

Brief Report

Measure-Dependent Variation in Burden of Disease Estimates Implications for Policy

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BACKGROUND. Health adjusted life years (HALYs) are used for estimating burden of disease and as outcomes in cost-effectiveness analyses of medical care and public health interventions.

OBJECTIVES. The impact of use of health-related quality of life (HRQL) scores associated with the disability-adjusted life year (DALY), the quality-adjusted life year (QALY), and the years of healthy life (YHL) measure on burden of disease estimates by income and race for five illnesses was studied.

RESEARCH DESIGN. Abridged life tables were constructed using 1997 death certificate data from the National Center for Health Statistics. These tables were then quality-adjusted using prevalence data from the National Health Interview Survey and HRQL scores obtained using the Quality of Well-Being scale, the DALY, and the YHL measure to estimate burden of disease for five common diseases. Separate estimates were made for low and higher

income families as well as black persons and white persons.

RESULTS. Measure-related burden of disease estimates differed substantially from one another. Rank order of disease burden was not maintained across measures. Discrepancies in the rank order of disease were greater when different sociodemographic groups were examined.

CONCLUSIONS. Diseases and demographic groups will receive differing priorities for intervention or research depending on which measurement system is used to inform decision-making. Refinement and standardization of measures is necessary to enhance their utility for medical care and public health policy applications.

Key words: Burden of disease; cost-effectiveness analysis; health-related quality of life; resource allocation. (Med Care 2002;40: 260–266)

Increasingly, cost-effectiveness and burden of disease studies are relying on outcome measures that merge estimates of life expectancy with measures of the quality of life with a disease. The morbidity or quality of life component of such studies is referred to as “health-related quality of

life” (HRQL), and is captured on a scale of 0 to 1.0 where 0 is equivalent to death, and 1.0 represents perfect health. These scores permit assessments of burden of disease and cost-effectiveness for both fatal and nonfatal conditions. For example, they allow comparisons of conditions as varied as can-

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cer, heart disease, homicide and unintended injury.

When HRQL is incorporated with life years, burden of disease is measured in health-adjusted life years (HALYs). One HALY is equal to 1 year of life lived in perfect health.¹⁻³ The HALY is an umbrella term that includes quality-adjusted life years (QALYs),² which were developed to evaluate economic outcomes from medical interventions, disability-adjusted life years (DALYs),³ which were designed to measure global burden of disease, and years of healthy life (YHLs),⁴ which were designed to monitor the health of Americans for *Healthy People 2000*.^{5,6} Each of these summary measures of population health has been used in estimations of burden of disease⁷⁻⁹ as well as in cost-effectiveness analyses.^{3,10-14}

Measures that include HRQL are increasingly used for policy development both domestically and internationally. For example, in the United States, clinical trials supported by the National Institutes of Health and the Agency for Health care Research and Quality, often use QALYs for assessing treatment outcomes and calculating cost-effectiveness of clinical interventions.¹⁵ Initiatives conducted and funded by the Centers for Disease Control and Prevention use a variety of approaches including QALYs and DALYs.^{16,17} The Department of Health and Human Services' (DHHS) recently released *Healthy People 2010* has as dual primary goals increasing quality and years of healthy life and eliminating health disparities among different segments of the population. A tracking strategy for HALYs has not yet been selected by DHHS. The World Health Organization uses DALYs (among other measures) to compare burden of disease across nations.³

A lack of standardization in methodological approach by influential organizations and agencies can diminish the utility of burden of disease measurement. In considerations of resource prioritization—for medical care services, public health programs or research investment—decision makers must, at minimum, have confidence that estimates represent a valid ordinal ranking of diseases and conditions for the populations they are concerned with. Although DALYs, QALYs, and YHLs share a common requirement for estimates of disease prevalence, years of life lost caused by disease, and condition-associated HRQL, each is calculated using different methods.¹⁹ The differences in measure-specific approach are particularly varied in the conceptualization and valuation

of HRQL. These differences may lead to discrepancies in the way diseases or conditions are prioritized.

To explore the question of how the HRQL scores associated with each of these measures might affect estimates of disease burden, we calculate the burden of disease for five conditions. In our models, we vary only the HRQL scores, using QALY, DALY and YHL-associated HRQL scores for diabetes mellitus, chronic obstructive pulmonary disease, stroke, asthma and peptic ulcer disease. We assess the level of disparity in the different estimations both between measures, and after adjusting for race and income and explore the implications for policy.

