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ORIGINAL ARTICLE

Quality of Life and Value Assessment in Health Care

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Abstract

Proposals for health care cost containment emphasize high-value care as a way to control spending without compromising quality. When used in this context, 'value' refers to outcomes in relation to cost. To determine where health spending yields the most value, it is necessary to compare the benefits provided by different treatments. While many studies focus narrowly on health gains in assessing value, the notion of benefit is sometimes broadened to include overall quality of life. This paper explores the implications of using subjective quality of life measures for value assessment. This approach is claimed to be more respectful of patients and better capture the perspectival nature of quality of life. Even if this is correct, though, subjective measurement also raises challenging issues of interpersonal comparability when used to study health outcomes. Because such measures do not readily distinguish benefits due to medical interventions from benefits due to personal or other factors, they are not easily applied to the assessment of treatment value. I argue that when the outcome of interest in value assessment is broadened to include quality of life, the cost side of these measures should also be broadened. I show how one philosophical theory of well-being, Jason Raibley's "agential flourishing" theory, can be adapted for use in quality of life research to better fit the needs and aims of value assessment in health care. Finally, I briefly note some implications of this argument for debates about fairness in health care allocations.

Keywords Quality of life · Philosophy · Social justice · Health care costs · Resource allocation · Health policy

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Introduction

According to a recent report, health spending is on the rise again as countries recover from the 2009 economic crisis [56]. If current trends continue, health care will consume an increasingly large share of economic resources.[1] This is particularly true in the United States, where health spending is on track to represent nearly 20% of GDP by 2026 [19]. As a result, there is a pressing need to find ways to control costs and use health resources efficiently.

Discussions of cost containment in health care often emphasize the importance of measuring and promoting high-value care as a way to control spending without compromising quality. When used in this context, 'value' refers to outcomes in relation to cost [13, 60, 62, 92]. To determine where health spending yields the most value, it is necessary to compare the benefits provided by different treatments. Assessments of value, then, depend in part on how 'benefit' is understood in this research.

While many studies focus narrowly on health gains in assessing value, there are times when the notion of benefit is broadened to include overall quality of life. This paper explores the implications of using subjective quality of life measures,[2] particularly measures of life satisfaction, for value assessment in health care. This approach is frequently claimed to be more respectful of patients and to better capture the purportedly perspectival nature of quality of life. However, subjective measurement also raises challenging issues of interpersonal comparability when used to study health outcomes. Because these measures do not readily distinguish benefits due to medical interventions from benefits due to personal or other factors, they are not easily applied to the assessment of treatment value.

In this paper, I argue that when the outcome of interest in value assessment is broadened to include quality of life, the cost side of these measures should also be broadened. If people's subjective assessments are important to measuring the impact of conditions and treatments, then a more detailed understanding of the ways in which these assessments change over the course of illness and medical care is needed to adequately address the ethical issues raised by decisions about spending priorities. I show how one philosophical theory of well-being, Jason Raibley's "agential flourishing" theory, can be adapted for use in quality of life research to better fit the needs and aims of value assessment in health care. Finally, because a clear assessment of benefits and burdens is also necessary for addressing concerns about

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[1] As of 2017, for instance, OECD nations have spent on average approximately 70% more on health care than they do on education for each citizen [56].

[2] The word 'subjective' can be used in different senses when describing quality of life research. In one sense, quality of life measures are subjective when they rely on self-report rather than direct measures of some state or condition—for instance, a subjective measure may ask a respondent to answer questions about some aspect of their current health (such as difficulty breathing) rather than using standard medical exams. However, 'subjective' can also refer to the theoretical underpinnings of the measure. In this sense, subjective measures are those that assume a subjective account of well-being or quality of life—one in which quality of life is in some way inherently perspectival. In this paper, I use 'subjective' in this latter sense.

distributive justice in health care, I also briefly note the implications of this argument for debates about fairness in health care allocations.

