending on their circumstances, and that the surrogate and the patient are at different places in their lives.

There is also a significant tendency for surrogates to project their own preferences onto patients. In a study of patients and those individuals likely to be chosen as their surrogates, Zweibel and Cassel found that those likely to be chosen as surrogates predicted patients' treatment preferences with only 63% accuracy.⁴⁶ There was a very strong correlation, however, between what the likely surrogates said they would want for themselves and what they predicted the patients would want. Surrogates overwhelmingly—ranging from 93% to 95% of the time, depending on the scenario—selected the treatment for the patient that they indicated they would want for themselves in the same situation.⁴⁷

A similar pattern of projection was found in a study by Fagerlin et al. that paired undergraduate students with the students' parents.⁴⁸ After the two engaged in a discussion of end-of-life issues together, the parents were surveyed about their treatment preferences as to a variety of serious healthcare decisions, and students were surveyed as to what they believed their parents would want.⁴⁹ The study found that the best predictor of what students thought their parents would want is what the students wanted for themselves in same situations.⁵⁰ While there was only a 64% rate of agreement between parents' preferences and students' predictions of parents' preferences, there was a 78% rate of agreement between what students predicted parents would want and what students wanted for themselves.⁵¹ Fagerlin et al. also ran a parallel study with older adults (mean age 73.7 years) and their self-selected surrogates.⁵² Although there was a markedly higher rate of congruence in this study—surrogates accurately predicted principals' preferences 72% of the time—surrogates' preference for their own care were still the best predictor of what the surrogate reported the principal would choose; 80% of the time, surrogates believed principals would choose what the surrogates wanted for themselves.⁵³

46. See Nancy R. Zweibel & Christine K. Cassel, *Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies*, 29 GERONTOLOGIST 615, 618 (1989) (more specifically, surrogates made a treatment decision that was the opposite of what the patient would make between 24% and 50% of the time, depending on the decision; findings were based on a sample of 55 patient-surrogate dyads).

47. See *id.* at 618–19.

48. Fagerlin et al., *supra* note 15, at 168–69.

49. *Id.* at 167–68.

50. *Id.* at 169–70.

51. *Id.* at 169.

52. *Id.* at 171.

53. *Id.* at 171–73.

Likewise, Moorman et al. analyzed data from 2750 married couples in their mid-60s.⁵⁴ They found that spouses reported each other's preferences for life sustaining care at a rate only slightly better than chance.⁵⁵ The study found that the patterns of congruence witnessed were consistent with spouses projecting their own care preferences onto one another.⁵⁶

More recently, McDade-Montez et al. studied dyads of newly married couples. The researchers asked the couples to predict end-of-life preferences for one another. The study found that the newly married individuals' predictions as to their spouses' end-of-life treatment preferences were more closely related to their own treatment preferences than to their spouses' treatment preferences.⁵⁷ This finding was true for both husbands and wives.⁵⁸ The researchers attributed the finding to spouses' assumed similarity, that is, spouses assumed that their spouses had similar beliefs. Notably, the researchers found that wives were less accurate in predicting husbands' preferences where the two members of the couple had greater differences in spirituality, moral strictness, and conservativeness; however, such differences did not affect husbands' predictive accuracy.⁵⁹

While surrogates' tendency to project their own values on patients is often discussed as if it is subconscious, surrogates may sometimes be aware that they are projecting. A qualitative study of decisionmaking for patients with end-stage dementia in Germany found that relatives who had been appointed as surrogate decisionmakers, either by the patient or through a guardianship proceeding, referred to their own preferences to explain why they would make a particular choice in 22% of decisions.⁶⁰ Likewise, in a qualitative study involving structured interviews of fifty surrogate decisionmakers for older, chronically ill veterans, Vig et al. found that a subset of the surrogates explicitly said they would consider their

54. See Sara M. Moorman et al., *Do Older Adults Know Their Spouses' End-of-Life Treatment Preferences?*, 31 J. AGING RES. 463, 470 (2009).

