

Measuring health in a vacuum: examining the disability weight of the DALY

DANIEL D REIDPATH,¹ PASCALE A ALLOTEY,² AKA KOUAME³ AND ROBERT A CUMMINS⁴

¹*School of Health Sciences, Deakin University, Australia,* ²*Key Centre for Women's Health in Society, Department of Public Health, The University of Melbourne, Australia,* ³*Institut de Formation et de Recherche Demographiques, Cameroon and* ⁴*School of Psychology, Deakin University, Australia*

The Disability Adjusted Life Year (DALY) is a widely used summary measure of population health combining years of life lost due to mortality and years of healthy life lost due to disability. A feature of the DALY is that, in the assessment of morbidity, each health condition is associated with a disability weight. The disability weight lies on a scale between 0 (indicating the health condition is equivalent to full health) and 1 (indicating the health condition is equivalent to death). The disability weight associated with each health condition is currently fixed across all social, cultural and environmental contexts. Thus blindness in the United Kingdom has the same disability weight as blindness in Niger in spite of structural interventions in the UK that make the disability less severe than in Niger. Although the fixed disability weight is defended on grounds that it supports a strongly egalitarian flavour in the DALY, we argue that the lack of consideration of realistic contexts results in a measure that will underestimate the burden associated with morbidity in disadvantaged populations and overestimate the burden in advantaged populations. There is, consequently, a loss of information on possible non-clinical points of intervention. Disaggregated estimates of the burden of disease such as those in the *World Health Report 2000* should be interpreted with caution.

Key words: disability adjusted life year, DALY, population health, health status measurement, health outcomes, morbidity

Introduction

The 'Disability Adjusted Life Year' (DALY) is a summary measure of population health, developed as a means of combining morbidity and mortality in a single index (World Bank 1993). It is intended to serve the dual purpose of measuring the burden of disease and informing resource allocation (Murray 1996). In 1996 Jamison suggested that the DALY was so robust that it would become something of a *de facto* standard for the official reporting of health outcomes (Jamison 1996).

The DALY that Jamison wrote of, however, has been evolving ever since its debut in 1993 (see the discussion by Reidpath et al. (2001, pp. 62–3) for an example of this developmental process). With each cycle of development, some past concerns have been addressed, but equally, some have not, and new ones continue to arise.

The purpose of this paper is to develop a critique of a single feature of the DALY, namely the 'disability weight' and the role of the social, cultural and environmental context on the measurement of the burden of disease. Although others have critiqued the DALY (Barker and Green 1996; Anand and Hanson 1997, 1998; Sayers and Fliedner 1997; AbouZahr 1999; Arnesen and Nord 1999; Hanson 1999; Williams 1999; AbouZahr and Vaughan 2000; Priya 2001), only some of them have commented on weaknesses associated with the disability weight and those have tended to be a part of more general critiques (Barker and Green 1996; Anand and Hanson 1997, 1998; Sayers and Fliedner 1997; Priya 2001). To date, there has been a limited analysis of the problems that

arise from a burden of disease measure that excludes the context in which the disease occurs, in effect assessing health 'in a vacuum'.

Notwithstanding the narrow focus of our critique, we believe that it is so important that it raises major concerns about the validity of the DALY in its current form and brings into question how it should be applied in epidemiology and the development of evidence-based policy. Equally, it raises doubts about the validity of other measures, such as the Health Adjusted Life Expectancy (HALE),¹ that make use of a similarly constituted disability weight. Most importantly, the critique highlights the importance of social, cultural and environmental context, not just as a determinant of health states (which is already well established), but also as a determinant of the severity and impact of those health states – an area that has been lacking in the consideration of mainstream health policy.

Our critique, however, should not be interpreted as a blanket condemnation of summary health measures (Reidpath and Allotey 2003). They provide critical information, but their construction can obscure subtleties that may leave content-free managers and the uninitiated unreasonably confident about their universal application (Priya 2001).

Background to the DALY

The DALY is a time-based measure accounting for years of life lost due to premature mortality and healthy years of life lost due to disability (Murray and Lopez 1994). The years of life lost for a given health state, *i*, are calculated as:

$$\text{DALY}_i = \text{YLL}_i + \text{YLD}_i$$

where YLL_i is the years of life lost in a population due to premature mortality attributable to health condition i , and YLD_i is the healthy years of life lost in a population due to disability attributable to health condition i . The measure is moderated by four factors (Murray 1996; Murray and Acharya 1997). Three of these factors affect both the YLL and YLD calculation, and are:

- A 3% time discount rate to years of life lost in the future (at least insofar as the DALY has been applied in studies like the global burden of disease study). In fact, any discount rate could be used, including no discounting at all.
- An age weight such that a year of premature death or disability occurring in childhood or old age accrues fewer DALYs than similar loss occurring in the middle years of life.
- A sex adjustment such that two people of the same age with the same health condition but of different sexes accrue a different number of DALYs.

