The privileging of the substituted judgment standard as the gold standard for surrogate decision making in law and bioethics has constrained the research agenda in end-of-life decision making. The empirical literature is inundated with a plethora of “Newlywed Game” designs, in which potential patients and potential surrogates respond to hypothetical scenarios to see how often they “get it right.” The preoccupation with determining the capacity of surrogates to accurately reproduce the judgments of another makes a number of assumptions that blind scholars to the variables central to understanding how surrogates actually make medical decisions on behalf of another. These assumptions include that patient preferences are knowable, surrogates have adequate and accurate information, time stands still, patients get the surrogates they want, patients want and surrogates utilize substituted judgment criteria, and surrogates are disinterested. This article examines these assumptions and considers the challenges of designing research that makes them problematic.

Key words: substituted judgment, surrogate decision making, research design

There are sometimes moments in an academic life when one’s scholarly agenda and personal biography unexpectedly, sometimes tragically, overlap. This collision opens a window into one’s research that had been previously opaque and affords an opportunity to see it with new eyes. It exposes what had been invisible and imposes an overlay of shades of gray over what had formerly appeared black and white. And so it was that, just as I was beginning an observational study of surrogate decision making at the end of life, I took up residence – quite unexpectedly – in a hospital where my father would spend his last days. This article, which was written when my father was healthy and vibrant, is now retold through the lens of a recent denizen of the world my research hopes to understand. It draws on what the scholarly literature tells us about surrogate decision making and is overlaid with preliminary observations from my research site and 3 weeks of experience as a research subject in a quite different setting.

My experience, however momentous it was to me, is not all that uncommon. Over the last century, advances in science, medicine, and public health have yielded dramatic changes, not only in the life expectancy of older adults, but also in the patterns, causes, and places of death. In some respects these changes “have made living easier and dying harder.” More effective treatments may significantly extend life but may also confront dying individuals, their families, and health care providers with a prolonged period of dying that involves complex choices about end-of-life care. … [T]he timing of an individual’s death has also changed. In 1992, it was estimated that 70% of the 6,000 deaths that occur daily in the United States are somehow timed or negotiated with family, doctors, and the dying person when competent, quietly agreeing to not use death-delaying technology.

But dying persons are not always able to “negotiate” their own deaths. Two studies found, for example, that of all decisions to withhold or withdraw life support in the medical-surgical intensive care units (ICUs) of two urban hospitals, only 3%–4% were made by the patients themselves; the other patients were not considered competent. Of course, patients who end up in an ICU may lack competence more often than those who face death

Susan P. Shapiro, PhD, is Senior Research Fellow, American Bar Foundation, Chicago, Illinois.

Top Stroke Rehabil 2007;14(4):80–92
© 2007 Thomas Land Publishers, Inc.
www.thomasland.com
doi: 10.1310/tsr1404-80
at home or in other settings. One does not have to do the math to recognize that the final days of an extraordinary proportion of patients’ lives are being choreographed by others. The most significant life-and-death decisions of our lives – literally – are being delegated to others.

Some of us plan for the possibility that we will lose the capacity to choreograph our lives or deaths. We write living wills,5–7 “Ulysses”8–10 pre-commitment contracts, or durable powers of attorney in which we (1) specify our values, preferences, and decision rules; (2) designate parties to carry them out and to exercise discretion on our behalf; and (3) delineate the conditions under which these documents go into effect or desist. We opt for contract over trust to protect our future interests.11–15

For the majority of us who fail to provide a contract or whose instructions are too vague or incomplete, legal statutes and court decisions seek to preserve our constitutional rights of autonomy and self-determination16,17 and to restore our voices when they have been otherwise silenced. Most jurisdictions in the United States specify who is to speak on the patients’ behalf when they have not named a surrogate18 and enunciate standards by which surrogates make decisions for the patients and evidentiary rules to guide their judgments.

In most states, the substituted judgment standard is considered the gold standard and given highest priority. It dictates that surrogate decision makers should choose as the patients would now choose, if they were competent and aware of all the relevant facts and circumstances, including the fact that they are incompetent. It is as if the patients were to miraculously awaken from their coma or attain lucidity for a few moments, knowing that they will soon lapse back into their former state.16 Surrogates must “don the mental mantle”19(p545) or stand in the patients’ shoes20 – taking into account the patients’ prior statements, actions, instructions, personal value system, character, goals, beliefs, attitudes, and lifestyle – to try replicate what the patients would have wanted.21,22 Where the patients’ preferences cannot be determined, legal doctrine instructs surrogates to adopt a best interest standard to advance the patients’ interests, promote their well-being, and choose, after weighing the benefits and burdens, a course of action with the greatest net benefit.7,20,23,24

