

Penultimate draft of: Peter Ditto & Cory Clark (2014): Predicting End-of-Life Treatment Preferences: Perils and Practicalities. *Journal of Medicine and Philosophy* 39(2), 196-204. For the final version, please contact the authors (phditto@uci.edu or clarkcj@uci.edu) or go to the *Journal of Medicine and Philosophy* website (<http://jmp.oxfordjournals.org/>).

Predicting End-of-Life Treatment Preferences:
Perils and Practicalities

Peter H. Ditto & Cory J. Clark
University of California, Irvine

Running head: Predicting End-of-Life Treatment Preferences

Keywords: end-of-life decision making, advance directives, actuarial prediction, personal autonomy, surrogate decision making

Word count: 3497 (main text plus references)

Correspondence to:

Peter H. Ditto

4001 Social & Behavioral Sciences Gateway

Department of Psychology & Social Behavior

University of California, Irvine

Irvine, CA 92697-7085

Abstract

Rid and Wendler (2013a; 2013b) propose the development of a Patient Preference Predictor (PPP), an actuarial model for predicting incapacitated patient's life-sustaining treatment preferences across a wide range of end-of-life scenarios. An actuarial approach to end-of-life decision-making has enormous potential, but transferring the logic of actuarial prediction to end-of-life decision-making raises several conceptual complexities and logistical problems that need further consideration. Actuarial models have proven effective in targeted prediction tasks, but no evidence supports their effectiveness in the kind of broad spectrum prediction task that is the proposed goal of the PPP. We argue that a more focused approach, targeting specific medical conditions and generating treatment predictions based on the preferences of individuals with actual disease experience, is both more firmly grounded in past research and is a more prudent initial strategy for exploring the efficacy of actuarial prediction in end-of-life decision making.

Predicting End-of-Life Treatment Preferences: Perils and Practicalities

"The great tragedy of science -- the slaying of a beautiful hypothesis by an ugly fact."
Thomas Huxley (1870)

Effective end-of-life decision-making has proven to be one of the most difficult challenges facing modern medicine. Dramatic advances in our ability to prolong life have created a tragic medical catch-22. At precisely the point at which difficult decisions must be made about life-sustaining medical treatment, a substantial proportion of patients have lost the capacity to make those decisions for themselves. This has led to several high profile cases of individuals struck down by illness or injury, left for years unresponsive and in need of constant care, while their families wrestled the court system over whether their incapacitated loved one could be released from medical limbo. On a societal scale, the same dilemma has resulted in an unsustainable proportion of medical care costs being expended during the last days and weeks of individuals' lives, on treatments that often do little besides prolong the dying process.

The first attempt to address this problem was proposed over 40 years ago by attorney Luis Kutner (Kutner, 1969). If individuals are frequently too sick to make their own decisions about life-sustaining medical treatment, they should record their wishes while still healthy. This so-called "living will," now generally referred to as an advance directive, could then be used by family members to enact the desired decisions of an incapacitated loved one.

As Thomas Huxley portended, however, realizing this beautiful goal has proved difficult in the face of an accumulating number of ugly facts, including but not limited to: a) relatively few people complete advance directives (Perkins, 2007), b) when they do, these directives often contain little useful information (Teno et al., 1997), and c) even relatively high quality advance directives do not necessarily improve surrogates' accuracy at predicting their loved ones' preferences (Ditto et al, 2001).

In this volume, Rid and Wendler (2013a; 2013b) propose the first alternative strategy for end-of-life decision-making that is more than just a refinement of Kutner's basic insight. The authors argue that their *Patient Preference Predictor* (PPP), an empirically derived system for inferring life-sustaining treatment preferences, addresses both core ethical goals of end-of-life medical care: honoring the wishes of incapacitated patients and minimizing burden on family

members thrust into the role of surrogate decision makers. In this essay, we evaluate Rid and Wendler's intriguing proposal through the lens of psychological science, taking up in turn outcomes for patients and surrogate decision makers. Our core contention is that while the PPP has enormous potential to improve end-of-life decision making, there remain a number of logistic obstacles to its use in the broad form advocated by Rid and Wendler. We argue that a more focused strategy, targeting specific medical conditions with well-known disease trajectories, is both better grounded in research and a more prudent strategy for exploring the efficacy of an actuarial approach to end-of-life decision making.

