Advance Directives and Cancer Decision Making Near the End of Life

Peter H. Ditto and Nikki A. Hawkins
University of California, Irvine

Seriously ill individuals, including those seriously ill with cancer, are frequently encouraged to complete instructional advance directives (i.e., living wills) to ensure that their wishes about the use of life-sustaining treatment are honored if they should lose the ability to make decisions for themselves. The authors present a social psychological analysis making explicit a series of steps that must necessarily take place if living wills are to honor the wishes of incapacitated patients. They then focus on 3 key steps in the analysis and review relevant research from the medical and psychological literatures. In each case, this research raises serious questions about the psychological assumptions underlying the effective use of living wills in end-of-life decision making. Discussion focuses on the need for policy and law guiding the use of advance directives to be informed by both basic and applied research on judgment and decision making.

Keywords: advance directives, end-of-life decision making, cancer decision making, life-sustaining treatment preferences

There has been an important shift in American medicine toward acknowledging the fundamental right of seriously ill individuals to make their own choices about the use of life-sustaining medical treatment (Dresser, 2003). The landmark legal decisions marking this shift were prompted by severely injured individuals seeking relief from persistent vegetative states (e.g., Cruzan v. Director of the Missouri Department of Health, 1990), but nowhere does this change have more important implications than in the treatment of individuals in advanced stages of cancer. Near the end of life, cancer patients often endure intense pain, fatigue, delirium, agitation, and a host of other symptoms that can severely diminish their quality of life. Although few individuals are inclined to take active steps to end their life in these conditions (Ganzini et al., 2000), many more express a desire to forego medical treatment that will serve only to prolong life in such low-quality states (e.g., McCarthy, Phillips, Zhong, Drews, & Lynn, 2000).

Yet, in asserting their right to make their own medical decisions at the end of life, cancer patients face a dilemma that confronts many seriously ill individuals. The mental and physical effects of end-stage cancer often render people unable to make decisions for themselves. For this reason, cancer patients, like seriously ill individuals, are encouraged to complete advance directives to guide their end-of-life medical care (National Cancer Institute, 2003).

As the name implies, an advance directive can be defined as any statement given in advance of decisional incapacity directing the provision of life-sustaining treatment in incapacitated states. Proxy advance directives (e.g., a Durable Power of Attorney for Health Care) allow people to name someone to make decisions on their behalf. The prototypical example of an advance directive, however, is an instructional advance directive, more colloquially referred to as a “living will,” in which patients provide instructions regarding the care they would like to receive. Living wills vary in formality from legal documents prepared with the help of an attorney using a standardized (often state-specific) form to brief written or even verbal statements made to loved ones or physicians. Similarly, instructions in living wills range from very general statements (e.g., “no heroic measures”) to careful delineations of specific medical treatments to be used or withheld in specific medical conditions (see Figure 1 for an example of a form created by the Centre for Bioethics at the University of Toronto, Ontario, Canada, that is intended to elicit this latter type of detailed “disease and treatment” directive; Singer, 1993). Regardless of their particular form, however, all advance directives share the essential characteristic of allowing people to express their wishes, while they are still able, regarding how they want medical decisions made for them if they become too sick to make decisions for themselves.

Advance directives have been advocated enthusiastically by ethicists, legal scholars, and virtually every relevant medical organization as a crucial means of improving decisions made at the end of life (Ditto, in press; Dresser, 2003). Legislation supporting advance directives (proxy, instructional, or both) has been passed in all 50 states and the District of Columbia, and is reinforced at the federal level by the Patient Self-Determination Act (1990). This institutionalization of advance directives in American law and medical practice, however, stands in stark contrast to a growing body of research challenging their effectiveness in producing specific improvements in end-of-life medical care (e.g., Ditto et al., 2001; The SUPPORT Investigators, 1995). The reason for this disconnect between policy and research is a fascinating topic in its own right, but in the current context we focus on the issue of why
an idea as intuitively appealing as advance directives has proved so difficult to implement effectively.