The privileging of the substituted judgment standard in law and bioethics has inspired much of the research on surrogate decision making. The literature is inundated with scholarly versions of the Newlywed Game25,26 in which researchers test whether surrogates get decisions “right” and when they are most likely to do so. Most of these contests pose hypothetical medical scenarios to potential patients and their potential surrogates (and occasionally their physicians as well) to assess the correspondence in predicted treatment preferences.20,27–34 (Some studies even invite conversation on end-of-life issues between patient and surrogate before they complete the questionnaire – typically to no effect.) Other studies focus not on specific wishes or treatment preferences, but on general goals for care or preferences about the process by which patients want end-of-life decisions to be made.34 Without going into great detail, the results of several dozen studies suggest that some of the assumptions underlying the use of substituted judgment may be illusory. A recent meta-analysis of 16 of these studies (encompassing 151 scenarios and 2,595 patient/surrogate pairs) found an overall prediction accuracy of 68%, which varies somewhat by type of health problem or type of medical intervention offered in the scenario.35

Individual studies found substantial discrepancies between subjects and surrogates in their assessment of the subjects’ satisfaction and quality of life; they also found that spouses and children tend to underestimate the subjects’ functional status. Both these assessments are essential to the surrogate’s ability to make either substituted or best interest judgments. Indeed, in several studies, surrogates did no better than chance (and occasionally did worse). Nor did the surrogates named by subjects as their preferred decision maker (akin to a person appointed under a durable power of attorney) do any better than the others. Moreover, neither frequency of contact, similarity in age or gender, nor type of relationship affected the accuracy of their predictions.
Data collected by the SUPPORT study from thousands of “real” hospitalized patients, many of them critically ill, and their actual surrogates found much the same thing. Patients (if able) and surrogates were interviewed on multiple occasions throughout the course of hospitalization and after release/death and asked about care, prognosis, quality of life, treatment preferences, and decision making. As in the hypothetical studies, researchers compared patient and surrogate preferences (for those hospitalized patients who were competent and able to speak – a potentially biased sample, of course). They found a slightly higher level of agreement (74%) than in the hypothetical scenarios administered to healthy subjects. Again, researchers found differences in perceptions of quality of life between patients and their surrogates, for example, in their willingness to give up months of life in their current state of health for a shorter life in excellent health (what they call “time trade-off scores”). Many surrogates also got wrong patients’ willingness to live in a nursing home. Although they were reasonably accurate predicting those patients who indicated that they were unwilling to live in a nursing home, they correctly predicted only 37% of those patients willing to live in a nursing home. Among patients who indicated that they were very willing to live permanently in a nursing home, surrogates said that 14% would rather die.

Most of these studies conclude that the disparities between preferences and predictions cast doubt on the capacity of surrogates to reproduce substituted judgments. As one overview of the empirical evidence observed, “…the imaginative capacity required for accurate prediction of a patient’s wishes may be beyond most people.” Another concluded that surrogate decision making – “far from having scientific accuracy and objectivity – in most cases represents a complicated form of guesswork, suffused by the decision maker’s biases.”

But substituted judgment is much more than a parlor game. There are many reasons surrogates get the “wrong” answers, which illuminate the complex medical, normative, interpersonal, epistemological, and social–organizational context in which end-of-life decisions are made. The “Newlywed Game” model makes several problematic assumptions about that context.

Our Wishes Are Knowable

One reason surrogates guess wrong is that the subjects in these studies behave like the rest of us. Few of them had discussed life-sustaining interventions with their physicians or families, even those “at relatively high risk of terminal events.” Because the vast majority of the surrogates were confident that they knew the subjects’ preferences, they were probably even less likely to confer or check out the accuracy of their assumptions and understandings. Family members, socialized in the same cauldron of values and beliefs, may assume that they share the same worldview and confuse their values and preferences for those in whose shoes they now stand. Social psychologists label this phenomenon a false consensus effect, in which individuals – even strangers – tend to overestimate how much others agree with their judgments, values, positions, choices, or behaviors.

Even when surrogates separate their values from those for whom they substitute, they encounter many challenges in their quest to identify the other’s values. For one thing, they face a moving target. As Emanuel and Emanuel observe, “There are few, and conflicting data, to suggest that a patient’s preferences are durable and thus that views expressed at one point in time reflect the patient’s true wishes months or years in the future.” Our preferences – about spending or saving money, taking risk, our need for independence, our tolerance of limitations or impairment, what gives us pleasure, who we trust or love, what we value, our religiosity or faith, and so on – change, especially as we age, experience illness or disability, or approach death. Some may interpret these changes as consequences of impairment or of undue influence rather than legitimate shifts in our values and preferences and refuse to honor them. Indeed, we may ourselves fail to appreciate in advance how impairments that undermine our competence may simultaneously alter other judgments and preferences. Numerous studies
document the instability of patient preferences even over much shorter periods of time.6,7,42,48–52