Measuring Benefit and Value in Health Research

Quality of life research can be used for a variety of purposes in patient care, medical research, and health policy (see, e.g., Brock [11] and Hausman [34]). For instance, this research can be used in clinical practice to guide treatment decisions and to aid communication between patients and physicians [39]. Health-related quality of life can also be used as an endpoint in clinical trials; in the United States, the Food and Drug Administration allows new treatments to be approved based on quality of life data even when they show no improvement in survival or health status over existing drugs [18, 61]. Finally, quality of life measures can also be used to assess the effectiveness of treatments, providers, and health care systems.

When quality of life measures are used to make cost-effectiveness comparisons between treatments, these research findings can then inform debates about health spending priorities. Whether a treatment is considered high-value depends in part on the outcomes selected for measurement. Many studies focus on objective health gains, such as symptom relief or mortality reduction, as the outcome of interest in value assessment. However, improvements on objective medical measures do not necessarily constitute an overall benefit for the patient. Some gains (such as minor decreases in cholesterol levels) might not make any meaningful difference in patients' lives, while others (including extended life) can involve severe side effects that make the overall benefit of treatment questionable. In these cases, information about the impact on quality of life is needed to assess treatment value, but different ways of conceptualizing and measuring quality of life can lead to very different conclusions about the impact of a treatment [7, 28].

Within health research, an extensive array of instruments—including the EuroQol Index (EQ-5D), the Medical Outcomes Study Questionnaire Short Form 36 Health Survey (SF-36), and the Schedule for the Evaluation of the Individual Quality of Life (SEIQoL), just to name a few—are used to measure patients' quality of life. These measures vary in both their content and theoretical underpinnings. Although such theoretical assumptions about the nature of quality of life are not always made explicit, some researchers draw on philosophical accounts in developing or justifying their use of quality of life measures. Because questions about overall benefit are often considered questions about well-being, and since philosophical theories of well-being face the same challenges discussed in this paper, it can be useful to explore some of the connections between philosophical theories and empirical measures of quality of life.

Theories of Well-Being and Quality of Life

Within philosophy, subjective theories of well-being are described as those in which a person's well-being is attitude-dependent: whether something benefits someone in a well-being (or prudential) sense depends on whether she has some sort of positive attitude toward it. Two of the most common types of subjective account are desire theories and life satisfaction theories. In their most basic form, desire theories (also known as preference theories) hold that the achievement of some good or state provides a prudential benefit only if the individual desires it.[3] For life satisfaction theories, something counts as improving someone's well-being only if it increases her overall satisfaction with her life.[4]

Objective theories, on the other hand, deny that well-being is purely dependent upon attitudes. Instead, they hold that some goods and states (such as autonomy and friendship) are objectively beneficial in themselves. Aristotle's account of *eudaimonia* (usually translated as 'flourishing' or 'happiness') is a paradigmatic objective account. Aristotle held that people could be—and often are—wrong about their own good. Eudaimonistic accounts such as Aristotle's, instead of emphasizing individual variation in and authority over well-being, typically focus on what it is to live well *as a human being*; well-being for humans depends on developing or perfecting essential human traits, such as rational and social abilities.[5]

Quality of life research in health care can be divided along similar lines. Some studies utilize an objective framework in measuring quality of life; for instance, the capabilities approach of Martha Nussbaum and Amartya Sen is sometimes referenced in the empirical literature when explaining or justifying the choice of measures used to study health-related quality of life (see, e.g. Entwistle et al. [27] and Verkerk et al. [91]).[6] Other studies take a subjective approach. Just as desire and life satisfaction theories of well-being are prominent in philosophy, health researchers frequently look either to people's preferences or judgments of satisfaction as evidence of their overall quality of life. For instance, as noted later, assessments of quality adjusted life years (QALYS) typically employ a preference framework in making health state valuations [40, 95], while many researchers include measures of life satisfaction in their investigations of health-related quality of life.[7]

A variety of arguments have been offered in favor of subjective quality of life measurement. Given the diversity of viewpoints about what it means to live well,

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[3] Sidgwick [83], Rawls [67], Brandt [10], and Heathwood [38] have all developed desire accounts of well-being.

