Utilities for health states: Whom to ask (August 2012)

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Synopsis: Health state utilities elicited from actual patients are generally higher than those elicited from hypothetical patients. Thus, whose ratings to use in CEA is an issue of practical importance. The issue is also complex, with numerous conceptual and normative elements. One promising comprehensive answer carefully distinguishes between individual utilities and social values. Cogent conflicting arguments, however, render the matter unresolved, and some elements in the discussion continue to pose fundamental challenges for CEA.

Keywords: adaptation, chronic illness, decision utility, disability, equal value of life, experience utility, health state utility, individual utility, patient values, prevention, public values, quality adjusted life year (QALY), response shift, social value

Overview: Two Main Approaches

For use in cost-utility or cost-effectiveness analysis (CUA or CEA), evaluations of health outcomes in terms of quality-adjusted life years (QALYs) require judgments of the quality of life in different health states (see separate entry on QALYs). The quality of life of a state is often referred to as its ‘individual utility.’ There are two main sources for estimating a state’s utility. One is people who have experienced it themselves. For example, people with paraplegia can evaluate the state of being paraplegic. Utility thus measured is called ‘experience utility.’ ‘Ex post utility’ and ‘patient value’ are other names for the same. But a score for quality of life in paraplegia can also be obtained by having members of the general public, who mostly have not experienced paraplegia, consider a description of its manifestations and consequences and imagine what it would be like for them to be paraplegic. Utility assessed in this way is referred to by a variety of labels: ‘ex ante utility,’ ‘hypothetical utility,’ ‘public value,’ ‘hypothetical patient value,’ or ‘non-patient value.’ (A further term is ‘decision utility,’ which can include both ex ante and ex post utilities; see section on “Decision Utility...” below.)

Standard practice in QALY calculations is to use hypothetical (ex ante) utilities, on the grounds that they are more representative of the values and interests of the population at large than values from patient subgroups. But the practice has been challenged by many, and the issue is of more than mere theoretical interest. It takes on practical importance because of the empirical fact that health state utility ratings are typically higher when elicited from patients, particularly those with chronic illness or disability, than from non-patients who only hypothetically imagine themselves in such conditions. Debate is further fueled by the fact that a major factor accounting for the discrepancy between patients’ and non-patients’ values is patient adaptation to diminished health. Expressing time trade-off (TTO) preferences (link to Josh Salomon’s entry on elicitation techniques), for example, people with paraplegia, having experienced and adapted to it, may rate their quality of life as 0.95 (they are willing to trade away only 5% of their time alive to regain full function), while members of the general public imagining themselves being paraplegic may...
evaluate the condition as 0.8 (willing to reduce longevity by 20%). If these are the ratings for paraplegia, using patients’ adapted values will reduce the value of preventing or curing paraplegia to a quarter of the value it would have if the general public’s values were used. (1.0 minus 0.95 is one-fourth of 1.0 minus 0.8.)

Ultimately the questions here are normative. Whose ratings of health related quality of life should be used? Is it fair to those who do not yet have paraplegia to assess the cost-effectiveness of efforts to prevent this condition by using the higher utility values registered by someone else – patients who have adapted? Such normative discussion will be pursued explicitly in the last part of this entry. The next three parts focus on descriptive and conceptual issues in experience utility.

The Facts of Variation

The so-called “standard story” of health state valuation data is that patients, particularly people with chronic illness and disability, rate their quality of life more highly than do hypothetical patients only imagining themselves with those conditions. For instance, of 39 studies reviewed by G.A. de Wit and colleagues in 2000, 23 reported patient values higher than public ones, two reported higher public values, and eleven found no difference. In 2009 David Arnold and colleagues, in a review of 32 studies, found the mean TTO value for all of the disease states evaluated by current patients to be 0.83, compared to a mean value by hypothetical patients of 0.65. Moreover, the difference in ratings does not seem due to cognitive flaws; a mood assessment study by Jason Riis and colleagues in 2005 of hemodialysis patients not only produced higher patient values but found that patients were less flawed in their prior expectations and later recollections than were non-patients.

Generalization, though, is dangerous. Damschroder and colleagues in 2005 found some of the most extreme differences in valuing life with new onset of paraplegia, compared to life with pre-existing paraplegia, but they also found that when the non-patients engaged in a simple exercise virtually all of the difference with patient values disappeared. In the exercise they were merely informed about adaptation and encouraged to consider their own ability to adapt.

For some conditions patient ratings may actually be lower than non-patient ratings. Traumatic brain injury (TBI) is an outstanding case. The effects of TBI often involve depression, and adaptation to depression is extremely difficult. Moreover, as shown by Cynthia Wallace and Jennifer Bogner in 2000, non-patients may have a very incomplete a picture of how low one can sink in depression, and many of the symptoms of TBI – anxiety, hostility, distress, etc. – may worsen, not improve, with time and increased awareness.

