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The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis

Paul Menzel^{a,*}, Paul Dolan^b, Jeff Richardson^c, Jan Abel Olsen^d

^a Pacific Lutheran University, Tacoma, WA 98447, USA

^b University of Sheffield, UK

^c Centre for Health Program Evaluation, West Heidelberg, Victoria, Australia

^d University of Tromsø, Norway

Abstract

Chronically ill and disabled patients generally rate the value of their lives in a given health state more highly than do hypothetical patients imagining themselves to be in such states. Much of this difference may be due to actual patients' adaptation to their health states, a phenomenon that would not typically affect the ratings of persons who only hypothetically imagine themselves to be patients. This article pursues a non-empirical, normative question: does such adaptation render actual patients' ratings of quality of life morally questionable for purposes of resource allocation? Distinguishing the different basic elements in patient adaptation reveals why, and in what respects, people are pulled strongly in opposite directions in responding to this question. Several more explicit moral arguments against using adapted patients' ratings have been articulated by economists and philosophers, and others are developed by the authors. While most of these arguments do not survive careful analysis, several do. Given the subsequent complexity of the matter, it is argued that: (1) Neither solely actual nor solely hypothetical patient perspectives should be used for rating quality of life. (2) Even if representatives of the general public acting as hypothetical patients provide ultimately the best perspective from which to discern societal values about health states, patients' values that are often influenced by adaptation must still be conveyed to and clearly understood by public representatives as a critically important fact about health-related quality of life. The article also points to the need for much additional work on adaptation, both empirical research and normative analysis. © 2002 Elsevier Science Ltd. All rights reserved.

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Introduction

Whose preferences should be used in determining the values of health states that influence resource allocation decisions—the values of actual patients, or those of the general public? This question gained empirical significance in the 1970s when Sackett and Torrance (1978) found considerable differences in how the general public and dialysis patients valued the health-related quality of life with dialysis and Brickman, Coates, and Janoff-Bulman (1978) found that paralyzed accident victims

were only somewhat less happy than either a control group or major lottery winners. More recently, Boyd, Sutherland, Heasman, Trichler, and Cummings (1990) found that colostomy patients value various states of health related to their condition more highly than a healthy population values those states, and Hurst et al. (1994) found that patients with rheumatoid arthritis give higher scores to life in that state than the general public does. Generally, such studies have found that patients perceive higher quality of life in their health states than the general population perceives in those same health states.

The question of whose preferences to use can be especially important in economic evaluation that may influence the allocation of resources. Take, for example,

*Corresponding author. Tel.: +1-253-535-7126; fax: +1-253-535-8760.

E-mail address: menzept@plu.edu (P. Menzel).

the findings of Sackett and Torrance (1978) that public representatives rated the health related quality of life (HRQoL) of a remaining lifetime with chronic home dialysis at 0.39, while home dialysis patients themselves rated it at 0.56. The difference can make a cost-effectiveness analysis look quite different. If it were possible to return such patients to full health, then using the patients' value, the gain would be 0.44 QALYs per year (1.0–0.56). Were we, however, to use the value elicited from public representatives, the gain would be considerably higher: 0.61 QALYs per year (1.0–0.39). To be sure, cost-effectiveness analysis is not meant to dictate allocation decisions but only, along with other considerations, inform them. Still, the difference between an analysis run with patients' health state values and an analysis run with public representatives' values could be influential.

The issue of whose preferences to use affects the application of any instrument for assessing HRQoL, but discussion and debate over two decades have hardly resolved it. The US Public Health Service Panel on Cost-Effectiveness in Medicine (Gold, Siegal, Russell, & Weinstein, 1996) advocated the use of representatives from the general public who would be asked to imagine themselves in the health state being evaluated (hereafter referred to as "hypothetical patients"). Others such as Nord (1999, pp. 89–90), Nord, Pinto Prades, Richardson, Menzel, and Ubel (1999) and Menzel et al. (1999) have advocated use of actual patients for estimating HRQoL.¹

This question of whose perspective to use in health state valuation becomes more complex when it is noticed that much of the empirical difference between patients' and the general public's ratings of HRQoL may reflect patients' adaptation to their condition. Doubts quickly surface about the use of patient preferences that are influenced by adaptation. Adaptation may reflect cognitive deficiencies such as denial of some of the realities of illness or a newly suppressed recognition of the nature of full health, deficiencies that certainly justify caution before using preferences influenced by adaptation. Moral doubts of other sorts also arise. Patient adaptation that raises HRQoL ratings, for example, necessarily reduces the apparent benefit from curing the conditions to which patients adapt, as illustrated above

in the case of dialysis patients. Ironically, then, laudable adaptation by patients may reduce the influence of their condition on the setting of allocation priorities.

