Published in final edited form as:

J Aging Health. 2012 October ; 24(7): 1157–1178. doi:10.1177/0898264312454572.

Elders' Preferences for Life-prolonging Treatment and their Proxies' Substituted Judgment: Influence of the Elders' Current Health

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Abstract

Objectives—People in poor health tend to view life-prolonging treatments (e.g., tube feeding) as more acceptable than do healthier people. Do proxies' substituted judgments reveal a similar tendency, showing greater acceptance when the elder is in worse health?

Methods—In a cross-sectional telephone-based survey of 202 elderly individuals and their proxies, preferences for 4 life-prolonging treatments in 7 health prospects were examined in relation to the elder's current health status, operationalized as number of deficits in activities of daily living.

Results—Stronger preferences for life-prolonging treatments in worse-health prospects were expressed by both elders and proxies when the elders' current health was relatively poor. The interaction effect was at least as pronounced for proxies' substituted judgment as for elders' own preferences.

Discussion—Findings provide important insight into proxy decision making and have particular implications for proxy decision making on behalf of elders with dementia or other causes of decisional incapacity.

Introduction

It has long been recognized that life-prolonging treatments tend to become increasingly acceptable to individuals as their health status declines. Research on the response shift phenomenon has documented changes in internal standards, values, or conceptualizations of quality of life when the individual's health undergoes a change, with a shift toward increasing tolerance for treatment (e.g., Schwartz & Sprangers, 2000). In research by Winter and associates, both preferences for life-prolonging treatments and the years of desired life in future prospects of poor-health were associated with the individual's current health status, with healthier individuals wanting less life-prolonging treatment (Winter & Parker, 2007) and fewer years of life (Winter, Lawton, & Ruckdeschel, 2003) in worse health prospects. The strengthening of preferences for longer life and more aggressive life-prolonging

treatment in prospects of poor health helps to explain shifts in treatment preferences expressed in advance care planning (Winter, Moss, & Hoffman, 2009).

In addition, much observational research has documented this shift in the same individuals over time. Fried and her associates (2006) found increasing acceptance of life-prolonging treatments among patients who had experienced a decline in the same domain. Straton and associates' (2004) longitudinal study of physicians revealed that those with functional decline were more likely to prefer high-burden life-sustaining treatment. Lockhart, Ditto, Danks, Coppola, & Smucker (2001) showed that some hypothetical states of health that were initially viewed as worse than death often came to be viewed as more acceptable at follow-up.

This helps to explain why patients change their views on treatments as they approach the end of life. Yet most end-of-life treatment decisions are actually made by family proxies rather than patients themselves. Seriously ill patients are often decisionally incapacitated as a result of dementia, delirium, coma, persistent vegetative state, or other conditions (Silveira, Kim, & Langa, 2010; Field & Cassel, 1997). Although advance directives help guide treatment decisions, and increasing numbers of Americans do complete advance directives (Silveira et al., 2010; Teno, Gruneir, Schwartz, Nanda, & Wetle, 2007), many still do not make advance care plans. Even for those who do, healthcare providers generally also consult with next-of-kin family members when patients are incapacitated (Teno, Stevens, Spornak, & Lynn, 1998; Torke, Moloney, Siegler, Abalos, & Alexander, 2010). Thus, proxies (or surrogates) have a crucial role in end-of-life care decisions.

