Burden of disease methods: analytic reflections

Introduction

Methods to measure the burden of disease (BOD) on populations have been employed for decades, but have only received increasing attention in the past twenty years. At the same time, a number of concerns have also been raised, especially with the use of summary measures of population health. Seven BOD studies were funded by the Global Forum for Health Research (Global Forum) to explore the application of BOD methods in developing countries. This chapter is based on these studies and reviews the lessons learned during the process of a BOD study and reflects on what can be improved. In this chapter we briefly revisit the key components of a BOD exercise. In addition to describing the major elements of a BOD study, a special effort has been made to link them with the objectives, principles and innovations from the seven Global Forum studies (see Appendix 1). Then the overall strengths and challenges of these BOD studies are discussed. An extrapolation of these findings to assist with the process of implementing such an exercise at the national level to inform health decision-making is the topic of the next chapter.

Section 1. Description of methods

BOD methods became widely known with the release of the 1993 World Development Report (World Bank, 1993). This report built on the work related to quality-adjusted life years based on individual preferences (Zeckhauser and Shephard, 1976) and days of life lost of the Ghana Health Assessment Team (Ghana Health Assessment Team, 1981). The methods have been extensively studied since then. During the process, several composite measures of the burden of ill-health have become frequently used, including Potential Years of Life Lost, Quality-Adjusted Life Years, Healthy Life Years and Disability Adjusted Life Years, each indicator characterized by specific features as briefly described below.

PYLL

The Potential Years of Life Lost (PYLL) is one of the oldest indicators, introduced by Dempsey in a paper studying Tuberculosis in the US (Dempsey, 1947). It is the simplest measure of the gap between current and ideal health conditions. It measures the number of years lost due to the fact that individuals fail to live the years they were expected to live based on a standard life expectancy. Though it is not a real summary measure of both premature death and disability burden, it provides the basis for other measures. More recent versions have added economic and social productivity weights to PYLL (MacKinney et al, 1994).

QALY

The Quality-Adjusted Life Year (QALY) is an indicator based on personal preferences for nonfatal health outcomes (Nord, 1992; Nord, 1993). Based on subjective weighting of individual health states, QALY is not a strict burden of disease measure at population level; however, it inspired the development of other BOD indicators. A disability weighting scale is used in QALY with perfect health rated as 1 and death as 0.
HeaLY
The healthy life year (HeaLY) is a measure based on the original work done on summary measures of population health in Ghana (Hyder et al, 1998a; Hyder et al, 1998b; Hyder et al, 1999; Hyder et al, 2000). HeaLY applies the natural history of disease concept using knowledge of the pathogenesis of disease conditions. Special attention has been paid to data problems in developing countries and various patterns of healthy life lost in different conditions.

DALY
The disability adjusted life year (DALY) is a combination of Years of Life Lost (YLL) and Years of Life Lived with Disability (YLD). It first appeared in the 1993 World Development Report (World Bank, 1993). Since then, the methods have been extensively and systematically reviewed, especially in the conduct of the Global Burden of Disease studies (Murray and Lopez, 1996). WHO also adopted these methods in the late nineties, and it was during that time that BOD methods gained a lot of international attention. Despite its worldwide fame, the DALY has been critiqued on several aspects related to application and methodology; one of them is its technical intensity. It is estimated by a complex formula, inclusive of age weighting and discounting. Methods to generate disability weight in the YLD part have also opened an extensive debate. However, DALY is the most widely used indicator in national burden of disease studies.

Other tools and Quality of Life measures
There are other measures related to assessing quality of life which are used in BOD studies, such as Short-Form-12 (SF-12), Comprehensive Quality of Life (ComQoL), WHO Disability Assessment Schedule (WHODAS), and WHO Quality of life (WHOQOL). Details of these instruments are available in the literature (Ware et al, 1996; Luo et al, 2003; Cummins, 1993; McCabe et al, 1998; World Health Organization, 2001; World Health Organization, 1999). Some were used in the Global Forum studies reviewed in this chapter.

Methods
Several elements are common to most BOD studies. Firstly, time is used as a measurement scale as applied in Ghana as the primary unit to count burden of disease, either “days of life”, or other indicators where “years” is the basic unit. Second, the burden of mortality and morbidity is combined. Though the methodological details are still being refined, the accounting of the burden of disability in addition to mortality is an innovation and requires the use of “summary” measures. Disability measurement is the third element and one of the most controversial ones. The methods and populations for estimating disability weight are still being debated after more than two decades of work. Discounting future life years and age weighting of life years are also features of BOD indicators. Discounting is used fairly regularly, often at a rate of 3% per year. Age weighting, on the other hand, was used in the original formulation of the DALY and generated considerable debate. Additional features of BOD studies, especially applied elements, are discussed in chapter 2.