However, it may still seem that it is patients, not the general public, who should be asked to provide the values for HRQoL. Patients certainly have a better understanding of what life is like in states of impaired health, and it is their preferences, whether significantly influenced by adaptation or not, that represent what is actually experienced in the conditions that health services aim to remedy or prevent. Orthodox economic theory reinforces this, focusing primarily as it does on individual utility as defined by actual preferences. The fact that these preferences may have undergone some form of transformation in a process of adaptation would not normally be regarded as any more significant than the mutation of preferences through time that may occur because of other sorts of influences on people.

In the present paper we pursue specifically this question: Should adaptation be regarded as rendering actual patients' generally higher ratings of HRQoL of dubious value for purposes of resource allocation? The question is fundamentally normative, one that Murray calls "a vexing moral problem" that "must be addressed" (1996, p. 32). While many different generic descriptive systems for health state evaluation exist (e.g., EQ-5D, 15D, AqoL, HUI), our discussion of this normative question does not pursue any of those in particular but is relevant to the application of any instrument for discerning the value of HRQoL.

In focusing on such a normative question our analysis is distinguished from other significant work on adaptation. Sprangers and Schwartz (1999), for example, propose a helpful theoretical model of an important mediator of the adaptation process, "response shift", but their purpose is to *clarify and predict changes* in HRQoL as a result of the interaction of the different factors articulated in their model. Our purpose, by contrast, is to clarify various *moral considerations for and against* using ratings of HRQoL influenced by adaptation.

While our focus is on a normative question, however, our primary goal in the paper is not to argue for a specific answer to that question, but to articulate the major arguments on both sides. Our normative analysis is thus intentionally "preliminary".

In the next section we provide an analytical breakdown of different elements in what is generally referred to as "adaptation" and note the direction in which each element initially pulls in the normative debate. Subsequently we ask whether, to avoid making a factual mistake when they imagine life with a particular health impairment, public representatives must imagine themselves to have the actual values of patients, including those shaped by adaptation. Then we articulate and assess five specific normative arguments against using

¹ Ratings of HRQoL typically constitute measures of what economists call the "individual utility" of health states—their value strictly to the individuals who are in them. "Social" or "societal" values, by contrast, incorporate distributive and interpersonal concerns, even if those are still expressed by individuals. The general method of economic analysis for priority setting within health care is "cost-effectiveness analysis" (CEA). The method that deliberately and exclusively focuses on individual health state utility is "cost-utility analysis" (CUA).

values influenced by adaptation. Finally, in the last section before we conclude, we evaluate, as it affects the present controversy about adaptation, a general approach to cost-effectiveness analysis that preserves roles for the perspectives of both patients and imaginative public representatives.

Elements of adaptation

The primary meaning of “adapt” appropriate for the present context of disability and chronic illness is “to adjust oneself to new or changed circumstances” (*Webster’s New World Dictionary*, Third College Edition, 1994). This can be articulated even more specifically as changing “oneself so that one’s behavior, attitudes, etc. will conform to new... circumstances” (*Webster’s New International Dictionary*, Third Edition, 1969, emphasis added).

Accordingly, because the primary focus of adaptation is on a change in the adapting agent (“oneself...”), we will interpret the concept of adaptation as not encompassing the use of corrective devices such as prostheses, eyeglasses, or contact lenses. Similarly because of the focus of adaptation on an adapting agent, we believe that another phenomenon associated with adaptation, increased cognitive awareness of a health state, should also not be interpreted as an instance of adaptation. Persons experiencing adverse health conditions may realize and understand aspects of their particular health state that the general public does not. Such differences in knowledge are quite different from the alteration of activities, desires, goals, and values—the changing of oneself—that more typically characterizes what people understand by “adaptation”.

Eight other constitutive elements, we believe, fall more clearly under what people regard as adaptation to illness. Given that these elements are usually perceived as either deficiencies or admirable achievements, they contribute directly to moral controversy about adaptation’s role in resource allocation and can provide a useful initial framework for the normative task of this paper.

Cognitive denial of functional health state

Patients may find it difficult to admit how poor their objective, functional health really is. This is a largely cognitive matter, but it may still represent the need of a person to accommodate to a new reality and can therefore easily be seen as adaptation. This form of adaptation leads directly to moral doubts about adaptation’s role, for it hardly seems desirable to base the value of a health state that is used to shape social policy on judgments that are factually mistaken.

Suppressed recognition of full health

A related cognitive deficiency that comprises part of the adjustment to chronic, long-term illness occurs when patients cease to realize anymore what full health is like or what it would enable them to do. Here again, it hardly seems desirable for such cognitive blindness to influence the measurement of health state utility and consequent resource allocation.

By contrast with these two cognitive deficiencies, which militate against using adapted patient ratings, we suggest that four other elements of adaptation carry a sense of achievement or expanded insight. They thereby support the case for using post-adaptation ratings and help to create the genuine dilemma on which we focus.