Proxies are usually asked to apply the standard of substituted judgment, according to which they follow the patient's wishes. Unfortunately, they are known to be quite inaccurate in their ability to represent their relatives' wishes for treatment (Ditto, Danks, Smucker, Bookwala Coppola, et al., 2001; Diamond, Jernigan, Moseley, Messina, & McKeown, 1989; Fagerlin, Ditto, Danks, et al., 2001; Gerety, Chiodo, Kanaten, et al., 1993; Hare, Pratt, & Nelson, 1992; Karel & Gatz, 1996; Marks & Arkes, 2008; Shalowitz, Garrett-Mayer, & Wendler, 2006; Silveira & Schneider, 2004; Sulmasy, Terry, Weisman, Miller, Stallings, et al., 1998; Suhl, Simons, Reedy, & Garrick, 1994; Zettel-Watson, Ditto, Danks, et al., 2008; Zweibel & Cassel, 1989). Some research has identified predictors of accuracy in proxy judgment. For example, the best agreement between patients and proxies is consistently found in best-case and worst-case scenarios, the lowest agreement for intermediate states such as physical disability (Gerety, Chiodo, Kanaten, et al., 1993; Fagerlin, Ditto, Danks et al., 2001; Ouslander, Tymchuk, & Rahbar, 1989; Uhlmann, Pearlman, Cain, 1988).

Substituted judgment is most accurate for the extreme health prospects (current health or poorest health) perhaps because people are most likely to have previously considered and discussed these situations with family members. Regarding types of proxies, findings have been mixed, with some studies finding family members more accurate than healthcare providers (e.g., Ouslander et al., 1989), some finding spouses more accurate than others (e.g., Parks, Winter, Santana, Parker, Rose, & Myers, 2011), and yet others reporting no differences among types of proxies (e.g., Suhl, Simons, Reedy, & Garrick, 1994; Sulmasy, Haller, & Terry, 1994; Sulmasy et al., 1998; Shalowitz, Garrett-Mayer, & Wendler, 2007; Tomlinson, Howe, Notman, & Rossmiller, 1990). Family conflict surrounding the care of a

relative is also a predictor, with more conflict associated with less accurate substituted judgment (Parks et al., 2011). In light of well-documented racial differences in EOL treatment preferences and advance care planning behavior (e.g., Allen-Burge & Haley, 1997; Blackhall, Frank, Murphy, Michel, Palmer, & Azen, 1999; Bullock, 2011; Caralis, Davis, Wright, & Marcial, 1993; Garrett, Harris, Norburn, Patrick, & Danis, 1993; Gessert, Curry, & Robinson, 2001; Hopp & Duffy, 2000; Johnson, Elbert-Avila, & Tulskey, 2005; Kwak & Haley, 2005; Phipps, True, Chong, Tester, Chavin, & Braitman, 2003; Steinhäuser, Christakis, Clipp et al., 2000), race has also been examined as a possible predictor of proxy accuracy, with some suggestion that African-American proxies may be more accurate than Whites (Schmid, Allen, Haley, & DeCoster, 2009).

Yet, studies of sociodemographic characteristics or types of situations that are associated with proxy inaccuracy do not address the more fundamental question of how proxy decision makers think. This represents a limitation in research on accuracy in substituted judgment. Is proxy decision making different from the decision making of patients themselves, and if so, in what respects?

Prospect Theory

The present study posed this question in relation to the response shift phenomenon, the tendency of sicker people to more strongly prefer life-prolonging end-of-life treatment than do healthy people. Winter and her associates interpreted response shift within the framework of Prospect Theory, a powerful decision model with wide applicability (Kahneman & Tversky, 1979; Kahneman & Tversky, 1984; Tversky & Kahneman, 1992; Winter, Moss, & Hoffman, 2008). According to Prospect Theory as it applies to health, individuals view future health prospects (e.g., living with pain that requires the constant use of medication) from a reference point on a health continuum from perfect health on the right-most pole to death on the left (e.g., Treadwell & Lenert, 1999; Lenert, Treadwell, & Schwartz, 1999). The reference point, defined by the individual's current health status, and health prospects (i.e., imaginable states of health) are represented on the x axis. Prospects to the right of the reference point are in the gain domain, those to the left the loss domain. The individual's y axis represents the acceptability of each prospect, its subjective value to the individual. The individual's y axis intersects the x axis at the reference point (as stipulated in Prospect Theory). The value of each prospect to the individual is determined by the point at which the vertical line from P intersects the individual's value function and the corresponding point on the individual's y axis that is intersected by the horizontal line from the value function. Figure 1 represents the S-shaped value function.