Specifically, we begin this article by presenting a series of steps that must be negotiated if instructional advance directives are to be effective aids in end-of-life decision making. The analysis makes explicit a number of social psychological processes that policy and law encouraging advance directives implicitly assume to occur. We then focus on three key assumptions and review research (both applied and basic) bearing on their validity. Throughout the article we highlight research and issues of special relevance to decision making about cancer and conclude with comments about how psychological research might inform attempts to improve cancer decision making near the end of life.

<table>
<thead>
<tr>
<th>Current Health</th>
<th>Ventilation</th>
<th>Dialysis</th>
<th>Surgery</th>
<th>Blood Transfusion</th>
<th>Antibiotics</th>
<th>Tube Feeding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild Stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe Stroke</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mild Dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate Dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Severe Dementia</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Permanent Coma</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Syndrome</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Figure 1. Instruction grid (Singer, 1993). For each combination of health state and treatment, the person completing the living will is told to imagine him- or herself in the indicated health state and write one of four choices about his or her desire to receive each treatment in that health state: yes (if he or she wants the particular treatment in that health state), no (if he or she does not want the particular treatment in that health state), undecided (if he or she is undecided about the particular treatment in that health state), or trial (if he or she wants a trial of the particular treatment in that health state). CPR = cardiopulmonary resuscitation. From “The University of Toronto Centre for Bioethics Living Will,” by P. A. Singer, 1993, Ontario Medical Review, 63, p. 35. Copyright 1993 by P. A. Singer. Reprinted with permission of the author.

Living Wills: A Social Psychological Analysis

Policy and law advocating living wills are grounded in the ethical priority of self-determination in medical decision making (Dresser, 2003). When illness or injury deprives individuals of decisional capacity, living wills are intended to maintain the patient’s voice in treatment decisions by enhancing the ability of surrogate decision makers (e.g., loved ones or physicians) to make the same treatment choices that the patient would have made for him- or herself if able (Ditto et al., 2001).

Initially, it seemed self-evident to policymakers (and most researchers) that living wills would accomplish this goal of honoring the wishes of incapacitated patients, and thus, the focus of early intervention research was simply to get more people to complete them (Sachs, 1994). This view, however, dramatically oversimplifies the complicated set of psychological and social hurdles that must be negotiated if living wills are to be effective in producing the outcome policymakers intend (and hope) them to produce. In the tradition of past sequential analyses of social psychological phenomena (Darley & Fazio, 1980; Ditto & Hilton, 1990), Figure 2 lays out, in decision tree form, a series of steps that must take place if living wills are to achieve their goal of improving the likelihood that an incapacitated individual’s wishes about the use of life-sustaining medical treatment would be honored.

First and most obviously, a living will must be completed. Of course, individuals can and do express treatment preferences verbally, but for the current purposes we take the most straightforward example of treatment wishes expressed in writing.

Once an individual completes a living will, it is necessary that the wishes expressed in it be “authentic.” An authentic treatment preference is one that is rooted in considered and important values and thus is both consistent with the individual’s past life narrative and persistent in the face of actual illness experience (Elliott, 1993). That is, it is assumed that when individuals express in a living will their wishes about how they would like to be treated in future states of serious illness, they are able to adequately imagine themselves in that state and predict accurately what their preferences will be should they actually experience it.

Assuming that an individual completes a living will, it is necessary that the wishes expressed in it are “authentic.” An authentic treatment preference is one that is rooted in considered and important values and thus is both consistent with the individual’s past life narrative and persistent in the face of actual illness experience (Elliott, 1993). That is, it is assumed that when individuals express in a living will their wishes about how they would like to be treated in future states of serious illness, they are able to adequately imagine themselves in that state and predict accurately what their preferences will be should they actually experience it.

Assuming that an individual completes a living will that expresses authentic wishes, the document must be seen by the individual responsible for making decisions in the patient’s stead. No matter the quality of a living will, it cannot be honored if the patient’s surrogate decision makers never see it.

Next, assuming that surrogates have access to a living will containing authentic wishes, they must be able to interpret those wishes in such a way that, for any given medical situation that may arise, surrogates can make the decisions for patients that the patients would make for themselves. This transfer of information from patient to surrogate is a crucial link in the maintenance of an
individual’s right to self-determination during periods of incapacitation. Surrogates cannot honor their incapacitated loved one’s wishes if they do not understand them.