Another complicating factor, explored in only a few studies, is that former, recovered patients sometimes provide lower ratings of quality of life in a given condition than current patients. In a study by Dylan Smith and colleagues in 2006 of quality of life with colostomy, for example, not only did public representatives provide lower ratings than patients; those who had their colostomies successfully reversed also provided lower ratings. The finding is notable. Former patients, presumably, are at least as knowledgeable, if not more, about the comparative quality of normal life and life with colostomy. Current patients may not be as good judges, repressing or misremembering how good their previous life without the impairment was.

Still, generally, patient values are higher than public ones.
Reasons for Variation: Knowledge and Adaptation

The difference is due to a number of factors. An obvious one is simply that patients directly know life in a particular health state; non-patients do not. In so far as non-patients fear the condition because it is different – presumably worse than pre-illness “normal” life, and in any case relatively unknown – they rate their prospective quality of life low. Even if actual and hypothetical patients were equally knowledgeable about all the facts about a condition, however, and hypothetical patients were no more fearful, their ratings would still likely differ because patients adapt to their condition. Adaptation has thus attracted considerable attention in accounting for higher health state utility ratings by patients.

It is a very broad phenomenon, undoubtedly comprised of many different elements. While there is no complete agreement on the elements of adaptation, Paul Menzel and colleagues in 2002 described eight components. Skill enhancement: people develop skills they previously did not have, or had not developed as much. A person with paraplegia, for example, becomes very accomplished in maneuvering a wheelchair. Adjusted choice of activities: given limitations that make previous activities difficult, one develops new interests. A person with congestive heart failure, for example, gives up the gardening that was her previously quite physically demanding hobby and devotes time to watercolor painting. Revision of substantive goals: not just particular activities but fundamental goals in life are revised. Instead of ambitious career success, for example, a person may shift her most life-defining goals to aesthetic appreciation and personal relationships. Heightened stoicism: a person becomes more patient, taking events in life as less within her control. Lowered expectations: without significantly changing activities or fundamental life goals, and in addition to becoming more patient, one does not expect to operate or perform at the same level. Altered conception of health: a person who previously thought of paraplegia as diminished health now looks upon it as a limitation not essentially different than previous and continuing limitations (not being able to run the high hurdles, for example); she retains a vigorous conception of health but one that now does not include some previous physical capacities. Suppressed recognition of full health: one loses sight of how someone can be as healthy as one was before. Cognitive denial of a lowered health state: one refuses to acknowledge that one’s health has diminished, not because one has adopted a revised conception of health, but by ignoring the pain or limitation. A variant of cognitive denial is focusing illusions: people focus more readily on new things they can do than on the things that they can no longer do.

Several of these elements – lowered expectations, heightened stoicism, revision of substantive goals, and altered conception of health – were included but categorized differently by Schwartz and Sprangers in 1999 in a well-known comprehensive framework for analyzing adaptation known as “response shift”. In the response shift typical of adaptation, persons living for a considerable length of time in an altered state of health make three changes: in their internal standards of measurement (“recalibration”), in their values (“reprioritization”), and in their definitions of essential constructs such as health (“reconceptualization”).

Different contexts for adaptation may lead to wide variations in the proportionate influence of these different elements. There is, in any case, little agreement on their relative influence. Discerning the different elements of adaptation and their relative roles may be important to any normative assessment of the proper place of adapted patients’ values in CUA and CEA. If
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adaptation is dominantly constituted by skill enhancement, adjusted choice of activities, and revision of substantive goals, for example, it will tend to be accorded greater respect. By contrast, suppression and cognitive denial diminish respect for adaptation. In a later section of this entry the normative issues about adaptation will be pursued.

Conceptual Issues in Choosing an Approach

Numerous issues arise in choosing between public and patient values. Two involve distinctions between different concepts and types of value. Articulating these distinctions clearly lays important background for more explicitly normative aspects of the discussion.

Individual Utility and Social Value

In approaching the choice of whose values to use in CEA, it is important to understand the role that individual utility plays more generally in the framework for health state evaluation in health economics. If individual utility’s role is not dominant but more limited, the question of whose values to employ can be pursued with an awareness that other dimensions of the value of health may be available to resolve certain quandaries.

Individual utilities of any sort, including health state utilities, contrast with social values for priority setting (also referred to as ‘societal values’). The former concern individual well-being; the latter concern relationships between persons or the well-being of communities, including considerations of fairness (see separate entry on cost-value analysis). The difference between individual utility and social value lies not in who expresses or holds the values but in the individual versus inter-personal nature of object to which value is attributed. Both individual utility ratings and social values get expressed by individuals.

