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The impact of considering adaptation in health state valuation ☆

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Abstract

Patients with chronic health conditions often rate their quality of life (QoL) significantly higher than non-patients. One explanation for this discrepancy is that non-patients focus on the negative aspects of the onset of a condition, especially the early difficulties people face when they first experience a debilitating condition, without considering that patients can adapt to it over time. To test this hypothesis, we had 359 people perform person tradeoff (PTO) elicitations in an online survey, varying whether the treatment programs under consideration saved the lives of patients (a) with *pre-existing* paraplegia; or (b) who would experience *new onset* of paraplegia. Half of each group completed an "adaptation exercise" which encouraged them to consider their own ability to emotionally adapt to negative events in general and specifically to having paraplegia. The adaptation manipulation increased the value participants placed on pre-existing paraplegia ($p = 0.03$) and on new onset paraplegia ($p = 0.05$), relative to saving healthy lives. Moreover, the adaptation exercise dramatically reduced the differences between evaluations of pre-existing and new onset paraplegia to values within 2% of each other. Our findings suggest that asking non-patients to do an adaptation exercise before giving QoL ratings may help close the gap in ratings between patients and citizen non-patients.
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Keywords: Adaptation; Person tradeoff; Health state valuation; Cost-effectiveness analysis; Utility measure; Internet survey

Introduction

Chronic illness and disabilities often have far less influence on patient's overall ratings of their own quality of life (QoL) than non-patients would otherwise have imagined. When asked to imagine life on dialysis, for example, healthy people predict being unhappy the majority of the time, and yet most dialysis patients report being happy the majority of the time (Riis et al., in press). When asked what it is like to live with a serious spinal cord injury (SCI), most people imagine experiencing a significant drop in their overall QoL (Ubel et al., 2001), and yet most people with SCI emotionally adapt

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to their disabilities, and many report mood levels approaching those of healthy people (Bach & Tilton, 1994; Richards, 1986; Ville, Ravaud, & Tetrafigap Group, 2001).

Discrepancies in the QoL reported by patients and the QoL predicted by the general public have potentially important implications for cost effectiveness analyses. Cost-effectiveness experts incorporate QoL estimates into their mathematical models by asking the general public to imagine how they would feel if they had the illness or disability being evaluated, a process referred to as "utility elicitation." Through such elicitations, cost-effectiveness experts place health conditions on a 0–1 scale, where 0 is death and 1 is perfect health. This scale allows them to compare the relative benefits resulting from different health care interventions. For example, an intervention that cures people of a chronic condition with a utility of 0.8 brings twice the benefit of one that cures people of a condition with a utility of 0.9. When responding to such elicitations, the general public often expresses very different attitudes than patients do (Ashby, O'Hanlon, & Buxton, 1994; Boyd, Sutherland, Heasman, Tritchler, & Cummings, 1990; Froberg & Kane, 1989; Hall, Gerard, Salkeld, & Richardson, 1992; Hurst et al., 1994; Kane, Bell, & Riegler, 1986; Nord, 1992; Polsky, Willke, Scott, Schulman, & Glick, 2001; Sloan, Viscusi, Chesson, Conover, & Whetten-Goldstein, 1998; Tsevat et al., 1995, 1998). For example, in one study, the general public estimated the utility of end-stage renal disease to be 0.39, while end-stage renal disease patients estimated a utility of 0.56 (Sackett & Torrance, 1978). Another study found that patients without a colostomy estimated a utility for a condition requiring one at 0.80, while colostomy patients estimated a utility of 0.92 (Boyd, Sutherland, Heasman, Tritchler, & Cummings 1990). Clearly, results of cost-effectiveness analyses based on these kinds of valuations could vary dramatically because of such differences.

