Misremembering Colostomies? Former Patients Give Lower Utility Ratings Than Do Current Patients

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Community members often evaluate health conditions more negatively than do the patients who have them. The authors investigated whether experience with a health condition reduces this discrepancy by surveying colostomy patients by mail ($n = 195$), some of whom ($n = 100$) had their colostomies reversed and normal bowel function restored. The authors also surveyed a community sample recruited via the Internet ($n = 567$). They then compared all 3 groups’ utility value for life with a colostomy by using the time trade-off utility measure and by examining ratings of current quality of life. Despite having direct experience with the health condition, former colostomy patients provided much lower utility valuations than did current patients. In fact, their valuations were similar to those given by a community sample. Rather than accurately remembering their actual experiences with colostomies, the former patients may have applied a theory of how colostomies had influenced their lives; this is consistent with other research on theory driven recall bias.

Keywords: health utility, recall bias, quality of life

When considering a health condition, members of the general public often give discrepant utility values from those given by patients who have the health condition being valued. Generally, the public gives lower ratings, often believing that the health condition would have a more negative effect on quality of life (QOL) than is reported by people currently experiencing the condition (De Wit, Busschbach, & De Charro, 2000). The presence of systematic differences in perceptions of health utilities creates problems for policy makers. When groups disagree, this raises questions about whose values should be used to guide policy—those of patients who are directly affected by and have directly experienced the health state or those of the general public who will bear part of the costs of the policies and who may have a more detached, objective perspective (Ubel, Loewenstein, & Jepson, 2003).

Researchers have proposed, and tested for the impact of, a variety of different causes of the discrepancy between valuations of health states by the public and by patients (Ubel, Loewenstein, Schwarz, & Smith, 2005). One factor that has not received very much attention is the possibility that the different groups have different ideas about what life with a health condition is like. Members of the public rely on information provided by researchers, often in the form of a vignette, which will inevitably be integrated with prior, often stereotypical, views that they might hold about the condition being evaluated. Patients, in contrast,
have direct, albeit often idiosyncratic, experience with their health condition.

Concern about this issue has led some researchers to examine whether members of the public who have some exposure to the illness give valuations that are closer to those given by patients (Badia, Herdman, & Kind, 1998; Dolan, 1996). Presumably those with exposure are less likely to hold basic misconceptions about what it means to have an illness. Some of these studies have shown that utility valuations are consistent before and after exposure to a health state (e.g., Llewellyn-Thomas, Sutherland, & Thiel, 1993). Other studies have found that experience affects, but typically does not eliminate, discrepancies with patients (De Wit et al., 2000; O’Leary, Fairclough, Jankowski, & Weeks, 1995). For example, one study compared the utility for living with a colostomy given by patients with a colostomy, physicians, healthy controls, and rectal cancer patients with no colostomy. The physicians’ valuations were closer to those of the colostomy patients than were the valuations from the other groups, but they were still lower than the valuations provided by the patients themselves (Boyd, Sutherland, Heasman, Trichtler, & Cummings, 1990). In another study, focusing on metastatic breast cancer, patients’ physicians and family members provided estimates of patients’ QOL that were below those reported by the patients themselves (Wilson, Dowling, Abdolel, & Tannock, 2000).

It is not surprising that discrepancies persist even among people with a close acquaintance with the health condition being valued. After all, a colorectal surgeon may have a lot of experience interacting with colostomy patients in a clinical setting, but she will rarely, if ever, interact with her patients outside of a clinical setting. Friends and relatives of colostomy patients, though they may interact with these patients on a daily basis, will still never have experienced what it is really like to live with a colostomy.

What, then, would we expect from people who have had experience with the condition being valued? Our study was designed to extend knowledge about how experience with a health condition affects valuations of health conditions by exploring a unique circumstance: former patients who have actually “walked in the shoes” of patients because they have previously experienced the health condition in question.

Given that former patients have had direct experience with the medical condition, one might expect them to provide recollections of the QOL associated with the condition that are similar to the self-reported QOL of those currently experiencing the condition. However, there are reasons to expect that even those who have previously experienced a health condition will provide QOL recollections that are different than the reports of current patients.

