Measuring Health Burden without Discriminating Against the Disabled

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Abstract. This paper addresses an ethical implication of some health metrics used for evaluating population health, with particular reference to the Disability Adjusted Life Year (DALY). Specifically, the paper considers the concern that, such measures may discriminate against the disabled. An analysis of this problem is offered, alongside the formulation of three principles upon which an alternative measure is developed –the Ethically Adjusted Life Year (EALY).

Keywords. Health measures, Disability discrimination, DALY, Health interventions; Global burden of disease

1. Background

Summary measures of population health are important for health policy and planning. They can be used for many purposes including priority setting, evaluating population health over time, health system administration, and policy and planning –see Murray et al. (2000). These measures typically combine information on mortality and disability (taken to include any diminishment in health status however minor or temporary) into a single metric. The measure we focus on is the Disability Adjusted Life Year (DALY) due to the wide interest it generated and its many applications (see Oostvogels et. al. 2015), although much of the discussion we carry out also applies to other health metrics. The DALY is the basis for the most comprehensive attempt to measure global population health, embodied in the Global Burden of Disease (GBD) study (Murray et al, 2012a,b, 2015), and is widely used for cost effectiveness analyses and to set medical priorities.

This paper considers the objection that the DALY discriminates against the disabled; not only does the measure give less credit to (otherwise equivalent) health interventions that save the lives of disabled people, but it also gives priority to health-improving interventions over life-saving interventions when the life at stake is that of a disabled person.[1] This concern generated a body of literature arguing for avoiding disability-based discrimination –see Nord (1999 and 2001), Nord et al (1999, 2003 and 2009), Ubel et al (2000), and Johannesson (2001). In the words of Mont (2007), "The fear is that this fact will drive resources away from disabled people, making them even more vulnerable and disadvantaged than they already are in many societies" (p. 1658).

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[1] An additional disability discrimination objection is that the same amount of health care given to a person with a disability will often yield less health benefit for that person; this may be because some disabilities make it harder to successfully treat others. This second issue is beyond the scope of our paper –for a discussion, see Brock (2000 and 2009).

2. Methods

We lay out a novel measure, which we label the *Ethically Adjusted Life Year* (EALY). Rather than lessening the degree of discrimination through a multiplicative functional form bringing about a revaluation or upper-end compression of health states (see Nord et al, 1999), this measure is developed using a fixed-plus-variable measurement framework adopted in welfare economics (see Bourguignon and Fields, 1997, Esposito and Chiappero-Martinetti, 2010 and Anderson and Esposito, 2014).[2] This enables the researcher to introduce a discontinuity in the possible tradeoffs among bearers of value when one value is lexicographically more important than another. We outline and discuss three principles delineating the importance of alleviating disability and extending life-years (*Disability Monotonicity*, *Life Egalitarianism* and *Life Supremacy*).

3. Results

3.1 Summary measures of population health: the DALY

The DALY is calculated by summing up i) years of life lost because of death occurring earlier than the approximately 80 years of age taken as benchmark (each year lost counts 1) and ii) years of full health lost due to disability (every year in non-perfect health counts between 0 and 1 depending on the severity of the disability). The DALY measure reads as follows:

DALY = YLL (Years of Life Lost) + YLD (Years of Life lost due to Disability)

Imagine two people, *h* and *d*, who on their 60th birthday die of a heart attack. Both fall 20 years short of the 80 years benchmark – and for them both *YLL*=20. However, while *h* has been healthy throughout all of the 60 years lived, at the age of 50 *d* became disabled. The DALY accounts for this disability-related health burden through the *YLD* component. These 10 years count not as 'full years' but as 'fractional years': to each of these years a weight between zero and one is applied depending on the severity of the disability. While the *YLD* component for *h* would be zero (she has spent all of her years alive in perfect health), for *d* it would be 0.6*10=6 (assuming a weight of 0.6). The total burden for *h* would be 20+0=20, while for *d* it would be 20+6=26.

3.2 DALY: assessing impact and evaluating interventions

While it appears reasonable to say that the health burden was larger for *d* than for *h*, in the following two illustrations it is more difficult to accept the DALY's evaluation of the outcome. This is because the existence of a disability automatically reduces the value of a life year of a disabled person. Since we address the discrimination brought about by the DALY between a healthy and a disabled person, our illustrations feature two individuals. The evaluation of longevity vs healthiness trade-offs for the same person does not present the same type of discrimination concerns and hence, whilst interesting, is not pursued in this paper.

