Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public

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Abstract

There is often a discrepancy between quality of life estimates from patients and the general public. These discrepancies are of concern to the disability community, who worry that the public does not understand how valuable life can be for people with disabilities; policy planners, who must decide whose quality of life estimates to use in economic analysis; and practitioners and patients facing difficult medical decisions, who may have to worry that people have difficulty imagining unfamiliar health states. We outline several factors that may contribute to these discrepancies. Discrepancies might occur because patients and the public interpret health state descriptions differently – for example, making different assumptions about the recency of onset of the health state, or about the presence of comorbidities. Discrepancies might also arise if patients adapt to illness and the public does not predict this adaptation; because of response shift in how people use quality of life scales; because of a focusing illusion whereby people forget to consider obvious aspects of unfamiliar health states; because of contrast effects, whereby negative life events make people less bothered by less severe negative life events; and because of different vantage points, with patients viewing their illness in terms of the benefits that would result from regaining health, while the public views the illness in terms of the costs associated with losing good health. Decisions about whose values to measure for the purposes of economic analyses, and how to measure discrepancies, should take these potential contributing factors into account.

Key words: Cost effectiveness analysis, Disability, Quality of life, Utility

Introduction

If asked to imagine they have paraplegia, most people predict that it would have a devastating effect on their quality of life [1]. Yet, there are often discrepancies between the quality of life estimates of patients and the public [2–11]. For example, the general public estimates the health related quality of life (HRQoL) of dialysis at a value of 0.39 (on a scale where 0 represents death and 1 represents perfect health), whereas dialysis patients estimate their HRQoL at 0.56 [12].

Patients without colostomies estimate the HRQoL of living with a colostomy at 0.80, while patients with colostomies rate their own HRQoL at 0.92 [13]. In fact, in a famous study, the happiness of people who had recently developed paraplegia or quadriplegia following a motor vehicle accident did not differ substantially from that of recent lottery winners [14].

These discrepancies suggest that either the public does not understand how valuable life can be for people with disabilities or that people with disabilities consciously or subconsciously overstate

their HRQoL [15]. It raises important questions about whose HRQoL estimates should be used in economic analyses [16].

Whether patients' or the public's HRQoL are used can have important consequences for policy. For example, imagine a treatment that delays, for 10 years, a patient's need for a colostomy, costs \$10,000, and has no side effects. As stated above, people who have not experienced colectemies estimate that having a colostomy would yield an HRQoL of 0.8. This treatment, then, would increase that person's HRQoL from 0.8 to 1, yielding 0.2 quality adjusted life years or QALYs, for a total of 2 QALYs over 10 years, at a cost of \$5000 per QALY. Now suppose, instead, that HRQoL estimates were taken from people who have colostomies. In that case, the intervention would increase HRQoL from 0.92 to 1, for a 10 year gain of 0.8 QALYs, and an overall cost effectiveness of \$12,500 per QALY, less than half the cost effectiveness based on general public HRQoL estimates. As this extremely simplified example suggests, the choice of whose HRQoL estimates to use could significantly impact cost effectiveness estimates.

Currently, the common practice is to rely on QALY estimates derived from the general public, by eliciting the general public's attitude towards specific illnesses or disabilities [17]. But what if public attitudes reflect misunderstandings about what it is like to live with paraplegia? Should such misunderstandings be included in economic analyses? More generally, why might discrepancies occur between HRQoL estimates of patients and the general public? And are there any reasons to

wonder whether patients' reports of their own quality of life could themselves be in error? The answers to these questions are important not only for policy makers who are in charge of allocating scarce health dollars, but also to patients facing difficult medical decisions. For example, if people with inflammatory bowel disease considering colon surgery overestimate the HRQoL impact of a colostomy, they might make the wrong decisions about how to treat their illness [18].

In this article, we briefly outline some factors (gleaned from the medical literature, psychology literature, and also based on our own speculation) that could potentially contribute to discrepancies between patient and public HRQoL estimates, discuss the implications these factors have for health care policy and clinical practice, and explore some of the challenges facing quality of life researchers who are trying to sort out these issues.