The rationale underlying measurement of population health in general is to better assess current health status and monitor its changes over time. Summary measures of population health present a quantified measure of the disease burden. Detailed discussion of how data on population health informs decision-making processes is presented in the next chapter.

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\[^{1}\text{YLL is estimated based on the following function:} \]

\[
Y_{\text{LL}} = \frac{KCa^{\alpha} \phi}{(r+\beta)} \{e^{\phi \cdot (r+\beta) (a - \alpha) - 1} - e^{\phi \cdot (r+\beta) a - 1} \} + \frac{1 - \frac{K}{r}}{1 - e^{\phi \cdot \beta}}
\]

where \(r\) (the discount rate) is 0.03, \(B\) (the parameter from the age weighting function) is 0.04, \(K\) (the age-weighting modulation factor) is 1, \(C\) (a constant) is 0.1658, \(a\) is the age at death and \(L\) is the standard expectation of life at age \(a\). To calculate the number of YLLs lost to a condition, the number of YLLs lost per death at each age must be multiplied by the number of deaths at each age and then summed across all ages (Murray, 1996, p. 65).
## Table 1A - Descriptive summary of reviewed studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Authors</th>
<th>Title</th>
<th>Source</th>
<th>Country</th>
<th>Diseases</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Allotey, 2001</td>
<td>Daniel D. Reidpath, Pascale Allotey, Aka Kouame and Robert Cummins</td>
<td>Social, cultural and environmental contexts and the measurement of burden of disease: An exploratory study in the developed and developing world</td>
<td>Melbourne: Key Center for Women’s Health in Society, The University of Melbourne, Australia</td>
<td>Australia and Cameroon</td>
</tr>
<tr>
<td>2.</td>
<td>Kim, 1996</td>
<td>Chang-Yup Kim, Seok Jun Yoon, Hyejung Chang</td>
<td>Measuring the burden of major cancers in Korea</td>
<td>Korea</td>
<td>Major cancers</td>
</tr>
<tr>
<td>3.</td>
<td>Kvale, 2001-2005</td>
<td>Gunnar Kvale, Lydia Kapiriri, Candida Moshiro</td>
<td>Poverty and BOD in Tanzania; value choices in DALY; using BOD for health planning; community identified health priorities; burden of injury</td>
<td>Tanzania, Uganda</td>
<td>Paper-specific</td>
</tr>
<tr>
<td>4.</td>
<td>Saxena, 2004</td>
<td>Shekhar Saxena and Somnath Chatterji</td>
<td>A methodological approach to the measurement of Disability Adjusted Life Years in selected mental and physical health conditions in India</td>
<td>All India Institute of Medical Sciences, Delhi, and the National Institute of Mental Health and Neurosciences, Bangalore</td>
<td>India</td>
</tr>
<tr>
<td>6.</td>
<td>Fox-Rushby, 2003</td>
<td>J. Fox-Rushby, C. Nzioka, M. Mugo, K. Johnson, M. Isika, J. Kamau, H. Naughton-Green et al.</td>
<td>Community-based valuations of health-related quality of life to value the burden of disease: testing methods in Kenya</td>
<td>Health Policy Unit, Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, University of London</td>
<td>Kenya</td>
</tr>
<tr>
<td>Study</td>
<td>Study design</td>
<td>Sample characteristics</td>
<td>Major instruments and data analysis methods</td>
<td>Data source, collection and analysis methods</td>
<td></td>
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<tr>
<td>1. Allotey, 2001</td>
<td>Qualitative and quantitative methods with purposive sampling based on self-report</td>
<td>N=152; Age 25-35; equal # of males and females in the total sample</td>
<td>SF-12 (PCS, MCS, health, pain, physical and emotional); ComQoL (with and without satisfaction of health)</td>
<td>Qualitative: in-depth interviews and Photo Voice; Quantitative: t-test and ANOVA</td>
<td></td>
</tr>
<tr>
<td>2. Kim, 1996</td>
<td>NBD: Korean data + GBD methodology</td>
<td>NA</td>
<td>DALY=YLL+YLD; SEYLL; estimation of incidence rate, case-fatality rate, disability weight (Delphi method), expected duration of disability and the average onset age (DISMOD)</td>
<td>Vital registration data (NSO); health insurance claim data</td>
<td></td>
</tr>
<tr>
<td>4. Saxena, 2004</td>
<td>disability and quality of life estimation; disability weight development</td>
<td>N=1100. Respondents include patients, their family or caregivers, health professionals and policy-makers.</td>
<td>The WHO Disability Assessment Schedule; WHO Quality of Life; VAS, TTO, PTO1, PTO2</td>
<td>Patients and family members recruited at the clinic sites after obtaining consent from their health-care providers. Interviewed in privacy in multiple sessions. Other respondents include health professionals, policy-makers etc. Descriptive analysis, ANOVA</td>
<td></td>
</tr>
<tr>
<td>6. Fox-Rushby, 2003</td>
<td>Health state valuation; qualitative study (e.g. participant observation, focus groups discussion and interview); anthropological methods</td>
<td>community-based sample</td>
<td>Reviewed standard gamble, TTO, EQ5D and PTO</td>
<td>Qualitative data collection and analysis methods</td>
<td></td>
</tr>
</tbody>
</table>