Within the influential “welfarist” utilitarian tradition in health economics, people can easily lose sight of the difference between individual utility and social value. In the welfarist view only individual utilities are needed to build judgments about social value; the highest social value just is maximum aggregate individual utility. In the case of health care procedures and programs specifically, not only cost-utility analysis (CUA) but conventional CEA (link to entry on QALYs) are conducted by measuring and aggregating the individual health state utility gains and losses ingredient in the outcomes. In this view, procedures and programs producing the greatest aggregate net health state utility have, ipso facto, the greatest social value.

The point here is not to defend or reject such a welfarist utilitarian position in normative economics or social philosophy. The point is to be aware that other options are available once the distinction between individual utility and social value, as categories of value, is recognized. Social values do not have to follow welfarist utilitarianism. The paraplegia example is again illustrative. Person trade-off (PTO) questions (see separate entry on cost-value analysis) can reveal equal social value in saving the lives of persons with and persons without paraplegia, even when both rate the individual utility of life with paraplegia as less than 1.0. It would appear, then, that a sophisticated model for discerning the value of health will need to account for the distinction between social value and individual utility. PTO questions can be used to elicit social values, but using them does not rule out the use of visual analogue scale (VAS), TTO, or standard gamble (SG) (link to Salomons entry on elicitation techniques) questions to elicit ratings of health state utility.
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Answers to the question of whose values to use may thus be different for individual utility and social value ratings. One view on the proper overall structure for health valuation, proposed by Nord and colleagues in 1999 divides its answer this way: (a) Patients should be asked questions to obtain quality of life ratings. (b) Public representatives should be informed thoroughly of those patient ratings. Then (c) public representatives should be asked PTO questions to obtain social values. Such an architecture for eliciting values illustrates the possibility that the question of whose values needs answers on two different levels: whose judgments to use in discerning health state utility, and whose to use in discerning social value.

Decision Utility vs. Hedonic Experience

Heretofore we have been dealing with ‘experience utility’ as the quality of life in a state rated by people who have experienced that state themselves. A different, second sense of the term used in economics needs to be acknowledged. Experience utility in this other sense refers to the direct, intrinsic hedonic experience of an outcome. The opposite of experience utility in this sense is not utility estimated by people who have not directly experienced the condition being evaluated, but what economists and psychologists call ‘decision utility’ – utility measured by people’s choices about an outcome. Those choices can be manifested in either actual behavior or expressed preference. For health states, decision utility is measured by TTO or SG preferences about that state, whereas experience utility is measured by direct estimates people make about their hedonic level in a given state. Over the centuries such direct hedonic experience utility has often been referred to as satisfaction/dissatisfaction, pain/pleasure, happiness/unhappiness.

If direct hedonic experience judgments are used to rate health states, they will presumably be made by patients in those states. Decision utility ratings, though, can be obtained by asking either actual patients or people imagining themselves as patients. Understandably, then, empirical studies of the difference between patient and non-patient valuations usually focus on decision utility discerned through TTO or SG. Rarely have the direct hedonic experience utility levels of patients and healthy non-patients been compared.

With direct hedonic experience ratings of health states thus being made by patients in those states, whereas decision utility ratings can be made by either actual or hypothetical patients, the argument between direct hedonic experience utility and decision utility has implications for the debate about whose values should be used in CEA. If direct hedonic experience utility wins and decision utility loses out, patient values will need to be used. On the other hand, if decision utility wins, whose values to use remains an open question.

For which of these kinds of utility, decision utility or direct hedonic experience, can the stronger case be made? Decision utility suffers from three significant disadvantages. (1) Because it takes choices as basic in discerning and measuring utility, no independently discerned utility is available with which those choices can be assessed. By contrast, “if we equate welfare with [direct hedonic] experience utility…, it should…be possible to assess whether people’s choices actually maximize their own (experience) utility.” Such assessment is often seen as necessary because, as noted by George Loewenstein and Peter Ubel in 2008, “behavioral economists have identified myriad ways in which people take actions…patently contrary to their own interests”. (2) Beyond deficiencies in serving people’s own interests, moreover, there is abundant evidence that choices and preferences routinely manifest various kinds of inconsistency and irrationality. This poses a
challenge: is it morally defensible to be guided in policy decisions by utilities discerned by preferences that are so frequently flawed? (3) In a number of studies where the standard gamble and/or the time trade-off have been used to get self ratings from patients, a large share of the subjects have been unwilling to sacrifice any life expectancy in order to become well - even when symptoms and dysfunctions have been quite severe. As noted by Erik Nord, Norman Daniels and Mark Kamlet in 2009, this is not necessarily because the health problems are without consequences for well-being, but because life itself is so highly valued that it takes quite large health gains to justify any sacrifice of length of life. The ‘non-trading’ subjects automatically receive utility scores of 1.0, which does not seem helpful in evaluations of programs that clearly have value in terms of improving health and health related quality of life. In order to obtain usable (policy relevant) values for health states from patients, one may therefore have to have recourse to measures of happiness, etc., rather than decision utility tools like the standard gamble and the time trade-off.

