


# Context matters for disability and priority setting for musculoskeletal diseases: revisiting the egalitarian approach to disability weights and disability-adjusted life-years

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## ABSTRACT

Health metrics have evolved with increasing sophistication. The disability-adjusted life-year (DALY) has emerged as a widely used metric. While DALYs vary between countries, the global disability weights (DWs) that are integral to the DALY ignore the potential impact of local factors on the burden of disease. Developmental dysplasia of the hip (DDH), a spectrum of hip pathologies, typically develops during early childhood and is a leading cause of early hip osteoarthritis. This paper explores the variability in the DW for DDH in relation to local health environments using select health system indicators. The DW for DDH increases with decreasing income level of countries. The Human Development Index and the Gross Domestic Product per capita are both negatively correlated with ( $p < 0.05$ ) the DW for DDH per country. For the indicators surgical workforce, surgical procedures and hospital beds per 1000 population, there is a significant negative correlation in countries not meeting the minimum standard of that indicator ( $p < 0.05$ ), while for countries meeting that minimum standard, the correlation between DW for DDH and the respective indicator is not significantly different from zero.

Consideration should be given to re-establishing the DWs for health entities in countries that do not meet the minimum standards of a functional health system. This would more accurately reflect the burden of disease from a functional perspective in LMICs, and perhaps allow for more informed priority setting within LMICs and for donors. The establishment of these DWs should not start from scratch; our data suggest that the variability in DWs due to context can most likely be modelled using health system and financial protection indicators already in use today.

## BACKGROUND

Since Dempsey first questioned the value of mortality rates as a measure of population health in 1947,<sup>1</sup> health metrics have been scrutinised with a resultant increase in sophistication. Health-adjusted life expectancy,

## SUMMARY BOX

- ⇒ The country-level disability weight for developmental dysplasia of the hip is higher in countries that do not meet the minimum standards of a functional healthcare system.
- ⇒ In countries where mobility aids are sparse, mobility issues are valued as more impactful than in countries with an abundance of aids and support systems available.
- ⇒ Poverty is a disease modifier that impacts how diseases are experienced by patients and how their effects are valued by patients and society.
- ⇒ Taking context into consideration when determining disability weights may significantly impact priority setting for global health programmes in low-income and middle-income countries.
- ⇒ Health system indicators should be considered as a new additional adjustment factor in the calculation of disability weights and disability-adjusted life-years.

health-adjusted life-years, quality-adjusted life-years (QALYs) and disability-adjusted life-years (DALYs): all require some means of quantifying states of less-than-optimal health short of mortality.<sup>2</sup> These means are subject to variation, philosophical differences and criticism.

The DALY aims to quantify and compare the burden of disease across various health conditions by combining years of healthy life lost to disability (YLD) and years of life lost (YLL) due to mortality. The calculation of YLDs relies on the disability weight (DW), a value representing the health burden of a condition by reference to absolute values of 0 (full health) and 1 (a state equivalent to death).<sup>3,4</sup> One difficulty in the quantification of the global burden for a specific disease

involves uniform assessment across communities, despite those communities having vast differences in culture, economic and healthcare resources. While DALY burden from a specific disease often varies between countries due to differences in YLDs and YLLs, global DWs as currently set are a fixed entity across settings. Consequently, they ignore the potential impact for local factors to influence disease burden.

The QALY can be thought of as the inverse of the DALY, as it quantifies years of healthy life while the DALY views years lost. QALYs combine a quality-of-life weight representing a patient's quality-of-life in a certain health state considering the number of years lived in this state.<sup>25</sup> QALYs are predominantly used in cost-effectiveness and cost-utility analyses and rarely used to compare the burden of disease between different diseases. In contrast to DWs, quality-of-life weights are made context dependent and can be calculated using different methods for every country, region or population of interest.<sup>5</sup>

Developmental dysplasia of the hip (DDH), a spectrum of hip pathologies, develops during early childhood and is a leading cause of early hip osteoarthritis in young adults.<sup>6</sup> Untreated DDH impacts patients' quality of life and generates significant disability through pain, reduced mobility and the development of osteoarthritis during peak income-earning years with societal and economic consequences.<sup>7</sup> The relationship between childhood musculoskeletal diseases and development of impaired mobility and osteoarthritis during adulthood is not unique to untreated DDH.<sup>8</sup> Therefore, we believe that untreated DDH can be considered representative of a wider group of childhood musculoskeletal diseases that impact mobility throughout adulthood.

