

REVIEW ARTICLE

Ethical Shortcomings of QALY: Discrimination Against Minorities in Public Health

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Abstract

Despite progress, discrimination in public health remains a problem. A significant aspect of this problem relates to how medical resources are allocated. The paradigm of quality-adjusted-life-year (QALY) dictates that medical resources should be allocated on the basis of units measured as length of life and quality of life that are expected after the implementation of a treatment. In this article, I discuss some of the ethical shortcomings of QALY, by focusing on some of its flawed moral aspects, as well as the way it relates to discrimination on the basis of age, race, and disability status. I argue that while this approach seeks to maximize efficiency, it does not place sufficient value on the preservation of life itself. Even more concerning is the fact that the use of QALY disproportionately harms minorities. While QALY is a well-intentioned approach to the allocation of scarce healthcare resources, new alternatives must be sought.

Keywords: discrimination; ethics; public health; QALY; medicine

Introduction

The COVID-19 pandemic has been a reminder that, despite the efforts of governments across industrialized nations, discrimination remains a problem. Disparities in many measures related to the pandemic (access to healthcare, access to vaccines, prognosis, added risk factors) have been observed, and minorities (mainly ethnic) are disproportionately represented in the disadvantaged groups.^{1,2,3,4}

In many settings, this is to a certain extent expected, as systemic racism ultimately affects the structure of healthcare systems. Inevitably, healthcare systems reproduce conditions of social exclusion, to the point that some commentators have pointed out that in countries such as the United States, a “medical apartheid” of sorts is well-established.^{5,6,7,8}

While the undoing of racism and discriminatory attitudes and practices in healthcare is a challenging task, further difficulties arise when considering that many public health systems, by their very nature, may contribute to the discriminatory state of affairs. This may occur with practices that, in principle, are well-meaning, but upon closer scrutiny, they are revealed to have discriminatory implications.

One such practice is the use of cost-efficiency concepts in the allocation of healthcare resources. In this article, I will examine some of the ethical shortcomings of these concepts and how they relate to discrimination on the basis of age, race, and disability.

How QALY works

Contrary to the claims of populists, it must be acknowledged that medical resources are scarce.⁹ This implies that there is a need for a distribution criterion, because not every single demand for healthcare can be met. This criterion must be grounded in efficiency, as there is a moral duty to avoid the waste of scarce resources.

In the medical realm, a commonsensical approach to this issue focuses on properly assisting emergencies that neutralize life-threatening risks. Consequently, the survival rates of particular treatments are taken as given for adequate calculation in the allocation of resources. Thus, this criterion allows for life extension after the removal of life-threatening conditions. In this regard, a satisfactory allocation criterion must examine how many years of a patient's life a particular treatment is likely to contribute. Yet, survival and quantity of time cannot be the sole variable. Additionally, the adequate living standard after being discharged from the medical treatment must also be taken into account.

This combination of quantitative and qualitative aspects has been incorporated into the measure of Quality-Adjusted-Life-Year (QALY).¹⁰ The National Institute for Healthcare and Excellence (NICE) defines QALY as follows: "A measure of the state of health of a person or group in which the benefits, in terms of length of life, are adjusted to reflect the quality of life. One quality-adjusted life year (QALY) is equal to 1 year of life in perfect health. QALYs are calculated by estimating the years of life remaining for a patient following a particular treatment or intervention and weighting each year with a quality-of-life score (on a 0 to 1 scale). It is often measured in terms of the person's ability to carry out the activities of daily life, and freedom from pain and mental disturbance."¹¹

QALY is grounded in utilitarian philosophy. As conceived by its foremost defender, Jeremy Bentham, there is a moral imperative to promote "the greatest amount of good for the greatest amount of people."¹² Longevity is certainly part of that endeavor, as living is a good thing, and consequently, the longer a person lives, the more good they experience.