Why Former Patients Might Provide Different Utility Estimates Than Current Patients

For former patients to give an assessment of utility requires them to accurately remember what life was like with the condition and then to construct an assessment of how much the condition detracted from their overall QOL during that time. Biases could occur at both stages of this process. For example, former patients may focus on certain aspects of their condition (e.g., the amount of physical limitation, pain) but may not accurately recall how these aspects affected their overall emotional well-being. Indeed, research has indicated that people do not necessarily recall emotional experiences accurately. Instead, when asked to recall how some event affected their emotional well-being, people rely on implicit theories to construct responses, creating a theory driven recall bias (Ross, 1989). In this case, former patients might apply a theory that a disability has a strong negative effect on happiness, and they might assume that they must have been much less happy than they are now, resulting in lower utility valuations.

In addition, there are reasons that former patients might provide higher retrospective utilities for the health condition than utilities given by current patients or by community members. Prior research on retrospective evaluations has found that people tend to judge sequences of experiences, in part on the basis of their end (Kahneman, 1999) or trend (Ariely & Loewenstein, 2000). Either tendency could lead patients whose condition was reversed to evaluate the overall experience as more positive than they otherwise would have. If all else were equal, one would expect that this would cause former patients to provide higher utility valuations compared with predictions of community members who have no experience with the health condition. In the extreme, it could even cause former patients to provide higher utility valuations than current patients.

The Current Investigation

Colostomy patients provide a unique opportunity to further investigate the public–patient discrepancy because many have their colostomies reversed, usually after several months, and normal bowel function restored. We surveyed patients who had undergone colostomy or ileostomy surgery in the last 5 years and compared the utilities each group assigned to colostomy by using a very common measure of utility, the time trade-off (TTO; described in the Method section). We also surveyed a sample of community members, who had no direct experience with colostomy. If lack of experience with the condition is the driving force behind the generally lower utilities, we should expect to see little or no discrepancy between the utility ratings of former and current patients, whereas the community sample should provide lower utility ratings. If one of the other biases that has been discussed in the literature is responsible for the discrepancy, however, then we would expect former patients’ valuations to be closer to those given by community members.

Consistent with prior research demonstrating a relatively mild effect of disability on overall well-being (Brickman, Coates, & Janoff-Bulman, 1978; Riis et al., 2005), we predicted that the current self-assessed QOL and health would not differ substantially among the groups. Also on the basis of prior research, we predicted that a community sample would give lower utility values for colostomy than current patients. And, consistent with a theory driven recall bias, we expected that former patients would remember being less happy in the past, before their colostomy was reversed, whereas current patients would remember being more happy in the past, before their colostomy surgery. The open question, for which we have little prior research to guide our expectations, concerns the relationship between the recollections of former patients, the reports of current patients, and the predictions of the general public. As we discussed, there are reasons why these three types of QOL assessments might exhibit any one of...
several different patterns. The central goal of the current research is to determine which of the possible patterns represents reality.

Method

Former and Current Colostomy Patients

Participants. Using a database derived from hospital billing records, we identified 330 individuals who had undergone colostomy or ileostomy surgery at the University of Michigan in the last 5 years. To be eligible, participants must have been 18 or older at the survey time. Of the eligible 330 individuals, 195 completed and returned the survey, giving us a 59.1% response rate. We paid participants $25 per completed survey.

Measures. The survey consisted of questions about participants’ type of colostomy (i.e., colostomy versus ileostomy; we use the term colostomy throughout to refer to both types), reason for undergoing the surgery, attitudes toward colostomy-related events, overall QOL, current health, happiness, health rating, the TTO, and demographic questions. The survey took approximately 45 min to complete.

Current health. The health utility question asked participants to choose a number between 0 and 100 that best represents their current health, where 0 represents the worst imaginable health, and 100 represents the best imaginable health.

QOL. An overall QOL question asked participants to choose a number between 0 and 100 that best represents their current QOL (0 = the worst imaginable QOL; 100 = the best imaginable QOL).

Life satisfaction. Overall life satisfaction was measured with the Satisfaction With Life Scale (Diener, Emmons, Larsen, & Griffin, 1985). This instrument comprises statements about respondents’ general feelings and attitudes concerning their life, such as “In most ways my life is close to my ideal” and “So far I have gotten the important things I want in life.” Respondents indicate how much they agree or disagree with these statements on a 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree).

Affect. Positive and negative affect was measured with the Positive Affect/Negative Affect Scale (PANAS) developed by Watson, Clark, and Tellegen (1988). This scale includes a list of 23 different feelings and emotions. Participants were asked to indicate to what extent they have felt each of these feelings or emotions during the last week on a 5-point scale ranging from 1 (very slightly or not at all) to 5 (extremely). Items included such feelings and emotions as “interested,” “excited,” “nervous” and “uncertain about things.”

