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Happily hopeless: Adaptation to a permanent, but not to a temporary, disability

Dylan M. Smith,
Department of Veterans Affairs and University of Michigan

George Loewenstein,
Carnegie Mellon University

Aleksandra Jankovich, and
University of Michigan

Peter A. Ubel
Department of Veterans Affairs and University of Michigan

Abstract

Objective: We tracked patients with either irreversible or reversible colostomies over a six month period, beginning a week after the procedure, to examine how they adapted hedonically over time. Based on prior research and theorizing, we hypothesized that, paradoxically, those with irreversible colostomies would adapt more fully, and become happier, than would those with colostomies that were potentially reversible.

Design: We contacted 107 patients who had recently received either a colostomy or ileostomy. The initial interviews were conducted while patients were still in the hospital recovering from their surgery. Consenting participants were mailed surveys at three time points: 1 week after release from the hospital, one month after release, and six months after release.

Main Outcome Measures: The surveys included measures of life satisfaction and perceived quality of life.

Results: As predicted, overall life satisfaction and quality of life increased with time for patients with permanent, but not temporary, ostomies..

Conclusion: These findings suggest that knowing an adverse situation is temporary can interfere with adaptation, leading to a paradoxical situation in which people who are better off objectively are worse off subjectively.

Emotional well-being has become a topic of intense interest in a variety of fields, including psychology, economics, and health policy. A large and rapidly expanding body of research has

Correspondence concerning this article should be addressed to Dylan Smith, 300 N. Ingalls #7D19, Ann Arbor, MI 48109; dylsmith@umich.edu..
Dylan Smith and Peter Ubel, VA Health Services Research & Development Center of Excellence, VA Ann Arbor Healthcare System and Center for Behavioral and Decision Sciences in Medicine, University of Michigan. George Loewenstein, Department of Social and Decision Sciences, Carnegie Mellon University. Aleksandra Jankovich, Center for Behavioral and Decision Sciences in Medicine, University of Michigan. Smith and Ubel are also affiliated with the Division of General Medicine, Department of Internal Medicine, University of Michigan. Ubel is also affiliated with the Department of Psychology, University of Michigan.

demonstrated that one's well-being is at least partially a reflection of one's objective circumstances (e.g., health, employment status, marital status, etc). Thus we would expect that the onset of a serious adversity–such as a new physical disability--should produce a decline in one's sense of well being. Further, the duration of the adversity should matter--almost no one would willingly choose a permanent disability over a temporary one. But this raises an interesting question; would a belief that an adversity will be temporary, versus permanent, influence one's experience of that adversity? It seems reasonable to suppose that such a belief could bring comfort, providing an emotional buffer against the present adversity, while knowledge that a bad situation is permanent could lead to feelings of hopelessness and depression.

But the links between objective circumstances and emotional well-being are often not so straightforward. For example, emotional well-being is often resistant to declines in objective circumstances, suggesting that people have considerable ability to adapt to adverse events. Adaptation is a widespread phenomenon, but there are some circumstances that people adapt to less well and some situational factors that impede adaptation (Diener, Lucas, & Scollon, 2006). One factor that could impede adaptation is a belief that one's current adversity is temporary, and should improve in time (Frederick & Loewenstein, 1999). Herrman and Wortman (1985), for example, argue that people adapt more readily to clear-cut situations, such as the loss of a spouse or permanent paralysis, that “confront victims with a life situation that is fundamentally altered,” as contrasted with situations that are uncertain, and that may be temporary, such as the failure to conceive a child. The idea that hoping one's circumstances will improve can impede adaptation suggests a paradox: people who are *objectively* better off, because they have reason to believe their circumstances will improve, might be *subjectively* worse off, because this hope impedes their ability to adapt to their current circumstances. This is the prediction we tested, in a field study with a unique population.

We recruited patients who had just received either a colostomy or ileostomy (we use the term “ostomy” throughout to refer to both procedures) and examined whether, over the next six months, there were differences between temporary and permanent colostomy patients in the trajectories of their perceived quality of life. Approximately half of the patients had undergone an irreversible procedure, and the remainder faced the potential to have their colostomies reversed and normal bowel function restored.

Although the study is not a true experiment with random assignment (indeed, it is difficult to imagine any ethical way to do random assignment of subjects to conditions, such as ostomy, that involve real adversity), whether someone gets a reversible colostomy depends mostly on anatomy and is unlikely to be related to factors connected with psychological adaptation or personal choice (Bailey, Wheeler, Birks, & Farouk, 2003). In addition, colostomy presents a situation, unusually well suited for addressing this issue, in which two groups of patients with a very different prognosis have essentially the same disability. Thus, this patient population represents a unique opportunity to examine the issue of temporary versus permanence in a group of people experiencing real, serious adversity.

