

Quality of Life, Disability, and Hedonic Psychology

RON AMUNDSON

“A common tendency in many otherwise divergent schools of sociological thought is to adopt the methodological tactic of beginning their analysis by discounting agents’ reasons for their action. . . . Such a stance . . . implies a *derogation of the lay actor*. . . . social incompetence is commonly attributed to people in lower socio-economic groupings by those in power-positions, or by their associated ‘experts’.” (Anthony Giddens, 1979, 71–72)

1. INTRODUCTION

This paper is a study of beliefs that people form about quality of life, both about the quality of their own lives and of the lives of others. The question is this: Who should we believe? Should we assume that first-person reports are more likely correct than judgments made by others? If not, when is it appropriate to doubt first-person reports about quality of life? The answer may seem obvious: honest reports of one’s own quality of life (QOL) must be correct. But most of us at one time or another have concluded that another person is just kidding themselves when they report about their own happiness. (Let us provisionally assume that ‘happiness’ and QOL mean the same thing.) Philosophers and economists who have discussed QOL have a standard scenario to illustrate this: the *happy slave* (Murray 1996, 31; Williams 2001, 583; Brock 2005, 69). Imagine a slave who knows no other life than his slavehood, is well adapted to the extremely limited life that he leads, and honestly reports that he has a very high QOL. Must we believe him? Surely not. If this slave were to experience freedom (we believe) he would certainly recognize the superiority of a free life to his present enslaved situation. He’s wrong about his own QOL. Although happy slave examples are simplistic and fraught with hazards (not the least of which is that they are completely imaginary), they do demonstrate the logical coherence of a claim that individuals can be mistaken about their own QOL.

One belief about QOL has been very widely demonstrated. Nondisabled people believe that the QOL of people who live with disabilities is extremely low. This belief will be termed the *standard view* of the QOL of disabled people.¹ The standard view is faced by an apparent falsification: When disabled people report

about their own QOL, they rate it only slightly lower than when nondisabled people self-report their own QOL. This produces the *anomaly* of the QOL of disabled people (Amundson 2005). The anomaly is the pair of conflicting assertions: the standard view on the one hand, and the conflicting self-reports of disabled people on the other.

I do not intend the generalization about high QOL for disabled people to imply that there are no differences among categories of people with impairments. We would expect that people with severe impairments would have lower QOL than people with only moderate impairments of a certain type (spinal cord injury for example). Outcomes of these studies are ambiguous. Many studies find no QOL differences between degrees of severity of impairments (Bach and Tilton 1994; Fuhrer et al. 1992; Nosek et al. 1995), but others find that QOL is lower with greater severity within a type (Mehnert et al. 1990; Clayton and Shubon 1994; Lucas 2007). More consistent results are seen in comparing ages of onset of an impairment; the earlier in life that the impairment is acquired (including impairments present at birth), the higher the resulting QOL (Uppal 2006). Progressive diseases produce lower QOL than stable conditions. This all makes sense when considered in terms of adaptation to an impairment (Frederick and Loewenstein 1999). Adaptation is a constant process for progressive diseases. Younger people can more easily adapt to a condition than a middle aged person. Even aside from the alleged plasticity of youth, middle aged people may have spent years training for a profession that becomes impossible due to an acquired impairment. Moreover, studies that do find associations between QOL and severity of impairment often find equally strong associations between QOL and social factors such as employment and community integration. The DR movement categorically rejects the assumption that a lack of community integration is an *intrinsic* effect of an impairment. Even though some categories of disabled people (those with very severe impairments, or who live in very inaccessible environments) do have an average QOL lower than the non-disabled population, the overall average is much higher than non-disabled people expect (Albrecht and Devlieger 1999). This is why bioethicists invoke scenarios like the happy slave in order to challenge the reality of such high QOL. It is this disagreement that I wish to address.

My use of the term 'standard view' derives not only from the fact that nondisabled people outnumber disabled people. It is motivated also by the fact that the view is widespread in the literature of bioethics and health care economics. In fact, nondisabled health care professionals judge the QOL of disabled people to be *even lower* than the judgments made by nondisabled people who are not health care professionals (Duckworth 1988; Brillhart, Jay, and Wyers 1990; Bach and Tilton 1994; Gerhart et al. 1994; Albrecht and Devlieger 1999). Disability rights advocates often argue against the standard view, in opposition to bioethicists (Wasserman, Bickenbach, and Wachbroit 2005; Asch 2001). Neither side is unanimous in its position, nor is there universal agreement that subjective well-being is the best understanding of the concept of quality of life (Kelman 2005). But the lines of this

debate are remarkably well-drawn. For purposes of rhetorical simplicity, therefore, I will sometimes adopt the strategic myth that bioethicists and DR activists are uniform in their opinions on this topic.