Skill enhancement

With time, chronically disabled or ill persons may develop greater skill in using whatever physical or mental capacities they retain. No activities or goals are adjusted; people simply improve their ability to accomplish their existing goals in their existing activities, beyond what they previously could ever have imagined was possible.

Activity adjustment

Realizing that a disease or disability is likely to be chronic, people may adjust their activities. Still desiring physical exercise, for example, a former cyclist, now paraplegic, may take up aerobic wheelchirking. Or a person may change occupations, not because she has altered her substantive goals in life, but because she now deems a different occupation to be a better avenue for achieving them.

Substantive goal adjustment

People may adjust not only the activities they select to pursue their goals, but the content and direction of the goals themselves. Their basic interests can change. A paraplegic, for example, may develop an interest in music to replace a previous interest in physical activity.

Altered conception of health

The previous three elements all involve the strengthening of a person’s psychosocial capacity. That process, in turn, can result in a profound shift in a person’s conception of health. Health’s usual conception is biomedical and statistically normative. A different conception might be called “humanistic”: health as the capacity to adapt positively to the problems of life, whether those problems be occupational, physical, personal, or social (Nordenfelt, 1993 and Seedhouse,

1986). In this view “the individual does not...stand passively before his or her illness, but rather engages with it.... In consequence...it might be said of two individuals with the same physical injury or disease that one is healthy and the other not.... The person who, after injury, is confined to a wheelchair, and who yet continues to lead a fulfilled and purposive life...is not...unhealthy...” (Edgar, Salek, Shickle, & Cohen, 1998).

Our point is not to defend such alternate conceptions of health. It is to note that people who have what is commonly thought of as “disability” or “disease” may be stimulated to adopt a radically different and, in their eyes, a more insightful definition of their health. To be sure, a person’s altered conception could reflect a depression of expectations, but “lowered expectations” is hardly an accurate general description of what occurs here.

If the previous four elements represent positive, laudable achievement, another element typically emerges more regrettably and carries little sense of achievement:

Lowered expectations

Lowering one’s expectations, unlike modifying the substance of goals, adjusting activities to reach goals, or altering the conceptual understanding of a basic goal like health, involves changing the particular level of achievement toward a goal that a person expects to accomplish. Regardless of other, more complex adjustments, chronically ill or disabled persons may simply lower their level of expected achievement, fatalistically accepting their diminished lot in life. Of all the elements of adaptation, this appears to be among the least admirable. Most people would regard it as distinctly regrettable, or at least sad, especially as compared with skill enhancement or substantive goal adjustment.

Another possible element in adaptation, however, elicits more varied reactions—to some it is regrettable, to others admirable:

Heightened stoicism

People not only adjust their activities, revise their substantive goals, or lower their expectations. They may also find that to be happy, they do not have to come as close to reaching their goals and expectations as they previously did. They control their happiness so that it is a function only of what they come to see as *achievable*. Such stoic willingness to change internally with external events, rather than struggle against those that cannot be changed, is perhaps the ultimate psychological adjustment.

In modern Western, consumer-oriented society, such heightened stoicism may not strike many as a positive development, but almost as sad as lowered expectations.

Stoicism, though, has a distinguished history, at least philosophically, and any heightened stoicism that develops in the process of adaptation should not be automatically regarded as simply lowered expectations. Moreover, from a stoic perspective, even lowered expectations can be defended as realistic, rational, and admirable, and perhaps even a central element in human maturity and wisdom.

These eight elements of adaptation can be seen as setting the initial landscape for the normative controversy about adaptation given in Table 1.

Two elements, cognitive denial and suppressed recognition of full health, militate against using adapted patient values. Another, lowered expectations, leans in the same direction; it emerges regrettably in the adaptation process and seldom carries any sense of achievement for the adapting person. Heightened stoicism possibly falls in that category, too, though many would defend it as admirable. Four elements—skill enhancement, activity adjustment, substantive goal adjustment, and altered conception of health—seem more clearly laudatory. Substantive goal adjustment and an altered conception of health appear to be the more far-reaching aspects of a person’s adaptation, requiring extensive self-examination and therefore often inspiring deep admiration of others.²

While our analysis of adaptation into these various elements thus clarifies the underlying dilemma about whether to use adapted values, it does not resolve it. It reveals reasons why people are torn in such opposite directions on the question of whether ratings of HRQoL shaped by adaptation should be used for purposes of resource allocation.