Methods

Participants

We contacted 107 patients at the University of Michigan Medical Center who had received either a colostomy or ileostomy (we use the term “ostomy” throughout to refer to both procedures).

The initial interviews were conducted while patients were still in the hospital recovering from their surgery. Eleven patients were determined to be ineligible, due to poor health or because

they were non-English speaking. Of the remaining 96, 74 (77%) agreed to participate, and returned the first survey by mail. Participants were paid $25 per completed survey.

Procedures and survey content

Consenting participants were mailed surveys at three time points: 1 week after release from the hospital, one month after release, and six months after release. If we did not receive a completed survey, we contacted participants by phone, and sent replacement surveys if necessary.

The surveys focused primarily on measures of psychological well-being, and included the primary dependent variable; overall quality of life, which was measured with two scales. The first, 'satisfaction with life scale' (Diener, Emmons, Larsen, & Griffin, 1985) comprises five 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 1 to 7 scale ranging from "Strongly disagree (1)" to "Strongly agree (7)." As in our previous research (D.M. Smith, Loewenstein, Rozin, Sherriff, & Ubel, 2007; D. M. Smith, Sherriff, Damschroder, Loewenstein, & Ubel, 2006) we did not include data from one item of the Life Satisfaction Scale in the composite ("If I could live my life over, I would change nothing") due to concerns that it would have a unique connotation for patients who had just acquired a new disability. The second, 'ladder scale', (Cantril, 1967) asks participants where on a 0–10 ladder they stand at the present time. The top of the ladder (10) represents the best possible life for them, and the bottom (0) represents the worst possible life. Additional measures included self-reports of ostomy-related symptoms, questions about their reasons for having an ostomy, and demographics. We measured both the frequency and degree to which patients were bothered by ostomy-related symptoms such as stoma bag leakage, the latter with a scale that ranged from 1 ("Not at all bothered") to 7 ("bothered very much").

Of the 74 patients who returned the first mailed survey, data were excluded from 3 who indicated that they did not know whether their ostomy was reversible. Of the remaining 71, 41 (58%) indicated that their ostomies were reversible, and 30(42%) indicated that their ostomies were permanent. Of the 71 participants who returned the one week survey and indicated whether or not their ostomy was permanent, 59 (83%) returned the one month survey, and 45 (63%) also returned the six month survey. The most common reasons for attrition from the study were death or a decline in health (n = 8; 4 in each patient group) and voluntary withdrawal (n = 9; 5 temporary, 4 permanent).[1]

Sample characteristics

Table 1 provides a breakdown of reasons for colostomy by type of colostomy (temporary versus permanent), along with demographic information. Because, as can be seen from the table, permanent colostomy patients were somewhat more likely to have had cancer, while temporary colostomy patients were somewhat more likely to have had IBD, we controlled for this factor in all statistical analyses. In addition, we controlled for the fact that temporary colostomy patients were more likely to be male.

[1]Some patients in the temporary group reported that their ostomy had already been reversed prior to completing the one month (n=3) or 6 month (n=13) surveys. Ladder and life satisfaction scores were recoded as missing for surveys completed after a patient reported that their colostomy was reversed.

Results

Our main hypothesis was that self-perceived quality of life would increase more for permanent colostomy patients than for temporary colostomy patients. As is evident in Figures 1a and b, the prediction was strongly supported. Patients with reversible ostomies initially reported higher life satisfaction (although not significantly, p = .34). However, after the first week, patients with a reversible ostomy reported declining life satisfaction (from 4.44 (s.d. = 1.72) to 3.95 (s.d. = 1.64), d = .28), whereas those with a permanent ostomy reported increasing life satisfaction (from 4.06 (s.d. = 1.46) to 4.52 (s.d. = 1.58), d = .32). On the ladder measure, the trends are similar for the first week and month, but then diverge in a similar fashion between the one month and six months points, resulting in a slight decline for reversible ostomy patients (from 5.80 (s.d. = 2.30) to 5.29 (s.d. = 2.37), d = .22), and an increase for permanent patients (from 5.57(s.d. = 2.13) to 6.89 (s.d. = 1.88), d = .62).

