Scandinavian Journal of Public Health, 2023; 51: 296–300

COMMENTARY

The increasing significance of disease severity in a burden of disease framework

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Abstract

Recent estimates have reiterated that non-fatal causes of disease, such as low back pain, headaches and depressive disorders, are amongst the leading causes of disability-adjusted life years (DALYs). For these causes, the contribution of years lived with disability (YLD) – put simply, ill-health – is what drives DALYs, not mortality. Being able to monitor trends in YLD closely is particularly relevant for countries that sit high on the socio-demographic spectrum of development, as it contributes more than half of all DALYs. There is a paucity of data on how the population-level occurrence of disease is distributed according to severity, and as such, the majority of global and national efforts in monitoring YLD lack the ability to differentiate changes in severity across time and location. This raises uncertainties in interpreting these findings without triangulation with other relevant data sources. Our commentary aims to bring this issue to the forefront for users of burden of disease estimates, as its impact is often easily overlooked as part of the fundamental process of generating DALY estimates. Moreover, the wider health harms of the COVID-19 pandemic have underlined the likelihood of latent and delayed demand in accessing vital health and care services that will ultimately lead to exacerbated disease severity and health outcomes. This places increased importance on attempts to be able to differentiate by both the occurrence and severity of disease.

Keywords: *Burden of disease, severity distribution, DALY,YLD, disability-adjusted life year, years lived with disability, European burden of disease network, disease severity, Scottish burden of disease*

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Date received 16 February 2021; reviewed 7 May 2021; accepted 13 May 2021

DOI: 10.1177/14034948211024478
journals.sagepub.com/home/sjp
SAGE

Recent estimates from the Global Burden of Disease (GBD) 2019 study have reiterated that non-fatal causes such as low back pain, headaches and depressive disorders are amongst the leading causes of disability-adjusted life years (DALYs) [1]. For these non-fatal causes, the contribution of years lived with disability (YLD) – put simply, ill-health – is what drives DALYs, not mortality. Being able to monitor trends in YLD closely is particularly relevant for countries that sit high on the socio-demographic spectrum of development, as it contributes more than half of all DALYs [2].

A recently published GBD capstone paper also highlighted the need to improve upon estimating severity distributions [1]. At present, severity distributions are assumed to be constant over time and location. This means that although the number of people suffering from a health condition may differ, the relative proportion who are suffering, for example, severe health loss is the same. This is also common in many national studies and is largely due to data deficits. It results in a linear relationship between estimates of prevalence and YLD across time and location, with very minor differences attributed to co-morbidity adjustment of YLD estimates. In other words, the prevalence of disease is the only driver in differences in estimates of YLD, which can be illustrated using the example of low back pain (Figure 1(a) and (b)). This is problematic, particularly as some health conditions are increasing not only in prevalence but also in severity [3]. To frame the importance of this, it is useful to think of the other part of DALY calculations: years of life lost to premature mortality (YLL). This would be akin to the number of deaths driving YLL estimates whilst the age distribution of deaths remained constant across time and location.

The last large-scale GBD exercise in estimating the severity of disease was implemented in the GBD 2013 iteration using data from the USA and Australia [4]. The motivation for this exercise was upfront about estimates of disease severity being an inherent weakness in estimates of YLD and acknowledged the potential to 'more precisely and comparably measure the severity distributions of important conditions in different settings'. This exercise used pre-2010 data, which are now more than a decade on from where we are now. It also recognised that severity distributions are likely to differ between countries due to issues such as differences in access to health care, availability and affordability of medication, and social and cultural environments. Furthermore, issues such as inequalities in health literacy can have a marked impact on whether preventative care is sought in a manner which prevents exacerbated disease severity [5]. These can vary significantly for countries with high levels of socio-economic inequality, which may have large implications for sub-national burden of disease estimates.