²Some of the eight elements discussed here correspond with the dimension of adaptation’s process that Sprangers and Schwartz (1999) and Schwartz and Sprangers (1999) call “response shift.” They define “response shift” as “a change in the meaning of one’s self-evaluation of a target construct as a result of (a) a change in the respondent’s internal standards of measurement (scale recalibration, in psychometric terms); (b) a change in the respondent’s values (i.e., the importance of component domains constituting the target construct); or (c) a redefinition of the target construct (i.e., reconceptualization).” Their third factor, redefinition and reconceptualization, might encompass, in our array, both altered conception of health and heightened stoicism; the former reconceives health itself, the latter reconceives happiness. Their scale recalibration might encompass our lowered expectations, and their change in a respondent’s values can easily be read to encompass our substantive goal adjustment. Our other four elements are more difficult to place in their model and are not, to our knowledge, described elsewhere in the literature on adaptation.

Table 1

Major elements of adaptation as factors for and against using values shaped by adaptation

Major elements of adaptation	For using adapted values	Against using adapted values
Cognitive denial	X	
Suppressed recognition of full health	X	
Skill enhancement	X	
Activity adjustment	X	
Substantive goal adjustment	X	
Altered conceptions of health	X	
Lowered expectations	X	
Heightened stoicism	X?	X?

Imagination, factual mistake, and evaluative privilege

Assume for purposes of discussion that it is proper to elicit health state valuations from representatives of the general public responding as hypothetical patients. The current dominant practice in such elicitation appears to be to describe the health state in neutral, factual terms. Within those terms, what should such respondents be expected to understand about the conditions they are asked to evaluate? We would contend that the underlying principle is that before evaluating life with illness or disability, they need to understand what in fact such life is really like. This suggests that how real patients are likely to adapt, not only objective medical conditions, should be included in factual description of the states being evaluated.

Could a hypothetical patient insist, without simply being factually mistaken, that he or she in particular would never evaluate life with paraplegia, for example, at so high a level? Generally not. A given individual could conceivably be factually correct in such insistence. On the basis of empirical evidence, however, we ought to be sceptical about what will happen to such insistent persons if they actually become paraplegic. Very likely, few would end up not actually adapting. Thus, not only should hypothetical patients be informed of the facts of adaptation, but if they refuse to accept these prospective facts, they should be regarded as factually mistaken in not understanding the health state they are evaluating.

Should this limited point about how to understand “factual mistake” drive us to using the values expressed by actual, typically adapted patients? If, in describing a health condition to hypothetical patients, we should be enriching the description with information about adapted patients’ altered ratings of HRQoL, why should we not simply use actual, adapted patients’ health state values to begin with?

Brock (1995) has resisted the direction of this rhetorical question. Even if hypothetical patients are

correctly said to be making a factual mistake if they imagine their later selves not adapting, he argues that they occupy a *legitimately* different perspective (Brock, 1995, pp. 182–184). The difference in HRQoL ratings stems significantly from the adjustment of substantive goals that an actual, adapting patient makes, thus becoming a “changed person”. Brock concludes that therefore the hypothetical patient’s earlier evaluation is not “mistaken”. Where we as disabled persons look back, we would “view ourselves as having become very different persons” but not as “having been mistaken in our earlier aims and values”.

To be sure, as long as the hypothetical patient accepts the fact that, were she to accrue the condition in question, her values would very likely become those of an adapted patient, we cannot fault her with being factually mistaken. She may still argue that she does not wish to become the new person, and that she must judge the future by the standards of the person she currently is. Nonetheless, how could she defend the practice of continuing to evaluate the condition at her current, non-adapted level? After all, in most of her prospective years in a chronic condition, she *will* be espousing adapted values. Why should she be trying to imagine herself as a non-adapted person with the condition, a person whom she will very likely not be if she does accrue the condition? We conclude that the adapted patient is in a privileged position not only “in regard to facts about the experience of having her disability”, as Brock admits, but in the very enterprise that asking hypothetical patients inherently involves—imagining what it would be like to be someone with the disability.

One way of partially accommodating Brock’s rejection of any evaluative privilege for the actual patient is tempting but ultimately not persuasive. It might be suggested that the rejection of any evaluative privilege for actual, typically adapted patients is still correct for the limited case of *preventive* services, where the real recipient of the service’s benefit is the unchanged person who has not adapted. The actual patient, it might be argued, should be accorded evaluative privilege for purposes of prioritizing curative and restorative services, but the hypothetical patient should be accorded evaluative privilege for preventive services.

This suggestion, however, runs into a fundamental objection. The person whose health will be damaged if preventive measures are not provided is still a person who will likely adapt. The real value of prevention would seem to be the difference between people’s quality of life before disease and their quality of life *with disease or disability*—that is, after likely adaptation to such conditions if they are *not* prevented. The perceived gains from prevention may be higher than the gains from cure, but the real gains are not.

In summary, this can be said so far. (1) As hypothetical patients, representatives of the general

public are very likely to be factually mistaken if they imagine themselves to have a health state to which they believe they will never adapt. (2) The adapted patient may indeed be a “changed person” in the sense that her view of the world has undergone a paradigm shift, but this does not mean that healthy persons, if they are asked to evaluate patients’ HRQoL, should stay in their own world and use their own criteria. The force of hypothetical patients imagining themselves to have a compromised health state points toward according adapted patients a good deal of evaluative privilege. (3) Even for preventive services, this basic, initial evaluative privilege does not move from actual adapted patients to non-adapted hypothetical patients.