Finally, the last two steps in Figure 2 capture the idea that even if a surrogate has access to a living will that provides perfect understanding of the patient’s wishes, it is still possible that those wishes will not be honored. First, understanding a loved one’s wishes does not mean that one necessarily agrees with them or that one has the emotional capacity to carry them out. Similarly, the final act of compliance with a patient’s wishes typically rests in the hands of physicians, who like the surrogate, may disagree with the patient’s decision or otherwise feel constrained by moral conviction or legal concern not to abide by it. Thus, even if all of the other obstacles in the path honoring a patient’s dying wishes are negotiated successfully, the ability of surrogates to honor known wishes and the willingness of physicians to “trump” the patient’s and surrogate’s desires (Brock, 1991) remain final potential barriers.

The point of this analysis is not to present a definitive account of all of the complexities of end-of-life decision making. Rather, our intent is simply to capture some portion of that complexity and highlight important psychological assumptions implicitly endorsed by policy and law advocating living wills. In the sections that follow, we present a more detailed examination of research bearing on three key assumptions highlighted in Figure 1. We chose to focus on these three steps because each (a) has received direct research attention, (b) is informed by basic research on judgment and decision making, and (c) has implications for cancer decision making near the end of life.

Do People Complete Living Wills?

Despite years of enthusiastic advocacy by major health care organizations and the widespread passage of state and federal law encouraging their use, less than 25% of Americans are estimated to have any kind of advance directive (Eiser & Weiss, 2001). Completion rates are even lower for many ethnic groups (Morrison, Zayas, Mulvihill, Baskin, & Meier, 1998), and interventions intended to increase rates of advance directive completion have shown only modest results (Sachs, 1994). Most important, seriously ill individuals have been found to complete living wills at rates only slightly higher than those found in nonpatient populations (Holley, Stackiewicz, Dacko, & Rault, 1997; Kish, Martin, & Price, 2000). For instance, Kish et al. (2000) found only a 27% completion rate in a sample of critically ill cancer patients.

A growing body of evidence suggests that an important factor working against living will completion is a general ambivalence many people feel toward “micromanaging” their own deaths. For instance, Hawkins, Ditto, Danks, and Smucker (2005) found that while most of the older participants in their sample had positive attitudes about the general issue of planning for the end of life, relatively few desired the standard approach whereby healthy individuals record their preferences for specific life-sustaining treatments in writing and these documents are strictly followed near the time of death. Many patients state that they are quite satisfied leaving end-of-life medical decisions to their families (Holley et al., 1997) and feel comfortable letting surrogates override their living wills if the surrogate thinks it in their best interest (Hawkins et al., 2005; Sehgal et al., 1992). Studies have found that many patients suffering from serious illnesses like prostate cancer prefer playing a “passive” role in decision making (Davidson & Degner, 1997) and often even prefer that a surrogate’s or physician’s decisions rather than their own be followed in the event of a disagreement between the two (Terry et al., 1999).

This body of research suggests an important gap between the autonomy-centered conceptual framework that has guided the development of advance directive policy and the actual desires of many patients. Although the majority of people have positive attitudes about advance directives in general, they do not seem to desire the kind of specific control over end-of-life care implied in the stereotypical image of the individual completing a detailed living will (see Figure 1).

There are several reasons to expect that this reticence to complete living wills might be particularly pronounced in cancer patients. Cancer often follows a very uncertain path. In addition to uncertainties about the prognosis and speed with which the disease will progress, there are many unforeseen side effects from both the disease and its treatment. This uncertainty may make delaying
decisions or delegating them to trusted others particularly attractive (Tversky & Shafir, 1992).

An even more potent factor that may work against advance care planning in cancer patients is the focus on optimism and positive thinking that have become core values in the culture of cancer support. Among cancer patients and care providers there is an emphasis on maintaining a mental focus on exclusively positive outcomes (Stiegelis et al., 2003), and research shows that positive thinking may be associated with better physical outcomes (Allison, Guichard, Fung, & Gilmain, 2003). An unintended consequence of this positive focus, however, may be a resistance in cancer patients, their families, and even their physicians to project themselves into undesirable future circumstances in order to document the patient’s wishes for treatment at the end of life.

Do Living Wills Express Authentic Wishes?