To test the apparent interactions displayed in Figure 1, we employed Hierarchical Linear Modeling (HLM), using SAS("SAS Statistical Software, Inc," 2000). HLM models separately analyze within subjects (Level 1) variance and between subjects (Level 2) variance, and thus provide standard errors that take into account the inherent dependency present because of the repeated measures. Our models examine change in well being scores over the course of the study, as a function of type of ostomy (permanent versus temporary). We entered main effects of time since surgery (in weeks) and ostomy type, plus the interaction of these two variables; a significant interaction term confirms the patterns observed in Figure 1. All of our models included three dummy coded variables to control for factors that potentially differ between the groups, including gender, and reason for ostomy (cancer versus IBD versus other). Because these between-subject variables are related to type of ostomy, we also entered interactions terms between each of these and the within-subject time variable. Finally, we controlled for the possibility that the experience of ostomy-related symptoms differed between the two groups, by including a linear composite score for our measure of frequency of bothersome ostomy symptoms (alpha = .83). As this variable was measured at all three waves, we included it as a within-subjects variable. All of the preceding variables were entered as fixed effects; time was also included as a random variable.

The first model examined the life satisfaction scale. An examination of the fixed effects confirmed a significant interaction between type of ostomy and time since surgery (b = .05 (S.E. = .02), t(83) = 2.19, p < .05). Ostomy symptoms were also a significant, negative predictor of quality of life (b = −.21 (S.E. = .06), t(83) = −3.39, p < .01); no other variable approached significance. To interpret the interaction, we restricted the model to just those patients in the permanent ostomy group and examined the effect of time, again controlling for gender, cause of ostomy, and symptoms. We observed a significant positive effect of time (b = .03 (S.E. = .01), t(44) = 2.12, p < .05) indicating an increase in well-being across the span of the study. We repeated this analysis, restricted to the temporary group, and found no effect of time (b = −.02 (S.E. = .01), t(41) = −1.21, p = .24). Thus, as predicted, and as depicted in Figure 1, we found evidence for adaptation—increasing life satisfaction--in the permanent group but not in the temporary group.

Next, we examined the ladder quality of life scale. Again, the interaction between time and type of ostomy was significant, (b = .09 (S.E. = .03), t(83) = 3.16, p < .01), as was the effect of symptoms (b = −.31 (S.E. = .09), t(83) = −3.56, p < .01). For permanent patients, we again observed a significant increase with time (b = .06 (S.E. = .02. t(44) = 3.44, p < .01). For temporary patients, there was no effect of time, and thus no evidence of adaptation (b = .00 (S.E. = .02), t(41) = −.21, p = .83). [2]

All models controlled for experiences of symptoms, but we also directly examined this variable, to see whether the two groups differed in how these experiences change with time since surgery. We entered symptoms as the dependent variable, and again examined the effects of time and type of ostomy, controlling for gender and reason for ostomy (and their interactions with time, as above). This analysis revealed no interaction between time and type of ostomy ($p = .78$). A second model dropped the interaction term, and found no differences between the two groups in terms of experiences with symptoms ($p = .93$). There was a significant effect of time, indicating an increase in being bothered by symptoms across both groups ($b = .03$ (S.E. = .01), $t(88) = 2.16$, $p = .03$).

Discussion

These findings are not consistent with models of adaptation which assume that negative reactions fade with time merely because of continued exposure to a negative stimulus (Diener et al., 2006). Both groups in our study had the same disability for the same period of time, and did not differ in terms of experiences with symptoms, yet the temporary group showed no evidence of adaptation, and actually declined somewhat in terms of life satisfaction. Instead, the current results emphasize a role for cognitions—especially expectations-- in understanding adaptation. Having reason to believe that an improvement in circumstances could be on the way may, paradoxically, result in decreased satisfaction with one's current situation.

There are several potential explanations for why the prospect of hope could impede adaptation. One obvious mechanism relates to differences in motivation between the two groups. Because acknowledging loss can be momentarily painful, people may not be willing to ‘take the hit’, and therefore may fail to engage in the conscious and/or unconscious processes that produce adaptation until and unless they have no alternative. People may also not want to expend the mental effort required to adapt if there is some possibility that such measures might later prove to have been premature and/or unnecessary. A belief that one's adversity is temporary may also impede adaptation by complicating reality and impeding sense-making – e.g., the ability to find a silver lining in a calamity (Taylor, 1983; T. Wilson & Gilbert, 2003; T. D. Wilson, Centerbar, & Kermer, 2005; T. D. Wilson, Gilbert, & Centerbar, 2003). Finally, knowledge of a potentially better future could remind people of ways in which their current circumstances are less than ideal, serving as an upward point of comparison that causes one's present circumstances to be viewed in a negative light.

This study suffers from several limitations, most notably a small sample size, which becomes smaller by the end of the six month observation period. Some participants were lost (or not recruited) due to health problems, including death, resulting in a final sample that was healthier, on average, than ostomy patients in general. Thus we cannot be certain that the adaptation affect we observed in the permanent group would hold for a more representative sample. Nonetheless, we argue that even a well functioning stoma in an otherwise healthy person represents a significant challenge to psychological well being, and that therefore the increase in well-being we observed represents meaningful adaptation.