Sources of discrepancies between patient and public HRQoL estimates

We group factors that could potentially contribute to the discrepancy between patients' and the public's HRQoL estimates into three rough categories, based on whether the discrepancy is caused by (1) a failure to get patients and the public to compare the same health states, (2) a failure to get them to use the same 'measuring stick,' or (3) real differences of opinion about the severity of various illnesses or disabilities (Table 1).

Table 1. Rough categorization of factors potentially contributing to discrepancies

- 1. Comparing apples to oranges failure to rate the same health states
 - a. Incomplete health state descriptions
 - b. Vagueness in health state descriptions about whether the health state is of recent onset
 - c. The focusing illusion: Forgetting to consider the big picture
- 2. Comparing apples to apples using different measuring sticks
 - a. Response shift: One person's '10' is another's '11'
 - b. Different vantage points: How it looks depends on where you stand
 - c. Poor hedonic accounting: Difficulty providing a global summary of moment to moment HRQoL
- 3. Comparing apples to apples using the same measuring stick
 - a. Patient adaptation and public failure to predict adaptation
 - b. Contrast effects: What is a small pleasure to a lottery winner?
 - c. Shifting inter- and intra-personal comparisons

Table 2. Scenario used by Boyd et al.* to describe aspects of life with a colostomy

Definition of colostomy: A portion of the colon is brought through the abdominal wall, thereby creating a

temporary or permanent opening

Reservoir: Limited

Incidence of evacuation: 24–48 hours with control measures

Consistency of discharge: Liquid to formed stool

Means of control: No voluntary control; potential control with diet, medication and/or irrigation

Maintenance: Usually requires an hour or less each morning or every other day

Special requirements:Plastic bag or dressing worn over the stomaActivity:Full range of normal activities should be possibleSocial problems:Unexpected odor, gas, or evacuation may occur

Other: In men, impotence may develop

Comparing apples to oranges: Failure to rate the same health states

Incomplete health state descriptions

Imagine the challenge of describing a colostomy to someone unfamiliar with one. Boyd et al. [13] presented people with the description of a colostomy shown in Table 2. This is a relatively complete description of a fairly discrete health state. But it still lacks relevant details. What does it mean, for example, to have 'no voluntary control' of the colostomy? What is involved in maintaining a colostomy? What percentage of men will develop impotence? Moreover, the description never really shows people what a colostomy looks like or how one operates.

One possible source of discrepancies in HRQoL ratings is that patients and the public may be evaluating different health states. Even when provided with identical descriptions of the health state being evaluated, such descriptions are necessarily incomplete, and patients and the public are likely to fill in the blanks idiosyncratically, with information based on their own personal experiences or stereotypes. As a result, patients and the public may, in effect, be evaluating different health states, leaving us with comparisons of apples to oranges [13].

Vagueness in health state descriptions about whether the health state is of recent onset

The incomparability of HRQoL ratings is aggravated because health state descriptions are often ambiguous about whether the health state is of recent onset. Most health state descriptions ask respondents to imagine what it would be like to live with a specific set of symptoms – 'Imagine you

are completely blind' – without specifying how long they have been in the health state. Consequently, some nonpatients will consider what it would be like to live chronically with the illness or disability, but others will think about what it would be like to receive the news that they had just become blind. People considering the news value of blindness might provide lower HRQoL estimates than those who assume it has been long-standing.

The focusing illusion: Failing to consider the big picture

When asked to estimate the HRQoL of paraplegia, many people focus on those activities affected by paraplegia, such as their ability to walk or play favorite sports, while ignoring activities unaffected by paraplegia, such as watching television and having a satisfying family life. Psychologists call this inattention to broad life domains a 'focusing illusion' – people overestimate the emotional impact of events by disproportionately focusing on narrow life domains influenced by the events [19, 20].

For example, in one study, college students in California and Michigan were asked to state how happy they are currently, and how happy they would be living in the alternate state (e.g. how happy do California students think they would be living in Michigan) [19]. Both groups of students reported similar levels of current happiness. Nevertheless, both groups also predicted that they would be happier living in California than in Michigan. The size of this predicted difference was correlated with students' beliefs about the relative impact that weather has on their happiness. This study

^{*} Reproduced from Med Dec Making 1990; 10: 61.

has been interpreted as evidence that students focused too narrowly on weather when making these predictions, ignoring the possibility that California might have more traffic jams, a higher cost of living, or other features that on balance make life just as good in Michigan.