The latter two factors (or more precisely the restriction of social factors to the latter two) are intended to support a strong egalitarian flavour in the DALY (Murray and Acharya 1997). In addition to the three moderating factors described above, there is a disability weight associated with each health condition. The disability weight, which is the principle focus of this paper, affects the calculation of the YLD. YLD is calculated as follows for each health condition.

$$\text{YLD} = D \times I \times L,$$

where D is the disability weight associated with the health condition (taking a value between 0 and 1); I is the incident number of cases; and L is the average number of years that the condition lasts (Mathers et al. 1999, p. 21). As noted above, the application of a discount rate to L adds an extra dimension to the calculation (Murray 1996).

For further details on the technical specifications of the DALY see Murray (1994, 1996), Murray and Acharya (1997), and Fox-Rushby and Hanson (2001).

The disability weight

The disability weight is a measure of the impact of a health condition and its calculation is based on the preferences of a panel of judges for each health state relative to full health and to death (Murray and Acharya 1997). The preferences are anchored between 0 (indicating indifference between the health state and full health) and 1 (indicating indifference between the health state and death). In general terms, each health state has a single associated disability weight. Thus, if the disability weight associated with epilepsy was 0.1, this same disability weight would be used in the calculation of the DALYs associated with epilepsy in Bogota, Beijing, New York and Newcastle. Separate disability weights have been developed for treated and untreated conditions, accounting for the fact that someone with, say, well managed epilepsy is better off than a person with poorly managed epilepsy. In

some cases different weights are also associated with different sexes and ages. For instance, the occurrence of infertility among the very young or the very old will not have the same disability weight associated with it as for a person of reproductive age, and a condition that is sex specific will obviously not have the same disability weight for both sexes.

The disability weight is estimated through an iterative process with the panel of judges, using the person-trade-off methodology (Murray 1996). In the original studies, the judges were asked to restrict their consideration to those aspects of the health state that fell within the definition of disability according to the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) (Murray 1994). In ICIDH, 'disability' was defined thus:

'In the context of health experience a disability is any restriction or lacking (resulting from impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.' (WHO 1980, p. 28)

If you were to estimate the disability weight associated with paraplegia, therefore, you would ignore the social, cultural or environmental context of the condition and confine your consideration to the lack of ability to perform an activity attributable to paraplegia.

In later evolutions of the DALY, however, it was understood that judges could not in fact perform the task behind a 'veil of ignorance' and some information about the context in which the life was lived was required (Murray 1996). Indeed, T Evans made the observation after one of the judgment exercises that even if it were unintended, the judgement necessarily required some contextual information, whether that information was explicitly provided or relied on judges' prior knowledge (see Murray 1996, note 33 on p. 73 in reference to p. 34). Others have also criticized the lack of context in the disability weight (e.g. Barker and Green 1996). Bobadilla (1998, p. 7), for instance, wrote:

'The disability weights ignore the handicap attached to some permanent disabilities in different societies. The same disability has different effects on the lives of individuals in different countries. Some traditional societies stigmatise and reject individuals with specific permanent impairments, such as infertility, AIDS or psychosis. The real health loss in these individuals is greater than that estimated by the DALY . . . [T]his poses a problem for national burden of disease assessments.'

Following Evans' observations, judges were asked to take into consideration 'average conditions of individuals and social responses' or the 'average handicap' in which the disability occurred (Murray 1996, p. 34) where, again, the ICIDH definitions were used. Handicap was defined as follows:

'In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the

fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.' (WHO 1980, p.29)

When estimating the disability weight for deafness, a panel would need to take account of both the functional loss associated with deafness and the impact 'average conditions of individuals and social responses' (Murray 1996, p. 8) or 'average social milieu' would have on life lived with deafness.

Even allowing for the move from 'disability' to 'average handicap' a disability weight based on a global, fixed context still has major conceptual problems. Principle among these, also recognized by Sayers and Fliedner (1997), is that the DALY fails to account for regional variation in the distribution of social circumstances that contribute to handicap. This is discussed below.