Maintaining Patient Autonomy

The guiding light of the advance directive movement is the ethical principle of personal autonomy: people have a fundamental right to make their own decisions (Buchanan & Brock, 1990). Widespread utilization of advance directives held the hope of extending autonomy to achieve the seemingly oxymoronic goal of allowing people who have lost the ability to make medical decisions for themselves maintain the ability to make medical decisions for themselves.

Recognizing the logistic obstacles facing reliance on advance directives, however, Smucker et al (2000) suggested that it might be possible to use a "community standard" to predict life-sustaining treatment preferences. Building on seminal work documenting the superiority of actuarial (i.e., data-based) over clinical (i.e., judgment-based) decision-making strategies (Dawes, Faust, & Meehl, 1989), Smucker and colleagues showed that a simple actuarial model based on the modal preferences of a few hundred elderly research participants was as accurate at predicting participants' life-sustaining treatment preferences as participants' self-selected surrogate decision makers.

To improve on these single predictor models, Rid and Wendler propose "supersizing" this approach to build a complex, multivariable actuarial model to predict individuals' preferences for life-sustaining treatment across a wide range of debilitating health conditions. This is a noble goal, and Rid and Wendler have carefully considered many conceptual and pragmatic issues facing the development and application of their PPP. It is clear, however, that this is an extremely daunting task, as transporting the logic of actuarial prediction to the realm of end-of-life decision-making evokes a number of novel and challenging complexities.

First, simple actuarial approaches have so far only matched (or very slightly surpassed) the modest accuracy of surrogate prediction (Houts, Smucker, Jacobson, Ditto, & Danks, 2002).

To make sense in a cost-benefit analysis, actuarial models must achieve considerably greater accuracy than they have so far exhibited, as development costs will be substantial.

The process would begin with a large-scale survey asking a diverse sample to state hypothetical treatment preferences for several end-of-life scenarios (manipulating information about the baseline health state as well as the risks, burdens and durations of multiple treatment outcomes), and also collect information on respondents' demographic, physical, and attitudinal characteristics. The specifics of such a survey raise a host of logistical problems that are not fully addressed in Rid and Wendler's proposal. Who should participate? How many health states and treatment outcomes will be needed to provide adequate predictive coverage? How can one insure that participants are in a state of mind in which the preferences expressed are most likely to match decisions made in response to real life-threatening illness? Each of these issues (and many others like them) require, at minimum, extensive pilot testing before a final survey can be constructed.

As an illustration, consider the difficulties of dealing with one of the most well established findings in the end-of-life decision-making literature: life-sustaining treatment preferences are only modestly stable over time and change with changes in the respondent's health condition (Ditto et al., 2003; Ditto, Jacobson, Danks, Smucker, & Fagerlin, 2006). Psychological research has demonstrated the "constructed" and context-dependent nature of many stated preferences (Slovic, 1995) and the consequent difficulty this creates in accurately predicting emotional and behavioral reactions to hypothetical situations (Loewenstein & Schkade, 1999; Gilbert & Wilson, 2007). This raises questions about whether any sample of individuals healthy enough to respond to a long and detailed survey is capable of accurately predicting the treatment wishes that they (and similar individuals) would make if seriously ill. Slevin et al. (1990), for example, found that while 42 percent of current cancer patients said they would be interested in receiving an arduous course of chemotherapy, only 10 percent of healthy people said they would choose this life-prolonging treatment. This is consistent with research showing that healthy people typically assign lower utilities to health states than do individuals who have actually experienced those states (e.g., Riis et al., 2005). To complicate matters further, however, research has also shown that desire for life-sustaining treatment may in some cases decline (rather than increase) among respondents experiencing physical and psychological ailments (Ditto et al., 2003; Ganzini, Lee, Heintz, Bloom, & Fenn, 1994). Chochinov, Tataryn,

Clinch, and Dudgeon (1999) found that terminally ill cancer patients' ratings of their "will to live" were highly dependent on their immediate discomfort and distress; the worse patients felt at the moment of assessment, the weaker their will to continue living.