When healthy individuals state preferences for the use of life-sustaining medical treatment in living wills, they are really making predictions about their future preferences. As illustrated by the decision grid presented in Figure 1, these predictions can involve very specific distinctions regarding the use of particular life-sustaining treatments in particular health states. Thus, it is important to consider the empirical evidence bearing on people’s ability to make these kinds of detailed predictions about their future preferences. Are treatment preferences stated by healthy people likely to reflect accurately the choices these same individuals would make for themselves should they become seriously ill?

A number of studies have found preferences for life-sustaining treatment in response to hypothetical end-of-life scenarios to be only moderately stable over time (e.g., Danis, Garrett, Harris, & Patrick, 1994). Ditto et al. (2003), for example, had older participants record their preferences for four life-sustaining treatments (e.g., cardiopulmonary resuscitation) in nine end-of-life scenarios (e.g., coma with no chance of recovery) three times at 1-year intervals. In only 67% of all cases did participants express the same preference in the same scenario 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 2-year study. In interpreting this level of stability, it is important to consider that in real end-of-life scenarios, the time period between the completion of a living will and its use in decision making is often much greater than 2 years, and both reason and some data (Lockhart, Ditto, Danks, Coppola, & Smucker, 2001) suggest that preference stability diminishes over time.

The instability of life-sustaining treatment preferences is consistent with a long tradition of psychological research suggesting that attitudes and preferences are often constructed “online” rather than accessed from a stable set of values and considered priorities (Payne, Bettman, & Johnson, 1992; Slovic, 1995). To the extent that a preference is constructed at the time it is expressed, it is likely to be dependent on the context in which it is made, and hence, unstable to the extent that decision context is also unstable.

There is also more direct evidence showing the context dependency of life-sustaining treatment preferences. Like other types of medical judgments (McNeil, Pauker, Sox, & Tversky, 1982), decisions about life-sustaining treatment can be dramatically affected by small changes in the way questions are framed (Forrow, Taylor, & Arnold, 1992). Life-sustaining treatment preferences have also been found to be affected by the respondent’s level of depression (Ganzini, Lee, Heintz, Bloom, & Fenn, 1994), physical functioning (Ditto et al., 2003), and even by general experience with illness (Danis et al., 1994). In a demonstration of this last effect, Ditto, Jacobson, Smucker, Danks, and Fagerlin (2005) examined the life-sustaining treatment preferences of participants who were hospitalized for at least 48 hr during their involvement in an ongoing, longitudinal study. On their release from the hospital, participants’ current preferences were assessed and compared with preferences stated at annual interviews conducted in the months before and after the hospitalization. Desire for life-sustaining treatment showed a significant “hospitalization dip.” Participants reported less desire to receive life-sustaining treatment immediately after hospitalization than they did either prior to hospitalization or several months posthospitalization. Unfortunately, the Ditto et al. study was unable to link specific changes in patients’ physical, emotional, or cognitive states with changes in desire for life-sustaining treatment. The decreased interest in life-sustaining treatment evidenced immediately after hospitalization may have been due to depressed mood, diminished energy level, the cognitive availability of the patient’s personal vulnerability to illness, or some other factor. Most important for the current purposes, however, is the fact that hospitalization produced only temporary changes in preferences that returned to prehospitalization levels within a few months after recovery. This pattern provides a clear demonstration of the contextual nature of what advance directive policy assumes to be stable, considered, “authentic” decisions.

Research showing that life-sustaining treatment preferences change over time and are dependent on decision context coincides nicely with growing bodies of research in both the medical and psychological literatures documenting more general difficulties people have in predicting their future preferences, behavior, and emotions. Several studies have used prospective designs to show that individuals assign different utilities to disease states and treatments prior to experiencing them than they do after experiencing them (e.g., Llewellyn-Thomas, Sutherland, & Thiel, 1993). Similarly, social psychological research on “affective forecasting” has provided evidence for a number of systematic biases in people’s predicted reactions to future events (Wilson & Gilbert, 2003). These biases are especially evident when the emotional context at the time of the prediction differs substantially from the emotional context expected at the time of the future event (see Loewenstein, 2005). Healthy people predicting their preferences for life-sustaining treatment in future states of serious, incapacitating illness would seem a prototypical example of this bias-prone form of decision making.

