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Ethical Challenges in Using DALYs to Inform Health Interventions: Some Lessons from Population Ethics

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Mimir Center is a project at the Institute for Futures Studies which charts paths to possible futures and provides early insights into topics that have long term importance.

1. Introduction

The Global Burden of Disease Study (GBDS) is an international and interdisciplinary effort to quantify health losses from a wide array of diseases and disabilities (Murray and Lopez 2013). These losses are expressed in units of disability-adjusted life-years (DALYS). The DALY is potentially useful for quantifying health loss because it integrates mortality and morbidity into a single metric. Health loss due to mortality is expressed in years of life lost (YLL) while health loss due to morbidity is expressed in years lived with disability (YLD). More accurately, YLD is meant to capture health that is lost during years lived with disability. Health loss during these years is determined by comparing a disabled person's health state to a reference point, which is "full health", or the state of living without disability (more on this below). The total number of DALYs is then derived as the sum of all YLL and all YLD. In the global health community, the total number of DALYs aggregated across the global population is called the global burden of disease.

In addition to quantifying health loss, the DALY can potentially be used to inform health policy (Murray and Acharya 1997; Lyttkens 2003; Arnesen and Kapiriri 2004). Estimates of the effectiveness of a health intervention can be expressed as the number of DALYs-averted, i.e. the number of DALYs the intervention would prevent. A cost-effectiveness estimate can then be given in terms of DALYs-averted per dollar spent to implement the intervention. In principle, such cost-effectiveness estimates would enable policy makers to set priorities in global health, the idea being to fund interventions in a way that minimizes DALYs (or maximizes DALYs-averted).

Recently, the GBDS has been extended to evaluate future threats to global health, from causes such as climate change, pandemics, and political conflicts (Kanem, Murray, and Horton 2023). The Lancet Commission on 21st Century Global Threats to Health has been established as an independent voice to call attention to these risks. The commission will assess the magnitudes of potential threats in terms of DALYs, and will also consider what interventions to reduce these threats might be deemed effective. Compared to past work of the GBDS, the Lancet Commission's task is broader in scope, focusing on the entire 21st century, and including the evaluation of threats of human extinction.

This paper focuses on a set of problems for using DALYs-averted as a measure of effectiveness for health interventions. These problems come from population ethics, the part of ethics that is concerned with formulating an adequate theory of the goodness, or choiceworthiness, of populations in which "the number of people, their welfare, and their identities may vary" (Arrhenius and Campbell 2018, 54). Such a theory would provide an ordering of populations with respect to goodness or choiceworthiness, and could be used to inform population policy. However, as is well-known among population ethicists, all general theories in this area face serious difficulties (Arrhenius 2011, 2016, forthcoming). I will show that similar difficulties arise for attempts to justify the use of DALYs-averted to measure the effectiveness of health interventions. I will review three candidate moral justifications for measuring the effectiveness of health interventions in DALYs-averted. For each justification, I show that it faces a problem akin to one that arises in population ethics. The upshot is that where health interventions would change the number or the identities of people in the global population, problems of population ethics will be inherited, in some form, by a general

ethics of priority-setting in global health. However, the third justification I will consider is the only one that plausibly captures the normative significance of interventions to avert human extinction. For this reason, it is best suited for the Lancet Commission's purpose of evaluating a wide range of threats that include threats of human extinction.

Section 1 explains in further detail what DALYs are and how they function. Sections 2—4 consider the three different justifications for measuring effectiveness of health interventions in DALYs-averted, demonstrating how each justification faces one of the problems in population ethics. Section 5 explains why the third justification, despite the problems it faces, is best suited for evaluating interventions to avert extinction. Section 6 concludes.

2. Details About DALYs

As stated above, the DALY incorporates both years of life lost and years lived with disability. To quantify years of life lost from a single death, one subtracts the age at which the individual dies from the life-expectancy at that age. Rather than use actual age-relative life-expectancies for this purpose, it is common to use a standardized life-expectancy. In the Global Burden of Disease Study (GBDS) 2015, the standardized life-expectancy is 86.6 years (Wang et al. 2016). This number is derived by looking at the lowest observed mortality rates across several different global populations, and may be thought of as "the ideal" life-expectancy—the age to which any individual could (in principle) be expected to live if she were to live completely free of disability.[1] The DALY is therefore a measure of health shortfall.