Where does one look for substituted judgments when patients’ minds are literally changed?50 Who is the patient whose preferences must be replicated? When illness and injury to the brain transform or alter identity, whose autonomy/interests are to be honored—the person before the onset of disease or injury or the person after?50,53

Research demonstrates that patients and surrogates are very bad at predicting how they will feel about medical problems in the future.7 Research on affective forecasting54 has found that we overestimate the intensity and the duration of our emotional reactions—our “affect”—to future events. …On average, bad events prove less intense and more transient than…predicted. …People adapt to serious physical challenges far better and will be happier than they imagine. …This gap between what we predict and we ultimately experience [is known as] the “impact bias.”55

So, what are surrogates to make of the instructions of healthy individuals (e.g., that they wouldn’t want to live with a particular infirmity), if these statements are likely to be tainted by bias? How do surrogates temper their biases in affective forecasting? Should they?

Then, there is the matter of evidence. Even when surrogates struggle through the patients’ convoluted biographies to discern their true preferences, it is unlikely that these ruminations will satisfy the letter of the law. It does not take a world-class methodologist to suspect that it will be difficult to secure valid measures of substituted judgments, let alone the “clear and convincing” evidence of what the patients would have wanted, which is required by courts in some jurisdictions to terminate life support.56 Some of us leave rather vague legacies of ambivalence, empty or imprecise words, mixed, ambiguous, or contradictory messages, and silences that can be interpreted in disparate ways by different interpreters with unique relationships and histories with us and with different interests. How certain must surrogates be? How conservative should they be when the data they have amassed are somewhat thin? Except where the most abundant, direct, specific, consistent, compelling, triangulated, and unwavering evidence is available, we are asking others to choose among various versions of ourselves or among different selves,53 to reconstruct an identity from ambiguous and fragmentary pieces, to decide whether the priorities and values we treasured as young and middle-aged adults trump those we have expressed in the last year or maybe only the last few weeks.

Indeed, we are asking others to do what our competent selves may be incapable of doing.6 Is it even possible for us to know how we would decide before we face the situation and experience the many changes that lead up to it?7,57,58 If we cannot make a substituted judgment for our future selves, how can we expect someone else to make it on even more slender evidence?

**Surrogates Have Adequate, Accurate Information**

There is no clear correspondence between values and specific choices; even if surrogates can perfectly reproduce the patients’ values, the appropriate decision does not automatically follow. (A surrogate may know that he or she should pull the plug, but not know when.) The beauty of hypothetical scenarios is that researchers control the fact pattern to which subjects respond. The experimental design may vary how the information is framed, the level of specificity, the degree of certainty, and so forth, but subjects are given a fact pattern about which to formulate a treatment preference. Their counterparts in the real world have far less to go on. They may receive little or no information at all from physicians when the latter do not need them to consent to a procedure. Surrogates may find that they must take the initiative, sometimes aggressively, to learn enough to exercise their responsibilities.

Prognostic information about functional status as well as survival can be especially hard to come by.59,60 The literature documents the difficulty of generating accurate prognostic information, the cognitive barriers physicians face when applying generic scientific models to unique individuals, and the reluctance of physicians to share prognoses with their patients or those who act on their behalf.61 Out of fear of being wrong, they may offer nothing at all.60 And, even when offered, such information is tainted by physicians’ consistent
over-optimism and by the “incommensurability of medical and lay knowledge [that] prohibits clear communication and may prohibit shared decision making.”

A dearth of information is only part of the problem. An abundance of conflicting, inconsistent information is another. In the hypothetical scenarios, incontrovertible facts just appear, seemingly from a single source, a rarity in 21st century health care. The social organization of the delivery of medical care plays a significant and largely invisible role in surrogate decision making. When a patient has a long-standing disease that is being managed by a trusted physician, information, when forthcoming, is delivered in one voice. When the patient enters the hospital, especially with a new ailment, the voices multiply dramatically as different shifts of unfamiliar physicians, nurses, technicians, and therapists rotate in and out of the room. In a teaching hospital, the choir becomes even louder. If the patient is treated with multidisciplinary specialists, an unorchestrated babel of voices intensifies the din. Physicians representing many disciplines may disagree about diagnosis and prognosis and about treatment options and their risks and benefits, but individuals within a given discipline or specialty may also disagree. Surrogates may be bombarded by the inconsistent prognostications of these specialists who parade past the bedside, even as these specialists sometimes fail to share their insights with their colleagues in other disciplines. Indeed, there may be no one at the bedside who has the “big picture,” whether or not it is being shared with the surrogate. Some organizational arrangements may integrate, translate, quiet, or manage the babel better than others, but surrogates are hard pressed to formulate substituted judgments when they have little reliable data about which to judge.