The problem of illness experience affecting end-of-life treatment preferences is a good example of how actuarial prediction becomes more challenging when transported from situations like deciding whether a high school student should be admitted to college to the more dynamic situation of predicting an incapacitated individual's wishes for end-of-life medical care. This is a problem even if we simply aim, as in Rid and Wendler's analysis, to predict an individual's "last competent" wishes. In many circumstances, end-of-life decisions are confronted only at the end of a long decline from health to debilitation, and thus an individual's last competent wishes are those of someone who has experienced the ravages of illness and the inconveniences and indignities of medical treatment first hand. There is good reason to believe that an individual expressing preferences after hard won experience with illness may view end-of-life decisions through a very different lens than a demographically similar individual who has been blessed with less first hand medical experience.

Rid and Wendler recognize this problem and propose two possible solutions: a) developing the PPP algorithm on a "representative sample of the population" and b) implementing some kind of "debiasing" procedures such as supplying respondents with "up-to-date information about common medical treatments and their clinical outcomes" or informing respondents "about widespread psychological biases that influence health state evaluations." These proposed solutions, however, are in need of substantial development and specification. Of what broader population should the survey sample be representative? Will any representative sample yield enough individuals with various serious illnesses to allow demographically contextualized predictions of treatment preferences for individuals with these illnesses? Is it possible to provide survey respondents, some of whom will have minimal education if the sample is representative, with enough information in simple enough form to correct the many misconceptions they are likely to hold about life-sustaining treatment and life-threatening disease? Given psychology's spotty record of success in debiasing judgment (Larrick, 2004), can we really hope to incorporate into an already arduous survey procedure a series of interventions that will make respondents bias-free predictors of abstract life-or-death

judgments? Specific questions like these must be addressed if an actuarial model that accurately represents incapacitated patients wishes is to be developed.

Reducing Surrogate Burden

Because the challenges of honoring incapacitated individuals' desires are substantial, they have been the focus of most scholarly work on end-of-life decision-making. Rid and Wendler should be applauded therefore for considering the implications of their PPP for the other key players in end-of-life decisions: people who make decisions for their incapacitated loved ones.

Rid and Wendler's analysis recognizes the inherent balance of burden involved in shared medical decision-making. Research has shown that most patients have little interest in "micromanaging" their own end-of-life decisions and many are content with delegating the specifics to their loved ones (Hawkins, Ditto, Dank & Smucker, 2005). Based on such findings, Hawkins and colleagues argued that too much attention has been focused on instructional advance directives rather than proxy advance directives (e.g., Durable Powers of Attorney for Health Care), which instead of providing information about a patient's treatment preferences merely shift decisional authority to a trusted surrogate. Rid and Wendler, however, smartly recognize that this redistribution of authority is a redistribution of burden as well. Although empowering a surrogate may satisfy the patient's need for a broad sort of autonomy--knowing they placed a trusted loved one in charge of their end-of-life care--without explicit guidance about their loved one's treatment preferences, the burden of making these weighty decisions falls squarely on the shoulders of surrogate decision makers (Wendler & Rid, 2011). The PPP is hypothesized to reduce surrogate burden by providing guidance about patient's likely treatment wishes similar to that instructional advance directives are intended to provide.

There are two major obstacles, however, to the PPP's ability to relieve surrogate burden. The first is the complicated nature of the predictive information that surrogates would be asked to use. Rid and Wendler (2013b) lay out five "domains" that must be specified in order to capture the complexity of real world end-of-life decisions, and offer this example:

"...a treatment scenario might stipulate the option of receiving (D2) high-burden/risk interventions in (D1) a state of complete or quasi-complete cognitive impairment, where there is (D4a) a good chance of returning to (D3a) good physical and cognitive condition (D5a) for the predicted normal duration of life; (D4b) a low chance of being in (D3b) a poor condition (D5b) for 6-12 months; and (D4c) a slight chance of (D3c) death – which is, by definition, (D5c) permanent."

Even if a clinician had the central responsibility for classifying patients' according to the PPP domains, surrogates would have to be comfortable with how their loved one's health state was characterized along each of these dimensions, and might be asked to estimate their loved one's religiosity, fear of dying or other variables (e.g., their loved one's income or previous experience with medical care) that they may not feel competent to evaluate. It is easy to imagine this complicated set of decisions overwhelming rather than helping a surrogate struggling to make the right decision in a highly emotional situation.