With the creation of the Sustainable Development Goals in 2015 and a shift in the global health community towards strengthening health systems, a number of 'health system indicators' were developed.<sup>9 10</sup> Within the Sustainable Development Goals' framework, the indicators number of beds and out-of-pocket costs for healthcare are essential to all medical specialties. In the field of surgery, the Lancet Commission on Global Surgery identified surgery-specific indicators and minimum standards to be met in any health system globally.<sup>9</sup>

This paper discusses the concept of improved computation of DWs with consideration of the interaction between disability and contextual factors for musculoskeletal diseases. We explore the variability in the DW for DDH in relation to select health system indicators across countries. The data used in this study are drawn from Franco *et al*, which determines the DW for DDH.<sup>11</sup> The complete methodology and data collection procedure is described in the respective article.

The underlying dataset with the corresponding surgical indicators and the survey used in this referenced study can be found in online supplemental file 1. The complete underlying dataset including the raw data can be found in online supplemental file 2.

## POVERTY AS A DISEASE MODIFIER

In the 1990s, when the DALY was developed, global health primarily focused on under-5 mortality, maternal mortality and mortality related to infectious diseases. Three decades later the epidemiological transition in LMICs has shifted attention from merely reducing mortality to reducing morbidity due to a wide variety of non-communicable diseases in addition to infectious disease.<sup>12</sup> For many surgical conditions, especially those that affect disability much more than life expectancy, we would go further, stating that disability cannot be assessed without considering context, the healthcare system, and the wider social security system.

Musculoskeletal conditions have a more significant impact on people living in low-income and middle-income countries (LMICs) compared with high-income countries (HICs).<sup>13</sup> These results are not surprising given resources such as wheelchairs, ramps, special education and specialised medical care that are available in high-income settings though sparse or completely unattainable in LMICs.

The argument that the impact of certain diseases is more significant in poorer countries and among poorer populations is not new. Both Anand and Hanson and King and Bertino argued that the impact of blindness and neglected tropical diseases is modified by poverty and that both diseases are valued as more impactful in areas without an accessible health system.<sup>14 15</sup> Limited data from paediatric musculoskeletal diseases show a similar disease-modifying impact of poverty on disease impact.<sup>16 17</sup>

In this context, it is important to note that poverty does not impact the severity of the disease itself, but rather modifies the severity of the impact experienced by patients. Available data from Mongolia suggests that the disease severity distribution of DDH is not different in a middle-income country than that of a HIC such as Sweden.<sup>6 18</sup> Therefore, calculating different DWs for different severity levels of DDH, which is occurring for several diseases like HIV and multiple sclerosis,<sup>19</sup> will not be able to capture the impact of poverty as a disease modifier as it does not impact the disease severity itself.

## DIFFERENTIATION OF DWS BY INCOME LEVEL

The DW for DDH was assessed through three different methods: ordinal preference ranking with a fixed ranklist, a time-trade-off approach and a Visual Analogue Scale (VAS). The adopted approach to the preference ranking in the underlying dataset uses a fixed reference framework of pre-established DWs. The participant is asked to rank DDH among an ordinal list of diseases with DWs drawn from the 2013 Global Burden of Disease (GBD) study.<sup>3</sup> This allows direct derivation of a DW for DDH based on the diseases' DWs above and below DDH's allocated position in the ranklist by participants.

A time-trade-off method asks participants to choose between 80 years with DDH or X number of years in

perfect health. As long as the participant chooses the option offering <80 years in good health over 80 years with DDH, the questionnaire keeps going. With every iteration the number of years in good health goes down, until an indifference point is reached. Based on the number of years in good health that are values equally by the participant to living 80 years with DDH, a DW for DDH can be deducted.

