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Disability Discrimination and Patient-Sensitive Health-Related Quality of Life

Lasse Nielsen 

Philosophy, Department for the Study of Culture, University of Southern Denmark, Odense, Denmark
Email: lasseni@sdu.dk

Abstract

It is generally accepted that morally justified healthcare rationing must be non-discriminatory and cost-effective. However, given conventional concepts of cost-effectiveness, resources spent on disabled people are spent less cost-effectively, *ceteris paribus*, than resources spent on non-disabled people. Thus, it is reasonable to assume that standard cost-effectiveness discriminates against the disabled. Call this the *disability discrimination problem*. Part of the disability discrimination involved in cost-effectiveness stems from the way in which health-related quality of life is accounted for and measured. This paper offers and defends a patient-sensitive account of health-related quality of life, which can effectively make cost-effectiveness less discriminatory against the disabled and thus more morally justified.

Keywords: cost-effectiveness; healthcare priority setting; disability; discrimination; health-related quality of life

Introduction

Rationing between competing healthcare needs is unavoidable.¹ It is commonly believed that a cost-effective scheme for healthcare priority setting discriminates against the disabled.² In this paper, I argue that for purposes of healthcare priority setting, we need an account of health-related quality of life (HQoL) that allows the assessment to focus on people's justified claims for healthcare resources, and I offer a patient-sensitive account of HQoL as a suggestion. The patient-sensitive account avoids the most troublesome problems with disability discrimination and thereby enables a cost-effective allocation of healthcare resources that does not discriminate against the disabled.

The patient-sensitive account says that the relevant health quality assessment should be concerned only with the effect of health-related outcomes of a given medical intervention from the particular patient's perspective. This means that the health outcome of a given intervention should refer narrowly to the effect of the intervention on the targeted condition for the particular patient and that we should not take into account information about the patient's health—such as a chronic disability—unless relevant for the patient's response to treatment. I give a needs-based defense of this account and draw support from some important inspirational sources. First, the account draws support from Frances Kamm's *Sufficient Only Option Argument*. Central to this argument is that when we take each person's subjective interest to be of equal importance, it is reasonable to judge disabled and non-disabled lives as equally valuable. Second, it draws on the view by Erik Nord et al. that a life year gained should be given the same weight regardless of disability, because what matters is the effect of interventions on the realization of a given person's particular health potential.³ As a third inspiration, I draw on Stephen Campbell, Sven Nyholm, and Jennifer K. Walters' recent philosophical exploration of the disability paradox—that while we from an impartial perspective typically judge disabled person's lives as of less quality, they rarely do so themselves.⁴ Fourth and finally, the account draws inspiration from Sean Aas and David Wasserman's understanding of health as, “the absence of harmful or harm-causing disease entities,” implying that a disability is not necessarily in contrast to being healthy.⁵

When cost-effectiveness analysis is conducted informed by the patient-sensitive account of HQoL, treatments and other healthcare interventions offered for disability-unrelated conditions will be of comparative value to disabled and non-disabled patients. Consequently, this redefinition of HQoL makes cost-effectiveness less discriminatory against disabled in a way that is both intuitively and theoretically attractive. Admittedly, the patient-sensitive account does not promise to solve the disability discrimination problem completely because it only improves upon the life-quality assessment in cost-effectiveness and part of the discrimination against the disabled from cost-effectiveness also concerns reductions in lifespan, to which my account has nothing to add. But as it is an ongoing debate in the literature whether lifespan-based discrimination is more justifiable than discrimination based on life-quality, I shall put the lifespan discussion aside in most of this paper, and only make a brief remark near the end on how it relates to my contribution.

My topic is disability discrimination in healthcare priority setting from an ethical point of view, and my contribution does not presuppose any particular understanding or definition of what a disability is. My argument concerns how cost-effectiveness analysis should approach, weigh, and measure disability, but it is compatible with different views on what counts as a disability.⁶ My argument proceeds as follows. The first section describes the problem of disability discrimination in relation to cost-effectiveness analysis. The next section offers an account of patient-sensitive HQoL and explains how it contributes to solving the disability discrimination problem. The final section concludes.