Generating stable, authentic treatment preferences may be a particularly difficult problem in the context of cancer decision making. Cancer is a uniquely feared disease. Because of this, and because people have been found to underestimate their capacity to cope with adversity (Wilson & Gilbert, 2003), healthy people are likely to underpredict their desire for life-sustaining treatment given a cancer diagnosis. Similarly, once a cancer diagnosis has been made, patients may continue to underpredict their desire for future treatment because of a tendency to view treatments (like chemotherapy) more negatively than they are actually experienced to be (Jansen et al., 2000). As the disease progresses, individuals with cancer often experience significant vacillations in both physical symptoms and emotional state (McCarthy et al., 2000). To the
extent that these factors also affect preferences for life-sustaining treatment, patients’ interest in pursuing aggressive treatment may depend, in an important way, on how they are feeling when the question is asked. This may be particularly true in the advanced stages of cancer as distressing symptoms such as fatigue, pain, and nausea ebb and flow. Consistent with this analysis, responses to a simple question about the “will to live” have been found to be highly unstable among terminally ill cancer patients (Chochinov, Tataryn, Clinch, & Dudgeon, 1999).

Can Surrogates Interpret Living Wills?

Although living wills are typically viewed as legal documents or medical procedures, they are more fundamentally acts of communication (Ditto et al., 2001). A number of studies have found that in the absence of a living will describing the patient’s wishes, potential surrogate decision makers show levels of accuracy equivalent to chance guessing when predicting patients’ treatment preferences in hypothetical end-of-life scenarios (e.g., Uhllmann, Pearlman, & Cain, 1988). This research is often taken as support for the necessity of living wills based on the assumption that a patient’s directive would improve surrogate accuracy (Emanuel & Emanuel, 1992). A study conducted among a sample of terminally ill patients, however, found that patients’ prior completion of an advance directive was not associated with greater accuracy in surrogates’ treatment predictions (Sulmasy et al., 1998).

A more direct test of the efficacy of living wills in communicating patient preferences was conducted by Ditto et al. (2001). In a randomized trial, older adults completed one of two types of living wills and either discussed the living will with their chosen surrogate (typically a spouse or child of the patient) or did not. Surrogates provided with either type of directive were no more accurate in predicting their loved ones’ wishes about the use of life-sustaining treatment than were surrogates making predictions without the benefit of a directive. Moreover, this was true even when the surrogate was allowed to discuss the directive with the patient immediately prior to the predictions. These results show that living wills are not necessarily effective in communicating treatment wishes. Indeed, the fact that surrogate judgment showed significant inaccuracy even under the relatively ideal situations created in this study (e.g., possession of a thorough living will supplemented by a structured patient–surrogate discussion) suggests that other psychological barriers exist to accurate surrogate prediction.

Psychological research, in fact, has provided ample evidence that social judgments are characterized by a host of persistent errors and biases that are particularly likely to reveal themselves under conditions of uncertainty such as those surrounding end-of-life medical decisions (Gilovich, Griffin, & Kahneman, 2002; Nisbett & Ross, 1980). Although people may believe that their living will will clearly express their preferences, their intentions are likely to seem much clearer to them than they do to surrogates (Keysar & Barr, 2002). Unlike the detailed directives used in the Ditto et al. (2001) study, real living wills are often brief and not very descriptive (e.g., “no heroic measures”) and thus provide little useful information to help surrogates make specific decisions (Teno et al., 1997). Even detailed directives, however, are no match for the panorama of medical scenarios that might await people at the end of life. It is simply impossible for any living will, no matter how comprehensive, to provide treatment instructions to address all future medical possibilities (Brett, 1991).