The grounds for this conflict are subtle and indirect. DR advocates are dedicated to social and environmental changes that will remove the barriers that (it is said) now prohibit disabled people from fully participating in public life. DR literature frequently claims that the disadvantages experienced by disabled people are primarily caused by social and environmental barriers, not by biomedical conditions (impairments) themselves. Many bioethicists, on the other hand, argue for biomedical policies aimed at reducing the numbers of people with impairments in the population, even if this reduction comes from prenatal diagnosis and abortion, or in some cases from the euthanasia of newborn infants with impairments. Justifications for these policies include very low estimates of the possible QOL of people with various impairments. Detailed justifications for these selection policies have been articulated. It is said, for example, that allowing the birth of infants with impairments would “increase unnecessarily the amount of net suffering or harm in the world” (Harris 1992, 94) and that abortions of fetuses with impairments should take place “for the sake of less overall suffering and limited opportunity in the world” (Buchanan et al. 2000, 251). Similar reasoning can play a role in policies regarding physician assisted suicide and euthanasia. DR advocates generally oppose these justifications. It is said, first, that they exaggerate the disadvantages of impairments with the constant emphasis on “suffering” (a feature of the lives of very few people with impairments, Amundson and Tresky 2008). Secondly, the justifications are said to underestimate or ignore the social origins of these disadvantages.

The contrasting estimates of the QOL effects of impairments play an important role in these arguments. If impairments carry a high intrinsic QOL penalty, then the “net suffering” that bioethicists are concerned to prevent is very large and the advantages to be gained by improvements in environmental accessibility are reduced. In effect, these arguments postulate a glass ceiling of QOL, above which people with impairments cannot rise. Such a glass ceiling would put a limit on the value of environmental barrier removal. If disabled people have intrinsic biological limits on their QOL, then the removal of barriers to their full integration carries less potential utility than it would if disabled people had a potential QOL as high as nondisabled people.

Those who (like the present author) defend the relatively high QOL of disabled people are sometimes warned that their arguments may backfire. If disabled people are found to have a relatively high QOL (it is said) their own argument for the removal of environmental barriers is weakened. If environmental barriers do not reduce happiness of disabled people, why should money be spent to remove them? This argument is tempting, but it is misconceived. First, the DR demands for accommodation are made on civil rights grounds of equal access, not utilitarian grounds of happiness.

Second, the stereotyped unhappiness of the disabled person involves a kind of misery so abject that improvements to accessibility are made to seem pointless. Of what use are curb ramps to people whose inherent unhappiness is characterized as “overall suffering and loss of opportunity in the world”? Amartya Sen expresses this stereotype of abject misery when he asks his readers to imagine “a case where one person *A* derives exactly twice as much utility as person *B* from any given level of income, say, because *B* has some handicap, e.g., being a cripple” (Sen 1973, 16–17). This stereotype depicts happiness as a remote and distant hope for disabled people, unlike the ambitions of nondisabled people. If Sen is right, and a paraplegic person has a maximum QOL only 50% that of a person with no impairment (for any given level of resources) then the removal of barriers to access for “cripples” must produce a lower improvement to QOL than the provision of benefits for people without such an intrinsic QOL limitation. The DR argument for the removal of barriers would be weakened because the benefits of barrier removal are (supposedly) limited by the intrinsic facts of biology.

On the other hand, suppose the bioethicists’ claims about intrinsic QOL reductions are mistaken and the disadvantages associated with impairments derive mostly from social barriers. Now the cost-efficiency of barrier reduction is much higher. Crudely put, if we take the self-reports of high QOL at face value, then a policy of barrier removal gains credibility. If we consider the self-reports to be delusional or inflated, then barrier removal goes down in value.

This may seem like a false dichotomy. It is surely true that we could (and do) invest both in prenatal selection/prevention programs and in the elimination of barriers to social integration. Nevertheless, funding is limited. Each side in this dispute sees the other as mistaken about the facts regarding QOL. If this opposition is based on a confusion, it will not be removed here. Instead, I will attempt to determine the contributions to this argument that might come from a new direction.²

A new field of research in social psychology opens the possibility that empirical, experimental evidence may be available, in addition to the so-far anecdotal arguments. The field is called *hedonics*. The practitioners are experimental social psychologists. One important feature of hedonics is that its practitioners have no prior commitments regarding the anomaly. They do not assume that self-reports should be regarded as incorrigible. Indeed, they come from a tradition in social psychology that takes great joy in showing that ordinary people are often badly mistaken about their own motivations, beliefs, and reasoning processes (Nisbett and Wilson 1977; Nisbett and Ross 1980; Kahneman, Slovic, and Tversky 1982; Gilovich, Griffin, and Kahnemann 2002). This body of literature is notable for debunking ordinary peoples’ reports about their own states of mind. If hedonics researchers believed that disabled people were kidding themselves about their own QOL, nothing would stop them from saying it. I therefore propose that we ask them who’s right about the QOL of disabled people. Does hedonic research support the standard view that disabled people have an intrinsically low QOL? Or

is there evidence that the standard view is mistaken, and the disabled people who report a high QOL are correct when they do so? Hedonic psychologists may not have the last word in the debate, but their contribution must be considered. The results are these: according to the experimental results of hedonic psychology, the judgments of nondisabled commentators about the QOL of disabled people are far more likely to be mistaken than are the self-reports of disabled people. Here are the details.