But the attempt to discern utility independent of choice and preference may not inspire any greater confidence. To be sure, processes are available through which people can rank their state of well-being directly, rather than through expressing some preference like TTO or SG: e.g. the “experience sampling method” (ESM) proposed by Arthur Stone and colleagues in 1999 and the “day reconstruction method” (DRM) described by Daniel Kahneman and colleagues in 2004. In ESM electronic devices are used to ask people at random times during the day how they rate themselves on certain feelings at the time (happiness, frustration, etc.). In DRM people are asked to divide the previous day into episodes and rate them for affective elements on a specific scale. However, as noted by Paul Dolan and Daniel Kahneman in 2008, these methods have their own problems: underestimating losses, misremembering, failing to attend accurately to a given moment because of distraction by other episodes during a day, etc. It is not clear that measurement of direct experience utility is any more accurate and reliable than measurement of decision utility through preference elicitation.

Moreover, playing a role in the larger argument is not just the fact that direct hedonic experience utility has its own difficulties as serious as those of decision utility. Decision utility has its own distinctly positive attractions. (1) Decision utility/preference questions are comparatively clear. Direct hedonic utility, well-being, happiness, and satisfaction, arguably, have a befuddling breadth, abstractness, ambiguity. Asked to rate one’s life/day/moment directly in terms of them, a person may wonder exactly what they are. “Am I really happy?” “In relation to what desires am I satisfied?” “What is my well-being? – there are a lot of candidates!” Almost any preference question for decision utility is clearer. “How much of your lifetime would you be willing to sacrifice to get a cure for your condition?” may be difficult to answer, but its meaning seems clear. Contrast such TTO or SG questions with the ambiguity of a technique like the VAS that asks for a direct ranking of health, analogous to direct hedonic experience utility more generally. “On this bar that extends from 0 (dead) up to 1.0 (full health), rate your health.” How is a person supposed to know what a proportion or an amount of health is? Even if the question is more explicitly focused on value, not health per se (as in “On this bar from 0 to 1.0, rate your health-related quality of life”), ambiguity persists: what would living with, say, half the quality of life that living in full health contains mean (as distinct from two-thirds, e.g.)? By comparison the meaning of any particular amount of decision utility in health related quality of life seems clear: one will trade off a certain portion of remaining life but not more to gain a cure, or one is willing to take a certain risk of death but not more.
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(2) Within the enterprise of CEA in health care, determining quality of life by eliciting preferences has another major advantage. The core function within CEA of a construct like the QALY is to serve as a common unit of value that incorporates both life extension and quality-of-life enhancement. Otherwise one is comparing apples and oranges and would not know what total value an array of diverse lifesaving and quality enhancing outcomes had. TTO and SG questions are appropriate precisely because they transparently involve a relationship between quality enhancement and longevity. The mystery about how the values of life extension and quality enhancement compare is removed by the very nature of the question(s) used to measure health state utility. Measurement methods for direct experience utility – VAS, DRM, ESM – leave the relationship murky.

If decision utility has thus not lost in its argument with direct hedonic experience utility, the question in health economics of whose values should be used in CEA remains open and vital.

Normative Considerations in Choosing an Approach

As a normative question, whose values for health states to use in cost-effectiveness analysis (CEA) may seem naturally weighted toward patient preferences. Patients presumably know more about living in a given health state. Thus, since the ultimate nature of utility is subjective well-being, they would seem to hold a privileged position in health state valuation even if they are no better informed of objective facts about their condition. As we shall see, however, this initial intuitive case for using patient values faces a number of difficulties. One can begin with what is arguably the standard defense of the relatively common practice of using public, not patient values.

The Standard Defense of Hypothetical Patient Utilities

The standard defense has two main points: the societal role of CEA, particularly its role in a democratic society, and practical feasibility.