Under these types of highly ambiguous decision situations, surrogates may default to using simple heuristics to infer the preferences of their loved one. For example, one of the most replicated findings in the social perception literature is that people “project” their own characteristics onto others as they assume that the majority of people are likely to behave and believe as they themselves do (e.g., Gilovich, 1990; Krueger & Clement, 1994). Fagerlin, Ditto, Danks, Houts, and Smucker (2001) provided evidence of this projection bias in surrogate predictions about the use of life-sustaining medical treatment. Surrogates showed a disproportionate tendency to make errors of projection (i.e., mispredict that their loved one had the same treatment preference as they themselves did). In fact, surrogates’ predictions were consistently found to be more similar to the surrogate’s own preferences than to those of the patients. Physicians have been found to show a similar projection bias (Schneiderman, Kaplan, Pearlman, & Teetzel, 1993). These results highlight the difficulty that surrogate decision makers have separating their own personal preferences from those of the patients whose wishes they are attempting to honor. They also provide just one example of how the basic psychological literature on judgmental bias can be fruitfully applied to the problem of identifying potential sources of error in surrogate medical decision making.

Many of the same factors that make it difficult for individuals to predict how they might react to a future case of cancer are likely to complicate surrogates’ attempts to predict the treatment wishes of an afflicted loved one. Most directly, if cancer patients’ desires for life-sustaining treatment vacillate with changes in their physical or emotional state, then surrogates attempting to predict those desires face the daunting task of trying to “hit a moving target.” Indeed, the task of predicting another’s wishes makes little sense if there exist no stable “wishes” to predict. There is also evidence that surrogate decision makers show a systematic bias to underestimate the quality of life of seriously ill cancer patients (Jansen et al., 2000). The implications of this underestimation for the accuracy of surrogate prediction, however, are unclear. One hypothesis would be that underestimating a cancer patient’s quality of life would lead to an analogous underestimation of the patient’s interest in life-sustaining treatment. This is consistent with studies showing that physicians underpredict their patients’ desires for life-sustaining treatment in hypothetical scenarios (e.g., Coppola, Ditto, Danks, & Smucker, 2001). With family surrogates, however, this tendency may be tempered by their pervasive inclination to err on the side of overestimating a loved one’s desire for life-sustaining treatment (Ditto et al., 2001; Fagerlin et al., 2001).

Implications for Policy and Research

Living wills were proposed as a simple and elegant solution to the problem of honoring the treatment wishes of people incapacitated by illness or injury. To most, the solution seemed so imminently commonsensical that in the little more than a decade since the passage of the Patient Self-Determination Act (1990), advocacy of advance directives has been institutionalized in American medicine.

When living wills are viewed through the prism of current research on judgment and decision making, however, a number of potential problems are revealed. Making decisions for a future self...
stricken by incapacitating illness is a tall psychological order. In the preceding pages we have reviewed a wealth of research from both the medical and psychological literatures questioning key psychological assumptions underlying the use of living wills in end-of-life decision making. However, this same body of research can also suggest possible directions for policy development and research attention that hold the hope of improving the decision-making process of individuals faced with advanced stage cancer and other serious illnesses.

People must complete living wills if they are to improve end-of-life care, but few people do. Cancer patients may find it particularly difficult to document specific plans for end-of-life care because of cancer’s often uncertain trajectory and a reluctance to dwell on negative outcomes, a reluctance that is likely to be shared and reinforced by loved ones and health care providers.

Although the culture of optimism that pervades cancer treatment may create a climate that is not conducive to living will completion, there is evidence that cancer patients are dissatisfied with physician–patient discussions that focus only on the positive aspects of their medical case (Pentz, Lenzi, Holmes, Khan, & Verschraegen, 2002). Physicians may be uncomfortable initiating a discussion of end-of-life care with cancer patients for fear of conveying an overly pessimistic prognosis (Doukas & Doukas, 1998). Cancer care providers must be informed, however, that these discussions are often desired by patients, and more research must be done on how to conduct them in a constructive and nonthreatening way. It may be helpful to reinforce with cancer patients that advance care planning need not include the documentation of specific treatment instructions but rather can focus on open discussion with family members and on the expression of broader process preferences (Hawkins et al., 2005), such as who they wish to make decisions on their behalf and how much leeway they want these individuals to have.

Living wills inherently assume that wishes stated in advance of serious illness remain stable over time and in the face of declining physical health, but research suggests that, like other types of preferences and attitudes, preferences for life-sustaining medical treatment can be unstable over time and highly dependent on decision context. These issues may be particularly acute in the context of cancer decision making, given the wide range of debilitating symptoms that can accompany cancer and the vacillations in physical and emotional state that often occur as the disease progresses.