The contribution of YLD has become increasingly relevant, although the estimation process is perhaps less obvious to users due to its seeming complexity. This highlights the importance of making sure we work to improve the data inputs and users' understanding for all parameters in the calculations. Not only is YLD a key input to estimates of DALYs, it also contributes to estimates of healthy life expectancy. The World Health Organization selected healthy life expectancy as an indicator to monitor The Triple Billion targets due to alignment to Sustainable Development Goal 3 (ensure healthy lives and promote well-being for all at all ages) [6]. Additionally, healthy life expectancy will be used for monitoring each member state in future years.

More recently, the wider health harms of the COVID-19 pandemic have underlined the likelihood of latent and delayed demand in accessing vital health and care services that will ultimately lead to exacerbated disease severity and health outcomes [7]. For example, compared with previous years, hospital admissions in Scotland reduced by 22% during the period March to December 2020 [8]. Additionally, information has emerged to indicate the worsening of some conditions such as mental health and musculoskeletal disorders, which were already leading causes of DALYs [9,10].

There is no silver bullet to improve estimates of disease severity, but the work being carried out within the European Burden of Disease Network (burden-eu) COST Action can provide some inspiration and contribute new insights. In addition, steady progress is being made to estimate national, sub-national and temporal severity distributions for particular health conditions. For example, the Australian Burden of Disease Study uses Australian-specific data to estimate national severity distributions for a number of chronic conditions, as well as by location (state/territory, remoteness) and over time for conditions such as injuries [11]. In South Korea, severity distributions have also been estimated for a range of causes using population surveys [12]. Other examples evidencing substantial relative differences, when compared to the GBD study, can be found from the Scotland Burden of Disease study (SBoD) for cancers and in the German study for headaches [13,14].

It is important that users of burden of disease estimates understand that current YLD estimates lack