2. HAPPINESS: FIRST-PERSON REPORTS AND THIRD-PERSON ESTIMATES

Recent empirical discoveries have refuted both popular and scholarly assumptions about the nature of human happiness. One such assumption is the importance of financial wealth; it is empirically demonstrable that money doesn't bring happiness, a view documented by numerous sources beginning with (Brickman, Coates, and Janoff-Bulman 1978). Another is the view that happiness amounts to getting what we want, a view that philosophers call *preference utilitarianism*. Hedonic research makes mincemeat of this presumption. We are such poor predictors of what will make us happy that Gilbert and Wilson invented the term *miswanting* to name our habit of desiring things that do not make us happy when we get them (Gilbert and Wilson 2001). Hedonic research makes it easy to imagine people whose strongest desires are completely fulfilled but who are nevertheless miserable.

I will offer a taxonomy of the hedonic results that differs somewhat from the psychologists' usual presentation, because my goals are different from theirs. I will present the data in its relevance to the dispute over the QOL of disabled people, a dispute that hedonics researchers are seldom concerned with. I will sort the results into two categories that correspond with the DR-versus-bioethics disagreement. The first and more basic category is direct, contemporary, first-hand reports of hedonic states. Hedonic studies are made of how these reports change through time, and how they are affected by changes in the life circumstances of the subjects. The second category examines the indirect estimates people make of hedonic states that they are not currently experiencing. These judgments may be about the happiness of other individuals ("Are people who live in large cities happier than those in small towns?") or about one's own happiness under different circumstances ("How happy would you be a year after you won a million-dollar lottery?"). The distinction between direct and indirect studies is not simply first-person versus third-person. Direct judgments include only *contemporaneous* first-person reports. First-person judgments about one's own expected happiness under counterfactual conditions (how happy you would be if you won the lottery) will count as indirect. I will adopt the convention of calling direct studies *reports* of happiness, whereas indirect studies are *estimates* of happiness. Reports and estimates will together be termed *judgments*. (A third category is our memory of past

hedonic states, which can be mistaken for well-studied reasons. These will not concern us.)

Direct studies have revealed a greater complexity that one might expect. The simplest expectation is that subjective happiness is a linear accumulation of hedonically positive life factors: a good job, good health, a good marriage and family, and so on. It is now obvious that this is not the case. Happiness is not a direct response to circumstances, but a response that is mediated by our (possibly changing) psychological reactions to those circumstances. Important generalizations have been discovered about how these factors change.

Indirect studies have produced a corresponding discovery. When we estimate the happiness of other people (or of ourselves in counterfactual circumstances) we usually ignore the mediating effect of psychological factors, and assume that hedonic responses are nearly direct functions of stimuli. We make this mistake even about our own reactions to possible or future events. Even though we have a lifetime of experience in what causes us to be happy and sad, we seem not to have learned much from it.

Overwhelming evidence has been gathered to support one generalization: *Large changes in hedonic states don't last very long* (Gilbert et al. 1998; Gilbert et al. 2004). Experiences of extreme happiness or sadness are soon followed by milder hedonic states—not necessarily neutral states (neither happy nor sad) but states of much less extreme nature. A number of psychological mechanisms have been identified that maintain hedonic equilibrium when world events disturb the equilibrium. The generic term for this phenomenon is *hedonic adaptation* (Kahneman 1999; Frederick and Loewenstein 1999). We are much more resilient in our responses to bad circumstances than we expect to be. The price for this resilience is that extreme happiness is also short-lived. This is the single most striking discovery of recent years regarding our hedonic lives: hedonic adaptation is amazingly effective.

I will first discuss the known processes that influence both the direct reports and the indirect estimates of hedonic states. Then I will examine how the hedonic researchers assess these influences; under what circumstances judgments are likely to be correct and incorrect. The results will give some grounds to decide, on the basis of empirical evidence rather than political or moral commitment, the legitimacy of the widespread belief that disabled people are mistaken when they report a high quality of life.

3. THE INFLUENTIAL FACTORS

Factors that influence hedonic judgments can be divided into two categories. The first is the nature of hedonic adaptation as a psychological process, together with certain sub-mechanisms that contribute to it. The second is a set of factors regarding the contexts in which hedonic judgments are made, both by direct and indirect judges.