How Cost-Effectiveness Discriminates Against the Disabled

Imagine two patients A and B suffering from condition C and consequently equally in need of some medical treatment T without which they will not survive. Treatment T functions as a cure against C and its effect on C will be the same for the two patients. Thus, if provided T, both A and B will return to their baseline level of functioning. However, the baseline level of functioning is different for A and B. Whereas patient A is a normal functioning, non-disabled person, patient B suffers from a chronic disability.⁷ The disability of B is unrelated to condition C—we can imagine that she is blind or partially paraplegic. Now, on the assumption that treatment T is a scarce resource and consequently can only be offered to one of the two patients, standard cost-effectiveness recommends giving the treatment to A rather than B because of B's disability. Thus, as a guiding principle for healthcare priority setting, standard cost-effectiveness discriminates against the disabled.

The explanation for why cost-effectiveness discriminates against the disabled is its inherent ideal of maximizing health outcome per cost. On the assumption that the cost (e.g., of providing treatment T) is the same for disabled and non-disabled patients, treatments offered to disabled patients are less cost-effective because they generate less health outcome than treatments given to non-disabled patients. There are two potential and analytically distinct aspects of this effect. One aspect relates to timespan. Many disabilities reduce lifespan, and thus life-saving treatments to non-disabled patients will save more life years than life-saving treatments to disabled people of the same age. The second aspect concerns life-quality. Since standard measures of HQoL give lower life-quality scores to years lived with a disability than they give to years lived without a disability, life-saving treatments to non-disabled patients will generate more life-quality per year than treatments to disabled patients.

A QALY calculation can account for this. A quality-adjusted life year (QALY) assessment measures health benefit by multiplying the timespan (duration of time spent in a given health state) by HRQoL. HRQoL can be based on simple individual evaluation such as visual analog scale—judging one's own health on a scale from 0 to 100—but is often supplemented by immediate comparative evaluations such as standard gambles or time trade-offs. The HRQoL will provide a 0–1 coefficient representing what 1 year in a particular health state is worth (where 0 = death and 1 = full health), to be multiplied by the duration of time. In other words, the HRQoL provides the information of the life-quality deficiency from full health within a specific health state.

Cost-effectiveness is not always analyzed using QALY. An important alternative measure is disability-adjusted life years (DALY) most standardly used by the WHO to account for the global burden of disease.

A DALY measures the sum of the years of life lost due to premature mortality (YLLs) and the years of life spent in a state of disability (YLDs) due to prevalent cases of disease or health conditions. Note that “disability” here is used in its broadest sense to account for any disease or burdensome health condition and is thus different from the way the terms are typically used to describe some sort of functional incapacity or cognitive deficiency shared by the group of disabled. Like QALY, the DALY scale uses a 0–1 coefficient to account for the quality loss (in YLD) going from 0 = no disability (or just as good as no disability) and 1 = death (or just as bad as death). Importantly, the two scales are inverted, because QALY aims to capture the quality effect of a given treatment whereas DALY describes the burden of disease. Hence, where one QALY refers to the value of 1 year in full health, a DALY score of 1 refers to the equivalent of the loss of 1 year in full health. Despite their differences,⁸ they are substitute measures of the value of health which can be put to use comparably in cost-effectiveness analysis for healthcare priority setting, and the choice between them as metrics makes no substantial difference to how and whether cost-effectiveness discriminates against the disabled.⁹

It seems, then, that the discrimination against the disabled from cost-effectiveness can take two different forms (despite the underlying measure), one relating to timespan and the other regarding life quality, and it is plausible that these two forms call for different justifications.¹⁰ I can set aside this distinction here, as my contribution relates to health-quality specifically, and this is the part of the discrimination I focus on in this paper. Hence, to zoom in on the disability discrimination problem concerning life-quality, let us imagine that treatment T is curative of the condition C, that patients A and B are the same age and will both live for 60 additional life years, but that B has a disability involving a 10 percent life-quality reduction on a standard measure of HQoL (e.g., QALY or DALY). Let us further assume that B’s disability is unrelated to condition C in the sense that being disabled does not affect the way B will respond to treatment T. A QALY-based cost-effectiveness analysis would then give the following result.

Standard Case

Treatment to non-disabled patient, A = timespan (60) x HRQoL per year (1) = 60 QALYs.

Treatment to disabled patient, B = timespan (60) x HRQoL per year (0, 9) = 54 QALYs.