GBD: global burden of disease study; NBD: national burden of disease study; BOD: burden of disease study; SF-12: Short Form-12; PCS: physical sub-scale score of SF-12; MCS: mental sub-scale score of SF-12; ComQoL: Comprehensive Quality of Life; DALY: disability adjusted life year; YLL: years of life lost; YLD: years lived with a disability; SEYLL: standard expected years of life lost; NSO: national statistical office; VAS: visual analogue scale; TTO: time trade off; PT01 and PT02: person trade off type-1 and type-2; HeaLY: healthy life year; EQ5D: EuroQol with 5 domains; PPYLL: potentially productive years of life lost; YLLE: years of life lost to average life expectancy; PDHS: Pakistan Demographic and Health Survey; NA: not available.
Section 2. Reviewed BOD studies

The seven BOD studies reviewed in this book were funded by the Global Forum to explore the use and application of BOD methods in developing countries. They were implemented between 1996 and 2005 (Table 1A and 1B). The seven research groups represent BOD expertise in Africa, Asia, Europe, North America and Australia. Ten countries were covered by these studies, including five from Africa (Cameroon, Tanzania, Nigeria, Kenya and Uganda), four from Asia (Korea, India, Pakistan and Saudi Arabia) and Australia. Among the seven studies, three were national burden of disease studies (study #1 Allotey; study #5 Ogunseiten; and study #7 Hyder); while the other four examined contextual factors, value choices and preferences associated with BOD indicators. Both quantitative and qualitative methods were employed across the studies, and a variety of data sources were pursued, including primary data collection and secondary data synthesis and analysis. Collectively, the seven studies demonstrate the geographic and methodological emphasis of BOD methods to date (Table 2).

Table 2 - Quantitative summary of reviewed studies

<table>
<thead>
<tr>
<th>Study</th>
<th>Major results</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Allotey</td>
<td>• ComQoL: Paraplegia: 45.6 in Cameroon and 73.7 in Australia; Epilepsy: 54.2 in Cameroon and 66.4 in Australia.</td>
</tr>
</tbody>
</table>
| 2. Kim | • Overall, 2,692 DALYs/100,000 population were lost from 10 major cancers in Korea in 1996.  
• For males, liver cancer is the leading cause of cancer-related loss of healthy life, while for females it is stomach cancer.  
• Mortality losses far exceed those by morbidity/disability for cancers overall; the YLL/YLD ratios are 21.9 on an average across both genders. |
| 3. Kvale | • Changes of value choices led to an inversion of the ranking of the two diseases: the relative burden of developmental disability rose from 14 to 90% of the total burden.  
• 49% of the disability weights in noncommunicable diseases were reduced after treatment, while only 14% were reduced in communicable diseases after treatment. |
| 4. Saxena | • Significant differences in the disabilities experienced by patients of the four health conditions were found in WHODAS II domains 1 – understanding and communication, 2 – getting around, 4 – getting along with people, 6 – participation in society and overall disability. For example, patients with depression showed the highest WHODAS II scores, and in domain 1 – understanding and communicating, and in 3 – self-care. Diabetes and tuberculosis patients had the highest scores in domain 2 – getting around.  
• Quality of life among the four groups of patients was significantly different in WHOQOL physical and social components. Specifically, patients with diabetes had worst quality of life in the physical domain, and patients with mental disorders reported lowest score in social domain. |
| 5. Ogunseitan | • Environment-sensitive diseases, like malaria and diarrhoea, are prevalent in the entire geographic area of Nigeria, except in the highland central plateau.  
• 4.4% of the total burden is attributable to malaria in the local region between 1990 and 1998, compared to 9% for sub-Saharan Africa in 1990 GBD study. Vector control efforts can save more than 6 years of healthy lives.  
• Burden of diseases that are sensitive to water availability and quality is about 3% of the total burden. |
| 6. Fox-Rushby | • 60 respondents, 3 case study families and 4 life histories were purposively sampled to study the perception on deaths. |
| 7. Hyder | • More than 47 million HeaLYs were lost in Pakistan in 1997 due to premature deaths, which corresponded to 367 HeaLYs per 1,000 population.  
• 113 per 1,000 male population and 62 per 1,000 female population HeaLYs were lost as a result of premature mortality in Saudi Arabia in 1992-1995. The corresponding figures are 109 and 53 DALYs for males and females.  
• Sleeping sickness, perinatal conditions, malaria, acute diarrhoeal, trauma and AIDS were important causes of the loss of HeaLYs in Uganda. They each contributed to the total HeaLY 128, 105, 100, 47, 37 and 24 per 1,000 population, respectively. |
Chapter 1 - Burden of disease methods: analytic reflections

