

Bubbles under the wallpaper: healthcare rationing and discrimination

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It is common to allocate scarce health care resources by maximizing QALYs per dollar. This approach has been attacked by disability-rights advocates, policy-makers, and ethicists on the grounds that it unjustly discriminates against the disabled. The main complaint is that the QALY-maximizing approach implies a seemingly unsatisfactory conclusion: other things being equal, we should direct life-saving treatment to the healthy rather than the disabled. This argument pays insufficient attention to the downsides of the potential alternatives. We show that this sort of discrimination is one of four unpalatable consequences that *any* approach to priority setting in health care must face. We argue that, given the alternatives, it is far from clear that we should revise the QALY-maximizing approach in response to this objection.

The ethics of priority setting in public health is both difficult and crucial. It involves hard questions about life and death on a scale that ranges from choices for individual patients to health strategies for the entire world's population. The problems arise because we simply do not have enough resources to provide everyone with all the medical care they need. We must therefore make seemingly impossible choices.

Over the last forty years, a standard has emerged for facing such choices: the QALY approach. A *Quality Adjusted Life Year (QALY)* is a unit for measuring the gains from medical interventions and is designed to be equivalent to the health gained by saving a year of life at full health. To determine how many QALYs are gained by a medical intervention, one looks at the length and (health-related) quality of a person's remaining lifespan, both with and without the intervention. The length is measured in years, and the quality at a given time is assigned a weight between 0 and 1, where 1 is full health and 0 is a quality of life equivalent to death. The length of life is multiplied by the weight, so that (for example) ten years of life at full health is worth 10 QALYs, as is 20 years of life with a condition that has a quality of life weighting of 0.5 (a weighting commonly assigned to blindness). Once a QALY value is assigned to the person's future with the intervention and to their future without it, the difference between these is the gain due to the intervention. This method can thus measure benefits gained through the extension of life, as well as through the improvement of one's quality of life, or combinations of the two.

The QALY approach to priority setting is, roughly speaking, to rank all possible health interventions in terms of the ratio of QALYs gained to dollars spent and then to fund these interventions in order of their cost-effectiveness. This approach has a clear and important rationale: given a fixed health budget, it leads to the largest possible health gains. As such, it has been very successful in terms of promoting

aggregate health.¹

However, some ethicists and policy makers are concerned that the QALY approach achieves these gains in health at the expense of justice. For while it is uncontroversial that one gains in health by extending one's life, or by raising the health-related quality of a given period of one's life, the QALY approach also produces a seemingly unsatisfactory conclusion: since a healthy person gains more QALYs from having their life extended than does a person with a disability, other things being equal, we should save the life of a healthy person over that of a disabled person. This objection has been forcibly made by John Harris (who described it as 'double jeopardy' for the disabled),² and it rose to national prominence in the United States after attempts to use the QALY approach in the state of Oregon were overturned on anti-discrimination grounds.³

The status of this objection is thus of key importance with respect to priority setting in health care. Is the current approach unjust? If so, should we make large sacrifices in terms of aggregate health in order to remedy it? Or does the objection rest on a mistake, in which case these large sacrifices would be in vain?

Bubbles under the wallpaper

Attempts to resolve this problem have not met with great success. A solution favored by Erik Nord and others, involves ignoring quality-weights when deciding to whom we should give a life-saving treatment, provided the people to be saved regard their lives as worth living.⁴ As Magnus Johannesson has pointed out,⁵ Nord's proposal would sometimes conflict with individual preferences: it would sometimes rank one treatment higher than another, though this would be worse for someone and better for no one. Johannesson offers his own proposal, which also faces devastating objections.⁶ In looking at such proposals, one gets the feeling that the task may be like trying to get a bubble out from behind the wallpaper; pushing down in one place simply moves the bubble elsewhere.

¹ Here we are setting aside some important issues. For example, the QALY system will only maximize health gains if the weights are appropriately chosen. In practice, this can be difficult. But this is orthogonal to the issues that we discuss here. For the sake of argument, we assume that we are dealing with a system with reasonably chosen weights.

² (Harris 1987). See (Singer *et al* 1995) for a response to Harris.

³ For more on the Oregon cost-setting exercise, see (Hadorn 1991).

⁴ (Nord *et al* 1999).

