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Burden of Disease

BOD

**Application of Burden of Disease
Analyses in Developing Countries**

Implication for policy, planning
and management of health systems

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APPLICATION OF BURDEN OF DISEASE ANALYSES IN DEVELOPING COUNTRIES

Implication for policy, planning and management of health systems

By Adnan A. Hyder, Li Liu, Richard H. Morrow, Abdul Ghaffar

Acknowledgements

Foreword

There has been growing recognition in recent years of the importance to all countries of health systems policy-making that is informed by evidence. In trying to implement this approach, challenges for policy-makers – especially in developing countries – include finding and using information on the magnitude of burdens of ill-health due to different factors, as well as on what interventions are available and whether or not they are actually working in different settings. Summary measures of population health or 'burden of disease' are therefore of vital importance.

To date, there has been rather scant literature on the application of burden of disease measures in developing countries. This publication brings together the results of a series of seven case studies supported by the Global Forum over a period of several years. It provides an introduction to the concepts and illustrates the application of burden of disease approaches in real life settings.

The concept of burden of disease combines measures of mortality and morbidity and each presents problems. Mortality data is often incomplete or inaccurate in less developed countries, due to weaknesses in health information systems and in some cases to social pressures concerning the official recording of causes of death. The quantification of morbidity requires assessment of the quality and quantity of life lived with poor health – estimation of which is by no means straightforward or without controversy. The most widely used composite measure of burden of ill-health is the Disability-Adjusted Life Year (DALY) which was introduced in the 1993 World Development Report. However, as the introductory chapter discusses, there has been much criticism of the use in the DALY of weighting and discounting rates based on factors such as age and ability, as well as a lack of recognition of the importance of the physical and social environment in which the individual is situated. Other summary measures such as the QALY and HEALY have attempted to address these concerns, but the review points to the continuing need for an internationally agreed summary measure that adequately addresses equity issues.

Despite these concerns, this publication demonstrates the practical value for policy-makers and planners of collecting and using summary measures of population health. The authors highlight the important balance between the need for additional information and level of precision required against the time, person and monetary costs of such an undertaking. They also show how summary measures may be used in setting research priorities and point to their potential use for comparing populations and thus highlighting inequities. The synthesis of information gleaned from the experiences reported here highlights the issues and challenges faced and should be useful for national planners and policy-makers contemplating the use of population health measures.

Professor Stephen Matlin
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Table of contents

List of tables and figures

Summary

Methods to measure the burden of disease (BOD) on populations have been applied for decades, but have only received increasing attention in the past twenty years. During this period of time, a number of concerns have been raised with the use of summary measures of population health. Seven BOD studies funded by the Global Forum for Health Research were reviewed to summarize the lessons learned during the process of BOD studies and to reflect on aspects that can be improved. Key methods and results of these studies are summarized and compared. The overall strengths and challenges of these exercises are then discussed, with special emphasis given to questions encountered in developing countries. An extrapolation of these findings to assist with the process of implementing such an exercise at the national level is also addressed. The key findings from the work are summarized as follows.

Composite summary measures of BOD in populations based upon the amount of healthy life lost from disability and from death have been developed and gauged. These are coming to be important tools for comparison among populations and for assisting in health planning and resource allocation. 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.

BOD studies can also be used to examine the burden of ill-health amongst sub-populations according to sociocultural, economic, or other vulnerable feature. They must be used for ensuring that health-related decisions consider equity as well as cost-effectiveness criteria. Health systems across the world are greatly affected by the changes in disease profiles and population dynamics. These systems must develop the capacity to respond to such changes effectively within the resources of each nation. Timely collection and analysis of appropriate, high quality data to support such evidence are a prerequisite for improving equitable global health development.

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.[1] 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] YLL is estimated based on the following function:

$$YLLs = \frac{KCe^{ra}}{(r+\beta)^2}\{e^{-(r+\beta)(L-a)}[-(r+\beta)(L-a)-1] - e^{-(r+\beta)a}[-(r-\beta)a-1]\} + \frac{1-K}{r}(1-e^{-rL})$$

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

Study	Authors	Title	Source	Country	Diseases
1. Allotey, 2001	Daniel D. Reidpath, Pascale Allotey, Aka Kouame and Robert Cummins	Social, cultural and environmental contexts and the measurement of burden of disease: An exploratory study in the developed and developing world	Melbourne: Key Center for Women's Health in Society, The University of Melbourne, Australia	Australia and Cameroon	Epilepsy and paraplegia
2. Kim, 1996	Chang-Yup Kim, Seok Jun Yoon, Hyejung Chang	Measuring the burden of major cancers in Korea	Department of Health Policy and Management, Seoul National Univ. College of Medicine, Korea	Korea	Major cancers
3. Kvale, 2001-2005	Gunnar Kvale, Lydia Kapiriri, Candida Moshiro	Poverty and BOD in Tanzania; value choices in DALY; using BOD for health planning; community identified health priorities; burden of injury	Center for International Health, Univ. of Bergen, Norway	Tanzania, Uganda	Paper-specific
4. Saxena, 2004	Shekhar Saxena and Somnath Chatterji	A methodological approach to the measurement of Disability Adjusted Life Years in selected mental and physical health conditions in India	All India Institute of Medical Sciences, Delhi, and the National Institute of Mental Health and Neurosciences, Bangalore	India	Depression, schizophrenia, diabetes and tuberculosis in disability and quality of life estimation; 13 other health states in valuation exercise
5. Ogunseitan, 2001	O.A. Ogunseitan	Projecting local burden of disease in Nigeria: Planning for health in a changing global environment	School of Social Ecology, Univ. of California, Irvine	Nigeria	Focusing on environmentally-sensitive disease burden
6. Fox-Rushby, 2003	J. Fox-Rushby, C. Nzioka, M. Mugo, K. Johnson, M. Isika, J. Kamau, H. Naughton-Green et al.	Community-based valuatons of health-related quality of life to value the burden of disease: testing methods in Kenya	Health Policy Unit, Department of Public Health and Policy, London School of Hygiene and Tropical Medicine, University of London	Kenya	Conceptions of death and conceptions of time and numeration
7. Hyder, 2003	Adnan A. Hyder, Abdul Ghaffar, George W. Pariyo, Sameera Al-Tuwaijri, Salman A. Wali, Tayyeb I. Masood	Burden of disease measures: comparative measures in developing countries	Department of International Health, Health Systems Program, The Johns Hopkins University	Pakistan, Saudi Arabia and Uganda	Common diseases

Table 1B - Descriptive summary of reviewed studies

Study	Study design	Sample characteristics	Major instruments	Data source, collection and analysis methods
1. Allotey, 2001	Qualitative and quantitative methods with purposive sampling based on self-report	N=152; Age 25-35; equal # of males and females in the total sample	SF-12 (PCS, MCS, health, pain, physical and emotional); ComQoL (with and without satisfaction of health)	Qualitative: in-depth interviews and Photo Voice; Quantitative: t-test and ANOVA
2. Kim, 1996	NBD: Korean data + GBD methodology	NA	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)	Vital registration data (NSO); health insurance claim data
3. Kvale, 2001-2005		Paper specific		
4. Saxena, 2004	disability and quality of life estimation; disability weight development	N=1100. Repondents include patients, their family or caregivers, health professionals and policy-makers.	The WHO Disability Assessment Schedule; WHO Quality of Life; VAS, TTO, PTO1, PTO2	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, ANOV
5. Ogunseitan, 2001	Local BOD	Ilesa health district, southwestern Nigeria.	HeaLY	Morbidity and mortality data obtained through a network of health professionals and hospitals. Environmental data achieved through national and international databases. Sensitivity analysis. MIASMA model
6. Fox-Rushby, 2003	Health state valuation; qualitative study(e.g. participant observation, focus groups discussion and interview); anthropological methods	community-based sample	Reviewed standard gamble, TTO, EQ5D and PTO	Qualitative data collection and analysis methods
7. Hyder, 2003	NBD: Pakistan, Saudi Arabia and Uganda data + HeaLY methodology	National representative sample in Pakistan; Combination of various sourses of information in Saudi Arabia; And selected diseases in Uganda	HeaLY, DALY, PPYLL and YLLE	Pakistan: Pakistan Demographic Survey 1997, PDHS 1990-91; Saudi Arabia: Census 1992, mortality report 1995, Burial Permits Statistics 1994-95 and National Infant and Child Mortality Surveys 1991-92; Uganda: East African Burden of Disease study 1994 and personal communications with experts

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

Study	Major results
1. Allotey	• ComQoL: Paraplegia: 45.6 in Cameroon and 73.7 in Australia; Epilepsy: 54.2 in Cameroon and 66.4 in Australia.
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.

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, 2005a; 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.

Figure 1

ComQoL mean scores by disease and country, study #1 Allotey, 2001

ComQoL = Comprehensive Quality of Life
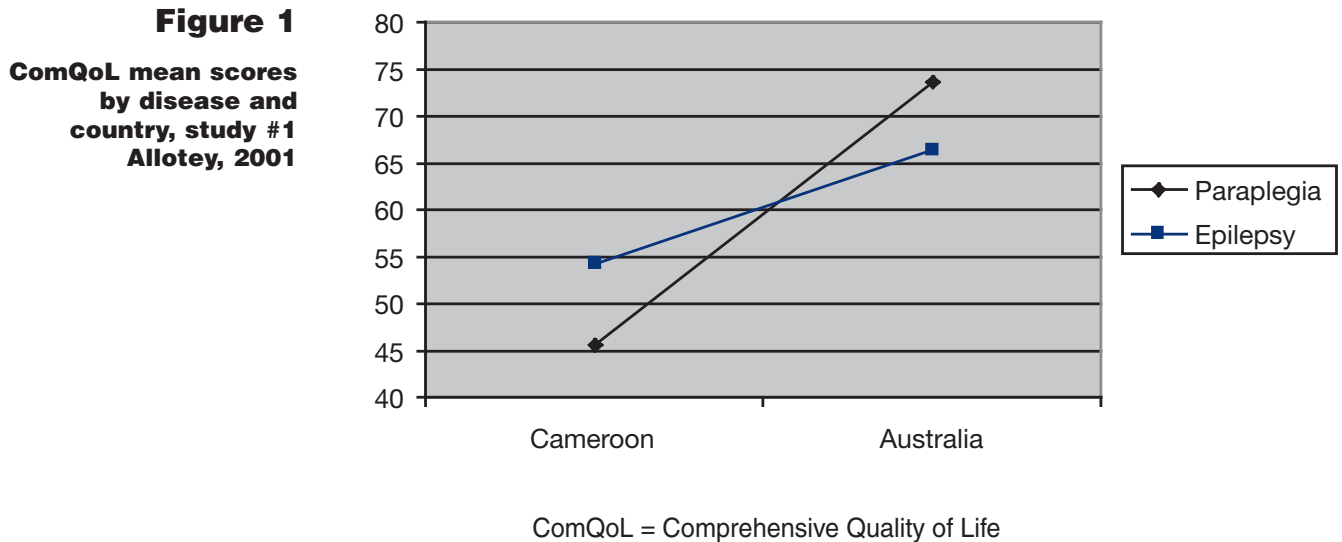
Discounting – social time preferences
People perceive and value future benefits or losses differently from present ones and hence the process of discounting is used frequently in economics. Discounting is the process by which an arithmetic stream of costs (or benefits or losses) is converted to a continuously 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

In Akamba, Kenya, they found that the major reported cause of death was "witchcraft".

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 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.

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.

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Burden of disease: programme and policy implications

Introduction

Recent developments in measurement of population health status and disease burden include increasing use of composite measures of health that combine the mortality and morbidity effects of diseases into a single indicator; more reports on national burden of disease studies; assessments of the effectiveness and costs of specific interventions; developments in the measurement of disability and risk factors; and approaches to measuring and valuing productivity, equity and valuing of healthy life itself. Some of these advances have been captured in the studies on burden measurement funded by the Global Forum for Health Research and reviewed in the previous chapter; others are found in recent literature and in the work done at both national and global levels. Important concerns raised by these developments are about their utility for health planning and about their impact on the quality of decisions taken in the health sector. These advances and the issues they raise will be discussed in this chapter in four sections: the first reviews the reasons for measuring disease burden; the second section explores the use of burden measurement for health decision-making as it pertains to cost benefit analysis in relation to productivity, equity and specific values; the third explores the application of burden measures for priority setting in health research; and the fourth section reviews how burden of disease studies contribute to the discussion on the health of vulnerable populations and poverty.

Section 1. Rationale and goals

Reasons for burden of disease studies

The many reasons for obtaining health-related information (such as burden of disease) all hinge on the need for data to guide efforts toward reducing the consequences of disease and enhancing the benefits of good health. These include the need:
- to determine the health status of the population (incidence and severity of disease by person, place and time variables) at present and over time
- to identify emerging trends and anticipate future needs
- to identify which interventions would have the greatest effect
- to assist in determining priorities for expenditures
- to provide information for education to the public
- to help in setting health research agendas.

The primary information requirement is for understanding and assessing the health status of a population and its changes over time. In recent years, much has been made of the importance of evidence-based decisions in health; its success depends upon how the evidence is used in assisting better decisions concerning health and disease.

Burden of disease studies frequently use measures of health status that combine mortality and morbidity (composite indicators) into a single number. The development of such measures entails two major processes:

It is important to emphasize that decisions within the health sector are concerned only about health interventions and not about diseases or disabilities *per se*.

- the measurement of healthy life-time lost, including that of time lost from premature mortality and that from disability; and
- the valuing of life, which incorporates issues such as values of duration, age, extent of future life, productivity, dependency, and equity (Morrow & Bryant, 1995).

The purpose of developing such measures and the need for refining them become clear if the following objectives are to be achieved in a burden of disease study:
- to quantify the impact (loss of healthy life) of different diseases and risk factors
- to facilitate comparisons within and across populations
- to estimate the quantitative health benefits from interventions
- to use these in the allocation of resources within the health sector
- to generate more relevant and useful data for policy-makers.

Meeting these objectives should help determine the planning, conduct and use of burden of disease studies at all levels.

Information for decisions in the health sector

The most important use of composite indicators of health status is to serve as a common denominator for comparing benefits to be gained per unit expenditure from health-related interventions. Much of the work to be done for guiding health policy and planning decisions are concerned with estimating the effects of interventions and determining the resources needed to support them. Although there are decisions that pertain to policy development, legislation, standard setting, and enforcement as well as those in the realms of manpower development and deployment – resource distributions underlie many of these as well.