[4] See Sumner [87] and Tiberius and Plakias [88] for examples of life satisfaction accounts.

[5] Other examples of eudaimonistic theories of well-being can be found in Kraut [43], Haybron [36], Annas [4], Russell [70], LeBar [45], and Besser-Jones [5].

[6] Sen's account, though influenced by Aristotle, emphasizes the *freedom* to exercise fundamental human capacities rather than the actual exercise and achievement of these goods. Accordingly, Sen conceives of his account more as a framework for thinking about justice and policies for human development rather than a full theory of well-being [81]. Because he believes this approach needs to remain flexible for application in different countries, he does not provide a definitive list of fundamental human capabilities [82]. Nussbaum, on the other hand, does develop this account with a list of capabilities, including bodily integrity, practical reason, affiliation, and control over one's environment. The quality of different people's lives can then be compared by the extent to which they possess and are able to pursue these capabilities [54].

[7] See, for instance, Frisch et al. [29] and Strine et al. [85]. Although I focus primarily on life satisfaction in this paper, much of what I say here also applies to the use of other subjective measures for value assessment.

it can be argued that respect for people in a democratic society demands that deference be given to people's own perspectives on their lives [37, 47]. Furthermore, the public is more likely to support policies—and patients more likely to comply with treatment recommendations—that are based on their own values and viewpoints [31, 37]. Subjective measures, in emphasizing the importance of people's own values, are also thought to be more consistent with the aims of patient-centered research [15, 24, 65]. In addition to these pragmatic and moral justifications for subjective measurement, an argument can also be made based on a substantive conception of the nature of quality of life. For instance, it is sometimes maintained that quality of life is inherently perspectival [50, 86]. If so, then it is necessary to know something about how a person views her life in order to understand the overall quality of her life. Although I agree with many of these points, I do not provide an argument in favor of the subjective approach here. Instead, I assume for the sake of argument that the use of subjective measures in health research is justified in order to focus on the issues raised in the application of this research to value assessment.

Challenges in Subjective Measurement

Even if the arguments in favor of the subjective approach are correct, the use of subjective quality of life measures in health outcomes research faces challenges that are compounded when they are applied to value assessment. Research on patients' quality of life yields surprising results, as reported levels routinely defy what would be expected based on objective medical status [78, 97]. People who develop serious illness and injury do not always report corresponding declines in quality of life [42, 59]. Over the course of treatment or disease progression, patients can adjust their values and expectations for life, emphasizing the importance of relationships with family and friends, for instance, or having a greater appreciation for whatever they are still able to achieve as functioning declines. Because of this type of adaptation, subjective quality of life measures are subject to what is known as "response shift" [1, 96]. Response shift was originally defined by Mirjam Sprangers and Carolyn Schwartz as "a change in the meaning of one's self-evaluation of a target construct" resulting from a change in values or standards or a change in how the respondent understands the concept being measured [84]. These changes in how people respond to quality of life measures raise questions about when (and whether) subjective assessments count as evidence of well-being. They also make it more difficult to interpret the impact of conditions and treatments on people's well-being.

Philosophical theories encounter similar worries regarding the relevance of attitudes to actual well-being. For instance, some desires seem too trivial for their satisfaction to count toward well-being. Rawls' illustration of a person who desires nothing more than to endlessly count blades of grass is a classic example of a desire the satisfaction of which would not seem to make someone's life go well [67]. The fulfillment of other desires can be deeply harmful, as with the desire of an addict to continue using drugs or the unwitting desire to consume food that has been poisoned.[8] Similarly, judgments of life satisfaction can also appear an unreliable guide to well-being. As Amartya Sen [80] notes, many people living in what seem to be objectively bad circumstances, such as conditions of oppression or extreme deprivation, still report being satisfied with their lives (see also Graham [30]). Since people's assessments of their lives are based in no small part on their expectations, people with low expectations due to poverty or other disadvantage can nonetheless be satisfied with their lives.[9] This is the problem of what Sen [80] calls "adaptive preferences,"[10] and many cases of apparent mismatch between people's assessments of their lives and their actual living conditions are thought to arise from this type of adaptation.