A cost-effectiveness analysis would recommend giving the treatment to A over B, then, because of the significant difference in cost-effectiveness of 6 QALYs per cost of treatment T.¹¹

In this example, I have merely pointed out how cost-effectiveness discriminates against the disabled. On a generic definition of discrimination stipulated for the case at hand, cost-effectiveness discriminates against the disabled in a priority setting because (1) B has a disability that A does not have, (2) cost-effectiveness treats B worse than A through its prioritization, and (3) it is because B has a disability that A does not have that cost-effectiveness treats B worse than A through its prioritization.¹² Hereby, I have said nothing about the normative status of this discrimination. At this point, it is simply differential treatment to the disadvantage of the disabled. For the disability discrimination problem to arise, it must furthermore be the case that the differential treatment of disabled people by a cost-effectiveness prioritization is unjustly discriminatory. Discrimination theorists disagree on what the wrong-making feature of unjust discrimination is—for example, wrongful mental-states, disrespect, or harm—but I shall set this dispute aside here.¹³ For the purpose of this paper, it will suffice to say that we are only interested in whether cost-effectiveness *unjustly* discriminates against the disabled.

Ethicists disagree on this issue. Some argue that the problem is not as troublesome as it seems either because they deny that cost-effectiveness relevantly discriminates against the disabled, or because they believe that the discrimination is justified as the lesser of two, together necessary, wrongs.¹⁴ Others find reasons to insist that the discrimination against the disabled by cost-effectiveness is indeed morally objectionable. One reason involves the *double-jeopardy argument*.¹⁵ The argument states that cost-effectiveness unjustly discriminates against the disabled because of its inherent double-harmful effect on

the disability. In Standard Case, the disabled patient B is already worse off than patient A, and the fact that she is worse off because of the disability is moreover the reason why she is also given lower priority in the cost-effectiveness analysis. Thus, cost-effectiveness creates a linkage between disability and entitlement where no such linkage is called for, and in a way that systematically disadvantages people to whom we feel we have a special moral duty.¹⁶

In a similar spirit, Dan Brock objects to cost-effectiveness because it fails to appreciate the equal value of equally effective treatments. Brock points out that cost-effectiveness analysis wrongly gives lower priority to equally effective treatments for disabled patients, even when the disability is unrelated to the treated condition.¹⁷ While this critique to some extent overlaps with the double-jeopardy argument, the site of the objection is somewhat different. This objection is more directly motivated by the intuitive ideal that healthcare effect should reflect how well a given treatment succeeds in performing its intended function in response to a given condition, rather than how much good it generates. In Standard Case, the effect of treatment T is given a lower moral simply because of the disability, despite that T's effect on condition C is the same for the two patients and hence unaffected by the disability. The treatment for diabetes, for example, can be equally effective for a blind and a seeing patient, but a cost-effectiveness analysis is likely to give the treatment of a blind diabetic lower priority in reference to the reduction in life quality from being blind. Since this has nothing to do with the relevant health-related effect of the treatment, it should have no weight in the priority setting. Call this *the equal effect argument* (my label).

While most agree that the double jeopardy and the equal effect argument point to relevant limitations, some insist that these problems do not necessarily imply that we should abandon cost-effectiveness altogether, because once we take account of the actual practice of cost-effectiveness, these problems seem much less worrisome. To elaborate, some might say that cost-effectiveness analysis is not discriminatory against the disabled in practice because of the way it includes the voices of disabled in its evaluation of HQL. The measures of health benefit in cost-effectiveness analysis—both QALY and DALY—use large scale survey data including disabled as well as non-disabled respondents to account for their respective health-quality coefficients and we can therefore expect the assigned values to be representative of the public's opinion in general and thus include the voice of the disabled.

