

Disability and Disability-Adjusted Life Years: Not the Same

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Because the disability-adjusted life year (DALY) measure is used in varied public health contexts, public health professionals need to understand how it relates to contemporary understandings of disability.¹ The DALY was developed as a measure of population health so that nonfatal outcomes could be considered alongside mortality in the prioritization of health resources.^{2,3} DALYs have been used to assess the magnitude of disease, health risks, and premature death both globally⁴⁻⁶ and at the national and local levels.⁷⁻¹⁰ DALY estimates have also been used to make the case for primary prevention programs for disorders such as stroke¹¹ and in recommending priorities for funding allocations.¹²⁻¹⁵ Although DALYs are not endorsed by leading U.S. experts for use in economic evaluation,¹⁶ they are commonly used in cost-effectiveness analyses of public health interventions in low- and middle-income countries¹⁷⁻¹⁹ in accordance with guidance issued by the World Health Organization (WHO)^{20,21} and the World Bank.⁵

Our concern is that DALYs are incorrectly used to measure the magnitude, burden, or causes of disability. We argue that DALYs measure the perceived desirability of different health states and not disability as the term is used in public health practice. DALYs are composed of two components: (1) years of life lost due to premature death and (2) years lived with disability (YLD) associated with nonfatal injuries and disease (Figure).^{2,3} YLD is calculated as the discounted present value of years lived in a condition multiplied by a disability or severity weight for that condition assigned on a scale from 0 (representing perfect health) to 1 (representing death). Weights closer to 1 imply that a year spent in that condition is perceived as being more equivalent to death than to a state of health. Because YLD is based on perceived desirability rather than measures of activity limitations, we do not believe the DALY meaningfully measures disability.

We support the International Classification of Functioning, Disability, and Health (ICF) adopted by the WHO in 2001,²² which is the internationally approved framework of concepts and measures of disability. The ICF is complementary to the International Classification of Diseases (ICD), which does not address the functional impact of health conditions. In the ICF, disability refers

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Figure. How DALYs are calculated

Formulas for DALY calculations without discounting or age weighting

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

$$\text{YLL} = N * L_1$$

$$\text{YLD} = I * \text{DW} * L_2$$

Source: World Health Organization. National burden of disease studies: a practical guide. Edition 2.0. Geneva: WHO; 2001.

DALY = disability-adjusted life year

YLL = years of life lost

YLD = years lived with disability

N = number of deaths

L_1 = standard life expectancy minus age of death

I = number of incident cases in reference period

DW = disability weight

L_2 = average duration of condition

to functional or structural impairments, limitations in personal activities, and restrictions on social participation within the context of environmental factors. That is, disability denotes the negative outcomes of the interaction between an individual's health condition and contextual factors (environmental and personal factors) that may affect his or her health.²² Injuries, illnesses, and developmental problems can be associated with varying degrees of impairment, activity limitation, and limitation in social participation, depending on the affected person's quality of health care, social and physical environment, and accumulated experience over time. Consequently, one cannot equate specific medical diagnoses or conditions with functional limitation. Likewise, people who have impairments can and do lead varied and healthy lives with the help of appropriate environmental accommodation, rehabilitation, and support.²³⁻²⁵

In contrast with the ICF, DALYs assume a causal link between an injury or disease state and disability and do not involve an empirical assessment of the functional or activity limitations actually experienced by those affected by injury or disease. A given medical condition is assumed to have the same impact on a person's YLD regardless of the social, economic, and built environments in which that person lives.^{1,4} Most importantly, the weights used to calculate YLD do not directly measure limitations in functioning, activity, or social participation. Rather, as explained further in this article, they reflect how experts perceive the relative desirability and economic value of different health

states and the quality of life experienced by people in those health states, not disability as understood in the ICF.²²

The prevalence of disability in a population is typically measured through questions about limitations in activity or functioning included in population surveys. In general, limitations are associated with a wide range of physical or mental conditions that may limit a person's vision, hearing, mobility, cognition, or ability to take care of personal needs. National surveys in the United States, Canada, and Australia, such as the 2000 U.S. Census long-form survey, Canada's Participation and Activity Limitation Survey, and the Australian Survey of Disability, Ageing, and Carers, use functional indicators of disability.²⁶

THE EVOLUTION OF DALYS

DALYs were first employed in the 1993 *World Development Report*²⁷ and the Disease Control Priorities Review.²⁸ Murray and Acharya² referred to this as the "preliminary" version of the DALY indicator, which is no longer in use. The developers of the preliminary DALY defined six disability classes based on presumed deficits in physical functioning (Table 1),²⁹ from a reduction of at least 50% in functional ability to perform at least one recreational, educational, reproductive, or occupational activity (disability class 1) to needing assistance with activities of daily living such as eating, personal hygiene, or toilet use (disability class 6). Medical experts assigned a weight to each class, on a scale of 0 (perfect health) to 1 (death) and assigned selected ICD, Ninth Revision (ICD-9) diseases or injury states to these classes. For example, deafness was assigned to disability class 3 (weight 0.400), and half the cases of mental retardation were assigned to class 2 (weight 0.220) and half to class 3 (weight 0.400).