Many possible explanations exist for the discrepancy between patients and non-patients (Ubel, Loewenstein, & Jepson, 2003). Valuation differences may be due to differences in how health state descriptions are interpreted and understood (Boyd et al., 1990), a response shift in the scale used to measure QoL (Gibbons, 1999; Schwartz & Sprangers, 1999a, b; Sprangers & Schwartz, 1999; Wilson, 1999), a focusing illusion (Schkade & Kahneman, 1998; Wilson, Wheatley, Meyers, Gilbert, & Axsom, 2000), contrast effects (Brickman, Coates, & Janoff-Bulman, 1978; Dar, Ariely, & Frenk, 1995; Tversky & Griffin, 1991), or the impact of different perspectives (Barrett, 1997; Fredrickson & Kahneman, 1993; Gibbons, 1999; Kahneman, 1999; Kahneman, Fredrickson, Schreiber, & Redelmeier, 1993; Kahneman & Tversky, 1979; Schwarz & Strack, 1991; Shiffman & Stone, 1998; Taylor & Lobel, 1989). In this study, we will focus on one of the most promising explanations: failure of non-patients to consider a patient's ability to adapt to a chronic health condition (Loewenstein & Frederick, 1997). If non-patients fail to anticipate how patients adapt to their health conditions, they might focus too much on the shock of being newly debilitated, and therefore overestimate the long-term effects that illness or disabilities have on people's lives.

Evidence of the potential for non-patients to overweight the negative impact of the new onset of a chronic health condition was shown in two studies conducted by Ubel and colleagues, using the person tradeoff (PTO) elicitation (Ubel, Richardson, & Baron, 2002; Ubel, Richardson, & Pinto-Prades, 1999). In both studies, the median subject agreed that saving the lives of people with pre-existing paraplegia was equally good as saving the lives of healthy people. This result is in accord with other empirical results (Abellan-Perpinan & Pinto-Prades, 1999; Damschroder, Miklosovic, Roberts, Goldstein, & Ubel (Working paper); Nord, 1993) and ethical arguments (Arnesen & Nord, 2000; Menzel et al., 1999; Nord, Pinto-Prades, Richardson, Menzel, & Ubel, 1999) that prior health state should not be considered when prioritizing life-saving programs. Clearly, people want to avoid discriminating against patients with chronic health conditions within the context of saving lives. However, when the scenario was altered to present choices between saving the lives of healthy people and saving the lives of people who would experience *new onset* of paraplegia as a result of the life-saving treatment, the median subject placed a 10-fold lower value on saving the lives of people in the latter group (Ubel et al., 2002). Why did people place so much less value on saving the lives of people who experience *new onset* of paraplegia compared to saving the lives of patients with pre-existing paraplegia? Ubel and his colleagues started to explore this question by asking subjects to respond to both scenarios and varying the order in which the scenarios were presented in a second study. They found an even larger disparity in valuations: a 50-fold lower value for saving the lives of patients experiencing new onset of paraplegia when subjects responded to this scenario first. The median subject who responded to the pre-existing scenario first, however, agreed that saving the lives of patients with pre-existing paraplegia was equally good as saving the lives of healthy people (Ubel et al., 1999). When subjects were asked to place a value on saving the lives of people experiencing new onset of paraplegia *after* responding to the pre-existing paraplegia scenario, the relative value placed on saving the lives of people experiencing new onset of paraplegia increased to within 79% of the value placed on saving the lives of people with pre-existing paraplegia; still a wide discrepancy but substantially smaller. One possible reason for this order effect is that subjects were thinking about the desire not to discriminate between the two groups when the only difference

between the groups was that one was healthy before the life-threatening infection and the other group had pre-existing paraplegia. This mindset may have carried over into the new onset scenario when it followed after the pre-existing scenario. But what were the attributes that subjects focused on in one ordering of scenarios versus the other?

One possibility is that when asked to imagine *new onset* of paraplegia, people focus on the trauma of experiencing a new disability without considering a patient's ability to adapt to adverse circumstances (Ubel et al., 2001). People frequently mispredict how they will feel about a future event; specifically, they tend to overestimate the duration (Frederick & Loewenstein, 1999; Gilbert, Pinel, Wilson, Blumberg, & Wheatley, 1998) and intensity of their reactions to positive and negative events (Buehler & McFarland, 2001) and fail to appreciate the speed and extent to which they will emotionally adapt to changes in life circumstances (Frederick & Loewenstein, 1999; Gilbert et al., 1998). In addition, when people are asked specifically to consider adaptation, they consistently underpredict their own ability to adapt (Loewenstein & Frederick, 1997). However, a recent study found that when people went through an "adaptation exercise," designed to encourage consideration of their own ability to emotionally adapt to having paraplegia, they gave significantly higher QoL ratings for paraplegia (Ubel, Loewenstein, & Jepson).