Within philosophy, worries about such "malformed" attitudes are often addressed by specifying the conditions under which people's desires or judgments of life satisfaction count for well-being. As a result, it is not just any positive attitude that matters to well-being; under most accounts, someone who is satisfied with her life because of brainwashing or due to a seriously mistaken understanding the facts of her life would not count as having a high level of well-being. Normally, only desires or assessments that are sufficiently informed and "authentic" count toward well-being (see, e.g. Sumner [87]).

Quality of life researchers could establish similar parameters for when reports of life satisfaction should be taken as evidence of actual well-being levels; for instance, a patient who reports a high level of quality of life because of mistaken beliefs about her physical condition may not be providing a reliable account [42], while one who adjusts her values and aims to those that are more achievable in her new condition may be providing an accurate report of high quality of life despite worsening health [16, 93]. However, this way of responding to these concerns is of only limited help when dealing with the issues faced by subjective measurement in health care. Researchers administering a questionnaire or physicians taking a few minutes to assess a patient's quality of life are not in a good position to determine whether the person's broader preferences or attitudes toward her life are adequately informed and authentic. Furthermore, the constraints specified in subjective theories of well-being do not fully resolve the moral concerns raised by adaptation and response shift. People whose expectations for their lives have adapted to illness and impaired functioning may be making no factual mistake, and their values and preferences may be authentically formed (in whichever way we consider values to be authentic), and yet it is still possible to think that it would be better for them if their circumstances improved.

There is a debate within the health-related quality of life literature about whether change resulting from response shift should be considered "true" change or should

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[8] For an overview of these issues and a defense of desire theories, see Heathwood [38].

[9] See, for instance, Schwarz and Strack [79]; Lucas and Baird [46]; and Ogden and Lo [57] for empirical research on factors affecting assessments of life satisfaction. See Haybron [35] for a philosophical discussion of why judgments of life satisfaction do not consistently track the circumstances of people's lives.

[10] For a good discussion of adaptive preferences and other objections to subjective measures in well-being research and policy, see Nussbaum [55].

instead be seen as some type of measurement error or bias [41, 51, 58]. If a subjective account of quality of life is accepted, then (as long as the patient is meeting the established conditions for an authoritative report), such changes should be considered true changes. But this leads to further complications, and the application of quality of life research to health policy raises issues that purely theoretical accounts do not always need to address. Things that improve well-being or quality of life are often described as benefits. In light of the many studies that show patients' quality of life improving following declines in physical health and functioning, this appears to lead to the unpalatable conclusion that if disease leads to higher quality of life reports (due to changed values or expectations), this means the disease was beneficial. Something seems to have gone wrong in this line of reasoning.

If the arguments for subjectivism are correct, then such improvements over time may indeed count as benefits for the patient. In cases of response shift, though, it is not the disease itself that provides the benefit, but instead the adjustments made by patients in what they value or how they conceptualize their good. Because of this, simply looking at quality of life reports at different points in time over the course of treatment does not provide enough information to make even approximate claims about the impact of health spending on well-being.