⁵ (Johannesson 2001).

⁶ (Nord *et al* 2003).

In this paper, we confirm this intuition by showing that *any* attempt to set priorities in health will face a highly counter-intuitive conclusion, often one of the counter-intuitive conclusions that people have tried to avoid in the above cases.⁷ To see how this works, consider the following simplified case:⁸

Example

Alice and Beth were both perfectly healthy 20-year-olds, but have recently contracted an unusual disease. This disease will kill them very soon unless treated, and even then they will suffer from serious complications, such as blindness and/or a reduced lifespan. To make matters worse, there are not enough resources to treat them both. There are, however three possible treatment options outlined in the table below:

	<i>Option X</i>	<i>Option Y</i>	<i>Option Z</i>
Alice	45 years (blind)	–	–
Beth	–	60 years (blind)	35 years (full health)

In X, Alice is treated and will live for 45 years but will lose her sight. Because Beth was infected by a slightly weaker strain, there are two treatment options available to her: in Y, she will live for 60 years but will lose her sight, in Z she will live for only 35 years, but will retain her sight. Beth has been asked which of options Y and Z she prefers, and (after considerable research and reflection) she arrived at a strong preference for 35 years of life with full health over 60 years of life with blindness (this is in line with most people’s preferences and with the commonly used QALY ratings).

Which of these options should we choose? Let us first consider them pair-wise: in other words, which would we choose if it were a choice between only X and Y, only Y and Z, or only X and Z. We will then see that there are three problems that we would like to avoid:

⁷ In an economist's vocabulary, we do this by establishing an *impossibility theorem*. We show that certain intuitively inevitable constraints on a fair system for prioritizing health are impossible to meet.

⁸ Note that in this case there is no pre-existing disability. In such cases, prioritarian and egalitarian adjustments to the QALY framework make no significant difference to which option is chosen.

Some might argue that, in this kind of case, there is nothing wrong with favoring the healthy over the blind. To address this point, we could change the case so that Alice became blind five years ago. Our analysis of the revised case would remain the same.

(1) *Preference for Smaller Benefits*

X produces a smaller benefit for Alice than Y does for Beth. Since there is nothing else to distinguish between the two people, choosing X over Y demonstrates a morally perverse preference for producing smaller benefits rather than larger ones.

(2) *Pointless Violation of Autonomy*

Y is worse than Z for Beth and they are equally bad for Alice. Choosing Y over Z thus involves violating Beth's autonomy for no gain at all (in fact, to produce what she and experts both regard as a worse outcome).

(3) *Disability Discrimination*

Z provides fewer years of life for Beth than X provides for Alice. The only thing Z has in its favour is that Beth would be at full health, whereas X would leave Alice with a disability. Thus, choosing Z over X involves discriminating on the grounds of disability.

We are thus left with a cycle of preferences: we must choose Y over X in order to avoid *Preference for Smaller Benefits*, we must choose Z over Y to avoid *Pointless Violation of Autonomy*, and we must choose X over Z to avoid *Disability Discrimination*.⁹ However, this puts us in a very precarious position. Having cyclic preferences opens one up to so-called 'money pump' arguments. For example, consider the following. If you think it is important to choose Y over X given a choice between the two, then presumably you would be prepared to sacrifice something — at least a single penny — to choose Y in such a case. Similarly if you think the same thing between Y and Z, and between Z and X then you would be prepared to pay a penny to transfer in each of these cases. But this would leave you back where you began: with option X and slightly less money. Moreover, you would still be prepared to trade a penny to move from X to Y and could be made to go around this cycle until you had very little money remaining. Of course it is not just money that can be 'pumped' but anything of value.¹⁰

We could thus add a fourth problem:

⁹ Note that we are using the term 'cyclic preferences' in a broad sense, referring both to cycles of preferences within a given set of option, and cycles of preferences across sets of options (such as the present case).

¹⁰ The status of money pump arguments is somewhat controversial. Sometimes they are used to argue that rational people do not have cyclic preferences. In that context, it is assumed that rational people always choose A over B when they prefer A to B. But someone who believes in the rationality of cyclic preferences may deny this, pointing to cases of strategic reasoning that appear to be counterexamples to this generalization.