Data needs

A distressing feature of much statistical data routinely collected in the developing world is its irrelevance to health planning or evaluation. A national burden of disease study can provide the structure for an efficient and directly relevant data system. The first step in burden of disease studies is to set a framework for what data are needed to determine the relative importance of diseases and risk factors in terms of healthy life lost. The next step is to work through the array of interventions that may reduce this loss. The third is to determine the costs of these interventions. Then it should be possible to work out the effectiveness / cost ratios so as to maximize the amount of healthy life gained per unit expenditure. This information should serve as the foundation for policy and resource planning decisions and should become directly incorporated into the routine data system.[2]

Much evidence-based information about the effects of diseases and risk factors are from clinical and epidemiological studies often of special populations or under special circumstances. Likewise evidence-based information concerning the effects of interventions is largely based on data from randomized clinical or field trials, again often under specially defined circumstances. The information about costs of interventions is often obtained separately. All this information must be translated to the circumstances of the population of concern to the policy- / decision-makers. Furthermore, all must be put in comparable terms of population, place and time. For example, the results of the analyses might be expressed as the amount of healthy life gained and costs expended per thousand population per year.

Burden of disease measures thus far have been used to directly inform decisions within the health sector. (See section of measures on productivity below.) They can be used to assess the health consequences that result from decisions made in other sectors – though of course they are not directly helpful in assessing the primary consequences from these interventions. It is important to emphasize that decisions within the health sector are concerned only about health interventions and not about diseases or disabilities *per se*.

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[2] The first version of these questions was initially introduced in: Hyder AA, Morrow R. Healthy life years. In: Murray CJL et al (eds), Summary Measures of Population Health, WHO, 2002.

Time frame

Ministries of Health, Planning and Finance, especially in the developing world, often work with three to five year development plans. This would be the time frame for major decisions within the health sector and data that supports this process needs to be made available. Measures of health, generated within the country, need to be available to affect this process. Burden estimates which are efficiently done, can aid in this process, especially if their generation allows for a sensible approach of optimally using available information, rather than spending excess time in refining esoteric epidemiological estimates. The framework laid out for data needs above has to be translated into a work plan so that the critical data is obtained in a consistent and timely fashion.

Level of precision needed for decisions

Decisions within the health sector may change if there is important evidence to support a change (and depending on the political process of decision-making). Available or easily collected data can be used for initial burden estimation, and this might be sufficient for many decisions as the development of better data systems continues within a country. See also Level of precision in Section 2 below.

Do burden of disease studies change decisions?

In the final analysis, the impact of health data will be felt if decisions based on them are different, perhaps substantially so, than those based on traditional approaches. Burden of disease information needs to be seen to inform these policy and priority-setting processes in countries and regions, and policy-makers must want to have information presented in this form. Proponents of evidence based health decision-making need to collect, demonstrate and disseminate such scenarios effectively. The case studies presented in Chapter 1 provide the kind of evidence needed for promoting such methods. Another example at sub-national level comes from the integration of burden of disease results in the Tanzania Essential Health Intervention Programme (http://reseau.crdi.ca/en/ev-3170-201-1-DO_TOPIC.html).

Section 2. Use of burden of disease measures in decision-making

Decisions on health interventions

Rationing of health care resources is a fact of life everywhere; choices about the best use of funds for health must be made (World Bank, 1993; Hyder, 1998). The global scarcity of resources for health care is a challenge for every country, rich and poor, (Evans, Hall, & Warford, 1981; World Bank, 1993), but the realities in low- and middle-income countries make the issue of choice that much starker. It is even more important for poor countries to choose carefully how to optimize health expenditures to obtain the most health in the most equitable fashion.

In most sectors decisions on resource allocation are based on perceived value for money, but the health sector has had no universally accepted, coherent basis for determining the comparative value of different health outcomes. To make decisions about whether to put money into programmes that reduce mortality in under-fives, as compared to those that reduce disabling conditions in adults, there is a need to have a common denominator. In recent years, the work carried out to measure the burden of disease with composite indicators that incorporate both morbidity and mortality provide the potential for a common denominator – the common unit of measure is *time lost from healthy life due to a disease or gained from an intervention* or healthy lifetime, commonly expressed in DALYs or HeaLYs.

Costs of health programmes are expressed in a uni-dimensional measure, such as dollars; therefore, the benefits to be achieved from their expenditure must also be so expressed. *Healthy lifetime* is a uni-dimensional measure that can be used to compress health benefits

and losses into a single time dimension. An explicit, objective, quantitative approach ought to enable better budgetary decisions and permit resource allocation in the health sector to be undertaken in a more effective and equitable fashion. The most important reason for attempting to capture the complex mix of incommensurable consequences resulting from disease into a single number is the need to weigh the benefits of health interventions against their costs.

Level of precision

In the collection and assessment of information, the level of precision required depends on the decisions to be taken. Sensitivity testing may demonstrate that quite crude estimates are sufficient for making a particular decision; in examination of healthy life per expenditure ratios, there may be orders of magnitude differences among alternatives. For example, the healthy life gained per dollar from treatment of childhood leukemia compared with that from measles immunization. On the other hand it may be that the current data is not sufficiently precise to differentiate between healthy-life gained per dollar from treatment of postpartum haemorrhage compared with prevention of hypertensive disease of pregnancy. In such a situation it would be helpful to know how much it would cost to obtain the data for the better precision needed to inform the decision. Note that there are likely to be wide variations in estimates of both healthy life to be gained and in costs of the intervention as it is to be used. The time, person, and monetary costs of further precision in information need to be justified by its potential impact on decision-making.

Limitations of burden of disease studies

Two major conclusions were drawn from the first comprehensive review of the early burden of disease studies supported by the World Bank (Bobadilla 1999): First, the data available in the countries involved list? were generally inadequate to provide robust guidance for decision-making purposes. Second, most of those responsible for health planning and resource allocation decisions had not been involved in these studies and were not knowledgeable about composite indicators (PYLL, DALYs), their computation, their use, and their limitations.

Since that review, a number of countries have made substantial improvements in both the data being generated and in the skills and knowledge of burden of disease tools for leaders responsible for health policy and planning, but in many countries major deficiencies persist. Though the countries themselves must accept the responsibility for this situation, the fact is that international support of these new ideas including efforts to measure health system performance have gone toward work at a global level rather than meeting the critical needs at national and local levels. Low- and middle-income countries with their scarce resources need timely and appropriate information to plan and implement health interventions that maximize the health of their populations. Methods, indicators, and assessments of disease burden must support and contribute to this primary purpose of health systems.

It is important to understand that a burden of disease study is simply a method or tool to be used to assist decision-makers in resource allocation. Conclusions that are reached on the basis of these studies must be carefully examined. Not only are there problems of trying to put so many dimensions of health together, but there can be serious concerns about the reliability and validity of information upon which they are based. Continuing vigilance in how data are obtained, compiled and used is critical, and those responsible for using these methods must have a clear technical understanding of what is behind the numbers and the underlying assumptions associated with these approaches.

Burden of disease studies combined with costing studies of the interventions provide the basis for cost-effectiveness (or cost-utility) analysis of the array of interventions under consideration. Thus the DALY or HeaLY gained per dollar invested (or dollars spent for gaining each DALY or HeaLY) can be used to determine what provides greater gains for lower costs. Provided that the data used is robust and the comparisons fair, these analyses lay the foundation for efficient allocation decisions concerning those investments.

Valuing economic and social productivity

Whether and how to value economic and social productivity for purposes of health care decision-making is highly contentious; to a large extent the age weighting incorporated into the original Disability Adjusted Life Years (DALY) formulation was considered by many to be a proxy for productivity. In general, economic productivity may be attributed to adult groups ages 15 – 64 and therefore those in these age groups could be given a higher value; those under age 15 and over 65 may be considered as dependants and given a lower value. People at different socioeconomic levels in a society are expected to have different capacities for productivity; yet to value life according to income levels or social class would not seem fair. In poor countries the value of marginal wages for subsistence agriculture is negligible, but the value of their lives certainly is not.

A fundamental question for decision-makers is whether to consider adding a productivity component to the burden of disease measurement? Many believe that human life should not be expressed in economic terms for decision-making purposes; however, efforts to avoid such expression nevertheless result in implicit valuation of life. Arguments for adding productivity to the valuing of human life have stated that it should not be ignored in health policy, that it is easily quantifiable, and that it does not ignore the welfare of children since the whole population is dependent on adult productivity for quality and sustenance (Barnum, 1987).

Disease most certainly affects human social and economic productivity in measurable ways. Disability reduces worker productivity and therefore reduces per capita GNP, both at its current level and for its potential for future growth. Death reduces lifespan and therefore reduces lifetime earnings. Costs of treating the illness divert the use of these resources from other purposes. Disease also has additional costs that may not be so readily quantified such as impairment of cognitive abilities and reduction in school attendance, There are in addition important consequences of disease that are not easily quantifiable: at the household level, disease of the breadwinner may precipitate bankruptcy and subsequently induce the 'poverty trap'; and at the national level where, because of high absentee rates and worker turnover, investment opportunities may be reduced.

Valuing healthy life

In the report of the Commission on Macroeconomics and Health (WHO, 2001) a DALY gained was stated to be worth at least an average annual income per head. The report states.

"Per capita income in the low-income countries is currently around US$ 410 per person per year in 1999. With growth of per capita income equal to two percent per annum, this would be $563 per year in 2015. 330 million DALYs would therefore result in a gain of $186 billion. There are good reasons to value each DALY at a multiple of per capita income, however, so that the direct benefits could be twice or more $186 billion.... The economics literature on the value of life has a very strong and consistent conclusion: the value of an extra year of healthy life – as a result of successfully treating a disease, for example – is worth considerably more than the extra market income that will be earned in the year. According to some estimates, each life year is valued at around three times the annual earnings. This multiple of earnings reflects the value of leisure time in addition to market consumption, the pure longevity effect, and the pain and suffering associated with disease. More work on explicit valuations on human life and what it produces are needed and will certainly impact on the importance of health-related cost-effectiveness decisions."

Establishing such valuation and obtaining consensus is a major research priority if composite indicators of health are to be used as the basis of overall resource allocation. For the time being, a reasonable approach would be that any such valuations should be considered separately, rather then being integrated into the estimation of disease burden. Such valuations need to be explicit and will depend upon the purpose of the assessment.

Poverty is strongly associated with high child mortality: a child born in Malawi or Uganda will live only half as long as one born in Sweden or Singapore; one in three babies born in Niger or Sierra Leone will not live to see his or her fifth birthday.

Valuing health equity

Decisions based upon cost effectiveness alone (e.g., cost per healthy life year) may not accord well with concerns about equity. These calculations are generally indifferent to equity; they are designed to steer interventions to what is efficient irrespective of differential needs. However, health decision-making ought to be based on equity and fairness as well as efficiency. Composite measures (HeaLY, DALY) can be and should be used not only to guide allocation of resources based on cost-effectiveness criteria, but also should be used to ensure equitable distribution of those resources so as to reach those most in need.

In terms of social justice, equity has to do with a fair distribution of benefits from social and economic development. Although equity is often used synonymously with equality, equality can be used in different conceptual senses: equal access to health services for all (access equality), equal resources expended for each individual (supply equality), equal resources expended on each case of a particular condition (equality of resource use to meet biological need), equal healthy life gained per dollar expended (equal cost-effectiveness); care according to willingness to pay (economic-demand equality), and equal health status for all (equality of outcome). Generally, inequalities that are avoidable, harmful to health, and unfair are considered 'inequities'.

For example, an evaluation of the disease burden in low- and middle-income countries reveals the persistence of infectious, childhood, and maternal conditions, all of which differentially impact the poor. Cost-effective interventions, such as immunization, exist for these conditions, and yet effective delivery has not been achieved. UNICEF reports that half the world's poor are children; they are paying an excessively high price for the failures of adults, while diseases and wars continue to threaten the lives of millions of children. It is estimated that more babies are being born into poverty than ever before. Poverty is strongly associated with high child mortality: a child born in Malawi or Uganda will live only half as long as one born in Sweden or Singapore; one in three babies born in Niger or Sierra Leone will not live to see his or her fifth birthday.

Moreover, mortality based results of the United States burden of disease study indicate that there is a 40-year differential between the life expectancy at birth of sub-groups of the population.[3] Native American males have an average life expectancy of 56 years, while that of Asian American women is above 95 years. This differential exists within one of the most developed nations in the world and similar disparities are likely to be found in most countries.

If fairness is to be used as a criterion for resource allocation decisions in the health sector, then it must be measured and planned for. The pursuit of health equity must go beyond promoting equality of access to health care by ensuring that there is high coverage with all interventions of all segments of the population. To make certain that health system responses are in accordance with equity as well as efficiency, the health status of ethnic, social and other kinds of vulnerable groups must become an integral component of health information systems (see also the section about poverty below).

Measuring equity

In most populations there is a strong positive correlation of income with health, and in order to assess equity, health status must be related to the distribution of socioeconomic and vulnerable groups. The main theme for health inequality analysis in the literature has been the comparison of the health status of groups defined by biological, socioeconomic class, ethnic/racial, and other commonly used poor-rich differences within populations.

Many basic health interventions, when there is high coverage of the population in need, would seem likely to increase equity in health outcomes. These interventions include

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[3] Centers for Disesase Control, USA. Premature Mortality in the United States. 1999

immunizations, Integrated Management of Childhood Illnesses, anti-TB programmes based upon diagnosis and treatment, Sexually Transmitted Infections syndromic treatment, and antenatal care. However a number of important PHC interventions that include a major educational or behavioural change component such as most anti-tobacco and family planning programmes tend to favour the better educated and better off, who are able to both understand and undertake the behavioural changes needed. In fact the better-off can better take advantage of most interventions through better understanding, better access, and more concern about the future. In each setting it may be useful to identify the specific components of an intervention that may give an edge to the better-off and examine what would be involved in strengthening these components in such manner as to facilitate the poor. (Note that this does not mean that these interventions should not be implemented; rather it points to the need for improvements in education, employment, infrastructure and other sectors in parallel with those in primary health care).

The most important responsibility of the health system, particularly at the district level, is to assure full coverage of the population with all affordable interventions. Meeting this responsibility would go a long way toward attaining improved equity in the health status of all. (Coverage is defined as the proportion of population that would benefit from an intervention who actually receive it.) Regrettably, this is rarely achieved; even if there is the political will to improve equity. At this time the data needed for burden of disease indicators are not generally available according to socioeconomic and vulnerable group. The availability of information in this form would provide a powerful tool for calculation of healthy life per dollar to be gained by each socioeconomic and vulnerable group, making it possible to assess the impact of specific health decisions on health equity in a quantitative manner.