Hedonic Adaptation

Adaptation is the process by which organisms adjust themselves to their environments. Hedonic adaptation is the process by which individuals' levels of happiness return towards homeostasis after some life experience causes it to become much higher or lower than it had previously been. The major discovery of recent research is the surprising efficiency of hedonic adaptation. When life experiences suddenly make people extremely happy, or extremely sad, they tend to return to their former levels of happiness within a remarkably short time. This phenomenon has been recognized for a very long time, but only recently has it received quantitative, experimental study (Gilbert et al. 1998, 619). An early study of the phenomenon compared lottery winners with people who recently became paraplegic in accidents (Brickman, Coates, and Janoff-Bulman 1978). In retrospect, and from a Disability Studies point of view, the Brickman study is less impressive than it seemed at the time. The subjects with paraplegia actually gave significantly lower QOL reports than the lottery winners: the authors were amazed that the paraplegic reports were still above the neutral point of "neither happy nor unhappy." There is an obvious reason why the Brickman subjects had such low QOL reports: they were interviewed less than six months after their accidents, and all of them were still living in rehabilitation hospitals! Subsequent studies gave more impressive results. Disabled people averaged closer to nondisabled people in their QOL reports, simply because they were interviewed after they had time to adapt to their new impairments and live with them in the community; outcomes are reviewed in (Albrecht and Devlieger 1999). Lottery winners very soon lost the thrill of victory. Their surroundings, which had seemed luxurious when they were first purchased with lottery winnings, soon became routine. The general phenomenon of hedonic adaptation is seen to include the following factors.

The hedonic immune system. Daniel Gilbert and colleagues have studied one particular process that mediates hedonic adaptation, which they term the hedonic immune system (Gilbert et al. 1998). Like its biological analog, the hedonic immune system protects the organism against attacks from the outside world. When one's hedonic well-being is challenged, the immune system protects it. The immune system is a cognitive mechanism, or a group of mechanisms, that enhances and speeds up adaptation in a positive direction. The exact mechanism is unclear; it may focus subjects' interest on the bright side of things and turn their attention away from misfortunes and losses. Experimental results will be discussed below.

Contrast effects. One of the ways that we adapt to a changed hedonic situation is by changing our hedonic responses to the ordinary life circumstances around us. In comparison to a *major effect* (the large hedonic change—a lottery win or a sudden

serious injury) other life circumstances of the same valence as the major effect are reduced in significance. It is as if we compare them to the major effect, and find them wanting. This may sound like another platitude, but again it has been experimentally observed. When asked to rate how much pleasure they feel from receiving a compliment, reading a magazine, or hearing a funny joke, lottery winners report less pleasure than do people whose life situations have not significantly changed. Similarly, people who have recently undergone invasive medical procedures will consider the filling of a dental cavity a relatively minor experience (Ubel, Loewenstein, and Jepson 2003, 603; Brickman, Coates, and Janoff-Bulman 1978). This phenomenon buffers the hedonic states of people who have experienced extremes. Little things *can* mean a lot, but only to people who have not recently experienced big things. Unlike the hedonic immune system, contrast effects apparently operate on both valences: they buffer hedonic highs and lows.

Recognition of hedonic adaptation among indirect respondents. Research on hedonic adaptation has also explored the extent to which indirect estimates of QOL take account of it. It appears that hedonic adaptation is greatly underestimated in extent and in rapidity by the public at large. Hedonic stimuli are treated as if they are linear and cumulative in their effects. People may confuse the experience of acquiring a very good or very bad life situation with the later experience of living with that same situation (Kahneman 1999, 16). Direct reports of subjects who experience hedonic highs and lows reveal that subjects soon return to a hedonic baseline. Indirect reports imagine the subjects as remaining at the hedonic heights or depths for almost as long as the relevant stimulus exists (i.e. the lottery winnings or the paraplegia).

Contextual Influences

The following factors do not influence hedonic states themselves. Instead they influence hedonic *judgments* by manipulating the contexts in which the judgments are elicited.

The Focusing Illusion (Schkade and Kahneman 1998) also called *focalism* (Gilbert et al. 1998). It is well known in social psychology that subjects' responses to a given stimulus are influenced by the context in which the stimulus is perceived. Hedonic judgments can be affected by focusing the experimental subject's attention on positive or negative aspects of the life whose quality is being judged. This factor can affect both direct reports and indirect estimates, but it is much more influential over estimates. The reason is clear; indirect subjects are typically given only a narrow description of the life whose quality they are being asked to estimate. They can hardly resist focusing their attention on the described aspect of that life, to the exclusion of other aspects. Other aspects aren't mentioned (the paraplegic person's happy marriage, the lottery winner's chronic indigestion). In contrast,

subjects who directly report their current hedonic states are responding not to a narrow description of their life situation (their lottery win or their paraplegia), but broadly and holistically reporting on their life. Focalism is less relevant for these subjects, but it can still be produced by a cleverly designed experiment that carefully focuses the subject's attention on the bad (or the good) features of their life.

