

The Cost of Visual Impairment: Purposes, Perspectives, and Guidance

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The Association for Research in Vision and Ophthalmology (ARVO) Workshop on the Economic Burden of Vision Loss was held on September 17, 2007, in Vancouver, British Columbia, Canada, under the auspices of ARVO and the International Agency for the Prevention of Blindness. The workshop's goal was to develop consensus on the best practices for measuring the burden of vision loss. The meeting was organized around a discussion of papers that had recently been published describing various methods of calculating the burden associated with vision loss. A result of the workshop is the publication of the results of the consensus-building process that was begun at the meeting and continued with correspondence and revisions of the statements regarding consensus after the meeting.

OVERVIEW

In recent years, there have been numerous attempts to quantify the costs associated with vision impairment in specific countries and around the world.¹⁻⁷ Analysts have used different approaches, making it difficult to draw general conclusions or compare studies. Over the past 15 years, numerous guidelines or standards for cost-related analyses have been set forth.⁸⁻¹⁰ Given the desirability of standardization, the Vancouver Economic Burden of Vision Loss Group was convened to standardize methods for burden-of-disease calculations for vision loss. The meeting included presentations of papers published before the meeting and discussion of the options for analytical approaches.

This article reflects the results of the first collaborative effort to discuss guidelines for burden-of-disease calculations in vision research. The objectives are (1) to delineate the difference between incidence- and prevalence-based calculations; (2) to list different types of economic evaluations; and (3) to specify how the elements of costs included in the burden

calculation depend on the type of economic evaluation (i.e., cost-effectiveness or cost-benefit), the perspective of the analysis, and the point of initiation of the analysis (i.e., screening for vision loss, preventing vision loss, treating vision loss, or describing the lives of individuals who already have vision loss). We conclude with several recommendations. Although a single set of standards would be useful, the context and requirements of the analysis dictate the manner and method of evaluation. Thus, recommendations will serve as guidelines rather than standards.

TERMINOLOGY

Incidence- and Prevalence-Based Costs

A variety of terms are used to refer to studies describing the costs associated with a disease or disability including cost of illness, burden of disease (which can be a bit more inclusive), and loss of well-being.^{1,2,11} A group in Australia found that "loss of well-being" was more acceptable to groups affected by blindness,¹² and as loss of well-being is at least as inclusive as "burden of disease," we will use that term rather than burden of disease. Regardless of the terminology, there is an important distinction between incidence- and prevalence-based studies.

Incidence-based cost analysis describes the lifetime (longitudinal) costs to an individual that are related to a particular condition and can begin at any point in the spectrum of the development of a disease or condition. Lifetime costs can include treatment to prevent progression, income that the patient loses because of an inability to work, and income that others lose because of time spent providing care. An example for vision care would be all costs related to glaucoma after the first sign of optic nerve damage. Incidence-based cost analyses are most often conducted with reference to a specific type of disease. This type of cost analysis is most useful for studies regarding prevention of a condition or of progression of a condition.

Prevalence-based cost estimates are a function of the costs associated with prevalent cases for a period (generally, 1 year).²⁻⁷ Costs are tabulated for all persons with the condition. Prevalence cost measures may be based on the number of cases prevalent at the start of the year or the average cases during the year and focus on the costs incurred within that year. The costs of treatment are counted for only 1 year, as are the costs to caregivers. Viewing prevalent costs as a snapshot would also include the costs of quality-of-life decrements for the year among those who survive the year and the costs of mortality of those who do not survive the year. Prevalence-based costs provide a snapshot that can be used to compare the impact of diseases, conditions, or risk factors on a population. Unless the disease is completely eliminated, this type of measure does not indicate savings that result from preventing the disease. A vision care example would be a report on all the

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annual costs associated with AMD, based on the prevalent cases that year.^{1,3} Policy makers and analysts may also be interested in the cost of all vision impairment or blindness.¹⁻³

Types of Economic Evaluations

A list of types of economic evaluations appears in Table 1. Cost-benefit, cost-effectiveness, cost-utility, and cost-consequence analyses all use loss of well-being measures as inputs.

Cost-benefit analyses (CBA) express both costs and benefits of an intervention in monetary terms. A CBA related to cataract requires that a monetary value be placed on health and other benefits of cataract surgery.