Subjective measures of well-being are what Dan Haybron describes as "lossy" [36]—they obscure information needed to understand the processes involved in well-being changes [76]. Even if treatment does not successfully enable patients to continue functioning in the ways they cared about prior to illness, adaptations in standards and expectations can fill the role that would otherwise be played by treatment in protecting quality of life. Focusing on quality of life using standard subjective measures thus leaves us under-equipped for addressing significant issues related to how such outcomes are achieved. Furthermore, the challenges faced in determining the role treatments play in quality of life changes are compounded when these measures are used to compare the effectiveness of different treatments. To determine which treatments offer the best value, it is necessary to compare outcomes in different patients, but this involves the further challenge of comparing subjective quality of life among people using different standards, values, and preferences to make these assessments.[11]

While these issues of causality and interpersonal comparability are easily handled by objective accounts of well-being and quality of life, they present significant problems for those committed to subjective measurement. One possible way to address these issues is through utilizing measures of quality adjusted life years (QALYs) to make priority decisions. In this approach, health states are assigned values on a scale between 0 and 1, where 0 is death and 1 is perfect health. Treatments can then be compared based on the values of the health states they enable multiplied by the time patients spend in these states. Although there are different ways of assigning these values, the most common method used is a preference-based approach wherein members of the public are asked to rank different health states. For instance, people

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[11] For detailed discussions of the challenges of interpersonal comparability, see, for instance, Elster and Roemer [25], Hausman [33], Boot [9], Chang [17] and Broome [12].

can be asked whether they would prefer to live a shorter amount of time in perfect health or a longer amount of time with some disease.[12] Because this approach allows respondents to draw upon their own goals and standards in expressing these preferences, it respects citizens' differing views about the good life, thus arguably satisfying the moral justifications for using subjective measures in liberal democracies. It also provides a way to put these otherwise incommensurable judgments about the subjective impact and value of different health states on more equivalent footing.

However, while there may be good reasons for using QALYs in value assessment, they are not without controversy [23, 32, 52]. Furthermore, although QALYs are widely used in some countries for allocation decisions (most notably in the United Kingdom), they are far less popular in the United States. When Congress passed the Patient Protection and Affordable Care Act in 2010, it also established the Patient Centered Outcomes Research Institute (PCORI) as a center for the study of comparative effectiveness. However, the legislation explicitly prohibits PCORI from using QALYs to measure cost-effectiveness or make funding recommendations [53]. It is useful, then, to explore other ways of making value assessments based on subjective quality of life measures.

Jason Raibley's account of "well-being as agential flourishing" [66] provides a philosophical framework that could be helpful in developing an alternative to QALYs for subjective value assessment. Raibley develops a life satisfaction theory of well-being in which a person is said to live well to the extent that she resembles a *paradigmatically flourishing agent*, which he describes as someone who, "(a) realizes their values, and (b) is stably disposed to do so, and both to a high degree" [66]. In this account, well-being is at least partly dispositional—to live well is not simply to realize one's current values, but also involves being able to continue to do so however one's values (or circumstances) change in the future. According to Raibley, then, physical and emotional health are non-instrumentally good in themselves (and not simply good if the individual happens to care about) because they constitute capabilities that enable people to live well under a variety of conditions. Under this account, someone suffering from a serious illness who still manages to maintain a high level of life satisfaction by editing her values and goals down to those currently achievable would still be directly harmed by the illness, since poor health limits the person's ability to achieve other things she might come to care about in the future. In the next section, I briefly explore how this account could be adapted to enable better subjective measures of value in health care.

Agential Flourishing and Value Assessment

Traditional value analyses, where health gains are assessed relative to costs, may be adequate for measuring the effectiveness of treatments on objective medical conditions. Even though health outcomes are also often influenced by personal or social factors, there is still a reasonable correlation between input and output in such cases.

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[12] For an overview of QALYs, see, for instance, Weinstein [95] and MacKillop and Sheard [48].

But when treatments involve serious side-effects that make overall benefit less obvious, the outcome of interest may need to be broadened to include quality of life in order to understand treatment impact and effectiveness. If a subjective approach is used to measure these outcomes, then continuing to look solely at medical costs when assessing value is likely to create a misleading measure.