QOL recall and prediction. Another item gauged participants’ general QOL in the past, present, and future. The Ladder Scale, or Self-Anchoring Striving Scale (Cantril, 1967) asks participants where on a 0–10 “ladder” they stand at the present time, where they stood 5 years ago, and where they think they will stand 5 years from now. The top of the ladder (10) represents the best possible life for them, and the bottom (0) represents the worst possible life.

Importance item. Participants were also asked to indicate how much they agreed with the statement: “Having normal bowel function is more important to me than just about anything else,” on a 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree).

The TTO utility measure. The TTO is a widely used method to evaluate the perceived utility of a health condition (De Wit, Busschbach, & De Charro, 2000). Our measure was adapted from Torrance, Thomas, and Sackett (1972) and was formatted for self-report in a written survey. The TTO measure asks participants to indicate how many months of life they would trade in exchange for having normal bowel function restored. Participants imagined they had to choose between living 10 years (an arbitrary but commonly used time frame) with a permanent colostomy (whether or not their actual colostomy had been reversed) and then dying in their sleep, or living a varying amount of time (between 1 month and 10 years) without a colostomy and then dying in their sleep. They also had the option of indicating that the two choices are equal. The TTO score was calculated from answers to a series of 10 forced choices, beginning with a “ping pong” set of extreme choices to make the trade-off evident. Higher values on the TTO indicate less willingness to trade off hypothetical months (from a minimum of 0 to a maximum of 119) of the participant’s life in order to restore normal bowel function, which in turn indicates a higher utility rating of the condition.

In order to generate an interpretable TTO score from a set of responses, the answers must be internally consistent. For example, if a participant indicates that he would not trade 24 months of life with a colostomy for perfect health, and then later indicates that he would trade 36 months, this is not interpretable and is coded as missing. In addition, some participants decline to engage in the exercise and leave all of the items blank or refuse to make any choice between the health states even though the varying time frame makes this illogical (i.e., if life with colostomy at 10 years has been rated equally to life without colostomy at 10 years, then it should be rated as superior to life without a colostomy for less than 10 years.)

Procedures. After receiving permission from 10 University of Michi- gan surgeons to contact their colostomy and ileostomy patients, we com- piled a list of 330 potential patient participants on the basis of our criteria. We sent each patient a survey, a payment form (mentioning that they would receive $25 for completing the study) and two self-addressed, stamped envelopes: one for the survey and one for the payment form. Respondents returned the surveys and payment forms separately to further ensure the confidentiality of their responses. If we did not receive a participant’s payment form within 2 weeks, we made a series of reminder calls over the next several days; we also sent a reminder letter and another copy of the survey. Those who responded were classified as current or former patients on the basis of their responses to the question: “Do you still have your colostomy or has it been reversed?” Our final yield was 95 current patients and 100 former patients.

The Community Sample

Participants. These participants were drawn from a panel of Internet users who voluntarily agreed to participate in research surveys. This panel is administered by Survey Sample International (SSI) and includes over 1 million unique, member households recruited through random digit dialing, banner ads, and other “permission-based” techniques. (For more informa- tion, see http://www.surveysampling.com). Individuals completing our Web-based survey were entered into a drawing to win a cash prize of up to $1,000. E-mail invitations were sent to a sample of panel members strat- ified to mirror the U.S.-census population on the basis of gender, education level, and income. Respondents over the age of 50 were oversampled.

A total of 7,240 people received e-mail messages inviting them to participate in an online survey, and 606 clicked the embedded link to begin the survey (an 8.4% response rate). Of these, 567 completed at least one measure, and 523 completed the full survey instrument, a completion rate of 86%.

Measures. The community sample provided demographic information, read a brief description of colostomy (provided in the Appendix), and answered questions regarding their perception of QOL with a colostomy. Relevant to the current investigation, they also provided a TTO valuation and rated their own current health (0–100), overall QOL (0–100), and current life satisfaction by using the same measures described earlier.

