

RUNNINGHEAD: Imagining the End of Life

Imagining the End of Life:
On the Psychology of Advance Medical Decision Making

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Abstract

Near the end of life, individuals often become too sick to express their wishes about the use of life-sustaining medical treatment. Instructional advance directives (i.e., livings wills) are widely advocated as a solution to this problem based on the assumption that healthy people can predict the types of medical treatment they will want to receive if they become seriously ill. In this paper, we review a large body of research from the psychological and medical literatures that challenges this assumption. This research demonstrates that across a wide variety of decision contexts people show limited ability to predict their affective and behavioral reactions to future situations. We outline several ways that policy and law regarding the use of advance directives could be informed by this research, and suggest a number of issues involved in advance medical decision making that could benefit from additional empirical and conceptual attention.

Keywords: Advance directives, medical decision making, predictive accuracy, affective forecasting

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In the spring of 2005, the decision about whether or not to discontinue life-sustaining treatment for a young Florida woman named Terri Schiavo became the focus of worldwide media attention. Characteristically, the energy that politicians, interest groups, and the major news organizations directed toward this event was intense, but late in coming and relatively short-lived. In contrast, the decision process faced by Terri Schiavo's family had been agonizingly long, drawn out over a period of 15 years and almost as many court decisions, all with the goal of determining whether or not this now 41 year old woman, immobile and uncommunicative since heart failure severely damaged her brain at the age of 26, should be disconnected from the food and fluids maintaining her life. Unfortunately, Terri Schiavo left no written record of her wishes, and the two factions of her family vehemently disagreed about what those wishes might be. In one form or another, the refrain was heard again and again in the media commentary on the case, "If only Terri had made her wishes known while she was still healthy, this whole tragedy could have been avoided."

Terri Schiavo died on March 31, 2005, 13 days, several frantic court appeals, and one Act of Congress after her feeding and fluid tubes had been ordered disconnected (for the third time) by a Florida trial judge. Her death did little to resolve the thorny ethical issues surrounding end-of-life medical care, and even less to quell the acrimony and mutual contempt felt by the opposing sides of this media-supercharged family feud. One tangible legacy of the case, however, has been a dramatic increase in the American public's interest in living wills and other forms of advance medical decision making. Completion of advance directives (i.e., documents like living wills that specify how decisions about the use life-sustaining medical treatment should be made

if an individual becomes too ill to speak for him or herself) has been vigorously advocated by a number of private and public organizations for more than a decade, to little effect. It was estimated that prior to the wave of publicity surrounding the Schiavo case, fewer than 25 percent of American adults had completed any form of advance directive (Eiser & Weiss, 2001). A recent report in the New York Times, however, stated that in the three months after Schiavo's death, Aging with Dignity, a national nonprofit group located in Florida, received requests for more than 800,000 copies of its advance directive form—60 times the normal request rate (Schwartz & Estrin, 2005). Whether this interest will be as fleeting as the media's infatuation with the Schiavo case is hard to know. But at least in the short term, it seems clear that the confusion, conflict, and controversy surrounding Terri Schiavo's final days of life spurred many people to try to avoid her sad fate by making decisions now, while they are still healthy, about the types of medical treatment they would like to receive--or not receive--should they become seriously ill at some time in the future.

The intuitive arguments for advance directives are compelling, and from this perspective they seem an ideal solution to the dilemma of making medical decisions for individuals incapacitated by injury or illness. In this paper however, we challenge this intuition by examining the psychological underpinnings of advance medical decision making. That is, the question we address in this paper is not whether there are persuasive legal or ethical reasons for people to record their wishes about the use of life-sustaining medical treatment in advance of serious illness--there surely are--but rather whether people are *psychologically* capable of foretelling what those wishes might be. People's ability to predict their future preferences, feelings and behavior has become an issue of intense interest in both the medical and psychological literatures

over the last several years, and this research suggests that anticipating the nature of one's reactions to future events is not nearly as simple a task as it may at first seem.

We begin this paper with a brief overview of the practical, legal, and ethical arguments for the use of advance directives in end-of-life medical decision making. We then review three bodies of research bearing on a key psychological assumption implicit in these arguments, that people have the ability to predict accurately their desire for future medical treatment. Finally, we conclude the paper by revisiting the case for advance directives in light of the empirical data. We will outline several ways that policy and law regarding the use of advance directives could be informed by basic research on judgment and decision making, and suggest a number of issues that could benefit from additional empirical and conceptual attention.

Self-Determination and the Logic of Living Wills

The ethical argument for advance directives flows from a belief in the priority of *self-determination* as the guiding principle in medical decision making. The right of individuals to control the important outcomes in their lives, especially regarding their bodily integrity, is well founded in U.S. law (*Cruzan v. Director, Missouri Department of Health*, 1990; Dresser, 2003; President's Commission, 1983). Not only is this right generally acknowledged as giving competent patients the freedom to refuse any form of medical treatment (even if that treatment is necessary to sustain their life), but it is equally well accepted that the right to self-determination extends to formerly competent individuals who lose decision making capability due to illness or injury (Dresser, 2003).

But how can incompetent people make decisions for themselves? How can someone like Terri Schiavo, trapped in a vegetative state for more than a decade, exercise her right to determine her own medical care?