Cost-effectiveness analyses (CEA) summarize the monetary value of resources used for an intervention and describe the results, by using either a single most important clinical outcome or a summary measure (e.g., years of sight preserved). A specific type of a CEA is a *cost-utility analysis* (CUA), in which outcomes are quality- or disability-adjusted life years (QALYs or DALYs). A CEA of different screening methods for uncorrected refractive error could compare the costs of screening and fitting with glasses with the number of cases identified and fitted with glasses under each scenario. CUA links the receipt and use of glasses over time to changes in disability or quality of life to indicate the costs to change QALYs or DALYs in a population.

Cost-consequence analyses (CCA) describe the monetary value of resources used and multiple measures of the effects, usually in natural units. A CCA related to a low-vision rehabilitation intervention may describe changes in functional outcomes, such as mobility, alongside changes in clinical outcomes, such as depression, without using an instrument that summarizes these outcomes in terms of money, quality of life, or disability. Leaving outcomes in natural units forces users of the analyses to assign their own relative weights. In contrast, analyses including summary measures provide the decision maker with explicit weighting of different outcomes.

As shown in Table 1, cost-benefit analyses include all elements of the cost-of-illness calculation. For a CBA of a new intervention intended to slow AMD progression, a cost-of-illness study describing the lifetime cost of blindness would indicate the value of each case of blindness avoided. Cost-of-illness studies focusing specifically on a single disorder such as AMD are essential, as costs vary by cause of impairment.^{1,3,13}

In contrast, anyone conducting a CUA, CEA, or CCA should be cognizant of the possibility that including all cost-of-illness elements may result in a double count of some of the results. There is a professional debate around this issue.^{8,14} A researcher performing a CUA of the treatment of AMD would assess the disability or utility associated with AMD, most likely through responses to patient questionnaires. Some argue that an individual, in responding to a quality-of-life questionnaire,

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accounts for her earnings potential. Thus, including lost earnings as a separate consequence represents double counting. A U. S. recommendation argued against including income lost due to illness in studies in which QALYs are used.⁸ However, other health economists have noted that productivity losses not borne by the individual should be included, suggesting alternative ways to word questions about quality of life, or using alternative health state measures such as DALYs.^{14,15} Avoiding double counting does not mean that an intervention cannot affect both future productivity and quality of life. The key is to avoid double counting or to note where it is unavoidable in an evaluation.

Perspective of the Analysis

The perspective guides researchers on which costs to include and guides readers on which costs to expect to find in the analysis. Table 2 shows the costs that would be included in analyses from different perspectives. The societal perspective is most consistent with economic theories of public welfare. Analyses conducted from the societal perspective include a comprehensive list of costs and effects associated with a condition or its treatment. A vision-related example from the societal perspective would be the cost-effectiveness of low-vision rehabilitative devices. This analysis would include the costs of a device, the cost of training a patient to use the device, the time necessary for the patient to learn to use the device, the time expended by family members who transport the patient, the time saved by the caregiver after rehabilitation, and others. If individuals with low vision and blindness receive transfer or

TABLE 1. Types of Analyses and Specific Costs Assuming a Comprehensive Societal Perspective

	Medical	Other Health	Aids/Adaptations	Caregivers	Deadweight Loss from Transfers	Loss of Income*	Loss of Well-being†
Cost-benefit	X	X	X	X	X	X	X
Cost-effectiveness, with one natural unit outcome	X	X	X	X	X	X	X
Cost-utility	X	X	X	X	X	X	X
Cost-consequence	X	X	X	X	X	X	X

* The U. S. Panel on Cost-Effectiveness in Health and Medicine considers the inclusion of both loss of income and loss of well-being as double counting, but this is not universally agreed, as it depends on measurement method and components of each item included.

† The definition of Loss of well-being must net out all costs borne by the individual that would have been considered in the individual's estimate of well-being. For cost-benefit, well-being is measured in dollars, but for the other analyses it is measured in other metrics.