55. *Id.* at 476.

56. See *id.* at 480. By contrast, the study found that neither the surrogate's appointment as a health care agent pursuant to a health care proxy nor discussions between the surrogate and patient as to the patient's care preferences predicted congruence. *Id.*

57. Elizabeth McDade-Montez et al., *Similarity, Agreement, and Assumed Similarity in Proxy End-of-Life Decision Making*, 31 FAMILIES, SYS. & HEALTH 366, 377 (2013).

58. *Id.*

59. *Id.*

60. Ralf J. Jox, *Surrogate Decision Making for Patients with End-Stage Dementia*, 27 INT'L J. GERIATRIC PSYCHIATRY 1045, 1048 (2012). By contrast, professional guardians rarely referred to their own preferences. *Id.* It should be noted that the sample size was very small.

own personal beliefs when making end-of-life decisions for the patients, and some admitted that they would consider their own needs as part of the decisionmaking process.⁶¹

IV. CURRENT STRATEGIES FOR IMPROVING CONGRUENCE

There have been numerous recommendations for improving congruence in treatment decisions.

A common recommendation is that surrogates be selected based on their relationship with the patient.⁶² This is consistent with the conventional wisdom that surrogates who are closely related to patients or who otherwise know them well are in the best position to predict patients' treatment preferences.⁶³ Thus, attorneys, medical professionals, and others who help patients execute advance directives frequently advise patients to select a surrogate who knows them well, who is familiar with their wishes, and whom they trust. This approach is also adopted in the specific hierarchies established by default surrogate decisionmaking statutes,⁶⁴ and is consistent with current practices for appointing guardians for incapacitated persons.⁶⁵

Despite the prominence of this approach and the expectation that those who are closely related to the patient will know the patient's wishes, the research suggests that the degree of relatedness between a patient and a family member acting as a surrogate does not predict surrogate accuracy.⁶⁶ That said, compared to physicians, surrogates who are family members of the patient tend to make treatment decisions that are more consistent with the patient's wishes.⁶⁷ Accordingly, while choosing family members may

61. See Vig et al., *supra* note 42, at 1690–91.

62. See *supra* note 16 and accompanying text.

63. See *supra* note 16 and accompanying text.

64. See *supra* note 20 and accompanying text.

65. See *supra* notes 17–18 and accompanying text.

66. See Shalowitz et al., *supra* note 30, at 496 (reviewing four studies and finding that a surrogate's familial relationship to a patient was not correlated with accuracy).

67. See Susanna E. Bedell & Thomas L. Delbanco, *Choices About Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk With Patients?*, 310 NEW ENG. J. MED. 1089, 1091 (1984) (concluding that physicians' opinions as to patients' desire for life-sustaining measures correlates poorly with preferences expressed by patients); Kristen M. Coppola et al., *Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences with and Without Advance Directives*, 161 ARCHIVES INTERNAL MED. 431, 431 (2001); Joseph G. Ouslander et al., *Health Care Decisions Among Elderly Long-Term Care Residents and Their Potential Proxies*, 149 ARCHIVES INTERNAL MED. 1367, 1369, 1371 (1989); Príncipe-Rodríguez et al., *supra* note 15, at 408; Allison B. Seckler et al., *Substituted Judgment: How Accurate Are Proxy Predictions?*, 115 ANNALS INTERNAL MED. 92, 95 (1991); Shalowitz et al., *supra* note 30, at 496; Uhlmann et al., *supra* note 38, M117–19; see also Tom Tomlinson et al., *An Empirical Study of Proxy Consent for Elderly Persons*, 30 GERONTOLOGIST 54, 59 (1990) (reporting that “[c]lose family members performed slightly better than physicians in

be good practice, when choosing among relatives, degree of relatedness should not be expected to predict congruency.⁶⁸