But some utilitarian philosophers have also recognized that in measuring goodness, there are other factors involved. For example, Derek Parfit famously acknowledges as much: "Suppose that I can choose between two futures. I could live for another 100 years, all of an extremely high quality. Call this the Century of Ecstasy. I could instead live forever, with a life that would always be barely worth living. Though there would be nothing bad in this life, the only good things would be muzak and potatoes. Call this the Drab Eternity. I believe that, of these two, the Century of Ecstasy would give me a better future." Parfit makes the point that, apart from the quantity of years, their quality must be considered.¹³

As applied to public health decisions, this approach allows policymakers to decide which medical intervention ought to be prioritized in terms of funding. Alan Williams, one of the formulators of the concepts, explains as much: "the essence of QALY is that it takes a year of healthy life expectancy to be worth one, but regards a year of unhealthy life expectancy as worth less than 1... The general idea is that a beneficial health care activity is one that generates a positive amount of QALYs, and that an efficient health care activity is one where the cost of QALY is as low as it can be. A high-priority health care activity is one where the cost-per-QALY is low, and a low-priority activity is one where cost-per-QALY is high."¹⁴

Ethical shortcomings of QALY

As presented above, QALY is a reasonable measure of efficiency in treatment. It helps public health policymakers decide which treatment is better suited to patients, and the healthcare system preserves its efficiency in doing so. There is a moral imperative to be altruistic, but it must be done efficiently. Therefore, the movement of "effective altruism" embraces QALY as a central concept. One of its main exponents, William Macaskill, explains the relevance of QALY as follows: "the same methods that were used to create the QALY could be used to measure the costs and benefits of pretty much anything... You can compare the impact of different activities in terms of how much and for how long they increase people's well-being."¹⁵

But there is a much somber aspect to QALY that is not as frequently discussed. QALY serves as a measure to decide not only which treatment to use but also what groups to treat. To the extent that QALY seeks efficiency, it decides that some patients who suffer particular diseases (or even worse, belong to particular demographic groups) ought not to receive treatment, because in so doing, they will take away efficiency from the whole, as their probability of improvement or extension of lifespan is low. With this premise, the road is paved for discrimination.

A key question policymakers and healthcare workers must ask is, when it comes to meeting the ethical obligation to offer medical treatment, should the numbers count? In a seminal essay titled “Should the Numbers Count?,” philosopher John Taurek famously answered in the negative.¹⁶ He makes the case that when it comes to the valuing of lives, quantitative considerations are irrelevant. *Prima facie*, all persons have equal moral worth, and therefore, they should all get the same opportunity to receive treatment, regardless of quantitative notions of efficiency.

Taurek considers the dilemma of distributing a drug that could save five people, or only David. QALY would dictate that the drug must be given to the five (assuming that, after being saved, all six would have the same number of quality-adjusted life years). But Taurek disagrees as follows: “If I gave my drug to the five persons and let David die, I cannot see that I would thereby have preserved anyone from suffering a loss greater than that I let David suffer. And, similarly, were I to give my drug to David and let the five die, I cannot see that I would thereby have allowed anyone to suffer a loss greater than the loss I spared David. Each person’s potential loss has the same significance to me, but only as a loss to that person alone. Because, by hypothesis, I have an equal concern for each person involved, I am moved to give each of them an equal chance to be spared his loss”. Taurek proposes that a more ethical solution in this dilemma is simply to flip a coin.

Taurek’s position has been extensively criticized,^{17,18,19} and it is sensible enough to admit that, at the end of the day, some appeal to numbers must be done. But the relentless and mechanical way in which QALY elicits such calculations warrants concern. For, in the name of efficiency, ultimately minorities are typically the ones unfavored by these decisions.

QALY has the great risk of removing the equality of moral worth that characterizes truly democratic societies. A democratic society cannot give preferential treatment to groups on the basis of ethnicity, gender, sexual orientation, and so forth. QALY does not do such a thing directly, but it certainly does so indirectly. QALY sets up a rigid social hierarchy, a caste system, so to speak. At the top are those who are eligible for treatment options, and who receive (in the form of subsidies and taxpayers’ funds) privileges from the entire society. At the bottom are those who are not eligible for treatment, and therefore, their lives are cut short. Viciously, this very fact further contributes to their illegibility for treatment, as a shorter life expectancy makes the QALY score ever lower. Ultimately, with QALY, not all people are created equal. They may be formally equal before the law, but some are certainly not equal in terms of their worth to public health officials.

The fundamental ethical shortcoming of QALY is that in its orientation toward numbers, it fails to value life itself. Consider two treatments that use the same amount of funds. In treatment A, the life of a 35-year-old man with a rare disease is saved. In treatment B, the erectile dysfunction of 200 35-year-old patients is successfully treated. Given the large amount of people in scenario B, QALY will probably be higher. Yet, it seems more sensible to admit that even with reduced QALY, choosing A is more ethically appropriate, as a life is being saved.