In this study, we set out to answer whether non-patients are ignoring the potential for patients to adapt to a debilitating condition in their valuations. We predict that the value people place on saving the lives of patients with pre-existing paraplegia and on patients who experience new onset of paraplegia will be increased after asking people to consider how they themselves have emotionally adapted to negative events in the past and whether having the disability would get more or less upsetting over time. Moreover, we predict that the change in valuation will be greatest for new onset of paraplegia because the adaptation exercise will encourage people to think beyond the initial shock of experiencing a new disability.

Methods

Study subjects were members of a panel of Internet users who voluntarily agreed to participate in research surveys. This panel (the "Survey Spot Internet panel") is administered by Survey Sample International (SSI), a company that maintains information on over 1 million unique member households recruited through random digit-dialing, banner ads, and other "permission-based" techniques. (They do not use unsolicited e-mails or spam; for more information, please visit http://www.surveysampling.com/ssi_home.html). Subjects who completed our web-based PTO survey were entered into a drawing to win one of several cash prizes totaling $10,000. Email invitations were sent to a sample of panel members stratified to mirror the US Census population based on age, gender, race, education level, and income.

Elicitation technique

The PTO utility elicitation measure has been proposed as an alternative to traditional utility measures that incorporates the value people place on fairness and equity in cost-effectiveness analyses (Nord, 1995; Nord et al., 1999; Ubel, Loewenstein, Scanlon, & Kamlet, 1996, 1998; Ubel, Richardson, & Menzel, 2000). A typical PTO elicitation will ask subjects to choose between two alternative treatment programs. For example, subjects may be asked to choose between a treatment program that will save the lives of 100 previously healthy patients and an alternative program that will save the lives of 100 patients with pre-existing paraplegia. Subjects would then be asked to provide an indifference point by specifying the number of patients with pre-existing paraplegia who would have to be saved to be equally good as saving the lives of previously healthy patients. The higher the indifference point, the lower the value (in this example) people place on saving the lives of paraplegia relative to saving the lives of healthy people. We used life-saving scenarios in this study to extend the work of Ubel and his colleagues, which showed wide disparities in how people valued saving the lives of patients based on whether patients had pre-existing paraplegia or experienced new onset of paraplegia as a result of the life-saving treatment (Ubel et al., 2002, 1999). Many past studies using the PTO method have elicited social values of health states by presenting tradeoffs between saving healthy lives and curing the health state of interest. Valuations of these health states tend to compress toward 1 on a 0–1 utility scale (see, for example, Nord, 1992; Pinto-Prades, 1997; Ubel et al., 1998). At least part of this compression is because of the high value people place on saving lives compared to curing a pre-existing condition (Nord, 1992; Pinto-Prades, 1997; Ubel et al., 1996, 1998). Our decision to compare two life-saving alternatives, therefore, not only extends the work described earlier, but also avoids the confounding that can occur when comparing a life-saving treatment to a treatment that cures a non-life-threatening condition.

Subjects responded to one of two PTO elicitations via a web-based survey instrument. We prefaced all scenarios by asking subjects to:

> Imagine that you are the executive director of a regional health system responsible for providing health care for 1,000,000 (one million) people. The

health system operates with a tight budget, and you have only enough money to fund one of two treatment programs. Although other members of your staff may offer their input, the final decision is up to you. Imagine you must choose between two treatment programs, either of which would use up all the money that is available. The money cannot be split between the two programs, so you will only be able to fund one of them. The other program will not be funded, and the people who have the condition covered by that program will go untreated.

The baseline treatment program was the same for all subjects and would save the lives of patients with no pre-existing medical conditions. This treatment program had the following description:

> One program will cure people who have a blood infection. If these people are not treated within 48 hours, they will die. With treatment, they will be completely cured of their infection and they will return to their former health.