Further normative arguments

The previous discussion of epistemic and evaluative privilege only establishes an initial, *prima facie* case for using the perspective of actual, typically adapted patients in evaluating HRQoL. There are other more direct moral arguments against using values shaped by adaptation. We assess five, three of which are made in the literature and two of which we have constructed.

The analogy with slavery

Murray (1996, p. 31) quotes Alexis de Tocqueville (1839) concerning the “happy slave” phenomenon as a reason for hesitating to use patients’ values influenced by adaptation: “Should I call it a blessing of God, or a last malediction of his anger, this disposition of the soul that makes men insensible to extreme misery? Plunged in this abyss of wretchedness, the slave hardly notices his ill fortune; he was reduced to slavery by violence, and the habit of servitude has given him the thoughts and ambitions of a slave”.

While de Tocqueville’s passage may be powerful, its argumentative force when applied to the matter of patient adaptation is not clear. The pull of the passage as it focuses on slavery turns on the fact that slavery is a violent violation of the rights of individuals. If we have pushed people into such depths of deprivation that they have to adapt to retain their self-esteem, and then if also, much to their credit, they actually do adapt, they have still experienced a harm for which we are responsible. Adaptation does not remove the harm, which lies in the initial injustice. Only according to an ethic of hedonistic utilitarianism could it conceivably be said that because of adaptation, no injustice has been done.

Slavery, however, differs from disease and disability in an important respect. Most disease and disability are caused by either natural misfortune or, if by human negligence, by *non-culpable* human negligence. Usually there exist no unjust transgressors who could then be

regarded as perversely attempting to remove the stain of their aggression by claiming that because of adaptation, their victims have lost little well-being. De Tocqueville, by contrast, starts off his passage with a reference to God, setting a context in which the reader already imagines a culpable agent. If that element of responsible causal agency is removed from the picture, the analogy with slavery breaks down and adaptation regains its normally less suspicious role.

The problem of entrenched deprivation

Amartya Sen articulates a point about the alleged perversity of utilitarian reasoning that focuses, not narrowly on slavery, but more broadly on entrenched deprivation (Sen, 1992, pp. 149 and 55). Utilitarian ethics is guilty of an “overdependence on what people ‘manage to desire’” that is “neglectful of the claims of those who are too subdued or broken to have the courage to desire much... . A thoroughly deprived person, leading a very reduced life, might not appear to be badly off in terms of the mental metric of desire and its fulfilment, if the hardship is accepted... . In situations of long-standing deprivation, the victims do not go on grieving and lamenting all the time... . The extent of a person’s deprivation, then, may not at all show up in the metric of desire fulfilment... .” Sen’s conclusion is that ethically, measuring well-being by desire fulfilment is greatly misleading.

Undoubtedly these are important points to which utilitarianism as a moral philosophy must respond. The question in our context, however, is whether the deprivation factor throws the ratings of HRQoL that are carefully procured from adapted patients into the same kind of doubt that deprivation generally throws a utilitarian metric of desire fulfilment. Adaptation often involves genuinely successful achievements and shrewd control over the trajectory of a person’s inner life. In these cases, the adapted person is anything but “broken”, and hardly “subdued”. If what is still seen as deprivation is handled by a person in terms of challenge and “achievement”, does not a metric of desire fulfilment regain its integrity? Thus, while Sen’s argument from entrenched deprivation should give us pause about too readily or generally using adapted patients’ quality-of-life ratings, it does not justify an across-the-board rejection of values shaped by adaptation.

The sadness of accommodation

The force of the de Tocqueville passage may not be related to deprivation per se, a la Sen, but to the sadness of the larger situation in which the deprivation and adaptation occur. No matter how laudable adaptation may be, it is still unfortunate and regrettable that people have to endure the conditions that stimulate it. Serious

chronic illness or disability may not remotely “subdue” or “break” a person, as in entrenched deprivation, but it marks an unfortunate situation.

The relevance of this contextual fact for the issue of adaptation in effectiveness analysis in health care, however, is doubtful. No matter how sad the circumstances are in which disabled and chronically ill people adapt, we would seem to be ignoring their laudable adaptation were we merely to proceed as if they had not adapted. Yet we may also doubt that we are fully respectful of disabled persons if we proceed simply on the basis of their own values, forgetting the circumstances which caused them to adapt. Here lies the kernel of truth in the argument from the sadness of the accommodation: we should not sweep all these values, including those influenced by adaptation, into the same impersonal container of cost-effectiveness analysis without, somehow, recognizing the fact that some have been shaped by often severe misfortune.