Study #1 Allotey et al in Australia/Cameroon
Allotey and colleagues (University of Melbourne, Australia) studied the impact of social, cultural and environmental context in measurement of BOD in 2001 (see Appendix 1: study #1, Table 1.4 and Table 1.5). They compared these contextual factors in Australia and Cameroon, representing the developed and developing countries, by focusing on two different diseases – epilepsy and paraplegia. Purposive sampling based on self-report was applied to collect both quantitative and qualitative data. 152 adults aged 25 to 35 years, with equal numbers of women and men, were interviewed in the study. Short Form-12 and Comprehensive Quality of Life were used as the major instruments to measure quality of life. Epidemiological and anthropological methods were applied together to examine the effect of country, residence, gender and socioeconomic status on the two health conditions.

Subjective quality of life scores suggested that people with either paraplegia or epilepsy were “better off” in Australia than in Cameroon. However, the severity ranking of paraplegia and epilepsy was different in the two countries based on quality of life measurement. It was concluded that contextual factors, especially “country”, significantly influenced the severity of a health condition. The authors suggest that as a result, a global disability weight used in all countries is not appropriate for individual BOD studies at national level.

Study #2 Kim et al in Korea
The burden of major cancers in Korea was systematically studied by Kim and colleagues (Seoul National University College of Medicine) in 1996. Classic national BOD study procedures using the DALY indicator were applied. In addition to the conventional vital registration and facility based data, health insurance claim data was also included to help estimate the diseases burden (see Appendix 1: Study #2, Table 3). A disability weighting scheme in the Korean social and cultural context was developed.

Overall, 2,692 DALYs per 100,000 population were lost from the top 10 cancers in Korea in 1996. Liver, stomach and lung cancers stood out as the major contributors of cancer burden in Korea. The leading causes were different for men and women, being liver cancer and stomach cancer, respectively. As expected, the burden of mortality far exceeded that of morbidity and disability for cancers, with the YLL/YLD ratio being 21.9 on average. Though great efforts were made to identify multiple data sources, the study still suffered from incomplete health information.

Study #3 Kvale et al in Tanzania and Uganda
Kvale and colleagues, from University of Bergen, Norway, carried a series of pilot studies on BOD in Tanzania and Uganda between 2001 and 2005. A broad body of content was covered including poverty and BOD in Tanzania, value choices in DALY, applying BOD for health planning, identifying health priorities in communities based on BOD, and estimating burden of injuries (see Appendix 1: study #3 Kavle for details). A consensus was reached in a final seminar on poverty and BOD in Tanzania that there is health information already in existence, and yet further collaboration and networking is warranted to utilize such data. Community involvement was also identified as one of the essential components of a BOD study in this seminar.

In addition, sensitivity analysis was performed to examine the robustness of DALY results based on different value choices in one sub-study (Arnesen et al, 2004). The results showed that a change of value choices led to an inversion of the ranking of two diseases (disability due to malnutrition and major depression) by DALY estimates. Another study explored the utility of a BOD study for health planners in Uganda (Kapiriri et al, 2004), and the quantitative features of a BOD study was found to be appealing for advocacy purposes. However, the process of a BOD study was considered less transparent and hence less acceptable to planners due to its technical intensity.

One of the sub-studies aimed to compare health problems identified by a BOD study versus those identified by the community in Uganda (Kapiriri et al, 2002). Health issues identified by a BOD study were generally similar to those by the community, but an inversion of
ranking was observed. In addition, social stigma and cultural values were raised as major determinants of disease burden at the community level.

A study on the burden of injury was also conducted in Tanzania as part of this series of studies (Moshiro et al, 2001). Nonfatal injury, risk factors of injury, and the effect of recall bias on injury estimation were covered in this exploration (Moshiro et al, 2003a; Moshiro et al, 2005b).

**Study #4 Saxena et al in India**

Measurement issues related to disabilities were examined in an Indian study by Saxena and colleagues (All India Institute of Medical Sciences and the National Institute of Mental Health and Neurosciences) in 2004. Six types of health state valuation tools were utilized to assess disability burden and disability weight of selected mental and physical conditions in India. A diverse group of 1,000 people including patients, family members, health professionals, health policy-makers and health care volunteers were invited to participate in the study (Appendix 1: study #4 Saxena).

Significant differences were found in the disability experienced by patients compared to other groups across the four health conditions (depression, schizophrenia, diabetes and tuberculosis). As a result of taking care of sick relatives, family members also experienced some disability. Health professionals usually attributed a higher disability burden to the health condition, compared to patients and family members. Misunderstanding of BOD measures by policy-makers was noted at the end of the study. The study also demonstrated the feasibility of operating a complex protocol of health state valuation in a low socioeconomic setting.