Another frequently recommended strategy for increasing congruence is for patients to discuss their wishes with their selected surrogate. Indeed, there are currently a number of nonprofit organizations leading efforts designed specifically to encourage such conversations.⁶⁹ However, such discussions do not necessarily increase the likelihood that the surrogate will make the decision the patient would have made. Indeed, many studies suggest that such discussion is of little value in improving surrogates' substantive accuracy.⁷⁰ This appears to be true when the patient and surrogate discuss the patient's specific treatment preferences⁷¹ as well as when they discuss the patient's values related to treatment.⁷² There is some limited evidence that such discussion may improve surrogates' understanding of patients' personal beliefs about the process by which decisions should be made, but that this understanding does not lead to improved congruency with regard to specific treatment decisions.⁷³

reflecting the elderly person's wishes"; however, that finding was not statistically significant, and was true for proxies making substituted judgments, but not for "general proxies," who were slightly—but not statistically significantly—worse than physicians). On a positive note, physicians may recognize their limitations in this regard. See Seckler et al., *supra*, at 94–95 (finding that physicians reported only 59% confidence that their decisions accurately reflect patient wishes).

68. Notably, however, existing studies examining the impact of degree of relatedness of typically examine differences among closely related relatives. Degree of relatedness might well predict congruence if close relatives were compared to quite distant relatives.

69. See, e.g., THE CONVERSATION PROJECT, www.theconversationproject.org [http://perma.cc/SE4C-J6WW] (last visited Apr. 20, 2015).

70. See Peter H. Ditto et al., *Advance Directives as Acts of Communication: A Randomized Controlled Trial*, 161 ARCHIVES INTERNAL MED. 421, 426 (2001); Angela Fagerlin et al., *The Use of Advance Directives in End-of-Life Decision Making: Problems and Possibilities*, 46 AM. BEHAV. SCI. 268, 275–76 (2002) (citing the Ditto study); Smucker et al., *supra* note 15. However, prior discussion between surrogates and patients was found to improve accuracy in a study by Suhl et al., *supra* note 15, at 94. That said, in that study, the patients self-reported the amount of such discussion and this may have influenced the results. *Id.*

71. See, e.g., Ditto et al., *supra* note 70, at 426; Moorman et al., *supra* note 54, at 463.

72. See, e.g., Carol Matheis-Kraft & Karen A. Roberto, *Influence of a Values Discussion on Congruence Between Elderly Women and Their Families on Critical Health Care Decisions*, 9 J. WOMEN & AGING 5 (1997) (finding that prior discussion of values between patients and their proxies impacted proxy accuracy but acknowledging methodological limitations).

73. Robert A. Pearlman et al., *Improvements in Advance Care Planning in the Veterans Affairs System*, 165 ARCHIVES INTERNAL MED. 667, 671 (2005) (finding that an

A third type of intervention designed to improve surrogates' substantive accuracy is to specifically instruct surrogates to use substituted judgment. There is some evidence to indicate that this intervention has utility. For example, some studies have found that family members and patient-selected surrogates make decisions that are more consistent with patients' wishes when explicitly told to use substituted judgment.⁷⁴ In a recent study of decisionmaking by guardians, Whitton and Frolik compared how guardians make personal and healthcare decisions for persons subject to guardianship in a state that requires guardians to make decisions in the "best interest" of the person subject to guardianship with how guardians make such decisions in states that require guardians to use substituted judgment where there is evidence of what the person would want.⁷⁵ Compared to guardians in the jurisdictions with substituted judgment standards, guardians in the state with a "best interests" standard reported that they placed greater weight on the views of family members, family harmony and consensus, and what the guardian would want in the same circumstances when making decisions for a person subject to guardianship.⁷⁶ These findings suggest that the decisionmaking standard that surrogates are instructed to use may affect how they make decisions, and that a best interests standard is detrimental to the cause of congruent decisionmaking.⁷⁷ Other research, however, has not found that instructing surrogates to use substituted judgment has a statistically significant effect. For example, in a study on decisions regarding life-sustaining treatment, patient-selected surrogates who were instructed to make treatment decisions based on what the patient would choose were not statistically more did not achieve a level of congruence that was statistically greater than what would be expected

intervention that increased advance care planning discussions between patients and surrogates did not improve congruence as to treatment preferences and values, but did somewhat improve the ability of proxies to predict patients' "personal beliefs," beliefs which were largely related to decisionmaking processes).

