



influenza

More than just numbers: Exploring the concept of “burden of disease”

Why should we care about the concept of burden of disease?

In a world affected by numerous diseases, disabilities, and illnesses, how do governments, health care providers, media, or the general public decide which ones are most important? If a disease strikes close to home, everyone affected will naturally consider that condition to be of utmost importance. But public health practitioners and policy-makers have a responsibility to ensure the health of all. As a result, they must be able to evaluate the relative importance of disease and disability for the entire population. Understanding which diseases pose the greatest threat to health and well-being helps public health practitioners and policy-makers decide how to use limited resources for maximum benefit. They can plan interventions and deliver services to enhance prevention, control the spread of disease, improve disease outcomes, and reduce health inequities—unfair differences in risk that lead to differences in health

outcomes between individuals and populations.

The human and economic costs that result from poor health are frequently described as burden of disease.¹ Many researchers use the phrase “‘the’ burden of disease,” which suggests that there is a single, accepted definition. This is not the case. The term burden of disease has a variety of meanings, depending on who is talking and what they are talking about.

This backgrounder provides information on common concepts and measures of disease burden used in population and public health. It also reflects on emerging interpretations of disease burden and suggests questions that might be asked of those writing and speaking about burden of disease.

How is burden of disease usually understood and measured?

In population and public health, there are two main ways of thinking about and measuring burden of disease. The most common approach has been labelled “biomedical.” It involves

gauging the impact of disease and disability on bodies, from the onset of illness to the outcome—sickness or disability, recovery, or death. It also involves assessing the potential of medical interventions to alter the course of diseases and future disability and illness. Information is gathered about how diseases and interventions affect individuals and these data are combined to create an overall picture of the health of the population.

Researchers using a biomedical understanding of burden of disease are interested in the following:

- **Morbidity** – the number of people in a population who are unwell or disabled, and the severity of their illness or disability;
- **Mortality** – the number of people in a population who die as a result of a specific disease or disability, and whether or not their deaths are

1. Burden of illness and burden of disease are both commonly used terms. For simplicity we use burden of disease throughout this document.



considered premature (before the expected duration of life).

- **Trends** – morbidity and mortality patterns within and among populations over time and from one disease to another, as well as the likelihood, or risk, of becoming ill or disabled.

- **Risk attribution** – some studies also comment on links between illness, disability or death outcomes to recognized risk factors.

The other main approach to thinking of burden of disease is economic. It focuses on the financial costs of illnesses for individuals, households, healthcare systems, and societies. Researchers and policy-makers measuring economic burden of disease are interested in:

- **Direct costs** – the value of expenditures on prevention, diagnosis, and treatment, such as immunization and screening programs, in-hospital and out-patient care, visits to physicians, and medications;

- **Indirect costs** – the value of labour and productivity losses, such as lost income and economic output due to illness-related absences from work, reduced productivity at work due to illness, or premature death.

Estimating the biomedical or economic burden of disease might seem like a relatively straightforward process—a matter of “counting noses” or tracking expenditures. But it is not that simple. Assessing burden of disease involves grappling with fundamental questions about the “worth” of a human life as well as the value of quality versus quantity of life. We might ask, for

example, how burden of disease measures determine:

- Whether dying prematurely from a disease is more “burdensome” than living for years with poor health or disability;

- Whether living with a disease is more costly than dying from it, in terms of health care expenditures;

- How to find a balance between life-saving treatments for a few people and interventions that provide modest benefits to a large number of people.

Social values shape our understanding of which burdens and whose burdens matter. They also inform our approach to measuring burden of disease, and, ultimately, influence decisions about public health policies and interventions.

Are there other ways of thinking about and measuring burden of disease?

Health specialists have led the way in measuring the biomedical burden of disease. As early as the 17th century, doctors and public health practitioners were tracking causes of death in

populations. During the 20th century, researchers refined their understanding of biomedical burden of disease and developed sophisticated measures to capture the impact of illness, disability, and premature death. Since the 1970s, economic specialists have deepened our understanding of burden of disease by gauging the economic impact of illness, disability, and premature death.