A solution to this problem, elegant in its simplicity, was first suggested by attorney Luis Kutner in 1969. Because individuals are often too sick to make decisions for themselves near the end of life, Kutner suggested that people record their preferences for the use of life-sustaining medical treatment *before* they get sick in what he dubbed a “living will.” That is, just as people maintain control over the dispersal of their material wealth after their death with an estate will, a living will can allow people to maintain control over their medical care after illness or injury has caused them to lose their ability to express their wishes for themselves.

Living wills are now more generically referred to as *instructional advance directives*, and distinguished from *proxy advance directives* which do not provide instructions about the type of treatment an individual would want to receive, but simply identify an individual to make decisions on the patient’s behalf. By any name, however, Kutner’s basic insight has achieved wide acceptance in American medicine. Instructional advance directives are advocated by virtually every relevant organization (e.g., American Medical Association, the American Association of Retired Persons, the National Cancer Institute). Legislation supporting advance directives (instructional, proxy, or both) has been passed in all 50 states and the District of Columbia and these state laws are reinforced at the federal level by the Patient Self-Determination Act (1990) which stipulates that all hospitals receiving Medicaid or Medicare reimbursement must ascertain whether patients have or wish to have an advance directive.

Unfortunately, the enthusiastic acceptance of living wills by the medical, legal, and lay communities belies the fact that policy and law encouraging their use rests on a number of psychological assumptions of questionable validity (Ditto et al., 2001; 2003; Ditto & Hawkins, 2005). Most fundamentally, reliance on treatment preferences to guide medical decisions in the case of serious illness, assumes that healthy individuals can predict accurately whether they

would want to receive or forego various life-sustaining treatments if they were to actually experience serious illness.

But what if people lack this kind of insight into their future treatment preferences? What if healthy people cannot anticipate how they will respond to serious illness? In short, what if the wishes stated in a living will are wrong?

At first blush, this may seem an odd proposition. Wishes stated in living wills are generally characterized as *preferences*, which because they are personal, subjective, and affective in nature are usually considered “correct” virtually by definition (Zajonc, 1980). How can someone be wrong about what they want?

In fact, however, wishes stated in living wills are not simple preferences, but rather *predictions of future preferences*. That is, living wills do not state the kind of medical treatments people want now, in their current state of relatively good health, but rather the treatments that people will want in the *future*, if they should happen to experience a situation fundamentally different from their current circumstances (i.e., serious, debilitating illness or injury). From this perspective, it seems quite reasonable to ask whether people are capable of this kind of prediction task, and thus whether the wishes stated in a living will are likely to be correct in their representation of an individual’s true end-of-life medical wishes.

Research on Prospective Insight

Both the initial groundswell of enthusiasm for living wills, and the recent resurgence of interest in the wake of the Terri Schiavo case, are based on the powerful intuition that we are accurate predictors of our future preferences and, thus, the best way to have our medical wishes honored near the end of life is to make those decisions in advance. Unfortunately, the ideal study to address this issue--a prospective study in which preferences stated by healthy individuals are

compared to those of the same individuals when incapacitated--is impossible. In the sections that follow, however, we review evidence from three different research literatures that raise significant doubts about people's ability to predict their future wishes for life-sustaining medical treatment.

Illness Experience and Health State Evaluations

The first literature to raise doubts about people's ability to anticipate their reactions to serious illness is that on the measurement of health state utilities. The use of formal decision analytic techniques to improve clinical decision making or perform economic comparisons of alternative health care programs requires careful measurement of the value individuals place on various health outcomes (e.g., Kaplan & Bush, 1982). A crucial question facing the measurement of such health care utilities is whether the appropriate judgments to incorporate into decision analyses are those derived from members of the general public or those of individuals who have had experience with the health state or treatment to be evaluated (Ubel, Loewenstein, & Jepson, 2003). This question only becomes important, of course, if health state utilities are affected by illness experience, and thus a number of researchers have sought to compare how health states are evaluated by experienced and nonexperienced individuals.

In an early examination of this issue, Sackett and Torrance (1978) compared evaluations of the quality of life of kidney dialysis patients made by members of the general population with the ratings of an actual sample of kidney dialysis patients. Dialysis patients consistently evaluated their quality of life as better than it was perceived to be by the general public. This basic discrepancy between experienced and healthy evaluators has since been replicated with a number of different health conditions (Baron et al, 2003; Boyd, Sutherland, Heasman, Trichler, &

Cummings, 1990; Buick & Petrie, 2002; Ubel et al., 2001) and with prospective designs (Jansen, Kievit, Nooij, & Stiggelbout, 2001) as well as cross-sectional ones.