In CEA the health state utilities at stake in a medical practice/policy decision are aggregated to generate a picture of the overall value of expected health changes. The perspective of CEA as an enterprise, then, is necessarily societal, not merely individual. CEA is “for” society (or some subgroup, such as a private or regional insurance plan). Arguably, then, the perspective on the value of health changes needs to be as encompassing as possible: everyone in the society (or the insurance pool). When CEA is located in a democratic society this line of thought is reinforced further by a higher level societal value that everyone’s perspective should be represented in any process like CEA whose wide scope affects potentially everyone. The best way of ensuring that every person potentially affected by a CEA is represented is to elicit health state values from the public, few of whom will be actual patients with the conditions they are evaluating.

Supplementing this argument for public values is a further consideration about fairness. In its 1996 report, after recommending that CEA employ a “societal perspective” for reasons similar to those just elaborated, the 1996 U.S. Public Health Service panel on cost effectiveness in health and medicine (Marthe Gold and colleagues) proceeded to discuss fairness. Fair decisions are best made as choices behind a veil of ignorance, where decision making parties do not know whether they are advantaged or disadvantaged by the matter at hand. For CEA, then, they claimed that “aggregating the utilities of persons who have no vested interest in particular health states seems most
appropriate.” If we have already agreed that whatever values are used, they should come from perspectives that are informed, rational and unbiased, a challenge is presented for patient values: patients are likely to be biased by having a vested interest in treating the disease they know they have. One skirts this bias by asking people who express themselves only as hypothetical patients.

Practical considerations also play a role in the standard defense of hypothetical patient utilities. If utility ratings are elicited from hypothetical patients, convenience and efficiency is gained by eliciting ratings for many health states from the same people at the same time. This advantage is difficult to dispute factually. Any procedure for eliciting utilities directly from patients will undoubtedly be more cumbersome and expensive, especially if CEA is used to compare measures and programs across a comprehensive range of health states. The case for using patient values will have to be strong enough to justify additional expense.

Adaptation

Adaptation raises the utility ratings patients express about reduced health related quality of life. In doing so it lowers the value achieved from restorative, quality of life improving treatments. In this respect adaptation reduces ill persons’ leverage in the competition for health care resources. That alone will make a positive role for adaptation controversial. Critical normative argument about adaptation, however, cuts different ways in the debate between patient and public values.

Epistemic Privilege

A strong first line of argument for using adapted patients’ values amplifies the initial, intuitive case for patient values in the first place: since patients presumably know more about living in a given health state, and since the ultimate nature of utility is subjective well-being, they hold a privileged epistemic position for discerning health state utility. To see how attractive this claim can be, suppose, for the moment, that we have adopted the opposite practice and are eliciting health state valuations not from patients but from representatives of the general public. People already agree that the states that public representatives are asked to evaluate need to be described in neutral, factually accurate, and sufficiently complete terms. As part of that they need to understand what life in fact is really like in the condition they are evaluating. How actual patients typically adapt to a condition is part of that understanding. It is an objectively real aspect of the lives that patients in diminished health states actually lead.

Suppose, in turn, that a hypothetical patient challenges this need to absorb the facts of adaptation and insists that she in particular would never evaluate life with paraplegia, for example, at so high an adapted level. The insistence would be suspect. To be sure, a given individual could conceivably be correct in claiming she would not adapt (or adapt much), but given the empirical evidence, we ought to be skeptical about what will happen to even such insistent persons when they actually become paraplegic. Very likely most of them, too, would end up adapting considerably. But then, when hypothetical patients refuse to accept these prospective facts, they should be regarded as factually mistaken – they do not understand the state they are evaluating. Thus, we ought to enrich the description of a condition provided to hypothetical patients with information about actual patients’ adapted values, and we should insist that hypothetical patients truly absorb those facts. But then why not simply use actual patients’ health state values?
Such an argument for the epistemic privilege of actual patients is attractive, but it has not been universally accepted. In a 1995 paper Dan Brock argues that since the difference in health related quality of life ratings stems significantly from an adjustment of substantive goals by adapted patients, they have become “changed persons.” He concludes that the hypothetical patient’s earlier evaluation is not “mistaken.” If we look back now as chronically ill or disabled, we “view ourselves as having become very different persons,” not as “having been mistaken in our earlier aims and values.”

Brock’s move may or may not be a plausible gloss on the meaning of “mistaken” in relation to “changed person.” In any case, it is debatable whether it provides a defense for hypothetical patients if they have not absorbed the essential facts about actual adaptation. How can they defend the practice of continuing to evaluate the condition at their own non-adapted level, it will be asked. In most of their prospective years in the chronic condition in question, should they ever experience it, after all, they will likely espouse adapted values. Why should they now be trying to imagine themselves as persons who do not adapt to the condition, people they almost certainly will not be? We find ourselves pushed back to the view that the patient, adapted or not, is in a privileged position in the very enterprise that asking hypothetical patients involves, imagining what it would be like to be someone with the condition.