More recently, social scientists have been raising important questions about both the biomedical and economic approaches to burden of disease. Many researchers have argued that important types of burden are not seen or counted in measures of either mortality and morbidity, or in economic costing. For example, because the biomedical approach focuses on the individual who is ill, it tends to ignore the burden of disease for families, households, and social networks. Similarly, researchers have amply demonstrated the significant social and economic contributions of unpaid caregivers, yet this work is generally not included in calculations of burden of disease.ⁱ Other, less tangible, aspects of disease burden, such as pain and suffering, are also not factored into most estimates of burden of disease.ⁱⁱ

Some researchers have also argued that biomedical and economic measures of disease burden may mask critical differences between sub-populations.ⁱⁱⁱ For example, in 2014, the prevalence of tuberculosis in Canada as a whole was amongst the lowest in the world, but First Nations and Inuit populations had much higher rates—4.5 to 45 times higher.^{iv} Differences such as these are rooted in historic and persistent

social and economic inequities that are often not captured in typical measures of disease burden. In the same vein, some measures of burden of disease are based on the view that interventions should do the greatest good for the largest number of people. But achieving greater equity in health may involve doing the most good for a small number of people who carry the heaviest burden of disease.^v Biomedical measures also tend to focus on the “direct” or immediate causes of sickness and death, such as smoking or exposure to communicable diseases. In the process, they sometimes ignore systemic or societal contributors to disease burden, such as low income, environmental contamination, prejudice, or inadequate health care infrastructure.^{vi}

Burden of disease is, by definition, a negative term—it focuses on the hardships and losses associated with disease, disability, and death. It is not surprising, then, that many measures of disease burden focus on the factors that cause illness or make it worse. But a few researchers have argued that a full understanding of burden of disease involves an appreciation of factors that protect and promote health, such as social cohesion, healthy peer relationships, and supportive school or work environments.^{vii} This view is consistent with decades of health promotion research and policy-making, but as yet it has little place in the biomedical and economic approaches to understanding and measuring burden of disease.

What impact has the increase of non-communicable diseases had on perceptions of burden of disease?

Burden of disease measures have their roots in infectious diseases public health. The earliest measures were developed to track and identify causes of death related to typhoid, cholera, malaria, and other infectious diseases. In recent decades, rates of heart disease, stroke, and other non-communicable diseases have increased, particularly in the developed world, and these health conditions are now being factored into measures of burden of disease. Patterns of morbidity and mortality vary greatly between as well as within countries, reflecting inequitable burden of disease among populations disadvantaged by history, circumstances and social and economic conditions. While it can be challenging to understand how reports on global burden of disease relate to the Canadian context, national level measures of burden of disease for Canada may also mask health differences and disparities among sub-populations in this country.

At the same time, it is important to pay attention to the ways in which shifts in morbidity and mortality may affect perceptions and measures of disease burden. Because non-communicable diseases are less likely than infectious diseases to kill quickly, they may be regarded as more burdensome—to individuals, families, health care systems, and societies. If the prevalence of non-communicable diseases continues to rise, it might seem sensible to concentrate resources on addressing disease burden associated with these conditions. Both

Typical Measures of Burden of Disease

Health-Adjusted Life Years (HALYs):

HALYs is an umbrella term for population health summary measures typically used in estimates of the burden of disease. These measure calculate the combined effects of mortality and morbidity in populations, allowing for comparisons across illnesses or interventions as well as between populations.

Two common approaches to measuring HALYs are:


1. Disability-Adjusted Life Years (DALYs)

DALYs measure the difference between the current state of population health and an ideal situation where everyone reaches the age of standard life expectancy in perfect health. DALYs are based on an assumption that “time” is the most appropriate gauge of burden of disease: the greater the time lived with a disability, or with the disabling results of an illness, or the more time lost due to premature death, the greater the burden of disease is considered to be.

2. Quality-Adjusted Life Years (QALYs)

QALYs measure both the quantity and the quality of life lived. They are typically used to analyze the cost-effectiveness of clinical (or public health) interventions. For example, QALYs can compare an intervention that helps prolong life but has serious side effects (such as permanent disability caused by radiation or chemotherapy for cancer), with an intervention that improves the quality of life without prolonging it (such as palliative pain management).