**Study #5 Ogunseitan in Nigeria**

Environmentally sensitive diseases were explored by Ogunseitan (University of California) in a Nigerian BOD study in 2001 (Appendix 1: study #5 Ogunseitan). The HeaLY was employed to study the morbidity and mortality burden of selected disease conditions in Nigeria. Disease data were obtained through a network of health professionals and hospitals, and environmental data was obtained from national and international databases. Sensitivity analysis based on different discount rates ranging from +1.5% to +4.5% was included. A modeling framework for the health impact assessment of Man-Induced Atmospheric changes (the MIASMA model) was utilized to explore the trend of vector-borne disease burden.

Infectious and childhood diseases accounted for the major disease burden in Nigeria during 1990-2000 and HIV was found to be another major source of disease burden. It was discovered that there is a disproportionate fraction of disease burden that is actually due to preventable environmental factors. The BOD result was found to be different from that estimated for sub-Saharan Africa in the global BOD study of 1990.

**Study #6 Fox-Rushby et al in Kenya**

Community-based health valuations were conducted by Fox-Rushby and colleagues (University of London) in Kenya in 2003. The universal concepts of death, time, and numeration were examined in a rural Kenyan context (Appendix 1: study #6 Fox-Rushby). Four health valuation instruments were reviewed at the beginning of the study, including Standard Gamble, Time Trade-Off, European Quality of Life 5-Domains and person trade-off methods. A number of qualitative methods, such as participant observation, focus groups discussion and in-depth interview were applied to gather anthropological data.

The study suggested that death was not viewed in the same way across cultures and was not openly discussed before it occurred. People in the study community had vague time concepts. Other basic concepts, including trade price, bride price, and how resources were allocated in daily life were also touched upon to better understand the concepts of counting and numeration. Despite the fact that health valuation scales have been used in less developed countries, the impact of the diversity of culture and the heterogeneity of application of instruments in different settings had not been properly recognized. Therefore, the study suggested that health state valuation techniques need to be localized to generate meaningful results.
Study #7 Hyder et al, multi-country

National BOD was compared across Pakistan, Saudi Arabia and Uganda in a study by Hyder and colleagues (The Johns Hopkins University) in 2003. Both HeaLY and DALY were utilized to estimate the disease burden (Appendix 1: study #7 Hyder). Various sources, such as census, health surveys, burial permits and data from published studies were pursued to obtain demographic and epidemiologic data across these three countries.

358 HeaLYs per 1,000 population for males and 376 HeaLYs per 1,000 population for females were lost in Pakistan in 1997 due to premature deaths. The corresponding numbers were 113 for males and 62 for females in Saudi Arabia between 1992 and 1995. While in Uganda sleeping sickness, perinatal conditions and malaria topped the disease burden, each contributing 128, 105, and 100 HeaLYs lost per 1,000 population respectively. Pakistan, Saudi Arabia and Uganda all experience an unexpectedly large burden due to chronic diseases and injuries. The study suggested that evidence-based health decision-making needs to be based not only on mortality data, but also on morbidity and disability information. However, due to the paucity of basic data and incomplete coverage of national health information systems, implementation of BOD studies in less developed countries (Pakistan and Uganda) is challenging.

Summary

Across the seven studies, the application of BOD methods in a developing country context has been demonstrated. Strengthening basic data collection, and capacity building in health information systems will facilitate better BOD studies. Localized value choices and preferences elicitation are important components of a BOD study at the disaggregate level. Further discussion on value choices in BOD studies is presented in the next section.

Section 3. Value choices

Several features were considered by the authors of the studies introduced above, as innovations of BOD methods. Among them disability weights, discounting, age weighting, as well as concepts of death, time and numeration were studied and tested in some of these studies.

Disability weight

The disability weights used in the first Global Burden of Disease study for 1990 were based on the opinions of experts; and this was followed by extensive population-based, empirical work to support those weights during the next decade. The Ghana Health Assessment Team used disability weights based on both experts and community leaders’ opinions. Currently, there is a growing interest in exploring local opinions in the development and testing of disability weight as shown by the reviewed studies.

Disability weights were estimated by the Delphi method in the Korean study on burden of cancers (Appendix 1: study #2 Kim, Table 3), and for each cancer professional panels were recruited to develop such weights. Disability weights were also generated and evaluated in the study in India (study #4 Saxena) where patients, family members, health professionals and policy-makers were all involved in the process of disability weight development. The goals of the Indian study were to gather opinions on disability weight from a population as diverse as possible, and to evaluate the validity of the weights comprehensively. Four health state valuation methods – Visual Analogue Scale, Time Trade Off, Person Trade Off (type-1 and type-2) – were used in this exercise. Results showed that while there were relatively high correlations between some of the methods, there were systematic differences between different types of respondents. Compared to patients family members gave lower values, whereas health professionals scored higher values. The study emphasized the importance of perceptions of disability in a local population for local use.