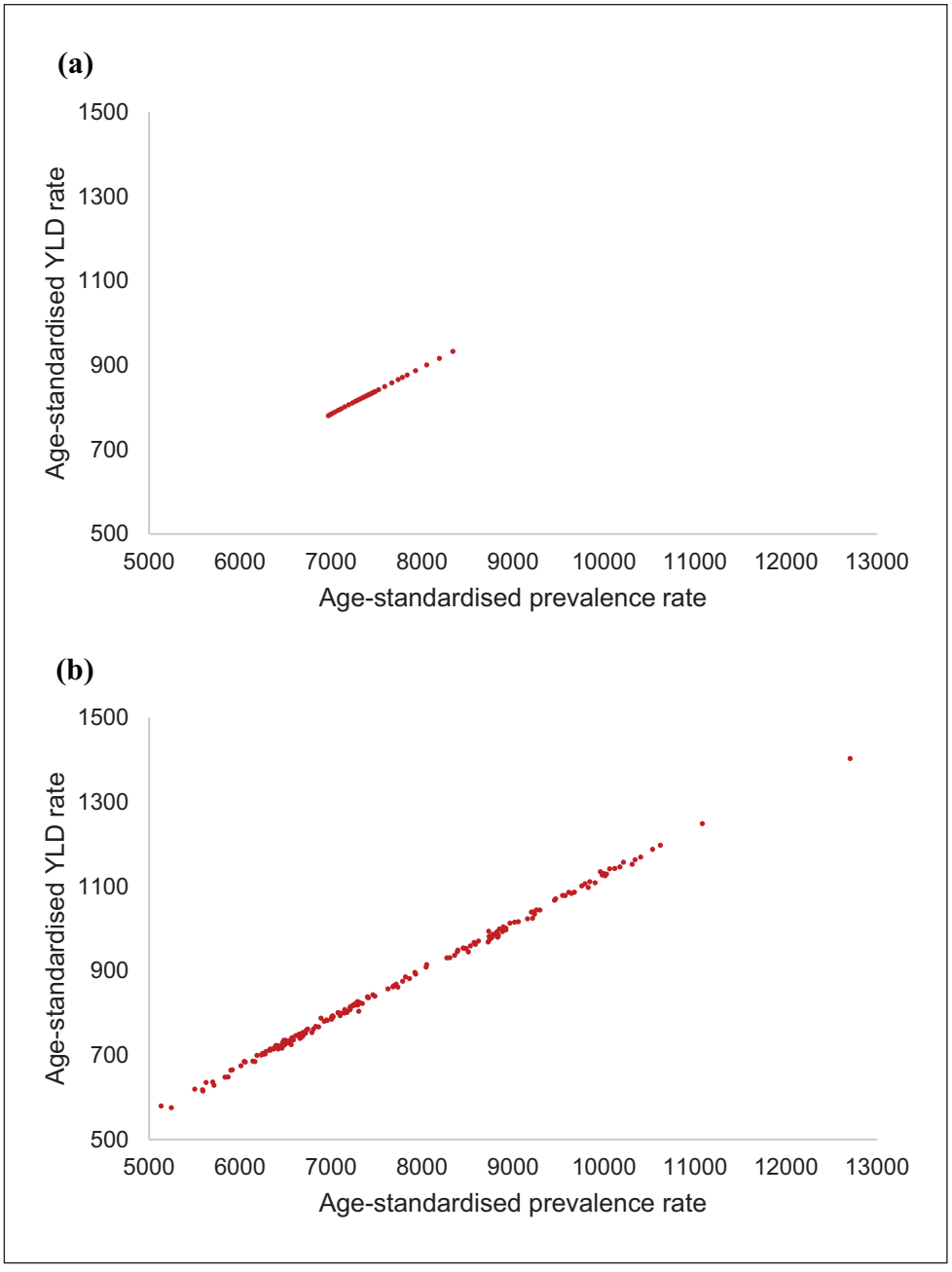

Figure 1. Relationship between the age-standardised prevalence rate and age-standardised years lived with disability (YLD) rate for low back pain by (a) time and (b) location. (a) Global relationship by time, 1990–2019. Each data point represents an annual estimate (total of 30; 1990–2019). Rates illustrated are per 100,000 population. Data extracted from Global Burden of Disease (GBD) study results tool. (b) Relationship across 204 countries and territories, 2019. Each data point represents a country/territory (total of 204). Rates illustrated are per 100,000 population. Data extracted from GBD study results tool.

the ability to differentiate changes in severity across time and location. For national users, we would advise that interpretation of temporal changes in causes with a large YLD component are triangulated with available national statistics or surveys and studies which are nationally representative. We are largely supportive of the idea that a focus in future rounds of the GBD study should be on the large YLD contributors. However, it is also important to acknowledge that health conditions where the health state disability differences are the highest may also warrant immediate attention [15].

On a pragmatic level, a paucity of data and available resources continue to present major barriers to improving estimates of disease severity. Where resources are scarce, it would be sensible not to prioritise severity distributions for causes of disease where the health state disability weights have a small range between the highest and lowest values [15]. Whilst it is unlikely that estimates may not be required on an annual basis, there is certainly an increased need for closer monitoring to assess the likely indirect short- and long-term morbidity shocks from the COVID-19 pandemic [7]. A harmonised approach could be achieved through investing in a specific standardised survey designed to estimate severity distributions. This could be carried out in a similar way to, or integrated into, the European Health Interview Survey to develop specific estimates for many countries [16]. Further opportunities exist for using routine data sources to make progress. Successes in developing country-specific severity distributions in Scotland and Germany have been in areas where the GBD definitions are clear at the health state levels [13,14]. Clear health state definitions that can be implemented on routine data sources (such as health-care service or insurance claims data) are needed. Finally, recognising that this research is not always possible, at a minimum, it would be preferable to ensure that severity distributions are adjusted to reflect differences between the population of a location and the cohort(s) from which the estimates were generated rather than a crude application.

Networks, such as burden-eu, present important opportunities to facilitate conversation and action between those contributing to national burden of disease assessments and those contributing to the GBD study. Increased engagement between the two efforts offer opportunities for how national studies and practices can be incorporated to improve the GBD study and increase certainty and confidence around GBD estimates of DALYs.