74. See, e.g., Tomlinson et al., *supra* note 67, at 59 (finding that close family members—including patient-selected surrogates—were no better than treating physicians at making decisions that were consistent with patients' wishes unless explicitly told to use substituted judgment).

75. Linda S. Whitton & Lawrence A. Frolik, *Surrogate Decision-Making Standards for Guardians: Theory and Reality*, 2012 UTAH L. REV. 1491, 1526–29 (2012).

76. *Id.*

77. Since the study relied on self-reports, however, it is possible that the effect observed is not on the actual processes that are used but on what processes guardians claim to use, either because they sincerely believe they use those processes or because they wish to appear compliant with state law. It is also possible that differences in processes do not lead to differences in outcomes.

by chance.⁷⁸ Thus, while instructing surrogates to use substituted judgment may hold promise, this intervention alone cannot be expected to “fix” the problem of incongruency.

Finally, some scholars have proposed abandoning, in whole or in part, the substituted judgment model in favor of models that seem more likely to result in congruent decisions. For example, Houts et al. have suggested that treatment decisions may be more consistent with patient wishes if they are based not on substituted judgment, but rather on an actuarial model in which decisions are made by looking to what others are known to have chosen in like circumstances.⁷⁹ Others have suggested that decisions simply be made based on the best interests of the patient.⁸⁰ A fundamental problem with such alternative models is that even if they significantly improve congruency as to treatment decisions, they may not result in a decisionmaking process that is any more consistent with patients’ overall wishes. This is because congruency is not the only goal of surrogate decisionmaking. Another important goal for many patients is that their family, or certain members of their family, be involved in the decisionmaking process.⁸¹ Indeed, many people report that they “are less concerned with the specific treatment decisions that are made than about having the decisions made by someone they trust.”⁸² Such alternative models do not account for patients’ desire for family involvement in the decision making process.

78. Hare et al., *supra* note 15, at 1049. Despite 70% agreement, the kappa statistics were not significantly different from zero; thus, corrected agreement was not significantly different from chance.

79. Renate M. Houts et al., *Predicting Elderly Outpatients’ Life-Sustaining Treatment Preferences over Time: The Majority Rules*, 22 MED. DECISION MAKING 39, 49 (2002) (suggesting that such a model could, for example, “guide” surrogates making decisions without an advance directive and guard against certain types of predictive errors).

80. See, e.g., Kristine Bærøe, *Patient Autonomy, Assessment of Competence and Surrogate Decision-Making: A Call for Reasonableness in Deciding for Others*, 24 BIOETHICS 87, 93–94 (2010) (arguing in favor of using teams to make decisions in the best interests of incapacitated patients).

81. In a literature review examining patients’ goals for surrogate decisionmaking processes, Kelly et al. identified three goals that individuals have for surrogate decisionmaking in the context of health care: “involve their family, be[] treated consistently with their own preferences and values, and minimize the burden on their family.” Brenna Kelly et al., *Systematic Review: Individuals’ Goals for Surrogate Decision-Making*, 60 J. AM. GERIATRICS SOC’Y 884, 894 (2012).

82. Fagerlin et al., *supra* note 70, at 278. It is worth questioning, however, whether their faith in trusted others would persist if fully aware of the research cited in this Article.

Thus, existing proposals may well improve congruency, but they fall far short of providing a complete solution to the problem of incongruency. The next Part therefore proposes a new approach to surrogate decisionmaking that should, if not replace, at least supplement existing strategies for improving congruence.