**Time Stands Still**

The hypothetical scenarios offer surrogates a snapshot in which time stands still. Surrogates assess a static fact pattern and treatment option and say aye or nay. As the previous discussion suggests, real-world decision making is a dynamic process. Rarely are surrogates given only one opportunity to make a particular decision, and their views may understandably change over time. The same decision may be revisited many times. What may be most important in understanding surrogate decision making is not how surrogates process facts or values but simply observing the rhythms of illness, treatment, and organizational routines and how surrogates respond to them and the passage of time.

Because diagnostic and prognostic information sometimes comes in fits and starts and may be incomplete, inconsistent, or equivocal or some messengers may be more certain than others, surrogates may need time to assimilate and process the information or come to an understanding of what the future likely holds, given an array of treatment options and potential risks and benefits. While surrogates await information from health care providers, they may also be monitoring the patient themselves (fashioning lay neurological exams, for example) and making their own diagnostic and prognostic determinations. One ICU family recently rescinded a DNR order after the patient blinked; another refused to believe the patient was brain dead because they saw a tear roll down her cheek.

Decisions may be postponed while surrogates await further tests for more conclusive information, to see whether an ailment resolves, to give a particular therapy a try, or to assess an evolving situation (potential new metastases, diminution of spinal chord swelling, etc.). They may be postponed while surrogates await prognostic benchmarks. Some decisions will change after the surrogate sees firsthand what a particular procedure entails (e.g., a full code after cardiac arrest). Sometimes decisions will change when the surrogate hits certain medical (the need for a tracheostomy) or bureaucratic (e.g., insurance rules require that the patient be moved to another facility) deadlines that demand a response or force the patient down a new and unwelcome pathway.

Sometimes delay is for the benefit of others. Over the course of treatment, the patient’s medical condition and mental status may improve or deteriorate, wax and wane. Some surrogates will postpone a decision in the hope that the patient’s mental status will improve to the point that he or she is competent to make medical decisions. Others postpone a decision while they try to get every-
one in the family on the same page or in the hope that they can secure the assent of a recalcitrant, uncertain, or missing significant other. Sometimes the surrogate’s mind will change after ongoing reflections and conversations with members of the patient’s social network clarify the patient’s wishes and values. And sometimes the surrogate simply requires time to be certain about what may turn out to be an irreversible decision.

Reversibility poses a significant constraint. Although some decisions can be revised repeatedly, surrogates sometimes have a very small window of opportunity to terminate or refuse what may, in hindsight, turn out to be futile care. In the very early stages of a traumatic injury, when prognosis is still very uncertain, a surrogate may have the opportunity to withhold treatment (e.g., surgical intervention, resuscitation, a ventilator or feeding tube) necessary to sustain life. Later in the course of treatment, when the patient is stable and the prognosis known, there may no longer be life-sustaining treatments that can be withheld or withdrawn, if the surrogate then seeks to end the patient’s life. So early on, the surrogate sometimes faces the impossible choice of ending a life that may turn out to be worth living or waiting to see and then having no recourse if the prognosis is grim.

These observations assume that surrogates are actively engaged in making medical decisions and can control their timing. In reality, the timing of many treatment decisions is orchestrated by the caregivers. In some instances, choice is but an illusion. Drought and Koenig note, for example, that “[e]ven though the providers actively voiced support for patient involvement in treatment decisions, they offered true choice only when highly limited options shaped by dire biologic imperatives left little at stake.” Russ and Kaufman observe that “…‘choices’ that families are asked to make about a patient’s dying are most often presented at precisely the time that death has become inevitable, and choice is meaningless.”

We Get the Surrogates We Want

A recent survey found that patients do not always get the surrogates they want when they do not name them in advance. A third of married patients in the survey indicated that they wanted a surrogate other than their spouse (the default decision maker in most jurisdictions). A quarter preferred a surrogate other than the emergency contact person on file in their physician’s office. Although legal default rules are indifferent to gender, most patients preferred their mothers, daughters, and sisters over their fathers, sons, and brothers, respectively. Another study found that patients believed that their children understood their wishes better than their spouses.

The legal default rules assume rather conventional nuclear families. Patients arrive in many alternative configurations, however. They bring common-law spouses, committed partners, and intimate friends; stepchildren and illegitimate children; and estranged spouses, parents, and siblings. For some, the legal configuration of intimacy and entitlement does not correspond to that in their family, where grandparents, aunts, nieces, or neighbors have stronger ties than spouses, parents, children, or siblings. Others arrive with injuries (e.g., falls, assaults, gun-shot wounds) for which their presumptive surrogates are potentially responsible. Some surrogates may be of questionable competence, because of illness or substance abuse. Some patients have medical secrets they have struggled for years to keep from their families who now, as the default surrogates, are entitled to unearth.