Source: Understanding Summary Measures Used to Estimate the Burden of Disease: All about HALYs, DALYs and QALYs. (2015)



this conclusion and current measures of burden of disease ignore the tremendous impact that immunization and antibiotic treatment programs have had on burden of infectious diseases. Non-communicable disease rates are rising, in part, because the battle against infectious diseases has been so effective. If successful prevention and early intervention are not factored into burden of disease measures, there is a real danger that critical efforts to prevent burden of disease will be eroded.

What questions might we ask about burden of disease?

Burden of disease is a complex idea and it rests on a foundation of complex mathematical calculations. Burden of disease measures are often presented as “objective,” but decisions about what and how to measure are influenced by social values. How then should we approach research on burden of disease or engage with experts in the field? Consider some of the following questions and prompts as you read or talk about burden of disease:

1. Which understanding of burden of disease is being used?
2. Which aspects of burden of disease are being measured?

3. Whose burden of disease is being measured and whose is not?
4. How and where should we intervene to have the greatest impact on burden of disease, including prevention, control, and treatment?
5. Who is likely to benefit least and most from specific interventions aimed at reducing disease burden?
6. Will decisions based on disease burden measures have the best outcomes for a population that is already advantaged?
7. How do we eliminate inequitable burden of disease?

You can find out more about measures and concepts of burden of disease in these NCCID publications:

Framing Burden: Towards a new framework for measuring burden of disease in Canada

Understanding Summary Measures Used to Estimate the Burden of Disease: All about HALYs, DALYs and QALYs

Thinking about burden with equity in mind

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i Barry, J. A. (2014). Caregiving men of Alzheimer's disease sufferers in Nuevo León (Mexico) experiences and meanings, *Vulnerable Groups and Inclusion* (5), 1–23; Rivera-Navarro, J., Morales-González, J. M., and Benito-León, J. (2003). Informal caregiving in multiple sclerosis patients: data from the Madrid Demyelinating Disease Group study. *Disability and Rehabilitation*, 25(18), 1057–1064.; Zan, H., and Scharff, R. L. (2014). The Heterogeneity in Financial and Time Burden of Caregiving to Children with Chronic Conditions. *Maternal and Child Health Journal*, 615–625.

ii Englisch, S., Esser, A., Enning, F., Hohmann, S., Schanz, H., Zink, M. (2010). Augmentation with pregabalin in schizophrenia. *Journal of Clinical Psychopharmacology*, 30(4), 437.; Kobeissi, L., Araya, R., Kak, F., Ghantous, Z., Khawaja, M., Khoury, B., Zurayk, H. (2011). The relaxation exercise and social support trial-rest: Study protocol for a randomized community based trial. *BMC Psychiatry*, 11(1), 142.; Zink, A., and Huscher, D. (2004). Longterm studies in rheumatoid arthritis—the German experience. *The Journal of Rheumatology. Supplement*, 69, 22–26.; American Diabetes Association. (2013). Economic costs of diabetes in the U.S. in 2012. *Diabetes Care*, 36(4), 1033–46

iii Mowat, D. L., and Butler-Jones, D. (2007). Public health in Canada: A difficult history. *Healthcare Papers*, 7(3), 31–36.

iv Tuberculosis in Canada 2014. <http://healthycanadians.gc.ca/publications/diseases-conditions-maladies-affections/tuberculosis-2014-tuberculose/index-eng.php#a4>

v Isfeld-Kiely, H., Balakumar, S. 2015. Framing burden: Towards a new framework for measuring burden of disease in Canada. Winnipeg: NCCID; Gold, M. R., Stevenson, D., and Fryback, D. G. (2002). HALYs and QALYs and DALYs, Oh My: Similarities and differences in summary measures of population Health. *Annual Review of Public Health*, 23, 115–134.

vi Link, B. G., and Phelan, J. (1995). Social conditions as fundamental causes of disease. *Journal of Health and Social Behavior, Spec No*, 80–94..

vii Thacker, S.B., Stroup, D. F., Carande-Kulis, V., Marks, J.S., Roy, K., and Gerbeding, J.L. (2006). Measuring the public's health, *Public Health Reports*, 12(1), 14–22.

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