This is not to say that the direction of the discrepancy is always the same. Although the clear majority of studies show that healthy individuals give lower evaluations of health states than do individuals who have experienced the health states, one exception to this rule seems to be conditions characterized by significant pain. In a well-known study by Christensen-Szalanski (1984), for instance, preferences for the use of anesthesia during labor were solicited several times before, during, and after childbirth. Both one month before labor and during early labor, women expressed a clear preference to avoid anesthesia. As labor progressed and the women experienced significant discomfort, however, their preferences shifted strongly toward favoring pain relief. In other words, prior to their direct experience with childbirth, the women in this study seemed to underestimate the actual discomfort of labor, perceiving it more *positively* than they did during the experience of active labor (judging by their newfound desire for pain-reducing treatment). Taken alone, this finding would hardly seem surprising to any woman whose has gone through labor (nor perhaps to any man who has witnessed it firsthand). More intriguing, however, was the women's post-labor evaluations. Intuitively, one might expect the women in this case to "learn" something from the experience and continue to express positive evaluations of analgesia long after childbirth had taken place. When the women were interviewed again one month after delivery, however, they had already returned to their pre-childbirth preference for avoiding anesthesia. Moreover, this was true not only for first time mothers, but for women who had been through the pain of childbirth before. This pattern is important in its suggestion that it was not the experience of childbirth per se that affected the women's reactions, but rather the women's inability to appreciate, when they were free from

pain, how the pain of childbirth was likely to affect their preferences for pain-relieving medical treatment.

Stability of Life-Sustaining Treatment Preferences

Another body of evidence questioning people's ability to predict their interest in life-sustaining medical treatment comes from research examining the stability of life-sustaining treatment preferences over time. A number of studies have been conducted in which individuals are presented with hypothetical end-of-life scenarios (e.g., incurable cancer, advanced Alzheimer's Disease) and asked to state their desire for a variety of life-sustaining medical treatments (e.g., cardiopulmonary resuscitation, artificial feeding and fluids) multiple times over a period of months or years. These studies have consistently found life-sustaining treatment preferences to be only moderately stable over time periods up to two years (e.g., Carmel & Mutran, 1999; Danis, Garrett, Harris, & Patrick, 1994; Ditto et al, 2003; Emanuel, Emanuel, Soeckle, Hummel, & Barry, 1994). Ditto et al. (2003), for example, had elderly participants record their preferences for several different life-sustaining treatments in a wide range of end-of-life scenarios. They then contacted the patients again approximately one- and two-years later, and asked them to record their current preferences for the same treatments in the same scenarios. In only 67% of all cases did participants express the same preference at all three measurement points. Even in a bleak scenario describing terminal colon cancer marked by significant pain, 28% of participants' preferences changed at least once (from wanting to not wanting treatment or vice versa) at some point during the two-year study. These levels of preference instability were confirmed by a recent meta-analysis examining 11 studies where life-sustaining treatment preferences were solicited at multiple time points (Jacobson, Ditto, Coppola, Danks, & Smucker,

2005). The average stability of life-sustaining treatment preferences across all judgments and all studies was 71% (ranging from 57% to 89%).

The fact that a substantial minority of individuals change their wishes about the use of life-sustaining treatment over periods of time as short as two years suggests that living wills completed by young, healthy adults are likely to contain statements that do not reflect current preferences when these individuals are most likely to confront serious illness years or even decades later. This is not a problem, of course, if individuals are cognizant of changes in their preferences over time and make the effort to update their living wills accordingly. A study by Gready and colleagues (2001), however, suggests that people are often unaware of changes in their life-sustaining treatment preferences. The study followed a sample of older adults over two years and measured both actual and perceived change in life-sustaining treatment preferences. For every preference examined, the overwhelming majority of participants whose preferences had changed were unaware of the change. In other words, most of the participants who had changed their preferences during the course of the study mistakenly believed that the preferences they stated during the second interview were identical to the ones they expressed during the first interview.

Although the notion that preferences for the use of life-sustaining medical treatment can change without an individual being aware of that change might seem counterintuitive, a number of studies have demonstrated a tendency for people to overestimate the stability of their attitudes and beliefs over time (Goethals & Reckman, 1973; Markus, 1986; Ross, 1989). Markus (1986) for example, tracked attitudes on various political issues over a nine-year period and found that although many participants' attitudes changed substantially over this time, most of these participants incorrectly believed that their attitudes had remained the same.

Part of this phenomenon may be due to an inherent preference people have to attribute change to the external environment rather than admit that they, themselves, have changed (Eibach, Lilly, & Gilovich, 2003). It is also quite consistent with a long tradition of social psychological research suggesting that many attitudes and preferences are constructed "online" rather than accessed from a stable set of values and considered priorities (Bem, 1972; Nisbett & Wilson, 1976; Payne, Bettman, & Johnson, 1992; Slovic, 1995). To the extent that a given preference is constructed at the time of expression, it is likely to be highly dependent on the context in which the judgment is made (e.g., current mood, information made salient by recent media coverage) and thus unstable to the extent that the decision context itself is unstable. Moreover, individuals are unlikely to be sensitive to changes in constructed preferences, as the influence the context has on the judgment is likely to be subtle, and there may often be little or no memory of past constructed preferences that can be accessed to compare to one's current opinion. All this should be particularly true with regard to topics such as life-sustaining medical treatment, about which individuals have little concrete information or direct experience, and think about only very rarely in the course of their day to day lives.