V. A NEW APPROACH TO SURROGATE SELECTION

As discussed in Part III, research consistently suggests that because surrogates tend to project their own preferences, the best predictor of surrogates' decisions on behalf of patients is surrogates' preferences for themselves in the same situation.⁸³ While researchers typically portray this tendency as a barrier to appropriate decisionmaking or as a challenge to be overcome,⁸⁴ this Part shows how it can be capitalized on to improve surrogate decisionmaking. Specifically, it explains how those selecting surrogate decisionmakers—whether they be individuals executing advance directives, judges appointing guardians, or policymakers designing systems for selecting legal surrogates—can increase congruency by capitalizing on surrogates' tendency to project their own values and preferences.

A. A Shared Preferences and Values Approach to Surrogate Selection

The repeated finding that surrogates' preferences for their own treatment predict the decisions they make for others indicates that surrogates selected based on the extent to which they share patients' preferences and values are likely to achieve a higher rate of congruency than are surrogates selected based on conventional factors. Therefore, I propose that all three types of healthcare agents should be selected based, at least in part, on the extent to which they share patients' treatment-related preferences. When treatment preferences cannot be compared, or when the individual cares less about individual treatment decisions than about consistency with a set of values, then surrogates should be selected based on shared values.

This proposal differs significantly from existing recommendations that surrogate decisionmakers should consider patients' values when making treatment preferences, or that a discussion of values should be part of the

83. See *supra* notes 46–61 and accompanying text.

84. See, e.g., McDade-Montez et al., *supra* note 57, at 377 (suggesting that surrogate decisionmaking might be improved by discussing family members' biases and recognizing the potential impact of surrogates' own preferences on end-of-life decisionmaking); Zweibel & Cassel, *supra* note 46, at 620 (describing projection as a source of error).

conversation that patients have with their surrogates.⁸⁵ This proposal brings the role of values into the surrogate decisionmaking process at an earlier stage: to consider values not only when determining *how* the surrogate should act but also to consider values when determining *who* should act as surrogate.

When matching surrogates and patients based on values, a perfect match will rarely be possible. The challenge, therefore, is to identify the values that are most important for the patient and surrogate to share.

As a general matter, the greatest weight should be placed on values that have the greatest impact on the most important and fundamental treatment choices, such as those about whether to consent to life-sustaining treatment and those that involve significant tradeoffs between quality and length of life. Three types of values should therefore be given special consideration: (1) values that are most predictive of treatment choices, (2) values that remain stable over time, and (3) foundational values that individuals employ to prioritize among other values.⁸⁶ Values related to prioritizing among competing goals are critically important because many of the most difficult and fundamental healthcare decisions involve making tradeoffs between desired outcomes, such as between minimizing pain and prolonging life.

Existing research provides some insight into which types of values are likely to meet these criteria. McDade-Montez et al. found that differences in spirituality, moral strictness, and conservativeness between newlywed husbands and wives correlated with wives making less accurate predictions of husbands' preferences.⁸⁷ Thus, surrogates who are similar in terms of these three characteristics may be preferable to those who are not. Research indicating which values are most predictive of patients' own treatment choices may also be used to identify which values are particularly important to share⁸⁸ because surrogates tend to project their own values.

85. See, e.g., Leslie P. Scheunemann et al., *The Facilitated Values History: Helping Surrogates Make Authentic Decisions for Incapacitated Patients with Advanced Illness*, 186 AM. J. RESPIRATORY & CRITICAL CARE MED. 480, 480 (2012) (arguing that surrogates need to understand patients' values and that such values should be discussed with surrogates).

86. Cf. Michele J. Karel et al., *Three Methods of Assessing Values for Advance Care Planning: Comparing Persons with and Without Dementia*, 19 J. AGING & HEALTH 123, 145 (2007) (arguing, in a study of methods for assessing patient values, that the most important values to consider are those related to prioritization).