A VAS asks the participant to point a value on a 10 cm line where the end points are anchored as ‘perfect health’ and ‘death’. The distance of the allocated point to the end point allows for the calculation of a DW for DDH. The VAS methodology is always to be used in combination with other methodologies given its less granular nature in determining the DW. The ordinal preference ranking, time-trade-off approach and VAS methodologies are extensively discussed in the literature<sup>20–23</sup> and will not be discussed further.

It is important to note that the preference ranking methodology bases its calculation of the DW directly on already established DWs and thus is indirectly influenced by the methodology and value-system applied to the generation of the DWs used in the ranklist. In contrast, the time-trade-off approach and VAS methodology are not based on a direct comparison or reference to other diseases or already established DWs and thus take only the value-system of the current participants into consideration.

We calculated weighted and unweighted DWs for DDH. The unweighted DW is the mean DW per methodology. The weighted DW (WDW) considers the proportion of the global population included in each response. This was calculated using the following formula: the total population of a given country ( $p$ ), the individual questionnaire responses ( $D$  for a given methodology and the number of respondents per country ( $r$ ). We generated the following formula to calculate the WDW for different income groups ( $q$ ) who are part of the total surveyed population ( $Q$ ).

$$WDW = \frac{\sum_{i \in q} \frac{D_i \cdot p_i}{r_i}}{\sum_{q \in Q} p_q}$$

The WDW was higher than the unweighted DW for all three methodologies. The WDWs were smaller in the high-income group than in the lower-middle-income group. The WDWs using the preference ranking and the time-trade-off approach methodology are similar for the high-income group. The WDWs using the time-trade-off approach and VAS methodology in the lower-middle-income group and in the weighted global DW are similar as well. The difference in weighted and unweighted DWs using the preference ranking is negligible; this can be explained by the fact that the preference ranking determines the DW for DDH in relation to already established DWs and not solely on the value system of the respondent. Therefore, it can be concluded that there is relative

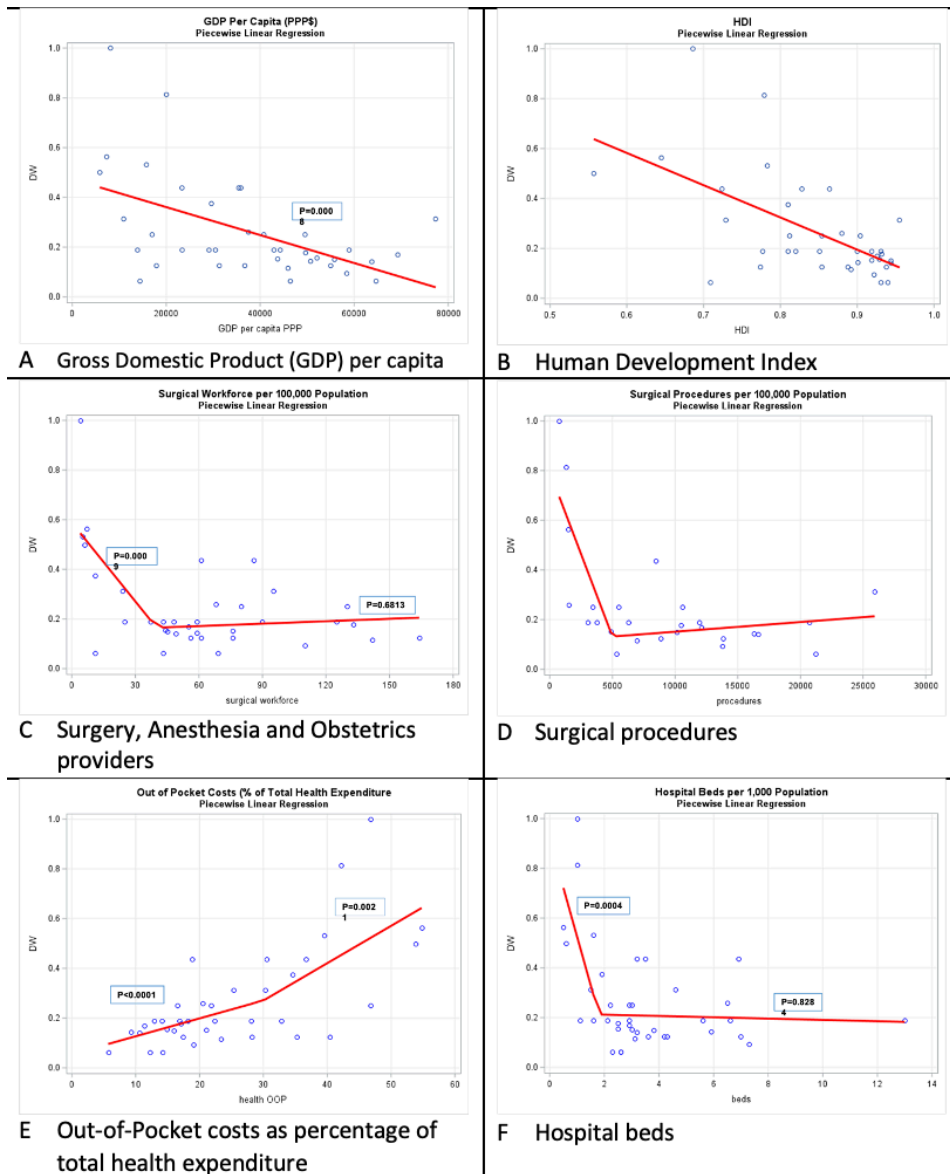
agreement among surgeons globally in how the severity of DDH relates to other diseases.