Materials and Methods

Using race-specific and income-specific abridged life table cohorts,²⁰ we estimated health-adjusted life-years (HALYs) lost to diabetes mellitus, chronic obstructive pulmonary disease, stroke, asthma, and peptic ulcer disease. We then calculated the burden of disease in HALYs by incorporating the HRQL scores (Table 1) associated with the disability-adjusted life-year (DALY), the Health and Activity Limitation Index (HALex) associated with the years of healthy life (YHL) measure, and the quality of well-being (QWB) scale, an HRQL measure designed for the construction of QALYs, into these abridged life tables.^{3,4,21-23} All calculations were conducted using Excel 98 for the Macintosh (Microsoft, Redmond, WA).

A separate abridged HRQL-adjusted life table was constructed for each demographically defined cohort (three measure-specific life tables for each of the five diseases) using data from the National Center for Health Statistics (NCHS).^{3,4,21-23} The methods we used are described in detail elsewhere²⁴ and are summarized below.

In a life table, a hypothetical cohort of 100,000 persons is born each year. All persons are subjected to the age appropriate risk for death or illness, but there is no migration into or out of the population. To determine the burden of disease in a life table cohort, the person-years in each age interval are multiplied by the HRQL score and summed across age intervals.

Disease prevalence ratios were obtained from National Health Interview Survey data and mortality rates were obtained from death certificate

TABLE 1. Age-Adjusted Health-Related Quality of Life Scores^{1,4} Used in the Analysis

	Stroke	Diabetes	Chronic Obstructive Pulmonary Disease	Peptic Ulcer Disease	Asthma
YHL*	0.46	0.62	0.48	0.68	0.77
QWB*	0.68	0.69	0.67	0.67	0.68
DALY*	0.78	0.80	0.61	0.997	0.94

*YHL = HRQL scores associated with the years of healthy life measure,²¹ QWB = HRQL scores for the Quality of Well-Being index derived from the Beaver Dam Study,²⁰ DALY = HRQL scores associated with disability-adjusted life-years for treated disease.³

data.^{25,26} Disease-specific mortality rates by income were not available. We therefore applied all-cause mortality data from Lantz et al²⁷ to develop disease-specific mortality estimates by income.

The burden of disease was calculated for the US population, families earning less than \$10,000, families earning more than \$35,000, black persons, and white persons. The age, income, and racial characteristics used in our study were necessary caused by sample size and categorical constraints specific to the National Health Interview Survey, which was used to generate prevalence ratios for the life table cohorts. We chose these categories to ensure that all model inputs would be consistent across each of the life tables we generated.

We validated the model by comparing our estimate of health-adjusted life expectancy at birth to a 1990 estimate obtained by Erickson et al.⁴ Our estimate of health-adjusted life expectancy differed from their estimate by 0.5 years, approximately reflecting fluctuations in life expectancy and HRQL between 1990 and 1997.¹⁸

Results

The burden of disease caused by chronic obstructive pulmonary disease (COPD) calculated using the HRQL score associated with the Quality of Well-Being scale predicts that a random sample of a United States cohort of 100,000 persons suffered a loss of 169,927 HALYs; using HALex associated values, the model predicts that the cohort suffered the loss of 265,184 HALYs (Table 2). For PUD, the predicted values for the US population ranged from 597 HALYs lost when

scores associated with DALY measure were used to 44,535 HALYs lost when scores associated with the QWB scale were used; these variations were attributable to the fact that the DALY score for PUD was three hundredths of a decimal place short of perfect health (Table 1).

The burden of disease ranking for COPD, diabetes, and asthma varied by measure, different demographic group, or both. Although all measures estimated COPD as ranked highest in terms of the overall burden of disease in the US population cohort, the QWB scale predicted that this disease would rank 2nd to diabetes mellitus among black persons. Both the HALex measure and the QWB scale estimated that diabetes mellitus would rank 2nd for the US population cohort but 3rd among persons earning more than \$35,000. Using DALY scores, however, this disease ranked 2nd for all groups. Burden of disease estimates obtained using HRQL scores associated with the YHL and QWB measure ranked asthma as the 3rd leading cause of disability or death for most demographically-defined groups whereas HRQL scores associated with the DALY measure assigned asthma the second lowest ranking for all groups.

Discussion

The use of HRQL scores associated with DALYs, QALYs, and YHLs produced discordant HALY estimates for the five conditions examined. More importantly, the absolute rank order of each condition varied both by the measure used and the demographic group under study.