TABLE 2. Perspectives and Specific Costs

	Medical	Other Health	Aids/Adaptations	Caregivers	Deadweight Loss from Transfers	Loss of Production	Loss of Well-being
Comprehensive societal regardless of who bears the costs	X	X	X	X	X	X	X
Government	X	X	X	X		X	
Health care system	X	X					
Patient	X	X	X	X		X	X
Payer/other	X	X	X	X	X	X	

welfare payments from the government (e.g., income support allowing a visually impaired individual to choose which to adopt), only administrative costs of the program and inefficiency costs associated with taxes funding the program (called deadweight losses) would be included.

Other perspectives include the government (for which transfers represent a true cost affecting the budget), the health care system, the payer, and the patient. The fraction of costs included within each category varies depending on the degree to which the payer bears specific costs: For example, the government may pay some health care costs, other payers (insurers) may also pay a share of these, and the patient may bear a further component out of pocket. Each of these perspectives is likely to be more relevant to specific decision makers, but interpreting each is difficult.

The government perspective lacks specificity. Many countries have multiple levels of government divided into departments; more than one department at each level may have responsibility for payments related to vision impairment. Realistically, government expenditures related to vision impairment may occur at the national and local levels and be incurred by departments of health and education. An analysis from the government perspective focusing on the government as the payer for low-vision aids would include the cost saved by avoiding government-funded care after falls caused by vision deficiencies, as well as the additional tax revenue that results from the decrease in time that caregivers spend in providing care, and the increase in time that they are thus able to work and earn more money. Lost income may also be of interest to the government because it will ultimately cost the government some amount of lost tax revenue and, downstream, may cause increases in welfare expenditures such as disability payments.

Describing all costs in the health care system is useful for understanding the resources used in the health care sector, but accounting for only these costs places an unnecessary, artificial limit on the resources being considered. A payer perspective also fails to capture all costs. For example, Medicare in the United States would not reap the benefits of increased tax revenue from decreasing the need for unpaid informal care. Moreover, the boundaries of the health care system may be difficult to define and vary across countries, leaving gray areas such as community or home care services for blind people that involve a health component.

The patient perspective is described infrequently in the academic literature, although this perspective is critical in the understanding of actual behavior. In the patient perspective, all costs are included except for deadweight loss. However, only a fraction of the costs may be considered for many of the categories, as the patient may not pay the entire cost in any category except for loss of well-being. No matter how favorable the results of an economic evaluation from a societal perspective, if the individual does not benefit, she is unlikely to comply. Policy analyses should at least qualitatively consider the patient perspective.

We recommend performing analyses from a societal perspective with details on who bears the costs. With a comprehensive set of costs in hand, it is the better, more straightforward approach to describe who bears them, so that the more narrow perspectives can be described for the purposes of setting policy.

Point of Initiation of the Analysis

The costs that are appropriate to include in a study also depend on the point of initiation with respect to the timing and progress of the condition. In studies focused on screening for or preventing a condition, resources used for screening or prevention are considered to be costs. The resources saved later when further progression of the condition does not occur are a benefit in this case (i.e., costs avoided). In contrast, for economic impact studies of particular eye conditions, the value of the resources used in all interventions for that condition are costs. Costs included will necessarily vary by the starting point and purpose of the analysis.

MOVING TOWARD CONSENSUS

Costs in Comprehensive Analyses

The most comprehensive study of the costs related to visual impairment to date was produced in Australia by Taylor et al.^{1,16} Costs were classified into the categories listed in Table 3, which shows the costs included in the Australian study¹ and two others with which it will be contrasted. The categories include direct health care costs, indirect costs, and the costs associated with the loss of well-being. Direct health care costs can be further divided into hospital (both inpatient and outpa-

TABLE 3. Cost Categories Included in Several Assessments of Costs Related to Visual Impairment

Category	Taylor et al. ¹	Rein et al. ³	Frick et al. ²
Hospital (monetary cost of care)	X	X	X
Out-of-hospital medical (monetary cost of care)	X	X	X
Other health (monetary cost of care)	X	X	
Aids/adaptations (monetary costs other than care)	X	X	
Caregivers (loss of family member income)	X		X
Dead weight losses from transfers	X		
Lost production (loss of patient income and taxes)	X	X	
Loss of well-being	X		X

tient) and other health costs (pharmaceuticals, imaging, pathology, optometry, aged care, other health professionals, and other medical expense). For this discussion, we have relabeled the costs because the term “indirect costs” has been used in different studies to refer to overhead, productivity loss, or any cost not directly related to the monetary costs of medical care. The relabeled terms include monetary expenditures on health care (medical and other), monetary expenditures on things other than health care (mainly aids and adaptations such as Braille devices and stair lighting, but also potential travel costs and other monetary expenditures), loss of family member productivity, deadweight losses, loss of patient productivity, and loss of patient well-being. We have placed these alternative labels in parentheses beside the item labels in Table 3. The simplest way to clarify costs in a study is to provide a comprehensive list in a manuscript that allows both the peer-reviewers and the readers of the published manuscript to regroup if necessary.