In fact, there is evidence that life-sustaining treatment preferences show just this kind of context-dependency. Forrow, Taylor, and Arnold (1992), for example, found that like other kinds of medical (McNeil, Pauker, Sox, & Tversky, 1982) and nonmedical judgments (Tversky & Kahneman, 1981), preferences for life-sustaining treatment can be altered by the way the questions soliciting the preferences are framed (i.e., in terms of mortality vs. survival rates). There is also evidence that desire for life-sustaining treatment can be affected by the respondent's level of depression (Ganzini, Lee, Heintz, Bloom, & Fenn, 1994), physical functioning (Ditto et al., 2003), general experience with illness (Danis et al., 1994), and even a

recent hospitalization experience (Ditto, Jacobson, Danks, Smucker, & Fagerlin, in press). In perhaps the most dramatic illustration of this effect, Chochinov, Tataryn, Clinch, and Dudgeon (1999) had a sample of terminally ill cancer patients complete twice a day ratings of various aspects of their physical and emotional state (e.g., pain, nausea, depression, anxiety) as well as their overall “will to live.” They found that the patients’ will to live often fluctuated dramatically between 12 hour rating periods and that these changes were highly correlated with changes in the individual’s self-reported physical and emotional state. In other words, patients’ will to live did not have the characteristics of a stable judgment based on some relatively long-term assessment of their medical condition or overall happiness, but rather was highly dependent on their immediate feelings of discomfort and distress; the worse patients felt at the moment they made their assessment, the weaker their will to live.

Affective Forecasting

Research on the stability of life-sustaining treatment preferences and the role of illness experience in health state evaluations raises significant questions about whether treatment preferences stated by healthy individuals will still reflect these individuals’ wishes should they fall victim to serious illness or injury. Both literatures suggest that medical decisions made at one point in time, in a particular physical and/or psychological state, may not be the same decisions that would be made at a different time when physical or psychological conditions have changed.

Because the bulk of this research was done outside of the field of psychology, it tends to be largely descriptive in nature with most of the attention directed toward documenting differential judgments under different conditions rather than identifying specific psychological processes that might account for these differences. In the last few years, however, people’s ability to predict

their future affective and behavioral reactions has become a topic of intense interest in the field of social psychology. Although this work is not concerned with medical decision making specifically, its empirical findings clearly reinforce those of the research just reviewed, and most importantly, provide evidence for a number of psychological processes that help to explain why predicting one's future medical decisions is such a difficult judgmental feat.

Beginning at least as early as Bem's influential research on self-perception theory (Bem, 1972), there has been a rich tradition in social psychology of questioning people's insight into their own thoughts, feelings, and behavior. This work has revealed that people's beliefs about the causes of their current behavior and feelings are often mistaken (Nisbett & Wilson, 1977; Wilson, 2002) and also that their memory for past life events is less accurate than it is perceived to be (Loftus, 2003). It was only a matter of time then, that psychologists would turn their attention to the accuracy of people's prospective beliefs about the self, and the factors that might bias our predictions of how we are likely to react to future events.

The ability to predict how we will respond to future circumstances is not just important to decisions that are explicitly concerned with future preferences (like those made in living wills). Many (arguably all) decisions are based on how we believe the choice alternatives will make us feel in the future (Loewenstein & Schkade, 1999). For example, when we decide to spend our money on a new sports car rather than a new front porch, we are predicting that the car will bring us more happiness than the home improvement. To the extent that our predictions about our future feelings are wrong—that sitting on a new front porch will actually bring us greater happiness than sitting in the front seat of a new car--we are likely to engage in nonoptimal behavior, that is, we will make a purchasing decision that will fail to maximize our long term well-being.

Because of its important role in everyday decision making, research in this area, often referred to under the rubric of *affective forecasting* (Wilson & Gilbert, 2003), has generated significant attention from psychologists, economists, and decision scientists (Loewenstein & Schkade, 1999; Wilson & Gilbert, 2003; Trope & Liberman, 2003). This work has identified a number of systematic biases in people's predictions of their future feelings that have relevance for issues of advance medical decision making.

It is important to note, first, that people may often make inaccurate predictions about their future feelings because of a lack of information, or misinformation, about the situation in question. A woman may get married believing that marriage will bring her long-term happiness, only to discover that her chosen spouse is not the attentive and committed man she thought him to be. This simple kind of misprediction, in fact, is likely a common problem in end-of-life decisions. The average person has limited information about the complex clinical realities of serious illness and life-sustaining treatment and the information they do have is often based on unrealistic portrayals of medical care in the popular media. As such, people may document wishes for end-of-life care that are based on inaccurate beliefs about certain treatments (e.g., people overestimate the effectiveness of cardiopulmonary resuscitation; Coppola, Danks, Ditto, & Smucker, 1998) or conditions (e.g., media attention to salient events likely leads many people to overestimate the likelihood of a comatose individual recovering consciousness). The assumption here is that if individuals had more accurate medical information (as they would likely have if they were well enough to make their own decisions at the time of their actual illness) the decisions they would make about the use of life-sustaining medical treatment would differ from the relatively uninformed decisions they made in advance of serious illness.

Most interesting to affective forecasting researchers, however, are the biases that people show even when they seem to have all of the relevant information available to them about the future situation. Perhaps the most general of these biases, and the one that has received the most research attention, is called the *impact bias* (Wilson & Gilbert, 2003). A number of studies have now shown that people often predict that events will have a more intense and longer lasting effect on them than they actually do when experienced (Buehler & McFarland, 2001; Gilbert, Pinel, Wilson, Blumberg, Wheatley, 1998; Schkade & Kahneman, 1998). This effect has been found for both negative events like the breakup of a romantic relationship and the loss of a favored political candidate (Gilbert et al., 1998) and positive events such as moving to a state with a desirable climate (Schkade & Kahneman, 1998) and receiving a better course grade than expected (Buehler and McFarland, 2001).