Fig. 1 shows the potential paths that a patient would take, starting from a point prior to the life-threatening illness, the potential for death if not treated, and the end state after treatment for each of the treatment programs (these figures are merely for illustrative purposes and were not included in our questionnaire). Graph 1a shows patients who had perfect health (x) before the life-threatening illness (a value of 1 on a 0–1 utility scale; with 0 being death and 1 being perfect health) in the baseline treatment program. If not treated, these patients would suffer death (y; utility of 0). If treated, they would be restored to perfect health (z; utility of 1). The line in Graph 1a goes down to 0 to depict the potential for death without treatment and travels up to a utility of 1 to depict the restoration of full health with the life-saving treatment. Subjects were randomized to compare this group with a group of patients receiving one of two alternative treatment programs.

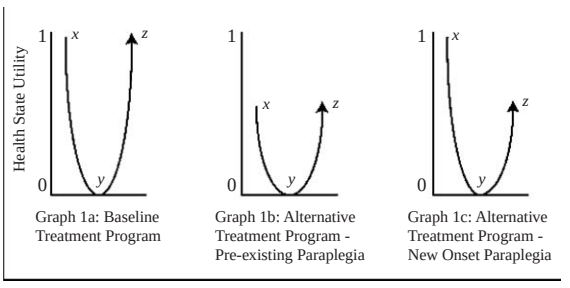

Fig. 1. Graphs depicting potential paths of patients in terms of utilities for the three treatment programs.

Graph 1b shows the potential path a patient would follow in the alternative treatment program presented in the *pre-existing paraplegia scenario*. These patients enjoy a somewhat lower QoL as measured by traditional utility elicitations (x; a value somewhere between 1 and 0). Without treatment, they would suffer death (y; utility = 0) and with treatment they would be restored to their former health (z; with paraplegia). This alternative treatment program was described as follows:

> The other program will cure people who have a blood clot. This condition only occurs in people with paraplegia (people who are paralyzed from the waist down). If they are not treated within 48 hours, they will die. With treatment, they will be completely cured and they will return to their former health, which means they will remain paralyzed from the waist down.

Graph 1c shows the potential path a patient would follow in the alternative treatment program used in the *new onset paraplegia scenario*. Without treatment, these patients would suffer death (y; 0) but with treatment, their lives would be saved and they would suffer new onset of paraplegia (z; with a utility between 0 and 1). This alternative treatment program was described as follows:

> The other program will cure people who have a spinal cord infection. If these people are not treated within 48 hours, they will die. With treatment, they will be completely cured of their infection but they will be left with paraplegia, which means they will be paralyzed from the waist down for the first time.

We informed subjects that the two programs (the baseline and the alternative) would treat the same number of patients and asked, "Who would you cure, thereby leaving the other group without treatment?" Subjects could choose one of the programs, or they could say, "I have no preference (cure either group and leave the other group untreated)."

If a subject chose one treatment program over the other, we asked, "how many people would have to be cured of a blood clot (or spinal cord infection, depending on the group assignment) to make the two programs seem equally good?" The subject first selected a range within which contained their indifference point and then they were prompted to give a numeric estimate of their PTO indifference point. A PTO indifference point of 200, for example, would indicate that the subject thought that saving the lives of 200 patients with new onset paraplegia (or pre-existing paraplegia) would be equally good as saving the lives of 100 patients with no pre-existing medical conditions—reflecting a relative

value that is half that for saving the lives of healthy people. The specific process we used to obtain the PTO indifference point is detailed in Appendix A. The ranges presented to subjects in Screen 2 in Appendix A were developed based on responses in an earlier study where subjects tended to provide "simple numbers" (e.g. 1000, 10,000, etc.) that ranged from 101 all the way up to the maximum number (300 million) allowed by the system (Damschroder et al., 2004). In addition, many subjects in the two precursor studies gave extremely high values within contexts that are similar to those presented in this study using a written open-ended response format (Ubel et al., 1999, 2002). The two earlier studies had 75th percentile values of 1,000,000 for most of the scenarios.

Half of subjects were randomized to an "adaptation exercise," detailed in Table 1, before responding to a PTO elicitation. In the exercise, we asked people to remember an "emotionally difficult life experience" and then reflect on how they actually felt 6 months later, versus how they predicted they would feel. We then asked subjects to imagine what it would be like to "experience paraplegia" and whether it would get more or less upsetting over time. We designed the questions to encourage people to reflect on their own ability to emotionally adapt to a negative situation before they responded to the PTO elicitations.