Health-related quality of life scores typically differ as a result of: (1) differences in the domains

TABLE 2. Burden of Disease in Health-Adjusted Life-Years Lost Per 100,000 Persons for 5 Conditions by Race, Family Income, and Health-Related Quality of Life (HRQL) Index

	US Pop.	>\$35,000	<\$10,000	White	Black
Chronic obstructive pulmonary disease					
YHL score*	265,184 (1)	225,121 (1)	321,489 (1)	280,249 (1)	185,834 (1)
QWB score*	169,927 (1)	143,585 (1)	206,412 (1)	179,534 (1)	119,283 (2) [†]
DALY score*	199,005 (1)	168,475 (1)	241,541 (1)	210,278 (1)	139,598 (1)
Diabetes mellitus					
YHL score*	126,188 (2)	88,294 (3) [†]	194,562 (2)	117,297 (2)	179,115 (2)
QWB score*	117,297 (2)	72,302 (3) [†]	159,483 (2)	96,235 (2)	147,121 (1)
DALY score*	67,984 (2)	47,171 (2)	104,360 (2)	63,138 (2)	96,845 (2)
Asthma					
YHL score*	102,928 (3)	92,067 (2) [†]	135,302 (3)	97,801 (3)	112,415 (3)
QWB score*	88,530 (3)	88,549 (2) [†]	112,085 (3)	88,458 (3)	100,946 (3)
DALY score*	28,884 (4) [†]	24,729 (4) [†]	37,622 (4) [†]	27,073 (4) [†]	33,827 (4) [†]
Stroke					
YHL score*	80,302 (4)	62,928 (4)	105,849 (4)	77,584 (4)	91,168 (4)
QWB score*	49,602 (4)	38,189 (4)	65,248 (5) [†]	47,868 (4)	56,861 (4)
DALY score*	36,206 (3) [†]	27,394 (3) [†]	47,531 (3) [†]	34,902 (3) [†]	41,891 (3) [†]
Peptic ulcer					
YHL score*	43,191 (5)	25,563 (5)	78,251 (5)	43,142 (5)	47,026 (5)
QWB score*	44,535 (5)	26,356 (5)	80,688 (4) [†]	44,484 (5)	48,488 (5)
DALY score*	597 (5)	434 (5)	980 (5)	599 (5)	666 (5)

*YHL = HRQL scores associated with the years of healthy life measure,²¹ QWB = HRQL scores for the Quality of Well-Being index derived from the Beaver Dam Study,²⁰ DALY = HRQL scores associated with disability-adjusted life-years for treated disease.³

[†]Break in rank order of disease.

(attributes associated with a disease) that are captured by the measures used;^{8,28} (2) disparate methods used to generate the HRQL “weight” or value (ie, time trade off, standard gamble, visual analogue scale, person trade-off);¹⁰ (3) the way in which comorbid illnesses are incorporated; and (4) differences in the populations sampled. In assigning values to HRQL, QALY-related measures such as the QWB elicit preferences for disease-related health states from a representative community sample.⁸ Values for DALYs are obtained by asking health professionals to judge the level of disability associated with particular conditions, rather than members of a representative community sample, using person-trade-off exercises.³ The HALex calculates HRQL weights using correspondence analysis, a mathematical technique that maximizes correlation between two domains of health (role function and self perceived health) reported in a nationally representative sample.⁴

There are a number of limitations to this study that could affect the accuracy of the burden of disease estimates we generated. First, disease-specific mortality rates were unavailable by education or by income. We therefore relied on all-cause mortality rates for lower versus higher income households, using data obtained from a longitudinal mortality study.²⁷ The five illnesses presented may, in reality, exhibit different SES-associated mortality patterns.

Second, in this study, consistent with the findings of others that health status is affected by socioeconomic status,^{29–32} loss of HALY by income and race were greater in low-income persons and black persons than in high-income persons and white persons. The single exception to this is for COPD, an illness that appears to be less common in black persons.³³ When race is considered, the YHL measure predicts a lower HRQL score for black persons than for white persons.²²

Because only the HALex permits adjustment of HRQL on the basis of sociodemographic descriptors,²² we were unable to explore the impact of any systematic differences between measure-associated HRQL scores in the different subpopulations studied. Because it was not possible to incorporate these differences into our HRQL scores, our estimates likely represent an underestimate of true disparities in HRQL between black persons and whites.

Third, for some of the conditions, there were insufficient subjects with which to assure reliable age-specific prevalence rates in low income and black persons. Finally, prevalence rates, which were generated from self-reported survey data from the National Health Interview Survey (NHIS)²⁵ may be subject to recall bias. Analyses by the National Center for Health Statistics have shown a κ of 0.43 for overlap between medical chart identified and self-reported conditions with conditions requiring ongoing medical care such as diabetes and hypertension having higher agreement ($\kappa = 0.73$ and 0.82 , respectively),³⁴ presumably because patients are more likely to recall such conditions. It is likely that recall bias is minimized in symptomatic or severe conditions.

