

Editorial

## **Does blindness count? Disability weights for vision loss**

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How important is blindness? Is being blind 17%(1) or 60%(2, 3) as bad as being dead? More importantly, why is there such disagreement?

These numbers are from disability weights. They were introduced by the Global Burden of Disease (GBD) Study (1990) to give a new population health measure, the disability adjusted life year (DALY).(2) DALYs aimed to capture a societal assessment of the burden of disease resulting from premature mortality and the non-fatal consequences of disease and injury.(2) Their concern was for social justice and the association between the health states resulting from disease, and lost welfare, subjective wellbeing and quality of life.(2) DALYs differed from quality adjusted life years (QALYs), which measure individual preferences for time spent in different health states.(4) DALYs aimed to facilitate a more explicit and consistent comparison of health outcomes for health sector evaluation, and resource allocation.

DALYs are the sum of years of life lost (YLL) due to premature mortality and years lived with disability (YLD). Calculation of the latter includes the disability weight – a number on a scale from 0 to 1.0. A weight close to zero indicates a state of minimal impact, whilst a weight close to 1.0 indicates a state so severe its impact is almost as bad as death. Disability weights are obtained from ordinal measurement of preferences (paired health state comparisons). Advanced modeling transforms these data into weights. To date, eight studies have estimated disability weights for blindness (Table 1),(5) using different approaches.(1-3, 6-10). These weights vary from 0.60 in the original GBD study to 0.19 in the 2010 GBD study. This 3-fold reduction in the recent GBD disability weight reduces the apparent importance of cataract blindness(11, 12), questioning the validity of the disability weights. Applying the weights from the original and 2010 GBD studies gives very different estimates of the effectiveness of cataract surgery: In one study, from 2599 DALYs averted (disability weight 0.60 for blindness) to just 156 DALYs averted (disability weight 0.033 for moderate distance vision impairment).(13)

There are a number of possible explanations for the discrepancy. In our opinion, the most significant is the change from rating “disability” to rating “health”. Health, as

conceptualised by the World Health Organisation (WHO), is a multidimensional construct, defined as, "*a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.*" In the original GBD Study six weights captured 'loss of wellbeing'; blindness was assigned a weight of 0.60.(2) These were defined in reference to limitations in ability to perform activities of procreation, occupation, education and recreation or needing assistance with activities of daily living. Fundamentally this is the measurement of disability. In contrast, the recent GBD Studies(9, 10) framed questions about 'loss of health'. Although this resulted in only small changes to the disability weights for most disease states, for disabling conditions, including vision and hearing loss, the reduction was dramatic, attributed by some to the change in construct (14, 15). This is not surprising; blind people often say, "I am not sick, I just can't see!"

A second factor is variability in the description of different effects of the "disease". The original GBD Study (1990) defined blindness as, "*maximal visual acuity of less than 3/60 with the best possible correction,*" resulting in, "*limited ability to perform most activities in all of the following areas: recreation, education, procreation or occupation.*"(3) The recent GBD studies defined blindness as, "*completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance.*" (See Table 2)(9, 10) After criticism of some of the GBD 2010 disability weights, including those for vision loss,(14)(15) the GBD 2013 study tested a revised lay definition for some conditions. For example, the revised definition for deafness included a more explicit description of social isolation. When retested, the weight changed dramatically from 0.09 to 0.32, leading to the conclusion that, "*in some cases, responses are evidently highly sensitive to particular details in these descriptions*".(10) The definition for blindness was not modified in the GBD 2013 study and the weight changed negligibly, from 0.195 to 0.187, in comparison to that reported in the GBD 2010 study.(9, 10)

A third factor for the variability in disability weights may be the way questions were asked in different studies. Comparing two health problems with different limitations requires complex judgment about which characteristics are more important.(10, 14)

The recent GBD studies asked who, of two hypothetical people, was 'healthier' (See Table 2).(9, 10) A definition was given at the start, but not repeated for each of the 14 paired comparisons, so respondents may not have retained the intended definition of 'health' all the way through.(14)

A fourth factor may be differences in the respondents in different studies. The original GBD study used medical or health experts. Others, including the recent GBD studies, used members of the general public, with no expectation of understanding of health conditions, who may not have been population-representative.