Section 3. Use of burden of disease measures in setting research priorities

In 1990, the Commission on Health Research for Development (CHRD) reviewed global health needs and priorities for health research, and identified a great inequity in the allocation of research funds – the 5/95 gap – less than 5% of global health research funds were devoted to 95% of the world's health problems which were measured using years of life lost. This led to the subsequent promotion of the concept of "Essential National Health Research" (ENHR), in which countries take responsibilities to delineate a research agenda by themselves. This movement was based on assessments of the disease burden at that time and used composite measures in the 1990 commission report.

Insert 1 **Conceptualizing health research priorities**	**BURDEN OF DISEASE**		
MAX:100%	**BOX 4** Unavertable with existing interventions **(IDENTIFY NEW INTERVENTIONS)**		
Combined efficiency of intervention mix (0-100%)	**BOX 1** Averted with current mix of interventions and population coverage	**BOX 2** Avertable with improved efficiency **(STUDY HEALTH SYSTEMS AND POLICIES)**	**BOX 3** Avertable with existing but non-cost-effective interventions **(REDUCE THE COST OF EXISTING INTERVENTIONS)**
MIN: 0%			
	MIN: 0% Effective coverage in population (0-100%) MAX: 100%		

Source: WHO, 1996

The World Health Organization's Ad Hoc Committee on Health Research Relating to Future Intervention Options published a report in 1996 called "Investing in Health Research and Development". This report analyzed and recommended policies for research investments of particular relevance to low-income nations. This report used the burden of disease paradigm and the DALY measure to conceptually explore research priorities as shown in Insert 1. The illustration shows how progress in health research may be classified from the perspective of the potential for reduction of different components of disease burden. On the X-axis of this graph, effective population coverage by a mix of interventions is shown, which can theoretically range from 0-100%. On the Y-axis, combined efficiency of intervention mix is shown, which could, theoretically, also range from 0-100%. The maximum area of the disease burden rectangle is the situation in which risk exposures are maximal, while there is no efficient mix of interventions delivered.

The WHO Committee also identified a 5-step process to be consistent with the framework above and to think through the research priority setting process. The five-steps were as follows:
- estimate the magnitude of the disease burden (this would include estimating the overall burden and its distribution)
- analyze the determinants responsible for persistence of the disease burden
- assess existing interventions and efforts to reduce the burden of disease
- estimate the potential cost effectiveness of future interventions to reduce the burden of disease
- identify the level of resources being invested to address the burden of disease.

Again the notion was prioritizing research to reduce the burden of disease or condition and thus the approach begins with an analysis of such burden.

The Global Forum for Health Research took the WHO work forward and developed a useful priority setting tool for health research - the Combined Approach Matrix (Global Forum 2000). The matrix incorporates the 5-steps above along one axis, and on the other axis it disaggregates the information by determinants of health at different levels (Insert 2). The Combined Approach Matrix again incorporates measurement of disease burden as a core requirement for priority setting in health research.

Insert 2 **Combined Approach Matrix**	Economic Dimension	Institutional dimension		
		The individual, household and community	Health Ministry and other health institutions	Sectors other than health	Macro-economic policies
	Disease Burden	—-	—-	—-	—-
	Determinants	—-	—-	—-	—-
	Present level of knowledge	—-	—-	—-	—-
	Cost and effectiveness	—-	—-	—-	—-
	Resource Flows	—-	—-	—-	—-

Source: Global Forum for Health Research

If such research priority setting processes are to address all aspects of health – mortality, disability, morbidity – then measurement of the burden must also incorporate all of these elements as well. As a consequence, burden of disease studies using composite measures become critical, especially at national level. In fact, assessment of the disease burden thus becomes the starting point for setting priorities.

Section 4. Poverty and burden of disease

Health interventions are implemented to benefit populations and improve their health status. As discussed above, the criteria for decisions concerning interventions should include both cost-effectiveness and equity. Most national health systems are intended to benefit all

There have been suggestions that new health care interventions tend to first reach population groups that least need them – the rich.[4]

people by assuring full coverage of all interventions performed according to evidence-based standards. It is important to monitor the coverage and quality of interventions, especially in regard to the poor and vulnerable. Since the poor and vulnerable are generally at a higher risk of ill-health, it is imperative that they are specially monitored to receive all appropriate interventions and to ensure that they achieve positive gains in their health status (see sections about valuing productivity and measuring equity).

Considering the interaction between the poor and non-poor segments of any defined group or society, a health intervention may have differential impact on the absolute health status of each group and on their relative positions. For example, an intervention which selectively benefits the poor will improve their health status and reduce the poor/non-poor differential; while another intervention might selectively benefit the non-poor and further increase the poor/non-poor differential. This type of equity analysis is needed to monitor the impact of interventions on the poor and the poor/non-poor differential.

There have been suggestions that new health care interventions tend to first reach population groups that least need them – the rich.[4] Thus the initial impact would be to improve the health of the rich more rapidly than that of the poor. Observations from South America indicate that poor-rich differential in child mortality narrowed between 1960 and 1990, while the differential for infant mortality widened. Case studies from Brazil also revealed that health programmes launched in a city or state level could result in very diverse results for the specific interventions that comprise a programme.[4] Antenatal care and immunizations were reported to benefit the poor more than the rich, but the rich were already receiving these services in Pelotas, Brazil. On the other hand, introduction of neonatal intensive care provided benefit to the rich only. Similarly, analysis of a state-wide programme in Ceara state of Brazil indicated the lack of definable changes in the poor-rich differential with respect to health outcomes.[7] Despite the specific limitations of each case study, these examples serve to show the importance of planning and monitoring of health interventions for their impact on the poor.

The global community has the opportunity to contribute to the declared goals of international development of reduction of poverty and improvement of the health status of the poor. Health research is a key mechanism for the generation of new solutions, testing of strategies, and exploring the poverty-health interface. The current global interest in the association of ill-health and poverty provides another use of pursuing burden of disease studies and making the case for further research. Areas for priority action and research may be identified in analyzing the burden of disease at a country, regional or global level, such as:

- Region-specific burden analysis leading to research evaluating how specific regions, such as Africa, move out of the vicious circle of poverty and ill-health
- Equity analysis of the burden of a disease by vulnerable groups leading to research on specific high-risk groups, such as exploring how poor women can regain and maintain their health
- Burden of disease studies leading to research on how to strengthen management systems focusing on supportive supervision to ensure both full coverage and performance according to standards
- High burden of preventable diseases leading to operations research, such as investigating why optimum immunization levels have still not been reached in the poor populations despite several years of programmes
- Health systems research into why existing interventions are not being implemented for the reduction of common diseases, both infectious and non-infectious, for the poor in the developing world
- In each setting, identify the specific components of an intervention that give an edge to the better-off and strengthen them so as to facilitate full coverage of the poor
- Disease-specific research on conditions prevalent in poor countries such as malaria and their impact on economic growth.

[4] Victoria C. Presentation at the health Nutrition Population and Poverty Seminar. The World Bank, July 1999.

Conclusion

The health of populations is the fundamental concern of public health. The first step in the pursuit of population health improvement is the measurement of health and disease in the complete population. Measurement is required to establish the magnitude of disease problems, define causal factors, explore potential solutions, and determine the impact of interventions by assessing their coverage and quality. Measuring the impact of diseases on populations in terms of mortality and morbidity and their consequences is essential for planning effective ways to reduce the burden of illness and for setting priorities.

The burden of disease in populations has been gauged in many ways; however, for purposes of comparison among populations and for assisting in health planning and resource allocation, a common denominator is needed. Composite summary measures of population health based upon the amount of healthy life lost from disability and from death have been developed to serve that purpose. Composite indicators (such as HeaLYs and DALYs) use duration of time (years, weeks, days) to measure the loss of healthy life from disease and the gain from interventions. These are coming to be important tools for assisting health-related decision-making.

Burden of disease studies can be used to examine the burden of ill-health amongst sub-populations according to sociocultural, economic, or other vulnerable feature. They must be used for ensuring that health-related decisions consider equity as well as cost-effectiveness criteria. Trends in disease burden provide important clues to the success of ongoing health programmes and the need for development of new interventions. At the same time, they reflect non-health factors that are important to the production or maintenance of health in populations. Inter-country and inter-regional comparisons in disease burden allow for measuring progress among nations and can highlight inequalities in health status and examine these in relation to social, economic and educational factors.

Health systems across the world are greatly affected by the changes in disease profiles and population dynamics. These systems must develop the capacity to respond to such changes effectively within the resources of each nation. Decisions must be based on evidence about the patterns of diseases, their risk factors, the cost-effectiveness of alternative interventions and their effect in improving equity. Timely collection and analysis of appropriate, high quality data to support such evidence are a prerequisite for improving equitable global health development.

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Individual reviews of seven BOD projects funded by the Global Forum for Health Research

Case Study 1 – BOD study in Australia and Cameroon - Allotey et al, 2001

Main objective

The specific aim was to examine the justification behind the use of one single global severity weight for each health condition without regard to contextual factors. The objectives of the study were to examine the notion that the burden of a disease is broadly similar without regard to country, environment, gender or socioeconomic status (SES), and to develop detailed descriptions of the experiences of the burden of disease as they related to these contextual factors.

Main methods

- A cross-sectional, multi-factorial, exploratory study, employing mainly qualitative techniques, complemented by some quantitative techniques, with epidemiological and anthropological components.
- The effects of country (Australia or Cameroon) by environment (urban or rural), by gender, and by socioeconomic status (high or low) on two health conditions (epilepsy and paraplegia) were examined.
- Data were collected combining instruments for measuring subjective quality of life (ComQoL) and health-related quality of life (SF-12), with qualitative techniques such as Photo Voice and in-depth interviews.
- Total of 152 participants, with equal number of women and men aged 25-35, were included in the study.

Main results

- People with either paraplegia or epilepsy were "better off" in Australia than people in Cameroon, as far as the subjective quality of life scores were concerned.
- In Cameroon, people with epilepsy had higher ComQoL scores than people with paraplegia. However, it is the other way around in Australia. This fact contradicts the global ranking of severity weights used in DALY calculations.
- Environmental factors played a role in Cameroon but not in Australia; SES affected both countries, but not epilepsy.
- Among contextual factors of country, gender, environment and SES, country is the major predictor of the scores of quality of health measures.

Strengths

- Comparison of developed with developing country
- Attention on the contextual factors (disease, country, gender, environment and SES) of burden of disease
- Combination of qualitative and quantitative techniques, especially the detailed compilation of informative qualitative results

- Disaggregation of the data used to construct a burden of disease analysis

Limitations
- Hard to determine whether similar health conditions were compared
  ○ The inclusion criteria for epilepsy participants were not uniformly applied across both countries.
  ○ Hard to ensure the clinical comparability of epilepsy, especially when use of medication was considered.
- Sampling
  ○ Non-random sampling may result in selection biases.
  ○ Lack of a means of sampling from equivalent SES categories makes the cross-country comparison problematic.
  ○ The study carried coincided with the Paralympics 2000 in Australia, together with recruitments from the Wheel Chair Sports Association, made a potential underestimate of the burden of paraplegia possible.
- Validity issues of the instruments
  ○ The scoring and interpretation of the scores of instruments followed US norms. It is open to question whether the method can be applied directly in other countries, particularly developing countries like Cameroon.
  ○ Practical issue of Photo Voice, e.g. quality of cameras.
- Use of self-report data
  ○ Individuals' own perceptions of health may not coincide with their actual health status. Hence biases may be produced by data.
- Statistical analysis
  ○ Small sample size provided less power.
  ○ Increase of type I error (inflated the difference) due to the large amount of tests.
- Reliance on the interpretation of qualitative data to overcome the weakness of quantitative data is not convincing for generalizability.

Implications
- Reversal of the rank order of severity of two health conditions between countries suggests the possible failure of one single global severity weight.
- Social, cultural and environmental factors should be given enough attention when considering the burden of disease in a specific region. It is especially so when resource allocation decisions are to be made based on the burden of disease estimates within that area.
- Obtaining and comparing "like" cases is not simple across countries. Therefore, a qualitative description may be a better means to illustrate the situation.
- An inclusion of a "development gradient" and "cultural gradient" in DALY should be considered.
  ○ "Development gradient": development level of a country has a modification effect on the severity of disease, functioning through environmental factors. Specifically, in less developed countries, the severity of a disease tends to be worse than that indicated by the global average. Hence the burden of disease is actually an underestimate. On the contrary, in more developed countries, it is an overestimate.
  ○ "Cultural gradient": besides development level, culture specific factors are playing an important role as well. Infertility will not be considered as serious elsewhere as compared to women in sub-Saharan Africa where high fertility is a social norm.
- Social determinants of a health condition and the severity of this health condition is to be studied. The former is partly considered in the DALY. But the latter is not yet.

Conclusions
- Context can have a significant impact on the severity of health conditions.
- Criticism of the use of global severity weight for disaggregate units.

Tables and figures

#1. Allotey - disaggregate data, quantitative results

Introduction:
- Table 1.1 and 1.2 present the means, medians and 95% Cis of quality of life measure on paraplegia and epilepsy for Cameroon and Australia.
- Both of these two tables are saying that in general people with paraplegia or epilepsy in Australia have better quality of life than people in Cameroon.