If the ideal life-expectancy is 86.6, the death of a newborn (aged 0) contributes 86.6 years of life lost, and hence, 86.6 DALYs to the global burden of disease, the death of a young adult aged 20 contributes 66.6 DALYs, etc.

The GBDS 2015 assumes that all years of life lost is given equal weight—each contributes one DALY. However, not all years lived with disability are treated the same; some disabilities are considered worse than others. For example, the health state associated with Tuberculosis with HIV infection is considered worse than the health state associated with Tuberculosis without HIV infection. To account for such differences between health states, the Global Burden of Disease Project makes use of disability-weights. These are numbers ranging from 0 (representing a state of perfect health) to 1 (representing a state of being dead). Different disabilities are assigned different disability weights—the greater the weight, the greater the health loss associated with the disability. For example, in the GBDS 2010, the health state associated with Tuberculosis without HIV infection has a disability-weight of 0.331, whereas the health state associated with Tuberculosis with HIV infection has a disability-weight of 0.399 (Salomon et al. 2012, Appendix 21, Table 3). Ten years of life in the latter state generates 3.99 DALYs, while ten years of life in the former generates only 3.31 DALYs. DALYs are thus used to compare health losses from different disabilities, and to compare health losses from disability with those from premature death.

[1] The assumption of an ideal life-expectancy is controversial for many reasons that I will not consider here. For criticism, see Bonneux (2002).

But why should the effectiveness of a health intervention be understood in terms of minimizing DALYs? Why should the aim of health policy be to minimize total health loss? In the following three sections, I consider three different candidate justifications, each of which faces its own difficulties.

3. The Individual Improvement Justification

According to what I call *the Individual Improvement Justification* (IIJ), a health intervention is effective to the extent that it improves the health states of particular individuals, and this extent is measured by the number of DALYs-averted by the intervention. When an intervention improves the health state of a particular individual, it causes this individual to be in a health state that is better (i.e., closer to the ideal life-expectancy) than the health state she would have without the intervention. In other words, it involves comparisons of two different possible health states of a single individual—the health state she would have given the intervention, and the health state she would have in the absence of the intervention. If the intervention improves the health state of an individual, it makes that individual *better off* (at least with respect to health) than she would otherwise have been.[2] The improvement in the overall health of the population is then treated as the sum of all individual health improvements (minus any individual health diminishments). The more DALYs-averted, the greater the overall improvement in gobal health.

IIJ is simple and intuitive. It reflects the plausible claim that the goal of health policy should be to improve the health states of as *many people* as possible *as much* as possible. It also reflects a certain ideal of beneficence, that of making individuals better off than they would otherwise be.[3]

However, IIJ seems to go wrong when policy decisions affect not only the health states of individuals, but also which particular individuals exist. In such cases, IIJ faces a problem related to *The Non-Identity Problem* in population ethics.

The Non-Identity Problem was originally named and introduced into the literature by Derek Parfit (1984, 351—360). It can be illustrated using an example in public health.[4] In 2015, there was an outbreak of the Zika virus in Brazil. Zika can cause the offspring of pregnant women infected to develop microcephaly, a condition that causes underdeveloped brains and small heads. In Brazil, from 2010 to 2015, there were roughly 200 reported cases of microcephaly per year. During the epidemic, between November 2015 and February 2016, that number rose to 5,280 (de Araujo et al. 2016).

Microcephaly causes infant mortality and can curtail the life-expectancy of those who survive beyond infancy. Moreover, those with microcephaly live in a state of *severe intellectual disability* with an associated disability weight of 0.16 (Salomon et al. 2015). Alfaro-Murillo et al. (2016) estimate that, on average, a case of microcephaly in Brazil during the Zika epidemic generated roughly 30 DALYs. The increased incidence of microcephaly in Brazil during this time may have generated hundreds of thousands of DALYs.

[2] For discussion of this type of justification, see Goodin (1988: 20–22).

[3] On theories of beneficence, see Parfit (1984), Part IV.

[4] The example that I discuss here has been raised in connection with the Non-Identity Problem by Beard (2016).