A fifth factor may be the different valuation methods used; paired comparison, population health equivalence, person trade off, or a visual analogue scale. The potential impact of these different approaches is unknown. To add further potential confusion, the DALY itself is not a single measure, but combines YLL and YLD, which may vary with different combinations of data on prevalence, incidence, and life expectancy,(16) adding complexity when comparing conclusions from different studies.(16, 17)

The downgrading of the disability weight for blindness has considerable consequences. Over the past two decades both the disability weight and the DALY have gained credence as important advocacy tools to highlight the burden and impact of disease at a population level. DALYs and QALYs have been used in 825 national studies to demonstrate that surgical interventions are cost-effective global priorities.(18) Disability weights have been used to estimate the potential global productivity loss associated with uncorrected refractive error,(19) and with uncorrected presbyopia.(20) Multiple organisations advocate 'DALYs averted' as bottom-line performance metrics for guiding strategic and resource prioritisation decisions in relation to competing public health interventions.(21, 22)

In the ranking of the global burden of DALYs by cause, the recent GBD Studies ranked cataract and other blinding eye diseases much lower than in the original GBD study,(23) sparking controversial debate, even between the GBD Core and Vision

Loss Expert Groups.(15, 24) The ophthalmic community has been left in a state of understandable confusion. Which summary outcome measure should be preferred for advocacy, benchmarking and resource allocation decisions at the population level? If the DALY is a useful metric, which disability weight should be used to calculate it?

The WHO has not endorsed the recent GBD disability weight for blindness, given the significant and unexpected reduction in its value, and proposes an alternative weight of 0.338 obtained from modeling utility data.(25) Understanding the context of deriving disability weights is important, as is recognising that the recent weight for blindness, 0.19, represents a valuation of health loss rather than disability.(26) Further empirical research is needed to better understand societal valuations of blindness, by isolating the impact of what questions are asked and how, and through ensuring conceptual clarity on the key construct under investigation (is it disability or is it health?).

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## TABLES

**Table 1:** Summary of studies estimating a disability weight for blindness

First author	Year	Region	Panel	n panel	n health states	Valuation methods	DW (95% CI)	Construct in the question
Murray(2)	1994	Global	Independent experts	NS	6	Magnitude estimation	0.6	Disability
Murray GBD 1990(3)	1996	Global	Medical experts	10	483	PTO and VAS	0.6 (0.50 – 0.70)	Disability
Stouthard (6)	1997	Netherlands	Medical experts	38	175	PTO and VAS	0.43 (0.34 - 0.52)	Disability
Baltussen (7)	2002	Burkina Fasso	Health professionals, Population	39 lay people, 17 health workers	9	Culturally adapted VAS	0.36	Disability
Lai (8)	2009	Estonia	Medical experts	25	283	PTO and VAS	0.478	Disability
Salomon GBD 2010 (9)	2012	Global	Population-based samples	30,230	220	PC and PHE	0.195 (0.132-0.272)	Health loss
Haagsma GBD Europe (1)	2015	Europe (4): Sweden, Italy, Netherlands, Hungary	Population (quota sampling of internet panels, population representative , 18-65 years)	30,660	255	PC and PHE	0.173 (0.145 -0.213)	Health loss
Salomon GBD 2013 (10)	2015	Global	Population (combined data)(7, 8)	60,890	183 or 235	PC	0.187 (0.124 - 0.260)	Health loss

GBD = Global Burden of Disease, PC = Paired comparison, NS= Not specified, PTO=person trade off, VAS=visual analog scale, PHE = Population Health Equivalence

**Table 2:** Example of paired comparison question used in GBD 2013 Study(10) to determine a disability weight for two disease effects, distance vision blindness and severe neck pain

Example of GBD 2013 Paired comparison question	GBD 2013 disease effect and disability weight
<p>"Now, we want to learn how people compare different health problems.            A person's health may limit how well parts of his body or his mind works. As a result, some people are not able to do all of the things in life that others may do, and some people are more severely limited than others. I am going to ask you a [series of] question[s] about different health problems. In each question I will describe two different people to you. You should imagine that these two people have the same number of years left to live, and that they will experience the health problems that I describe for the rest of their lives. I will ask you to tell me which person you think is healthier overall, in terms of having fewer physical or mental limitations on what they can do in life. Some of the questions may be easy to answer, while others may be harder. There are no right or wrong answers to these questions. Instead we are interested in finding out your personal views.</p>	
<p>The first person is completely blind, which causes great difficulty in some daily activities, worry and anxiety, and great difficulty going outside the home without assistance</p>	<p>Distance vision blindness            0.187 (0.124-0.260)</p>
<p>The second person has constant neck pain and arm pain, and difficulty turning the head, holding arms up, and lifting things. The person gets headaches, sleeps poorly, and feels tired and worried</p>	<p>Severe neck pain            0.304 (0.202-0.415)</p>
<p>Who do you think is healthier overall, the first person or the second person?"</p>	