When looking at what improves patients' quality of life, resources besides health spending play a significant role. To illustrate, imagine trying to determine which of two treatments offers the best value in terms of overall quality of life benefits for patients with a debilitating medical condition. Both groups might show equal improvements after the completion of treatment compared to initial reports. If both treatments cost roughly the same, do they both provide equal value? We need information about more than people's self-reported quality of life to answer this question.

As previously noted, equivalent quality of life improvements could potentially be seen in both patient groups through very different routes. If treatment A is successful, enabling most patients to resume their normal (pre-illness) activities without major alteration, it seems plausible that these quality of life improvements are due to the treatment itself (barring any countervailing considerations). However, if treatment B is unsuccessful, and yet most patients are able to adapt to their new state, changing their expectations for what life will be like and what they will be able to achieve, then their reported quality of life may return to pre-illness levels. If someone believes she has the things that matter to her in spite of poor health (even if only by reframing what matters to her), she could still report being highly satisfied with her life. However, this report would rest on a very different foundation.

The question, then, is how to describe those values and goals that are dropped in making these adaptations. Under a strict reading of Raibley's account, the loss of capabilities resulting from disease would also count as a direct prudential harm, since health, according to Raibley, is a non-instrumentally valuable component of well-being. However, by distinguishing someone's well-being at any given point in time from her potential for future well-being, it is also possible to distinguish goods contributing to someone's current well-being from goods that enhance one's *disposition* to live well, even if these goods are not currently important to the individual.[13] Rather than basing a list of these "dispositional goods" on a particular objective theory of well-being, this list could be constructed using empirical research into the main contributors to long-term, sustainable life satisfaction.[14] Then, instead of saying that someone who has adapted to ongoing illness must necessarily be living a prudentially worse life than before, we can say that her long-term well-being is more vulnerable than it otherwise would be—the adaptations she has made in response to illness leave her potentially less able to adapt similarly to future well-being threats.

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[13] In this way, Raibley's account is consistent with Daniels' [21] argument regarding the role of health in protecting opportunities (see also Hausman [34]).

[14] Such a list could also be informed by Sen [82] and Nussbaum's [54] capabilities accounts. Instead of being justified by an objective theory of well-being, though, the items on this list would be justified by their contributions to dispositional well-being.

This framework enables more nuance in how we describe adaptation. Consider someone who is no longer able to work or engage in athletic pursuits due to ongoing illness. Even if these things were centrally important to her before becoming ill, she may no longer feel their loss if her values change following her decline in health. She could therefore be authentically satisfied with her new life. Under an objective account, the loss of capabilities that instigates these changes in perspective can simply be seen as direct prudential harms, and she would thereby have a lower level of well-being. But, as previously noted, this conclusion is unpalatable to many of those committed to patient-centered medicine and liberal neutrality about the good life. Furthermore, the claim that a loss of capabilities necessarily makes one's life go worse in a prudential sense contradicts the lived experience of many people living with chronic illness and disability [14].

Under standard subjective accounts, on the other hand, the impact of illness can seem to be downplayed too much; unless a person's quality of life is measured at a certain point in time—before she has fully adapted—this loss may not show up as having any meaningful effect on her life. If we instead distinguish prudential goods and opportunities that are important for enabling future well-being from those that are currently valued, it is possible to better capture the impact of illness. Having to eschew things once valued and pursued is still a loss, even if it is necessary for adapting to new circumstances. But these losses are not readily noted when using standard subjective measures of quality of life.

The loss of dispositional goods from illness or disability may be better described as *costs* rather than as *harms*. The costs of pursuing well-being (whether in effort, time, or opportunities left behind) are not necessarily harms; tradeoffs are inevitable in decisions about how we spend our time and which goals we prioritize. But they nonetheless represent resources that are no longer available for future use. If someone has had to reprioritize her goals, abandoning those that are no longer possible, then this editing of her life is a type of personal cost, even if she ends up being as happy as she had previously been (or even happier) because of it. Recognizing these costs is important to any deliberations about whether such costs are worth the benefit, whether they are preventable, or whether they are fairly distributed.