Table 1
Adaptation exercise

Think back to one emotionally difficult life experience that happened to you at least 6 months ago (e.g., divorce, death of a loved one, setback in school or work).
Immediately after this emotionally difficult experience, you probably felt pretty awful.
But think about how you felt six months after the event.
At the end of those six months, how did you feel compared to what you would have predicted immediately after it happened?

1 = I felt ***much worse*** than I would have predicted.
3 = I felt ***about the same*** as I would have predicted.
5 = I felt ***much better*** than I would have predicted.

Compared to the first few weeks after the event, how strong were your emotions six months later?

1 = ***Much stronger*** than before.
3 = ***About the same*** as before.
5 = ***Much weaker*** than before.

When you imagine what it would be like to experience paraplegia (paralyzed from the waist down), do you think it would become more or less upsetting over time?

1 = ***Much more*** upsetting over time
3 = ***Equally as*** upsetting over time
5 = ***Much less*** upsetting over time

Questionnaire versions

We randomized subjects to receive one of four questionnaire versions, varying the scenario (pre-existing paraplegia or new onset paraplegia, as described in the previous section) and whether the subject received the adaptation exercise.

Analysis approach

PTO indifference points were compared across the experimental groups non-parametrically using the Mann–Whitney *U*-test. We compared demographic characteristics across the experimental groups using analysis of variance for continuous variables and χ^2-tests for categorical variables. All analyses were executed using SPSS Version 10.

Results

Sample characteristics

Of Internet users who received an email invitation, 19.4% responded by clicking onto the survey site from the email invitation. Of those who responded, 42% completed the survey, of whom 6% admitted they gave "intentionally wrong answers." Overall, 36% of people who initially responded to the invitation were included in the analyses. People excluded from analyses tended to be older (average age of 50 versus 46; $p<0.001$) and less educated (32% of excluded subjects had a bachelor's degree or higher versus 39% of those included in the analysis; $\chi^2 = 9.6$, d.f. $= 3$, $p = 0.02$). This process yielded a total sample of 359 people who were included in the analyses. Of these, 178 were randomly assigned to the group receiving the adaptation exercise, with 84 subjects receiving the pre-existing paraplegia scenario and 94 receiving the onset scenario. The remaining 181 subjects were not presented with the adaptation exercise, with 93 subjects receiving the pre-existing scenario and 88 receiving the onset scenario.

Eight percent of subjects identified themselves as a racial/ethnic minority (African American, Hispanic, Pacific Islander, and American Indian, Latino/a or Alaskan Native). Reported age ranged from 18 to 78 years and mean age was 46 years (s.d. = 13). Overall, 57% of subjects were women and 62% of subjects had at least some college or trade school education. There were no significant differences in subject characteristics between experimental groups (p's $\geqslant 0.053$). Subjects took an average of 16 minutes to complete the survey (s.d. = 11) and there were no differences in time between the versions ($p = 0.18$). Subjects who had durations over 100 minutes or took the survey over several days'

duration were excluded from the duration analysis. These subjects most likely logged on and returned to finish the survey later. It is impossible to compute actual duration for these subjects.

PTO indifference points

Table 2 shows the median PTO indifference points, along with 25th and 75th percentile values, for each of the experimental groups. The median subject in the pre-existing paraplegia/no adaptation group had a PTO indifference point of 102. This means that the median subject in this group thought that saving the lives of 102 patients with pre-existing paraplegia was equally good as saving the lives of 100 healthy people. The relative value of saving the life of a patient with pre-existing paraplegia, therefore, was 98% of the value placed on saving the life of a previously healthy person. In the new onset/no adaptation group, the median PTO indifference point was 1000; the median subject thought that saving the lives of 1000 healthy people who would experience new onset paraplegia was equally good as saving the lives of 100 healthy people. The relative value for saving the lives of patients who would experience new onset paraplegia, therefore, was only 10% of the value placed on saving the life of a previously healthy person. Further, the valuation in the new onset paraplegia scenario was also only about 10% of the relative valuation in the pre-existing paraplegia scenario ($p = 0.02$). The spread in distributions was substantially different between the two no-adaptation groups. The interquartile range for the pre-existing paraplegia scenario was 4900 compared to 999,900 for the new onset scenario. The 75th percentile subjects in the latter group implied (with a 75th percentile value of 1,000,000) that new onset paraplegia is nearly as bad as death.