But this objection is misplaced for a number of reasons. First, and most importantly, cost-effectiveness is accused of being discriminatory against the disabled not because it fails to take account of the preferences of the disabled, but because on a cost-effectiveness analysis healthcare resources generate less health benefit (at the same cost) when given to disabled compared to non-disabled people, and this will incline toward an allocation of resources that discriminates against the disabled. Hence, importantly, cost-effectiveness will discriminate against the disabled regardless of whether the health-quality measure includes responses from the disabled or not. Second, it is indeed a complicated matter how to weigh the preferences of the disabled themselves in matters of the health-quality assessment of a given disability. Empirical studies report that disabled and non-disabled people have quite different assessments of a given disability,¹⁸ but by itself this does not settle how to set the proper value of a disability.¹⁹

Another, more important, counterargument says that although cost-effectiveness might involve disability discrimination in principle, it can be put to use in ways where these problems do not arise. And in fact, cost-effectiveness analysis is rarely used in practice in a way that discriminates against the disabled. The double jeopardy and equal effect argument implicitly assume cost-effectiveness analysis as a procedure for setting priorities between patients by the bedside, but in real world, priority setting this is almost never the case. Cost-effectiveness analysis is a health-economic tool enabling economists to make large-scale macro-priority recommendations to be weighed against other relevant considerations. To that purpose, health economists use average quality-of-life measures, which seldomly expose differences between disabled and non-disabled patients, and they focus on clinical added value rather than absolute QALY benefits.²⁰ For these and other reasons, cost-effectiveness analysis is very rarely discriminatory against the disabled in practice. We can call this *the not-in-practice response*.

While the not-in-practice response is certainly important for the relevance of the double jeopardy and equal effect argument for practical purposes, and to the extent that it limits the scope of applicability of the disability discrimination problem, we still need to take account of disability discrimination as a theoretical problem. One reason for this is the following: The not-in-practice response assumes that we

would have to take the objections by the double jeopardy and the equal effect argument seriously *if* cost-effectiveness analysis was discriminatory in practice. It is just that, as things are, cost-effective analysis is arguably not used in a way that discriminates. But this assumption misses the target, because even when cost-effectiveness *analysis* is not used to discriminate in practice, it will still be the case that *cost-effectiveness* by itself, as a distributive principle, would in principle involve disability discrimination, and consequently that a perfectly cost-effective distribution would involve unjust differential treatment of the disabled. Ironically, then, the not-in-practice response admits from the outset to the central moral claim of the disability discrimination problem—that cost-effectiveness *is* discriminatory. Regardless of its use in real-world priority setting, cost-effectiveness is discriminatory against the disabled, and thus we need to take the objections seriously. And, as the above-mentioned objections show, this is problematic because it uses the fact of the disability as a reason for giving disabled people lower priority even when the clinical effect of the treatment in question is the same.

This section has elaborated how cost-effectiveness involves discrimination based on life-quality assessment. But this need not be the case. What is required is an alternative, *patient-sensitive* understanding of HQoL. This conception focuses on life-quality effects of medical interventions from the perspective of the patient, and I will argue that while this definition might not serve as a suitable conception of life-quality or health in all contexts, it is both plausible and particularly useful for healthcare prioritization. The next section unfolds the conception of patient-sensitive HQoL for use in cost-effectiveness analysis and thereby contributes to solving the disability discrimination problem.

Patient-Sensitive HQoL

In this section, I suggest a patient-sensitive account for the assessment of HQoL. To introduce the idea, let me revisit the case from above. Imagine that patients A and B approached the healthcare system with a request for treatment T *before* condition C. This addition to the Standard Case helps us to see how the patients' claim to treatment involves an actualized need for treatment. When approaching the healthcare system before condition C, none of them suffers any treatable condition, and more particularly no condition for which T will be effective. A is requesting treatment despite being in full health, and B is requesting treatment despite suffering an incurable disability, for which treatment T will have no effect. We can imagine that they consult the health authorities in the false belief that treatment T will benefit them because of how they have witnessed it to work on others.

Surely, we would judge that neither A nor B have a claim for treatment, because they have no *need* for it. This is because while healthcare services carry omnipresent potential importance, because everyone might come to need it, the intended value of specific healthcare resources is actualized only when they serve a needs-related function.²¹ For example, coronary bypass surgery may become critical for any given person's continuous life and wellbeing, but only as a response to obstruction of blood flow in a coronary artery. Moreover, once provided the necessary surgery, the patient will (if surgery is successful) be in no need for more health care of this type, and there will be no inequalities in relation to this resource between this and other patients who had no use of it. In other words, the realized value of the healthcare resource is, in this case, conditional upon the functional deficiency represented by blood-flow obstruction.