Attrition over the course of they study also raises concerns about interpretation of the HLM results; differences in well-being over time could be due to changes in the composition of the study sample. To address this concern, we ran an additional analysis restricted to participants who completed both baseline and 6 month follow up surveys. Results of this analysis were

[2]We ran additional models testing for quadratic effects of time, and found no evidence for them in the permanent ostomy group. In the temporary group, there was a marginally significant quadratic effect, but only for the life satisfaction measure, $p < .06$ (see Figure 1). We also ran models that imposed different assumptions regarding the structure of the within-person error covariance matrix (auto regressive, unstructured), and found that our fixed effects estimates did not change meaningfully, and all of the significant results remained so.

highly consistent with the HLM analyses on the full sample, suggesting that study attrition did not substantively affect our results.[3]

A second source of concern is potential non-comparability between our two patient samples. As we noted in the introduction, whether someone gets a reversible colostomy is largely determined by anatomy, and therefore unlikely to be related psychological well being. In addition, our analyses suggested that these two groups had a similar experience of ostomy related symptoms and difficulties. But we cannot rule out the possibility that these two groups differed in their experience of ostomy in ways that account for our results, apart from knowledge that one's colostomy is permanent or temporary. Of course, it is not possible to employ random assignment to study the effects of a temporary versus permanent disability, but we did attempt to address potential confounders analytically; specifically we controlled for the reason people had a colostomy (e.g., IBD or cancer), for gender, and for the experience of colostomy related symptoms.

Third, our analysis was restricted to two measures of overall well-being (life satisfaction and overall quality of life). But there are other ways to conceptualize emotional well-being, and we cannot conclude that our results would extend to these. It is plausible, for example, that while temporary patients did not show evidence for adaptation on the two global measures, they would have shown improvement on a measure of average moment-to-moment mood quality.

While it would probably not make sense for physicians to recommend permanent ostomies when temporary ones are possible, our results may have implications for how information about prognosis is delivered to patients. Health professionals generally find it easier to deliver optimistic news to patients even when they believe the prognosis is unfavorable, and have until now been able to justify that it was not only easier to deliver such news but also in the interests of the patient and his or her friends and family. For example, when it comes to many health conditions that experts view as relatively hopeless, such as spinal cord injuries, many patients and their families are often more optimistic, either that natural healing or medical science will cure the condition, and some evidence suggests that physicians are willing to play along with such hopes (Christakis, 2001). These results suggest, however, that while hopeful news may be easiest to deliver, it may not at all be in the interests of the recipients because it may interfere with emotional adaptation. The natural tendency to provide hope, even when a situation is inherently hopeless, may help the bearer of news but have adverse long-term consequences for the recipient of such news.

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[3]As noted in the methods, we observed a 37% attrition rate over the six month period of the study, and an additional subset of temporary ostomy patients could not provide 3 and 6 month data because their ostomy had already been reversed. As a result, while temporary ostomy patients comprised 58% (41/71) of the sample at baseline, they comprised 42% (14/33) at 6 month follow up. These factors introduce a potential source of non comparability between baseline and follow-up measures of well-being. To address this, we compared participants who did or did not contribute follow up data in terms of their well being at baseline, and observed no differences in terms of life satisfaction or quality of life (both p's > .20). We also reran our primary analyses using within-subjects ANOVA, which restricted the sample to patients who provided data at both baseline and at six months (n = 33, 19 permanent and 14 temporary). In this analysis, time from surgery is represented as a within-subjects variable with patient group (temporary versus permanent) as a between-subjects variable. Results of this analysis were highly consistent with the HLM analyses on the full sample. For both the life satisfaction and ladder dependent variables, we again observed significant time by patient group interactions (for life satisfaction, $F(1, 31) = 5.12$, $p = .03$); for ladder, $F(1, 31) = 4.87$, $p = .03$). Again, well-being increased for permanent patients (from 4.02 to 4.52 for life satisfaction, and from 5.32 to 6.89 for ladder), but not for temporary patients (from 4.62 to 3.95 for life satisfaction, and from 5.50 to 5.29 for ladder).