Table 1.1 Means and 95% confidence intervals of quality of life measures on paraplegia, by country

Measures	Cameroon					Australia				
	Mean	Median	N	2.5%	97.5%	Mean	Median	N	2.5%	97.5%
SF-12										
MCS [1]	36.2		34	33.9	38.6	35.4		9	28.97	41.81
PCS [2]	29.2		34	27.8	30.6	31.4		13	29.41	33.37
General health [3]	1.6	1 ("poor")	40	1.3	1.8	3.5	4 ("very good")	35	3.10	3.93
Pain [4]	3.8	4 ("quite a bit")	40	3.4	4.1	2.3	2 ("a little bit")	36	1.79	2.71
Physical/ emotional[5]	4.1	4 ("most of the time")	40	3.8	4.4	2.3	2 ("a little of the time")	36	1.84	2.78
ComQoL [6]	45.6		39	41.3	49.8	73.7		36	69.10	78.30
ComQoL - no health [7]	48.5		39	44.2	52.8	75.2		36	70.80	79.60
ComQoL - \health [8]	25.6	2 ("unhappy", original scale)	40	18.7	32.5	58.6	4 ("mostly satisfied", original scale)	36	50.79	66.42

Table 1.2 Means and 95% confidence intervals of quality of life measures on epilepsy, by country

Measures	Cameroon					Australia				
	Mean	Median	N	2.5%	97.5%	Mean	Median	N	2.5%	97.5%
SF-12										
MCS [1]	33.1		26	31.00	35.13	29.7		15	26.28	33.08
PCS [2]	29.0		28	27.54	30.37	28.4		13	25.90	30.83
General health [3]	1.5	1 ("poor")	42	1.26	1.78	3.1	3 ("good")	34	2.72	3.46
Pain [4]	3.1	3 ("moderately")	42	2.73	3.46	2.0	2 ("a little bit")	34	1.62	2.44
Physical/ emotional [5]	2.8	3 ("some of the time")	42	2.41	3.16	2.4	2 ("a little of the time")	34	1.99	2.78
ComQoL [6]	54.2		41	49.15	59.28	66.4		34	61.52	71.25
ComQoL - no health [7]	57.8		41	52.31	63.31	67.5		34	62.40	72.55
ComQoL - \health [8]	32.6	2 ("unhappy", original scale)	42	25.05	40.19	59.9	5 ("mostly satisfied", original scale)	34	51.90	67.81

Note:
(1) The SF-12 mental sub-scale score - (2) The SF-12 physical sub-scale score - (3) SF-12 self-rated health question
(4) SF-12 self-rated pain question - (5) SF-12 self-rated physical/emotional problems
(6) The mean score of the ComQoL satisfaction questions normalized to (0,100)
(7) The mean score of the ComQoL satisfaction questions excluding the health question normalized to (0,100)
(8) The ComQoL question about satisfaction with health normalized to (0, 100)

Introduction:
- Table 1.3 presents the differences of quality of life scores between gender (male vs. female), between environment (urban vs. rural), and between SES (high vs. low).
- t-tests show that in Cameroon, environment and SES, but not gender, are predictors of PCS of paraplegia. Though analysis of variance suggested that only environment is a significant predictor.
- In Australia, only SES is a significant predictor of some quality of life measures of paraplegia.
- In Cameroon, only environment factors are associated with physical/emotional scores of epilepsy.
- And in Australia, only SES predicts the health component of ComQoL of epilepsy.

Table 1.3 Significant score differences (95% CI) between gender, environment and SES, by disease and country

Disease and country	Sex	Environment (urban/rural)	SES (high/low)
Paraplegia			
Cameroon	N.S.	PCS: 3.95 (1.52 - 6.38) *	PCS: 2.7 (0.10 - 5.37)
Australia	N.S.	N.S.	Pain: p=.03
			ComQoL: p=.002
			ComQoL - health: p=.03
			ComQoL - no health: p=.002
Epilepsy			
Cameroon	N.S.	Physical/emotional: 0.83 (0.12 - 1.54)	N.S.
Australia	N.S.	N.S.	ComQoL - health: 16.08 (1.04 - 32.64)

Table 1.4 Description of the experiences of people with paraplegia

Contextual factors	Cameroon	Australia
Between countries comparison	People with paraplegia in Australia were substantially better off than people in Cameroon. One of the obvious distinctions between participants in Australia and Cameroon was the possession of a wheelchair.	
General	❍ None of the participants were under care of any of the formal institutions and none had access to professional care at home. ❍ All reported problems with managing incontinence, pressure sores and pain.	❍ There are a number of organizations that support people with paraplegia. ❍ Some participants were highly motivated achievers. ❍ Most raised the issues of difficult health-related experiences. ❍ Less than half of the participants took up smoking after their disability.
Gender		❍ Some problems in fulfilling gender roles and the need for dependence on others.
Women	❍ Domestic activities were severely restricted; ❍ Issues of reproductive health were raised; ❍ Perception of being repulsive due to incontinence; ❍ Concerns about safety of children. incompetent mothers just because they were	❍ Self-esteem and being sexual beings in intimate relationships. ❍ All women with children had learned to cope with childcare. ❍ But some found that they were treated as in a wheelchair.
Men	❍ "Sexual incapacity" was the first and foremost burden; ❍ Loss of their role as breadwinner and patriarchal figure.	❍ Lack of control ❍ Problems with sexuality and developing and maintaining intimate relationships.
Economic	❍ Wheelchairs available in Cameroon were manual and rudimentary. ❍ Most participants could not afford even basic health care. ❍ Participants also considered themselves as a major burden on their families. ❍ Only 2 out of 40 participants were able to continue their jobs. ❍ People with higher SES had some advantages because of their ability to purchase necessary goods and services.	❍ Curtailment of earning capacity. None of the participants were able to return to the jobs they had before injury. ❍ Some felt better off economically as a result of their injuries.
Environmental	❍ Environmental conditions were inadequate in both rural and urban areas. ❍ Poor road infrastructure, poor facilities for the disabled both within home and community and inadequate health services. ❍ Poor sanitation facilities were a salient problem in rural areas. But inadequate accessibility to toilets is the problem in cities. ❍ In general, participants felt better off in urban centres because more people were ready to offer a hand.	❍ There was less infrastructure in rural areas, and less support and services in regional centres and hospitals.
Other social sequelae	❍ Two-thirds of the participants lost their friends following injuries due to the general belief that they were responsible in some way for their disability. ❍ As a result of limited mobility, stigmatization or low self-esteem, ideas of suicide were often discussed by the participants.	❍ Stigmatization with effects on employment, access to quality health services and community facilities. ❍ Could not always ask for the help and support they would need from their families.

Table 1.5 Description of the experiences of people with epilepsy

Contextual factors	Cameroon	Australia
General	○ People suffered a high level of discrimination due to the cultural and social stigma associated with epilepsy. ○ No action was taken against noncommunicable diseases in general and epilepsy in particular. ○ Internalization of the sick role, which was reinforced by medical staff. ○ Experienced food restrictions.	○ Supported by an epilepsy organization. ○ It's possible to have a driver's license for people with epilepsy. ○ Most participants were on medications. ○ Second to stigmatization, side effects of anti-epilepsy drugs (AEDs) bothered people. ○ Comorbidities, burns and use of recreational substances.
Gender	○ Concerned about the effect of epilepsy on intimate relationships.	
Women	○ All single parents were women. ○ Urban women were not allowed to go to the market without being accompanied, which limited their domestic roles. ○ Rural women faced the risk of burn due to exposure to open fires for cooking.	○ Seizures were often linked to menstrual cycles.
Men	○ Almost half of participants reported abstaining on doctors' advice. Men expressed concern about abstinence vis-à-vis self-esteem.	○ Men complained about their loss of role and lack of control of their lives.
Economic	○ Employment options were greatly reduced, especially for people who were fishermen before, because people with epilepsy were prohibited from approaching lakes. ○ Inability to work made supporting families very difficult. ○ Most participants reported not being able to afford to maintain regular medications. required for a job.	○ Several professions exclude individuals with epilepsy. ○ Other symptoms attributable to epilepsy, including reduced ability to concentrate and increasing forgetfulness, restricted the job options. ○ Restrictions on driving were a major problem economically when mobility was
Environmental	○ Lack of health services and medications in rural areas. ○ Some of the urban participants wish to move to rural areas because of lower road traffic.	○ Higher unemployment in rural areas ○ Inability to drive around is the greatest concern in remote communities. ○ Public transportation relieved the problem in rural areas, but still not easy. ○ Stigmatization was more dramatic in rural than in urban areas since it is easier to be anonymous in large cities.
Other social sequelae	○ Epilepsy was highly stigmatized due to the perception that it was caused by the supernatural.	○ Stigmatization, losing friends.

Case Study 2 – BOD study in Korea - Kim et al, 1996

Main objective
To measure the gap between ideal health status and present health status with respect to the burden of disease (BOD) imposed by major cancers in Korea. Specifically, to apply the BOD methodology in Korea; to develop the procedure to estimate relevant epidemiological parameters; to establish priorities based on the disease burden of major cancers in Korea.

Main methods
The authors followed closely the methods in the original BOD study. Details are as follows:
1) To estimate YLL
   (a) Obtain age-sex specific life table (1995) and age-sex-cause specific mortality of major cancers (1996) from National Statistical Office (NSO).
   (b) Both period expected years of life lost (PEYLL, based on Korean 1995 life table) and standard expected years of life lost (SEYLL, based on standard life table, Coale and Demeny West Level 26) were estimated.

$$YLLs = \frac{KCe^{ra}}{(r+\beta)^2}\{e^{-(r+\beta)(L-a)}[-(r-\beta)(L-a)-1]-e^{-(r+\beta)a}[-(r+\beta)a-1]\}+\frac{1}{r}\frac{K}{}(1-e^{-rt})$$

   (c) Estimate YLL based on the following function
       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).
2) To estimate YLD
   (a) To estimate incidence rate. Health insurance claim data between 1991 and 1996 were utilized. Patients who sought health care for the first time for cancers in 1996 were considered incidence cases. To get the incidence rates, the incidence cases were divided by population.
   (b) To estimate case-fatality rate. CFR = # of deaths due to some malignant neoplasm / # of incidence cases.
   (c) To calculate disability weight. Delphi method: for each cancer, a professional panel was recruited to estimate the disability weight.
   (d) To estimate duration of disability and the average onset age. DISMOD: Software to model incidence and duration from estimates of prevalence, remission, case fatality and background mortality.
3) To estimate DALY. DALY = YLL + YLD (with 3% discount rate)

Main results
- 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.

Strengths
- Collaboration of multiple data sources to evaluate the impact of an important set of health conditions in Korea.
- National burden of disease (NBD) study. Based on Korean data and served local decision-making.
- Closely followed BOD study methodology, making it possible to compare with study results from other countries.
- Estimate study's own disability weight, considering Korean-specific social and cultural context.
- Use of innovative data sources – health insurance claims – to estimate incidence of morbidity and disability.

Limitations
- Replicate study without any improvement in methodology
- Data problem
  - Use of "professional panel" for disability weights without community perception.
  - Death registration data lacks completeness and accuracy in Korea. Specifically, the rate of registered doctor's diagnoses remains low (about half). In addition, there is a lot of disagreement (more than 50%) between hospital records and interviews.
  - Lack of information on disability, very low reliability of disability data and inconsistency between disability survey methods make it difficult to conduct morbidity statistics research.
  - Problems with medical insurance claims:
    - Discordance between medical record and insurance data. Incidence cases could have been an overestimate due to the tendency to document cases at a more severe level to claim more medical insurance.
    - Fail to clearly distinguish between final diagnosis and rule-out diagnosis.
    - Lack evaluation of the accuracy of doctors' diagnosis.
- Presentation of the study results was sometimes confusing in both the report and the paper.

Implications
- Application of study results
  - Help to determine public health priorities in Korea
  - Make it possible to compare DALY across countries
- Current research focus is not in accordance with the ranking of the disease burden of major cancers in Korea.
- Emphasize again the importance of accuracy and completeness of basic demographic and epidemiological data in the process of public health decision-making.

Conclusions
- Liver, stomach and lung cancer are important potential priorities for public health programmes, treatment, prevention or research, judged by the disease burden measures.
- Effective screening methods are available for diseases like cervical cancer and breast cancers, which have higher relative burden of disability. So investments in screening programmes could be cost-effective for Korea.
- Mortality plays a huge role in cancers in Korea; early detection may change that ratio.

Tables and figures

Table 2.1 DALY estimates of major cancers for females, Korea, 1996

Major cancers	YLL (person year)	YLL (person year per 100 000 population)	YLL Rank	YLD (person year)	YLD (person year per 100 000 population)	YLD Rank	DALY (person year)	DALY (person year per 100 000 population	DALY Rank	YLL/YLD
Stomach cancer	63 035	252.1	1	1 718.6	7.6	4	64 753.6	259.7	1	33.2
Liver cancer	33 767	135.1	2	1 119.4	5.0	5	34 886.4	140.1	2	27.0
Lung cancer	30 220	121.8	3	774.7	3.4	6	30 994.7	125.2	3	35.8
Colorectal cancer	19 194	86.4	4	1 906.9	8.5	2	21 101.1	94.9	4	10.2
Breast cancer	19 328	77.3	5	1 865.5	8.3	3	21 193.5	85.6	5	9.3
Leukemia	15 478	61.9	6	438.7	2.0	8	15 916.7	63.9	7	31.0
Cervical cancer	11 572	46.3	7	4 849.5	21.6	1	16 421.5	67.9	6	2.1
Pancreatic cancer	11 124	44.4	8	341.6	1.5	9	11 465.2	45.9	8	29.6
Ovarian cancer	6 436	25.7	9	569.3	2.5	7	7 005.3	28.2	9	10.3
NHL*	4 754	19.0	10	87.7	0.4	10	4 841.8	19.4	10	47.5
Esophageal cancer	1 849	7.3	11	80.3	0.4	11	1 929.5	7.7	11	18.3
Bladder cancer	N/A									
Prostate cancer	N/A									
Total	216 757	877.3		13 752.2	61.2		230 509.3	938.5		14.3

* NHL: non-Hodgkin's lymphoma

Table 2.2 DALY estimates of major cancers for males, Korea, 1996

Major cancers	YLL (person year)	YLL (person year per 100 000 population)	Rank	YLD (person year)	YLD (person year per 100 000 population)	Rank	DALY (person year)	DALY (person year per 100 000 population	Rank	YLL/ YLD
Stomach cancer	109 517	436.4	2	3 411.7	15.0	1	112 928.7	451.4	2	29.1
Liver cancer	128 649	514.5	1	3 252.3	14.3	2	131 901.3	528.8	1	36.0
Lung cancer	92 045	367.7	3	1 644.4	7.2	4	93 689.4	374.9	3	51.1
Colorectal cancer	22 287	88.0	4	2 014.3	8.8	3	24 301.3	96.8	4	10.0
Breast cancer	N/A									
Leukemia	20 427	81.7	5	613.3	2.7	6	21 040.3	84.4	5	30.3
Cervical cancer	N/A									
Pancreatic cancer	17 848	71.3	6	461.4	2.0	7	18 309.4	73.3	6	35.7
Ovarian cancer	N/A									
NHL*	8 806	35.1	8	159.9	0.7	10	8 965.9	35.8	8	50.1
Esophageal cancer	17 092	67.7	7	324.4	1.4	8	17 416.4	69.1	7	48.4
Bladder cancer	5 366	21.3	9	739.9	3.2	5	6 105.9	24.5	9	6.7
Prostate cancer	3 486	13.7	10	203.5	0.9	9	3 689.5	14.6	10	15.2
Total	425 523	1 697.4		12 825.1	56.2		438 348.1	1 753.6		30.2