Analysis Plan

We compared all three groups on their TTO valuations for colostomy by using a one-way analysis of variance (ANOVA). Planned contrasts com- pared (a) current patients to former patients and (b) current patients to the community sample. We also examined demographics to determine whether
the groups differed in terms of age, gender, or race, and we constructed regression models to control for these potentially confounding factors. We performed separate analyses of current and former colostomy patients that also controlled for time since colostomy surgery and reason for receiving a colostomy.

We next compared all three groups on their ratings of their current health, overall QOL, and life satisfaction again by using a one-way ANOVA with follow-up contrasts. We also compared the current and former patients on measures of current mood and happiness and on their perceived importance of having normal bowel function by using between subjects \( t \) tests. Finally, we used a within-subjects ANOVA to examine current versus past happiness for the two patient groups.

### Results

Sample demographics are presented in Table 1. These show that current patients are older than former patients \( (p < .05) \) and had their colostomy surgery longer ago \( (p < .01) \) and that the community sample included a larger proportion of women \( (p < .01) \) and minorities \( (p < .001) \) than did the two patient samples.

#### TTO Valuations of Former and Current Patients and Community Members

We first looked at the TTO valuations given by all three groups for the condition of having a colostomy. As described earlier, responses were calculated as the number of months, from 0 up to a maximum of 119, participants were willing to trade to not have a colostomy. Thus, a willingness to trade fewer months indicates a higher utility value for having a colostomy. Of the patients, 160 of 195 gave interpretable responses to the TTO (i.e., nonmissing responses that were internally consistent), which was 82\% of our total sample (former patients: rate = 80\%; current patients: rate = 84\%). For the community sample, 375 out of 563 provided interpretable responses, which was 67\% of our total sample.

Former patients and community members gave much lower utility ratings for having a colostomy than did current patients. Specifically, the former patients reported being willing to trade an average of 43 out of 120 months of life (utility: \( M = .64, Mdn = .80 \)) to live without a colostomy, compared with 19 months (utility: \( M = .84, Mdn = .94 \)) for current patients. A similar valuation was provided by the community sample, who were willing to trade an average of 44 months (utility: \( M = .63, Mdn = .75 \)). A one-way ANOVA revealed that these means are significantly different from one another, \( F(2, 532) = 13.06, p < .001 \). Two sets of planned contrasts revealed that (a) former patients’ valuations were significantly lower than the valuations of current patients, \( t(532) = -3.77, p < .001, d = .68 \), and (b) community members’ valuations were significantly lower than the valuations of current patients, \( t(532) = -5.07, p < .001, d = .70 \) (see Table 2).

As already noted, our three samples differed in terms of demographics: in particular, age, gender, and race. To control for these differences, we constructed a regression model with two dummy-coded variables to test the effect of patient status on the TTO (expressed as number of months willing to trade). Similar to the planned contrasts reported in the previous paragraph, the first dummy variable was computed to compare former with current patients, whereas the second was computed to compare community members with current patients. We also entered age, gender (dummy coded), and race (dummy coded to compare non-Whites to Whites). The results indicated that the overall model was significant, \( F(5, 517) = 5.74, p < .001 \), and that both patient effects remained significant. Specifically, former patients were willing to trade more months than were current patients \( (b = 23.96, p < .001) \).

**Note:** Less than 6\% of respondents had missing data on any item except for annual income (9\%).

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### Table 1

#### Sample Demographics

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Current patients ( (n = 95) )</th>
<th>Former patients ( (n = 100) )</th>
<th>Community members ( (n = 567) )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age ( M )</td>
<td>55.44</td>
<td>50.09</td>
<td>54.15</td>
</tr>
<tr>
<td>( SD )</td>
<td>15.01</td>
<td>17.34</td>
<td>16.03</td>
</tr>
<tr>
<td>( % )</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>50</td>
<td>47</td>
<td>64</td>
</tr>
<tr>
<td>Male</td>
<td>50</td>
<td>53</td>
<td>36</td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-White</td>
<td>12</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>White</td>
<td>88</td>
<td>95</td>
<td>72</td>
</tr>
<tr>
<td>Months since colostomy</td>
<td>50.49</td>
<td>31.08</td>
<td>31.08</td>
</tr>
<tr>
<td>( Mdn ) annual income**</td>
<td>$25K–$40K</td>
<td>$25K–$40K</td>
<td>$40K–$60K</td>
</tr>
<tr>
<td>Cause of colostomy/ileostomy</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Inflammatory bowel disease</td>
<td>29</td>
<td>42</td>
<td></td>
</tr>
<tr>
<td>Familial adenomatous polyposis</td>
<td>3</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Cancer</td>
<td>41</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Trauma/accident</td>
<td>1</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Spinal cord injury</td>
<td>1</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Other cause†</td>
<td>13</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>More than one reason listed</td>
<td>5</td>
<td>11</td>
<td></td>
</tr>
</tbody>
</table>