87. McDade-Montez et al., *supra* note 57, at 377.

88. Scheunemann et al. provide a list of values based on a review of the literature that appear to be relevant to end-of-life decisions. They include longevity, maintenance

Nevertheless, further research would be helpful to obtain a clearer picture of which values are most important to treatment decisions. As current research on the impact of values on treatment decisions tends to examine the impact of patients' values and not the impact of surrogates' values, research that directly looks at the impact of surrogates' values on their treatment decisions would be particularly beneficial.

B. Operationalizing a Shared Preferences and Values Approach to Surrogate Selection

The manner in which a shared preferences and values approach to surrogate selection should be operationalized depends on the type of surrogate. Those executing advance directives should be counseled to consider potential surrogates' own treatment preferences and values when selecting their health care agent and to consider favoring surrogates with similar values and preferences. Thus, as part of the surrogate selection process, an individual should not only discuss his or her own preferences with potential surrogates but should also discuss the potential surrogates' preferences for their own care.⁸⁹ Such discussions are likely to be of particular value when young persons are being considered as potential surrogates because some evidence suggests that younger surrogates are more likely to engage in projection.⁹⁰

Similarly, courts should take into account potential guardians' health care related preferences and values when choosing whom to appoint. Courts should favor those individuals whose preferences for their own care appear to mirror, or at least to be closely aligned with, what the person subject to guardianship is known—or, if actual knowledge is not feasible, reasonably believed—to have wanted. If the person's relevant

of bodily integrity, maintenance of physical function, maintenance of cognitive function, autonomy and independence, social and emotional engagement, avoidance of burdensome physical symptoms, and adherence to religious or spiritual beliefs. See Scheunemann et al., *supra* note 85, at 481. Investigating these values would be an excellent starting place.

89. Just as other aspects of an advance directive should be reevaluated on a regular basis, the choice of surrogate should be reevaluated as well, in part to ensure that the surrogate and the patient have not diverged in their values and preferences since the time of original appointment. Fortunately, the existing research base suggests that many values related to important healthcare decisions are fairly stable. For example, in a study of the values of patients both with and without dementia, Karel et al. found that both groups had relatively stable preferences as to the value they placed on quality versus quantity of life, the use of pain medications, where and from whom they wished to receive care, and feelings about dying. See Karel et al., *supra* note 86, at 145–46.

90. Fagerlin et al., *supra* note 15, at 169–70, 172 (finding that surrogates in their study of undergraduate-parent dyads were slightly more likely to project than surrogates in their study of older adults and patient-chosen surrogates; notably, however, students picked a parent to participate in the first study).

preferences cannot be ascertained, then the court should favor appointment of individuals whose health care related values appear consistent with those of the person subject to guardianship.

Finally, states should allow default surrogate decisionmakers to be selected based in part on their personal beliefs, not merely their familial status.⁹¹ For example, instead of prioritizing potential surrogates based on their relationship to the patients, states could authorize a group of “interested persons” to, based on a facilitated discussion, select a surrogate for the patient whose relevant preferences and values most closely match those of the patient.⁹² A more conservative alternative would be for states to continue to adhere to priority lists based on relationship but to allow the extent to which potential surrogates’ preferences and values match those of the incapacitated patient to determine whom is selected as a surrogate within a common class—for example, which adult child or which sibling is selected.

Fully implementing a shared preferences and values approach to surrogate selection will require law reform. Changes to state statutes authorizing default surrogate decisionmakers will be necessary in most states in order for a surrogate’s own preferences and values to be given adequate consideration

91. Jeremy Blumenthal and I suggested this idea in an earlier article, including it as one of several ways default surrogate decisionmaking processes might be improved upon. See Kohn & Blumenthal, *supra* note 12, at 1011–13.

92. As Jeremy Blumenthal and I suggested in a discussion of potential reforms to default surrogate decisionmaking laws:

States could consider modifying Colorado’s current default surrogate statute. That statute specifies that:

It shall be the responsibility of the interested persons [i.e., the patient’s spouse, parent, adult child, sibling, grandchild, or close friend] . . . to make reasonable efforts to reach a consensus as to whom among them shall make medical treatment decisions on behalf of the patient. The person selected to act as the patient’s proxy decision-maker should be the person who has a close relationship with the patient and who is most likely to be currently informed of the patient’s wishes regarding medical treatment decisions.