In response to the Zika epidemic, governments, corporations, and non-profits tried to delay the timing of conception of new children. One example of this was the formation of the Zika Contraception Access Network, a network of partnerships between health care providers to reduce the incidence of microcephaly by providing contraceptive counselling and free reversable contraception to women in Puerto Rico who chose to delay their pregnancies until after 2017 (Lathrop et al. 2018). The Centers for Disease Control and Prevention advised couples travelling to areas with risk of infection to delay conception by at least three months after their travels. And they advised those living in areas with Zika to follow similar timetables should they become infected with the virus (CDC 2016).

Such interventions may have averted many DALYs. But it is hard to see how they could have improved the health state of any child, in the sense of bringing about a health state for this child that is better than the one she would otherwise have had. If the interventions were successful, this is because they resulted in the existence of healthy children who would not otherwise have existed, and because they prevented the existence of microcephalic children. In other words, the interventions, if successful, replaced certain less healthy individuals with certain healthier ones. As Parfit (1984) states, "If any particular person had not been conceived within a month of the time when he was in fact conceived, he would in fact never have existed" (1984: 352). He arrives at this conclusion by the following reasoning: Each person develops from a particular ovum and a particular spermatozoon. Now consider any actual person, for example Maya Angelou. Suppose that rather than conceiving Maya Angelou at the time when she was in fact conceived, her parents had instead conceived a child more than one month later. In that case, the ovum and spermatozoon from which this later child would have developed would not have been the ovum and spermatozoon from which Maya Angelou in fact developed. A different spermatozoon would have fertilized a different ovum. The result would have been a person whose causal origins, experiences, physiology, and psychology would have been different; it would have been a *different person*—someone other than Maya Angelou—even if this person had been given *the name* 'Maya Angelou'.

If the actual timing of her conception had been delayed by more than a month, Maya Angelou would not have existed. This reasoning seems to apply to all actual cases of conception.

The upshot for IIJ is this. If we measure the health benefits of the interventions described above in DALYs-averted, our justification cannot be that the number of DALYs-averted reflects the extent to which the interventions improved the health states of particular individuals—giving them a better rather than a worse health state.

This exposes a general problem for IIJ. Sometimes, the gains from a health intervention, understood in terms of DALYs-averted, do not correspond to improvements in anyone's health state. The problem is general because, as Parfit also realised, most if not all interventions at the level of policy change who will exist in the future, assuming the effects of these policies are wide reaching:

> It is not true that, whichever policy we choose, the same particular people will exist in the further future. Given the effects of two such policies on the details of our lives, it would increasingly over time be true that, on the different policies, people married different people. And, even in the same marriages, the children would increasingly over time be conceived at different times. … [C]hildren conceived more than a

> month earlier or later would in fact be different children. Since the choice between our two policies would affect the timing of later conceptions, some of the people who are later born would owe their existence to our choice of one of the two policies. If we had chosen the other policy, these particular people would never have existed. And the proportion of those later born who owe their existence to our choice would, like ripples in a pool, steadily grow. We can plausibly assume that, after one or two centuries, there would be no one living in our community who would have been born whichever policy we chose. (It may help to think about this question: how many of us could truly claim, 'Even if railways and motor cars had never been invented, I would still have been born'?) (1984, 361)

If we think that large-scale (and even some small-scale) interventions make a difference to which individuals exist, then we cannot simply assume that all of the health benefits of these interventions, expressed in terms of DALYs-averted, come from improving the health states of particular individuals. For this reason, if we wish to provide a general justification of the use of DALYs-averted as a measure of effectiveness, we must reject IIJ.

4. The Ideal Health Justification

The next justification we will consider avoids the objection to IIJ. Recall that the Global Burden of Disease Project assumes an ideal health standard for an individual—the ideal age to which an individual could be expected to live if she had no negative health effects. The notion of an ideal health standard has also been applied to the global population as a whole. The World Health Organization (WHO) claims that DALYs measure the health gap between the actual global population and "an ideal health situation in which everyone lives to an advanced age, free of disability and disease" (WHO). One justification for measuring effectiveness in DALYs-averted builds on this idea of "an ideal health situation". According to what I call *the Ideal Health Justification* (IHJ), measuring the effectiveness of a health intervention in DALYs-averted is justified because it reflects the extent to which the intervention brings us closer to an ideal health situation in which everyone lives to an advanced age free of disability. If DALYs measure the health gap between the actual population and a hypothetical population in an ideal health situation, then DALYs-averted measure the extent to which a health intervention closes (or narrows) this gap. According to IHJ, the aim of health policy is not to improve the health of as many people as possible, as much as possible, but to come as close as possible to an ideal health situation, *regardless of which particular individuals exist*.