**Note.** Less than 6\% of respondents had missing data on any item except for annual income (9\%).

**Note.** Annual income was measured on a 7-point scale, on which 1 = <$10K, 2 = $10K–$25K, 3 = $25K–$40K, 4 = $40K–$60K, 5 = $60K–$80K, 6 = $80K–$100K, 7 = >$100K. † The most commonly cited reasons in this category involve various types of infections and surgical complications.
Table 2
Means and Standard Deviations of Utility, Subjective Quality of Life, and Other Measures as a Function of Colostomy Condition

<table>
<thead>
<tr>
<th>Measure</th>
<th>Current patients (n = 95)</th>
<th>Former patients (n = 100)</th>
<th>Community members (n = 567)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time trade-off utility (0–1)</td>
<td>.84 (.24, .94)</td>
<td>.64 (.35**, .80)</td>
<td>.63 (.36**, .75)</td>
</tr>
<tr>
<td>Life satisfaction (1–7)</td>
<td>4.13 (1.70)</td>
<td>4.46 (1.45)</td>
<td>4.21 (1.50)</td>
</tr>
<tr>
<td>Overall quality of life (0–100)</td>
<td>67.60 (24.43)</td>
<td>71.32 (19.89)</td>
<td>72.60 (20.67**)</td>
</tr>
<tr>
<td>Current health (0–100)</td>
<td>62.51 (23.34)</td>
<td>63.57 (21.25)</td>
<td>69.81 (22.51**)</td>
</tr>
<tr>
<td>Positive mood (1–5)</td>
<td>3.15 (0.88)</td>
<td>3.06 (0.78)</td>
<td></td>
</tr>
<tr>
<td>Negative mood (1–5)</td>
<td>1.82 (0.73)</td>
<td>1.88 (0.70)</td>
<td></td>
</tr>
<tr>
<td>Where on ladder at present (0–10)</td>
<td>6.11 (2.18)</td>
<td>6.51 (1.91)</td>
<td></td>
</tr>
<tr>
<td>Where on ladder 5 years ago (0–10)</td>
<td>6.79 (2.62)</td>
<td>6.09 (2.83*)</td>
<td></td>
</tr>
<tr>
<td>Importance of normal bowel function (1–7)</td>
<td>3.63 (1.77)</td>
<td>4.96 (1.64*** )</td>
<td></td>
</tr>
</tbody>
</table>

Note. The significance tests in the table indicate whether former and/or community members differed from current patients. When data are available for all three groups, the significance level is for the corresponding planned contrast following a significant one-way analysis of variance. Values in parentheses indicate scale/measure range.

.001), as were community members (b = 26.32, p < .001). No other variable in the model reached or approached conventional levels of significance (all ps > .15).

Other Differences Between the Two Patient Groups

The current and former patients also differed from one another with respect to how long ago their colostomy or ileostomy surgery occurred (50.49 months for former patients compared with 31.08 months for current patients). We again performed the multiple regression analysis described earlier for these two groups, with time since surgery included as the control variable. Results indicate that the effect of patient status on TTO valuation remained significant, after controlling for time since surgery as well as the other demographic variables (b = 20.21, p < .01). No other variable reached or approached significance, including time since surgery (all ps > .12).

We also observed differences in the listed reason for the colostomy surgery. For example, former patients were somewhat more likely to report that their surgery was needed because of inflammatory bowel disease (IBD; 42% versus 29% of current patients), and current patients were much more likely to report that their surgery was due to cancer (41% versus 11% of former patients). Because of the variety of reasons listed (more than 12), adjusting for all of these in analyses is not feasible given our sample size. However, by collapsing across many of the less frequently cited reasons, we were able to create three categories (cancer, IBD, and other), represented by two dummy-coded variables, one for cancer and one for IBD. A regression analysis that included all of the previously examined control variables, plus the two variables controlling for cause of colostomy revealed that the effect of patient status remained significant (b = 15.99, p < .05). Having had a colostomy because of cancer was also a significant (but negative) predictor of number of months willing to trade (b = −21.43, p < .01). Finally, we added a dummy variable to the model that indicated either that the colostomy surgery occurred because of something that came up suddenly, such as trauma, or because of something more gradual, like inflammatory bowel disease. In this analysis, the effect of patient status was significant (b = 17.95, p < .01), as was the negative effect of cancer (b = −19.39, p < .05), but neither the suddenness variable nor any other variable approached statistical significance.