A modified statute, which takes into account and capitalizes on surrogates’ tendencies to project, might change the second sentence to read as follows:

The person selected to act as the patient’s proxy decision-maker should be the person who has a close relationship with the patient, who most closely shares the patient’s values and beliefs regarding medical treatment, and who is most likely to be currently informed of the patient’s wishes regarding medical treatment decisions.

Kohn & Blumenthal, *supra* note 12, at 1012–13 (quoting COLO. REV. STAT. § 15-18.5-103(4)(a) (2007)) (including this suggestion as part of a series of suggestions for improving default surrogate decisionmaking statutes).

when selecting default surrogate decision makers. Likewise, it would be appropriate to amend statutes guiding judicial selection of guardians to explicitly instruct judges to consider shared values and preferences.

However, a shared preferences and shared values approach could be largely implemented with no legal reform. Most surrogate decisionmakers are selected by patients themselves, without any court involvement and with minimal legal constraints. Attorneys and others counseling would-be patients should urge those individuals to consider potential surrogates' values when determining whom to select. Would-be patients should consider interviewing potential surrogates by asking them what they would want done for themselves in situations of importance to the principal. Likewise, in the context of guardianship, statutory reform would also be desirable but may not be necessary, as judges have significant discretion in selecting whom to appoint as a guardian.

Of course, none of the three systems could operationalize a shared preferences and values approach to surrogate selection with perfect precision. It is impossible to ensure that surrogates and patients have precisely the same set of preferences or values. Even setting aside the problem that no two people are exactly alike, assessing the degree to which preferences and values are shared is complicated by the fact that the preferences of an incapacitated person can never truly be known and the fact that a person's status as the patient may itself affect his or her preferences and values. Indeed, individuals' health status interacts with their health care preferences, with the value that people place on their life (and thus on potentially life-saving treatment) tending to increase as their health status worsens.⁹³ Although surrogates' decisions for patients are also affected by changes in patients' health status, the nature of the interaction appears to be different for patients than it is for surrogates.⁹⁴ Thus, judging patients' health care related preferences based on similarity between patients' pre-incapacity values and their post-incapacity values may give an incomplete picture of their wishes.

In short, although a shared preferences and shared values approach to surrogate selection cannot ensure congruence, it has the potential to meaningfully increase the rate of congruency.

93. Winter & Parks, *Elders' Preferences*, *supra* note 45, at 1170.

94. Winter and Parks found that both patient and surrogate preferences depended on an interaction between current health status and hypothetical, worsened health conditions such that both displayed a greater preference for life-sustaining treatment for less healthy patients. For principals, the interaction occurred primarily at the extremes, strongly affecting preferences where the health condition was either very bad—for example, after suffering a severe stroke—or no different from their current condition. By contrast, proxies' preferences for life-sustaining treatment increased even with less severe negative health conditions. *Id.* at 1170–71.

C. Advantages of a Shared Preferences and Values Approach

In addition to encouraging the selection of a surrogate who is more likely to make treatment choices that a patient would have made if capable, a shared preferences and shared values approach to surrogate selection has other advantages.

One key advantage is that it draws attention to the fact that the healthcare decisions that surrogates make are often value-laden. As Scheunemann et al. argue, “[a]dvanced illness often raises tradeoffs between quantity and quality of life,” and that one barrier to good surrogate decisionmaking is that surrogates “may misconstrue their role” because they “believe that treatment decisions hinge on purely medical judgments rather than on value-laden ones and therefore underestimate the importance of their input regarding the patient’s values.”⁹⁵ Values-based surrogate selection may, accordingly, also increase congruence by drawing attention to the role that values play in making treatment decisions and thereby encourage more relevant and productive discussions among medical providers, surrogates, and patients.