The Australian study’s authors identified the limitation that health expenditure data included all eye disease, rather than only visually impairing conditions. However, this limitation is a minor one, as the proportion of non-visually impairing eye conditions included in the study was small.

Individual’s and family members’ expenditures for aids and other modifications are part of the non-health-care monetary costs. All costs related to the condition but not paid to someone in the health care system are in this category. For example, spectacles or intraocular lenses would be “other” health costs, whereas canes or guide dogs would probably be in this non-health-care category. Notably, different aspects of cost are “medicalized” in different countries; in some places families provide most of the care, whereas in others, formal health care is more common.

In addition to the monetary costs, the Australian study accounted for the value of the time that informal caregivers spend in providing care.^{1,16} Taylor et al.¹ used a small, detailed study of individual patients’ experiences to calculate the value of caregivers’ time. They also accounted for the loss of income and loss of well-being among those who were blind. Loss of income was based exclusively on the lower employment rate attributable to visual impairment. They did not include lower wages, reduced hours worked, or impediments to promotion; such data are available in the United States.³ The authors also included the time lost from future work as a result of premature mortality attributable to vision loss. They calculated the present value by using a 1.55% real discount rate, to express the value of future productivity loss as if the entire flow of productivity were available today. The 1.55% discount rate places a relatively high value on the future, incorporating an expectation of increased productivity. They also include a measure of the loss of well-being, monetizing the value of DALYs by using a 3.3% discount rate and assuming a value of a statistical life year of A\$162,561. They appropriately included only the economic inefficiency cost due to changes in behavior related to the taxes to support transfers.¹⁷

The discount rate deserves further discussion. Discounting formalizes the comparison of the value of costs and benefits today with those in future years. Suggested standard discount rates range from as low as 0% to as high as 6%.⁹ Future costs will be valued at only half their present value in 12 years if the discount rate is 6% and in 24 years if the discount rate is 3%. Thus, the rate chosen has important implications for the value of future outcomes. Some recommendations suggest a single discount rate for logical and mathematically pragmatic reasons.⁸ This notion contrasts with the Australian study, in which the discount rate was tailored to the nature of the stream being discounted.^{1,16} Differential discount rates are acceptable as long as researchers transparently state the rates and justify the choices.

Other Studies of Costs Related to Vision Impairment

Studies by Rein et al.³ and Frick et al.² addressed costs in ways that are largely complementary rather than overlapping. Rein et al. included a range of direct health costs for specific conditions. As in Australia, they used claims data rather than self-reported utilization data, and they included inpatient, outpatient, prescription, and optometry services, but not all home care services—many of which are paid out of pocket. They included nursing home care and the costs of guide dogs and other government programs. For loss of patient productivity, they included lower employment rates and lower wages. They also estimated lost taxes and welfare payments but did not estimate the inefficiency cost.

Frick et al.² focused on all health care costs, costs to informal caregivers, and loss of well-being. They included home care among the health care costs, because the survey dataset they used included self-reported utilization measures. The caregiver costs are limited because the survey that they used in a secondary analysis was not designed with a “bottom-up” approach. The survey asked only about the care provided by individuals living outside the household of the individual with visual impairment. They used QALYs as the measure of loss of well-being, calculated the loss of well-being for 1 year, and applied a value of US\$50,000/QALY. There is no publicly agreed upon value of a QALY in the United States.

UNRESOLVED ANALYTIC AND THEORETICAL ISSUES

Several unresolved issues deserve consideration. A primary one is the value of a life year, and there are other minor ones.