Response Shift. This is an influence that arises when subjects who are judging their current QOL do not compare themselves to others in the general population, but instead compare themselves to subjects within a specialized category. If that category includes people who are advantaged or disadvantaged in the same way as the subject (e.g. people who have recently won a lottery or lost a spouse), their QOL will be reported to be less extreme than if it were compared to the public at large. ("For a recent widow, I suppose I'm getting along alright.") Response shift is assumed to affect only the directly reporting subjects. It appears that researchers do not consider indirect estimators to be subject to this factor because the experimental situation makes it obvious that the life that subjects are estimating (the lottery winner or the paraplegic) should be compared to the public at large. However, the following kind of influence is somewhat similar, and applies only to estimators.

Misconstrual. Because the questions asked of estimators embody a description of a life situation, the subject is left free to interpret that description in various ways (Gilbert and Wilson 2001, 618; Ubel, Loewenstein, and Jepson 2003). The interpretation can be influenced by what the subject knows or doesn't know about the situation described, by the subject's own biases or fears, or by anything at all. For this reason, questionnaires that are designed to elicit health care evaluations (an estimate of one's own QOL under different hypothetical health situations) usually include extended descriptions of situations such as undergoing dialysis, living with a colostomy, and so on (Ubel, Loewenstein, and Jepson 2003). This is an attempt to reduce misconstrual. Nevertheless, the subject's mistaken understanding of the hypothesized life situation remains as another source of possible confusion. It is assumed that subjects who are directly reporting their QOL cannot misconstrue their own circumstances. (Only people who are truly delusional about their life situation would be subject to misconstrual regarding their own QOL.)

We now must ask whether hedonic researchers regard the factors described in this section to produce genuine changes, or illusory changes, in the hedonic state being judged. We will look first at hedonic adaptation.

4. ANALYSIS OF THE FACTORS: HEDONIC ADAPTATION

Hedonic researchers universally and almost unequivocally³ consider hedonic adaptation to produce genuine changes in hedonic states, and the reports of those

states to be veridical and trustworthy even when given by people who have significant impairments. The researchers are well aware of the standard view, and of rhetorical rationales such as the happy slave example. The researchers simply reject the bioethicists' view. Daniel Gilbert recently devoted an entire chapter of a popular book to convincing the reader that the reports of high QOL that come from the conjoined twins Reba and Lori Schappell should be taken at face value (Gilbert 2006, 29–64). In the entire psychological literature on hedonics, I know of no assertion that the happiness that results from hedonic adaptation (be it positive or negative) is anything other than genuine.

These researchers' attitudes are definitely not based on the assumption of incorrigibility of self-reports. Responses to direct QOL questionnaires are only a part of the evidence that hedonic researchers use to establish the genuineness of QOL reports. This breadth of research is described in the following passage:

“Indeed, it is so amazing to some people that quadriplegics and other people with severe disabilities could be happy that their self-reports are sometimes dismissed as unbelievable. It should be noted, however, that individuals who use wheelchairs are believed to be happy by their friends and family, can recall more good than bad events in their lives, are rated as happy by an interviewer, and report more positive than negative emotions in daily life.” (Diener and Diener 1996, 184)

Diener and Diener here refer to four distinct measures of QOL besides self-reports. All four measures confirm the accuracy of the reports. This is the same kind of evidence that is used with nondisabled people to establish the same facts. If these facts are taken to establish real happiness with nondisabled people, they should do the same for disabled people. At least this is the assumption of the hedonic researchers.

Gilbert has extensively studied the so-called hedonic immune system, which is seen to protect a person's hedonic well-being when it is challenged by outside circumstances. It is tempting at first to regard this notion as merely Gilbert's personal label for the platitude that we can get over our problems. Not so. Gilbert has experimentally manipulated the phenomenon, and discovered some surprising aspects. One is that the immune system operates only when the new life situation is accepted as permanent, not temporary. Another is that the immune system seems to operate only during a window of opportunity after the harmful event. If the subject continues to regard the new situation as temporary during this window, the immune system fails to operate. Hedonic adaptation to the new situation will be greatly delayed, and it may fail to take place entirely (Gilbert et al. 1998).

Indirect estimators appear to expect hedonic highs and lows to last, if not as long as the life situation does, at least for a very long time. The highly desired new automobile will give the owner the same thrill of ownership six months after the purchase as it did the first day, and a negative tenure decision will make the

former assistant professor just as miserable two years later as it does on the day of its announcement (Gilbert and Wilson 2001, 186). Both estimates are treated by the researchers as obvious errors on the part of the estimators. They are not accurate insights by outsiders into the confused lives of lottery winners, new car owners, people with paralysis, and former assistant professors. Life really does return to normal. Gilbert (ever ready with a neologism) uses the term “immune neglect” to designate the failure to foresee negative-to-positive hedonic adaptation. It is an interesting question why health care workers are even *more* neglectful of the hedonic immune system than other nondisabled estimators, but they are (at least regarding impairments).

