

Ethical Issues in Surrogate Decision Making

Summary: This project attempts to identify ways to improve decision making for adults who are unable to make their own research or treatment decisions.

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Background: Informed consent is a vital protection in both the research and clinical care contexts. Insisting that individuals decide for themselves whether they enter research or receive medical care respects those who can make their own decisions, but poses a dilemma for incapacitated patients, such as adults with advanced Alzheimer disease. This dilemma is common. In the research setting, study of adults who are not able to consent is vital to improving research on a number of important conditions. In the treatment context, many adults patients, especially those at the end of life, are not able to make their own decisions. Approximately half of all decisions regarding life-sustaining treatment for nursing home residents and three-quarters of decisions for hospitalized patients with life-threatening illnesses involve incapacitated patients.

Current practice is to rely on a patient-appointed or next-of-kin surrogate to make treatment decisions for these vulnerable individuals. This practice is intended to promote at least 4 important goals: 1) treat individuals consistent with their preferences and values; 2) treat individuals in a way that promotes their clinical interests; 3) respect individuals' preferences regarding how decisions are made for them; and 4) protect the individual's family and loved ones. Although clinicians have been relying on surrogates for over 30 years to make decisions for incapacitated adults, there are few systematic data on the extent to which these 4 goals are promoted by current practice. The Department has thus focused on evaluating how well current practice promotes these goals and considering ways to better promote them.

I. Accuracy of Surrogates: A previous systematic review by the Department confirmed worries expressed by some commentators that surrogates' choices of which treatments patients should receive are often inconsistent with the patients' own treatment preferences (Shalowitz 2006). Research in social psychology suggests that this surrogate inaccuracy is just one example of a more general human inability to predict the preferences and values of loved ones. This research finds that we all are subject to psychological biases in close relationships that are extremely difficult to correct. These biases suggest that improvements in surrogate accuracy are unlikely, a conclusion which is supported by our data showing that the two most widely-discussed methods for improvement – appointing a surrogate, and discussing one's treatment preferences and values with this person – are ineffective.

Based on this work, we evaluated whether there are alternative approaches that might be more accurate than surrogates. This work revealed that a preliminary population based treatment indicator, one based on currently available data, predicts patients' preferences as accurately as surrogates. These data suggest that a refined treatment indicator, one which took into account additional data on individuals' treatment preferences, likely would predict incapacitated patients' preferences more accurately than surrogates.

II. Burden on Family: How incapacitated patients are treated can have a significant impact on their families. With this in mind, many commentators have argued that asking families to make decisions provides a way to help them during a difficult time. The assumption is that serving as the patient's surrogate will benefit families by allowing them to take into account the impact on them when making decisions, providing them an opportunity to be involved in the patient's care, and possibly allowing them to process their own experience. Despite these claims, there have been no systematic analyses of the actual impact that making treatment decisions has on surrogates. To address this gap in the empirical data, we conducted a systematic evaluation of published studies evaluating the impact making treatment decisions has on surrogates. This evaluation reveals that surrogates often experience anxiety and stress, depression and family conflict, as a result of making treatment decisions (Wendler, Rid. In press).

III. Process Preferences: Many commentators claim that patients want their family and loved ones to make treatment decisions for them. These data are based on a few studies which find that patients, when asked who should make treatment decisions for them, often name their family members. Yet, these studies have failed to evaluate *why* patients want their family members to make decisions for them in the event of incapacity. This limitation is important given data which show that patients often assume that family members can accurately predict their treatment preferences. Thus, patients' preference to have family and loved ones make treatment decisions for them may be based on the mistaken assumption that loved ones can identify the treatments the patient would want to receive. This analysis, together with the work by the Department showing that current reliance on surrogate decision makers often does not realize the goals of providing treatment consistent with preferences, nor the goal of helping the patient's families and loved ones, raises the need for research on ways to improve how we make decisions for incapacitated patients.

To evaluate how patients want decisions made for them, once they recognize the extent of surrogate inaccuracy, the Department developed and conducted one of the largest surveys on

patient preferences regarding surrogate decision making. This survey, which enrolled 1180 patients at George Washington Hospital and Clinics, recently completed enrollment and data are currently being entered and cleaned. This survey also was designed to evaluate patient attitudes toward using a patient preference predictor.

IV. Implementation: The NIH Clinical Center was one of the first research institutions in the country to adopt an explicit policy regarding research with cognitively impaired adults (MAS 87-4). Since adoption of the policy almost 20 years ago, there has been an evolution in thinking on this topic. In this light, the department, working with the Clinical Center's ethics committee and the NIMH Office of the Clinical Director, developed a revision of the NIH policy to reflect, in practice, the recommendations we have made in this area. Implementing this policy requires resolving a number of practical challenges and developing instruments and SOPs to address them. In particular, it is necessary to determine whether and when adults who cannot provide informed consent retain the ability to assign a surrogate to make research decisions for them, and to ensure that the assent and dissent of these individuals are respected.

Impact of Work: The Department's work on surrogate decision making has revealed that current practice often fails to achieve the most important goals for decision making for incapacitated adults. This work has led to recognition of the need for future research to identify ways to increase the extent to which incapacitated patients receive treatment consistent with their preferences and also to identify ways to reduce the burden on the patient's family and loved ones.

Future Research: The Department plans to continue its work on developing a better way to make treatment decisions for incapacitated patients. In particular, we will focus on ways to collect data to create a refined patient preference predictor. We also will pursue a number of projects related to surrogacy for research. We are currently working on a tool to assess dissent in incapacitated adults, and a framework for evaluating whether incapacitated adults retain the ability to assign a surrogate. These efforts will provide the practical tools that are needed to protect incapacitated adults, while allowing important and appropriate research on the diseases that affect them.

Publications:

Wendler D, Rid A. The impact on surrogates of making treatment decisions. *Annals of Internal Medicine*. In press.

Rid A, Wendler D. Can we improve decision-making for incapacitated patients? *Hastings Center Report* 2010; 40:36-45.

Varma S, Wendler D. Medical decision making for patients without surrogates. *Archives of Internal Medicine* 2007; 167:1711-1715.

Shalowitz D, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision-makers: a systematic review. *Archives of Internal Medicine* 2006; 166:493-497.

Shalowitz D, Garrett-Mayer E, Wendler D. How should we make treatment decisions for incapacitated patients, and why? *PLoS Medicine* 2007; 4:e35.