* NHL: non-Hodgkin's lymphoma

Figure 2.1

YLL and YLD of major cancers for female, Korea, 1996

(person year per 100 000 population)
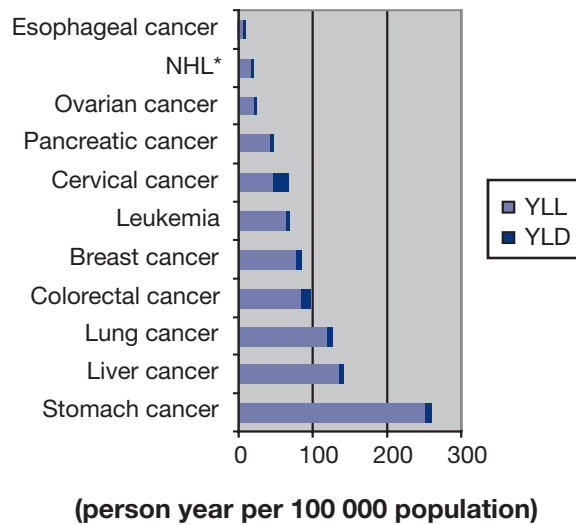
Figure 2.2

YLL and YLD of major cancers for male, Korea, 1996

(person year per 100 000 population)
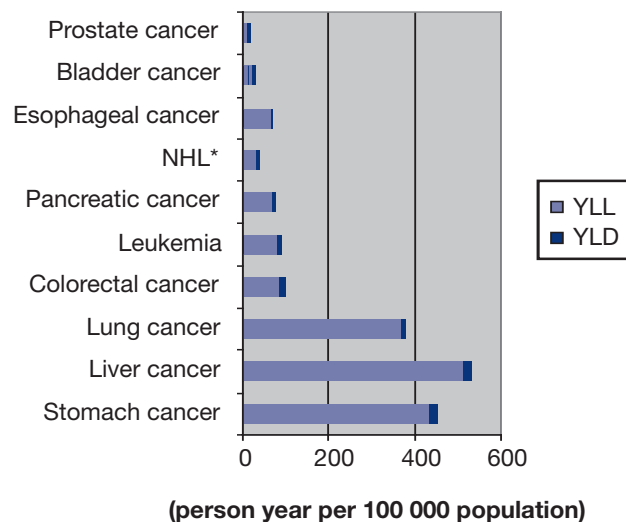
Table 2.3 Disability weight of major cancers by gender, Korea

Major cancers	Male	Female
Liver cancer	0.33	0.33
Stomach cancer	0.26	0.26
Lung cancer	0.25	0.25
Colorectal cancer	0.29	0.33
Leukemia	0.20	0.20
Pancreatic cancer	0.35	0.35
Esophageal cancer	0.30	0.30
NHL	0.18	0.18
Bladder cancer	0.17	N/A
Prostate cancer	0.18	N/A
Cervical cancer	N/A	0.17
Breast cancer	N/A	0.18
Ovarian cancer	N/A	0.17

N/A = Not Applicable

Table 2.4 Examples of morbidity data in Korea

Data	Source	Institution for responsibility
Registration data	Legally approved infectious disease data	Ministry of Health and Welfare (MOHW)
	Certain disease registry	MOHW, others
	Traffic accident registration data	National Police Agency
Health care utilization data	Medical claim data	National Federation of Medical insurance
	Occupational injury insurance data	Ministry of Labour
	Traffic accident insurance data	Private insurance company
Routine health exam data	Routine health exam data	National Federation of Medical Insurance
	Health exam data by occupational medicine	Ministry of Labour
	Health exam data of certain group (school, military force)	Ministry of Education, Ministry of National Defense
Survey data	Hospital patient survey data	MOHW
	National health behaviour and health utilization data	Korea Institute for Health and Social Affairs
	National nutrition survey data	MOHW
	National tuberculosis survey data	The Korean National Tuberculosis Association
	Certain local area survey data	Each university, public health centre, research centre
Hospital data	Medical record data	Each hospital/local clinic

Case Study 3 – BOD study in Tanzania and Uganda - Kvale et al, 2001-2005

Seminar on poverty and the burden of disease in Tanzania

Main objective
- To raise awareness of the burden of disease approach in obtaining equitable health development in Tanzania.
- To seek further collaboration between the government and research communities in setting health priorities based on burden of disease.

Main conclusions and recommendations
- Using country average numbers in national burden of disease studies should be avoided.
- Setting priorities should not be solely based on moving national averages in the desired direction.
- Burden of disease, severity of disease, magnitude of disease, cost-effectiveness of an intervention, as well as political pressure and donor priorities are the main criteria for priority setting.
- Plenty of information required for the BOD study already exists. More coordination and networking to exchange methodologies and experiences between countries are recommended.
- Sentinel surveillance, especially cause-specific mortality surveillance, is a good complementary resource to the national information system.
- It is necessary to differentiate between the concept of BOD and DALY.
- Involvement of community values and participation in the measurement of BOD and resource allocation is essential.
- BOD data should be fully utilized by policy-makers and used in the process of international comparison.
- Training of researchers in this area should be sustainable.
- Opinions of the poor and marginalized people should be included in the Burden of Disease exercise.

Related publications
Six papers from PhD students supported by Global Forum funding were summarized in the following section (four papers are put in the text and two in the appendix). The first three papers are by Lydia Kapiriri, and the last three are by Candida Moshiro.

3.1. Arnesen T and L. Kapiriri. "Can the value choices in DALYs influence global priority-setting?" *Health Policy* 2004 70(2):137-49.

Main objective
- To examine the robustness of DALY distribution based on changes of value choices (age weighting, disability weighting and discounting).
- To explore how transparent the DALY approach is at the point of use.

Main methods
- Reviewed formulae and information from WHO related DALY publications.
- Established alternative values based on a survey of international health workers.
- Calculated burden of "developmental disability due to malnutrition" and "major depression" using current and alternative value choices in a simple sensitivity analysis.

Main results and conclusion
- As a result of discounting, a smaller burden is being attributed to child mortality and disability. Less disability but more mortality was assigned to childhood due to age weighting. The combined effect of both age weighting and discounting leads to an underestimate of BOD in younger age groups.
- Changes of value choices led to an inversion of the ranking of the two diseases based on DALY estimates. The relative burden of developmental disability rose from 14 to

- 90% of the total burden assigned to these two conditions based on equal disability weight of 0.2.
- 49% of the disability weights in noncommunicable diseases were reduced after treatment, while only 14% of the disability weights in communicable diseases were reduced after treatment.
- It is almost impossible to disentangle mortality and morbidity information from the value choices inherent in the disability weights, age-weights and the choice of discount rate in DALY.

Strengths and limitations
- Explored the possibility of using alternative values in DALY calculation.
- Stressed the importance of estimating and presenting DALY results in a more transparent and easily understandable format.
- Ranking of health conditions in this study was still built upon responses from health professionals. No consideration of patients, family members or other parties of interest.
- Criticism of value choices seemed to ignore the fact that Global Burden of Disease (GBD) was designed to compare countries and regions. Therefore, the criticism is only valid in the context of area-specific studies, without any comparison involved.

Implications
- Conventional value choices in DALYs tend to underestimate burden of disease in young population and in communicable diseases, which is the typical disease profile of less developed countries. Therefore, current BOD estimates in developing countries could be lower than actual.
- Issues with disability weight, especially those of communicable diseases, those of a condition before and after treatment, and whether universal disability weights are valid, need further study and more attention.

3.2. Kapiriri L, O.F. Norheim and K. Heggenhougen. "Using burden of disease information for health planning in developing countries: the experience from Uganda." *Soc Sci Med* 2003 56(12):2433-41.

Main objective
- To explore health planners' perceptions of the usefulness of BOD measure in priority setting and planning in Uganda.

Main methods
- A qualitative approach, mainly in-depth interviews of key health policy-makers at district and national levels, was implemented.
- 15 respondents, 6 from the national level, were identified and interviewed based on snowball sampling strategy.

Main results and conclusion
- Results of BOD study have been used in national health policy-making and defining content of health packages.
- Five major themes were identified from the interviews: the appeal of quantitative data; data limitations; opaque methodology; planning as a political process; and opportunity cost.
  - Politicians like figures, so DALY is a good tool to help advocate for neglected health problems, and is considered to make resource allocation more systematic and objective.
  - BOD study exposed the weakness of the health information system in Uganda. Specifically, there is barely any morbidity data available. The quality of mortality data is worrisome as well.
  - The BOD methodology was a "black box" to many respondents. In addition, the value choices may not be acceptable and some non-economic issues were not well considered in Uganda.
  - The usefulness of BOD results for planning was compromised when social, cultural and political contexts of health conditions were involved in decision-making.

❍ The opportunity cost of BOD studies was stressed by respondents. Despite that, more detailed and regular BOD studies focusing on monitoring trends were suggested by interviewees.

Strengths and limitations
- Novel qualitative method was employed to explore how the bridge between science and advocacy was built up, i.e., the usefulness of BOD results in national policy-making.
- Potential barriers of applying BOD results were identified.
- Limited generalizability to other Ugandan or African health planners.

Implications
- More similar studies documenting the evidence of using BOD as basis of policy-making and priority setting will be appreciated, especially in developing countries.
- Strengthening health information systems is an imperative topic in developing countries.
- Decentralization of BOD study, i.e. the local involvement in DALY calculation, is essential. Practical issues in resource allocation should be addressed.

3.3. Kapiriri L and Norheim OF. Whose priorities count? Comparison of community-identified health problems and Burden-of-Disease-assessed health priorities in a district in Uganda. *Health Expect* 2002; 5(1):55-62.

Main objective
- To compare health problems identified by BOD study and those recognized by community in Uganda.
- To explore the potential of using qualitative participation methodologies in health planning and priority setting.

Main methods
- Perceived major health problems faced by the community were identified through nominal group discussion of 51 community members and in-depth interview of 6 community leaders.

Main results and conclusion
- Community perceived health problems were similar to BOD-identified ones, though there was some inversion of the rankings.
- Social stigma and cultural values, in addition to conventional prevalence and severity, were perceived as the major determinants of disease burden in the community.
- Poverty and lack of knowledge were considered the major causes of disease burden.
- Combination of qualitative methods like nominal group technique to capture community value, together with quantitative methods like DALY will provide a more solid basis for health planning and priority setting.

Strengths and limitations
- Participatory qualitative methods were used to capture the community value towards different health conditions. The results were compared with conventional BOD study results.
- Participants were purposively selected. Specific age and gender groups, such as male youth were lacking from the respondents. Hence, the sample opinion was not representative of the entire community.
- Perceptions may not reflect reality. They can be affected by personal knowledge and attitude.

Implications
- Triangulation of information and values, as well as application of multiple methods are helpful in BOD study and priority setting.
- Major causes of ill-health, for example, poverty and lack of knowledge, are beyond the scope of the health field alone. Hence, reducing disease burden is a collaborative work between the health sector and other parts of society.

3.4. Moshiro C., R. Mswia, KGMM Alberti, D.R. Whiting, N. Unwin and P.W. Setel for the AMMP Project Team. "The importance of injury as a cause of death in sub-Saharan Africa: results of a community-based study in Tanzania." *Public Health* 2001 115:96-102.

Main objective
- To study the incidence and causes of injury deaths among community members in three districts of Tanzania.
- To explore how cause of death information might be gathered in settings where such data is not available.

Main methods
- Number of deaths and population were obtained through a population-based prospective study conducted between 1992 and 1998 and census, respectively.
- Cause-specific death rates and years of life lost (YLL) due to injury were estimated.

Main results and conclusion
- Overall, YLL due to injury were 2,643 and 1,024 per 100,000 population per year for males and females respectively in Dar es Salaam, 2,935 and 1,251 in Hai, and 3,360 and 1,226 in Morogoro district, compared to 8,473 and 3,644 in sub-Saharan Africa as a whole (Murray and Lopez, 1996).
- Deaths due to injuries accounted for 5%, 8% and 5% of all deaths separately in Dar es Salaam, Hai and Morogoro districts.
- The age-standardized injury death rates were about three times as high in men as in women in all three areas (the death rates of males compared to females are: 108.8 vs. 40.5 per 100,000 population per year in Dar es Salaam, 138.3 vs. 48.5 in Hai and 145.3 vs. 51.4 in Morogoro).
- However, a larger proportion of girls than boys less than 5 years old died of injury.
- Transport accidents were the commonest cause of death in all injury-related deaths. They contributed to 40.3% to male and 30.9% to female mortality rates in Dar es Salaam. The figures are 23.0% and 17.1% in Hai and 33.0% and 23.3% in Morogoro.
- The authors concluded that injury deaths contribute a large amount of burden in Tanzania.

Strengths and limitations
- The study is the first direct estimate of injury death for a large population in Tanzania and in sub-Saharan Africa.
- The numerator of the study came from a population based survey, which is relatively more representative than the conventional source of hospital records.
- Verbal autopsy assessment of cause of death is relatively more simple and reliable than other methods.
- Calculation of incidence rate in 6-year period is relatively broad. Single-year estimates would be more informative, but may involve more uncertainty.

Implications
- The necessity of strengthening prevention and control of avoidable premature deaths due to injuries should be stressed.
- Application of BOD to a specific cause of death and disability in a low-income country.
- Lower estimates of YLL due to injury obtained in this study compared to those by Murray and Lopez raise a question of whether Tanzania has a lower burden of injury compared to other sub-Saharan African countries.

3.5. Moshiro C, I. Heuch, A.N. Astrom, P. Setel, Y. Hemed and G. Kvale. "Injury morbidity in an urban and a rural area in Tanzania: an epidemiology survey." *BMC Public Health 2005* 5(1):11.

Main objective
- To investigate nonfatal injuries and related risk factors in urban and rural settings of Tanzania

Main methods
- Population-based household survey based on selected clustering sampling strategy was carried out in 2002.
- 8,188 urban and 7,035 rural residents of all ages participated.
- All kinds of injuries resulting in one or more days of activity restriction reported in the year preceding the survey were included in the analysis.

Main results and conclusion
- Rural residents have higher overall injury risk than urban peers. The incidence of injury was 4.3% in rural area vs. 2.5% in urban area (adjusted odds ratio 1.66 (95% CI 1.37-2.02)). However, the level of major injuries (the number of days with restricted activity or disability ≥ 30) was comparable between rural and urban areas.
- Males were at 1.75 times higher risk of injuries than females (95% CI 1.46-2.12).
- The major causes of injury were transport injuries and falls in the urban area, whereas cuts and stabs, mainly due to agricultural activity, were the most common reasons for injuries in rural areas.
- Age was a primary risk factor for certain injuries. However, surprisingly, poverty was not a predictor of a nonfatal injury in this context.
- Different patterns of injuries in urban and rural areas reflected the different lifestyle and infrastructure.