How, though, could such recognition be made manifest in the practice of cost-effectiveness analysis? Certainly not, it would seem, by sweeping aside the influence of adaptation and using only non-patient values. Yet simply using actual patients’ values as just any values that go to make up a numerical average also fails to accord any recognition to the sadness of adaptation’s circumstances. We conclude that while the sadness of accommodation does not constitute a good argument against using values shaped by adaptation, it helps to sustain misgivings about them.

The possibility of equivalent quality

Murray claims that “it would be exceedingly perverse to argue that we should not prevent deafness simply because those who are deaf are able to adapt so well to their loss of hearing” that they might claim to suffer no net loss from their disability (1996, p. 31). If we are inclined to use patients’ values shaped by adaptation because they reflect the real lives of those for whom health services are provided, how do we exclude the influence of adaptation when it gets as robust as it does in this example? The deafness case then becomes the alleged counter-example that refutes the acceptability of using values shaped by adaptation.

Defenders of actual patients’ values can hardly respond to this argument by claiming that adaptation can never in fact be so successful that it fully offsets the loss of welfare in an illness, for occasionally it just might. Nonetheless, the argument is problematic. Very few disabled persons will ever claim that their actual adaptation reaches—or even can reach—this extent. To do so they would have to say that in the full scheme of things, they have lost *nothing* (net) from incurring their condition, but they seldom say that. If people really have adapted to that degree, presumably they themselves

would not place much if any value on their own curative services. The fact that almost all still do want those services suggests that the assertion of complete adaptation is usually an overstatement.

While the problem posed by the possibility of equivalent HRQoL does not thereby disappear, it does not constitute any general argument against using values shaped by adaptation. The empirical phenomena in which it is rooted are too rare and too fragile.

Laudable effort and just distribution

Enormous effort and achievement are potentially present in several components of adaptation—certainly in skill enhancement, and perhaps also in substantive goal adjustment, altered conceptions of health, and heightened stoicism. While the need to adapt may be sad, the adaptation itself may often be highly admirable. In light of such laudable effort and achievement, it would certainly be ironic, or even perverse or unjust, if disabled persons lost competitive advantage in the race for scarce resources because their adaptation diminished the estimated value of curative and rehabilitative services for them.

To be sure, in conventional health economics there is a ready objection to this argument. If the argument is accepted and values that are not directly influenced by adaptation are used, a debatable kind of advantage gets created for the disabled and chronically ill. Fully restorative measures will be more competitive for resources than is warranted by the size of the actual, experienced value that they produce in the chronically ill and disabled. Decisions will then be made as if those patients’ real gains in HRQoL count for *more* than do other patients’ actual, experienced gains, and that is unfair.

We would argue, however, that precisely here resides the cogent moral point of the argument from laudable effort: if disabled persons’ adaptation is the result of such effort, then they may indeed deserve to gain some advantage in the competition for resources above and beyond the actual experienced gain in HRQoL that they would receive from curative or restorative services. The extra value that services for adapted patients’ conditions accrue if “unreal” values not influenced by adaptation are used is simply a just compensation for those patients’ struggles. Regardless of whether it is compensation for the burdens of their disability generally or compensation specifically for their determination to adapt, such compensation is arguably just.

The argument from laudable effort is thus perhaps the most persuasive objection to the use of values influenced by adaptation. We do not suggest, however, that it alone should control the final outcome of the debate. For society to use a framework for making allocation decisions that effectively ignores their adaptation may

still be insensitive, even condescending, to those who have struggled to adapt. Certainly, however, by cogently pulling against the use of adaptation-shaped values despite the failure, in large part, of other arguments against using those values, the argument from laudable effort sharpens the fundamental moral dilemma posed by adaptation.

To summarize this section: (1) The analogy with slavery has only very limited relevance for the typical health care context and therefore cannot ground an argument against use of values influenced by adaptation. (2) The argument from entrenched deprivation may be a telling challenge to utilitarian theories generally, but its characterization of life under entrenched deprivation as “subdued” or “broken” has limited application to life for the disabled and chronically ill. (3) The sadness of accommodation makes an appropriate point—do not lose track of the special context of misfortune that creates the need for adaptation—but that point does not argue persuasively against using values shaped by adaptation in the methodologies that influence health care allocation. (4) The possibility that adaptation may generate virtually equivalent quality for life for some persons with illness and disability adds little to the argumentative situation, based as it is on rare and empirically fragile phenomena. (5) The relationship of laudable effort to distributive justice appears to create the most persuasive argument against using ratings of HQoL influenced by adaptation. It is arguably fair and just to compensate the chronically ill and disabled more than in proportionate relationship to the actual gains in individual utility that they achieve from health services. Given the very limited relevance of the other arguments, and in the face of powerful attractions toward using preferences based on actual experience (attractions based in conventional economic theory in particular), the argument from laudable effort plays an important role in creating and sustaining genuine moral doubts about the use of adaptation-shaped values.