Acknowledgements

We would also like to thank COST (European Cooperation in Science and Technology, https://www.cost.eu), as this commentary was conducted within the framework of COST Action CA18218 (European Burden of Disease Network).

Declaration of conflicting interests

The author(s) declared the following potential conflicts of interest with respect to the research, authorship and/or publication of this article: G.W., R.A., E.F., M.G., I.G., J.H., H.H., J.I., T.L., E.L., M.M., E.P., S.P., D.P., M.P., M.S.-M., J.V.S. and B.D. declare that they are members of COST Action CA18218 (European Burden of Disease Network – www.burden-eu.net), a technical platform to integrate and strengthen capacity in burden of disease assessment across Europe and beyond.

Funding

The author(s) received no financial support for the writing, or authorship, of this article.

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Supplemental material

Supplemental material for this article is available online.

References

[1] GBD 2019 Diseases and Injuries Collaborators. Global burden of 369 diseases and injuries in 204 countries and territories, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet* 2020;396:1204–22.

[2] Institute for Health Metrics and Evaluation. GBD results tool. Seattle: University of Washington, 2020.

[3] Scottish Government. The Scottish Health Survey 2019 edition: volume 1 main report, https://www.gov.scot/publications/scottish-health-survey-2019-volume-1-main-report/ (accessed 5 February 2021).

[4] Burstein R, Fleming T, Haagsma J, et al. Estimating distributions of health state severity for the Global Burden of Disease study. *BMC Popul Health Metrics* 2015;13.

[5] Public Health England. Local action on health inequalities: improving health literacy to reduce health inequalities, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf (accessed 5 February 2021).

[6] World Health Organization. Thirteenth General Programme of Work 2019–2023, https://www.who.int/about/what-we-do/thirteenth-general-programme-of-work-2019---2023 (accessed 5 February 2021).

[7] Douglas M, Katikireddi SV, Taulbut M, et al. Mitigating the wider health effects of COVID-19 pandemic response. *BMJ* 2020;369:m1557.

[8] Public Health Scotland. COVID-19 wider impacts on the health care system, https://scotland.shinyapps.io/phs-covid-wider-impact/ (accessed 5 February 2021).

[9] Niedzwiedz CL, Green MJ, Benzeval M, et al. Mental health and health behaviours before and during the initial phase of the COVID-19 lockdown: longitudinal analyses of the UK Household Longitudinal Study. *J Epidemiol Community*. Epub ahead of print 25 September 2020. DOI: 10.1136/jech-2020-215060.

[10] Bevan S, Mason B and Bajorek Z. IES Working at Home Wellbeing Survey, https://www.employment-studies.co.uk/

resource/ies-working-home-wellbeing-survey (accessed 5 February 2021).

[11] Australian Institute of Health and Welfare 2019. Australian Burden of Disease Study: methods and supplementary material 2015, https://www.aihw.gov.au/reports/burden-of-disease/australian-burden-disease-study-methods-2015/contents/table-of-contents (accessed 5 February 2021).

[12] Ock M, Jo MW, Gong YH, et al. Estimating the severity distribution of disease in South Korea using EQ-5D-3L: a cross-sectional study. *BMC Public Health* 2016;16:234.

[13] Wyper GMA, Grant I, Fletcher E, et al. The impact of worldwide, national and sub-national severity distributions in Burden of Disease studies: a case study of cancers in Scotland. *PLoS One* 2019;14.

[14] Porst M, Wengler A, Leddin J, et al. Migraine and tension-type headache in Germany. Prevalence and disease severity from the BURDEN 2020 Burden of Disease Study. *J Health Monitor* 2020;5.

[15] Wyper GMA, Grant I, Fletcher E, et al. Prioritising the development of severity distributions in burden of disease studies for countries in the European region. *Arch Public Health* 2020;78.

[16] Eurostat. European Health Interview Survey, https://ec.europa.eu/eurostat/web/microdata/european-health-interview-survey (accessed 7 May 2021).