Strengths and limitations
- Population-based surveys provide a more representative picture of the injury pattern than facility based datasets.
- Data based on self-reported techniques bear potential recall biases. In addition, injuries due to intentional violence may not be adequately captured by a household survey. Underestimation of injuries is therefore highly possible.
- Number of disability days was a very rough measure of severity of injury. It is even less accurate when the data relies on self-reporting, especially for minor injuries with short-term disability.

Implications
- Strategies with different priorities are required for nonfatal injury prevention in urban versus rural areas.
- National representative samples are needed to estimate the injury burden in Tanzania as a whole.

3.6. Moshiro C, I. Heuch, A.N. Astrom, P. Setel and G. Kvale. "Effect of recall on estimation of nonfatal injury rates: a community based study in Tanzania." *Injury Prevention* 2005 11:48-52.

Main objective
- To examine the effect of recall on nonfatal injury estimation in Tanzania

Main methods
- Retrospective population-based survey
- A Poisson regression model was utilized to investigate the variation in incidence rates by recall period.

Main results and conclusion
- Significant decline (55% decline) of nonfatal injury incidence rate was recorded based on one-month recall period (72 per 1,000 person-years), compared to the rate based on 12-month recall period (32.7 per 1,000 person-years).
- The difference was mainly due to the dramatic decline of reported incidence in minor injuries with disability less than 30 days.
- The variation of incidence associated with recall period was greater in rural than in urban areas.
- Demographic factors (age, sex and education) were not significantly associated with recall biases.

- Longer recall periods underestimate injury incidence, especially for less severe injuries.

Strengths and limitations
- Among the few studies that examine the effect of recall bias on the estimation of injury in a developing world setting.

Implications
- Incidence of severe injuries was robust to the length of recalling period. But for minor injuries, shorter recall periods are recommended.

Case Study 4 – BOD study in India - Saxena et al, 2004

Main objective
To develop a methodology for BOD measurements for selected mental and physical health conditions in India. Specifically,
- to develop a method to estimate disability weight, using empirical assessment of disability, and a multi-method, multi-informant, and multi-centre approach;
- to calculate BOD based on disability weights generated by current study and recent available epidemiological data;
- to compare the BOD results based on disability weights with quality of life measures;
- and to disseminate the study results to raise awareness of health care policy-makers.

Main methods
- Study sites: All India Institute of Medical Sciences, Delhi and the National Institute of Mental Health and Neurosciences, Bangalore.
- Health conditions: four disabling physical and mental health conditions were included in the study: diabetes, tuberculosis, depression and schizophrenia.
- Respondents: groups of patients, their family members or caregivers, health professionals, health policy-makers and health care volunteers/advocates.
- Instruments:
  - The WHO Disability Assessment Schedule (WHODAS II) and WHO Quality of Life (WHOQOL);
    - WHODAS II was used to measure the disability of subjects with health conditions and family members. The measure was based on self-rated functioning of respondents.
    - WHODAS II is composed of 6 domains and overall disability. The six domains are: 1 – understanding and communication; 2 – getting around; 3 – self-care; 4 – getting along with people; 5 – life activities; and 6 – participation in society.
  - Health states were measured by multiple methods, both for respondents' own, and for 12 other states:
    - Visual analogue scale (VAS): 0 – death, 100 – perfect health
    - Time trade off (TTO)
    - Person trade off (PTO)
- Training workshop was carried out before the study. The instruments were properly translated into local languages. Patients and family members were recruited from clinics.
- Data analysis: Descriptive analysis, ANOVA, regression.

Main results
- 1,100 respondents in this study were largely urban; recruited from hospitals and clinics; most in the 30-50 year age range.
- Patients
  - 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 mental disordered patients reported lowest score in social domain.

- Family members
  - Relatives experienced considerable amount of disability, especially those of depression and tuberculosis patients. Specifically, family members of depression patients cannot get around as much and those of tuberculosis patients face difficulties with self-care.
  - Family members didn't seem to enjoy much better quality of life compared to their sick relatives. In addition, relatives of schizophrenia and diabetes patients had relatively lower quality of life in physical and social domains, in comparison with their counterparts who had other patients to take care of in families.
- As expected, when compared to other respondents (family members, health professionals, health policy-makers, and health volunteers), patients had significantly worse disability and lowest quality of life as a group.
- The health state valuation exercise:
  - The ordering of health states varied significantly across the four methods (VAS, TTO, PTO1 and PTO2) in the health state evaluation exercise.
  - There were relatively high correlations between the results of different methods (VAS, TTO, PTO2).
  - Systematic differences existed between different types of respondents. Specifically, compared to patients, family members tended to give lower values, while health professionals gave higher values on VAS.
  - Delhi centre, women and less education appear to be associated with lower valuations on VAS.

Strengths
- Measure disability and quality of life using unique tools of WHODAS II and WHOQOL.
- Involving patients, their family and caregivers, health professionals and policy-makers in the process of building disability weights, so that conventional bias of disability weights introduced by health professional opinions was likely to be overcome. Local perceptions of disability weights generated locally and for local use.
- Multiple methods to evaluate health states, including VAS, TTO and PTO. Hence, increased quality of health state results can be expected.
- This is one of the largest studies to examine systematically the feasibility and utility of doing health valuation exercises in a dozen health conditions.

Limitations
- Problems with data collection
  - Recruitment of patients and family members from clinics did not guarantee representation of the general population; hence, the generalization of the study is compromised.
  - Selection bias may be further introduced by first obtaining consent from health-care providers before interviewing patients.
  - Interview finished in multiple sessions may have relatively lower consistency and validity.
  - Low participation and completion rate of the interview by selected type of respondents may lead to bias in the outcome measures, such as female outpatients.
  - Long and inappropriately formulated questionnaires led to exhaustion and lack of cooperation by respondents to the interview.
- Problems with instruments
  - WHODAS II showed considerable amount of disability in relatives of patients. However, it may not necessarily mean that those family members did have some disability. It could be a result of the limited accuracy of the instruments, especially so when people only have a very small amount of disability.
  - PTO and TTO seemed difficult to understand for local people, and other (policy-makers) had difficulty in agreeing with the approach and assumptions (see Box 1).
- No comparison between WHODAS II/WHOQOL results and the health state valuation results, as suggested in the objective, was presented.
- No further calculations of BOD based on the estimated disability weight were mentioned.

Implications
- Simple ranking and visual analogue, instead of more complex procedures, can be undertaken in large samples to gather disability weight information, since there is relatively high agreement between the results across methods.
- Simplified valuation tasks, a better understood sample and more extensively trained personnel are desirable in future studies of the same type.
- Education affects disability assessments.

Conclusions
- Despite the lower SES status of patients, it was possible to carry such a complex exercise in this population. However, the value and use of such a process needs to be clear and justified.
- Patients were more disabled than respondents from other groups. Meanwhile, family members seemed to have some disability as a result of their caring role.
- The study results are generally comparable to other exercises by WHO.
- Health care professionals attribute higher values to health conditions.
- In India, quadriplegia, major depression and psychosis were considered more disabling, while mild vision disorder and infertility were considered least disabling.

Impression and feedback
- Poor commentary and explanation in results section
- No "summary" table for main results
- No policy implications of the results was presented.

Box 4.1 **Comments of policy-makers and health administrators on aim of the exercise and instruments**	• He felt that PTO is an unfair questionnaire, as policy-makers cannot ignore healthy individuals when they invest in people with some health condition. He felt his response would be skewed. Funds are not allowed on the basis of either investing in people with some health condition or for healthy people in particular. This kind of weighting is not possible in policy-making. He said, "We do not try to take away from one and give away to another. The one who designed the questionnaire does not believe in equity and has no idea of how funds are allocated in policy-making. No policy-maker can think in this black and white condition." • He felt that in HSV even comparing conditions is not right. He was uncomfortable in giving values and comparing these conditions among themselves. This is a "Nazi's approach", similar to how Hitler approached society. He emphasized that everyone is important in society. We concentrate on providing intervention and give preference to poorer strata in the society. • If etiologic factors are known, a policy-maker will go for prevention; if they are not known, he/she will go for care. • In policy-making, the more the number of affected people (by a particular disease), the more funds are allocated towards that. If incidence is low they usually go for prevention. • As a policy-maker they have to go for cure due to political reasons.

- Table 4.1. and 4.2. shows the WHODAS II and WHOQOL scores of patients and their relatives in four health conditions. It seems that in WHODAS II, the higher score, the more disability. In WHOQOL, the higher score, the higher quality of life.
- Significant differences in the disabilities experienced by patients of the four health conditions were found in WHODAS II domains 1, 2, 4, 6 and overall disability. For example, patients with depression showed the highest WHODAS II scores, in domain understanding and communicating, and in self-care. Diabetes and tuberculosis patients had the highest scores in 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.
- Relatives experienced considerable amount of disability, especially those of depression and tuberculosis patients. Specifically, family members of depression patients cannot get around as much and those of tuberculosis patients face difficulties with self care.
- Family members didn't seem to enjoy much better quality of life compared to their sick relatives. In addition, relatives of schizophrenia and diabetes patients had relatively lower quality of life in physical and social domains, in comparison with their counterparts who had other patient to take care of in families.

Table 4.1 Estimates of disability and quality of life by WHOQOL among patients and family members, India, 2004

Measures			Patients					Family members		
Measures	N	Mean	2.5%	97.5%	p-value	N	Mean	2.5%	97.5%	p-value
Physical										
Depression	104	49.55	46.85	52.26		107	60.91	58.65	63.17	
Schizophrenia	125	55.49	53.54	57.45		117	57.84	56.28	59.41	
Diabetes	129	47.70	45.13	50.27		131	55.97	53.94	58.00	
Tuberculosis	100	52.43	49.03	55.83	0.00	99	60.14	57.74	62.54	0.00
Psychological										
Depression	104	48.92	45.22	52.61		107	68.50	64.77	72.23	
Schizophrenia	125	53.63	50.48	56.79		117	67.41	64.39	70.44	
Diabetes	129	52.52	48.64	56.40		130	66.54	63.04	70.03	
Tuberculosis	100	48.13	43.35	52.90	0.13	99	66.88	63.19	70.56	0.87
Social										
Depression	104	57.53	53.82	61.25		107	73.13	69.65	76.61	
Schizophrenia	125	57.77	55.20	60.34		117	69.23	67.00	71.46	
Diabetes	129	64.92	61.67	68.18		131	69.97	67.19	72.76	
Tuberculosis	100	62.67	58.26	67.07	0.00	99	75.42	72.05	78.79	0.02
Environmental										
Depression	104	63.31	60.17	66.45		107	71.47	68.40	74.53	
Schizophrenia	125	64.04	61.84	66.23		117	69.12	66.80	71.44	
Diabetes	129	61.72	58.84	64.61		131	67.37	64.48	70.26	
Tuberculosis	100	59.56	56.26	62.87	0.15	99	68.15	64.97	71.34	0.21

Note:

(1) Understanding and communication; (2) Getting around; (3) Self-care; (4) Getting along with people; (5) Life activities;
(6) Participation in society

Table 4.2 Estimates of disabiilty and quality of life by WHODAS II among patients and family members, India, 2004

	Patients					Family members				
Measures	N	Mean	2.5%	97.5%	p-value	N	Mean	2.5%	97.5%	p-value
Domain 1 (1)										
Depression	104	29.04	24.29	33.79		107	5.89	3.46	8.32	
Schizophrenia	125	21.24	17.77	24.71		117	3.93	2.19	5.68	
Diabetes	129	14.65	11.29	18.01		131	5.23	3.05	7.41	
Tuberculosis	100	20.95	16.47	25.43	0.00	99	8.43	4.86	12.01	0.09
Domain 2 (2)										
Depression	104	21.88	16.65	27.10		107	11.04	6.83	15.25	
Schizophrenia	125	7.55	4.72	10.38		117	3.69	1.88	5.49	
Diabetes	129	31.44	25.69	37.20		131	6.92	4.20	9.63	
Tuberculosis	100	30.06	24.84	35.28	0.00	99	7.64	4.30	10.97	0.01
Domain 3 (3)										
Depression	104	14.62	10.65	18.58		106	2.08	0.63	3.52	
Schizophrenia	125	8.96	6.37	11.55		117	0.60	0.10	1.10	
Diabetes	129	11.55	7.70	15.40		131	1.91	1.00	2.82	
Tuberculosis	99	12.22	8.14	16.31	0.19	99	3.23	1.65	4.81	0.02
Domain 4 (4)										
Depression	104	19.23	14.22	24.24		106	4.32	1.49	7.16	
Schizophrenia	125	15.87	12.24	19.49		117	2.56	1.06	4.07	
Diabetes	129	6.72	3.67	9.67		131	3.31	1.55	5.06	
Tuberculosis	100	12.50	7.88	17.12	0.00	99	5.05	2.84	7.26	0.37
Domain 5 (5)										
Depression	104	25.58	18.96	32.19		107	6.45	2.85	10.05	
Schizophrenia	125	26.48	21.42	31.54		116	4.57	2.14	7.00	
Diabetes	127	25.91	19.54	32.27		130	7.00	3.79	10.21	
Tuberculosis	100	22.90	16.42	29.38	0.86	99	5.05	1.51	8.59	0.67
Domain 6 (6)										
Depression	104	40.02	34.50	45.55		107	8.61	5.24	11.97	
Schizophrenia	124	36.83	32.35	41.31		117	5.73	3.56	7.91	
Diabetes	129	31.17	26.88	35.46		131	8.33	5.97	10.70	
Tuberculosis	100	39.38	34.47	44.28	0.03	98	8.46	5.45	11.47	0.38
Overall disability										
Depression	104	27.44	23.32	31.55		105	7.06	4.50	9.62	
Schizophrenia	124	21.39	18.44	24.33		116	3.92	2.47	5.37	
Diabetes	127	21.51	18.22	24.80		130	5.92	4.30	7.54	
Tuberculosis	99	25.57	21.99	29.15	0.03	98	6.97	4.59	9.34	0.10

Note:
(1) Understanding and communication; (2) Getting around; (3) Self-care; (4) Getting along with people; (5) Life activities;
(6) Participation in society

- Table 4.3. shows the raw and adjusted values of VAS in the current exercise
- The raw VAS values are generally lower than those among highly educated respondents in other countries, but fall around the middle of those carried in the general population
- The VAS adjusted approach leverages valuations on VAS, TTO, SG and PTO in connection with flexible parametric models of responses to different methods.