Some might object that indeed patient B seems to have a stronger claim for care than patient A in some general sense, because B suffers an underserved disadvantage, and on most accounts of justice, their disability would render a justified claim for assistance—for example, egalitarian, prioritarian, and sufficientarian grounds. But the crucial point here is that just like A, B has no use for treatment T before condition C. While having a just claim for other goods—that is, circumstances that enable them to get around their community and to function socially—we ought to judge that the disabled have no (special) claim for disability-unrelated health care, and that, therefore, there is no injustice in ignoring the requests of B for treatment T (before C). We can safely conclude that *being in need of* a healthcare resource is a necessary condition for *being entitled to* the resource.

The central reason accounting for this is needs based. A and B are equal in terms of their demand for treatment T, because their need for T is the same (in this case, equivalently non-existent). As needs

theorists widely accept, the moral demand of needs stems from several central aspects. First, relevant needs have *objective* moral importance. Their moral value is independent of subjective valorization thereof. Certainly, in most cases, getting one's needs met is highly valorized, but this is not what makes the need morally demanding. Needs, are thus, as David Wiggins explains, non-intentional in the sense that a person in need of *x*, needs *x* not due to a contingent description of *x*—for example, like some people need a tattoo in order to look cool, which implies that they do not need a tattoo if it does not make them look cool—but because of some property of *x* which the person needs objectively.²² Relatedly, this sets needs apart from desires.²³

Second, needs demand to be responded to. If I *need* your help, it is morally demanding (on a needs-based account) that you help me. Surely, if I say that I “need” your help to understand Aristotle's *Ethics*, there is no *moral* demand that you help me. Then, we would say, I need your help “or else...”—for example, or else I will have to find a way to live in ignorance about virtue ethics, but it is not morally demanding that you take on this role of helping me. But this only shows that we often use the term “need” in a loose and hypothetical or contingent sense—person *P* needs *x*, if *P* is to do *y*. As we shall see, this has a certain relevance for healthcare needs. But moral needs are categorically morally demanding. They hold, as we can put it, *moral necessity*.²⁴ Seeing these two parts (objectivity and moral necessity) together enables us to understand the moral gravity of needs. Once there is an unmet need, we understand that this is something that calls for our help and that while what our help should consist in more particularly might depend on the needing person's subjectivity, the moral demand *that* we help, does not.

Thirdly, needs always reveal what is needed in the need. If a person really needs something to live or to exist, or to live a good enough life, that person is in need “of something.” This “being in need” involves a deficit from whatever would be morally required of us. Thus, needs always reveal a gap between the need and the point at which the need will be met as well as a directional moral call for whatever content the need demands. Needs, expressed by Soran Reader, “say what is wrong, describing the lack (or imminent risk of lack) in the needing being. And they thereby also say what a moral agent should do about it, describing the act of help that will restore the lack.”²⁵ Together, these three central aspects of a morally relevant need tell us that a need holds objective moral importance, to the extent that it is an item we owe each other in terms of morality or justice, and that any such need is at the same time a directed call for some specific content which is sensitive to the particular situation of the person in need.

Upon this foundation from the needs theory, we can elaborate the specifics of healthcare needs as morally relevant needs with a specifically healthcare substantial direction. Whereas needs theorists use the concept of needs to capture what we need *qua humans* in a general sense, healthcare needs are more appropriately conceptualized as directed needs of some specified patient subject (*x*) for some specified healthcare object (*y*) in order to achieve some specified health-related goal (*z*) such as pain avoidance or functionality.²⁶ On this account, Erik Gustavsson concludes, healthcare needs are most plausibly interpreted in the form, *y* is a healthcare need if, “*y* can benefit *x* in order to *z*.”²⁷

This account of healthcare needs gives body to the argument for why neither A nor B has justice claims for treatment T before C, while both have equal claims for T after C. To elaborate, B might (qua the disability) be more “in need” than A in some more general sense of morally relevant needs, but she does not need health care any more than A. More specifically, the healthcare resource T is not the appropriate help we can offer in response to any lack that B (or A for that matter) has before condition C enters. To that extent, A and B should be treated as equals in our healthcare priority setting before condition C. We should conclude, then, that A and B are equals in this respect, before condition C, because none of them have a reasonable claim for treatment T. If you agree, then it seems to follow that when condition C enters, a healthcare need occurs equally for both of them and hence a (pro-tanto) justice-claim for health care is identified. That is, our fundamental reason to offer T originates in the occurrence of condition C and it seems intuitive that our assessment of the benefit in HQoL of treatment T directed toward C is thus specifically concerning how valuable T is *as a response to* C for the patient in question. Call this the patient-sensitive account of HQoL assessment (or the patient-sensitive account, for short).