Table 2
PTO indifference points[a]

Percentile					p
Scenario		25	50	75	
Pre-existing paraplegia	No Adapt	100	102	5000	0.03
	W/Adapt	100	100	300	
New onset paraplegia	No Adapt	100	1,000	1,000,000	0.05
	W/Adapt	100	102	47,500	

[a]The PTO indifference point is the number of lives needed to be saved in the alternate treatment program (patients with pre-existing or new onset paraplegia) to be equally good as saving 100 lives of previously healthy patients.

The adaptation exercise significantly reduced PTO indifference points in both scenarios compared to indifference points without the adaptation exercise. The median subject in the pre-existing paraplegia/adaptation exercise group felt it was equally good to save the lives of 100 healthy people and 100 people with pre-existing paraplegia. Although this reduction appears slight (100 versus 102), the difference is statistically significant ($p = 0.03$) and the spread of responses was considerably reduced. The interquartile range was reduced from 4900 without the adaptation exercise to 200 with the adaptation exercise; a nearly 25-fold reduction in spread. In the new onset paraplegia scenario, adding the adaptation exercise reduced the PTO indifference point from 1000 to 102 ($p = 0.05$) for the two groups. The interquartile range was reduced from 999,900 without the adaptation exercise to 47,400 with the adaptation exercise. Though the relative value in the new onset paraplegia scenario moved to within 2% (102 versus 100) of the relative value in the pre-existing paraplegia scenario with the adaptation exercise, the values were still significantly different ($p = 0.03$).

Discussion

How much benefit is obtained by saving the life of a person who, after receiving life-saving treatment, will experience the onset of paraplegia? In this study, we found that the value people place on saving the lives of people with disabilities significantly increases when people think about the ability to emotionally adapt to difficult circumstances. The increase is especially large when people think about the *new onset* of a disability. As with earlier research, our study confirms that people place significantly less value on saving the lives of patients who experience new onset of paraplegia compared to saving the lives of people with pre-existing paraplegia. Though both groups of patients end up in the same objective state of health, a patient's previous health state significantly impacts people's valuations of alternative treatment programs. We also demonstrated that introducing an adaptation exercise, designed to encourage subjects to consider their own ability to adapt to difficult circumstances, as well as to paraplegia, significantly increased the value people placed on paraplegia in a life-saving context. The impact of the adaptation exercise was particularly dramatic (a nearly 10-fold increase in relative values) in the new onset paraplegia scenario. Though the statistical significance may be considered borderline by some ($p = 0.05$), the shift is materially and clinically important. Both the median and interquartile range were greatly reduced.

Scenarios that involve saving the lives of people with pre-existing conditions may focus respondents on the importance of giving equal value to saving lives

regardless of the presence of a pre-existing chronic condition. By contrast, scenarios that involve new onset of a debilitating condition like paraplegia may focus people on the trauma associated with a dramatic change of health state, e.g., losing mobility because of paraplegia. The adaptation exercise appeared to mitigate this effect, bringing the values people place on paraplegia, whether pre-existing or new onset, much closer together. Our results therefore support the notion that the degree to which people consider their own ability to adapt to adverse situations has a significant impact on how they value alternative life-saving programs.

While the adaptation exercise succeeded in moving the median and spread of responses closer together, the 75th percentile value in the new onset paraplegia scenario reflects a value that is only 1/475th the value of saving the life of a healthy person. It is possible that these subjects were, in part, influenced by the large spread in ranges that we presented to them. Nevertheless, it is clear that, on the whole, people still placed substantially lower value on saving the lives of patients who experience new onset paraplegia, regardless of the ranges that were presented.

Some subjects may be influenced if other descriptive factors are included in an exercise like the one used in this study. Non-patients may not consider the ethical implications of valuing one life less than another based on the presence of a disability within the context of the new onset of that condition. The exercise could be expanded to include more explicit references to the value that people with paraplegia place on their own lives: people who have adapted to paraplegia are no more likely to want to give up living than healthy people, nor is their right to live diminished just because of their health state.