The DALY and objectivity

The counter argument in favour of the DALY maintaining a fixed context disability weight is that it supports the 'objectivity' of the measure by ensuring comparability across space (and time). Knowing, however, that the global burden of disease attributable to AIDS is x , or that AIDS accounts for $z\%$ of the total global burden of disease is, in and of itself, of only limited use. For the estimate to be more useful one needs to be able to disaggregate it by region, in much the same way as was done in the *World Health Report 2000* (WHO 2000), and probably even at a national or sub-national level. These disaggregated data can show disparities in the burden of disease between regions and over time, and this in turn can be used in priority setting, resource allocation, and cost-effectiveness exercises. That at least is what has been argued – but a difficulty presents itself.

Judgements for deriving disability weights are based on the health state in 'an average social milieu'. It is unclear what this actually means. The 'average social milieu' is either (a) the average social conditions of the population as a whole or (b) the average social conditions in which the group of people with a particular health condition live. For the notion of 'social milieu' in either construction to be useful for a realistic assessment of the burden of disease, it would need to encompass a broad range of cultural, economic, gender and environmental factors. The problem with using the average social milieu of an entire population is that the average person with the health condition may not be the average person in the population. The unhealthy person may, thus, not live within the average social conditions of the population as a whole.

To illustrate this, imagine that the curve in Figure 1 (ignoring the shading) shows the distribution of social responses in a population as a whole. In this population, social response tends to be more negative (the left tail) than positive (the right tail). The shading within the distribution shows the distribution of some health condition, x , across the population. Most people with health condition x live among people with a negative social response (i.e. the darker shading in the curve), and very few people with health

condition x live among those with a positive social response (shown where the curve is shaded white). This shows that the average social conditions in which the group of people with x live are worse than the average social conditions for the population as a whole. Furthermore, the argument indicates that we would have to know the average social conditions in which the population of people lived with each and every health condition.

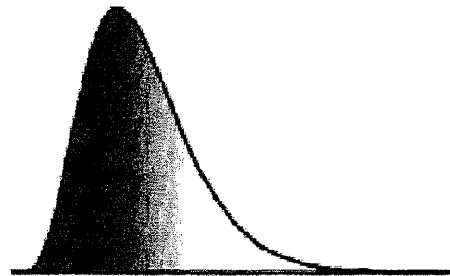


Figure 1. The distribution of a health condition x (the shading) overlaying the distribution of social responses in a population

The problem becomes even more complicated when we seek to disaggregate the data, because the magnitude of a parameter estimated on a global basis does not necessarily provide a valid estimate of the parameter in any one region. Yet one of the reasons for using the DALY in the global burden of disease study was to provide just such disaggregated estimates that would permit 'objective' comparisons of the burden of disease between regions (Murray and Lopez 1996). The average disability weight for paraplegia for instance is 0.671 (Murray 1996, p. 39). This average disability weight, however, misrepresents the reality of the life of a rural dwelling Cameroonian with paraplegia compared with an urban dwelling Australian with the same condition. People with paraplegia in Cameroon lead a highly stigmatized life of almost complete social disengagement; there is no social and environmental infrastructure to support their disability, and moving around their environment unassisted is impossible. In contrast, people with paraplegia in Australia experience a much easier life; the support infrastructure is considerably better, and significantly, the provision of infrastructure is mandated and enforced through social systems such as building codes (Reidpath et al. 2001).

Disability weights that account for the different country contexts and development gradients (Reidpath et al. 2001) would appear to be the simple solution. However, the idea of comparisons using estimates that are based on country or region-specific disability weights has been criticized because it challenges the very foundations of the DALY measure (Murray 1996). Murray and Acharya (1997) wrote: 'If the burden estimated from a given condition were to be completely context specific, meaningful comparisons across communities or within communities over time would be essentially impossible' (p. 726).

Notwithstanding the counter argument, the criticism of the fixed context disability weight cannot be so easily ignored. The DALY estimates given by the World Health

Organization (WHO) for each region in the *World Health Report 2000* (WHO 2000, p. 170) can only be correct if within each region the disability weight for a health condition were the same as the fixed context (global) disability weight used by the WHO to estimate the global burden of disease. This, in turn, could only be the case if the average social milieu within which a health condition was situated within each region were the same as the global average social milieu; and this situation is unlikely ever to arise.