Prospect theory differs from other decision models in positing that the relationship between prospects' x-axis locations and their values - the value function - is S-shaped rather than straight (Fig. 1). Crossing the x-axis at the reference point, the slope is steepest near the reference point and flattens out with greater distance from it (Tversky & Kahneman, 1992). Prospects close to an individual's reference point are therefore more distinguishable from one another than are remote prospects. For example, the difference between gains of \$100 and \$200 seems greater than the difference between gains of \$1,100 and \$1,000, although objectively the difference is the same, \$100.

This theory is relevant to end-of-life decision making because any decision concerning a life-prolonging treatment is by definition a choice between the treatment (and the quality of life it may prolong) and death, the left-most pole of the health continuum. Thus, a choice for or against a life-prolonging treatment involves a pair of prospects one of which is death. The idea that health prospects are viewed from the reference point of one's current health, together with the S shape of the value function, explains why two prospects closer to one's reference point are easier to distinguish than more distant prospects and why individuals in different health statuses would view the same pair of prospects differently. Figure 2 presents a pair of health prospects, P (e.g., living in pain) vs. death, and the value functions for two individuals, A and B, differing in current health. For both individuals the location of prospect P, the poles of the continuum (death and perfect health), and the S-shape of the value functions are the same. Only the individuals' reference points are different. From a reference point close to the Perfect Health pole, the prospect of living in this poor-health scenario might appear indistinguishable from the prospect of death; because the prospects are remote, the value-function curve is relatively flat. As an individual's health status declines and his/her reference point moves farther down the health continuum, the same two prospects become increasingly distinguishable as they intersect the value function near the reference point, the steep segment. Thus, to healthy Person A the perceived difference between P and death (d_1) is small, whereas to less-healthy Person B, the two prospects appear quite distinct (d_2). The healthy individual who perceives the two prospects as indistinguishable may reject the prospect of living in the poor-health scenario and therefore the life-prolonging treatment. By contrast, a less healthy individual would likely choose to live longer in the worse prospective health status and therefore accept a life-prolonging treatment.

The theory has clear implications for advance care planning, which involves decision making about the acceptability of one's quality of life in prospects of health. Prospect Theory would predict that current health status would interact with the severity of the hypothetical health scenario such that life-prolonging treatments in worse-case scenarios would be more acceptable to currently less healthy individuals than to healthier ones (Winter & Parker, 2007).

Does proxies' substituted judgment display the same tendency as elder's own preferences? If so, this would offer a novel and valuable insight into how proxies make treatment decisions. This issue has special relevance for dementia patients, who are decisionally incapacitated often for long periods, during which their physical health may deteriorate. On the other hand, if proxy decision making does *not* show an interaction of elder's current health status with health prospects, this would suggest that proxies do not bring this consideration to bear in their substituted judgment and would help explain proxy inaccuracy in representing their relatives' treatment preferences. We therefore examined treatment preferences of both elderly community-dwelling individuals in diverse states of health and the substituted judgments of their proxies.

Method

Participants

Participants were 202 community-dwelling elder-proxy pairs (404 total study subjects). Elders were aged 70 and over. Each proxy was named by the elder. Proxies were defined as individuals whom elders would choose to make healthcare decisions on their behalf if they were unable to speak for themselves. A legal designation of durable power of attorney for healthcare (DPAHC) was not required. Elders were recruited into the study through a variety of sources including two senior centers, two senior housing developments, two continuing care retirement communities, mailings to patients of two family medicine practices, and display ads in area newspapers. Eligibility criteria were age 70 or older and having a proxy willing to participate in the study. All elders and proxies were cognitively intact. The mean age of elders was 79 years and of proxies 60. Approximately 40% of proxies were daughters and 25% spouses. Two-thirds were Whites. Among the 67 nonWhite dyads, 63 were African-American, 1 was Asian, and 3 indicated no primary racial group. Characteristics of elders and proxies are displayed in Table 1.