We need not settle this issue here. What's true is that if policy-makers want to set health care priorities using a ranking system that they can follow in general, the ranking system will be susceptible to a money pump if the ranking is cyclic.

(4) *Cyclic Preferences*

Choosing Y over X , Z over Y , and X over Z , is an example of cyclic preferences, which violate the conditions of rational choice theory and leave one open to irrational behaviour such as money pumping.

It can be easily seen that any way of ranking health outcomes will therefore satisfy one of these four undesirable conditions. Given this conclusion, we must give up on producing a system of priority setting that avoids these problems and learn to live with the least of the evils, whichever it may be.

A rights based approach?

When confronted with this problem, it may seem natural to reach for a certain kind of rights-based approach. On this approach, when we have equally expensive treatments but can save only one person's life, the person who stands to gain the most life-years (ignoring any quality adjustments) is awarded the right to treatment. The person may then select the treatment that she most prefers to receive, under the advisement of her doctor.

Thus, if the choices are X and Z , Alice would be awarded the right to treatment and we would choose option X . Whereas if option Y were also available, Beth would receive the right to treatment, and since she prefers option Z to option Y , we would choose option Z .

In this section, we show that this approach faces considerable difficulties. These difficulties arise because the approach suffers from *Cyclic Preferences*. Objections of this kind can be extended to other theories that suffer from *Cyclic Preferences*, so the section can also be viewed as a way of illustrating the problems associated with embracing *Cyclic Preferences*.

To see that this approach suffers from *Cyclic Preferences* but avoids (1)-(3), note that in pairwise cases, it chooses Y over X , Z over Y , and X over Z . The rights based approach therefore cannot be applied across all individual cases without leaving the decision maker open to being money pumped. This is unlikely to arise in practice, but casts doubt upon the rationality of the approach.

Cyclic Preferences also lead to another strange problem for the rights based approach. Note that the rights-based approach chooses X out of the options X and Z , but when Y is added to the set of options, it switches its choice to Z . In decision theory, this is known as violating the *Independence of Irrelevant Alternatives*.¹¹ This violation may not seem like a deep defect: after all, it emerges naturally from a seemingly reasonable system of rights, and partially as a result of the autonomous choice of individuals.

¹¹ This strange feature arises directly from the *Cyclic Preferences*: one cannot stabilise a cyclic system of preferences in the case where all three options are presented at once without violating the Independence of Irrelevant Alternatives.

However, if we extend the example, we can see cases where this violation of the Independence of Irrelevant Alternatives seems particularly unreasonable.

First, let us add a few details to the Alice and Beth case. Suppose that for each treatment (X , Y , or Z) that could be delivered, there is a corresponding vial of medicine which must be administered. After this, the patient must receive a very uncommon medicine, of which the clinic has only a single dose. Following the rights based approach, the doctor decides on option Z , so he walks over to the table and selects vial Z , then fills a syringe with it. Just as he is about to inject Beth with this medicine, he hears a small crash: vial Y has just fallen off the table and shattered, making treatment Y unavailable. The doctor then realises that it would now be wrong to give treatment Z , as it has become a choice between only X and Z , so he goes back to the table and fills a syringe from vial X to give to Alice instead.

There is something very odd about this behaviour. This example brings the dependence on irrelevant alternatives to the fore and casts doubt upon whether the rights based approach is a reasonable protocol.

Alternatively, consider a case in which the doctor knows that they have treatment X and Z available, but can't remember whether they have any of treatment Y . In this case, the doctor is uncertain of which is the right treatment to deliver. If Y is available, he must administer treatment Z to Beth (to avoid a *Pointless Violation of Autonomy*), but if it is not, then he must administer X to Alice (to avoid *Disability Discrimination*). Since these are both weighty problems that adherents to the rights based approach wants to avoid, it is thus imperative for the doctor to spend some time searching the clinic to see if Y is available, or perhaps telephoning suppliers, even though he will not actually use it. More extreme examples could be constructed if the doctor would need to run moderately expensive tests in order to see if option Y was available or not.

Finally, consider a case in which we can help either Charles or Dan. They are both healthy 20-year-olds who were struck by a similar disease to Alice and Beth. To begin with, suppose that there are two options, P and Q , where P involves giving Charles 10 more years to live at full health and Q involves giving Dan 12 more years to live, but he would lose his sight. In this case, the rights based approach would suggest treating Dan.