Current Health and QOL Ratings of Former and Current Patients

We also compared the three groups on their perceptions of their own life satisfaction (Cronbach’s α = .92), overall QOL (0–100), and current health (0–100). The results are presented in Table 2. Results of a one-way ANOVA indicated no significant effect on life satisfaction (p > .2), an effect that approached significance on overall QOL, F(2, 748) = 2.32, p < .10, and a significant effect on current health, F(2, 743) = 6.41, p < .01. Follow-up contrasts of these latter two variables revealed that in both cases there was no significant difference between current and former patients (both ps > .2) but that community members rated their current QOL and health status higher than did current patients, t(748) = 2.14, p < .05, d = .23, and, t(743) = 2.82, p < .01, d = .32, respectively. We also collected data on positive and negative mood during the last week (α = .92 and α = .89, respectively) for the current and former patients and found no differences (both ps > .2). Overall, these results suggest that current perceptions of QOL do not appear to be greatly affected by whether patients’ colostomies had been reversed.

Final Comparisons

The current and former patients also responded to a question that asked them to rate both their current level of QOL and their remembered QOL from 5 years prior (see Table 2). Because all patients had their colostomy surgeries within the last 5 years, this item asks both current and former patients to recall their QOL before they had a colostomy. Within-subjects/between-subjects ANOVA revealed a significant interaction between patient status and current versus remembered hap-
piness, $F(1, 190) = 5.09, p < .05$. The means are presented in Figure 1 and suggest that although current patients believe they were happier prior to their colostomy, former patients believe they were less happy. Overall, former patients remembered a level of happiness that is marginally lower than the level remembered by current patients, $t(191) = 1.78, p < .10$, $d = .26$.

Finally, participants indicated their agreement with the statement that “having normal bowel function is more important to me than just about anything else.” Responses were consistent with the utility valuations given by the two groups. Former patients indicated more agreement with this statement than did current patients, $t(188) = -5.41, p < .001$, $d = .79$.

**Discussion**

Utilities from former patients for living with a colostomy were lower than utilities given by current colostomy patients. In fact, the difference was striking—former patients were willing to give up over 43 out of 120 months of life to live without a colostomy, which was similar to the 44 months that the community sample were willing to give up, but both were radically different from the 19 months specified by current patients. This discrepancy in utility ratings persisted after controlling for group differences with respect to age, gender, race, and elapsed time since surgery. Although we could not statistically control for all of the causes of the colostomy surgery that may differ between current and former patients, we were able to control for the two most frequently cited causes, inflammatory bowel disease and cancer. Having cancer was more common for current patients and was a positive predictor of TTO valuation, but the difference in utilities between current and former patients persisted after controlling for this effect.

This finding suggests that patients recall their colostomy as having a very negative impact on life quality. Yet, various measures of current life satisfaction, mood, and QOL differed little across these two groups. These data suggest that the discrepancy in valuations often observed between patients and the general public is not solely an artifact of the public having limited knowledge and no direct experience with the condition they are rating. Former colostomy patients, who directly experienced the health condition, still provided markedly lower valuations than did current patients in our study.

Some of our results were consistent with the idea that patients’ recall of QOL was biased by theories about the impact of disability (Ross, 1989). A within-subjects analysis indicated that current patients recall being more happy 5 years ago than they are now, whereas former patients remembered being slightly less happy. In addition, former patients expressed a stronger belief that bowel functioning is important to overall QOL. This belief may be a cause of their lower valuations for colostomy.

It is also possible that the former patients give a different valuation for colostomy because their experience was actually much worse than the experiences of current patients. For example, former patients would have known that their colostomy was likely to be reversed. Perhaps this knowledge undermined their motivation to adapt to their condition, resulting in a much worse experience with their colostomy. Or, perhaps patients who are struggling with their colostomies are more likely to seek the reversal procedure. However, according to a gastrointestinal surgeon we consulted, anatomical factors, rather than patient choice, largely determine which colostomies and ileostomies are reversed. In addition, although a minority of colostomy surgeries that were intended to be reversed eventually become permanent, usually this is not because of patient choice (Bailey, Wheeler, Birks, & Farouk, 2003).