To the extent that a focusing illusion is influencing people's health state ratings, they will no longer be evaluating the same health state as patients. The general public will focus on a few small aspects of the illness, whereas patients will consider all aspects of their illness. For example, someone might dwell on how a colostomy would affect her willingness to go swimming in public without reflecting on how infrequently she currently swims in public.

Comparing apples to apples using different measuring sticks

Discrepancies resulting from incomplete health state descriptions are not completely correctable. But the goal of HRQoL measurements should be to reduce this source of discrepancies to the greatest extent possible. However, even if it were possible to eliminate this source of discrepancies, discrepancies are likely to persist in part because patients and the public may not interpret HRQoL measures in the same way.

Response shift: One person's '10' is another's '11' Imagine a person who is asked before and after the onset of an illness to rate her HRQoL on a 1 to 10 scale. The illness may change her idea of what the numbers 1 and 10 represent, a phenomenon called response shift – changes in health lead to changing internal standards for evaluating one's own health, making it difficult to compare HRQoL before and after illness [21–25]. Response shift is due, in part, to social comparisons [23]. Some patients respond to HRQoL questions by comparing themselves to other patients rather than to healthy people, thereby artificially increasing their reported HRQoL [24].

Response shift is also related to changing expectations. Imagine a 30-year-old and an 85-year-old who both rate their HRQoL as 95 on the 0–100 scale. How confident should we be that their answers represent the same level of health? A rating of 95 for the elderly man might reflect his expecta-

tions of the best possible HRQoL at that age. This response shift confounds HRQoL comparisons of patients and the public.

Different vantage points: How it looks depends on where you stand

Much the way the distance we are from two objects affects our ability to judge the distance between them, people's current health affects their evaluations of the severity of other health states [26]. To a person in normal health, the difference between hemiplegia and hemiplegia with aphasia may seem small – both health states are extremely severe. But, to a patient living with either health state, the difference will appear much larger – having or not having the ability to speak makes a big difference to these patients.

Poor hedonic accounting: Difficulty providing a global summary of moment to moment HRQoL [27]

Discrepancies may occur because patients have difficulty providing a global summary of their moment to moment quality of life. This difficulty is illustrated by a study on people's perception of pain, in which subjects were exposed to two painful stimuli. One stimuli involved submersing a hand in very cold ice water for 60 sec. The other stimuli involved submersing the other hand in an equally cold bucket for 60 sec, then keeping the hand in the bucket for 30 more sec at a slightly warmer, but still painful temperature. Subjects were then told that they would have to repeat one of the two stimuli. Asked which they would prefer to repeat, unaware of the relative duration or temperature of each stimuli, subjects thought the second stimuli was less painful, because the final intensity of the pain diminished. Thus, despite receiving a greater amount of pain with the 90 sec stimuli, people generally wanted to repeat the 90 sec stimuli rather than the less painful 60 sec one [28]. Their recall of their experience was disproportionately affected by the intensity of pain at the end of each stimulus, and failed to adequately represent the stimulus duration.

Such a failure of recall could influence patients' HRQoL estimates. Moment to moment, people might feel bored or in pain or fatigued. But, when asked to summarize their overall HRQoL, people might consciously or subconsciously downplay

these feelings, or their estimates may reflect the strongest feelings they typically experience during the day, rather than the average feelings; or the most recent feelings may dominate their global accounting, which in research settings may mean that a good or bad parking spot at the medical center may influence HRQoL ratings more than patients' health related experiences [29].

The potential effect of poor hedonic accounting on the discrepancy can be illustrated with the example of a person with paraplegia who is given a pager or palm pilot and provides daily ratings of subjective well-being of 5, 6, 5, 9, 5, 6, and 6 over the course of a week [30, 31]. When asked to rate his overall HRQoL at the end of the week, the patient gives a rating of 8 out of 10 because he overweights the peak of the sequence, which is 9 [29]. The general public, on the other hand, who do not overweight any particular day, estimate his HRQoL at 6 out of 10 – the average of his HRQoL over the interval. The discrepancy occurs, in this example, because patients place great importance on peak intensity while the general public bases its estimates on their prediction of patients' overall averages.