Measures

Preferences for Life-prolonging Treatments—Treatment preferences were measured using an adaptation of the Life Support Preferences Questionnaire (LSPQ; Bookwala, Coppola, Fagerlin, Ditto, Danks, & Smucker; 2001; Coppola, Bookwala, Ditto, Lockhart, Danks, & Smucker, 1999). This instrument elicits individuals' preferences for 4 medical treatments – antibiotics, gall bladder surgery, CPR, and tube feeding - for acute life-threatening conditions. Preference for each treatment is elicited in the context of 7 hypothetical health prospects that vary in severity, prognosis, and level of pain, and a prospect for “return to current health” (i.e., if you could return to your current state of health). Participants consider their preferences for life-prolonging treatment in the context of each specific prospect rather than in the abstract. Appendix A presents the 7 prospects. The original LSPQ was changed by adding fuller descriptions of health scenarios.

Interviewers instructed proxies to use the ethical principle of substituted judgment as the method of decision making: “I would like you to respond to these questions as if you had to make decisions on behalf of (name of relative), because s/he is unable to speak for himself or herself. Please base your decision on what you think (the relative) would want. If you are not sure what (the relative) would want, please make your best guess.” Elder and proxy treatment preferences were elicited on 5-point acceptability scales from 0 (not at all) to 4 (very much).

Elders' Current Health Status—We operationally defined health in terms of physical functioning, a relatively objective measure of dependence (i.e., amount of help needed) in a standard set of activities of basic activities of daily living (ADL) and instrumental activities of daily living (IADL). This generic measure of health is reproducible with different patient samples, unlike condition-specific measures (e.g., Fried et al., 2006). Thus, current physical function was operationalized as number of deficits in six activities of daily living (ADL; getting around the house, eating, dressing, grooming, bathing, using the toilet; Katz, Ford,

Moskowitz, Jackson, & Jaffe, 1963) and eight instrumental activities of daily living (IADL; using the phone, shopping for groceries, preparing meals, doing housework or tidying up, doing laundry, taking medicine, managing money, getting to places out of walking distance; Lawton & Brody, 1981). Dependence on each activity was rated on 3-point scales (1 = “need no help,” 2 = “need some help,” 3 = “need complete help”). Summing across the 14 activities yielded a possible range from 14 to 42, with 42 indicating help needed on every activity and 14 no help needed on any activity. The actual range was 14 to 31, and 48% needed no help on any activity. Thus, the sample was relatively high functioning. Cronbach’s alpha for the 14 activities was .80 with this sample.

Cognitive Status—Cognitive Status was assessed using a telephone version of the Mini-Mental State Exam (Roccaforte, Burke, Bayer, & Wengle, 1992). Possible scores range from 0 to 23, with higher scores indicating fewer errors. All participants scored in the cognitively intact range (Table 1).

Demographic Characteristics—For both elder and proxy, age, race, gender, years of education, occupation, financial difficulty (Gitlin, Burgio, Mahoney, Burns, Zhang, et al., 2003), and marital status were elicited (Table 1). Financial difficulty was defined as difficulty paying for the basics such as food, housing, and medicine, on a 4-point Likert scale from 0 (not at all) to 3 (extremely).

Procedure

Interested elders called the office or returned a stamped self-addressed postcard and were contacted by telephone. A trained interviewer explained the study and confirmed the person’s eligibility by age and willingness to participate. Informed consent was obtained using an IRB-approved verbal consent script. The 35-minute interview was conducted by telephone. Proxies were contacted and interviewed separately. Participants were offered a \$25 honorarium.

Data Analysis

Selection of Covariates.—To select covariates for subsequent analyses, mean preferences for life-prolonging treatment across all treatments and prospects was calculated and their association with race, age, gender, and financial difficulty of elders and proxies were calculated using Pearson product moment correlations or t tests, as appropriate.