Nonetheless, this study cannot pinpoint a single causal factor, such as theory driven recall bias, for our results. Although we have tried to rule out obvious confounds (e.g., age, time since surgery), other explanations are plausible. For example, current patients may be exaggerating their happiness and their utility values for self-protective purposes. Such an interpretation would be consistent both with the discrepancy in TTO valuations (with patients not admitting to themselves or to the researcher how much they longed to get rid of their colostomy) and with the difference in reported importance of bowel function (again, with patients denying the importance of a condition they felt powerless to improve). However, we find this interpretation unlikely given substantial prior research that casts doubt on the idea that patients are overreporting their happiness (Diener, Suh, Lucas, & Smith, 1999; Kahneman, Diener, & Schwarz, 1999; Riis et al., 2005; Ubel et al., 2005).

Nevertheless, the possibility cannot be dismissed that current methods of measuring QOL are not able to adequately capture the detrimental effects of living with a colostomy. Additional research will be needed to further clarify these issues.

**Limitations**

Our study is limited by the nature of our samples. The patient groups completed a mailed, written survey and were recruited as a convenience sample from a medical center. Our community sample was considerably different because these participants completed a Web-based survey and were recruited from an Internet panel, raising the possibility of mode and recruiting effects. Furthermore, as is often the case in Web-based surveys, our response rate was low. To offset these differences, we controlled for key demographic attributes in our central analyses. It is also worth noting that the discrepancy in utilities between our current patient and community Internet samples were similar in magnitude to those observed in previously published research (Boyd et al., 1990). Moreover, a recently published study found no differences between computer-based and interview modes in a utility elicitation (Damschroder et al., 2004), suggesting that mode effects may not have been a serious source of bias. In addition, the most novel finding in our study is the discrepancy in valuations between

![Figure 1](image-url). Remembered and present quality of life among current and former colostomy patients, from 0 (worst possible life for you) to 10 (best possible life for you).
former and current patients, who were drawn from the same sample and who both completed the same mailed survey.

We learned about whether the colostomies had been reversed via self-report on the survey. As a result, we cannot rule out the possibility of differential response rates between the current and former patient groups. However, a subsequent data collection at the same hospital yielded a similar proportion of temporary versus permanent colostomies (51% temporary in both studies). Recruitment for this latter study was done face to face, and there was a much lower refusal rate (18%).

Finally, and echoing the experience of other researchers (e.g., Lalonde et al., 1999; Perez, Williams, Christensen, McGee, & Campbell, 2001), a substantial portion of our sample did not give us interpretable responses to the TTO measure. Given that the loss of sample was similar between former and current patients, however, it seems unlikely that the problem biased the central comparison between these two groups. The development of response formats that are less confusing to participants, as well as explorations into why some people simply refuse to engage in trade-off exercises should improve utility measurement in the future.

Conclusion

An implication of our findings is that simply providing more detailed information about a health condition probably will not eliminate public–patient discrepancies in valuations. However, in two recent studies, participants who underwent an “adaptation exercise,” in which they were encouraged to reflect on their own prior adaptation to positive and negative events, increased their estimates of QOL for paraplegia compared with those who did not do the exercise (Damschroder, Zikmund-Fisher, & Ubel, 2005; Ubel, Loewenstein, & Jepson, 2005). It could be that this manipulation worked by offsetting the implicit theory some people hold that a disability will have a permanent negative effect on QOL. Thus, health descriptions that directly target false or biased perceptions could lead to closer agreement between patients and community members. Ultimately, a better understanding of the reasons for the discrepancy holds out the promise of improving utility measurement and helping to illuminate how people think about health and disability.

References


Appendix

Colostomy Description Provided to Community Sample

Imagine that you have a colostomy. A colostomy is an operation involving the surgical redirection of your bowels through a hole created in your gut, called a stoma.

Waste passes through your intestines and out the stoma into a bag, which you must empty several times a day. If you wear relatively loose clothing, this bag will not be visible underneath your garments.

Occasionally, you will experience odors and noises caused by gas and waste passing through the stoma. There is also the chance that the colostomy bag may leak if it is allowed to fill past capacity.

Although you will be restricted from lifting very heavy weight, your daily activities will not otherwise be greatly affected.

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