Table 4.3 VAS value by health states, India, 2004

Condition	VAS		VAS_adjusted*	
	mean	median	mean	median
alc	37	35	0.48	0.49
bip	41	40	0.53	0.55
bko	50	50	0.63	0.66
dia	51	50	0.64	0.66
inf	63	70	0.75	0.85
ins	58	60	0.71	0.76
maj	30	25	0.40	0.36
mbk	57	60	0.70	0.76
mvi	67	70	0.78	0.85
own	78	90	0.86	0.97
psy	34	30	0.44	0.43
ptb	38	35	0.49	0.49
qua	14	10	0.19	0.15

*VAS_adjusted = $1-(1-VAS\_raw/100)^{(1/0.64)}$

Case Study 5 – BOD study in Nigeria - Ogunseitan et al, 2001

Main objective
To use burden of disease indicators as a tool to study the relationship between morbidity and mortality patterns and changing environment in Nigeria.

Main methods
- Morbidity and mortality data were obtained through a network of health professionals and teaching hospitals.
- Environmental data, including access to water and vector control, were obtained through national and international databases.
- HeaLY was used as the indicator of burden of disease.
- Changes of outcome based on two major scenarios were presented. The two scenarios were: 1) coverage of water availability changes from 39% to 20%; and 2) vector control coverage drops from 50% to 20%.
- Sensitivity analysis based on different discount rates ranging from +1.5% to +4.5% was included.
- The MIASMA model (a modeling framework for the health impact assessment of man-induced atmospheric changes) was utilized to explore trend of vector-borne disease burden.

Main results
- The baseline burden of disease for the region in this study is different from that for sub-Saharan Africa in the GBD study (Murray and Lopez, 1996), which justifies the necessity of doing BOD studies based on a smaller area where epidemiological data is more available and easier to collect.
- Detailed studies of "weights" and "discount rates" are needed for each category in the disease burden.

- Infectious and childhood diseases account for the major disease burden in Nigeria during 1990-2000.
- Qualitative studies discovered that there is a disproportionate portion of disease burden that is actually due to preventable environmental factors.
- HIV infection contributes to a substantial burden of disease. If 10% case-conversion was assumed, HIV represents 22% of the total disease burden, while vector-borne diseases only accounts for 6%.
- Environment-sensitive diseases, like malaria and diarrhoea, are prevalent in the entire geographic area of the country, except in the highland central plateau.
- 6% of the total burden is attributable to malaria in the local region in this study, 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.
- Mortality incidence is about 0.05% higher for males, which may be attributable to injury.
- On the other hand, the hospital admission rates are much higher for females, which can be mainly explained by maternal conditions.
- However, there is no significant difference between DALE (Disability Adjusted Life Expectancy) for males and females (38.4 vs. 38.1 years, respectively). The reason is likely to be the impact of a relatively gender neutral HIV epidemic.

Strengths
- Unique effort to examine association between mortality/morbidity pattern and environmental changes.
- Use BOD measures to study environmentally-sensitive diseases.

Limitations
- Content of the report and objective of the study is mismatched. There is considerable focus on other disease burden not closely related to environmental change (especially in the result section).
- Burden of disease estimation was obtained by HeaLY, hence the results can't be compared directly to GBD study which is based on DALY calculation.
- Information was mainly coming from a specific area (Ilesa health district), hence the generalizability of the results are limited.

Implications
- Lack of data is a bottleneck for BOD type of study, especially at the local level.
- HIV will dominate the BOD, setting environmentally-sensitive diseases to secondary significance in Nigeria.

Conclusions
- The morbidity and mortality pattern of environment-sensitive diseases are sensitive to the changing climate. Yet the relative importance of the burden of such kind of diseases may not be as great in the context of a HIV epidemic.

Impression and feedback
- No summary tables of key BOD results, though piles of spreadsheets are attached.
- Trivial project materials are included in the report, which is distracting.

Tables and figures

Table 5.1 Deaths, cases and case fatality ratios of notifiable diseases, Nigeria, 1990-1999

Disease	1990	1991	1992	1993	1994	1995	1996	1997	1998	1999[1]	Total
Cholera											
Deaths	61	7 869	663	266	471	140	4 546	851	277	2 085	17 229
Cases	4 101	62 418	8 687	4 160	3 173	3 364	59 136	13 411	9 254	26 358	194 062
CFR[2]	15	126	76	64	148	42	77	63	30	79	89
CSM[3]											
Deaths	784	695	563	472	437	1 388	11 231	965	797	165	17 497
Cases	7 804	6 992	6 418	4 209	6 119	7 376	108 546	39 973	10 793	1 946	200 176
CFR	100	99	88	112	71	188	103	24	74	85	87
Diphtheria											
Deaths	2	64	3	0	0	5	55	166	3	15	313
Cases	1 768	2 849	2 351	2 042	1 363	1 556	2 768	3 285	6 071	3 769	27 822
CFR	1	22	1	0	0	3	20	51	0	4	11
G Worm[4]											
Deaths	7	23	0	0	0	0	0	0	1	38	69
Cases	9 050	5 479	6 749	5 356	3 388	1 848	14 388	10 426	13 419	9 603	79 706
CFR	1	4	0	0	0	0	0	0	0	4	1
Hepatitis											
Deaths	69	60	48	53	33	54	38	39	42	20	456
Cases	5 495	8 897	8 291	6 312	4 283	3 599	5 436	2 664	8 158	3 264	56 399
CFR	13	7	6	8	8	15	7	15	5	6	8
Leprosy											
Deaths	7	17	35	0	0	1	0	0	0	0	60
Cases	20 557	13 641	14 875	14 706	10 422	8 105	7 687	8 524	10 177	3 704	112 398
CFR	0	1	2	0	0	0	0	0	0	0	1
Malaria											
Deaths	2 284	1 947	1 068	719	1 686	3 268	4 773	4 603	6 197	1 891	28 436
Cases	1 116 992	909 656	1 219 348	981 943	1 175 004	1 133 926	1 149 435	1 148 542	2 122 663	732 170	11 689 679
CFR	2	2	1	1	1	3	4	4	3	3	2
Measles											
Deaths	1 399	388	1 032	373	696	671	2 031	1 147	1 804	2 751	12 292
Cases	115 682	44 026	85 965	54 734	108 372	49 880	102 166	73 735	164 069	132 856	931 485
CFR	12	9	12	7	6	13	20	16	11	21	13
Pertussis											
Deaths	184	66	1	61	65	51	186	222	216	121	1 173
Cases	42 929	18 685	22 147	23 800	34 792	13 639	26 745	33 729	49 550	22 162	288 178
CFR	4	4	0	3	2	4	7	7	4	5	4
Tuberculosis											
Deaths	213	487	230	192	379	407	380	331	454	152	3 225
Cases	20 122	19 626	14 802	11 601	15 202	10 040	121 025	11 388	19 368	9 329	252 503
CFR	11	25	16	17	25	41	3	29	23	16	13
Onchocerciasis											
Deaths	1	4	0	0	25	1	90	85	2	0	208
Cases	2 002	758	2 879	82 634	6 401	7 272	5 111	3 125	2 948	1 024	114 154
CFR	0	5	0	0	4	0	18	27	1	0	2
Yellow Fever											
Deaths	421	661	8	8	415	0	0	0	3	0	1 516
Cases	6 035	2 561	149	152	1 167	0	0	0	5	0	10 069
CFR	70	258	54	53	356	0	0	0	600	0	151

Notes: 1. January to August only; 2. Case Fatality Ratio (deaths per 1,000 cases); 3. Cerebrospinal meningitis; 4. Guinea Worm; Shaded rows are diseases that are particularly affected by climate.

- Table 5.2 is extracted from HeaLY spreadsheets in the attachment of Ogunseitan's report.
- Three senarios with different discount rates were applied in the calculation.

Table 5.2 Local burden of notifiable diseases, Ilesa, Nigeria, 1999

	Senario 1 (discount rate is 0.03)		Senario 2 (discount rate is 0.015)		Senario 3 (discount rate is 0.045)	
	YHLL per 1 000 population	YHLL per case	YHLL per 1 000 population	YHLL per case	YHLL per 1 000 population	YHLL per case
Cholera	0.56	2.95	0.82	4.31	0.41	2.17
Meningitis	1.32	NA	1.96	NA	0.95	NA
Diphtheria	0.07	2.20	0.10	3.37	0.05	1.58
G Worm[4]	0.01	0.11	0.01	0.11	0.01	0.11
Hepatitis	0.30	0.99	0.41	1.36	0.23	0.77
Leprosy	1.57	13.10	1.87	15.61	1.38	11.51
Malaria	21.51	1.20	33.28	1.85	15.29	0.85
Measles	0.86	0.96	1.31	1.46	0.62	0.69
Pertussis	0.01	0.38	0.02	0.54	0.01	0.29
Tuberculosis	18.10	15.08	24.86	20.72	13.95	11.63
Onchocerciasis	0.04	NA	0.04	NA	NA	NA
Yellow Fever	NA	NA	NA	NA	NA	NA

NA: Not Available

Related publications

5.1. Ogunseitan OA. 2001. "The Nigerian Health System." In: Gutekunst, M.D. and K. Drame (Editors) *Selected Health Systems of Africa*. New York: Mellen Press.

Major contents
- Described the evolution of health care system in Nigeria since independence.
- Current burden of disease is still dominated by environment-mediated conditions hence a health system focusing on preventive health is more suitable for Nigeria.
- Both chronic diseases, such as malaria, and acute seasonal epidemic of meningitis exert a big burden on Nigerian health.
- HIV prevalence was about 6% in 1999 in Nigeria, which contributes to another heavy burden of disease.
- As a consequence of block allocation plan, the coverage of an expanded immunization programme dropped from 80% in 1992 to below 20% in 1995.
- Introduced national health insurance programmes, emergency health services, occupational health system and health information system.
- Acknowledged the Global Forum for the funding.

5.2. Ogunseitan OA. 2000. "Framing Vulnerability: Global Environmental Assessments and the African Burden of Disease." Belfer Center for Science and International Affairs (BCSIA) Discussion Paper 2000-21, Environment and Natural Resources Programme, John F. Kennedy School of Government, Harvard University.

Major contents
- Vulnerability assessment is an essential component of global environmental assessment, to evaluate the impact of climate on human well-being.
- The impact of environment on human health is a general concern in Africa.
- The paper explored the communication pathway from issue framing to political action on environmental health in Africa.
- Boundary institutions are identified as the major node in the communication pathway to translate global frames into local action. Yet perception of intellectual hegemony, scarceness of local data and financing issues all limited the credibility of their projections of health impacts.

- Indigenous programmes focusing on open-ended vulnerability assessments would promote better communications.

5.3. Ogunseitan OA. 2000. "From Global Framing to Local Action: Translation of Climate Change Impacts in Africa." Pp E1-11 in Scott, D. et al (Editors). *Climate Change Communication Proceedings*. Environment Canada.

Major contents
- A shorter version of paper 2.

Case Study 6 – BOD study in Kenya - Fox-Rushby et al, 2003

General objectives
- To test the applicability of health related quality of life (HRQL) valuation techniques across cultures.
- To determine whether to adopt existing HRQL valuation techniques in the new context.
- To assess whether HRQL valuation techniques hold universal validity and acceptability.

More specifically,
- to examine concepts embedded within existing valuation tools;
- to review the use of health state valuation (HSV) tools in low-income countries, such as Kenya; and
- to implement in the field a qualitative study of conceptions of death, time and numeration in Kenya.

General methods
- HSV tools evaluation and literature review.
- Literature review of the Akamba (study site) ideas embedded in the existing HRQL tools.
- Qualitative study on related conceptions (death, time and numeration) in Kenya.

General conclusions and implications
- Death may not be viewed and interpreted in a similar way across cultures.
- HSV techniques need to be localized to produce meaningful results.
- The relevance and applicability of HRQL instruments is questionable across cultures.

Strengths
- It is among the few studies focusing on culture relevance of HSV instruments.
- Combination of extensive literature review and empirical fieldwork generate solid ground for the argument of inappropriateness of HSV tools in this special setting.
- Acknowledges the Global Forum for funding.

Limitations
- Some inconsistency arises in the reports. For example, in section 6, death is not considered as a complete annihilation of a person. But in section 7, the future stops at the death of a person.
- There is substantial overlap and redundancy among different sections of the report. An overall summary paper would be much more efficient.

Section specific review

Section 4. Are health state valuation techniques likely to be understood in the same way in Kenya?: Moving towards an assessment of conceptual equivalence

Objective
- To assess "conceptual equivalence" before assessing the equivalence of questionnaires across cultures.

Methods
- Four HSV instruments were reviewed. The instruments were: the standard gamble, time trade-off, EQ5D rating scale and person trade-off.

Results
- The study identified eight key concepts in the reviewed instruments.
  (1) individual autonomy in decision-making for personal future;
  (2) linear conception of time stretching into a future for up to 10 years;
  (3) risk is a random event that cannot be 'protected' against;
  (4) access to treatments to improve health;
  (5) death is the end of personal time in the future;
  (6) numbers have ratio properties;
  (7) the future can be contemplated with certainty; and
  (8) death is tradable for future health either in an individual, or across individuals.

Section 5. Review of health state valuation in low-income countries

Objective
- To critically review the use of HSV techniques in low-income countries (LICs). Specifically, to describe the use, how the use has been researched and to raise potential concerns.

Methods
- Literature review:
  - Medline, Popline, EMBASE, BIDS and Web of Science were searched for the full period of their histories.
  - Search words are "health", "health state valuation techniques" and "low income countries".
  - All articles using any scaling technique in a LIC were selected for the review, which yielded 17 articles in total.
  - The review criterion consisted of nine areas of assessment, i.e. background details, methodological details, conceptual equivalence, item equivalence, semantic equivalence, operational equivalence, measurement equivalence, functional equivalence and definitions.

Results
- The most common method of scaling was the direct estimation method.
- Most of the scales were applied without any modifications and the scalar equivalence issue was not addressed.
- Nearly half of the papers focused on pain.
- Kirigia (1998) attempted to apply a valuation instrument in a LIC. It was noted in the paper that appropriate tools need to be developed in the specific setting. Yet the equivalence issue was not comprehensively addressed.
- Only four papers translated the English version into the local language. But no scaling technique was developed in LICs.
- Though scales have been used in LICs, diversity of cultures and heterogeneity of application of instruments in different settings were not recognized. This should be addressed in future research to facilitate international comparison of HRQL.