Comparing apples to apples using the same measuring stick

The final general category includes those factors that potentially reflect real differences of opinion and between patients and the public about the HRQoL of various health states.

Patient adaptation and public failure to predict adaptation

Patients with chronic illnesses often adapt physically and emotionally to their health states. Adaptation is, in part, physical. A person with blindness may learn how to read Braille and how to ambulate with a cane. Adaptation is also *psychological*. When people lose the ability to perform certain activities, they start preferring alternative activities – an amateur musician with carpal tunnel syndrome may give up performance and spend more time listening to music or reading novels. Psychological adaptation also occurs through a reduction in expectations. A patient with severe emphysema may forget that long walks in the park used to be an important part of her life. Psycho-

logical adaptation also occurs because strong emotions rarely persist, similar to the way that people's sensory perceptions adjust to changing conditions [32]. People feel intense delight after being relieved of a painful toothache, but soon return to their baseline level of happiness. This lack of persistence of strong emotions partly explains the lottery winner and paraplegia study. Once people get over good or bad news, they revert to their baseline emotional state [33]. Adaptation would not contribute to discrepancies between patient and nonpatient HRQoL ratings if nonpatients were able to predict adaptation and adjust their ratings accordingly. However, when specifically asked to consider adaptation, people consistently underpredict their own ability to adapt [34].

What is the difference between a focusing illusion and failure to consider adaptation? A focusing illusion is the failure to appreciate that not all life domains or life events will be equally affected by a given change in circumstances. For example, when considering the impact of paraplegia on their quality of life, people may fail to consider that paraplegia will not affect their ability to enjoy a good television show, a pleasant conversation, or a dinner with family and friends.

By contrast, a failure to consider adaptation is the failure to appreciate the fact that one's emotional response to the given change in circumstances will diminish *over time*. Anyone who has read a description of paraplegia should recognize that paraplegia does not affect his or her ability to enjoy a good television show. However, they may fail to consider that the grief they will feel upon finding out that they have become paraplegic will subside over time and that the sense of loss that they feel because they have to abandon favorite pastimes will be replaced by the joy they feel in other pastimes.

Contrast effects: What is a small pleasure to a lottery winner?

When asked to rate how much pleasure they would gain from receiving a compliment, reading a magazine, or hearing a funny joke, lottery winners report less pleasure than does the nonlottery winning general public [14]. Apparently, the pleasure of winning a lottery makes smaller pleasures appear inconsequential.

The pleasure of good events and the pain of bad ones are moderated by contrast effects [35]. Positive experiences, while making people happy, can also make them less excited about similar experiences. An exquisite meal at a three-star French restaurant makes people less satisfied with a two-star French restaurant. Similarly, horrible life events make people less bothered by less severe bad events [36]. A patient with MS may shrug off the emotional impact of a disfiguring rash that would devastate someone else. Because of contrast effects, patients' HRQoL may be relatively unaffected by other bad events.

If the general public overlooks contrast effects when rating unfamiliar health states, they will overestimate the detrimental impact illness has on well-being. For example, if a patient with MS is evaluating the probable quality of life of another hypothetical person with MS, she might have learned from her own experience that MS has made it easier for herself to emotionally deal with minor day-to-day frustrations that used to bother her significantly. When she responds to the HRQoL elicitation, she will bring that knowledge to bear upon her final response. A member of the general public, on the other hand, may not consider the likelihood that having MS would create these types of contrast effects. Consequently, their HRQoL estimates will be uninfluenced by the presence of contrast effects.

Shifting inter- and intra-personal comparisons Pleasure and pain result, in part, from comparisons we make, to other people and to ourselves at earlier points in time [24, 37–39]. The first few weeks driving a new car are extremely enjoyable, because we compare it to the clunker we traded in. Over time, the importance of this comparison diminishes and so too does our elation with the automobile, even if it is still running perfectly. Analogously, patients' early experiences with illness, especially sudden illness, will be very distressing if they compare it to their previous health. Over time, their experience will not be so influenced by such comparisons, and hence, the distress that they cause will dissipate. Likewise, as patients gradually come into contact with other patients, some of them with more severe conditions than their own, these changing comparisons may reduce their own level of distress. To the degree that the

public is unaware of these effects, these shifting comparisons will lead them to underestimate patients' quality of life.