	<i>Option P</i>	<i>Option Q</i>	<i>Option R</i>	<i>Option S</i>	...
Charles	10 years (full health)	–	14 years (blind)	–	...
Dan	–	12 years (blind)		16 years (blind & deaf)	...

But now suppose that there was a third option, R , in which Charles could live for 14 years at the expense of being blind. Like most people, Charles does not prefer this to 10 years at full health, but if Option R is available, then the rights based approach recommends treating Charles. Now suppose there is a fourth option, S , where Dan

could live for 16 years but would be both blind and deaf. Dan does not prefer this to 12 years with blindness and hearing, but now the rights based approach would recommend treating Dan. Notice that we are now deciding between P and Q (which are the only options that will conceivably be chosen) on the basis of R and S . One could imagine a long sequence of increasingly irrelevant alternatives, the existence of which keeps swinging the balance between P and Q . Moreover, as it is very important on this view whether such options exist, we would often be required to spend some time and money investigating whether such options exist before making our decisions.

We thus find that the rights based approach looks increasingly unreasonable. As noted above, these examples can be extended to other theories that possess *Cyclic Preferences*, thereby demonstrating how important it is for a theory to avoid this problem.

Randomness to the rescue?

Many philosophers are convinced on independent grounds that fairness requires us to leave some of our most important decisions up to chance, so it is natural to wonder whether a move to lotteries could resolve the present problem. The purpose of a lottery system is to give each person a fair chance of being treated — where this may be an equal chance or a chance weighted by how much the person involved stands to gain.¹²

Although lotteries may seem like a sensible solution in a case where we must allocate treatments to a small number of individuals in the same hospital, they seem less sensible as a general approach to priority setting. Given the numbers of people affected, we are most concerned with getting global priorities right. On that note, it is hard to believe that the government should draw numbers in order to decide which kinds of medical research to fund, which kinds of doctors to hire, or which kinds of treatments are worth funding. We won't pretend to have established that lotteries are unreasonable in this setting, but we note that randomness does not look like promising as a solution to our problem, at least on the most important level.

However, even in its most plausible application, a lottery approach affords no traction on our problem. To defend this claim, we can give an argument that is highly analogous to the one given earlier. The first step is simply to use analogues of (1)–(3) that apply to gambles. In this case, we'd like to avoid policies that have any of the following three undesirable properties:

¹² (Broome 1984).

(1*) *Preference for Smaller Benefits**

When the potential treatments are X and Y , the policy allows Alice at least a great a chance as Beth even though Alice and Beth are equally healthy and Beth would live for an additional 15 years.¹³

(2*) *Pointless Violation of Autonomy**

When the potential treatments include Y and Z , the policy allocates a non-zero probability to Y , even though Beth prefers treatment Z and Beth's favored treatment would come at no one else's expense.

(3*) *Disability Discrimination**

When the potential treatments are X and Z , the policy demands a lottery over X and Z that gives Beth at least a great a chance as Alice, even though (i) Beth stands to gain fewer years of life and (ii) we would favor Alice if she were not disabled.¹⁴

In the previous section, avoiding (1)–(3) required having cyclic preferences over X , Y , and Z . Here, we replace that cyclic ranking with another. In this case the relation “ A merits more probability than B , when the choices are A and B ” turns out to be cyclic. To avoid *Preference for Smaller Benefits**, we must give Y more probability than X . To avoid *Pointless Violation of Autonomy**, we must give Z more probability than Y . To avoid *Disability Discrimination**, we must give X more probability than Z . That this relation could be cyclic is strange in itself. More importantly, it seems that we are dealing with the same problem all over again. Intuitively, treatment A should get more probability than treatment B only if we should prefer that treatment A be given rather than that treatment B be given. And, for the reasons noted above, we should not have cyclic preferences.

In case it seems that the problem just noted can somehow be avoided, note that it is impossible to satisfy (1*)–(3*) if we want to avoid a policy with the following undesirable (disjunctive) property:

¹³ Some people may be tempted to think that it isn't so bad to satisfy *Preference for Smaller Benefits** on the grounds that a fair coin toss is the appropriate response to this case. We think that a difference of 15 years should be enough to make this implausible. We could adjust the case by choosing a more debilitating condition and allowing an even larger gap in years. For this solution to work in general, one must be willing to do fair coin tosses even when the difference in benefits could be very great. We find this idea absurd; it is anathema to the very idea of priority setting in health care.