Even when patients name their surrogates in advance or the default rules or procedures empower the person they would have chosen as their surrogate, had they bothered to do so, decisions in the real world are not always so simple. Both legal rules and most research protocols look to a single party as the surrogate decision maker. This assumption may work reasonably well when the surrogate is a spouse, but the other tiers in the priority hierarchy tend to be populated by more than one candidate, many of whom are unwilling to defer to another. They may jockey for primacy or make decisions collectively. In other instances, the uncontested official surrogate is silent, deferring to another or other members of the patient’s social network. Sometimes the role of surrogate is passed around as family members and others take turns maintaining a vigil at the hospital; whoever is there or has the cell phone gets to decide.
the course of medical care is protracted, some potential surrogates will drop out along the way and others will appear in the eleventh hour. Certainly the group dynamic of the social network in which one or more surrogates are members will shift over time. Despite the legal and methodological fiction and even the preferences of some patients, surrogate decision making is often an oscillating collective enterprise.

Surrogates Should Try to Reproduce Our Wishes

The hypothetical scenarios ask surrogates to predict patient preferences. In the real world, that is not what some surrogates attempt to do or, apparently, what some patients want them to do. Real-world surrogates, few of whom have even heard of legal standards like substituted judgment or best interests, undoubtedly use many criteria not always found in legal statutes or court opinions. Some follow or give assent to recommendations/decisions of the medical staff. Some project their values onto those of the patient, choosing what they would want for themselves under the circumstances. Some seek to end pain and suffering. Others leave the decision to God or cite their religious values as central to the decisions they make. Some fear loss or are unable to let go of a life partner they cannot bear to live without. Others consider the impact of the decision on their family, giving priority to what is best for the family. Some are undoubtedly influenced by financial considerations, the burdens of caretaking, guilt, or the demands of ongoing litigation (that often provides more compensation for live plaintiffs than dead ones).

Certainly, some surrogates are nudged away from their instincts or evolving decisions by physicians, nurses, or ethics consultants who instruct them that they are to decide as the patient would decide. The mantra, “It’s not what you want; it’s what the patient would want,” echoes occasionally though the hospital. But many surrogates are given no guidance or feedback regarding criteria for decision making, and others reject the advice they receive.

After all this angst that emerges from trying to reproduce the patients’ wishes, it turns out that many patients do not care if their surrogates do so or even prefer that they do not. A diverse collection of studies has found that, when asked, a substantial number of patients indicate that they feel the wishes of their surrogates ought to trump their own. In the SUPPORT study of critically ill hospitalized patients, described earlier, 78% of the patients indicated that, if they were to lose decision-making capacity, they preferred that their family and physician make resuscitation decisions rather than follow the patients’ previously stated preferences. Two other studies found that slightly less than or slightly more than half of respondents felt that their surrogates should have “a lot” or “complete” leeway to override their advanced directives; a third study found that more than half of the respondents wanted the preferences of their surrogates to apply, even when the surrogates had expressed preferences that were the opposite of their own.

In short, just because some surrogates are able to accurately reproduce patient preferences, that does not mean that those preferences direct end-of-life decision making. The results of the “Newlywed Game” contests – even if the correlations had been much higher – may be largely beside the point. If some surrogates embrace decision-making criteria other than substituted judgment and/or if some patients prefer that they do, the responses to hypothetical scenarios tell us little empirically or normatively about how end-of-life decisions are formulated in the real world. The question is when is this true and for what kind of people?

Surrogates Put Our Interests First

As if donning the mental mantle or formulating the best interests of another is not formidable enough, surrogates must proceed encumbered by weighty baggage imposed by conflicts of interest. Perhaps the greatest irony of fiduciary or trust relationships (of which serving as a surrogate is an instance) is that the most able and desirable trustees – who offer familiarity and intimacy, caring and commitment, esoteric knowledge, inside information, expertise, hands-on experience, and political, financial, and social capital – are also
least likely to be disinterested. In other words, they may not put the patients’ interests ahead of their own.

Surrogates often have the most to gain or lose by discretionary decisions they make on the patients’ behalf. This tug of war is most palpable when family members serve as surrogates. The compelling case for entrusting them with this profound responsibility, especially with making substituted judgments, reverberates from Presidential Commissions to court opinions to empirical data. Rhoden summarizes the argument:

Not only are family members most likely to be privy to any relevant statements that patients have made on the topics of treatment or its termination, but they also have longstanding knowledge of the patient’s character traits. Although evidence of character traits may seem inconclusive to third parties, closely related persons may, quite legitimately, “just know” what the patient would want in a way that transcends purely logical evidence. Longstanding knowledge, love, and intimacy make family members the best candidates for implementing the patient’s probable wishes and upholding her values.