At least two different psychological mechanisms have been posited to account for the impact bias. First, when people predict their reactions to future events, their predictions tend to overweight the event itself in determining their post-event well-being and neglect the fact that many other factors beside the event contribute to a person's happiness (Wilson et al., 2000; Schkade & Kahneman, 1998). This tendency is variously referred to as *focalism* or the *focusing bias*. Second, people often underestimate the impressive human ability to both adapt to negative events and habituate to positive ones, and consequently overestimate the intensity and (especially) the duration of an event's affective impact (Gilbert et al., 1998; Riis, Loewenstein, Baron, Jepson, Fagerlin, & Ubel, 2005). Drawing an analogy between the body's response to disease agents and the mind's response to threatening information, Gilbert et al. (1998) dubbed this phenomenon *immune neglect*.

Research on the impact bias predicts that healthy individuals will often underestimate their interest in receiving life-sustaining treatment in terminal illness situations (believing that they would respond more poorly to the illness than they would in actuality). This prediction dovetails nicely both with the research described earlier showing that healthy people typically assign lower utilities to health states than do individuals who have actually experienced those states (e.g., Sackett & Torrance, 1978; Boyd et al., 1990), and with the familiar intuitive example of the individual who steadfastly asserts his or her disinterest in heroic medical treatment while healthy, but becomes more aggressive about life-prolonging treatment once faced with the genuine possibility of death. At least a few studies of end-of-life medical decisions have yielded results consistent with this impact bias pattern (Bryce et al., 2004; Slevins et al., 1990). Slevins et al., for example, had different groups of respondents state their interest in receiving an arduous course of chemotherapy that would extend their lives by three months. No radiotherapists, only 6 percent of oncologists, and only 10 percent of healthy people said they would choose this life-prolonging treatment. Among a group of current cancer patients, however, 42 percent said they would take the treatment. Research on focalism would suggest that this pattern is due to the fact that the healthy respondents were likely to base their treatment decisions solely on the discomforts of the treatment, whereas the cancer patients were more likely to evaluate the difficulties of chemotherapy in the broader context of the many other factors contributing to their desire to continue living (e.g., their interactions with loved ones and ability to engage in other valued activities). Similarly, the notion of immune neglect suggests that healthy individuals may underestimate the ability of cancer patients to cope with their condition and to adjust their desires and expectations to fit with the realities of their new, more limited quality (and quantity) of life.

Another bias that has been found to characterize predictions of future feelings is a tendency for people to “project” their current preferences onto future situations where they may not apply (Loewenstein, 2005; VanBoven & Loewenstein, 2003). This *projection bias* occurs because people have difficulty appreciating how their preferences might be affected by their current affective or motivational state and is particularly problematic when there is a mismatch between the individual’s current state and the state to which s/he is predicting. Thus, people in a “cool,” unemotional state may have difficulty predicting how they would feel or behave were they in a “hot,” more emotional state and vice versa. This effect is well-illustrated by an experiment conducted by VanBoven and Loewenstein (2003) in which participants were asked what sort of supplies they would bring with them on an extended camping trip. Participants who were made thirsty from vigorous exercise prior to the decision task were much more likely to value bringing extra water on the trip, while participants who did not engage in prior exercise placed higher value on bringing extra food. The insensitivity shown by participants in the Christensen-Szalanski (1984) study to how pain might affect treatment preferences would seem another good example of the projection bias phenomenon in that people not currently experiencing pain seem to have difficulty imagining how pain might affect their decision making process (Read & Loewenstein, 1999).

The difficulty people have appreciating how their preferences might be different under different affective conditions raises important issues in the context of end-of-life decision making. As noted earlier, completion of advance directives typically involves individuals predicting what their treatment preferences will be in states quite different from the one they are in when they make their predictions. The most obvious example of this is a healthy individual completing a living will regarding preferences for life-sustaining treatment in future conditions

(e.g., end stage cancer) marked by pain, fatigue, anxiety, and depression. The converse prediction problem also occurs, however. Individuals are often prompted to complete advance directives in the throes of their own or a close other's serious illness¹, and these highly emotional conditions may be quite different from those experienced in the later stages of illness when people have had time to adjust to and accept the imminence of their own demise. The research reviewed earlier clearly demonstrates that life-sustaining treatment preferences can be affected by changes in an individual's physical and psychological condition (Chochinov et al., 1999; Ditto et al, in press; Ganzini et al., 1994). To the extent that people are insensitive to how such changes in decision context can affect their preferences for life-sustaining medical treatment, the assumption of prospective insight underlying livings wills is severely challenged.