In response to criticisms that the original DALY measure did not reflect trade-offs between death and health states,^{2,30} the 1990 Global Burden of Disease (GBD) report, published in 1996,⁴ used a revised DALY measure that has supplanted the original DALY. The revised measure differed primarily in how disability weights were derived to estimate YLD. In a person trade-off (PTO) process, panels of health professionals were asked to assess the expected relative burden of 22 indicator conditions in two trade-off exercises. In one exercise (PTO1), they were asked to trade off extending the lives of different numbers of "healthy" people and people with a condition such as blindness. In the second exercise (PTO2), participants were asked to choose between prolonging life for one year for people with perfect health and restoring to perfect

Table 1. Definitions of six classes of disability used in determining DALYs and the weights assigned to each

Class	Description	Weight
1	Limited ability to perform at least one activity in one of the following areas: recreation, education, procreation, or occupation	0.096
2	Limited ability to perform most activities in one of the following areas: recreation, education, procreation, or occupation	0.220
3	Limited ability to perform most activities in two or more of the following areas: recreation, education, procreation, or occupation	0.400
4	Limited ability to perform most activities in all of the following areas: recreation, education, procreation, or occupation	0.600
5	Needs assistance with instrumental activities of daily living such as meal preparation, shopping, or housework	0.810
6	Needs assistance with activities of daily living such as eating, personal hygiene, or toilet use	0.920

Source: World Bank. World development report 1993: investing in health. New York: Oxford University Press; 1993.

DALY = disability-adjusted life year

health a different number of people with the same condition used in PTO1.¹ If the results of the PTO1 and PTO2 exercises differed, participants were forced to reconcile their estimates.^{31,32} Published critiques of the PTO method employed in the GBD are detailed in the literature.³¹⁻³⁵

The 22 indicator conditions reflected various manifestations of morbidity (e.g., physical, neuro-psychiatric, pain, sexual/reproductive, and social). The indicator conditions were grouped into seven bands, with ranges of severity weights for each band (Table 2). Next, panel members used their professional judgment to assign other conditions to the seven bands or “disability” categories on the basis of their perceived similarity to the 22 indicator conditions.

A relatively high DALY weight for a condition means that panels of health professionals, who were asked to speak on behalf of society, placed a lower value on one year lived in that condition than on one year lived in other health states. As the WHO manual put it, “. . . on average, society judges a year with blindness (weight 0.430) to be preferable to a year with paraplegia (weight 0.570), and a year with paraplegia to be preferable to a year with unremitting unipolar major depression (weight 0.760).”²¹ These weights imply that society believes that one year of living in good health (1 year \times 1.000–0.000 disability weight = 1.000 DALY) is more valuable than two years of living with paraplegia (2 years \times [1.000–0.570 disability weight] = 0.860 DALY). A number of authors have addressed the ethical implications of these trade-offs, including the question of whether society really puts a lower value on extending the life of people with disabilities than people in “perfect health.”^{1,30,31,34-38}

In the GBD 1990 study, disability weights for selected conditions and sequelae were adjusted according to whether a person was assumed to have received medical treatment and whether the treatment was believed to have led to remission. For example, the disability weight was 0.583 for patients with untreated bipolar disorder and 0.383 for treated bipolar patients who remained depressed.⁴ For most disabling conditions (e.g., spina bifida, limb loss, or spinal cord injuries),

Table 2. Disability classes and weights for 22 indicator conditions

Class	Severity weights	Indicator conditions
1	0.00–0.02	Vitiligo on face, weight-for-height <2 standard deviation
2	0.02–0.12	Watery diarrhea, severe sore throat, severe anemia
3	0.12–0.24	Radius fracture in stiff case, infertility, erectile dysfunction, rheumatoid arthritis, angina
4	0.24–0.36	Below-the-knee amputation, deafness
5	0.36–0.50	Rectovaginal fistula, mild mental retardation, Down syndrome
6	0.50–0.70	Unipolar major depression, blindness, paraplegia
7	0.70–1.00	Active psychosis, dementia, severe migraine, quadriplegia

Source: Murray CJL, Lopez AD, editors. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries, and risk factors in 1990 and projected to 2020. Cambridge (MA): Harvard University Press; 1996. p. 40.

disability weights reflected the assumption that no improvement in functioning occurred as the result of rehabilitation or environmental accommodation. It has been argued that this assumption constituted a bias against rehabilitation interventions for people with disabilities,²⁵ although in principle disability weights could be modified on the basis of data on the effectiveness of rehabilitation therapies.