... The family is the context within which a person first develops her powers of autonomous choice, and the values she brings to these choices spring from, and are intertwined with, the family’s values. A parent may understand a child’s values because she helped to form them, a child may grasp a parent’s values because the parent imparted them to her, and a couple may have developed and refined their views in tandem. ...[I]t makes sense, when trying to identify the choice the patient would make if she could, to defer to the family as one of the groups from which the patient’s former power to make rational choices arose. 75,76

These virtues also make it difficult for family members, however well meaning, to distinguish or separate their interests from the patients’ interests. In the literature, there is a litany of reasons why loved ones may defy patients’ interests in decisions to let them “die with dignity” – because they suffer as the patients do (perhaps even more so if the latter are comatose or unaware of their mental incapacity or degrading treatment) or because of the extraordinary emotional burden, disruption in their lives, and caretaking responsibilities that have been imposed on them, all of which may be relieved by the patients’ death. Some may even defy the patients’ interests out of anger or because they dislike them. Other relatives may insist on aggressive, heroic, or futile treatments to keep the patients alive – which the latter would not have wanted – out of guilt, fear of being responsible for death, fear of loss and concomitant feelings of attachment or love, their “own fear of dying, or a religious view that life must be prolonged at all cost, or even a perverse satisfaction in seeing [the patients] suffer.” 72 And, of course, financial interests frequently roil family systems. Expensive custodial and medical care may be imposing substantial financial burdens on the patients’ loved ones. Decisions on the patients’ behalf may drain or deplete the inheritances surrogates expect to receive, 73 bequests to which they may feel especially entitled as compensation for all of this wrenching surrogacy.

This is not to say that surrogates intentionally put their interests first or are even mindful of this tension between their interests and those of the patients. It is simply to say that conflict of interest is inherent in surrogacy, as in all other fiduciary relationships, and it adds one more reason why those who speak on the patients’ behalf may fail to provide accurate substituted judgments of their wishes. 75,76

Methodological Problems

I have saved the most obvious critique for last. Dispassionate paper-and-pencil answers to hypothetical questions
• without life-and-death consequences (or indeed any consequences at all),
• stripped of social context
• and the extended families and friends who interact with or influence surrogates,
• reported over the course of a few minutes
• by largely healthy, young respondents
• who may never actually have a surrogacy relationship with one another,
• about unambiguous medical scenarios
• few of them have ever faced
provide a limited understanding of how surrogate decision making actually occurs. Some of these studies are more realistic than others, especially those that focus on hospitalized and elderly patients and their actual surrogates in the midst of
real health crises, but all fall short in simulating the conditions under which medical decisions are actually made. Moreover, because most of these studies examine outcome rather than process, the data, even if meaningful, tell us what decisions would-be surrogates might make not how and why they made these decisions.

Existing scholarship has utilized alternative research strategies that examine the participants and settings in which surrogate decision making takes place and that better interrogate the assumptions inherent in the hypothetical substituted judgment scenario studies. They include interviews, retrospective interviews, and observation – either directly or from audiotaped family conferences.

Variations on these research strategies can explore how surrogates understand their role and what criteria they actually use to make their decisions. Moreover, they can examine the impact of self-interest or other commitments and constraints facing surrogates on their decisions. For those surrogates who seem to be making substituted judgments, these methods can discover how surrogates try to know or determine the patients’ preferences, the memories they invoke, and the evidence they find compelling. These methods are dynamic; they can explore how the passage of time, the course of the disease and its treatment, even the impact of previous decisions affect subsequent ones. Similarly, they can make problematic the network and organizational context in which surrogates are situated and examine the impact of family, friends, health care personnel, and others on how surrogates exercise their role.

These methodologies have limitations, of course. They face considerable logistical challenges. On the one hand, surrogates may be in shock, overwhelmed, distraught, and experiencing considerable stress and disruption of their lives and other responsibilities; at the very least, to elicit their participation in a research protocol will be burdensome for many surrogates. On the other hand, medical decisions unfold 24/7, and behavior may occur at any time or place, often without notice. It is difficult to predict when and where surrogates will be available for interviews or where conversations will occur that warrant observation. Conversations may sometimes occur “out of range” – in the car driving home, on the telephone, in bed – where observers are denied access. This research is of necessity very labor intensive and therefore likely to yield rather small samples.

As a result of these logistical challenges, these studies also face significant nonresponse and selection bias. Those surrogates on site or willing to be observed or interviewed are unlike those who are not. For all of the reasons that hospital routines are not socially organized randomly, access is problematic, some surrogates are always around and others communicate only by phone (if at all), and surrogates (and physicians) are differentially willing to participate in the research, the data gathered are likely to represent some kinds of illnesses or injuries, demographics, characteristics of surrogate decision makers, and kinds of decisions more than others.

Because interview and survey methods usually interrogate one respondent at a time, they provide a limited window on what is frequently a collective process in which various family members, friends, and associates interact with an assortment of medical personnel. Although interviewers can certainly ask individual respondents how parties jockeyed for position, who was influential, what impact physicians and their framing of information had on how decisions were made, and so forth, individual informants may not be the most accurate reporters of the social dynamics that swirled around them.