Health trumping life case. Imagine that on their 60th birthday *d* (who has a 0.6 disability) has a heart attack while *h* (who is completely healthy) has a stroke. Available resources only allow one intervention to be carried out. Not intervening on the heart attack would mean death for *d* while not intervening on the stroke would mean that *h* gets a 0.7-weighted disability. What should we do? The impact of acting on *d* would be 8 DALYs averted; the impact of acting on *h* would be of 14 DALYs averted. The DALY would favour the maintenance of *h*'s healthy state at the expenses of *d*'s life, a judgment reminiscent of Sparta's cliff. Many find this behaviour undesirable because they believe sensitivity to the

[2] An alternative approach, suggested by Johannesson (2001), differs from ours and was criticized by Ubel et. al. (2000), Norheim et al. (2012) and Ord (2013).

extent of disability should not translate into preference for a health improvement over life saving because the person whose life is at stake is disabled.[3]

Lifeboat dilemma case. Suppose that both *d* and *h* face a life-threatening heart attack and due to resource constraints only one of them can undergo a life-saving procedure If we were to decide whether to act on *d* or on *h* on the basis of which intervention would maximise the DALYs averted, in the case of *h* the impact of the procedure would be 20*1=20, while in the case of *d* it would be 20*(1-0.6)=8. The procedure saves their lives and grants 20 additional life years to both *h* and *d*; but in the case of the latter it leads to less benefit because this person has a disability –and this would be so whether the disability is a major or an extremely mild one. This may be discriminatory, because the life of a disabled person counts for less than the life of a healthy person; prioritising the latter may also be unfair, for example, since on top of having enjoyed better health, *h* would also enjoy longer life than *d*. Note this critique does not require denying the existence of reasons for deciding to save *h's* life. In this life-boat-dilemma type of situation where a (however tough) decision has to be taken, one could certainly argue that a world with *h* rather than with *d* would be a healthier world, or that the pressure on the health system would likely be lower with *h* alive rather than *d*. This lifeboat-dilemma illustration highlights a tension between the desirable behaviour of a health measure and that of a measure of the ethical value of health interventions –we shall come back to this tension below.

3.3 Ethical principles for assessing impact and evaluating interventions

In order to tackle the two types of discrimination discussed above, we lay out the following ethical principles:

I. *Disability Monotonicity (DM)*: disabilities should count according to their severity; more severe disabilities should count more than less severe disabilities.

II. *Life Egalitarianism (LE)*: an additional life year granted should count equally, regardless of the health status of the person; i.e. a *k*-year increase in the life of a disabled person should count as much a *k*-year increase in the life of a non-disabled person.

III. *Life Supremacy (LS)*: a life year saved counts more than any disability year alleviated; i.e. extending a person's life by *k* years (whatever her disability) counts more than alleviating a disability for *k* years (whatever the disability).

Note that we have laid out the above properties in 'per year' terms (i.e. granting 1 life year has priority over a 1-year health improvement). We do not blindly favour procedures which extend life for a short time over long-lasting health improvements –e.g. the treatment of a child's disability can be given priority over saving the life of an elderly person. In addition, by 'saving life/extending life/granting a life year' we do not consider situations such as extending the life of a person in a vegetative state, where doubt can be cast on the value of such life years altogether. Understanding how to deal with futile care interventions is certainly an important issue, which, however, goes beyond the scope of our paper.

The EALY builds upon the fixed-plus-variable framework proposed in welfare economics by Bourguignon and Fields (1997) in unidimensional evaluation and extended by Esposito and Chiappero-Martinetti (2010) and Anderson and Esposito (2014) in multidimensional evaluation. The EALY framework includes a fixed component reflecting the status of being alive and a variable component accounting for the degree of healthiness. The EALY reads as follows:

[3] This should be intended in per-year terms, as will be clarified below, so that we are not comparing, say, extending life for 1 year against a health improving procedure yielding benefits for 30 years

EALY=LYA (Life Year Alive)+LYQ (Life Year Quality),

For each individual, life is accounted for by the fixed component *LYA* and degree of healthiness by the variable component *LYQ*. *LYA* will be chosen as ≥*α* (we will suppose *α*=1 in what follows) when the life year is spent alive (or when the life year is lost if we are measuring burden) and 0 otherwise. *LYQ* is a healthiness/unhealthiness parameter ranging from 0 to *α* depending on the health status of the individual, in a similar fashion to the disability weights used in the DALY. The variable component accounts for the severity of the disability and hence grants the accommodation of principle *DM*. Since *LYA* is fixed and is weakly greater than the maximum of the variable component, life-saving interventions are prioritised over health-improving ones, as prescribed by principle *LS*. When the choice is between two life-saving interventions regarding individuals with different health statuses (like *h* and *d* in our examples), discrimination against the less healthy is avoided (as prescribed by *LE*) as long as the components *LYA* and *LYQ* are interpreted as truly separate domains, as we shall clarify in Section 4 below.