One possible solution is to avoid documenting specific treatment wishes in the early stages of cancer, as cancer patients may maintain the ability to express their wishes until very late in the progression of the disease. In more advanced stages of illness, the patient’s particular pattern of symptom experiences situate decisions in their most relevant context, and a clinician can prognosticate about a limited number of potential situations that may require a choice about a particular life-sustaining treatment. The inherent problem with this strategy is that the window of opportunity for such focused discussions may be narrow (a few days or even a few hours) and unpredictable. Delaying decisions until clinical trajectories can be accurately anticipated runs the inevitable risk of waiting too long. Moreover, it is worth noting that implicit in all of the prior discussion of preference instability is the assumption that choices made in the throes of serious illness are somehow “better” (i.e., more authentic) than decisions made by healthy individuals in the calm detachment of hypothetical consideration. There are many situations, however, in which this valuation would be reversed, and most people would consider emotional detachment the preferable context for optimal decision making (Elster, 1979; Emanuel, 1994). At an empirical level, then, a crucial goal for future research is to gain a more sophisticated psychological understanding of how preferences for life-sustaining treatment are affected by changes in an individual’s physical and emotional state. This empirical research can only provide clear policy guidance, however, if it is accompanied by an equally sophisticated ethical analysis of the relative value to be placed on decisions made by healthy versus ill individuals.

Finally, living wills can only help to honor the wishes of an incapacitated patient if they improve others’ ability to understand those wishes, but research suggests that surrogate understanding is not necessarily improved by having access to a patient’s living will. Surrogates attempting to predict the wishes of cancer patients face the particularly difficult task of trying to imagine how the varied physical and psychological symptoms of the disease (and its treatment) may affect the patient’s quality of life and desire to prolong that life with medical treatment.

The consistent finding that people have difficulty predicting others’ preferences for life-sustaining treatment is less troubling in light of research suggesting that most patients are willing to delegate responsibility for end-of-life decisions to trusted surrogate decision makers (Hawkins et al., 2005). Still, improving surrogate decision making remains a valuable goal, and research should continue to explore ways to achieve it. It is important to recognize that the Ditto et al. (2001) study examined the efficacy of only two of the many different varieties of existing advance directives. As such, the study is most valuable in laying out an approach for evaluating the effectiveness of instructional advance directives; it is certainly possible that more effective methods of improving the accuracy of surrogate decision making can be developed. What is crucial is that these methods be constructed based on state-of-the-art research in communication, decision making, and social cognition rather than on the mixture of common sense and political consensus that have guided the development of current advance directive documents (e.g., living wills forms developed by state legislatures). For example, recent psychological research has greatly enriched researchers’ understanding of the conditions under which people are likely to be better or worse at predicting the emotional reactions of both themselves and others (e.g., Van Boven & Loewenstein, 2003; Wilson, Kraft, & Dunn, 1989), and this research might form the basis for techniques to improve the quality of people’s predictions of both their own future treatment preferences and those of their loved ones. Technological advancements, such as the use of interactive video or virtual reality simulations, might also have potential for helping individuals imagine the physical and psychological effects of diseases like cancer in more vivid and realistic ways.

---

1 Consistent with this logic, the Centre for Bioethics at the University of Toronto advocates the use of “disease-specific” living wills (Singer, 1994). These documents are similar in structure to the generic living will presented in Figure 1 but focus on health states and treatment choices most likely to be faced by individuals with a particular illness. The development of a cancer-specific advance directive is described by Berry and Singer (1998).
In conclusion, cancer is a uniquely feared disease, not just because of its perceived threat to mortality but also because of the belief that the descent toward death in cancer patients is so often marked by uncontrollable symptoms that severely deteriorate the quality of the end stages of life. Effective end-of-life decision making has the potential to relieve some of this fear and the suffering that engenders it, but this goal can only be achieved if policy development is informed by contemporary research on judgment and decision making. The use of advance directives to honor the wishes of dying individuals is a noble cause. Like most noble causes, however, realizing the ultimate objective will not be easy. It will require a concerted and coordinated effort involving both basic and applied science as well as compassionate medical care.

References


Morrison, R. S., Zayas, L. H., Mulvihill, M., Baskin, S. A., & Meier, D. E.