Patient-Sensitive HQoL

Measures the impact of the effect of a given treatment T (or other medical intervention) in response to a given condition C on a patient's life-quality from the perspective of the patient in question.

Some criteria are warranted. First, a patient-sensitive account is concerned merely with how well a given person responds to treatment for a specific condition.²⁸ It will thus be appropriate to include in the assessment, information about personal disposition to respond to treatment, and it may be justified to make interpersonal comparisons on that basis. Consequently, if a certain disability makes people less disposed to respond well to treatment T for the condition C, it could be justified for the assessment of HQoL to take that into account, despite that this is in some sense discriminatory according to the generic definition given above. Obviously, this will not apply in Standard Case, because when this is the case, the assumption that the disability is unrelated to the condition is false.

Second, since a patient-sensitive account evaluates the value of treatment from the perspective of that person, it should be *insensitive* to interpersonal comparisons of overall quality of life. This is so, because the value bedrock from where the assessment begins is the life of that person, not the comparison of that person's life with other could-have-been lives. Thus, it follows, the patient-sensitive account will give equal value to equivalently effective treatment for similar conditions for disabled and non-disabled persons, when the disability is unrelated to the effect of the treatment.

This account draws inspiration from some important sources. First, it draws support from Frances Kamm's *Sufficient Only Option Argument*. The upshot of this argument is that when we take each person's subjective interest as of equal objective moral importance in our priority setting—Kamm refers to this as *subjectivism*—we should judge disabled and non-disabled lives as equally valuable. Kamm gives the following example.

One may reasonably want 0.5 as much as one would want 1 if one could have it. So, for example, given that 0.5 is all that one can have and 0 is very bad, one might reasonably do as much to achieve 0.5 (e.g., spend as much money, suffer as much) as one would do to achieve 1 if one could have it. This is consistent with the willingness to even risk losing 0.5 and falling to 0 for a chance at 1.²⁹

Kamm's example shows that the value of prolonging the life of a particular person must depend on the option of life available from that subjective point of view. This implies that extending the lives of disabled people can reasonably be judged to hold as much moral value as extending the lives of non-disabled people, despite that we from an impartial point of view consider non-disabled lives preferable for all. Kamm's argument can be defended by imagining the justification we would have to give to disabled patients if we decided against treating them for the benefit of the abled-bodied. "We understand that this is disappointing to you," we would say, "but you will have to admit that this treatment is simply more valuable for other, non-disabled, persons." What Kamm reminds us of is that a disabled person can reasonably deny this and reject it as a justification. The central point is that the life available to the disabled person can be just as valuable *for the disabled*, as the non-disabled life is for a non-disabled person. Thus, taking individuals as the appropriate entities, for which the health quality assessment should apply, the best available option from the individual, personal perspective must be the point of departure against which health outcomes should be evaluated.

Second, informed by preference data on equity weights, Erik Nord et al. suggest that a life-year gained for people with disabilities or chronic diseases should be given the same weight as for non-disabled people, as long as the year in question is worth more for the person concerned than death, since what matters is the effect of interventions on the realization of a given person's particular health potential.³⁰ The idea of setting the aim based on health potential supports the patient-sensitive account, and since Nord et al. build their suggestion on public preference data, it seems that we can rely on public preferences to also support it. In that case, the argument by Nord et al. offers some empirical support for the patient-sensitive account, while the patient-sensitive account returns the

favor by adding theoretical force to the view suggested by Nord et al. That is, their view is further strengthened by the needs-based argument above: that only deficiency from particular patients' realistic health potential represents actual healthcare needs and that these ground the basis for assessment of HQoL.