Allotey et al’s work found that there was a significant difference in the disability experienced by patients of epilepsy, compared with those of paraplegia (study #1 Allotey). Substantial discrepancy was also found when comparing the same diseases in Australia versus Cameroon. Even more striking, epilepsy ranked higher in terms of disability than paraplegia in Cameroon,
but lower in Australia (Figure 1); the universal ranking of a severity weight was challenged in this case. The study provided some explanation of the discrepancy, and among several contextual factors, location turned out to be a major predictor of disability weight. The authors suggest that when using disability weights in a BOD exercise, it would be more appropriate if contextual factors, e.g., social, cultural and environmental factors, are considered for evaluating disease experiences.

Discounting – social time preferences
People perceive and value future benefits or losses differently from present ones and hence the process of discounting is used frequently in economics. Discounting is the process by which an arithmetic stream of costs (or benefits or losses) is converted to a continuously depreciating amount (Hyder and Morrow, 2001). Though there is no consensus on the value of the discount rate for use in health related outcomes, 3% per annum seems to be widely accepted.

Three discount rates, +1.5%, +3% and +4.5% were applied in the Nigeria national BOD study (study #5 Ogunseitan). The HeaLY results were relatively comparable, especially for diseases ranked lower by HeaLY. The study calls for more rigorous studies of culture-specific discount rate for each disease category. Hyder et al showed a sensitivity analysis for different rates, but used +3% for final results in Pakistan, Saudi Arabia, and Uganda (study #7 Hyder). However, some researchers have pointed out that a smaller burden is being attributed to child mortality and disability due to the use of discounting in BOD studies (Arnesen et al, 2004).

Age weighting
Age-related valuing of life is a common phenomenon in human society; individuals seem to value their own life differently at different ages. To take account of this fact, summary measures of population health can incorporate age weighting, such as giving a year at age 25 years more weight than a year of life at 5 or 60 years. Such age weighting was used in the formulation of the DALY. However, this has been criticized as contrary to notions of egalitarianism. QALY and HeaLY both value one year of life at any age equally.

Standard age weighting was applied in the Korean study and in Saudi Arabia when using the DALY indicator (study #2 Kim; study #7 Hyder). Studies using the HeaLY did not use age weighting.

Conceptions of death, time and numeration
As the basis for health state valuation, concepts of death, time and numeration are often assumed to be the same around the world. However, Fox-Rushby and colleagues found that this is not always the case (study #6 Fox-Rushby). In Akamba, Kenya, they found that...
the major reported cause of death was “witchcraft”. Only older people were socially permitted to talk about death; for others, thinking about another person’s death was thought to cause it. Thus a discussion of death was very limited in that society, making it difficult to gather cause of death information.

It was also found that the understanding of time was different from conventional concepts. The Akamba people could think about the future in bigger units like years, but not in smaller units. In addition, their time perception, instead of being based on units of time itself, was event based. These types of studies suggest that health state valuation techniques may need to be localized to produce meaningful results, and researchers should pay attention to the cultural relevance of a BOD study. If a health state valuation exercise is blindly implemented, the conceptual differences in the meaning of death or time may be masked, which may lead to misinterpretation of study results.

Section 4. Strengths of BOD studies

BOD studies evaluate health information and apply different analytical methods to generate meaningful results in order to inform public policy. Strengths inherent in each segment of such studies are reviewed in this section.

Data evaluation

Ideally a BOD study is a process of optimal utilization of available demographic, epidemiologic and health service data. Basic demographic data serve as the denominator for most statistics, therefore, age and gender-specific population data from a recent census is a necessity. In the case of inadequate vital registration (less than 90% coverage), post-census enumeration is a good alternative. For cause-specific mortality, the use of International Classification of Disease based data is fundamental for calculating mortality losses. Overall, accurate estimation of mortality data is key to a successful BOD study in less developed countries. Morbidity data, on the other hand, often comes from institutional based sources or non-representative studies.

Three national level BOD studies were available for review in this book that processed data from multiple sources. The Korean study is a classic national burden of disease study focusing on cancer (study #2 Kim). It used information mainly from vital registration data and health insurance claims. The utilization of health insurance data is a unique feature of this study, which complemented information available from other major sources. In Nigeria, Ogunseitan did a local BOD study using the HeaLY indicator (study #5 Ogunseitan). Environmentally-sensitive diseases were the major topic for this study, and mortality and morbidity data were acquired from a network of health professionals and hospitals. Hyder and colleagues performed a comparative study based on BOD methods in three countries (study #7 Hyder). Demographic surveys, census, mortality reports, burial permits, national statistics, infant and child mortality surveys were all employed to attain data for their study.