Another advantage of a shared values and preferences approach is that it encourages more flexible decisionmaking. Although individuals executing advance directives are often urged to provide surrogates with explicit instructions as to the care that they do and do not wish to receive, such instructions may not result in treatment decisions that are consistent with patient preferences. Research on affective forecasting suggests that patients’ own wishes, as expressed in an advance directive or other means, are often inconsistent with the preferences they express at a later time.⁹⁶ In addition, many patients want their surrogates to have the leeway to make context-specific decisions.⁹⁷ Choosing a surrogate based on shared values may

95. Scheunemann et al., *supra* note 85, at 481.

96. In states that require clear and convincing evidence of patient wishes to terminate life-sustaining treatment, there may still be a significant need to put some such details in the instructions so that the surrogate will be permitted to terminate such treatment.

97. See Ashwini Sehgal et al., *How Strictly Do Dialysis Patients Want Their Advance Directives Followed?*, 267 J. AM. MED. ASS’N 59, 59 (1992) (finding that subjects varied widely in the extent of leeway they would grant surrogates to override their instructions—“complete leeway” (31%), “a lot of leeway” (11%), “a little leeway” (19%), and “no leeway” (39%)—and on the weight to be given to factors such as pain or suffering, quality of life, the possibility of a new treatment, indignity caused by continued treatment, the financial impact of treatment on family, and religious beliefs); see also Fagerlin et al., *supra* note 70, at 278–79 (“[I]n fact, [patients] commonly desire to let surrogates override their living wills if the surrogate thinks it is in the patient’s best interest.”); Nikki Ayers

reduce the extent to which patients need, or think they need, to reify treatment preferences in their health care proxies and thus may facilitate the type of context-specific decisionmaking that patients often favor.

Finally, selecting surrogates based on shared values and preferences, as opposed to on conventional factors such as trustworthiness, may have substantial psychic benefits for both patients and their families. In many cases, individuals selecting surrogates face the unpleasant choice of choosing between loved ones, such as between their various adult children. Family members who are not selected may feel rejected or otherwise insulted. If those selecting surrogates justify their selections based on shared values or preferences, the decision may seem less like a referendum on the trustworthiness or abilities of those not selected and thus cause fewer hurt feelings.

VI. CONCLUSION

Surrogate decisionmakers do a poor job of predicting patients' treatment preferences. By contrast, they do an excellent job of projecting their own preferences onto patients. Health care decisionmaking for incapacitated persons can be improved by capitalizing on this phenomenon. Specifically, as this Article has proposed, individuals should be selected as a health care surrogate based, at least in part, on the extent to which they share the patient's treatment preferences. Where patients' specific preferences are not known or where patients care less about specific treatment decisions than about making decisions consistent with their underlying values, surrogates should be selected based at least in part on the extent to which they share patients' relevant values. Fully implementing this approach will require changing advance planning practices, encouraging judges to consider shared values and preferences when appointing guardians, and revising statutes governing the selection of guardians and default surrogate decisionmakers.

Incorporating a shared preferences and values approach into the practice and law of surrogate selection could both increase the frequency with which surrogates make the decisions patients want made and facilitate more context-appropriate treatment decisions. It is a simple antidote for the

Hawkins et al., *Micromanaging Death: Process Preferences, Values, and Goals in End-of-Life Medical Decision Making*, 45 *GERONTOLOGIST* 107, 110–11 (2005) (in a study of patients age 65 and over, finding that only 9% of patients thought that a surrogate should have no leeway to override patient wishes if they believed it was in the patient's best interest, and that over half thought that a surrogate should have "a lot" of leeway or "complete" leeway to do so). The Author suspects that patients might, however, be less willing to allow their surrogates leeway if they were aware of the extent to which surrogates ignore patients' wishes.

problem of incongruence, but perhaps a reminder that even complex problems may have simple remedies.