A second problem is the potentially offensive nature of accepting that a loved one's life and death decisions can be distilled down to a statistical model. Early proponents of actuarial prediction noted that psychologists often resisted the approach due to a sense that it dehumanized their patients (Dawes et al., 1989). Imagine how much more intense this feeling might be when applied to someone you had known and loved in the full richness of their individuality for decades. As demographic variables are included in the model, feelings of stereotyping and "profiling," with all of their moral baggage, are introduced as well (Tetlock, Kristel, Elson, Green, & Lerner, 2000). Many surrogates are likely to respond poorly if they are encouraged, in essence, to forgo providing life-sustaining treatment for a loved one based on that individual's race, gender, or ethnicity. Thus, just as predicting treatment wishes is challenging in the context of end-of-life decision making, specific logistic challenges must also be addressed before the PPP can be expected to meet its second goal of reducing surrogate burden.

Potential for a Practical, Pared Down PPP

From our perspective, the key "glitch" in translating research on the superiority of actuarial prediction to improve end-of-life decision-making is the substantial difference in the scope of the actuarial endeavor in the two domains. The prediction tasks where actuarial approaches have proved effective are constrained and specific, for example, diagnosing one specific medical condition like jaundice or predicting college academic performance. Rid and Wendler are proposing using this same approach as a full service end-of-life decision maker, able to predict preferences across a wide spectrum of incapacitating health states and life-sustaining medical treatments. There is no evidence for the effectiveness of actuarial prediction in this kind of a multifaceted prediction task.

Accordingly, one fruitful strategy for realizing the benefits of actuarial prediction in end-of-life decision-making would be to adopt a scaled down approach focused on building preference prediction models for specific health conditions. This would be analogous to an approach advocated by medical researcher Peter Singer suggesting that medicine move away from generic advance directives to develop “disease-specific advance directives” (Singer, 1994). Focusing on a specific health condition like HIV (or a class of health conditions like cancer) allows one to anticipate with much greater precision the expected disease trajectory—what specific symptoms will develop and which specific treatment decisions will need to be made—and focus efforts appropriately. It also presents patients with a set of realistic and personally relevant decisions, as the individual knows that there is a high probability these exact decisions will be confronted in the future.

Most important in the context of actuarial prediction, a disease-specific approach enables model building using individuals who have experience with the medical condition in question, particularly if it focuses on chronic, progressive diseases like cancer or emphysema. Reliance on experienced predictors – even those in the early stages of illness – would help address both of the key limitations of the PPP described in the previous sections. First, if a crucial limitation of building accurate actuarial models is healthy respondents’ inability to anticipate their reactions to hypothetical medical conditions, developing models using experienced patients should improve predictive accuracy. Second, actuarial models derived from experienced patients should also be less likely to arouse resistance in surrogate decision makers. Although surrogates may view generic actuarial prediction as cold and dehumanizing, they may respond more warmly to receiving advice from people who have “been there, done that.” The voice of experience may speak to surrogates more persuasively (as well as more accurately) than a statistical algorithm.

Conclusion

When evaluating a proposal translating research findings from one domain into practical applications in another, it is easy to identify points where the translation is underspecified. We conclude then by again recognizing the creativity and boldness of Rid and Wendler’s proposal, as well as their thoughtful attempts to anticipate the critiques that were likely to arise. We agree that actuarial approaches have enormous potential to improve end-of-life medical decisions, but also believe that key logistic challenges to their effectiveness exist. Our

recommendation to downscale initial attempts at actuarial modeling derives from research suggesting that generating predictions based on responses of individuals having experience with a target medical condition may improve both predictive accuracy and surrogate reactions to the actuarial prediction process. Be assured that any ugly facts we offered in support of our recommendation were not designed to slay Rid and Wendler's beautiful hypothesis, but to refine and improve it.