Implications

We have listed a variety of reasons why patients and the public may provide different HRQoL estimates for health states. Our list is not exhaustive, and the categories are not always mutually exclusive. For example, contrast effects may, in part, explain how people adapt to adversity. Nevertheless, the list should help policy experts and quality of life researchers think through the implications of discrepancies that occur between patient and public HRQoL estimates.

An understanding of the causes of the observed discrepancies could illuminate debates about whose values, or HRQoL estimates, should be used in economic analyses of health care [40]. For example, as stated above, the current economic standard is to elicit HRQoL estimates from the general public rather than from patients, because economic analyses are meant to guide social policies and not individual patient decisions [17]. Nevertheless, some potential sources of discrepancies between patients and the public suggest that public HRQoL estimates may be faulty. If, for example, members of the public are susceptible to a focusing illusion state their estimates may not be appropriate for determining social policies. At the same time, our discussion shows ways that patients' HRQoL estimates may also be inappropriate for determining social policy. If, for example, patients' responses are due to response shifts may not want this to influence policy decisions [15].

Challenges for quality of life researchers

We have outlined a number of factors contributing to discrepancies between patient and public HRQoL estimates. One of our goals in doing this is to bring together insights from disparate fields and bring them to the attention of quality of life researchers. For example, among those debating whose values ought to be included in cost effectiveness analyses, we have yet to hear much discussion about the role of a focusing illusion, or of contrast effects, in explaining these discrepancies.

Another goal was to provide a framework around which researchers could study discrepancies. The most important challenge facing researchers, we think, is to conduct studies that shed light on why these discrepancies occur. Several obstacles stand in the way of such research efforts.

Making health state descriptions complete and balanced

A challenge for researchers is to find ways to improve the completeness and balance of health state descriptions. Such descriptions can never be complete, of course. But there may be ways to standardize health state descriptions to make sure that the effect of illnesses on common or important life functions is not overlooked.

Researchers may want to build some 'debiasing techniques' into their health state descriptions. For example, if it is important to avoid a focusing illusion when eliciting public attitudes toward paraplegia, then health state descriptions should remind people that paraplegia does not affect their ability to watch television, enjoy a good meal, etc. [1]. Such efforts would raise questions of balance, however. How many unaffected life activities should be mentioned? Should people be reminded of their ability to adapt to adversity too? And if so, how should they be reminded?

In making health state descriptions more complete, researchers may want to experiment with video and computer based methods of describing health states. Such methods can allow the public to witness testimonials from patients with the illness in question, or see pictures relevant to understanding the illnesses. Nevertheless, such vivid information itself may have an undue influence on people's perceptions [41].

Keeping in mind the goals of health care

Researchers studying the discrepancy between patients' and the public's evaluations of health states, we believe, will benefit by thinking clearly about the policy implications of their research. Suppose, for example, that researchers concluded that a major contributor to discrepancies was failure among the general public to predict how much they would

adapt to adversity. Suppose, similarly, that state of the art research on utility measurement showed that significant illnesses had large effects on people's functional abilities but relatively small effects on their mood or utility. In such a case, it is worthwhile to ask ourselves whether the goal of health care ought to be to maximize subjective well-being, health related utility, or something else [15]. If people really are on a hedonic treadmill, and tend to revert to their baseline level of happiness after suffering permanent disabilities, should society spend large amounts of money to keep them from becoming disabled? What if, as we believe is likely to be the case, the same patients who report a high quality of life would be willing to pay substantial amounts to restore their former health? This is a case of discrepancies, not between different people being asked the same question, but between the same person being asked different questions. And, again the question is which answer, if either, should guide policy.

Conclusion

To date, there are no perfect measures to determine just how happy people are. And there is no gold standard to estimate people's subjective quality of life. Nevertheless, whatever makes up happiness or quality of life, it appears that many illnesses have far less impact on subjective quality of life than many of us would predict. This is good news. As much as we strive to reduce the burdens of illness, it is comforting to remember the strength of the human spirit. At the same time, it is worth remembering how this strength of spirit complicates quality of life measurement.

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