The distinction between societal value and individual utility

In an earlier section we articulated the initial, *prima facie* case for according evaluative privilege in the discernment of HQoL to actual, typically adapted patients. Then in the immediately preceding section we assessed five arguments against staying with that *prima facie* privilege and finally using actual, adapted patients' values. A more refined approach to the adaptation issue might be to step back at this point and distinguish between the kind of evaluation of a health state expressed by patients and defended as their prerogative and the kind of judgement being made in the moral arguments about the use of adaptation-shaped values in

resource allocation discussed in the section just concluded. The former (patient) evaluations are arguably only expressions of individual utility—people's judgements about their own well-being. Conventional economic theory often distinguishes between individuals' utility and their wider well-being as reflected in their “social” or “societal” values—their preferences for the kind of society in which they think it best to live (Menzel, 1999). (For a specific proposal for how to use actual patients' ratings of HQoL in the process of eliciting societal values from the public, see Ubel, Richardson, & Menzel, 2000) In the arguments discussed in the previous section, the critical judgements about whether to leave adapted patients' evaluations of their individual utility relatively unfiltered as they come to influence resource allocation are precisely such expressions of societal value, not individual utility (Nord, 1999; Nord, Pinto Prades, Richardson, Menzel, & Ubel, 1999; Dolan, Olsen, Menzel, & Richardson, 2001).

An allegedly more refined approach to the adaptation problem would exploit this difference. In this view, the appearance of conflict between the advocates of non-patient and adapted patient values is illusory, for the competing sides are focusing on two different things—respectively societal values and individual health-related utility. Both, in a sense, are correct. The perspective of adapted patients is appropriate for discerning their HQoL (individual utility), but then societal values expressed by public representatives can be used to mitigate any morally objectionable aspect of using values shaped by adaptation. If citizens, reflecting critically about adaptation, believe that the dangers of lowered expectations and entrenched deprivation, for example, demand a buffer between adapted patients' HQoL ratings and societal decisions about resource allocation, they can accord health services even to adapted patients who have regained a remarkably high subjective quality of life.

This approach provides a potentially helpful framework for understanding the relationship between hypothetical and actual patient perspectives. Citizens, judging hypothetically as patients, would imaginatively adopt all the values of real patients, but then, as members of society, they would decide what degree of influence adaptation ought to have on resource allocation. Citizen non-patients would still have the important task of assessing how persuasive the various arguments for and against using adapted values in resource allocation were, but they would have to assume that as they put themselves in the shoes of patients, they were living with the HQoL that actual patients say they experience.

Such an approach in which individual utility and societal value are carefully distinguished may provide much needed clarification for the debate about

adaptation, but it does little by itself to *resolve* arguments at the level of societal value about the proper role of adaptation. For example, it does not by itself resolve the debate about how much recognition should be accorded ratings of HRQoL that are shaped by the less admirable elements in adaptation such as cognitive denial of functional health state or suppressed memory of full health. While it is important not to confuse individual utility and HRQoL with societal value, it is also important not to inflate the distinction's helpfulness.

Conclusion

The following points emerge from our discussion. (1) At least eight major elements are ingredient in the patient adaptation that complicates the issue of whose perspective to use in measuring HRQoL. These are listed in Table 1, with an indication as to whether they attract us towards or against the use of values shaped by adaptation. (2) Most hypothetical patients are factually mistaken if they imagine themselves to have only the condition being evaluated but believe that they will never significantly adapt. Moreover, the very activity of imagining oneself to be a patient pulls the hypothetical patient toward according the adapted patient's perspective the primary role in determining HRQoL. This creates an initial, *prima facie* privilege for the perspective of the actual, typically adapted patient. (3) Four moral arguments against using values influenced by adaptation are either highly problematic or relevant only in very limited contexts—the analogy with slavery, the problem of entrenched deprivation, the sadness of accommodation, and the possibility of equivalent quality of life with disability. A fifth moral argument, the argument from the relationship of laudable effort to distributive justice, is more persuasive. Three other considerations arising from the constitutive elements of adaptation also mitigate against using adapted values—cognitive denial of functional health state, suppressed recognition of full health, and lowered expectations. (4) Clearly distinguishing the ratings of HRQoL by patients at the level of individual utility from the societal values expressed by both patients and representatives of the general public is a helpful clarification. By itself, however, it does not resolve the substantive arguments about how much influence adaptation should finally have.