References

- Buchanan, A. E. & Brock, D. W. 1990. *Deciding for others: The ethics of surrogate decision making*. Cambridge, UK: Cambridge University Press.
- Chochinov, H. M., Tataryn, D., Clinch, J. J., & Dudgeon, D. 1999. Will to live in the terminally ill. *Lancet* 354: 816-819.
- Dawes, R. M., Faust, D., & Meehl, P. E. 1989. Clinical versus actuarial judgment. *Science* 243: 1668-1674.
- Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., Zyzanski, S. 2001. Advance directives as acts of communication: A randomized controlled trial. *Archives of Internal Medicine* 161: 421-430.
- Ditto, P. H., Jacobson, J. A., Smucker, W. D., Danks, J. H., & Fagerlin, A. 2006. Context changes choices: A prospective study of the effects of hospitalization on life-sustaining treatment preferences. *Medical Decision-making* 26: 313-322.
- Ditto, P. H., Smucker, W. D., Danks, J. H., Jacobson, J. A., Houts, R. M., Fagerlin, A., . . . Gready, R. M. 2003. The stability of older adults' preferences for life-sustaining medical treatment. *Health Psychology* 22: 605-615.
- Ganzini, L., Lee, M. A., Heintz, R. T., Bloom, J. D., & Fenn, D. S. 1994. The effect of depression treatment on elderly patients' preferences for life-sustaining medical therapy. *American Journal of Psychiatry* 152: 1836-1837.
- Gilbert, D. T. & Wilson, T. D. 2007. Propection: Experiencing the future. *Science* 317: 1351-1354.
- Hawkins, N. A., Ditto, P. H., Danks, J. A., & Smucker, W. D. 2005. Micromanaging death: Process preferences, values, and goals in end-of-life medical decision-making. *The Gerontologist* 45: 107-117.
- Houts, R. M., Smucker, W. D., Jacobson, J. A., Ditto, P. H., & Danks, J. H. 2002. Predicting elderly outpatients' life-sustaining treatment preferences over time: The majority rules. *Medical Decision-making* 22: 39-52.
- Kutner, L. 1969. Due process of euthanasia: the living will, a proposal. *Indiana Law Journal* 44: 539-554.
- Larrick, R. P. 2004. Debiasing. In: *Blackwell Handbook of Judgment and Decision Making* (pp. 316-337), D. J. Koehler & N. Harvey (eds). Oxford, UK: Blackwell Publishing Ltd.

- Loewenstein, G., & Schkade, D. 1999. Wouldn't it be nice? Predicting future feelings. In: *Hedonic psychology: Scientific approaches to enjoyment, suffering and well-being* (pp. 85–105), E. Diener, N. Schwarz, & D. Kahneman (eds). New York: Russell Sage Foundation.
- Perkins, H. S. 2007. Controlling death: the false promise of advance directives. *Annals Internal Medicine* 147: 51-7.
- Rid, A. & Wendler, D. 2013a. Use of Patient Preference Predictor to help make medical decisions for incapacitated patients. *The Journal of Medicine & Philosophy*.
- Rid, A. & Wendler, D. 2013b. Treatment decision making for incapacitated patients: is development and use of a Patient Preference Predictor feasible? *The Journal of Medicine & Philosophy*.
- Riis, J., Loewenstein, G., Baron, J., Jepson, C., Fagerlin, A., & Ubel, P. A. 2005. Ignorance of hedonic adaptation to hemodialysis: A study using ecological momentary assessment. *Journal of Experimental Psychology: General* 134: 3–9.
- Singer, P. A. 1994. Disease-specific advance directives. *The Lancet* 344: 594-596.
- Slevin, M. L., Stubbs, K., Plant, H. J., Wilson, P., Gregory, W. M., Armes, P. J., & Downer, S. M. 1990. Attitudes to chemotherapy: Comparing views of patients with cancer with those of doctors, nurses, and general public. *British Medical Journal* 300: 1458–60.
- Slovic, P. 1995. The construction of preferences. *American Psychologist* 50: 364–371.
- Smucker, W. D., Houts, R., Danks, J. H., Ditto, P. H., Fagerlin, A., & Coppola, K. M. 2000. Modal preferences predict elderly patients' life-sustaining treatment choices as well as patients' chosen surrogates. *Medical Decision-making* 20: 271-280.
- Teno, J. M., Licks, S., Lynn, J., Wenger, N., Connors, A. F. Jr., Phillips, R. S., . . . Knaus, W. A. 1997. Do advance directives provide instructions that direct care? Support investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Geriatrics Society* 45: 508-512.
- Tetlock, P. E., Kristel, O. V., Elson, B., Green, M. C., & Lerner, J. S. 2000. The psychology of the unthinkable: Taboo trade-offs, forbidden base rates, and heretical counterfactuals. *Journal of Personality and Social Psychology* 78: 853-870.
- Wendler, D. & Rid, A. 2011. Systematic review: The effect on surrogates on making treatment decisions for others. *Annals of Internal Medicine* 154: 336-346.