The final factor included under hedonic adaptation was contrast effects. Brickman and colleagues report that people who recently experienced extreme hedonic events tend to evaluate less-dramatic events of the same valence as having less importance than do people who have not experienced dramatic events: an ice cream cone gives less pleasure to someone who has recently won a lottery and a parking ticket is less unpleasant to someone whose house has just burned down (Brickman, Coates, and Janoff-Bulman 1978). Do these influences produce veridical or distorted consciousness of one’s own QOL? The topic seems open to question. For one thing, the Brickman study was of people who had undergone only a brief period of adaptation while living in an institution, so the eventual effects might have been very different. For another, one might reasonably regard contrast effects as merely a factor in the course of adaptation. If so, we need not dismiss it as producing false consciousness but rather true consciousness of a changed person. In any case, contrast effects are minor influences at best. Even if they are interpreted as producing false consciousness, they do so by tiny changes in the response to hedonic events which are *by definition* much smaller than the major event (the lottery win or the automobile accident).⁴

We must conclude that hedonic researchers regard hedonic adaptation as a primary cause of change in genuine quality of life, not in the mere *perception* of the quality of one’s life. If researchers have found grounds to dismiss disabled peoples’ reports of high QOL, the evidence can only come from the factors not yet discussed, namely the contextual influences on QOL judgments. To those we now turn.

5. ANALYSIS OF THE FACTORS: CONTEXTUAL EFFECTS

By far the most powerful contextual effect on reports of hedonic states is the focusing illusion, or focalism. This phenomenon can affect both reporters and estimators. Reporters can also be affected by response shift and estimators can be affected by misconstrual.

The focusing illusion is far more likely to produce erroneous judgments in people indirectly estimating QOL than in people reporting their own current

QOL. The best illustration of why this is so is an elegant experiment that actually elicits focalism in directly reporting subjects (Strack, Martin, and Schwarz 1988). In this experiment undergraduate college students were dividing into two groups and asked the same two questions, but in different orders. Question A was “What is your overall QOL?” Question B was “How many dates did you have last month?” I suggest the following exercise to my readers: What will be the results of asking these questions in opposite orders—A, then B; and B, then A. Is QOL correlated to dating frequency?

The correlation between the answers depended on the order in which the questions were asked. If the QOL question was asked first, there was no correlation between dating frequency and quality of life. But if the dating question was asked first, there was a significant correlation. Under the second condition it *appeared* that the number of dates was an extremely large contributor to life quality. This was an illusion, of course, caused by the fact that when the dating-question-first subjects reported their QOL, their attention had been focused on their dating success. The students’ report of their QOL was unduly influenced by that aspect of their lives. I say “unduly” because I assume that the students who were asked the QOL question before the dating question were responding more spontaneously and holistically, without their attention having been focusing on a particular aspect of their lives. This is the interpretation given by the researchers (both the authors and many other commentators on the study). It also illustrates that hedonic researchers are willing to disbelieve direct reports when evidence leads them to do so.

The subjects whose answers are least subject to focalism are those whose attention was not focused on any particular aspect of their life that might carry hedonic valence. This includes the majority of direct reporting experiments (excluding the dating study of Strack and colleagues). Compare this to the questionnaires for people who are asked to indirectly estimate QOL. They are given a description of a particular aspect of a hypothetical person’s life, and asked to estimate that person’s QOL. By the very nature of the task, their attention is directed at particular aspects of the life they are estimating, in exactly the way that researchers would *avoid* when seeking an accurate report on a person’s own current QOL. An ideally accurate indirect subject would not concentrate on any one aspect of the life whose QOL they are estimating, but would integrate all of that life’s aspects into one holistic estimate. That is, they would indirectly estimate QOL in the same way that a direct-reporting subject goes about judging her own QOL. But this is impossible—such extensive knowledge about the life of another person is beyond the scope of any psychology questionnaire. *Of course* an indirect estimator’s judgment is distorted by its focus on the single characteristic that they know about the hypothetical life they are estimating—they are given nothing else to focus on!

The hedonic researchers explain in great detail how focalism will produce unrealistically low estimates among people asked to estimate the QOL of hypo-

thetical disabled people. They also show how to remedy this distortion. As in the earlier quotation from Diener and Diener, one need only to give a questionnaire to people who are personally acquainted with individuals with significant impairments (as friends, not as patients). Ask them how often their disabled friends are in a good mood and how often they are in a bad mood. Uninfluenced by focalism, the reports indicate a relative high QOL for those disabled individuals. In a related study, Schkade and Kahnemann asked a group of subjects to estimate the relative predominance of bad moods as compared to good moods among people with paraplegia. They controlled for whether the subjects had personally known someone with paraplegia. Personal knowledge had a highly significant ($p < 0.005$) effect on the reports. Subjects who had not known a person with paraplegia estimated that bad moods predominated over good (43% to 32%). Subjects who knew people with paraplegia estimated the reverse (20% versus 53%). Their conclusion: "The less you know about paraplegics, the worse off you think they are" (Schkade and Kahneman 1998, 340). This shows how focalism results in mistakenly-low estimates of the QOL of disabled people. People who are not personally acquainted with a person with paraplegia focus on the paraplegia when asked the question. People who know a person with paraplegia focus on the person. The latter report a higher QOL than the former, and their knowledge is based on better evidence.