These considerations establish the initial case for using the values of patients with actual experience of a condition regardless of how much their ratings may be elevated by adaptation. That does not, though, end the moral debate. As noted by Paul Menzel and colleagues in 2002, other arguments can be made against the use of adapted values. Among them is the problem of entrenched deprivation.

Entrenched Deprivation

Amartya Sen has focused on this reason to discount adaptation in a well-known critique of utilitarian reasoning generally from 1992. At its very basis, he says, utilitarian ethics is guilty of excessively depending “on what people ‘manage to desire’ … [that neglects] 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 fulfillment, 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 fulfillment…. ” Sen concludes that measuring well-being by the fulfillment of people’s actual desires is ethically wrong-headed.

Utilitarianism, as a general moral philosophy, must respond to Sen’s critique. The issue in the context of whose preferences to use in health state evaluation for CEA, however, is narrower: does the deprivation factor that renders a general utilitarian metric of desire fulfillment ethically questionable also render the ratings of health related quality of life procured from adapted patients morally dubious? Adaptation in contexts of chronic illness and disability often involves achievement and shrewd and successful control over the trajectory of one’s inner life. Here the adapted person is anything but broken. She is hardly subdued. If deprivation is handled by people as challenge and achievement, why isn’t a metric of actual desire fulfillment appropriate? Sen’s argument may serve as an appropriate warning about too readily or generally using adapted patients’ utilities, but it is highly problematic as a full rejection.
Though the argument from entrenched deprivation against using adaptation influenced values may thus be neutralized, other arguments may be more successful. Suppose that after comprehensive assessment we end up thinking that the basic dilemma posed by adaptation remains unresolved. Here the distinction between individual utilities and social values detailed previously may provide constructive help. This would be the line of reasoning:

The health state utilities of real life with chronic illness and disability are those expressed by patients. Those are the real utilities of health states, and we should use them in cost-utility analysis. But people also make moral arguments against the use of adaptation influenced values – values that are higher than public values and which therefore reduce the value of the health gained by patients from curative/restorative services. They believe, for reasons of justice or whatever, that those services should be accorded higher value than their real utility value for the disabled and chronically ill alone would indicate. In such beliefs they are expressing social values. At the level of individual utility itself, there is no “problem of adaptation” at all; the real utility of moving from illness/disability back to full health just is the utility indicated by patient values. The “problem of adaptation” occurs only when social value intersects with this utility. Maximizing health state utility is hardly the only philosophical choice for social value, and any influence of adaptation on decision making can be altered at the level of social value. Hypothetical patients need to know that real, adapted patients’ health state utility values are higher than their own, and they must absorb those facts in imagining prospective illness. Both hypothetical and actual patients, however, may hold social values that blunt adaptation’s effect on social decision making.

The Equal Value of Life

The picture portrayed by the discussion so far is incomplete. We have been wrestling, in part, with the fact that as adaptation increases the value of deficient health states, it decreases the utility gain from restorative, quality-of-life improving measures. That, however, is only half the effect of adaptation in CEA. In increasing health state utility, adaptation also increases the utility gain from life extension. In so far as these opposite effects on the utility gain in life-extending versus restorative interventions balance each other out, adaptation may leave the total utility gain claimed for health care relatively unaffected. The matter of whose preferences to use would then be of little consequence.

It would not be correct, however, to conclude that counterbalancing effects rendered the debate about adaptation unimportant. The aggregate effects in the two types of programs – restorative and life extending – may not in fact balance each other out, and specific programs being evaluated will often be largely life extending, others largely quality of life restoring. Most importantly, perhaps, adaptation augments a problem for CEA created by any claim of equal value for different lifesavings. Such equal value for saving the life of a person back to full health and saving the life of a person who will continue in chronic illness or disability was cited as a serious problem for traditional CEA by John Harris already in 1987 and later by Erik Nord in 1999. It gives rise to what Peter Ubel and colleagues in 2000 called the “QALY trap”.

On the one hand, if the value of life extension for the disabled and chronically ill is equal to the value of life extension for the fully healthy, then the value of curing a chronic illness or disability (restoring such patients to full health) is apparently zero. This implication follows given the very structure of CEA, using as it does a common metric like the QALY to put life extension and quality enhancement on the same
value scale. On the other hand, if restoration and cure retain value, then the respective life extensions cannot be of equal value. Yet they do seem to be of equal value. Meanwhile, the first option – no value for cures – also seems contradicted empirically. Virtually everyone, including the disabled and chronically ill, accords considerable value to restorative measures. The traditional QALY model for CEA is then trapped between two propositions – that the different life extensions are of equal value, and that restorative cures have positive value – which the model says cannot both be true.