The 'within the skin' counter argument

One possible solution to our critique is to abandon context entirely (i.e. to return to the 'health in a vacuum' scenario). There has been a suggestion, for instance, that summary measures of population health should focus on health dimensions such as impairments and activity limitations that lie 'within the skin' or are intrinsic to the person, entirely removing context from consideration (Mathers 1997; Mathers et al. 1999).

This apparent solution fails, however, for a number of reasons. First, if the intention of the exercise were to provide a measure of the burden of disease in populations, then it is important that one measures the burden, as much as possible, as it truly occurs, not as it occurs in some arbitrarily distorted reality. The health conditions with which health services need to deal are the ones experienced by real people, and the health conditions that occur in real people are a product of the interaction between the clinical state, the person and the context.

The second problem is that the edges between functional limitations that are intrinsic and extrinsic begin to blur as one examines those limitations in different contexts. For example, in Australia people with paraplegia have wheelchairs. In Cameroon many do not have wheelchairs and their mobility is severely restricted. Wheelchairs do not lie within the skin, so it is the interaction between the individual and things extrinsic (i.e. the wheelchair) that improves the mobility. A counter argument is that the provision of a wheelchair is essentially treatment and therefore relates to the intrinsic nature of the condition. Even if this point were conceded, however, moving the 'treatment' one step further away from 'within the skin' is not hard. Wheelchairs alone are of no use unless the environment is designed to support their use. Australia has building codes and laws covering equity of access for people with disabilities, which mean that wheelchairs are a useful intervention to improve the mobility (Reidpath et al. 2001). In Cameroon, the basic infrastructure to support the free movement of a wheelchair is not available. So, the provision of a wheelchair in one context would not have the same 'treatment effect' that it would have in another context (Reidpath et al. 2001).

Pain provides another important 'within the skin' example. Stressful environments (including stressful social and cultural environments) are known to increase levels of chronic pain (Markenson 1996; Varni et al. 1996). Reducing external stress not only improves the ability to cope with a certain level of pain, it also decreases the pain itself. The 'within the skin'

position that argues against contextual factors is, therefore, largely indistinguishable from the mainstream DALY view (Murray 1996; Mathers 1997; Mathers et al. 1999).

The DALY and equity

The technical problems associated with using a fixed disability weight and the restriction of the contextual information to 'an average social milieu' (and age) could, arguably, be tolerated if this made the measure more equitable (i.e. fair). Explicit social choices that favour the inclusion of some (contextual) factors such as income, race, religion or ethnicity in the measurement of the burden of disease could, for instance, lead to the unjust allocation of health resources (Murray 1996; Murray and Acharya 1997). This was illustrated with a case involving two patients, identical in all respects except that one was rich and the other poor. When they simultaneously arrive at a hospital accident and emergency department in a meningitis induced coma, what rule should be used to decide who should receive priority treatment? It was argued that we should be completely indifferent to one person over the other in order to avoid making a statement about the value of a rich person compared with a poor person (Murray 1996, p.7). For the measure to be equitable, so the argument goes, the burden of the meningitis in the rich person must be valued the same as the burden in the poor person.

Although intuitively appealing, the argument has a number of problems. For instance, it makes no distinction between treating people fairly and treating people the same; conflating equity and equality. Furthermore, the type of equality sought by the argument is in the domain of resource allocation (i.e. the treatment of a health condition) and not in the measurement of the burden of disease. Everyone with a particular health condition without regard to the context of that health condition is to be *treated* equally. Equality, however, can occur over any number of domains such as equality of opportunity or equality of income. Equality in one domain will often result in inequality in another (Sen 1992).

An alternative domain over which the DALY could have sought equality was in the assessment of the gains and losses attributable to the health state (i.e. the impact of the health state on the lived experience). By taking account of the effect of context on the impact of a health condition, one could achieve an equally egalitarian measure, but over a different domain. Thus, two people would have equal disability weights for a condition if, after taking into account social, cultural and environmental factors, the impact of the condition was the same. Taking context into account may reduce the egalitarian flavour of the DALY with respect to resource allocation; however, it would improve the egalitarian flavour of the DALY with respect to accounting for the impact of health conditions. Furthermore, a measure that included context would, in measurement terms, have improved validity over the current DALY because it would more closely reflect the realities of the burden of disease.

Most importantly, the measure would be more equitable (i.e.

fair) because it would reflect the realities of life with a health condition and not arbitrarily discount the burden of a health condition in one context over the burden of the same condition in another context.