Testing the Prospect Theory Prediction.—Based on Prospect Theory (illustrated in Figs. 1 and 2), we drew a hypothesis regarding treatment preferences: The same pair of prospects (a poor health prospect vs. death) will be closer to a sick person’s reference point than to a healthy person’s. Because of this relative proximity, the sicker individual will view the poor-health prospect as more distinguishable from death and therefore more acceptable. This hypothesis was tested by the interaction between the subject’s current health status and preferences for health prospect; the worse the prospect, the more acceptable it should be to less healthy individuals relative to healthy ones. The test of this interaction required a repeated-measures analysis of covariance (ANCOVA) on treatment preferences for poor-health scenarios.

Comparison of Elders' and Proxies' Treatment Preferences.—The primary question was whether elders and proxies differed in the interaction effect between elder's current health and hypothetical health prospects. Therefore, in the first ANCOVA the within-subjects variables were decision maker (elder vs. his/her proxy), the 6 health hypothetical poor-health prospects and the 4 types of treatment. Elders' age, race, and financial difficulty were used as covariates. Two *post hoc* repeated-measures ANCOVAs were conducted on elders' and proxies' treatment preferences separately.

Results

Selected Covariates

Mean treatment preferences of both elders and proxies were found to be associated with the elder's age ($r = -.184$, $p = .009$), race ($t [200] = 3.02$, $p = .003$), and financial difficulty ($r = .268$, $p < .0001$). No other sociodemographic variables were associated with mean preferences for life-prolonging treatments ($p > .05$). Therefore, these served as covariates in the subsequent analyses.

Elders' Current Health Status: Effect on Preferences for Life-prolonging Treatments among Elders vs. Proxies

The 2 (elder vs. proxy) X 7 prospects X 4 treatments repeated-measures ANCOVA revealed a main effect for health prospect only ($F [6,192] = 3.161$, $p = .006$, $\eta^2 = .090$). No main effect was found for decision maker (elder vs. proxy; $F [1,197] = 2.626$, $p = .107$, $\eta^2 = .013$), indicating that elders and proxies did not differ overall in treatment preferences. Similarly, no effect was found for treatment type ($F [3,195] = 1.281$, $p = .282$, $\eta^2 = .019$). The interaction between health prospect and elders' health status was statistically significant ($F [6,192] = 4.355$, $p < .0001$, $\eta^2 = .120$), as Prospect Theory would predict. Among sociodemographic covariates, only race ($F [1,197] = 16.404$, $p < .0001$, $\eta^2 = .077$) and financial difficulty ($F [1,197] = 11.959$, $p = .001$, $\eta^2 = .057$) were associated with treatment preferences. Stronger preferences for life-prolonging treatment were expressed by nonWhites and those reporting greater financial difficulty.

Because there were no significant differences among the 4 treatments, means treatment preferences were calculated for each health prospect, and *post hoc* repeated-measures ANCOVAs were conducted on the 7 health prospects for elders and proxies separately, adjusting for race, elders' age, and elders' financial difficulty.

Elders' Treatment Preferences and Current Physical Functioning

For the ANCOVAs on elders' treatment preferences, a significant main effect was revealed for health prospect ($F [6,192] = 2.347$, $p = .003$, $\eta^2 = .068$), and prospect interacted significantly with elders' health status ($F [6,192] = 4.471$, $p < .0001$, $\eta^2 = .123$). As Prospect Theory would predict, the healthiest elders most strongly preferred the life-prolonging treatments in the best-case prospect ("as you are now" and shortness of breath) but least wanted life-prolonging treatment in the worse-case prospect. Figure 3 illustrates this interaction effect for elders. Values in the figure represent estimated treatment preferences (mean across the 4 treatments) for individuals at the highest and lowest levels of current