The DW as calculated using the fixed framework of the PR method, in which DDH is simply compared with other disease processes, was the same across countries regardless of income or other health system indicators. This indicates that there is relative agreement among surgeons globally in how the severity of DDH relates to other diseases. In contrast, the time-trade-off approach and VAS—both based solely on the respondents’ allocated value outside of a fixed framework as used for preference ranking—show an apparent gradient between increasing DWs with decreasing resources, a relationship that is confirmed when plotting the DW against various health system indicators (figure 1). These results suggest that people value a loss of mobility as more impactful in settings where the minimum standards of a functional health system are not met. In this context, DDH can most likely be seen as a proxy for a larger group of musculoskeletal disorders that impact walking and mobility.

### DW AS A FUNCTION OF HEALTH SYSTEM INDICATORS

The correlation between select health system indicators and the DW for DDH per country is assessed with a piecewise linear regression. For the four selected health systems indicators, the association between the DW for DDH and the respective indicator was determined separately for countries meeting the minimum standard of that indicator and for those countries that do not, which generated a piecewise linear regression below and above this cut-off. For the indicators: Human Development Index and gross domestic product, there was no cut-off available to compare to distinct groups, and a piecewise linear regression comparing both indicators and the DW for DDH was done without subgroup analysis. A  $p < 0.05$  in the piecewise linear regression was considered significant.

Figure 1 shows the relationship between selected indicators and the DW determined using the time-trade-off approach for DDH per country. Generating graphs using the DW calculated using the preference ranking and the VAS were not considered useful given the nature of the methodology as discussed above. The Human Development Index (figure 1A) and the gross domestic product (figure 1B) per capita in PPP\$ both have a trendline with a slope significantly different from 0 ( $p < 0.05$ ) when plotted against the DW for DDH per country. For the indicators surgical workforce, surgical procedures and hospital beds per 1000 population, results show a significant negative correlation in countries not meeting the minimum standard of that indicator ( $p < 0.05$ ). For countries meeting that minimum standard, the correlation between the DW for DDH and the respective indicator is not significantly different from 0. No international minimum standard has been set for out-of-pocket expenditure as a percentage of total health expenditure. However, a cut-off of 30% has been proposed in literature, with a significantly higher



**Figure 1** Association between country-level disability weights (DWs) for developmental dysplasia of the hip and selected health system indicators. HDI, Human Development Index.

rate of impoverishment due to healthcare costs in countries where more than 30% of all healthcare costs are paid out of pocket.<sup>24</sup> There is a positive correlation for countries below and above the 30% cut-off, with a steeper trendline in those countries with higher out-of-pocket costs.