Analytical requirements

Quantitative and qualitative methods can both be applied to study burden of disease. However, the contribution of qualitative techniques is often under-appreciated. For example, in Allotey et al’s study, photo voice and in-depth interviews were used to collect data on quality of life in Cameroon and Australia (Appendix 1: study #1 Allotey, Table 1 and Table 2). A variety of qualitative methods, such as key-informant interviews, in-depth interviews, participant observations and focus group discussions were also applied in the Kenya study to understand the concepts of death, time and numeration (study #6 Fox-Rushby). Qualitative methods provide valuable anthropological data and vivid descriptions of a situation, which facilitate better understanding of specific cultures and settings under study.

An important feature of one category of summary measures of population health is that they are additive; data can be added or disaggregated by gender, age, geographic areas or other characteristics. This is true for ‘health gap’ measures such as DALY and HeaLY. For example, the Cameroon/Australia study and the Korean study disaggregated BOD data to make comparisons between genders (study #1 Allotey and study #2 Kim). In addition,
BOD results can also be stratified into major disease categories, such as: (1) infectious, maternal and perinatal causes; (2) chronic noncommunicable diseases; and (3) injuries. This was done in the Pakistan study by Hyder et al (study #7, Hyder).

**Use of information**

A BOD study makes the comparison of data and its potential use more explicit. The results can be used to assess national health information systems, to provide evidence for future health planning, and to evaluate the performance of health systems. In addition, as elaborated in chapter 2, BOD results can be used for cost-effectiveness studies of health interventions. International sharing and publication of BOD studies also facilitates communication and dissemination of national statistics, and informs global discussions.

In the studies reviewed here, BOD results have been utilized for assessing disease patterns, priority setting, and health planning. The burden of cancers was systematically evaluated in Korea to determine health priorities and facilitate resource allocation (study #2 Kim). As a major output, research priorities were found to be inconsistent with the ranking of disease burden of major cancers in Korea. In another study, health planners’ perceptions of the usefulness of BOD study were explored in Uganda (study #3 Kvale; Kapiriri et al, 2003). Ogunseitan utilized the HeaLY method as a tool to study the relationship between mortality and the changing environment in Nigeria (study #5 Ogunseitan). Chronic diseases and injuries were identified as major sources of disease burden in three countries in another BOD study (study #7 Hyder). The use of burden data to inform health decision-making is an important rationale for doing such studies.

**Section 5. Challenges of BOD methods**

It is critical to understand and manage the challenges of conducting a BOD study, especially in low- and middle-income countries. These challenges are surmountable with careful planning and proper execution of a well designed BOD study.

**Data needs**

A BOD study is data-intensive and even some of the basic data needs might be a challenge in less developed countries. Several significant data issues are discussed here.

*Disaggregated information:* Gender and age-specific health and population data is difficult to obtain under some circumstances. For demographic data, 5-year age groups are the standard, and it is also crucial to have detailed age categorization for children under the age of 5 years. Age categorization may need to be standardized across different types of data in a country. Age-specific information is especially needed when detailed age weighting is to be implemented in a BOD study.

*Cause of death:* Consistency in defining causes of death is critical prior to any comparison of mortality burden. Although International Classification of Disease version 10 (ICD-10) is currently recommended as the disease classification tool, there are countries using either older ICD versions or non-ICD systems. Hence, BOD results may not always be comparable across regions if different disease classification standards are employed. The validity of the cause of death system is another important issue. In less developed countries, only a varying proportion of the population attend hospitals when they get sick, and institution-based death certificates are available mostly in urban areas. In other places, the cause of death is usually obtained by self-reporting from family members in surveys. Death information is gathered either by personal interviews or verbal autopsy, and these methods can be challenging, especially when the target population has multiple causes of death. Hence, improving the accuracy of a cause of death system should be an essential step for implementing a BOD study.

*Morbidity and disability:* Compared to information on death, data on morbidity and disability is more difficult to obtain and as a result, the burden of disability is much more challenging to estimate in developing countries. If country-specific estimation of disability weights is needed, the study can become very time and resource intensive. Moreover, the
morbidity and disability estimates can be more difficult to compare across countries. Further studies are needed, however, on morbidity and disability of disease burden in developing countries.

Other data sources: Health insurance claims can be used as an alternative data source (study #2 Kim). As discussed in the Korean study, serious cases may be overestimated due to a tendency to document cases at a more severe level to claim more medical insurance. Failure to clearly distinguish between final and rule-out diagnosis, and varied accuracy of diagnosis can both contribute to a discordance between medical records and insurance data. Personal communication with experts can also be cited as another source of information when data is scarce (study #7 Hyder). It can provide some useful information, but more objective data is desirable.

Analytic requirements
A specific and often sophisticated skill set is required to implement a BOD study. The technical complexity makes a BOD exercise less practical if corresponding local capacity is weak. As a result, development of national capacity to implement a BOD study is important and should be considered prior to embarking on a study.