The monetary value applied to a life year (quality adjusted, disability adjusted, or otherwise) is not universally agreed upon. Elsewhere in the literature and in decision-making (e.g., Australia) the value of a QALY has been related to what people are willing to pay for a statistical year of life.^{1,18,19} The value of a statistical life year or a statistical life is determined by assessing how individuals are willing to make tradeoffs between money and mortality risks or between money and risks of injury or disability. These have been derived from individual differences in wages and differences in mortality or morbidity risks in jobs, how increases in speed limits allow people to get places faster and how they change health risks and other examples.

In the United Kingdom, an explicit public financing threshold value is £30,000 per QALY gained, although recommendations on coverage do not always adhere to this threshold.²⁰ In the United States, the cost of US\$50,000/QALY for the public financing threshold has been discussed in the literature since 1982, although it has not been indexed, and more recently amounts of up to US\$200,000/QALY have been proposed.²¹ In other countries, a variety of thresholds have been discussed in the literature, but there is not a fixed level of willingness to pay that is used in policy making. The World Health Organization has suggested considering any intervention that costs less than the gross national income (GNI) per capita per DALY averted to be highly cost-effective and any intervention that costs between one and three times the GNI per capita per DALY averted to be cost-effective.²²

There is no inherently correct societal valuation of a QALY or DALY. Each country must decide what it is willing to pay for health improvements and what evidence will inform that decision. Analysts should both use values relevant to the decision makers in their own context and provide analyses with other values that would make a study comparable with other international studies.

Several other issues may arise, particularly when planning studies in economies at different levels of development. Friction cost approaches to productivity loss measurement (i.e., approaches that focus on costs of replacing an individual or that

limit lost productivity to the time until a worker is replaced) are more useful in countries where there is relatively high unemployment and underemployment, whereas human capital approaches are more appropriate in countries close to full employment.¹¹

Further, there are different ways of valuing informal caregiver costs, including opportunity cost of their time, the cost of replacing the care itself or the cost of what they would have been doing if they had not been providing care, and self-valuation. Opportunity cost approaches are generally best, although replacement valuation is appropriate if the informal care option is being compared to a situation in which the care would otherwise have to be purchased at market rates.

DISCUSSION

Standardization of methods is useful and achieves several objectives. First, it allows peer reviewers to judge proposals based on whether best practices are being followed. Second, it allows peer reviewers and journal editors to assess the scientific quality of manuscripts. Third, it allows those making comparisons across studies to perform the task more easily.

We propose the following guidelines:

1. A comprehensive list of costs should include monetary expenditures on health care (hospital, outpatient, and other), monetary expenditures on things other than health care, loss of patient productivity, loss of family member productivity, deadweight losses, and loss of patient well-being.
2. In any assessment of either prevalent or incident costs, the authors should identify the specific items included under the major categories in the recommendation.¹
3. Costs should be presented as separate line items, to facilitate comparisons among studies, so that those making comparisons can determine whether the differences in overall costs are due to differences in the specific items included. This approach also allows others to re-group costs to meet their own needs.
4. A default position is to use a single discount rate for all calculations in an analysis. If different discount rates are chosen for costs and effects due to risk or other differences between future cost streams, it must be spelled out in a transparent way. Sensitivity analyses varying the discount rate will facilitate comparisons among studies.
5. The assumed value of purchasing a DALY or QALY should be clearly stated and justified. No single value is likely to be appropriate in all cases. Varying the value in sensitivity analyses will help decision makers understand the implications of the choices they make.
6. The perspectives that determine which costs are included are essential to designate and should match the matrix presented in Table 2, with specific line items detailed. Any variance from Table 3 should be clearly explained and left to reviewers to determine the importance of the results when the methods are not or cannot be followed exactly.
7. The decision-making context and the starting point of the analysis should both be clear. A statement of whether and how the analysis will be used as part of other analyses is essential.

This effort is a first collaborative attempt to develop a set of guidelines for cost-of-illness studies related to vision care. Moving forward, there is no reason that this set of guidelines could not be applied to other conditions or risk factors, and it should be expanded to economic evaluation in general. The principles behind these guidelines should stand for some time to come. However, the fields of vision care and economic evaluation will

change. The fields must keep up with changes in technique and nuances that must be considered and revisited over time so that guidelines evolve. We look forward to continuing discussion over time and expect that more standardized methods will be adopted as the field continues to develop.

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