Within the medical literature, there is a growing awareness of the importance of recognizing patients' treatment burden when planning care. Treatment burden refers to the effort patients must put forward to deal with chronic illness; this can include adopting particular diets, adjusting activity levels, and finding ways to remember to take medications on a consistent schedule (possibly multiple times per day) [8, 22, 49, 71–74, 90]. Just as much of the work in maintaining health takes place outside of the clinical setting, so too does much of the work put into pursuing well-being. This work may require numerous resources—whether cognitive, emotional, or physical—that are not counted in financial analyses. Furthermore, it is likely that the relatively high (compared to expectations) levels of well-being that can be found among the ill is supported in part by accommodations made by loved ones [64, 75, 98, 99]. It is important to take the spending of all of these resources into account when assessing the impact of treatments on quality of life.

Due to the diverse array of factors influencing people's perspectives on their lives, then, it may not be reasonable to expect financial spending to correlate well enough with this outcome to allow meaningful value assessment.[15] While it may be justifiable to exclude these other factors when looking at the relationship between spending and health gains in the narrow sense, it is harder to justify their exclusion when using subjective quality of life measures to assess value. Neglecting to account for the contribution of these other resources to quality of life when assessing treatment value allows these personal resources to subsidize health spending and warp measures of treatment effectiveness. In order to develop a more meaningful assessment of value when using these broader quality of life outcomes, care must be taken to account for response shift and separate the spending of these other resources from health spending when measuring effectiveness. Raibley's agential flourishing account could be used to capture the costs of discarded goals and lost capabilities even when these losses no longer affect people's subjective appraisals of their lives.

Value Assessment and Justice in Health Policy

Finally, although I have focused on value assessment in this paper, this is not the only area in which it is important to account for different sources of well-being improvement. This accounting is also important for many debates about distributive justice in health policy. Questions of fairness in resource allocation are of course distinct from questions about the effectiveness of treatments, but clear information about burdens and benefits is needed to adequately address both concerns [20, 69]. As a result, though I do not have room to present a full argument regarding justice in health spending here, it is worth briefly noting these issues.[16]

To illustrate the relevance of these considerations to debates about health justice, I will return again to the example discussed earlier. Imagine that, in addition to the two patient groups receiving treatments A and B, there is a third group of people who have the same medical condition but receive no treatment because they are unable to afford medical care. As with the group that received the unsuccessful treatment, this group adapts to ongoing illness by changing their goals and standards, so that they also show equivalent quality of life improvements over time. Although all three groups may report identical levels of well-being at some point following the onset of illness, their situations should be addressed differently. As already argued, the first group's improved quality of life can be counted as a treatment success while the second group's cannot. But it is also important to distinguish the group whose treatment happened to be unsuccessful from the group that was not able to receive treatment at all, particularly when quality of life studies inform decisions about spending priorities.

Even if both groups use the same strategies to buffer their well-being against the effects of poor health, their situations may raise different concerns about justice. If it

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[15] Discussions of open and closed systems in economics may be relevant to these debates about quality of life assessment. Open systems are those that have a variety of external interactions, and this additional complexity makes modeling and assessing such systems more difficult. See, for instance, Bigo [6]. Thanks to an anonymous reviewer for making this point.

[16] See Emanuel [26], Pratt and Hyder [63], and Walker [94] for detailed discussion of these issues.

would be a mistake to count the improved well-being in the group that received the unsuccessful treatment as a marker of treatment value, it would be at least as much of a mistake to count the improved well-being in the untreated group as a marker of the fairness of a health system or as a reason not to prioritize the prevention and treatment of their condition. The effort this group puts into restoring their quality of life while living with untreated illness may be the result of unfairness in a way the second group's is not. Similarly, it is plausible that the untreated group was harmed by policy decisions in a way that the other group was not; if so, though, this harm is not easily captured through standard subjective measures unless care is taken to explicitly account for factors such as response shift.