Surrogates may not be the most objective dispassionate reporters of their experience; this problem is even more likely when interviewees are describing events that are often surrounded by guilt, fear, ambivalence, conflict, self-interest, and betrayal. Surrogates’ stories may change to impress or elicit the approval or sympathy of the interviewer or to tell him or her what respondents think the interviewer wants to hear.

More significant, both interview and observational methods are vulnerable to problems of reactivity – the act of asking questions or observing behaviors may affect or alter the behaviors. The very act of asking surrogates what they are thinking might change that thinking. Especially if interviews occur repeatedly over the course of treat-
Surrogate Decision Making

ment or a hospital stay, the questions that the researcher asks—no matter how carefully chosen and articulated—or the memories they evoke may guide, sensitize, or influence decision makers, spark a conversation with family members or physicians they would not otherwise have had, or in some other way provoke surrogates to take a different path than they were following prior to the interview. Observational methods are potentially reactive as well, as subjects are influenced by the presence of the observers, try to impress them or say or do what they think the observers want to hear or see, or censor their behavior.

Retrospectively interviewing surrogates and other participants minimizes the risk of reactivity and avoids burdening respondents with interviews solicited in the throes of medical crisis or tragedy. But there is also a unique danger. Retrospective interviews will necessarily unearth a different version of events than contemporaneous ones. Studies using this methodology show how surrogates “manipulate,” “reconcile,” “alter,” “optimize,” “sacrifice,” and rationalize their memories. Retrospective accounts of the decision-making process are created, edited, and rewritten to make sense of the experience for the respondents themselves, to reconcile their grief, to regain control of their lives, to allay their guilt, or to please or escape the accusations of family members.

These methods are imperfect but can be refined with triangulated data and sensitivity to the sources of bias and creative strategies to compensate for them. Although the challenges are considerable, there is no other way to come to understand this rite of passage that most of us will experience as we near the ends of our lives and of those we love or for whom we have responsibility.

I never played the substituted judgment parlor game with my father, though I am virtually certain that I would have gotten a perfect score. And yet I am still haunted that we did the wrong thing. Perhaps some day our research will explain why.

Acknowledgments

This project received support from the American Bar Foundation.

REFERENCES

5. For excellent critiques of the difficulties of living wills and other forms of advanced directives, see refs. 6 and 7.
8. Inspired by Homer’s tale of Ulysses, who asked his crew to bind him to the mast of his ship (and bind him even tighter if he pleaded for release) as it passed the island of the Sirens, so that he would not be lured to his death. So-called “Ulysses contracts” have been proposed as a way for the “present self” to control the “future self.” For example, individuals with recurrent mental disorders may execute an irrevocable contract when they are in remission that binds them for specific treatment or institutionalization when they suffer a relapse, even if their relapsed self adamantly refuses such treatment. See ref. 9.
11. The contractual approach, especially favored among economists, is captured in a literature on “multiple selves.” See refs. 12 and 13.
14. In a book about aging, for example, Richard Posner [see ref. 15] writes variously about “two or more persons ‘time-sharing’ the same identity” or body, about “continuous” vs. “punctuated” selfhood, or
about a “master self” integrating or “bargaining among the successive selves.” For many economists, the dilemma is how various chronological selves with incompatible interests protect those interests from those of other selves — for example, how to get young selves to save money or engage in healthy lifestyles for the benefit of older selves, or how younger competent selves try to ensure that their preferences about how they want to be treated if they suffer dementia or life-threatening illness will be honored, even if incompatible with those of their demented or even predemented selves. Strategies of precommitment — of which Ulysses contracts are an example — provide a solution, at least in theory.