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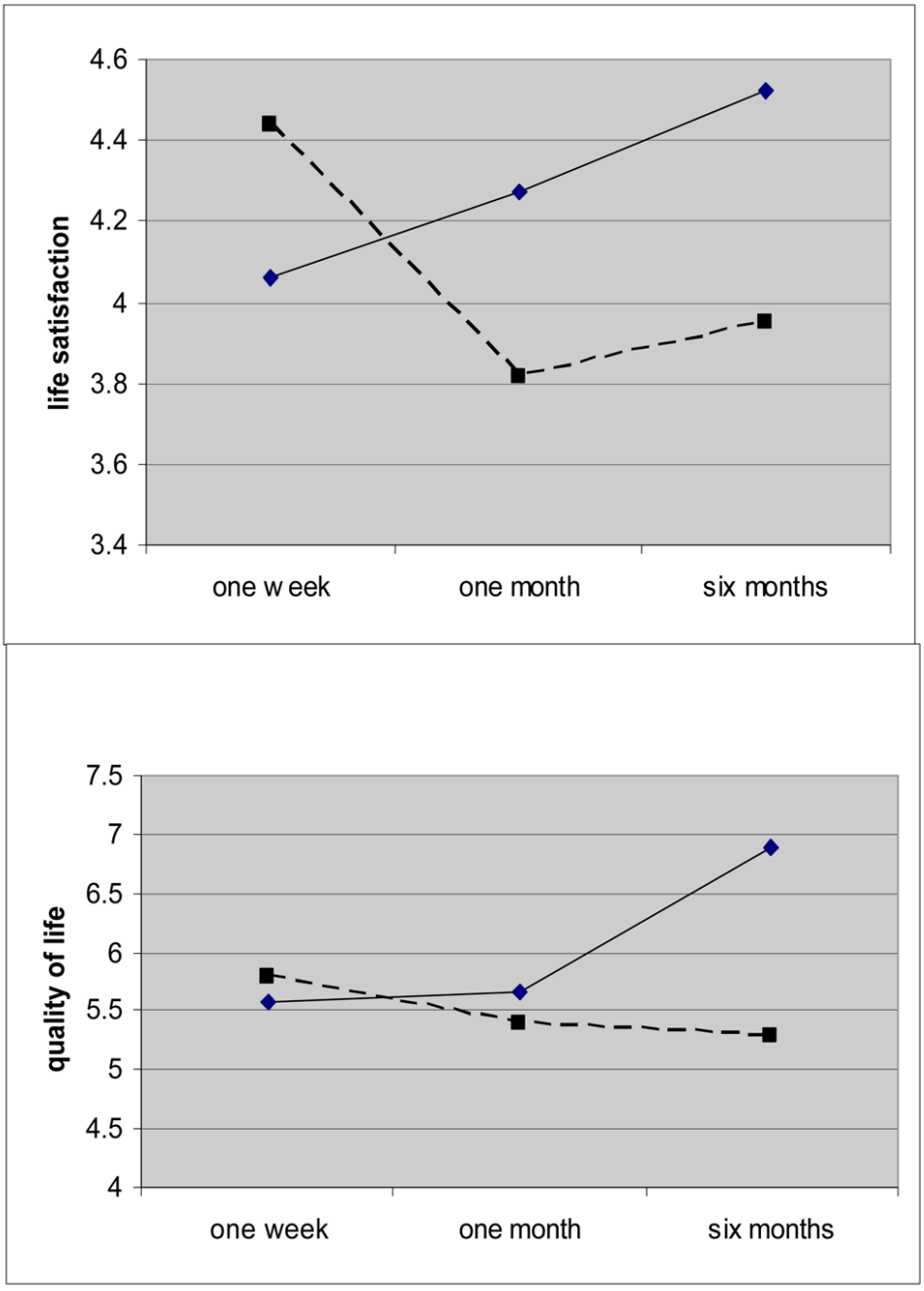

Figure 1.
Self-reported life satisfaction (1-7) and overall quality of life (0-10), at one week, one month and six months after colostomy surgery, by type of colostomy (temporary (dashed line) versus permanent (solid line)).

Table 1

Sample demographics

	Permanent patients (n=30)	Temporary patients (n=41)
Mean Age (standard deviation)	54.00 (11.72)	48.20 (14.82)
Gender		
% Female	53%	27%
Race		
% Non White	20%	7%
Median annual income (1-7)	4	4
1 = < $10K		
2 = $10K—$25K		
3 = $25K—$40K		
4 = $40K—60K		
5 = $60K—$80K		
6 = $80K—$100K		
7 = > $100k		
Cause of colostomy/ileostomy		
Inflammatory bowel disease	8	18
Familial adenomatous polypsis	1	3
Cancer	18	7
Trauma/accident	1	2
Spinal cord injury	1	1
Other cause*	3	15
More than one reason listed	2	4

*The most commonly cited reasons in this category involve various types of infections and surgical complications.