Social determinants and the DALY

Some critics of the DALY have argued that it is too biomedical in its focus and that it does not permit an analysis of the social determinants of health (Barker and Green 1996; Anand and Hanson 1997, 1998; AbouZahr 1999). This criticism has been rejected, however, on the grounds that it relies on a conceptual fallacy (Mathers 1997, p.21). The critics, so the counter argument goes, have failed to realise that an outcome measure of population health need not include all the important determinants of that outcome in order to be used in analyses that look at the relationship between the determinants and the outcome measure itself (Mathers 1997). Indeed, if the social determinants occurred on both sides of the equation, the analyses would be of little value. It would be like looking for predictors of poverty when level of income was used as both a marker of poverty and as a predictor of it.

We argue, however, that this counter argument is itself based on a misunderstanding. In order to detect a relationship between two measures they must co-vary. If a single disability weight is used for each health condition, it is by definition fixed in all contexts and cannot co-vary with any of those contextual factors. Any analysis, therefore, of the effects of context on the impact of a health condition (if a fixed context disability weight is used) will necessarily show no association.

There has been a failure to recognize that two different types of social determinants of the burden of disease exist. There are (a) the social determinants of the occurrence of the health condition and (b) the social determinants of the severity and impact of the health condition. For instance, one social determinant of the occurrence of paraplegia is the strength of the regulatory environment, particularly as it relates to such things as occupational health and safety, industrial codes of practice and road safety. A social determinant of the impact of the condition, however, is the level of infrastructure available that makes *living* with paraplegia easier or harder. The former type of social determinant is recognized (e.g. Mathers 1997), but not the latter.

HIV/AIDS provides a further example of how the two types of social determinants differ from, and yet can be related to, each other. The level of stigmatization in some societies negatively affects the lives of those who are HIV positive and thus increases the negative impact of the condition – a social determinant of the impact of the disease. Stigmatization also drives the disease underground and makes it harder to deliver health promotion/safe-sex campaigns, which in turn increases the population's risk of infection – a social determinant of the occurrence of disease.

By ignoring the social determinants of the impact of a health condition, a critical opportunity is lost to avert some of the burden associated with disease. The use of the fixed context

disability weight hinders the accurate measurement of population health, and therefore interferes with the possibility of sound management. Simply put, if one does not recognize the negative effect that contextual factors can have on a health state, then any interventions that address those contextual factors and minimize the negative effects of disability (without changing the actual incidence of a disease) will be seen as wasteful because they do not reduce the burden of disease as measured by a fixed context measure such as the DALY.

Conclusions

The conceptualization of the DALY as it currently stands contains a number of social preferences including an age adjustment and a sex weighting. Disagreements in the public health arena about social preferences are important; however, it is unlikely that they will ever ultimately be resolved. The DALY makes a number of technical assumptions, one of which is that regional estimates of the burden of disease can be compared only if a fixed context disability weight is used for each health condition. This assumption is demonstrably flawed, and undermines the credibility of the DALY in its current form as a valid measure of population health.

It appears likely, for instance, that a fixed context disability weight will underestimate the burden of disease in populations that lack social infrastructure and overestimate the burden in well-resourced populations (see, for example, Reidpath et al. 2001). Of particular concern is that measures such as the DALY that utilize fixed (or no) context disability weights will be unable to detect changes in the impact of health conditions that are attributable to changes in the social, cultural or environmental context. This effectively gives little value to interventions that address those unmeasured contributors to the burden of disease. The problem for health researchers, health policy makers and health managers is not with the use of disability weights, it is with their measurement and application. As things stand, the WHO has promulgated a measure that embodies a raft of assumptions, including the disability weights, which (for all the counter rhetoric) remain poorly understood and largely unexamined.

Endnote

¹ Formerly referred to as Disability Adjusted Life Expectancy.

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Biographies

Daniel D Reidpath, Ph.D., is a Senior Research Fellow in the School of Health Sciences, Deakin University, Australia.

Pascale A Allotey, Ph.D., is a Senior Research Fellow in the Key Centre for Women's Health in Society, Department of Public Health, University of Melbourne, Australia.

Aka Kouame, Ph.D., is Director of Research at the Institut de Formation et de Recherche Demographiques, Cameroon.

Robert A Cummins, Ph.D., is Professor of Health Psychology in the School of Psychology, Deakin University, Australia.

Correspondence: Daniel D Reidpath, School of Health Sciences, Deakin University, 221 Burwood Hwy, Burwood, VIC 3125, Australia. E-mail: reidpath@deakin.edu.au