A third reason in favor of the patient-sensitive account is found in recent philosophical explorations of the effect of disability on personal well-being. As a particular example, Steåhen Campbell, Sven Nyholm, and Jennifer K. Walter explore the so-called disability paradox arising from the apparent tension between the popular conclusion that disability lowers life-quality, and the relatively high scores given by disabled people in self-reported happiness studies. The authors identify four widely recognized goods of life—happiness, rewarding relationships, knowledge, and achievement—ecumenically appreciated on different well-being theories (objective-list, hedonism, and preference-based theories), and they argue that disabilities—even when considering quite different types of disabilities—are in principle compatible with realizing most of these central goods. To the extent that this analysis informs us about the popular assumption that disability limits persons' access to essential life-quality goods, the authors conclude that their investigation, “into the in-principle compatibility of four prominent disabilities and widely recognized goods of life suggests that, at least on most theories of well-being, this assumption is simply mistaken.”³¹ This compatibility argument should not be taken too far. We should be careful not to interpret it as saying that disabilities are irrelevant, not significant limits on what persons can do, or that disabled people are not relevantly worse off than non-disabled people in many instances. But what the argument does imply, very plausibly, is that we have no reason to expect that being disabled leads to lower life quality. This brings additional philosophical force to the adjustment of cost-effectiveness analysis suggested by the patient-sensitive account of HQoL.

At this point, critics might object that the potential benefit of the patient-sensitive account in making cost-effectiveness less discriminatory against the disabled comes at the cost of failing to fully acknowledge the harm factor involved in a disability. If each life-year with a disability should count the same as a life-year without the disability, would this not imply, critics could ask, that disabled people would lose their moral priority in claim rights to also existing treatments that could actually benefit them? We can illustrate the problem by imagining that a new pill was invented that could immediately cure paraplegia. It seems that my suggested view implies that whereas the paraplegic's life was as good as everyone else's before the pill, her life is now suddenly worse after the invention of the pill, because the impact of the effect of available treatment on life quality changes. But this seems absurd—if anything, her quality of life seems improved. In response, the patient-sensitive account merely concerns the impact of the effect of a given treatment on a person's life quality and thus states nothing about the life quality (or health) of the person in general. That is, on the patient-sensitive account, a paraplegia pill (if invented as imagined) would certainly be judged as immensely health-effective if given to a relevant target patient precisely *because* of the impact of such a pill on that person's life quality, and in that sense, it is completely accurate to judge that in regard to the distribution of such pills (in contrast to the distribution of other types of medicine), people suffering from paraplegia are relevantly worse off than others, which is to say, their quality of life could be increased significantly by taking the pill. When used, as suggested, merely for healthcare priority setting, the patient-sensitive account seems to fit our intuitions of the harm of disability perfectly.

As a fourth and final inspiration, Aas and Wasserman offer a conception of health as, “the absence of harmful or harm-causing disease entities.”³² In their view, healthcare prioritization is typically discussed in relation to an account of health that does not lend itself well to considerations of justice, which is unfortunate. Their view, therefore, focuses on health deficiencies that ground a relevant justice entitlement for healthcare resources, rather than, say, mere deviation from normal functionality,³³ or less than perfect conditions for the achievement of vital goals.³⁴ On this account, people can be equally healthy with quite different opportunities for life quality. And particularly, many types of disabilities may be compatible with being healthy in their sense. While my argument is compatible with and even strengthened by Aas and Wasserman's view, it is not committed to any particular theory or conception

of health. The patient-sensitive account I am suggesting here is silent on the question of *what health is*, it is only concerned with the assessment of HQoL.

Let us now revisit the case with A and B both and equally suffering condition C. In the original case, a cost-effectiveness analysis would recommend priority to A over B, because this would generate more aggregate quality of life, for example, QALYs. The patient-sensitive account suggests revising the HRQoL coefficient to only take into account the value of the treatment and its effect on the targeted condition from an individual patient's perspective. This implies that we should consider the lives of A and B of equal health-related quality and therefore judge the benefits of treatment T equal for both of them, because the only relevant quality-reduction is the condition C to which they respond equally well. Consequently, the QALY calculation should be revised to the following:

Patient-Sensitive Account Case

Treatment to non-disabled patient, A = timespan (60) x HRQoL per year (1) = 60 QALYs.

Treatment to disabled patient, B = timespan (60) x HRQoL per year (1) = 60 QALYs.