What is the effect of focalism on first-person reports of current QOL? There is little reason to think that it has any effect at all. A researcher *could* manipulate the questions to focus the individual's attention on positive or negative aspects of their life situation and thereby produce falsely high or falsely low reports of their own QOL (as compared with spontaneous, unfocused reports). There is no evidence that the typical direct QOL questionnaires are manipulated in this way.

Our next case is response shift. This happens to disabled subjects when they evaluate their own QOL by comparing it to the QOL of other disabled people, rather than to the general public (usually meaning the non-disabled public). It could produce artificially high QOL reports. If this is the outcome, then the subject is not answering the question that the experimenter intended to ask. It is a failure of communication on the part of the researcher, not of self-understanding on the part of the subject. This outcome was actually investigated in one valuable study (Schulz and Decker 1985). A complex instrument measuring well-being was given to a group of 100 individuals, aged 40 and over, who had had paraplegia for an average of twenty years. Their responses were compared to the same questionnaire given to a group of 6,928 from a general population of adults.

The questionnaire was based on a seven-point scale with 1 representing high well-being and 7 representing low well-being. The paraplegic population mean was 4.04, and the general population mean was 3.77. (The questionnaire was adjusted to prevent the clustering of high-end reports that had produced statistical problems in earlier studies like Brickman's.) The experimenters suspect that response shift had artificially elevated the reports of the paraplegic subjects. So

they try to elicit evidence of this effect. The results are quite entertaining. The experimenters go into contortions as they try to prove that the disabled subjects' reports were distorted by response shift:

"Subjects were also asked with whom they compared themselves 'to decide how good their life situation was.' Respondents had difficulty responding to this question, stating that they did not compare themselves with other people. The interviewer then explained that 'we all compare ourselves with others even though we're not always aware of it' and repeated the question." (Schulz and Decker 1985, 1165).

This is overt pressure by the investigators to get the subjects to say that they compared themselves to others. If this were a trial, it would be witness tampering. The experimenters were simply lying to the subjects when they said that people actually *do* always "compare themselves with others" in questions like these—they had no grounds for the claim. They simply wanted to manipulate the subjects' responses to match the experimenters' prejudices. But justice triumphs; the pressure didn't work.

"Only 25% of the respondents said that they compared themselves with other disabled persons. Sixteen percent said that they compared themselves with nondisabled persons, and 59% said that they didn't compare themselves with any particular group of persons, 'just people in general.'" (*ibid.*)

These researchers did their best to challenge the truth of the QOL reports of the disabled respondents. In the end, they had to confess that even this pressure didn't work. "[C]hoice of comparison person was not significantly related to any of the well-being measures" (Schulz and Decker 1985, 1166). In other words, the 25% of subjects who said (after arm-twisting) that they were comparing themselves to other disabled people *did not report their QOL as any higher* than the 75% of subjects who said that they did not compare themselves to other disabled people. Even when the experimenters unfairly manipulated the disabled informants to devise a way to discount their reports, it didn't work. Especially in the face of this embarrassing result, there is no evidence that response shift distorts disabled peoples' QOL reports.

Lastly we have misconstrual, the factual misunderstanding of the hypothetical condition of impairment in a questionnaire for subjects who are asked to estimate a disabled person's QOL. Given what we now know, misconstrual is almost certain to be slanted against high QOL among disabled people. (It might be based on the assumption that people with paraplegia cannot have sex, for example.) It is difficult to separate the effects of misconstrual from those of focalism, but they are almost certainly mistakes in the same direction (i.e. underestimating the QOL of people with impairments).

In summary, focalism is a strong influence towards incorrectly low judgments among subjects indirectly estimating the QOL of disabled people, and probably

has no influence at all among those directly reporting QOL. Response shift is a possible cause of minor errors in self-reporting, but these are all the results of poor experimental design, not false consciousness among the disabled subjects. Misconstrual is probably an influence on some factual error among indirect estimators. None of our contextual factors involves error on the part of direct reporters (apart from small confusions possibly caused by response shift), but the factors do produce significant amounts of error from subjects who indirectly estimate QOL. A preponderance of the psychological evidence shows that the third-person estimates of the low QOL of disabled people (for example, the estimates of bioethicists) is far less likely to be correct than the direct reports of disabled people themselves (for example, DR advocates). This conclusion is based on a neutral source, the psychological study of hedonics.

6. THE BEST USE OF THE IMMUNE RESPONSE

My purpose in studying the hedonics literature was only to determine the relative credibility of the two sides of the anomaly regarding high QOL of disabled people. I didn't expect that anything new about life with disability would come from hedonics. That judgment may have been wrong. The studies of the hedonic immune system have revealed an interesting phenomenon that may be directly applicable to the experience of disability.