Finally, another bias that may affect people's predictions about their future treatment preferences involves the value we place on different kinds of information when viewed from different temporal perspectives. As an example, consider having to make a decision about whether or not to volunteer at a soup kitchen next month. Then, consider volunteering at the soup kitchen tomorrow morning. When the decision is being made about volunteering next month, the decision is likely to be based upon abstract features of the decision, such as your desire to involve yourself in more community activities and the value of volunteering to those in need. In contrast, when deciding whether or not to volunteer tomorrow, the decision is more likely to center around specific, concrete details of the decision—all the things you have to do tomorrow, how early you have to get up, the traffic you may have to battle just to get there, etc. In the language of construal level theory (Trope & Liberman, 2003), temporal distance changes the way people respond to and evaluate future events by changing the way people mentally represent those events. Specifically, when events are considered at a temporal distance, we tend to

represent those events in terms of the general, abstract, evaluative aspects of the event (what Trope & Liberman term “high-level construals”). When considering events that are closer in temporal proximity, however, we are more likely to utilize “low-level construals,” representing the event more in terms of specific, concrete, and practical aspects. To the extent that the different levels of construal have different evaluative or behavioral implications, the same event can be responded to quite differently depending on the temporal distance from which it is considered. Returning to our example, when considering volunteering a month from now, we are likely to respond positively to the idea, given the high value we place on the abstract concept of helping others and the consistency of volunteering with our goal of becoming a better person. When the time looms near to actually go to the soup kitchen, in contrast, the desirability of these abstract goals tends to fade from consideration, the difficulties of enacting the specific tasks involved in volunteering become more salient, and our enthusiasm for this particular act of community service quickly diminishes.

The predictions of construal level theory have received strong empirical support (see Trope & Liberman, 2003 for a review) and much of this research has potential implications for end-of-life medical making. A number of studies, for example, have shown that temporally distant judgments tend to be based almost exclusively on the desirability of potential outcomes (a high-level construal) whereas temporally near judgments are affected most by the probability or feasibility of obtaining the outcomes (low-level construals; Liberman & Trope, 1998; Sagristano, Trope, & Liberman, 2002). This suggests that when considering whether to receive life-sustaining medical treatment in the distant or unknowable future (the perspective most people, especially young healthy ones, are likely to have when completing a living will), preferences are likely to be based primarily on issues of desirability (e.g., “terminal cancer and comas are bad

and so I wouldn't want life-prolonging treatment if I was in those conditions"). When making the same judgments from a more proximal temporal perspective however (the perspective someone may have when very old or already sick), decisions are less likely to be determined solely on the desirability of the medical conditions and more likely to take into account information about prognosis and treatment effectiveness (e.g., "I would want life-prolonging treatment if there was some reasonable probability that it would extend the quality time I have left or there was a chance I could regain consciousness"). Similarly, construal level theory would predict that other high-level considerations (such as abstract moral or religious principles) are likely to be better represented in decisions made well in advance of serious illness than when that illness is closer, or already, at hand. Importantly, high-level decisions tend to be held quite confidently because they are assumed to be based on things that are unchanging such as goals and values, while temporally proximal decisions may not be as confidence-inspiring because they are influenced by minor details that may seem less reliable (Trope & Liberman, 2003).

Implications of Research for End-of-Life Policy, Law, and Ethics

A wealth of empirical research challenges the assumption--crucial to reliance on instructional advance directives to inform end-of-life medical decisions--that people can accurately predict their future preferences for life-sustaining medical treatment. Among a list of potential problems, this research suggests 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) underappreciate how well they will cope with serious illness, and d) weigh specific aspects of information differently when making decisions about immediate and more distant futures.

The crucial question, of course, is how to use this knowledge about the psychological limitations of advance medical decision making to inform attempts to develop policy, law, and medical practices that will help people deal most effectively with the inescapable decisional challenges that await us near the end of life. In the sections below, three such possibilities are briefly discussed.

Developing Empirically-Informed Advance Directives and Advance Directive Policies

The advance directive forms most easily accessible to the public are those developed by state legislatures in conjunction with the adoption of state-specific laws supporting their use. These forms are typically based on a mixture of commonsense, legal concerns, and political negotiation, with little or no consideration of relevant empirical research. One advance directive form that is grounded in substantial empirical research, the Health Care Directive (Emanuel, 1991), was developed well prior to the research reviewed here demonstrating the limitations of people's ability to predict their future preferences. Accordingly, one way to utilize empirical research to improve end-of-life medical decision making is to examine whether it is possible to develop methods of completing advance directives that help people to be more accurate predictors of their future treatment wishes.

The first step in any such approach would involve maximizing the extent to which people have relevant and accurate information about the medical details of various clinical conditions and treatments at the time they complete advance directives. Another straightforward recommendation would be to include in the instructions that accompany advance directive forms information about potential biases in advance medical decisions such as how current physical and psychological states might affect predictions of future treatment wishes. It might also be possible, however, to draw on empirical research to develop more elaborate methods for

“debiasing” predictions of future treatment preferences. For example, some promising research has been conducted on methods that seem to diminish the focusing bias and enhance people’s appreciation of their ability to adapt to adversity (Buehler & McFarland, 2000; Ubel, Loewenstein, & Jepson, 2005). The next step in this process is research that takes an explicitly “translational” approach, and examines whether these methods can form the basis of techniques that could improve the ability to document wishes about life-sustaining medical treatment that are durable over time and across changes in an individual’s psychological, physical, and social condition.