Although the limitations noted may influence the accuracy of the burden of disease estimates reported here, it is unlikely that the variation between measures is affected given our use of the same data sources for disease prevalence and life tables for each measure. These differences are real, and the problems they generate need scrutiny. Burden of disease estimates have been taken into account in prioritizing funding for public health projects, and the rank order of conditions can influence priorities for disease-specific research investments.³⁵ In addition, when QALYs are primarily used for the evaluation of medical system interventions and DALYs or YHLs for public health interventions, opportunities for generating meaningful comparisons between population-based programs, and medical interventions vanish.

Canada has attempted to harmonize its approach to the evaluation of population health and clinical medicine by using the Health Utility Index in its National Population Health Survey. This measure is used commonly in clinical settings, and placement in a national survey allows clinical and public health information to be collected in a common HALY language which has been promoted as a means for rationalizing health care policy.³⁶ The addition of the EuroQol (EQ-5D)

measure³⁷ to the Agency for Health care Research and Quality's Medical Expenditures Panel Survey, and the collection of US weights for the measure are recent and welcome developments that will provide a mechanism for developing one form of QALY estimates for the US population. Given less experience with the EQ-5D in clinical settings and relative lack of familiarity to US researchers, it is unclear, however, how extensively it will be used in assessments of medical interventions.

Health-adjusted life years improve burden of disease estimates and cost-effectiveness analyses by allowing considerations of mortality and morbidity in the same measures. Although variations currently exist in the how life expectancy is estimated for HALY measures, movement to a common approach would be relatively straightforward. It is the debates about how to measure and value health status that remain most open-ended. The measures used in this paper represent a convenience sample intended for illustrating that HRQL variations will affect HALY estimates. This is a limitation of the QALY methodology, which is well reported within the clinical literature.^{38,39} Reaching consensus on the best HRQL measure for cost-effectiveness and burden of disease analysis will require more side-by-side comparisons of these instruments in representative populations to understand how they perform across groups and across illnesses and conditions. Also crucial to advancement will be gaining a fuller understanding of which measurement schema are most comprehensible, useful, and palatable to the decision makers, clinicians and public health professionals whose needs they were intended to fill.

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References

1. Fryback DG. Methodological issues in measuring health status and health-related quality of life for population health measures: A brief overview of the "HALY" family of measures. In: Summarizing Population Health. Institute of Medicine. Washington, DC: National Academy Press; 1998.