The choice of the exact value of *LYA* will depend on the degree of substitutability between extending by *k* years one person's life and:

i) alleviating for *k* years a certain disability of *n* people;

ii) alleviating the disability of one person for *l*>*k* years;

iii) both things, that is, alleviating a certain disability of *n* people for *m* years (with *m* larger or smaller than *k*).

For example, the choice of *LYA=1* implies that extending by *k* years one person's life is as valuable as bringing about a 0.1 alleviation for 2*k* years in a disability affecting five people (or for *k*/2 years and twenty people, etc.).

4. Discussion

Main findings of this study

We discuss here the recommendations offered by the EALY in the case of the illustrations proposed in section 2.2. We account for two possible interpretations of the relation between *LYA* and *LYQ*. The first interpretation sees *LYA* and *LYQ* as genuinely different components and focuses on the strict impact of interventions (i.e. the impact of refraining from a life-saving intervention is confined to the loss of life and does not reverberate to the *LYQ* component). The second interpretation implicitly views *LYQ* as a function of *LYA* in the sense that when an individual loses her life, her health goes to zero.

Health trumping life case. As shown by the calculations below, in the choice between *d*'s life or *h*'s health, the EALY recommends intervening on *d*, regardless of the interpretation given to *LYQ*:

$$\mathrm{I}^{h}_{\mathrm{EALY}} = \mathrm{EALY}^{h}_{\text{Non Intervention}} - \mathrm{EALY}^{h}_{\text{Intervention}} =$$

$$\left(\underbrace{LYA^{h}_{\text{Non Intervention}}}_{1} + \underbrace{LYQ^{h}_{\text{Non Intervention}}}_{1-0.7=0.3}\right) - \left(\underbrace{LYA^{h}_{\text{Intervention}}}_{1} + \underbrace{LYQ^{h}_{\text{Intervention}}}_{1}\right) = -0.7$$

$$\mathrm{I}^{d}_{\mathrm{EALY}} = \mathrm{EALY}^{d}_{\text{Non Intervention}} - \mathrm{EALY}^{d}_{\text{Intervention}} = \left(\underbrace{LYA^{d}_{\text{Non Intervention}}}_{0} + \underbrace{LYQ^{d}_{\text{Non Intervention}}}_{1-0.6=0.4} \right) - \left(\underbrace{LYA^{d}_{\text{Intervention}}}_{1} + \underbrace{LYQ^{d}_{\text{Intervention}}}_{1-0.6=0.4} \right) = -1$$

Figure 1 illustrates the framework on the basis of the first interpretation (for the sake of a more intuitive illustration, the graph is produced in the positive quadrant). It can be seen that saving *d*'s life always outperforms any improvement of *h*'s health.

[Insert Figure 1]

Following the second interpretation of *LYQ*, this component goes to zero in the case of non-intervention and the assessment of the impact on *d* becomes as follows:

$$\mathrm{I}^{d}_{\mathrm{EALY}} = \mathrm{EALY}^{d}_{\text{Non Intervention}} - \mathrm{EALY}^{d}_{\text{Intervention}} = \left(\underbrace{LYA^{d}_{\text{Non Intervention}}}_{0} + \underbrace{LYQ^{d}_{\text{Non Intervention}}}_{0} \right) - \left(\underbrace{LYA^{d}_{\text{Intervention}}}_{1} + \underbrace{LYQ^{d}_{\text{Intervention}}}_{1-0.6=0.4} \right) = -1.4$$

Figure 2 provides a graphical illustration for this second interpretation. It can be noted that $\mathrm{I}^{d}_{\mathrm{EALY}}$ is an upward translation of $\mathrm{I}^{d}_{\mathrm{DALY}}$ in the figure provided in Appendix –i.e. the red line for *d* is lifted up exactly by 1, which is the *LYA=1* component accounting for the life-saving character of the intervention.