Gilbert has shown that the immune system operates during a small window of opportunity after the drastic hedonic event, and it only operates if the changed condition is perceived as permanent. When a situation is perceived to be permanent, the immune system begins to adjust the individual to it. By experimentally manipulating whether or not a condition is perceived as permanent by their subjects, researchers have changed subjects' degrees of satisfaction with a new life situation. This was interpreted as changing their hedonic adaptation. One such study involved undergraduates who had signed up for a course in black and white photography. The course involved taking photographs of a number of people and places that were personally meaningful. At the end of the course two of their best photographs were printed under professional guidance, and the students were allowed to keep one of the prints. The other was to be kept as a sample of student work. The offers of the prints were made under two experimental arrangements. One group (called the 'inescapable group') was told that the choice of print was final. The other group ('escapable group') was told that they could take one print home, but during a period of several days they could exchange it for the other print if they decided they preferred the other. The students were later given surveys that asked (among other things) how well they liked the prints that they chose. The students in the escapable group liked their prints *less than* the students in the inescapable group (whether or not they actually decided to exchange their print). Why should the ability to exchange an item affect how well we like it?

Gilbert's interpretation is that the immune system, which helps us appreciate the life that we have to live, only kicks in when a condition is regarded as permanent (Gilbert 2006, 183 ff). It worked for the inescapable prints but not for the escapable prints.

We must not over-interpret such experiments. After all, a photographic print is not much like paraplegia. However, it has been extensively argued and sometimes demonstrated that social psychological phenomena like these, discovered and demonstrated in the laboratory, can successfully be exported into important real-world circumstances (Wilson 2005; Wilson 2006). A stunning recent example is a study of a very simple 15 minute intervention that eliminated about 40% of the expected drop in academic performance among middle school minority students that was due to racial stereotyping during a year of school (Cohen et al. 2006). Moreover, the observation that hedonic adaptation is actually impeded by a "ray of hope" is supported by a number of studies in a range of contexts. A review of this literature leads Frederick and Loewenstein to conclude that "a small remaining hope may impede the onset of adaptive processes that could eventually return one to normal hedonic levels" (Frederick and Loewenstein 1999, 317).

To the extent that these experiments are projectable, they have an interesting implication. They suggest that people who accept the permanence of an acquired impairment soon after its occurrence adapt more successfully than those who "heroically" hold out hope for an improbable cure. This is a real-world fact. It shows that the bravado of "I'm going to walk again" shown by such figures as Christopher Reeve is detrimental to hedonic adaptation. The nondisabled public gives high approval to such behavior. The less likely the recovery, the greater the public adulation of the person who swears to achieve it. Such attitudes can be a genuine instrument of maladaptation. An important outcome of hedonic studies may be that the social valorization of unrealistic beliefs and behaviors on the part of individuals with new impairments is detrimental to their overall well-being.

7. CONCLUSION

Hedonic psychological experimentation is still in its early stages, but current evidence is unequivocal with respect to the QOL of disabled people. First, hedonic adaptation produces real changes in QOL, not false consciousness. Second, research has discovered psychological mechanisms that explain why nondisabled estimators of the QOL of disabled people are likely to *mistakenly* judge them to have a low QOL (based on the ignorance of hedonic adaptation and the focusing illusion). Third, although some mechanisms are known that might lead to mistakenly high QOL reports by disabled people (the first-person focusing illusion and response shift), these mechanisms will probably operate only in rare circumstances and produce negligible results. In the view of hedonic researchers, the high QOL reports of disabled people are accurate. The lower QOL estimates of disabled

people's lives that are made by nondisabled observers, including many bioethicists and health care economists, are errors caused by well understood psychological processes. There is no glass ceiling of QOL for people with impairments.

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Ron Amundson

Dept of Philosophy

University of Hawaii at Hilo

Hilo, HI 96720

ronald@hawaii.edu

NOTES

¹ The expression 'disabled person' is currently disfavored in North America because disability is conceived as a biomedical category. In Britain the expression is preferred to 'person with a disability' because the term 'disabled' is taken to designate socially-caused disadvantage rather than a biomedical condition. This paper follows the British convention. 'Impairment' designates a biomedical condition.

² It has recently been argued that taking the self-reports seriously raises a number of questions regarding health care rationing (Dolan and Kahneman 2008). This paper will consider only the conflict just described.

³ On rare occasions researchers are driven to discuss contexts in which there is no evidential way to decide whether people are correct or not about their own contemporary mental states. They call this a 'philosophical question,' sometimes actually cite the views of philosophers, and they immediately return to experimentally manipulable situations (for example Gilbert et al. 1998, 634).

⁴ Ubel and colleagues consider contrast effects to have potentially larger influences on adaptation than suggested here, but also consider them to be genuine and not illusory influences. They are seen to be a mechanism of hedonic adaptation (Ubel, Loewenstein, and Jepson 2003, 603–604).

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