Integrating values
Social stigma and cultural values are perceived as major determinants of disease burden in a community (study #1 Allotey). However, these factors have not been directly incorporated in BOD methods. Researchers have suggested that a BOD exercise at national or sub-national levels could include two scales to take account of such issues — the “development gradient” and the “culture gradient”. The development level of a country may have an effect on the severity of disease through environmental factors. Specifically, in less developed countries, the severity of a disease may tend to be worse; hence the burden of disease based on a global severity weight may actually be an underestimate.

Culture-specific factors may also play an important role in disease burden estimation, especially at the community level. For example, infertility may not be considered as serious elsewhere as compared to when it happens to women in sub-Saharan Africa, where high fertility is a social norm.

The idea of development and culture gradients is consistent with the concept of generating local disability weights, where researchers are encouraged to consider the contextual factors of the area under study. This is important at both intra- and sub-national levels. However, for global comparative purposes, a more standard system is required.

Use of information
The large amount of data and the technical nature of a BOD study make dissemination of results challenging and often limited to specific audiences. The BOD study was considered a “black box” in Uganda and the subjective features of some components of the indicators made it hard to be accepted (Kapiriri et al, 2003). A similar problem was also reflected in India where health policy-makers considered BOD measures to be somewhat unfair and hence hard to accept (study #4 Saxena: Box 1). The health state valuation exercises may be hard to implement in practice. As a result, a dissemination plan for a wide spectrum of target audiences should be developed at the beginning of a BOD study.

Section 6. Implementing a burden of disease study.

National level team building
A BOD study should serve the capacity development needs of a comprehensive health system. Correspondingly, a sustainable training process with the development of a capable national team is warranted. Some of the elements of a BOD study may not be well understood or accepted by health professionals in the beginning. Hence an exposure to the relevant technical background materials is recommended before implementing a local BOD study.
A BOD study is not free of caveats, like any other tools to assist problem solving. Applicants need to possess a clear understanding of underlying assumptions, and know how to interpret the input data and results. As seen in the work in Uganda and Tanzania, information on BOD might be widely available (study #3 Kvale) and yet networking and exchanging methodologies and experiences are still needed. The need for disaggregating data, especially to assess the BOD on poor and marginalized people should be considered as an important part of national capacity development.

Review of health information systems
A BOD study is a valuable tool for national health information system assessment. It requires basic demographic, epidemiological and health service data, which are essentially the major components of a national health information system. Implementation of a BOD study helps to identify gaps and weakness in such data. For example, problems with morbidity data were discovered in Uganda (Kapiriri et al, 2003), while gender-based data came up as a serious gap in Pakistan and Saudi Arabia (study #7 Hyder; Hyder et al, 2005).

The lack of reliable vital registration information in developing countries makes the development of a cause-specific mortality surveillance a complementary resource to the national information system (study #3, Kvale). On the other hand, inconsistency of disability survey methods makes it more difficult to conduct research on morbidity statistics. Supplementary studies on the validity and completeness of basic data might be needed in many cases. Health information systems need to adjust for ongoing demographic and epidemiologic transitions, including aging of the population, shifts from communicable diseases to noncommunicable diseases, and presence of the HIV epidemic. A national health information system should also target the major types of disease burden. In Nigeria, environmentally-mediated conditions such as malaria are the predominant burden of disease; hence the health information system needs to make more effort on collection of good malaria data (study #5 Ogunseitan).

Under most circumstances, there is always some information available in less developed countries. However, due to technical deficiencies or lack of experience, the available information is not always fully utilized; therefore, it is of great benefit for countries to evaluate such information in a BOD study. During the evaluation process, fragmented information can be integrated; data from different parts of a health system can be combined; and information from sources such as surveillance systems, population based surveys, and census can be used to complement each other. This will promote the careful and appropriate use of available information which might have previously been neglected. The newly founded Health Metrics Network provides a set of indicators to facilitate evaluation of health information systems (see Appendix 3).

Quality assurance of data
A BOD study is also a useful method to check the quality and internal consistency of health information within a country. For example, in Korea Kim et al examined death registration data and found that only half of the records were from registered doctors. In addition, there was more than 50% disagreement between hospital records and interviews (Appendix 1: study # 2). A disease modelling software tool (DISMOD) is also available from WHO to check the internal consistency of epidemiological data, e.g., incidence, prevalence, duration of disease and case fatality ratio (see Appendix 3). A BOD study can also be implemented on a regular time interval to monitor trends of disease and mortality.

Chapter conclusion
Burden of disease methods are a rigorous set of approaches and tools to systematically review health information and generate summary measures of population health. The conduct of a national BOD study should be valued as an opportunity for developing national capacity. The output of such a study ought to be fully utilized to facilitate public policy-making. Despite the paucity of data and limitations of the method, the BOD approach has been extensively tested and improved in the past decade. It is a methodology with substantial overall benefit to a country, provided it is planned and conducted appropriately.
References