QALY also faces the unsurmountable problems of total utilitarianism, as typified by Derek Parfit in his much-discussed concept of the “repugnant conclusion.”²⁰ If adding QALY is all that counts, then a very efficient way of doing so is by massively increasing the world population, at the expense of treating people in old age. Given that the young require little investment in terms of healthcare, the most efficient way of increasing QALY is by massively adding young people to the world. Likewise, this efficiency is boosted by getting rid of the old, as they consume large amounts of healthcare resources, with diminishing returns. This is the ruthless utilitarian approach of QALY, which is ultimately more concerned with the value of numbers than with the value of life itself.

The discriminatory nature of QALY: Age, race, and disability

QALY is fundamentally ageist.²¹ While age is not a prime discriminatory factor in our modern societies, the elderly can still be considered a vulnerable minority.²² QALY augments the discrimination against them. Young people are at an unfair advantage with QALY, given that their higher health status makes them more likely to produce greater amounts of QALY when receiving treatments. Since QALY relies on

life expectancy, young people are privileged with this criterion. And the quality-of-life years also play a role, as young people are also significantly more likely to fully recover from interventions.

This has had the practical implications. For example, NICE has pursued a policy of not including drugs for dementia on the grounds that they are too expensive and do not provide sufficient QALYs, as compared to other treatments, to which funds are allocated.²³ Defenders of QALY often claim that this is not discrimination *per se*, as the disadvantages of the elderly are only a side-effect of the policy. But this is irrelevant. Whenever a particular group is disproportionately affected by a policy, it ought to be considered unjust, regardless of the policy's explicit intent.^{24,25,26} If a policy offers preferential treatment to young people over old people, ultimately that implies not valuing every life equally.

QALY's discrimination is also salient in terms of race and ethnicity. Groups with higher life expectancy receive preferential treatment, given that they are in a better position to maximize QALY.²⁷ This preferential treatment often falls along racial lines, with whites being offered treatment ahead of ethnic minorities.²⁸ To the extent that life expectancy is shorter among ethnic minorities,²⁹ they are excluded from the priorities.

However, it has been firmly established by research that social variables play a major role in life expectancy,^{30,31,32,33,34} and oppression and discrimination are central in this regard. Therefore, a vicious circle comes into effect. Systemic racism in society shortens life expectation of disadvantaged ethnic and racial groups. As per QALY standards, reduced life expectancy takes away priority in the allocation of resources.³⁵ Lack of medical assistance increases stress³⁶ and further decreases life expectancy,³⁷ causing minority ethnic groups to be further displaced in the order of priorities in QALY allocation.³⁸

Various commentators have noticed the double jeopardy situations that are entailed by QALY.^{39,40,41,42} John Harris discusses the case of a person who has suffered an accident: "QALYs dictate that because an individual is unfortunate, because she has once become a victim of disaster, we are required to visit upon her a second and perhaps graver misfortune. The first disaster leaves her with a poor quality of life and QALYs then require that in virtue of this she be ruled out as a candidate for lifesaving treatment, or at best, that she be given little or no chance of benefiting from what little amelioration her condition admits of. Her first disaster leaves her with a poor quality of life and when she presents herself for help, along come QALYs and finish her off!"⁴³

Racial discrimination operates in the same manner. Being part of a society that is systematically racist, racial and ethnic minorities are harmed once. Being victims of societal discrimination, they are left in a position with poor quality of life. In turn, as a result of the first harm, they are condemned to suffer a second harm: discrimination in the healthcare system.^{44,45,46} To paraphrase Harris, their discriminatory experiences leave them with a poor quality of life, and when they present themselves for help, along comes QALY and finishes them off. Surely the intention is not genocidal: it is unlikely that the designers of such policies intend to deliberately cut short the life expectancy of racial and ethnic minorities. But the effects are certainly perverse, to the extent that victims of racism suffer double jeopardy and must pay for the consequences of an initial act (discrimination's effects on health) for which they bear no responsibility.

The way treatments are tested for efficiency also reveals the racist dimension of QALY. In countries such as the United States, randomized control trials are mostly conducted with white participants, therefore presenting yet another disparity in healthcare.⁴⁷ In many trials, treatments do not render significant results. But it is crucial to keep in mind that the failure to produce significant results may occur because such treatments are tested with white subjects, when in fact, they could very well be efficient for ethnic minorities. Research has established that the performance of some treatments may vary across ethnic lines.^{48,49,50} However, most randomized control trials are conducted with white populations; and therefore, ethnic minorities are left unrepresented in such trials. As the National Minority Quality Forum explains, "if a particular therapy is effective for an African American population, but less effective for a Caucasian population, but the enrolled trial cohort is dominantly Caucasian, with African Americans under-represented, its average effect size demonstrated by the RCT will be small, and the therapy will have a lower chance of being approved."⁵¹

QALY is also a very ableist measure.⁵² From the onset, patients with particular chronic conditions are likely to not score a 1 in each year of life after a given treatment, given that their condition impedes them

from living with full quality of life. As in the example provided above with race, QALY is a form of double jeopardy, to the extent that victims of accidents (or some other harm-causing circumstance) are affected twice: by the original event, and by the refusal of healthcare.