Our results have important implications for the continuing debate over whether to use values elicited from citizens who, acting as hypothetical patients, have not experienced the condition being valued versus patients who have adapted to the condition. The question of whose value to use is unresolved and researchers have made cogent arguments for patients (Boyd et al., 1990; Nord et al., 1999) and for non-patients (Gold, Siegel, Russell, & Weinstein, 1996). The answer to this question has large implications for how alternative programs are prioritized in a context of constrained resources. Based on results from our study, it appears that, at a minimum, non-patient citizens should be given an adaptation exercise before being asked to place a value on a chronic health condition. This exercise may significantly close the gap in values between patients and non-patients, though not completely.

Further work is needed to determine whether the adaptation exercise will change valuations using other commonly used elicitation methods including the time tradeoff and standard gamble methods. Ubel and his colleagues found trends similar to the findings we report here using an analog scale with 0 being death and 100 being perfect health, and with and without an adaptation exercise. Subjects who did the adaptation exercise rated paraplegia significantly higher than those who did not do the adaptation exercise (Ubel et al., Working Paper). More research is needed to confirm that this result will carry over to the time tradeoff and standard gamble methods.

Menzel and his colleagues conducted a normative analysis to define a framework for determining the role adaptation should play in valuing health-related QoL. They maintain that "as hypothetical patients, representatives of the general public are very likely to be factually mistaken if they imagine themselves to have a health state to which they believe that they will never adapt" (Menzel, Dolan, Richardson, & Olsen, 2002). We posit that most people, when asked to imagine living with a debilitating condition, do not think of their ability to adapt to the condition over time. Menzel and his colleagues point out the need for a better understanding of adaptation and its influence on stated preferences for various health conditions. Until we understand why preferences of the chronically ill and the public are different, we cannot discern whose voice is appropriate in providing societal values for health states—patients or non-patients. Our results provide important insights into the role of considering adaptation in non-patients valuations. It is clear that encouraging non-patient's to think about their own ability to adapt to difficult situations changes the majority of stated preferences for saving the lives of people who have paraplegia; whether it is newly onset or pre-existing.

Our results are limited to a context that asks people to value trade-offs between saving the lives of people with existing versus new onset paraplegia. Future research is needed to explore whether these results extend to contexts that ask people to consider tradeoffs between life-saving versus curing the condition. In addition, our study is limited by the fact that Internet samples can be affected by response bias associated with the generally younger and more educated subjects who completed the survey compared to subjects who responded but dropped out of the survey. Though our response rate appears low (19%), it is not out of line with other Internet-based studies that use opt-in panels like the one in this study. Couper, in a comprehensive review of using the Internet to conduct surveys, cites response rates ranging from 8% to 60% from studies conducted in the US and Japan (Couper, 2001). One published study, using the same SSI opt-in panel as the one used in this study, documented a 20% response rate (Couper, Tourangeau, & Steiger, 2001). The average response rate in the SSI panel used in our study is 15%

(REF: personal communication, MSI Research, Inc.). Though we attempted to recruit a sample representative of the US population by stratifying the invitation list to mirror the US population with respect to age, gender, and income, we found that fewer people of minority status responded to the invitation (about 20% of invitations were sent to minorities but only 8% of subjects who completed the survey were self-reported minorities). Our 42% completion rate, combined with the 19% response rate means that, overall, only 7% of people who were invited to participate actually completed the survey. However, this low percentage is of lesser concern here than in other survey contexts. Our intent was to elicit responses from a diverse sample of subjects in order to compare an experimental manipulation in a randomized study and we do not intend to generalize the specific values obtained in our study to the general population. We did succeed in recruiting a relatively diverse pool of subjects to demonstrate whether people would be influenced by an adaptation exercise prior to providing valuations of alternative treatment programs. Clearly, the adaptation exercise had an impact on the value that a diverse sample placed on paraplegia. Importantly, our results mirror those found in previous studies (Ubel et al., Working Paper; Ubel et al., 2002, 1999), in spite of the fact that the sampling frames (Internet users versus prospective jurors) and elicitation methods (computerized versus paper-and-pencil) were remarkably different. Given the dramatic impact we observed and corroboration of our results with earlier studies, this phenomenon is likely widely applicable and deserves further exploration.