These results raise important questions regarding the appropriate methodology for determining DWs and the effect on determining burden of disease and subsequent priority setting in LMICs. Based on this study, preference ranking does not seem to be a valid methodology to apply in LMICs as responses are analysed using high-income or globally averaged comparisons, which seems to undervalue many disease states in non-high-income settings. Though our data imply that the ranking and subsequent prioritisation of diseases achieve reasonable agreement among providers worldwide, it is unclear

how the gradient in these rankings may differ between income levels or countries.

The approach to DW calculations used for the GBD has been reassessed on several occasions to make DWs more representative.<sup>3</sup> However, some form of preference ranking applied as a vignette technique is still the preferred methodology to obtain DWs, given its intuitiveness and easy application.<sup>23</sup> A wide variety of techniques remain in use in the literature.<sup>25</sup> It may be argued that the implementation of the theoretical approach to DWs, unaffected by context as proposed by Murray, while quite sound conceptually, has failed in practice, as the GBD has evolved to be a major determinant in priority setting, and thereby in funding, for health in LMICs. Valuing disability without considering context or one's own experiences has proven to be very difficult, as shown by our data and previous studies by Salomon *et al*<sup>26</sup> and Ponaru

**Table 1** Weighted and unweighted disability weights per income level

	Preference ranking	Time trade-off	Visual Analogue Scale
Unweighted global disability weight	0.143	0.207	0.380
Weighted global disability weight	0.145	0.424	0.477
Weighted high-income disability weight	0.141	0.181	0.363
Weighted upper-middle-income disability weight	0.111	0.419	0.376
Weighted lower-middle-income disability weight	0.155	0.563	0.564

*et al.*<sup>27</sup> Additionally, the utility weight, an entity considering utility and impact and used in QALY calculations to assess loss of quality of life, has been widely accepted as a context-dependent entity. The calculation of utility weights differs in terms of the methods applied. Preference ranking as used in our dataset and vignette techniques as used by the GBD research team are not used. Utility weights are generally based on a combination of time-trade-off methodologies or VAS.<sup>20</sup> For many diseases, the DW approaches 1-(utility weight),<sup>5 28</sup> meaning that they assess the same entity and that disability clearly cannot be assessed without considering utility and impact.

#### LIKE AS LIKE APPROACH

The introduction of the DALY in the literature in 1994 by Murray<sup>4</sup> saw an approach to determining DALYs and DWs rooted in a comprehensive theoretical framework. DWs were to measure disability as a function of human functioning independent of context, and not handicap, a function of impact and utility. Murray argued that human functioning, as a function of a certain disease state is a universal value, and therefore, the DW should be a fixed entity. One of the underlying arguments was that ‘like events’ should be treated as ‘like’.<sup>4</sup> This means that the death or disability of a person should be allocated the same value, irrespective of where they live.

We understand the underlying ethics of this decision, and agree that every life should be valued equally. However, we also believe that adequately valuing human lives and allowing flexibility in DWs should not be irreconcilable. Our data for DDH and previous data collected by Salomon *et al.*<sup>26</sup> have shown that for mobility issues, there is relative agreement across settings on how certain mobility-related diseases are valued against each other. We find, though, that the functional result of these same issues differs markedly among HIC versus LMIC populations. Additionally, Murray feared that the value placed on a certain disability might become dependent on the diseases circulating in the entire community when DWs would be allowed to fluctuate by context and setting. This fear is most likely valid; however, priority setting for disease investment is a community-based exercise and should balance protecting the rights of an individual while considering the broader community’s needs. It should also be noted that the approach of treating ‘like events’-as-‘like’-approach may be equally harmful to those it aims to protect.<sup>15</sup> Transferring the value HICs

place on mobility to LMICs risks severely undervaluing mobility issues. When used as the GBD is used today, this risks stripping individual children from accessing the care they deserve, and risks stripping entire communities from their autonomy to prioritise programmes for the diseases and disabilities that matter most to them. Therefore, we believe that there are more arguments in favour of taking context into consideration when calculating DWs than against.