functioning for this sample. These values were derived by multiplying the B coefficient for the current health (operationalized by independence in daily activities) by the corresponding ADL value and adding the prospect-specific intercept value to each product ($y=Bx + a$). Thus, the line labeled “No ADL deficits” shows the estimated relationship between treatment preferences and health prospect for an individual at the highest functioning level (14). The “High deficits” line shows this relationship for an individual with a 31. The horizontal location for each line is the range of health prospects. Because the vertical location varies with covariate values, no vertical scale for treatment preference is shown; the actual vertical location of the lines on the treatment preferences scale depends on the values of the other covariates in the analysis. The value of the vertical axis is set arbitrarily for the combination of worst health prospect and lowest functioning level. Thus, the graph represents the differences in treatment preferences between different levels of physical functioning but not the actual treatment preferences value; hence, the y-axis does not show scale values. (Note that Figures 3 and 4 represent interactions between current health status and mean treatment preferences. These figures do not represent the S-shaped value function used to illustrate Prospect Theory in Figures 1 and 2.) Inspection of Figure 3 shows that the slope for the highest functioning elders is steeper than for the lowest functioning. The difference in treatment preferences between best- and worst-case prospects for the highest functioning elders was 2.923, whereas this difference for the lowest functioning elders was only 0.679.

Among the covariates, race and financial difficulty again emerged as predictors of treatment preferences, with stronger preferences for life-prolonging treatments expressed by nonWhites ($F [1,197] = 4.813, p = .029, \eta^2 = .024$) and those reporting greater financial difficulty ($F [1,197] = 10.071, p = .002, \eta^2 = .049$).

Proxies' Treatment Preferences and Elders' Current Physical Functioning

For the proxies, a similar pattern was revealed, viz., a main effect for health prospect ($F [6,194] = 14.341, p < .0001, \eta^2 = .307$) and an interaction between prospect and elders' current health status ($F [6,192] = 4.471, p < .0001, \eta^2 = .123$). In the best-case scenario, life-prolonging treatments were more strongly preferred by proxies of the healthiest elders, but in the poor-health scenarios (Alzheimer's disease, both stroke scenarios, and both cancer scenarios), the reverse was found: Proxies of lower-functioning elders more strongly preferred life-prolonging treatment. Figure 4 presents this interaction effect using the same procedure as described above for the elders' data. As found for the elders' preferences, the slope for proxies of the highest functioning elders (no deficits) was relatively steep, with the difference between the best-case and worse-case prospect being 2.848. By contrast, this best-case vs. worst-case prospect difference for proxies of the lowest functioning elders was only 1.471. Concerning the sociodemographic characteristics, nonWhites and those with greater financial difficulty expressed stronger wishes for life-prolonging treatment.

Discussion

Both elders' and proxies' treatment preferences displayed an interaction between elders' current health status and health prospect: When elders were relatively healthy, preferences

for life-prolonging treatment dropped off sharply as hypothetical prospects worsened. For less healthy elders, by contrast, preferences for such care dropped off much less steeply. Proxies of healthy elders expressed preferences for more life-prolonging treatment in the best prospects but the weakest preferences for such treatments in prospects of poor health. Differences between best- and worse-case prospects were larger for currently healthy elders than for currently less-healthy ones, and this was true for both elders and proxies.

Even though both elders' and proxies' data revealed significant interactions between elder's current health and health prospects, the slopes for elders and proxies were quite different. For elders' preferences, the interaction occurred at the extreme health prospects ("as now" and severe stroke). Preferences of healthy and less healthy elders were quite similar in the intermediate health prospects (shortness of breath, Alzheimer's disease, moderate stroke, and both cancer prospects). For proxies, on the other hand, the interaction effect occurred markedly between the more-acceptable health prospects – "as now" and shortness of breath – and the five worst prospects. Proxies of sicker elders wanted consistently more life-sustaining treatment than did proxies of healthy elders, with no progressive widening of differences as these health prospects worsened.