Thus, even if a group of people manages to achieve a reasonably high quality of life while coping with serious illness, this does not mean that treating or preventing that illness should receive lower priority than less serious illnesses that do not trigger the same adaptation processes. Though two patient populations might have similar improvements in self-reported quality of life over time, the burdens and benefits supporting such improvements may not be fairly distributed. If the arguments in favor of subjectivism are correct, then perhaps we should accept that people in very different health states, and with very different responses to treatment, can nonetheless be equal in terms of *current* well-being and quality of life. But even so, accepting people's assessments of their lives as authoritative does not entail that we can make no further distinctions between them for policy purposes. If some are having to lower their expectations or change their standards in order to maintain or improve quality of life, this should not be factored into value assessment in the same way as quality of life changes following improved health.

The costs of adapting to disease and disability are personal costs paid by individuals, rather than costs associated with health care itself. To adequately inform debates about fairness in resource allocation, it is important to obtain more detailed information about how people's assessments of their lives change over time, as well as some understanding of the dispositional goods that enable people to sustain future well-being—however they may end up conceiving of it.

Conclusion

Traditional analyses of value in health care assess the impact of treatments on medical outcomes relative to cost. This conception of value may be adequate when concerned solely with measuring the effectiveness of care on medical conditions. However, when treatments involve serious tradeoffs, looking solely at objective medical outcomes does not provide enough information to determine the impact of care on patients' lives. To know whether treatment provides an overall benefit in these cases, the outcome of interest should be broadened to include overall well-being or quality of life.

Quality of life is often studied using subjective measures, and this approach is claimed to better capture the perspectival nature of the construct and to be more justifiable to patients. However, the use of standard subjective measures also makes it more difficult to discern the overall impact of treatment. If the notion of benefit used in value assessments is broadened to include quality of life, then the cost side of these analyses should be similarly broadened to include resources beyond the financial used to achieve improvements.

When assessing value, then, it is important to carefully separate benefits and harms due to disease and treatment effects from benefits and harms resulting from adaptation, and to distinguish these from changes in overall quality of life. To make these distinctions, researchers should look at more than people's self-reported health and quality of life.[17] Research should also explore how people's values, goals, standards, and conceptions of what it means to live well change over time.

Of course, studying changes in *how* people assess their lives will be more difficult than administering standard subjective measures, but existing work on response shift in health-related quality of life research provides examples of how this can be done. For instance, instruments such as the Patient Generated Index (PGI) and the Schedule for the Evaluation of Individual Quality of Life (SEIQOL), which allow respondents to assess their lives according to their own goals and priorities rather than measuring the domains selected by researchers or scale developers, can be used to study changes in values over time [2]. In addition, conducting concurrent "think-alouds"—asking respondents to explain their answers as they fill out quality of life surveys—provides a more detailed picture of how people's standards and conceptualizations change over time [57, 96, 97]. These techniques can be adapted to provide more insight into the likely sources of any changes in reported quality of life.

Quality of life researchers who study response shift argue that failing to explicitly look for this phenomenon leads to both over- and underestimating treatment effectiveness. This has worrying implications for clinical trials as well as for applications in policy and patient care, since different drugs might trigger different types of response shift [3, 44, 68, 77, 89]. These arguments also apply to the assessment of treatment value when 'benefit' is understood as overall well-being or quality of life. If quality of life is conceptualized and measured subjectively, explicitly looking for response shift and any other factors likely to affect patient self-reports enables research to better capture the complex pathways of benefit and harm. This could then help put subjective quality-of-life-based assessments of cost effectiveness on a path toward more meaningful and appropriate measures of value.

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[17] Although I have suggested adapting Raibley's account of agential flourishing—and thus measuring the dispositional well-being goods people possess—this is just one example of how a subjective account of well-being could be adapted to fit the needs of value assessment in health care.

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