#### SEVERITY LEVELS AND AGE-WEIGHTING IN DALYS ACROSS CONTEXTS

Murray proposed to adjust for severity levels and differences in value allocation across age-groups in the DALY calculation instead of the DW calculation, keeping the latter a fixed entity.<sup>4</sup> Age-weighting is an integral part of the calculation of the YLLs and YLDs, and adjusts for the higher value people tend to give to diseases that are more prevalent in their own age group. Additionally, YLLs and YLDs will be higher in countries with a poor health infrastructure than in countries with high-quality, affordable and easily accessible healthcare allowing for variability in health system functioning to influence the final calculation of the DALY. As stated earlier, difference in severity levels across countries is addressed by generating different DWs per severity level, and allowing the severity mix to differ per country.<sup>19</sup>

Salomon *et al* showed the need to for age-weighting and differentiation of severity levels in one of his earlier works.<sup>26</sup> People from the general population across several countries were asked to rank a number of diseases and health states relating to mobility issues in terms of severity. There was strong agreement across countries and participants on the ordinal order of severity, however, when participants were asked to allocate a cardinal value for the severity of the diseases in question the allocated values differed based on participants’ age and level of mobility.<sup>26</sup> Furthermore, the allocated values, also differed significantly across countries,<sup>26</sup> an observation not previously considered as an adjustment factor in DW or DALY calculations.

In our dataset, we observe a clear difference across countries when comparing health system indicators in relation to DWs (figure 1C-F). In countries where the respective indicator is met, the DW for DDH stabilises around 0.18–0.20 which is very similar to the HIC DW calculated using the time-trade-off approach methodology (table 1). This

indicates that the health system indicators currently in use could serve as a new component or adjustment factor to be added to the DALY/DW calculation formula. We propose to model LMIC DWs based on the already existing GBD DWs and their underlying data, using the following formula using the established DWs from the GBD study ( $DW_{GBD}$ ), a country-specific adjustment factor ( $a, b, c, d, x$ ) for the unmet health system indicators workforce ( $WF$ ), number of treatments/procedures ( $TM$ ), out-of-pocket expenditure ( $OOP$ ), beds per population unit ( $BED$ ) and any additional health system indicator deemed useful ( $Y$ ).

$$DW_i = DW_{GBD}.a_i.WF.b_i.TM.c_i.OOP.d_i.BED.x_iY$$

### QALYS INSTEAD OF DALYS

From a mathematical perspective, musculoskeletal diseases have very small YLLs as they hardly ever cause mortality. Consequently, the DALY becomes a direct function of the DW and does not differ considerably anymore from the concept of a QALY. Considering that the QALY allows their quality-of-life weight to vary across settings; for non-lethal diseases such as mobility issues, one could argue that QALYs are better suited to capture the loss of quality of life. We strongly argue against using QALYs in global health because of the strength of the DALY in comparing different diseases across settings and its role in generating burden of disease estimates. Low back pain is an example of a musculoskeletal disease that generates a large amount of DALYs globally.<sup>29</sup> Therefore, it is paramount to maintain the ability to compare disease burdens across countries and compare the effect of public health measures and treatment programmes to minimise the impact of low back pain. Consideration should be given to establishing DWs that are adapted to the realities of musculoskeletal diseases around the globe and meets the requirements of musculoskeletal health economic researchers to generate high-quality research on this topic. This exercise should be executed with keeping the current epidemiological transition in mind with sufficient attention to non-lethal diseases such as musculoskeletal diseases.

### LIMITATIONS

Critical thinkers may raise the issue of the representativity of our data, regarding the number of people surveyed in certain countries and the fact that the data were collected surveying health professionals instead of the general population. It is correct that we consider the voice of a small group of respondents in LMICs representative of their entire country. Even though reality on the ground will be more nuanced than what a handful of voices can convey, their views remain infinitely more valuable and representative than any data modelled using HIC data or opinions. By showing that local voices matter and are heard in global health research we also believe local

research initiatives will be strengthened, leading to more representative studies and data samples over time.

### CONCLUSION

Our data suggest that variability in DWs for mobility issue can vary widely across different countries. This variability is most likely due to context and can be modelled using the health system and financial protection indicators used today. Additional research is necessary to see if the relationship between select health indicators and DWs per country holds when using other disability weighty data sets and when using data outside of the field of musculoskeletal health. Consideration should be given to re-establishing the current DWs for countries not meeting the minimum standards of a functional health system to allow for LMICs priority setting practices based on LMICs' values.

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