The IHJ avoids the non-identity problem because replacing a less healthy individual with a healthier one reduces the extent to which individuals fall short of the ideal standard of health for individuals, thus bringing the population *closer* to the ideal health situation.

However, IHJ faces a different problem, which originates in population ethics. According to IHJ, health interventions are justified when they prevent the existence of individuals who fall short of the ideal health standard. The vast majority of those who ever existed fall short of this standard. (Few have been lucky enough to live to age 87 free of disability.)

Proponents of IHJ are committed to the claim that preventing the existence of these less than ideally healthy individuals would have led to a much better health outcome, other things being equal.

To better understand the problem for IHJ, consider *the Mere Addition Principle*: The addition of individuals with good lives to a population does not make that population worse, other things being equal (Arrhenius 2016: 173). This principle appears in discussions in population ethics, originating with Parfit's discussion of future generations in *Reasons and Persons*. In considering how to evaluate and rank different possible populations, Parfit considers *the Average Principle*: the best population is the one with the greatest average quality of life (1984, 420). (Here, 'quality of life' can be treated as synonymous with 'welfare'.) Parfit points out that this principle has implausible implications. He imagines a population with only two individuals—Adam and Eve—each of whom enjoys a wonderful life. Next, he imagines a second population in which, in addition to Adam and Eve with their wonderful lives, there are a quadrillion other people all with a quality of life that is almost as high as that of Adam and Eve. According to the Average principle, this second population is worse than the population containing only Adam and Eve because the average quality of life is lower. But that is absurd. We cannot make a population worse merely by adding to it people with high quality lives.

IHJ seems inconsistent with a kind of mere addition principle—one that is couched in terms of health rather than well-being. Even if we are concerned only with individual health, not well-being, we should not think that the mere addition of people who, for example, can be expected to live only to, say, age 80, and be mostly, but perhaps not entirely, free of disease and disability, necessarily results in an outcome that is *less desirable* from a global health perspective.

Even worse, IHJ implies that a health intervention can be ineffective, and hence, not worth funding, even when it would be better (with respect to health) for some individuals and worse for no one. For example, consider *primary infertility*—a health state of couples who remain infertile after 1 or more years of attempting to become pregnant. Primary infertility has been assigned a disability-weight of 0.011 (Salomon et al. 2012, 23, Table 3). Consider a health intervention to reduce primary infertility. Intuitively, the effectiveness of such an intervention would be determined by the number of years lived with primary infertility averted by the intervention. One would estimate the number of fewer years lived with primary infertility as a result of the intervention, and then multiply this number by the relevant disability-weight, 0.011. But if one accepts IHJ, then one must also consider DALYs *resulting* from decreased infertility. For example, suppose that averting primary infertility for one couple results in 5 DALYs-averted when we consider only the effects on that couple. Intuitively, this entails that the intervention is effective. However, if the intervention is carried out in a country where the actual life-expectancy at birth is 80, then we can expect each case of averted primary infertility to produce 6.6 DALYs, since adding a new individual to the popularation can be expected to result in that person dying at age 80—6.6 six years less than the ideal life-expectancy. But then each instance of averted primary infertility would produce 1.6 DALYs, and have a net negative health impact. This is extremely odd.

5. The Simple Justification

There is a general moral justification for measuring effectiveness in DALYs-averted that avoids both the problems of IJJ and those of IHJ. One could treat the number of DALYs-averted by a health intervention as equal to the number of additional years of healthy

life that exist because of the intervention. The justification could be that health policy should aim to maximize the number of years of healthy life, whether this is achieved by improving the health states of existing individuals, creating new individuals with positive health states (i.e. with disability-weights less than 1), or some combination of these two means. Call this *the Simple Justification* (SJ).

SJ avoids the Non-Identity Problem. According to SJ, a health intervention that causes non-disabled individuals to exist (rather than certain others who are disabled) is effective to the extent that it results in a greater number of years of healthy life. SJ therefore justifies the use of DALYs-averted as a measure of the effectiveness of such interventions even when the interventions do not improve the health states of particular individuals.

SJ also avoids the implication of IHJ that an intervention can increase the global burden of disease merely by adding relatively healthy individuals (who fall below the ideal health standard) to the global population.