Empirical research can also be used to inform policy and law regarding how instructional advance directives should be used once completed. The recognition that life-sustaining treatment preferences often change over time and with changes in an individual’s physical and emotional condition, suggests that policy and law should encourage or even mandate the review and updating of instructional advance directives after a prescribed period of time or major changes in health state. For example, the current legal requirement that patients’ advance directive status be checked upon hospital admission (mandated by the Patient Self-Determination Act) could be supplemented with a provision that requires that the date of any documented advance directive be checked and that “expired” directives be discussed and recompleted. Determining the appropriate expiration period for advance directives would require extensive empirical work, but this type of mandated updating would address both the potential instability of life-sustaining treatment preferences over time, and the fact that people’s preferences for life-sustaining treatment often change without their awareness (Gready et al., 2000).

Finally, a more radical proposition derived from empirical research would be to abandon reliance on patient-completed advance directives in favor of actuarial methods that might better

predict future treatment wishes. A long tradition of psychological research supports the conclusion that data-based (actuarial) approaches are superior to judgment-based (clinical) approaches in terms of predicting a wide variety of future outcomes (Dawes, Faust, & Meehl, 1989; Grove & Meehl, 1996). In fact, there is some evidence that a simple actuarial model based on modal treatment preferences can often predict an individual's preferences for life-sustaining medical treatment with greater accuracy than can that individual's self-selected surrogate decision maker (Houts et al, 2003; Smucker et al, 2001). Similarly, if research can identify demographic and epidemiological predictors of the treatment preferences of seriously ill individuals, it might be possible to use this information to develop actuarial models that would predict the preferences healthy individuals are likely to have if they become seriously ill better than those individuals could predict these preferences themselves. Interestingly, reliance on such an actuarial approach to end-of-life decision making could produce a kind of "paradoxical self-determination" in which individuals' wishes about the use of life-sustaining treatment might be honored most faithfully by making these decisions for them (i.e., "You might not *think* that this is what you will want if you become seriously ill, but our statistical model tells us with a high degree of certainty that you will").²

Reconsidering the Value of Pre-commitment

Throughout this paper we have made the assumption that when people document medical wishes in instructional advance directives they are engaging in a prediction task. That is, we have assumed that living wills represent, in a straightforward way, people's attempts to anticipate which medical treatments they will want to receive, and which they will want to forego, should they at some time in the future become seriously ill. This assumption leads quite clearly to a second one, which is that decisions made by an individual when they are "sick" (or

decisions that a sick and incapacitated individual might have made if they were able) are somehow better, more valid, more “authentic” (Elliot, 1993), than are decisions made in advance of illness when the individual is still healthy. It is only if we assume that decisions made in the throes of illness are the most authentic ones, that an individual’s inaccuracy in predicting those wishes in advance becomes a relevant concern.

It is important to recognize, however, that both of these assumptions are questionable. Advance directives can be considered just one example of what are often referred to as pre-commitment or self-binding behaviors (Elster, 1979; Schelling, 1985). Pre-commitment can often be an ingenious way to solve problems of intertemporal choice. For instance, a drug-addict who is momentarily free from drug cravings may check herself into a drug rehabilitation clinic that radically limits her freedom, making a decision now that she believes will prevent her from making poor decisions in the future. Or, for a more mundane example, consider the behavior of a colleague. Because of the distractions posed by the internet and email while writing a paper, he once decided to disconnect his ethernet cable and send it to himself through the mail, guaranteeing himself at least a few days of distraction-free work.

Advance directives rely on a similar principle, but rather than pre-committing in anticipation of future drug cravings or work distractions, individuals pre-commit to a decision now because of the fear that they will be physically unable to make a decision in the future. And therein lies the crucial difference. Pre-commitments are usually made when it is assumed that the earlier decision is “better” than the decision that would likely be made at a later time. So, for instance, a dieter locks his refrigerator when he is not craving food, for fear that the decision he will later make when he is hungry will not be the “correct” one (i.e., the one that is the best reflection of his long-term self interest). In the case of advance directives these valuations are reversed, and

the general assumption is that it is the later judgment rather than the earlier one--the one made in the midst of illness rather than in the calm before it--that is the preferred one.

It is worth considering, however, whether some individuals might intend their advance directives not as predictions of future preferences but as pre-commitments to protect against unwanted forces that they fear may impinge on future decisions. Interestingly, the irrationality people fear may not always be their own. Some individuals may complete advance directives in fear that their loved ones will be pulled by emotional concerns to make decisions that will not be in their loved ones' self-interest. In these cases then, predictive accuracy may not be a crucial issue, but rather the living will should be viewed as a reasonable form of pre-commitment, similar to the way estate wills are typically treated.

Importantly, this comparison of advance directives to other forms of pre-commitment leads to a more general questioning of the assumption that decisions made at the time of actual illness are always the preferable ones. In the case of medical decision making, the default assumption is that the decisions made when the illness is actually experienced should trump previous decisions. This is likely based on the belief that at the time of actual illness, individuals (or surrogates charged with making decisions for an incapacitated loved one) have available to them relevant information that was not available at the time advanced decisions were made. However, experience not only brings with it information, but also stress, emotion, and the potential for bias and suboptimal decision making. As illustrated by the examples above, there are many situations when decisions made in the calm detachment of hypothetical consideration are viewed as more desirable than those made in the heat of emotional involvement. Thus, it might be argued that there is no a priori reason to favor contemporaneous over advanced medical decision making.