We have not proposed a conclusive answer to the central question pursued in this paper. As a result of our analysis, however, we would defend two claims that constitute a distinct orientation on the issue. First, any exclusive use of either patient or non-patient perspectives cannot currently be justified. Second, even if it is decided that representatives of the general public are a

more appropriate source of societal values about health states than patients are, patient values typically shaped by adaptation must be conveyed to hypothetical patients and emphasized very strongly as an important fact about quality of life with an illness or disability. Public representatives asked to evaluate health states must clearly understand the ratings of HRQoL by actual patients. Only, perhaps, when adaptation is comprised primarily of cognitive denial or suppressed recognition of full health does it become such an inappropriate influence on health care allocation priorities that actual patients' values do not need to be conveyed to and understood by public representatives being questioned.

If the debate about the use of health state values influenced by adaptation is as inconclusive as it may appear to be after our discussion, perhaps a good case can be made for even putting the very issue of whether adaptation makes patient ratings inappropriate for use in allocation decisions to sample groups of the disabled and chronically ill themselves. We cannot predict what they would say. If, for example, the disabled and chronically ill themselves, after lengthy discussion of this issue, were to doubt that most values influenced by adaptation should be used in setting priorities among health services, the case for using actual patient values might be weakened considerably.

At present there is little information about the ethical preferences of the public or chronically ill and disabled patients regarding this issue of adaptation, and relatively little attention has been given in the literature to its normative dimensions. Before any methodology for prioritizing health services might emerge as "established", there is need for much more work on adaptation and its influences on expressed evaluations of health states. This work should include both empirical research and normative analysis.

References

- Boyd, N. F., Sutherland, H. J., Heasman, Z. K., Trichler, D. L., & Cummings, B. J. (1990). Whose utilities for decision analysis? *Medical Decision Making*, 10, 58–67.
- Brickman, P., Coates, D., & Janoff-Bulman, R. (1978). Lottery winners and accident victims: Is happiness relative? *Journal of Personality and Social Psychology*, 35, 916–927.
- Brock, D. W. (1995). Justice and the ADA: Does prioritizing and rationing health care discriminate against the disabled? *Social Philosophy and Policy*, 12, 159–185.
- de Tocqueville, A. (1839). *Democracy in America*. New York: Anchor Books.
- Dolan, P., Olsen, J. A., Menzel, P., Richardson, J., 2001. An inquiry into the different perspectives that can be used when eliciting preferences in health. Submitted for publication.
- Edgar, A., Salek, S., Shickle, D., & Cohen, D. (1998). *The ethical QALY: ethical issues in healthcare resource allocations*. Haslemere, UK: Euromed Communications.

- Gold, M. R., Siegal, J., Russell, L. R., Weinstein, M. (Eds.), (1996). *Cost-effectiveness in health and medicine*. New York: Oxford University Press.
- Hurst, N. P., Jobanputra, P., Hunter, M., Lambert, M., Lockhead, A., & Brown, H. (1994). Validity of EuroQol—a generic health status instrument—in patients with rheumatoid arthritis. *British Journal of Rheumatology*, 33, 655–662.
- Menzel, P. (1999). How should what economists call “social values” be measured? *The Journal of Ethics*, 3, 249–273.
- Menzel, P., Gold, M. R., Nord, E., Pinto Prades, J. L., Richardson, J., & Ubel, P. (1999). Towards a broader conception of values in measuring health care cost-effectiveness. *Hastings Center Report*, 29(3), 7–15.
- Murray, C. J. L. (1996). Rethinking DALYs. In Murray, C. J. L., & Lopez, A. D. (Eds.), *The global burden of disease*. Cambridge, MA, and Geneva: Harvard University Press and World Health Organization.
- Nord, E. (1999). *Cost-value analysis in health care: making sense out of QALYs*. Cambridge, UK: Cambridge University Press.
- Nord, E., Pinto Prades, J. L., Richardson, J., Menzel, P., & Ubel, P. (1999). Incorporating societal concerns for fairness in numerical valuations of health programs. *Health Economics*, 8, 25–39.
- Nordenfelt, L. (1993). *Quality of life, health and happiness*. Aldershot, UK: Avebury Press.
- Sackett, D. L., & Torrance, G. W. (1978). The utility of different health states as perceived by the general public. *Journal of Chronic Diseases*, 31, 697–704.
- Seedhouse, D. (1986). *Health: the foundation for achievement*. Chichester, UK: Wiley.
- Sen, A. (1992). *Inequality reexamined*. Cambridge, MA: Harvard University Press.
- Schwartz, C. E., & Sprangers, M. A. G. (1999). Methodological approaches for assessing response shift in longitudinal quality of life research. *Social Science & Medicine*, 48, 1531–1548.
- Sprangers, M. A. G., & Schwartz, C. E. (1999). Integrating response shift into health-related quality of life research: A theoretical model. *Social Science & Medicine*, 48, 1507–1515.
- Ubel, P., Richardson, J., & Menzel, P. (2000). Societal value, the person trade-off, and the dilemma of whose values to measure for cost-effectiveness analysis. *Health Economics*, 9, 127–136.