These differences in the shapes of the interactions may be subject to various interpretations. Future research should further explore such differences. A better understanding of this phenomenon may help to elucidate proxy inaccuracy in substituted judgment. Nevertheless, the pronounced interaction for the proxies' treatment preferences indicate that the response shift phenomenon operates in the substituted judgments of proxies.

The racial differences in treatment preferences for both elders and proxies confirm the copious qualitative and quantitative research on such racial/ethnic differences (e.g., Blackhall et al., 1999; Bullock, 2011; Caralis, Davis, Wright, & Marcial, 1993; Hopp & Duffy, 2000; Johnson, Elbert-Avila, & Tulskey, 2005; Kwak & Haley, 2005; Phipps et al., 2003). They suggest the need for further research on race and EOL decision making.

Limitations of the Study and Directions for Future Research

The sample may not be representative of the elderly population in several ways. First, all elders in the study could identify proxies (although "proxy" was widely defined to include friends and neighbors as well as family members) willing to participate in the research. Thus it excluded elders who lack such a proxy. Second, the sample had a relatively low proportion of Roman Catholics and may therefore not be demographically representative. Finally, the sample was quite healthy, with nearly half indicating no functional limitations, and no one was terminally ill or approaching the end of life as far as we knew. Therefore this was a study of advance care plans, not choices made in the face of imminent death. Nevertheless, the sample did provide sufficient variability in current health statuses to test and confirm the hypothesis. Had we been able to recruit elders approaching the end of life, Prospect Theory would predict an even strong interaction effect between health status and treatment wishes.

Study findings should be interpreted with caution in light of these limitations. Future research should attempt to enroll more Catholic subjects and reach out to patients with serious illness and disability and those approaching the end of life.

Implications

The present findings provide insights into the psychology of proxy decision making, showing that proxies are subject to a similar effect of the elder's health status. The study makes a contribution to the end-of-life decision making literature by yielding important understanding of the decision-making process - that of the family proxy - that commonly guides final treatment choices. Healthcare providers should recognize that family proxies may display a tendency to prefer more aggressive treatment when their relatives' health has deteriorated and they are closer to the end of life. The prospect of continued life in poor health, and therefore the acceptability of life-prolonging treatments, may appear distinctly different from the prospect of death when the patient's health status is already poor, compared to when the patient is relatively healthy. From the reference point of a healthy individual (or his/her proxy), a remote prospect of poor health does not seem much different from the prospect of death. As the elder's health worsens, the difference between the same two prospects seems larger. This may seem paradoxical to healthcare providers, but it is quite consistent with the Prospect Theory prediction and provides another manifestation of the response shift phenomenon. The decision making of both elders and proxy decision makers shows effects of a reference point defined by current health status and Prospect Theory's S-shaped value function.

Appendix

Four Life-sustaining Treatments

Antibiotics:

Doctors use these medicines to treat serious infections (like pneumonia). Without antibiotics, serious infections can cause life-threatening complications or death.

Cardiopulmonary Resuscitation (CPR):

Doctors use cardiopulmonary resuscitation, or CPR, when a person's heart stops beating or a person stops breathing. Doctors press on the chest to help pump blood, and use artificial breathing. Artificial breathing means the doctor puts a tube in the windpipe. Then, a machine breathes for the patient through the tube. Patients usually get medicine by vein. Patients often need an electrical shock to help restart the heartbeat. Without CPR, the heart will not start beating again, and the patient will die.

Gall bladder Surgery:

Doctors use surgery to remove the gall bladder when it is inflamed and infected. If untreated, an inflamed and infected gall bladder can rupture and cause life-threatening complications or death.

Artificial Feeding and Fluids:

Doctors use artificial feeding and fluids when people are unable to take enough food and water to stay alive. The food goes through a feeding tube. Usually, the feeding tube is inserted into the stomach through the left side of the abdomen during surgery. The stomach is stitched closed around the tube. Without the treatment, patients die within 7–10 days.