Section 6. Literature review on local perceptions and experiences of death among the Akamba people

Objectives
- To describe the perception and experiences of different forms of death experience in Akamba. Also to explore the occurrence rates, the sociocultural rite and rituals undertaken when people die, ways of disposing the dead, purification ceremonies carried out after death and social response.

Methods
- Literature review:
  - Search words: death, Machakos, Makueni, Kitui, Kamba or Akamba, ritual or rites.
  - Search places: major libraries and university and research libraries in Nairobi.
  - Search disciplines: anthropology, sociology, philosophy and religion.

Results
- The major causes of death in Akamba tradition are witchcraft, magic and sorcery.
- The dead continue to live as long as they are still remembered by those who are alive (living dead). It can take up to five generations.
- Death is not considered as the complete annihilation of a person, but a departure to a more permanent stage.
- Death causes impurity. Hence purification is needed after the burial.
- Only old people talk about death. Others don't.
- Thinking about another person's death is thought to cause it through witchcraft. Thus discussion of death of others is very limited.

Section 7. Kamba notions of time and numeration: A literature review report.

Objectives
- To study how time and numeration are understood by Akamba people, and how the understanding influences the local experiences of health and well-being.

Methods
- Literature review:
  - Search words: Kamba or Akamba, time, numbers, music, dance, games, trade and bride wealth.
  - Search places: major libraries and university and research libraries in Nairobi.
  - Search disciplines: anthropology, sociology, philosophy and religion, history, economics and African literature.
  - Musical phases and time signature, the nature and types of games pertinent to counting, trading situations, methods of allocating scarce resources, bride wealth standards and conceptions, and determination of time were all reviewed.

Results
- Dead relatives live in the past dimension of time, people alive are in the present and their own deaths occur in the future. Yet the reviewer also stated that "the futuristic dimension of time is non-existent in Akamba thought".
- Time is meaningful at the event and not the numeric moment.
- Choices people made "today" directly or indirectly affect their future.
- Seers and prophets are responsible for predicting future events.
- The Akamba people can think about the future in big units like years; but they don't use small units like minutes or months.
- Akamba have an elaborate system of counting in all domains of life, e.g., music, games, bride wealth payment and trade.
- Counting is taught by folklores.

Section 8. Perceptions of numbers and time among the Akamba in Kibwezi Division, Makueni District: Preliminary fieldwork report.

8.1 The Kamba conceptions of time

Objective
- To study time conceptions among the Kamba people of Kibwezi. Specifically to study how they understand and calculate time, how time is recorded, experienced and valued, and past, present and future time perceptions.

Methods
- Qualitative study method: key informant interviews

Results
- People in Akamba have a vague definition of time.
- The Akamba time perception is event based.
- Precise time determination is lacking in traditional Kamba thinking, but it is evolving with westernization.
- The Akamba people have a very strong sense of the future.
- The future of a particular person depends on his/her age and health status.

8.2 Trade

Objective
- To investigate trade of commodities locally produced and sold in Kibwezi Division. Specifically to study price fixing, modes of weighting and measurement, price changes, product valuation and problems encountered during exchange.

Methods
- Qualitative study methods: participant observation, interviews and constructing trading records.

Results
- Factors determining the price in livestock market are size, quality, season, need of the buyer/seller, time of the day, social interaction and brokers' price.
- The value of a crop depends on the nutritious value of the crop and availability.

8.3 Bride-price

Objective
- To examine the local numerical system used with respect to dowry payment. Specifically forms of bride-price, people involved in bride-price negotiations and settlement, how numbers reflect value and the equivalence of dowry, and the symbolic importance of numbers in dowry.

Methods
- Qualitative study methods: in-depth interview, participant observation and focus group discussion.

Results
- There is no universal consensus on the amount to be paid.
- Money can be used as a replacement nowadays for livestock in bride-price.

8.4 Resource allocation

Objective
- To explore resource allocation using relief food distribution.

Methods
- Qualitative study methods: interviews and participant observation.

Results
- Distribution of relief food is considered fair in general.

- Basic numerical skills are demonstrated in the process of distribution.

Section 9. Perceptions about death among the Akamba in Kibwezi Division, Makueni District, Kenya.

Objective
- To study the perceptions of death among the Akamba. Specifically, to identify the perceived cause of death, the mortality rituals, the social response to death and the circumstances under which death is discussed.

Methods
- 60 respondents, 3 case study families and 4 life histories were purposively sampled.
- Qualitative study methods, including participant and direct observation, informal interviews, key informants interviews, case studies and life histories were applied in the study.
- Data analysis involved arranging and categorizing the information elicited by the objectives of the study.

Results
- Death must have a cause agent, albeit a medical diagnosis.
- Death is not the end of life but merely a bridge to the life thereafter.
- Mortuary rituals and purification rites are very critical when death occurs.
- Society responds to death in a positive manner.
- Death is not openly discussed before it occurs.

Section 10. An explanation of the ways in which Standard VII and Standard VIII grade pupils are able to use and manipulate concepts of time and measure.

Objective
- To investigate students' knowledge on units and measurement.
- To study students' perception of use, accuracy and relevance of time.
- To explore how concepts of time are taught in the modern curriculum.

Methods
- Assigned tasks, questionnaires and knowledge tests were used to study students' perceptions of time and measurement.

Results
- Students were good at describing the naturally occurring cues used for specific time determination.
- Students have a good sense of units of measurement.
- Reading a clock was difficult for half of the students tested.
- There are discrepancies in the time cues students identified, which may reflect the different traditions of the families.

Section 11. How well do health state valuation techniques cross cultures? Evidence from Kenya.

Section 12 and 13. How well do health state valuation techniques cross cultures? Implications of conceptions of death amongst the Akamba of Kenya.

Contents
- Evidence for and against the fact that the concepts of death in the questionnaire and those understood by the local population are similar
  - For:
    - Death is inevitable
    - Longevity is preferred
  - Against:
    - Thinking of death hastens it
    - Role of external agents is important
    - Death has different states and is "polluting".

- The cultural relevance of HSV techniques must be investigated.
- If the HSV exercise is blindly practiced, the conceptual differences may be masked, and the results may be mistakenly interpreted.
- Death is interpreted differently even among people of the same culture.
- HRQL cannot be universally applied in the Akamba context.
- HRQL techniques need to be localized to generate acceptable and meaningful results.

Case Study 7 – BOD study in Pakistan, Saudi Arabia and Uganda - Hyder et al, 2003

Main objective
- To measure the burden of diseases using summary indicators that are alternatives to the DALY.
- To evaluate various data sources in three developing countries, Pakistan, Saudi Arabia and Uganda.
- And to develop the capacity for local investigators to perform such kind of analysis.

Main methods
- The disability adjusted life years (DALYs), the healthy life years (HeaLYs), and the potentially productive years of life lost (PPYLL) and years of life lost to average life expectancy (YLLE).
- Data were collected by collaboration with researchers in the study countries, Pakistan, Saudi Arabia and Uganda.

Main results
- 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 per 1,000 population for males and females.
- Sleeping sickness, perinatal conditions, malaria, acute diarrhoea, trauma and AIDS were important causes of the loss of HeaLYs in Uganda in 1994. They each contributed 128, 105, 100, 47, 37 and 24 HeaLYs lost per 1,000 population, respectively.

Strengths
- A multinational burden of disease study, with representation of three countries in the three major developing regions, i.e. South Asia, Mid-East and East Africa.
- Acknowledged the Global Forum for funding appropriately, both in the report and in the related publication.
- Use of alternative health gap measures to the DALYs, and their application in low-income settings.

Limitations
- Data on disease onset and duration of disability were rough estimates and heavily relied on experts' opinions.
- Quality of the data utilized in this study was a general concern when constructing the composite measures in Uganda.
- Estimation in Pakistan and Saudi Arabia failed to include any morbidity and disability information, while calculation in Uganda concentrated only on a dozen selected diseases. Both facts made the comparison across the three countries less meaningful.

Implications
- The BOD process uncovered key information gaps, which provided further guidance to prioritize health research.
- Gender inequity, reflected by the under-reporting of female deaths, is a common issue in the three countries studied.
- The paucity of data and the incomplete coverage of the health information systems are two major barriers to implementing burden of disease studies in developing countries.

Tables and figures

Table 7.1 is based upon information extracted from Table 4 in Hyder et al's report.
Table 7.2 is based upon information from a presentation by Hyder et al In APHA 2002.
Table 7.3 is based upon information from Table 9 in Hyder et al's report.

Table 7.1 HeaLYs lost (per 1 000 population) due to cause-specific mortality, Pakistan, 1997

	Males		Females		Total	
Cause	HeaLYs lost	% of total HeaLYs lost	HeaLYs lost	% of total HeaLYs lost	HeaLYs lost	% of total HeaLYs lost
All causes	358.10	100.00	375.59	100.00	366.50	100.00
Infections, maternal and perinatal causes	180.57	50.42	232.58	61.92	205.56	56.09
Chronic non-communicable diseases	145.04	40.50	134.45	35.80	139.95	38.19
Injuries	32.49	9.07	8.55	2.28	20.99	5.73

Table 7.2 Comparison of age-specific DALY losses, Saudi Arabia (SA) 1995 and Middle Eastern Crescent (MEC) 1990*

	DALY loss (per 1 000 population)			
	Males		Females	
Age (years)	SA-1995	MEC-1990	SA-1995	MEC-1990
0-4	366.65	38740	229.16	36994
5-14	79.04	8561	25.74	7118
15-44	397.26	19063	84.91	19210
45-65	144.25	6123	60.74	4900
>65	101.83	5105	59.53	5035

*Source: Murray, 1996. Estimates for 1990.

Table 7.3 HeaLYs lost due to major diseases, Uganda, 1994

Disease	HeaLYs (per 1 000 population)
Malaria	99.83
AIDS	24.07
Acute LTRI	15.28
Acute diarrhoea disease	47.09
Tuberculosis	13.83
Trauma/injuries	36.82
Malnutrition	15.28
Perinatal causes	104.71
Sleeping sickness	127.60
Neonatal tetanus	9.16
Cardiovascular	15.34
Measles	24.46

Conclusion
- Pakistan, Saudi Arabia and Uganda are all experiencing a heavy burden of noncommunicable chronic diseases and injuries.
- Evidence-based health decision-making needs to be based not only on mortality data, but also on morbidity and disability information.
- The composite measures of disease burden, which have solid demographic and epidemiologic bases, are useful in developing countries, regardless of their limitations.
- The national BOD study is extremely difficult for developing countries. The lack of major demographic and health data highlighted the need for more investment in health research. This calls for national capacity building to collect and analyze BOD related data.

Related publication

Hyder AA, Wali SA, Ghaffar A, Masud TI, & Hill K. Measuring the burden of premature mortality in Pakistan: use of sentinel surveillance systems. *Public Health* 2005 119(6), 459-465.

Main objective
- To estimate premature mortality based on the HeaLY indicator from Pakistan Demographic Survey (PDS) 1997. Specifically, to construct the burden of premature mortality using the local surveillance system and to map the distribution of cause-specific deaths.

Main methods
- Burden of premature mortality based on the HeaLY measure using mortality data from PDS 1997.
- The mortality data from PDS 1997 was adjusted by General Growth Balance (GGB) methods. Infant and child mortality rates were reconstructed based on the Pakistan Demographic and Health Survey (PDHS) 1990-1991.

Main results and conclusions
- The burden of premature death for Pakistan was 367 HeaLYs lost per 1,000 population. Infection, maternal and perinatal conditions, and malnutrition contributed to more than half of the burden. Under-five child mortality accounted for 60% of the premature death burden.
- About one-fifth of male deaths and nearly one-third of female deaths were not recorded by the system, as indicated by the GGB adjustment methods.

Strengths and limitations
- One attempt at a national burden of disease study in a developing country.
- In view of the lack of reliable vital registration, using alternative surveillance data to construct summary measures of population health.
- The study did not use morbidity and disability data, which is crucial for health decision-making and priority setting.
- The reliability of self-reported causes of death is questionable.

Implications
- In the absence of a systematic effort to maintain vital registration, the sentinel surveillance systems serve as a satisfactory alternative to provide information facilitating health decision-making.
- However, the completeness of vital registration still needs to be substantially improved and the inequity of vital registration between females and males needs to be addressed.
- Health interventions to reduce infant and child mortality require urgent attention in Pakistan.
- Health systems need to be adjusted to deal with the epidemiological transition from communicable diseases to chronic noncommunicable diseases.
- The PDS has been operational for many years. Its usefulness and policy relevance should be more valued by researchers and policy-makers, especially if the reporting of cause of death can be improved by verbal autopsy.

List of publications from seven projects

Hyder AA, Wali SA, Ghaffar A, Masud TI, and Hill K. Measuring the burden of premature mortality in Pakistan: use of sentinel surveillance systems. *Public Health* 2005; 119(6): 459-465.

Moshiro C, Heuch I, Astrom AN, Setel P, Hemed Y, Kvale G. Injury morbidity in an urban and a rural area in Tanzania: an epidemiological survey. *BMC Public Health* 2005; 5(1):11.

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List of burden of disease related resources

WHO website
www.who.int

> **WHO/Global burden of disease**
> http://www.who.int/topics/global_burden_of_disease/en/
>
> **Quantifying environmental health impacts**
> http://www.who.int/quantifying_ehimpacts/en/

DISMOD
http://www.who.int/healthinfo/boddismod/en/

Health Metrics Network (HMN)
http://www.who.int/healthmetrics/en/

> **HMN tool – country logbook**
> http://www.who.int/healthmetrics/tools/logbook/en/
> http://www.who.int/healthmetrics/tools/HMN_assesment_tools.xls

Global Forum website
www.globalforumhealth.org

International Burden of Disease Network
http://www.ibdn.net/

Burden of Disease Unit, Center for Population and Development Studies at the Harvard School of Public Health
http://www.hsph.harvard.edu/organizations/bdu/index.html

> **The Global Burden of Disease Publication Series**
> http://www.hsph.harvard.edu/organizations/bdu/GBDseries.html

Other quality of life indicators
Short Form-36 and Short Form-12
http://www.sf-36.org/
http://www.sf-36.org/tools/sf12.shtml

Comprehensive quality of life
http://acqol.deakin.edu.au/instruments/com_scale.htm
WHO Disability Assessment Schedule
http://www.who.int/icidh/whodas/
WHO Quality of life
http://www.who.int/evidence/assessment-instruments/qol/

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