[Insert Figure 2]

Lifeboat dilemma case. Here both *d*'s and *h*'s lives are at stake and the interventions relate to saving life rather than improving health; it follows that for both *d* and *h* the *LYA* component in the case of non-intervention is zero while the *LYQ* component is not directly affected. A focus on the objective of the intervention (in conformity with the first interpretation which keeps the two components independent from each other), leads to the outcome that the two life-saving interventions are given the same importance –in accordance with the *LE* principle. The second interpretation instead imposes the collapse of the *LYQ* component in case of non-intervention (because the person would die); as a consequence, since this component is greater for *h*, the intervention saving her life would acquire more value –in contrast with the *LE* principle. In other words, analytically, the avoidance of the discrimination of *d* in a lifeboat dilemma situation is grounded in the independence of the *LYA* and *LYQ* components.

The translation of this analysis in society simply requires summing this measure across individuals. Consider the evaluation of two interventions on two societies of 100 people. Intervention X saves the life of 40 people, of which 10 have a 0.4 disability, 10 a 0.6 disability and 20 a 0.8 disability; in addition, intervention X alleviates by 0.4 the disability of 25 people, by 0.6 the d/disability of 20 people and by 0.8 the disability of 15 people. Intervention Y does not saves lives, but it alleviates by 0.4 the disability of 30 people, by 0.6 the disability of 30 people and by 0.8 the disability of 40 people. The EALY measures see more favourably intervention X, while the DALY measure suggests intervention Y.

What is already known on this topic

It is worth pointing out that the EALY differs significantly from the other proposals to address the disability objection. Nord et al. (1999) increase the value of life extension compared to health improvement through multiplicative weights and an upper end compression of health states, which "would eliminate much of this devaluation of life extending programmes for the disabled" (p. 36), an approach which can also be found in Nord (1999, pp. 118-120) and Ubel et. al. (2000). The separation of life extension and health improvement is implemented by adopting the values attached to health states (e.g. Tab. 14 in Nord, 1999) in the case of health improving interventions, while life-saving interventions are attached a value strictly equal to 1.

What this study adds

The difference with our proposal is neat and resides in the ability of our fixed-plus-variable framework to disentangle and jointly account for both life-saving and health-improvement interventions. These differences can also be appreciated in the light of the following example from Ubel et al. (2000): "Treatment A saves the life of a patient with a … [0.2] disability. Treatment B simultaneously saves the patient's life and cures her of a similarly severe disability. In the QALY model, treatment A would yield 0.8 QALY, and treatment B would yield 1 QALY. Yet in our model, both would have a societal value of 1" (Ubel et. al., 2000, p. 899). This is different from our fixed-plus-variable approach because treatments A and B would have a value of 1 and 1.2, respectively. Ubel et. al. (2000) argues that their model's inability to recognise the greater value generated by treatment A is less worrying than the DALY's undervaluing of life-saving treatments for disabled people. Finally, it is worth noticing that the DALY would be able to accommodate *LS* if its disability weights (which are derived through surveys) were capped at 0.5.

Limitations or this study

While DALY's deliberative approach is extremely valuable (yet see the methodological critiques in Voigt and King, 2014), we believe that the analyst can limit its scope in order to avoid undesired consequences such as undesirable discriminations (of which most likely respondents are not fully aware) –weights could still be determined through surveys but with a ceiling in order to avoid disability-based discriminations.

5. Conclusion

This paper addressed the concern that DALY-type measures discriminate against disabled people as they give less credit to health interventions that save the lives of disabled, as opposed to non-disabled, people, and allow priority to be given to health-improving interventions over life-saving interventions when the life at stake is that of a disabled person (while the same does not happen if the life to be saved is of a non-disabled person). We proposed a new measure, the EALY, and discussed it in light of three principles concerning disability alleviation and life-saving decisions. The EALY measure is sensitive to the amount of health improvement brought about by an intervention but, at the same time, gives priority to saving life over health improvement. As we remark, the importance attributed to saving life should not be taken as a sort of life-saving fundamentalism; we abstract from futile medical care situations and the priority to life saving interventions is intended in per-year terms. As to discrimination against the disabled stemming from the choice of saving the life of a healthy person over that of a disabled, the EALY framework illustrates that this can be avoided by keeping the life and the disability components separate and accounting only for the direct impact of interventions; in this way life-saving interventions are deemed equally worthwhile regardless of whose life is saved. When evaluating the ethical value of interventions, we may have to take other factors into account and depart from the goal of health maximisation. After all, it is by doing this that we leave Sparta's cliff behind.