However, some will find SJ problematic because it implies that we can attribute some number of DALYs-averted to a health intervention simply in virtue of the fact that it increases the global population. Moreover, the claim that we can avert DALYs by bringing an individual into existence in a positive health state seems to imply that the non-existence of such an individual contributes some number of DALYs to the global burden of disease. This is odd, since the health losses from non-existence are not incurred by any individual.

These worries about SJ are similar to worries about theories of the goodness of populations according to which a population is better, the greater the amount of welfare it contains. A consequence of such theories is that adding an individual with positive welfare to the population makes it better, other things being equal. This is sometimes treated as a reason to reject such theories. Although we are generally in favor of improving the welfare of existing individuals, many are neutral about creating new individuals with positive welfare. For instance, Ronald Dworkin describes what he takes to be a popular view when he says that "It is not important that there be more people. But once a human life has begun, it is very important that it flourish … " (1994, 74). Jan Narveson expresses a similar idea with the slogan "We are in favor of making people happy but neutral about making happy people" (1973: 80).

One might anticipate a similar kind of neutrality in our attitudes about creating new individuals in positive health states. While most of us are in favor of *making people healthy*, it may be that many of us are neutral about *making healthy people*.

6. Human Extinction

As mentioned in the introduction, The Lancet Commission on 21st Century Threats to Global Health is attempting to determine health priorities over a longer-than-usual timeline; one of its ultimate aims is to provide advice to countries on how to prioritize interventions to address threats to health, including extinction risks. The severity of threats is measured in the expected number of DALYs they would contribute. In this context, SJ is the only one of the three justifications we've considered that seems reasonable.

If we follow IIJ, then extinction-prevention would be effective only to the extent that it would give particular individuals better health states than those they would

otherwise have. But if policy decisions enacted now change the identities of individuals in the future, then efforts to avert extinction events in the far future, e.g., 100 years from now, may not improve anyone's health state.

On the other hand, IHJ might imply that preventing an extinction event would result in a worse health outcome, if it meant humanity would then survive for a sufficient number of centuries. According to IHJ, the health loss from extinction would be restricted to the size of the gap between the health of the population that dies in the extinction event, and an ideal health situation in which everyone in that population lives to an advanced age free of disability. But the survival of humanity would lead to an even greater health loss according to IHJ. Over a sufficiently long time horizon, the number of DALYs from non-extinction-related causes like heart disease and low back pain would pile up, and eventually be greater than the number of DALYs from an extinction event. If anything, IHJ seems to support speeding up extinction, as the resulting health outcome would be better than one in which sufficiently many less-than-ideally healthy individuals exist.

SJ is the only one of the three justifications that avoids these implausible implications. It implies that averting extinction would be effective to the extent that this would result in more healthy years of life. It doesn't matter whether these extra years would improve the health states of particular individuals. Hence, SJ seems better suited for at least one of the many important goals that has been set in global health.

7. Conclusion

I have reviewed three possible moral justifications for measuring the effectiveness of health interventions in DALYs-averted. I first considered the Individual Improvement Justification (IJJ): the use of DALYs-averted is justified because it measures the extent to which individuals' health states are improved by a health intervention. IJJ fails to explain why we should care about averting health loss when this does not improve anyone's health state but merely replaces less healthy individuals with healthier ones. This problem parallels the Non-Identity Problem in population ethics.

I then considered the Ideal Health Justification (IHJ): the use of DALYs-averted is justified because it measures the extent to which an intervention narrows the health gap between the actual population and an ideal population in which everyone lives to an advanced age free of disease and disability. Because IHJ is insensitive to which particular individuals exist, it avoids the problem that IIJ faces. However, it implies that health interventions increase health loss merely by adding relatively healthy individuals to the population. This is implausible, particularly when IHJ deems ineffective health interventions that are better for some and worse for none.

Finally, I considered the Simple Justification (SJ): the use of DALYs-averted is justified if the number of DALYs-averted by an intervention is considered equivalent to the number of additional healthy life-years that exist because of that intervention. SJ avoids the problems of IIJ and IHJ. But this seems to imply that we can reduce health loss simply by expanding the global population.

It will be difficult to find a justification for the use of DALYs-averted as a measure of effectiveness that does not have some counterintuitive implication.

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