In its approach to the disabled, QALY also clashes with a fundamental aspect of justice: giving priority to the worse off. This criterion has long been defended as integral to notions of fairness. In his defense of prioritarianism, Parfit explains that “benefiting people matters more the worse off these people are.”⁵³ The disabled are clearly the worse off and should therefore be given priority, yet QALY reverses this sensible approach to justice and places the disabled last in the order of priorities. In this aspect, prioritarianism has a major component of compassion⁵⁴ (a hallmark of medical ethics) that is lacking in QALY calculations.⁵⁵

Insights from John Rawls’ philosophy on the veil of ignorance also play a role.⁵⁶ No person in society can be assured that he or she is not vulnerable to any event that causes disability. Consequently, acting as if there were a veil of ignorance (i.e., designing rules and procedures without knowing in advance the specifics of those to be benefited), there is the ethical duty to anticipate that any person (regardless of gender, class, ethnicity, sexual orientation, etc.) who suffers a disability must be given proper care, as any of us could be disabled at some point.

QALY also has a corrosive effect on the equality of opportunities in its treatment of disabled persons.⁵⁷ Brock explains that “disabilities, understood as conditions that substantially limit one or more major life activity of persons, will by definition reduce individuals’ opportunity from that which otherwise similar non-disabled persons enjoy, and thereby deny them equality of opportunity with non-disabled individuals.”⁵⁸ A major ethical imperative in healthcare is to attempt to reestablish such equality of opportunity, or at least to try to counter its diminishment.^{59,60,61,62} Yet by relegating the disabled to the bottom of the list, QALY erodes equality of opportunity for the disabled, as they are impeded from getting a head start that would compensate for their initial disadvantage.

The use of QALY measures interferes with the disabled persons’ opportunity to reach their full potential in their life cycle. Having a disability is by no means an insurmountable obstacle to leading meaningful lives.^{63,64} There is a pernicious bias in the assumption that people with disabilities perceive their happiness to be diminished on account of their disabilities. Disabled persons are fully capable of living fulfilling lives. Yet, disabled persons cannot fully reach their potential if they are denied healthcare assistance from the onset.

As the theory of intersectionality would predict, discriminatory factors are rarely isolated.⁶⁵ Admittedly, given that age is not a fixed variable, ageism does not correlate with racism and ableism. But ableism and racism do correlate.^{66,67,68} Given the large role played by social determinants in health outcomes, ethnic minorities are overrepresented in chronic conditions and disability. Consequently, QALY doubly discriminates against them.

Conclusion

Resource allocation is an integral part of medical ethics, and a meaningful criterion must be sought. Pace Taurek’s philosophical musings, it cannot be simply left to the toss of a coin. Numbers should indeed count. But the way numbers are currently counted warrants ethical concern.

Additional considerations must be in place. First and foremost, the intrinsic value of life. This entails that the priority in healthcare ought to be the saving of lives, and in this endeavor, notions of cost efficiency should not be at the forefront. As John Harris meaningfully states, “the obligation to save as many lives as possible is not the obligation to save as many lives as we can cheaply or economically save”.

Saving the lives of discriminated minorities may indeed be less cost-efficient. However, this in no way relieves us of our ethical duty to do so. Their treatment is less cost-efficient through no fault of their own. If anything, the decreased cost-efficiency is a harm that society has done to them, on account of ableism and racism. That harm must be restituted through medical assistance; refusing healthcare by appealing to QALY is to further inflict harm.

In our times, discrimination in healthcare may be subtler, but the constant appeal to QALY makes it very pernicious. QALY is a seemingly egalitarian approach, to the extent that it does not allocate resources on the basis of race, gender, or ethnicity. However, ultimately, its effects are very discriminatory, targeting the most disadvantaged members of society. QALY was a well-intentioned and meaningful attempt to tackle the ever-present problem of healthcare resource scarcity. However, its ethical shortcomings are considerable, and they must be further discussed to arrive at more sensible ethical solutions.

Competing interest. The authors declare none.

Notes

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