DISCUSSION

The main reason for the widespread use of DALYs is that they provide a means of comparing the health impact of a wide range of medical conditions through the use of a standardized set of disability weights.³⁹ However, the disability weights do not measure disability as the term is understood by public health organizations.¹ This includes both the ICF definition of disability adopted in 2001 and the definition of disability in use at the time the DALY measure was first developed. In a 1980 trial framework for disability, the International Classification of Impairments, Disability, and Health (ICIDH), disability was defined as the impact of impairment on a person's functional ability, and handicap was defined as the limitations in social roles and activities experienced by a person with a "disability."²⁶ Murray and Lopez acknowledged that disability classes 1 through 3 in their system (Table 1) had no counterpart in the ICIDH.⁴⁰ Neither handicaps nor disability were actually measured by their system, but were instead assigned by experts on the basis of their judgments and clinical experience. At the time the DALY was unveiled in 1993, its developers stated that revised DALY estimates would be prepared with the use of survey data on the association between disability and various health conditions,²⁷ but that never happened. Empirical indicators of activity limitations and restricted social participation based on population surveys have recently been developed that reflect ICF-based concepts of disability.⁴¹

Another issue of concern to people with disabilities and those who work on disability and health issues is that DALYs are based on health experts' perceptions of the level of well-being associated with various conditions, not on the reported experience of people who have a disability.³⁷ The rationale for excluding people with disability from the DALY rating process was that they typically overstate their quality of life relative to how nondisabled people perceive it to be and that the perceptions of the latter are more appropriate to use.⁴ However, a similar exclusion of individuals on the basis of their gender or ethnicity would most certainly be deemed unacceptable.

Researchers have reported that people typically have great difficulty accurately envisioning the experience of people in conditions substantially different from their own.^{42,43} Several studies have reported that the values assigned to disabling conditions by people without disabilities are likely to reflect their perception of the undesirability of developing a disabling condition.^{33,36,44,45} Disability should be measured empirically through population surveys rather than assumed to affect people with certain diseases or impairments.

Part of the confusion over terminology reflects the evolution of the DALY concept. The original DALY measure in principle included indicators of activity limitations, although limitations were assumed to be associated with specific diseases and not empirically measured. The term *disability* was less applicable to the final DALY measure used in the GBD 1990 study, which reflected the desirability of various health-related conditions as perceived by nondisabled experts.³⁷ In *National Burden of Disease Studies*, the WHO stated, "The disability weights used in DALY calculations . . . quantify societal preferences for health states in relation to the societal 'ideal' of optimal health."²¹ We believe that only a population-based sample (not panels of experts) can yield valid estimates of "societal preferences."³⁸

An example of low correspondence between YLD and empirical estimates of disability is depression, which is the leading contributor to YLDs worldwide and the fourth-leading contributor to DALYs.⁵ Others have used these estimates to rank depression as the leading cause of disability.⁴⁶ However, although unipolar depression is certainly an important source of ill health, indicators of disability based on function and participation rank depression lower as a cause of disability.⁴⁷ For example, a Centers for Disease Control and Prevention study that analyzed data from the 1996 Survey of Income and Program Participation reported that mental and emotional problems, including depression, collectively ranked seventh as a cause of disability among U.S. adults.⁴⁸ The two health conditions most often associated with disability were arthritis or rheumatism and lower-back or spine problems. Similarly, an analysis of records from nine U.S. employers found that the five chronic conditions most often associated with absences among employees were, in descending order of frequency, hypertension, rheumatoid arthritis, bipolar disorder, chronic obstructive pulmonary disease, and lower-back disorders, and the five conditions most often associated with short-term work disability (in descending order) were lower-back disorders, heart disease, rheumatoid arthritis, bipolar disorder, and hypertension.⁴⁹ Depression ranked eighth in association with absences and sixth in association with short-term

disability. We lack consistent methods for the reporting of diagnoses and functioning.

Appropriate DALY estimates should reflect heterogeneity in health and functional limitations among people with a given medical diagnosis. The GBD study assumed a single weight for most diagnoses and some, such as major depression or bipolar disorder, might presume relatively severely affected individuals.^{33,50} A better approach would specify weights based on disease stages and complications. For example, the Dutch Disability Weights study estimated a weight of 0.070 for type 2 diabetes, with weights of increasing severity for complications, such as a weight of 0.170 for moderate vision loss and 0.430 for severe vision loss.^{51,52} An Australian burden of disease and injury study^{8,52} used the Dutch weights, including 0.270 for mild dementia (with impairments in daily activities of living), 0.630 for moderate dementia (unable to live independently), and 0.940 for severe dementia (requiring permanent supervision). The GBD study assumed a single weight of 0.730 for adults with dementia, with the same weights used in U.S. studies.^{9,10}

CONCLUSION

Despite the terminology, YLD does not measure limitations of functioning, activity, or social participation that by international consensus define disability. The impacts of disease vary across countries and socioeconomic strata, which invalidates the use of YLD estimates as measures of disability. Because DALY and YLD estimates do not measure limitations experienced by people, the most important medical factors underlying disability could receive less funding if DALYs were used to allocate funds across conditions than if direct measures of functioning were used.⁴⁷

We urge public health professionals to avoid using currently formulated DALYs (or the YLD component) to assess the impact of disabling conditions. Measurement of limitations of functioning, physical activities, and social participation derived from information gathered from those affected is essential to the development of meaningful measures of disability. Such an endeavor should be a high priority.

The findings and conclusions in this article are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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