2. **Weinstein MC, Stason WB.** Foundations of cost-effectiveness analysis for health and medical practices. *N Engl J Med* 1977;296:716–721.
3. **Murray CLJ, Lopez AD.** The global burden of disease: a comprehensive assessment of mortality and disability from disease, injury and risk factors in 1990 and projected to 2020. Vol. 1. Boston, MA: Harvard University Press; 1996.
4. **Erickson P, Wilson R, Shannon I.** Years of Healthy Life. *Statistical Notes* 1995;7:1–14.
5. **US Public Health Service.** Healthy People 2000. National Health Promotion and Disease Prevention Objectives. Washington DC: US Dept of Health and Human Services, 1991. Publication PHS 91-50212.
6. **McGinnis JM, Lee P.** Healthy People 2000 at mid decade. *JAMA* 1995;200:273:1123–1129.
7. **Bowie C, Beck S, Bevan G, et al.** Estimating the burden of disease in an English region. *J Public Health Med* 1997;19:87–92.
8. **Rosenberg MA, Fryback DG, Lawrence WF.** Computing population-based estimates of health-adjusted life expectancy. *Med Decis Making* 1999;19:90–97.
9. **Diehr P, Patrick DL.** Predicting future years of healthy life for older adults. *J Clin Epidemiol* 1998;51:343–353.
10. **Gold MR, Siegel JE, Russell LB, ed, et al.** Cost-Effectiveness in Health and Medicine. New York, NY: Oxford University Press; 1996.
11. **Akhaven D, Musgrove P, Abrants A, et al.** Cost-effective malaria control in Brazil. Cost-effectiveness of a Malaria Control Program in the Amazon Basin of Brazil 1988–1996. *Soc Sci Med* 1999;49:1385–1399.
12. **Miller MA.** An assessment of the value of Hameophilus influenzae type b conjugate vaccine in Asia. *Pediatr Infect Dis J* 1998;17:S152–9.
13. **Fiscella K, and Franks P.** Cost-effectiveness of the transdermal nicotine patch as an adjunct to physicians' smoking cessation counseling. *JAMA* 1996;275:1247–1251.
14. **Brazier J, Deverill M, Green C.** A review of the use of health status measures in economic evaluation. *J Health Serv Res Policy* 1999;4:174–184.
15. **Agency for Health Research and Quality.** Available at: <http://www.ahrq.gov>. Accessed February 2001.
16. **Muennig P, Pallin D, Sell R, et al.** The Cost Effectiveness of Strategies for the Treatment of Intestinal Parasites in Immigrants. *N Engl J Med* 1999;340:773–779.
17. **Haddix AC, Teutsch SM, Shaffer PA, et al.** Prevention Effectiveness. A Guide to Decision Analysis and Economic Evaluation. New York:Oxford University Press; 1996.
18. **National Center for Health Statistics.** Healthy People 2000 Review, 1998–99. Hyattsville, MD: Public Health Service; 1999.
19. **Patrick DL, Erickson P.** Health status and health policy: Allocating resources to health care. New York, NY: Oxford University Press; 1993.
20. **Anderson RN.** Life tables, 1996. *Natl Vital Stat Rep* 1998;47:1–20.
21. **Fryback DG, Dasbach EJ, Klein R, et al.** The Beaver Dam Health Outcomes Study: Initial catalog of health state quality factors. *Med Decis Making* 1993;13:89–102.
22. **Gold MR, Franks P, McCoy KI, et al.** Toward consistency in cost-utility analyses: Using national measures to create condition-specific values. *Med Care* 1998;36:778–792.
23. **Anderson RN.** Method for constructing complete annual US life tables. *National Center for Health Statistics. Vital Health Stat* 1999;11:129.
24. **Muennig PA, Gold MR.** Using the years of healthy life measure to calculate QALYs. *Am J Prev Med* 2001;20:12–17.
25. **Benson V, Marano MA.** Current estimates from the National Health Interview Survey, 1995. *National Center for Health Statistics. Vital Health Stat* 1998;10:1–105.
26. **Hoyart DL, Kochanek KD, Murphy SL.** Deaths: final data for 1997. *National Vital Statistics Report* 1999;47:1–146.
27. **Lantz PM, House JS, Lepkowski JM, et al.** Socioeconomic factors, health behaviors, and mortality. *JAMA* 1998;279:1703–1708.
28. **Froberg DG, Kane RL.** Methodology for measuring health-state preferences-II: Scaling methods. *J Clin Epidemiol* 1989;42:459–471.
29. **Wolf SH, Rothemich SF, Johnson RE, et al.** The functional status of inner-city primary care patients. Diminished function in a family practice populations and its potential determinants. *The J Fam Pract* 1997;47:312–315.
30. **Jenkinson C, Layte R, Coulter A, et al.** Evidence for the sensitivity of the SF-36 health status measure to inequities in health: results from the Oxford healthy lifestyles survey. *J Epidemiol Community Health* 1996;50:377–380.
31. **Roberge R, Bertheolot JM, Wolfson M.** The Health Utility Index: measuring health differences in Ontario by socioeconomic status. *Health Rep* 1995;7:25–32.
32. **Kind P, Dolan P, Gudex C, Williams A.** Variations in population health status: results from a United Kingdom national questionnaire survey. *BMJ* 1998;316:736–41.

33. **Gillum RF.** Chronic obstructive pulmonary disease in blacks and whites: mortality and morbidity. *J Natl Med Assoc* 1990;82:417–28.
34. **Edwards WS, Winn DM, Kuriantzick V, et al.** Evaluation of National Health Interview Survey diagnostic reporting. *National Center for Health Statistics Vital Health Stat* 1994;2:1.
35. **Varmus H.** Evaluating the burden of disease and spending the research dollars of the National Institutes of Health. *N Engl J Med* 1999;340:1914–1915.
36. **Wolfson MC.** Measuring health-visions and practicalities. *Stat J United Nations* 1999 ECE 16:1–17.
37. **EuroQol Group.** EuroQol: A new facility for the measurement of health-related quality of life. *Health Policy* 1990;16:199.
38. **Nease RF, Kneeland T, O'Connor GT, et al.** Variations in patient utilities for outcomes of the management of chronic stable angina: implications for clinical practice guidelines. *JAMA* 1995;273:1285–1290.
39. **Hornberger JC, Redelmeier DA, Peterson J.** Variability among methods to assess patients' well-being and consequent effect on a cost-effectiveness analysis. *J Clin Epidemiol* 1992;5:505–512.