Assessing the relative value to be placed on decisions made by healthy versus ill individuals makes for a fascinating ethical argument, but it is important to recognize that it is an argument worth having only after empirical data (such as those reported here) have established that these decisions are likely to differ. If research had revealed that healthy individuals were quite accurate predictors of the preferences they have when they are sick, then the ethical argument regarding whether medical decisions are better made when people are healthy or ill would be moot. However, given that a wealth of research now suggests that decisions made by healthy individuals for seriously ill future selves are likely to be imperfect reflections of the actual decisions those future selves would make, this empirical understanding must be supplemented by vigorous ethical debate before it can be translated into clear policy guidance.

Revisiting the Meaning of Self-Determination

Another even more fundamental assumption we have left unquestioned in the current analysis is the ethical priority of self-determination in medical decision making. If individuals want to maintain tight control over their end-of-life medical decisions, it makes sense that they complete living wills that state in specific terms what medical treatments they want in particular medical circumstances. Only then will surrogate decision makers have available to them the information they need to make the specific decisions for patients that patients would make for themselves if they were able. In the United States particularly, advocacy for greater use of advance directives has always been driven by the assumption that people desire this strict form of self-determination.

A wealth of recent research, however, questions whether the majority of people desire tight control over their end-of-life care. Although the majority people support the general notion of advance directives, relatively few people take the trouble to complete one (Eiser & Weiss, 2001).

This is true not just for healthy individuals but also for those who are seriously ill (Holley, Stackiewicz, Dacko, & Rault, 1997; Kish, Martin, & Price, 2000). Several studies have found that most people want their loved ones to have at least some freedom to override their living wills if their loved ones believe it is in their best interest (Hawkins et al., 2005; Sehgal et al., 1992) and many feel comfortable delegating complete authority over end-of-life care to their families (Holley et al., 1997). One study even found that many people prefer that their surrogate's or a physician's decisions rather than their own be followed in the event that the two decisions disagree (Terry et al., 1999). In sharp contrast to the trends seen in policy and law urging people to complete more and more specific and detailed instructional directives, relatively few people seem to endorse the standard approach to advance care planning in which preferences for specific life-sustaining treatments are documented in writing and these wishes are strictly followed near the end-of-life (Hawkins et al., 2005).

If, as research suggests, most people: a) are poor predictors of their future treatment wishes, and b), have little desire to micromanage their own end-of-life medical treatment, then attempts to encourage healthy people to document increasingly specific instructional advance directives seem particularly misguided. A more psychologically feasible goal, and one more consistent with the degree of control most individuals actually desire over end-of-life medical decisions, would be to encourage general advance directives and thus a more general form of self-determination. A commitment to self-determination does not require that people be forced to make specific decisions that they feel disinclined to make, only that people be provided with the level of control they desire. One important step in this regard would be to focus more attention on encouraging the completion of proxy advance directives such as durable powers of attorney for health care. Similarly, the goal of instructional advance directives might be reoriented, with

less emphasis placed on the documentation of specific treatment preferences and more placed on the documentation of general “process preferences” such as how much leeway people want surrogate decisions makers to have, and the general values people want to guide decisions about their end-of-life care (Hawkins et al., 2005). This more general approach to advance care planning would allow people to exert the level of control they desire over their end-of-life care.

Conclusion

A standard feature of almost every media outlet’s coverage of the Terri Schiavo case was a story in which medical or legal professionals urged the public—even individuals in their early 20’s as Schiavo was at the time of her collapse—to complete living wills to ensure that their end-of-life medical wishes be honored. This message echoes a conventional wisdom that has solidified throughout the American medical and legal establishments over the last two decades. Instructional advance directives are generally perceived as the solution to the problem of end-of-life medical decision making.

But while the motivation to honor the wishes of individuals too sick to speak for themselves is a noble one, accomplishing this goal by asking people to make these decisions in advance, we have argued, may be asking more of people than they are able to give. The review of research presented in this article should caution blanket recommendations of living wills as a quick fix to the complicated set of problems that will always surround end-of-life medical decisions. In fact, a recent report of the President’s Council on Bioethics (2005) expresses similar concerns about the “wisdom” of advance directives, and makes a similar call for increased emphasis on proxy rather than instructional directives, as well as embedding the completion of any kind of advance directive in an extensive process of discussion and information sharing between patients, their families, and health care providers.

It seems unlikely that Terri Schiavo could have possibly imagined how the end of her life would play out and made decisions in any adequate way for the shadow of her former self she was to become. If, however, her family had discussed their differences before rather than after her collapse, and Terri had designated, while she was still able, the person she wished to have ultimate responsibility for making medical decisions on her behalf, much of the chaos and animosity that ensued might have been avoided. Such discussions will be much more difficult than simply filling out a form. Given the complicated web of legal, ethical, and psychological issues involved in end-of-life decisions, however, it would be foolish to imagine that it will ever be easy.

References

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Footnotes

¹ This is particularly likely given the provisions of the Patient Self-Determination Act, which requires that all individuals be provided with the materials to complete advance directives upon hospital admission.

² A less radical approach would be to provide individuals with actuarial data to assist them in making their own decisions. Ultimately, it must be noted that the feasibility of developing an actuarial approach with an acceptable level of accuracy is highly speculative, and even if it were possible, institutionalizing such an approach to end-of-life decision making would be extremely controversial. We discuss it here primarily to highlight the fact that using empirical research to inform the development of policy and law can lead to novel solutions to traditional problems.