Conclusion

Presenting citizen non-patients with an adaptation exercise before evaluating health states, especially when the health state being evaluated is a new onset condition, is promising as a method to use to begin to close the gap in QoL ratings provided by patients and non-patients. Priming people to consider their ability to adapt to a debilitating condition such as paraplegia had a dramatic impact on the value people place on that condition in PTO elicitations. This finding explains part of the discrepancy between the values that patients, who have adapted to a condition, and non-patients, who may not consider their own ability to adapt to a debilitating condition, place on that condition. If citizen non-patients are not first encouraged to think about their own ability to adapt to a chronic health condition, the values that they assign to chronic health conditions when using other elicitation methods (for example, time tradeoff and standard gamble) are likely to be flawed.

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Appendix A. Detailed elicitation sequence

The following elicitation sequence is presented for subjects who were assigned to receive the new onset paraplegia scenario and is the same sequence used for the pre-existing paraplegia scenario (Screens 1–4).

Screen 1

Initial choice

Imagine that **you are the executive director** of a regional health system responsible for providing health care for 1,000,000 (one million) people. The health system operates with a tight budget, and you have only enough money to fund one of two treatment programs. Although other members of your staff may offer their input, **the final decision is up to you**.

Imagine you must choose between two treatment programs, either of which would use up all the money that is available. The money cannot be split between the two programs, so you will only be able to fund one of them. The other program will not be funded, and the people who have the condition covered by that program will go untreated.

- One program will cure people who have a **Blood Infection**. If these people are not treated within 48 hours, they will die. With treatment, they will be completely cured of their infection and they will return to their former health.
- The other program will cure people who have a **Blood Clot** . This condition only occurs in people with paraplegia (people who are paralyzed from the waist down). If they are not treated within 48 hours, they will die. With treatment, they will be completely cured and they will return to their former health, which means they will remain paralyzed from the waist down.

The two programs will treat the same number of people.

Who would you cure, thereby leaving the other group without treatment?

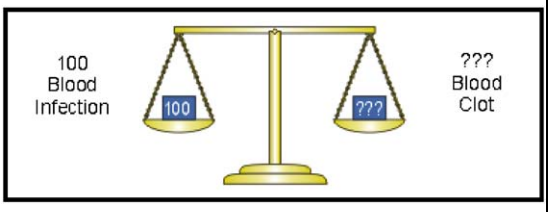
- The people with a Blood Infection
- The people with a Blood Clot
- I have no preference (cure either group and leave the other group untreated

Screen 2
Select a range

Remember that our goal is to find the number of people who would need to be cured by each treatment program so that the two programs seem equally good to you.

You just said that you would prefer a program curing people of a Blood Infection rather than one curing people of a Blood Clot.

Now imagine one program could cure 100 people of a Blood Infection.



How many people would have to be cured of a Blood Clot to make the two programs seem equally good?

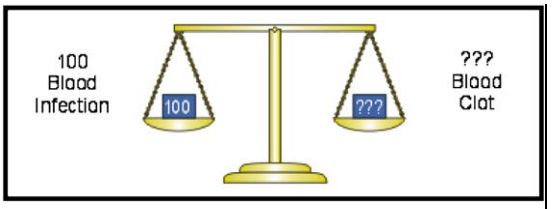
Remember, there are 1,000,000 people in the health system.

Choose a range from the following list

- 101 - 1,000
- 1,001 - 10,000
- 10,001 - 100,000
- 100,001 - 1,000,000
- More than 1,000,000 people
- I can't answer this question

Screen 3
Provide the PTO indifference point

Now, let's see if you can narrow down your answer.



Thinking of a number between 1,001 and 10,000, how many people would have to be cured of a Blood Clot to make the two programs seem equally good?

Remember, there are 1,000,000 people in the health system.

5000

Screen 4
Final confirmation

Let's see if that is your final answer.

Imagine that you must choose either to cure 100 people of a Blood Infection or to cure 5,000 people of a Blood Clot.

Who would you cure, thereby leaving the other group without treatment?

- ○ 100 people of a Blood Infection
- ○ 5,000 people of a Blood Clot
- ◉ I have no preference
- ○ can't answer this question

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