Six Poor-health Prospects

1. Alzheimer's disease: You have trouble remembering things and thinking clearly. You cannot recognize people you know, make decisions for yourself, or communicate. You have no chance of recovery. Your mental abilities may get worse quickly or may stay the way they are now for a long time. Your physical condition and abilities are unaffected.
2. Constant shortness of breath as result of a condition such as congestive heart failure, emphysema, or COPD. You are unable to climb stairs or walk more than a few feet. Your medical condition cannot improve. Your condition may get worse very quickly or slowly decline over several years. Your ability to think, reason, and remember is unaffected.
3. Severe stroke: You have suffered a severe stroke and have been in a coma for six weeks. In the opinion of the doctor, you have *no chance* for regaining awareness. Your current physical condition is stable but will slowly decline over time. You rely on others for help with feeding, bathing, dressing, and toileting. You may live in this condition for several years.
4. Moderately severe stroke. One arm and leg are paralyzed. You have trouble speaking and trouble understanding when others speak. You rely on others for help with feeding, dressing, bathing and toileting. In the opinion of your doctor, you have *a very slight chance* of improvement.
5. Colon cancer which has spread to the liver, no pain You are tired and weak. Your thinking and memory are unaffected. *You are not in pain*. In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.
6. Colon cancer which has spread to the liver, with pain You are tired and weak. Your thinking and memory are unaffected. *You have pain that requires the constant use of medication*. In the opinion of your doctor, you have no chance of recovery. Your doctor estimates that you have about six months to live.

Sample Question

You have Alzheimer's disease. You have trouble remembering things and thinking clearly. You cannot recognize people you know, make decisions for yourself, or communicate. You have no chance of recovery. Your mental abilities may get worse quickly or may stay the way they are now for a long time. Your physical condition and abilities are unaffected.

If you developed a serious infection, like pneumonia, would you want to use antibiotics to treat the infection?

Definitely do not want	Probably do not want	Unsure	Probably want	Definitely want	NA	Refused
0 ()	1 ()	2 ()	3 ()	4 ()	-2 ()	-4 ()

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Figure 1.
The S-shaped value function of one poor-health prospect in relation to a reference point on the health continuum

Figure 2.
Two loss-domain prospects – poor health (P) and Death – as perceived by healthy person A and less-healthy person B

Figure 3.
Elders' life-prolonging treatment preferences: Interaction of elders' current functioning and health prospects (each representing the mean preference across the 4 treatment types).

Proxies' Life-prolonging Treatment Preferences, by Elders' Current Health Status

Figure 4. Proxies' life-prolonging treatment preferences on behalf of elders: Interaction of elders' current functioning and health prospects (each representing the mean preference across the 4 treatment types)

Table 1.

Characteristics of sample

	Elders		Proxies	
	Percentage	Mean (sd)	Percentage	Mean (sd)
Age		78.9 (6.2)		59.6 (13.6)
Gender (% female)	73.0		71.8	
Race				
White	62.0		65.3	
Non-white	38.0		34.7	
Religious affiliation				
Protestant	49.0		41.6	
Catholic	15.8		17.3	
Jewish	25.7		21.3	
Other	3.6		6.4	
None	5.9		13.4	
Years of education				
HS or less	28.0		18.3	
Some college	29.0		20.8	
College degree	23.0		28.2	
Post-grad degree	20.0		32.7	
Financial difficulty *		.90 (.98)		.95 (.95)
Marital status (% married)	23.0		58.4	
Relationship to elder				
Wife			14.4	
Husband			11.4	
Daughter			40.1	
Son			14.4	
Other			19.7	
ADL total score		15.71 (2.90)		15.70 (2.96)
MMSE		20.54 (1.37)		20.91 (1.20)

* Financial well-being scale measures difficulty paying for basics like food, housing, medical care, from 0 (not at all difficult) to 3 (extremely difficult). The mean value represents "Not very difficult."