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Appendix 1

To see why the DALY leads to what we see as an undesirable behaviour, let us first formalise the net impact in terms of DALY (call this impact $\mathrm{I}_{\mathrm{DALY}}$) as the difference between what the burden would be in the case of non intervention (call this $\mathrm{DALY}_{\mathrm{Non\ Intervention}}$) and in the case of intervention (call this $\mathrm{DALY}_{\mathrm{Intervention}}$). Superscripts *h* and *d* will denote the person the impact refers to (so that mean $\mathrm{I}^{h}_{\mathrm{DALY}}$ and $\mathrm{I}^{d}_{\mathrm{DALY}}$ will denote the impact for *h* and *d*, respectively):

$$\mathrm{I}^{h}_{\mathrm{DALY}} = \underbrace{\mathrm{DALY}^{h}_{\mathrm{Non\ Intervention}}}_{20*0.7=14\ \mathrm{YLD}} - \underbrace{\mathrm{DALY}^{h}_{\mathrm{Intervention}}}_{20*0=0\ \mathrm{YLD}} = 14$$

$$\mathrm{I}^{d}_{\mathrm{DALY}} = \underbrace{\mathrm{DALY}^{d}_{\mathrm{Non\ Intervention}}}_{20\ \mathrm{YLL}} - \underbrace{\mathrm{DALY}^{d}_{\mathrm{Intervention}}}_{20*0.6=12\ \mathrm{YLD}} = 8$$

$\mathrm{I}^{h}_{\mathrm{DALY}}$ measures the net DALYs which would be averted by intervening on our healthy person *h* who acquires a disability. Per year, $0<\mathrm{I}^{h}_{\mathrm{DALY}}<1$: it ranges from a number close to 0 (in the case of a mild disability) to a number close to 1 (in the case of a severe disability).

$\mathrm{I}^{d}_{\mathrm{DALY}}$ measures the net DALYs which would be averted by intervening on our disabled or ill person *d* whose life is threatened. The situation is in a sense symmetric to the one just seen, with a range of $0<\mathrm{I}^{d}_{\mathrm{DALY}}<1$ per year: from a number close to 0 (in the case of a severe disability) to a number close to 1 (in the case of a mild disability).

Before generalising the problem, a few observations emerge. It is evident that $\mathrm{I}_{\mathrm{DALY}}^{h}$ and $\mathrm{I}_{\mathrm{DALY}}^{d}$ move within the same range from 0 to 1, and the former will exceed the latter whenever the disability which *h* would develop in case of non-intervention is more severe than the disability already afflicting *d*. The more severe someone's disability the less valuable it would be to save her life; by contrast, the more severe the disability the healthy person faces, the greater the concern for her. In fact in the DALY, saving a life does not have any intrinsic importance: it all depends on the severities of the disabilities affecting *d* and potentially affecting *h*.

Generalising the DALY framework in a situation such as the one described above, let $\omega_{\mathrm{Int}}^{d}$ and $\omega_{\mathrm{NonInt}}^{d}$ denote the discounting factors which would be applied to the remaining years of life of *d*, in the case of intervention and non intervention, respectively; the corresponding variables for *h* would be $\omega_{\mathrm{Int}}^{h}$ and $\omega_{\mathrm{NonInt}}^{h}$, respectively. These discounting factors are the disability weights that would be applied to remaining life years of *d* and *h* in the case of intervention or non intervention. The decision to target *h* will be taken whenever $\omega_{\mathrm{NonInt}}^{h}\text{-}\omega_{\mathrm{Int}}^{h} > \omega_{\mathrm{NonInt}}^{d}\text{-}\omega_{\mathrm{Int}}^{d}$. Noting that $\omega_{\mathrm{NonInt}}^{d} = 1$ (because *d* would die and each YLL is counted 1) and $\omega_{\mathrm{Int}}^{h} = 0$ (because *h*'s health would be fully restored), the above inequality becomes $\omega_{\mathrm{NonInt}}^{h} > 1 - \omega_{\mathrm{Int}}^{d}$.

The terms of this inequality are can be represented graphically in Figure 1 below. In the horizontal axis we have the discounting factor (or disability weight); in the left and right vertical axes we have the yearly DALYs averted if we intervene on *d* and *h*, respectively. In the figures below what appears in red refers to person *d* while what appears in blue refers to person *h*.

i. $1 - \omega_{\mathrm{Int}}^{d}$ has a negative slope and an intercept of 1 (if *d*'s disability is very mild, saving her life would avert almost a whole DALY; conversely, if her disability is very severe then almost no DALY per year would be averted by extending her life).

ii. $\omega_{\mathrm{NonInt}}^{h}$ is positively sloped and has no intercept (if the disability *h* would get in the case of no intervention is very mild, intervening would avert almost no DALYs; conversely, if the potential disability is very severe almost a whole DALY per year would be averted).

[Insert Figure 3]