¹⁴ To avoid *Disability Discrimination** one must give Alice a greater chance of being treated when the choices are X and Z (equal chances would not be allowed). We can run a version of our argument using another version of this requirement that allows giving each person an equal chance in this situation. To see this, note that we make use of a weak inequality rather than a strict one in line 6 of the proof in the next footnote.

(4*) *Dependence on Irrelevant Treatments**

a. The policy allows that adding a potential treatment for one person could decrease her odds of being treated. Intuitively, it would be unfair (and bizarre) to decrease a person's odds of being treated on the grounds that additional possible ways of curing that person (and no one else) were discovered, or

b. The policy allows that adding a potential treatment for one person could decrease another person's chances of being treated, even though the first person prefers an alternative treatment that is already available. Intuitively, the person whose chances decrease could complain that she was being given a lesser chance for irrelevant reasons.

We relegate the proof that it is impossible to avoid all of (1*)–(4*) to a footnote, since the argument is slightly more technical than the previous one.¹⁵ The basic problem is that any lottery system that avoids *Preference for Smaller Benefits**, *Pointless Violation of Autonomy**, and *Dependence on Irrelevant Treatments** will give more probability to Z than X when the choices are X, Y, and Z. On the other hand, any lottery system that avoids *Disability Discrimination** and *Dependence on Irrelevant Treatments** will give at least as much probability to X as it does to Z. It is not possible to have both.

This result about lotteries can be viewed as a generalization of our original argument. Whatever the merits of randomization elsewhere, a move to lotteries cannot solve the present problem.

¹⁵ We proceed by assuming the four conditions do not hold and deriving a contradiction. For some simplifying notation, let $\Pr(A:ABC)$ be the probability assigned by a lottery to A when the alternatives are A, B, and C. Likewise, $\Pr(B:BC)$ is the probability assigned to B when the alternatives are B and C. Then we can argue as follows:

1. $\Pr(Y:XY) > \Pr(X:XY)$ to avoid *Preference for Smaller Benefits**
2. $\Pr(Y \text{ or } Z:XYZ) > \Pr(X:XYZ)$ to avoid *Dependence on Irrelevant Treatments** and satisfy 1
3. $\Pr(Y:XYZ) = 0$ to avoid *Pointless Violation of Autonomy**
4. $\Pr(Z:XYZ) = \Pr(Y \text{ or } Z:XYZ)$ from 3 and probability theory
5. $\Pr(Z:XYZ) > \Pr(X:XYZ)$ from 2 and 4
6. $\Pr(X:XZ) \geq \Pr(Z:XZ)$ to avoid *Disability Discrimination**
7. $\Pr(X:XYZ) \geq \Pr(Z:XYZ)$ to avoid *Dependence on Irrelevant Treatments** and to satisfy 6
8. contradiction! from 5 and 7

Conclusion

We have shown that it is impossible for a moral theory to provide guidance in multi-person trade-offs between length of life and quality of life without facing one of four very challenging conclusions. Of these, we think that the ones most likely to be accepted are *Disability Discrimination* and *Cyclic Preferences*. Thus, while we have not explicitly argued in favour of the QALY approach and its controversial applications in situations with respect to life-saving treatment for the disabled, we have shown it to be substantially more plausible in light of the challenges faced by all of its competitors. This makes it a lot less clear that we should change the QALY system and thereby throw away the great health gains it has achieved.

We should also note, in passing, that the specific issues addressed here are part of a wider problem in the discourse on ethical theories. Some systems, such as the QALY approach, make their consequences clearly known in advance, making them easy targets for attack by intuitive counterexample. A single, confidently held, pre-theoretic judgment is often regarded as enough to reject such a position. Incomplete competitors frequently avoid this challenge because it is usually hard to see that what problems an incomplete alternative will face.. In the present case we were able to produce an argument that applies to *all* competitors to the QALY approach, getting around the issue of underspecification, but unfortunately this is not always possible. Proponents of highly incomplete ethical positions must be careful when challenging more systematic competitors; the next impossibility argument may be around the corner, even if no one has been clever enough to discover it yet.

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