18. Illinois surrogacy statutes, which are fairly typical of those of many states, specify a priority order for choosing surrogates that begins with the patient’s guardian of the estate. Some states do not specify a priority order and anyone willing may serve. When no one is available to serve as a surrogate, the courts will appoint a guardian (or conservator in some jurisdictions). See ref. 22, sec. 25.
21. For example, Illinois statute dictates: “A surrogate decision maker shall make decisions for the adult patient conforming as closely as possible to what the patient would have done or intended under the circumstances, taking into account evidence that includes, but is not limited to, the patient’s personal, philosophical, religious and moral beliefs and ethical values relative to the purpose of life, sickness, medical procedures, suffering, and death. Where possible, the surrogate shall determine how the patient would have weighed the burdens and benefits of initiating or continuing life-sustaining treatment against the burdens and benefits of that treatment.” See ref. 22, sec. 20.
23. Some surrogates embrace a “reasonable person” standard to identify our best interests, choosing what they believe most people would choose for themselves. Others advocate the use of “community-based” standards [see ref. 20]. On a variation on this theme, one legal scholar suggests a “constructive preference” approach when surrogates cannot ascertain our preferences. Data would be collected on “widespread preferences of competent people” and, where there is strong consensus, would serve as a default rule (except for those of us whose personal values and preferences deviate from prevailing norms) [see ref. 24, p. 1220]. Other academics propose formulating an algorithm or actuarial or mathematical model that predicts what a patient would want, based on ethnic or cultural background, religion, religiosity, and so forth [see ref. 7].
25. “The Newlywed Game was an American television game show where newly-married couples answered questions to find out how well the husband and wife knew each other. …[T]he show became famous for some of the arguments that couples had over incorrect answers and even led to some divorces” [see ref. 26].
36. These data come from the Study to Understand Prognoses and Preferences for Outcomes and Risks
of Treatments [SUPPORT] and the Hospitalized Elderly Longitudinal Project [HELP], studies of more than 9000 critically-ill patients with a projected 6-month mortality rate of 50%, hospitalized across five teaching hospitals (SUPPORT) or 1176 patients, 80 years old or older, regardless of prognosis, who were hospitalized at one of four teaching hospitals (HELP) and/or their surrogates. As of 2005, there had been 183 articles published that presented primary or secondary analysis of the SUPPORT or HELP data. For a description of the method, see ref. 37. For an overview of the findings, see ref. 38. For a critical review of the impact of the study, see the articles in ref. 39, a special issue of the Hastings Center Report.


40. Surrogates tend to underestimate patients’ satisfaction with their current state of health and therefore express greater willingness than the patients to give up months of life in the patients’ current state of health for a shorter life in excellent health [see ref. 41].


46. Fagerlin and Schneider cite a memoir in which the writer observes that he “quickly learned [that] cancer, even more than polio, has a disarming way of bargaining downward, beginning with your whole estate and then letting you keep the game warden’s cottage or badminton court; and by the time it has tried to frighten you to death and threatened to take away your very existence, you’d be amazed at how little you’re willing to settle for” [see ref. 6, p. 34].

47. As Buchanan and Brock observed, “...the active forty-year-old professor who relishes enjoyments requiring complex cognitive and social skills may be unable to appreciate adequately the less sophisticated pleasures and enjoyment that would constitute his or her well-being were he or she to suffer serious loss of some higher brain function due to stroke or other illness” [see ref. 16, p. 106].


52. One study of mentally competent terminal cancer patients admitted to palliative care found, for example, that, in the last few weeks of their lives, their own assessment of their will to live varied widely. Although average changes in their will to live were quite small, the maximum change over a 12-hour period fluctuated 33%; over a week, nearly 50%; and over a 30-day period, 68% [see ref. 48]. The SUPPORT study found that between the time of hospitalization and 2 months after hospitalization, 15% of patients initially preferring CPR and 31% of patients initially refusing CPR had reversed their preference [see ref. 42].


56. In constructing and evaluating substituted judgments, one might ask how many different sources of evidence are available; how reliable is the evidence; how consistent is it; how specific was our statement or reference; how unequivocal was it; in what context was it made; to whom was it made; was it a statement made about ourselves or about someone else; how casual or off-handed was it; how sincere was it; are there reasons to doubt or believe the statement; how frequently did we make it and over what period of time; how recently did we make it; have our views changed over time; are our statements consistent with our behavior; how directly does the evidence bear on the decision to be made on our behalf; how great is the inferential leap; do most of our significant others make the same inference about the evidence?


58. Ditto et al. argue that “people will often mispredict their future wishes because they (a) have inaccurate beliefs about life-sustaining medical treatments, (b) fail to appreciate how their current physical and emotional state affects their predictions about future states, (c) under-appreciate how well they will
cope with serious illness, and (d) weigh certain aspects of information differently when making decisions about immediate and more distant futures" [see ref. 7, pp. 493–494].


62. For example, recently a surrogate in my field research rescinded a DNR order so that the patient could be emergently intubated, then reinstated the DNR order a day later, with the concurrence of the now-competent patient, after she was extubated. (She died a few days later, though not of cardiac arrest or respiratory failure.)


65. One study found that a higher proportion of patients expect their surrogates to decide alone than their corresponding surrogates felt appropriate [see ref. 34].


73. Friedman and Savage, who examined conservatorship files in California, expressed their suspicion that some conservators “tended to act as if the money belonged to them. After all, they are often the heirs of the ward; they are waiting in the wings and see no harm in treating the money as if it were already theirs” [see ref. 74, p. 285].


75. Note that some bioethicists will reject the notion of conflict of interest as an appropriate lens through which to view surrogate decision-making [see ref. 76]. They argue that, within families, interests are profoundly intertwined and not in opposition in the way contemplated by the notion of disinterestedness. Indeed, they will point to the fact that many patients express that their highest priority is that they not be a burden on their families [see ref. 34]. But, again, some patients feel that way and others clearly do not.