As the case suggests, a given treatment or other healthcare intervention directed toward a disability-unrelated condition should be evaluated from the perspective of that particular patient, in which case disability would have no impact on the HRQoL measure, which then amounts to 1 for both A and B. This patient-sensitive account, for sound reasons, makes cost-effectiveness analysis less discriminatory against the disabled. Turning to our generic definition of discrimination, we can conclude that an assessment of HQoL informed by the patient-sensitive account does not discriminate against the disabled because despite that (1) B has a disability that A does not have, it is not the case that (2) B is treated worse than A (3) because of the disability. If we are motivated by the double jeopardy and the equal effect argument and inclined to be critical against cost-effectiveness on the grounds of disability discrimination, we ought to take seriously the possibility of the patient-sensitive account of HQoL.

Before concluding, let me make one final but important remark. It might be objected that even if we accept my suggested patient-sensitive account, this has only limited effect on the disability discrimination problem. This is because the patient-sensitive account only concerns the life-quality part of the discrimination and thus, as I indicated above, it leaves open the potential disability discrimination that relates to reduced lifespan. We can see this by considering a revised version of the initial rationing case. In Standard Case, I assumed that patients A and B had the same lifespan of 60 years. In many cases, however, this assumption will not hold as many disabilities will have a negative effect on lifespan. Hence, even when qualified by the patient-sensitive account of HQoL, a cost-effectiveness analysis can still involve disability discrimination based on lifespan information. Consequently, while the patient-sensitive account mitigates the problem of disability discrimination related to life-quality, it has no power against discrimination based on lifespan.

This, of course, raises the question of whether discrimination in reference to differences in lifespan is more morally justified than discrimination based on reduced life-quality. As I have presented the case here, it seems plausible to hold that the two are indeed separate types of discrimination, in which case it makes sense to consider their moral justification independently. And despite that this is rarely acknowledged in the literature, it seems plausible that the two are not only distinct types of discrimination but also different in terms of justifiability. Arguments accounting for this asymmetry have been given by for example Frances Kamm³⁵ and Samuel Kerstein,³⁶ respectively. On the other hand, many critics of cost-effectiveness analysis who are motivated by the disability discrimination problem do not accept the asymmetry that Kamm and Kerstein appeal to. Brock, for example, takes the Equal Effect argument to imply that life-quality *as well as* lifespan-related discrimination is unjustified.³⁷ It may be, then, that we should also be critical about cost-effectiveness because of the way in which it discriminates against the disabled based on lifespan information.

It is not my purpose here to offer a view on lifespan-based discrimination or to solve the disability-discrimination problem all together. Rather, my aim was to discuss the unjustified disability discrimination involved in the differential treatment of disabled patients by the HQoL measure in cost-effectiveness analysis and to suggest a way forward. My conclusion is that a patient-sensitive account of HQoL would significantly improve upon the current use of cost-effectiveness analysis in making it less unjustly discriminatory against the disabled and consequently, more morally justified.

Conclusion

If we are to make healthcare prioritization less discriminatory against the disabled, we need to understand how the distinct parts of the priority setting are discriminatory and investigate how they can be revised accordingly. In this paper, I have offered and defended a patient-sensitive account of HQoL as a step forward. My argument can be summarized as follows. Even though cost-effectiveness analysis is rarely used in practice in any explicitly discriminatory way, it is still the case that cost-effectiveness as a distributive ideal discriminates against the disabled. Part of this disability discrimination relates to the way in which HRQoL is accounted for, and this qualitative part (some would say) is especially problematic. If revised to employ a patient-sensitive account of HQoL, based on the impact of the effect of a given treatment in response to a given condition on a patient's life-quality from the perspective of the patient in question, cost-effectiveness analysis would be significantly less discriminatory, and maybe even only discriminatory in a largely justified way. This is so, because the patient-sensitive account assesses the value of a given treatment from the perspective of the person who benefits from it. While this cannot promise a completely non-discriminatory use of cost-effectiveness—as I have to a large extent set aside lifespan consideration for the purpose of this paper—it makes cost-effectiveness much less vulnerable to the disability discrimination problem.

Acknowledgments. For useful comments and discussions, the author is grateful to Andreas Albertsen, Anna Christine Dorf, Kasper Lippert-Rasmussen, and Joonas Räsänen.

Funding Statement. The research was funded by the Danish Research Council, Project DFF 9037-00007B.

Notes

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