To save CEA against this challenge, one might take one of two approaches. (1) Use the distinction between social value and individual utility to rescue CEA from the QALY trap. Call this the “value/utility distinction” approach. Or (2) give up the claim that life extensions for the disabled/chronically ill and the non-disabled/fully healthy have completely equal value but maintain that they have “almost equal value.” Both approaches affect how we view the issue of whose preferences to use in CEA.

In one particular version of the value/utility distinction approach, Erik Nord and colleagues in 1999 suggested that all gained life years should count as 1 as long as they are deemed preferable to death by those concerned (see also separate entry on cost-value analysis). In this and all other versions of the approach, the claim that the value of life extension for the disabled and chronically ill is equal to the value of life extension for those who can be saved to full health is seen as an expression of a societal value, and only societal value. It is not a claim that the individual utilities of the two life extensions are equal. If as a matter of individual utility they are not equal, the claim of positive value for quality restoring measures can be retained. Thus, keeping individual utility and societal value distinct frees CEA from the QALY trap (see also Paul Menzel et al. 1999).

A second approach, very different, backs away from the claim that the two respective life extensions have equal value. If one pays careful attention to the values expressed by patients through TTO preferences, for example, it is clear that quality of life ratings, though they are not much less than 1.0, are less than 1.0. In 1993 Dennis Fryback and colleagues reported results on the order of 5-8% for arthritis, severe back pain, migraine, angina, cataracts, ulcers, and other serious conditions, and 14-17% for depression, asthma, and chronic bronchitis. This suggests that the tension between “equal value for lifesaving” and “cure has value” can be reduced by attending to just how close to a maximum value of 1.0 people with disability or chronic illness rate their quality of life. We can then adjust the claim of “equal value” to “almost equal value,” and the claim of “cure has value” to “cure has very modest value compared to lifesaving.” Again we are out of the QALY trap, and now in a way that has not changed the structure of traditional, utility focused CEA.

In this approach one still needs to face front and center the question of whose values to use. No easy accommodation of “use both” (though in respectively different senses of value) is possible, as in the value/utility distinction approach. One must determine whether the higher, adaptation influenced values of patients that raise the value gained from life-extending measures but lower the value gained from restorative measures ought to be used. The advantage in using the value/utility distinction approach is that one can keep both of the key claims that create the dilemma – equal (social) value for the life extensions, yet significant (individual utility) value for restorative/curative measures (for further discussion, see Erik Nord, Paul Menzel and Jeff Richardson 2003).

Seeing the claim of equal value for the different life extensions as only a claim of societal value is the key move in the value/utility approach. Arguably, however, the equal value claim may
also hold at the level of individual utility. To see this, unpack the reasoning behind claims of value in a QALY framework. In responding to SG or TTO questions, patients are saying that a cure for their paraplegia, for example, has a certain proportion of the value of saving their very own life. In saying that, they have not said that their very life itself has less value than the very life of another person in full health. As noted by Paul Menzel already in 1990, compared to death they very likely believe that their paraplegic life is as valuable to them as anyone else’s allegedly “better” life is to him or her. This belief comes sharply into focus when people attend to the two comparisons involved: the value of their disabled or chronically ill life relative to death, and its value relative to the same sort of death-comparative value of another’s life, even a person in full health. Particularly compelling may be a further step: this very realization of equal individual utility value will likely be shared by healthy and non-disabled persons, too, once they think reflectively about the value of their own very lives compared to death. Who among them would want to claim that the value to them of their life is greater than the value of a paraplegic person’s own life to him or her?

The conundrum of the QALY trap thus continues. If lifesavings have equal value even as a judgment about individual utility, we face again the trap’s full dilemma: the value of curing paraplegia has become nothing. It is doubtful we would ever accept that. The implication of our resistance is that the QALY trap remains a challenge to the very framework of CEA, an enterprise whose current form requires a common unit of benefit like the QALY in which value for life extension and value for quality improvement are integrated on the same scale. Whether and how the field of CEA will meet this challenge remains unclear.

Evaluating Prevention

Is anything different about “whose values?” when preventive services, not treatments, are evaluated? Actual patients, arguably, hold legitimate evaluative privilege in rating health state utility. They are the only subjects who experience real life with chronic illness or disability, and hypothetical patients who are imagining themselves to be in such conditions must account for the reality of likely adaptation. The situation is arguably different in prevention. The real recipient of a preventive service’s benefit is the unchanged person who, if the prevention is effective, will never need to adapt to the illness or disability in question. It may be suggested, therefore, that while actual patients should be accorded evaluative privilege for purposes of prioritizing curative and restorative services, hypothetical patients retain evaluative privilege for the utility ratings that help determine the value of preventive services.

This suggestion immediately encounters an objection. The person whose health will be damaged if preventive measures are not provided is still a person likely to adapt. The real value of prevention is presumably 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 the conditions which have not been prevented. The perceived gains from prevention may be higher than the gains from cure, but the real gains are not.

This is only one interpretation of “real gains,” however. Most persons receiving a preventive service do not contract the condition the service aims at preventing, a fact that is true regardless of how objectively effective the preventive measure actually is. Recipients of prevention continue to experience its benefits from their perspective as healthy persons. Restorative services, by contrast, are received by persons already experiencing both the burdens of illness and disability.
and the value raising effects of adaptation. Many lifesaving services also apply to persons already experiencing the ravages of illness. One might argue, therefore, that while the utility value of health gain in the case of treatment services should be determined by patient ratings, the value of the avoidance of illness achieved by prevention should be measured from the perspective of hypothetical patients. Though adaptation lowers the value of restorative services, perhaps it should not be allowed a similar effect on the value of prevention.

Careful analysis of such considerations in comparing how the value of health benefits should be measured for treatment as compared to prevention has received little attention in the literature. An exception is a paper by Erik Nord, Norman Daniels, and Mark Kamlet in 2009, in which they side with using the lower public, non-patient, \textit{ex ante} values to measure what then becomes a higher benefit from prevention, while at the same time using the higher health state utility values expressed by patients to calculate what then becomes a lower value to benefit from treatment. They claim there is no inconsistency; with different reference points, the negative value of ill health just is not the same for these two different parties with their different perspectives. Another analysis, by Paul Menzel in 2012, of the relative value of prevention also emphasizes reference point differences but leans in the opposite direction, a lower value for prevention.

Summary and Conclusion

Utilities for health states can be measured by values elicited either from people who have experienced those states themselves or by hypothetical patients imagining themselves to have such conditions. Ratings by actual patients are generally higher than ratings by hypothetical patients, rendering the question of whom to ask to measure health state utility for CEA of practical importance.

Factors that help to explain patients’ higher ratings include their greater knowledge of the conditions and their adaptation, especially to chronic disease and disability. Adaptation is comprised of numerous different elements, the proportionate influence of which remains unclear.

Two conceptual distinctions affect positions taken on whom to ask. By distinguishing rigorously between individual utility and social value, one proposal argues for asking both patients and the general public, but differently: elicit utility ratings from patients, inform public representatives of those ratings, then elicit social values from the public representatives. Also affecting the debate is a distinction between two different senses of utility, direct hedonic experience and decision utility expressed through preference or choice. The latter, measured in health utility analysis by choices between preserving life and improving quality of life, has the advantage of yielding a common metric for measuring the value of all changes in health. With decision utility, unlike direct hedonic experience, the debate about whom to ask is kept open; either patient or hypothetical patient values can be sought.

Normatively, the initial intuitive case for patient values sees patients as having epistemic privilege in understanding what real life with disease or disability is actually like. On the opposite side, the standard case for public values cites both the societal perspective that is seemingly natural to CEA – and especially important in a democracy – and practical considerations of convenience and efficiency. The phenomenon of patient adaptation gives rise to numerous and conflicting moral arguments. One attempt to resolve the normative debate would elicit utility ratings from adapted
Whom to ask (Menzel)

patients but allow societal values elicited from others to discount adaptation’s influence on decision making.

The generally higher utility ratings of patients who have adapted to a diminished health state reduce the value gained from curative/restorative services, but those higher ratings have an opposite effect as well: raising the value of life extension for the chronically ill and disabled. Strong arguments are available to defend equal value for different lifesavings – life extension for the disabled/chronically ill and life extension for people returning to full health. Equal value for these lifesavings, while it can be celebrated as a removal of discrimination against the disabled and chronically ill, poses a difficult challenge for the very structure of CEA. A “QALY trap” emerges: with lifesavings held to be of equal value, restorative care loses its value. It is unclear whether carefully distinguishing between social value and individual utility enables CEA to handle this challenge; if the individual utility, not only social value, of such lifesavings is also equal, the challenge remains unsolved.

Even if the utility values expressed by patients affected by adaptation are the appropriate ones to use for evaluating treatment programs, objections have been made to using them to evaluate preventive programs. Attempts to resolve whether the treatment/prevention difference should affect whose values to use have recently been made; their success is far from clear.

Most of the moral questions about whose values for health utility should be used in CEA are well clarified. Some, perhaps, are even answered, but many are not. Vigorous debate is likely to continue.

Further Reading


Whom to ask (Menzel)


