Cost-of-Illness Methodology: A Guide to Current Practices and Procedures

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IT IS COMMON KNOWLEDGE THAT THE COSTS OF illness and disease have been on a dramatic upward trend that is projected to continue. The most recent estimates of national health expenditures indicate a 400 percent increase since 1965 (Freeland and Schendler, 1981). As a proportion of the Gross National Product (GNP), the costs associated with illness and disease are projected to reach nearly 11 percent by the year 1990 (Freeland and Schendler, 1981) compared to 9.4 percent in 1980 and 6 percent in 1965 (Gibson and Waldo, 1981). It should not be surprising that the analytic literature on these costs has also grown rapidly. Medical journals, in particular, contributed to this growth as the medical profession has become increasingly involved with economists, sociologists, public health specialists, and others in scrutinizing the cost of modern health care (Warner and Hutton, 1980).

Estimates of the costs of illness and disease are produced and used in cost-benefit and cost-effectiveness analyses and in other modes to set priorities and make government policy decisions, to prepare and deliver congressional testimony, and to support agency budgets. The application of the techniques of cost-benefit and cost-effectiveness analysis to health care, in particular, has been the subject of several

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recent publications highlighting the need for estimates of these costs in the evaluation of our health care system and its rapidly advancing technology (Office of Technology Assessment, 1980; Hellinger, 1980). As demonstrated above, however, one of the most common uses has been to simply convey the aggregate burden of illness on society. Many persons who have an interest in costs of illness—from those actively engaged in estimation to those who just want to know the magnitudes—are not economists. In this study we provide a background to the costs originating in illness and disease, discuss strengths and weaknesses of current practices and procedures in estimating these costs, and make recommendations to improve the application of existing methodology. This work is an outgrowth of recent efforts within the United States Public Health Service (PHS) to improve both the state of practice and the state of the art for such studies.

Early in 1978, a task force composed of representatives from within the PHS and chaired by Dorothy P. Rice, Director of the National Center for Health Statistics, was formed to address methodological concerns related to the estimation and measurement of costs of illness and disease. Among other things, the task force was charged with recommending methodological guidelines so that the results of future studies could be better compared. The charge reflected the increased recognition by policy makers and program managers that cost-of-illness estimates are an essential component in the evaluation of alternative demands on our scarce health care resources. It also reflected the concern that the usefulness of cost-of-illness studies has suffered from a lack of consistent methodologies—a problem resulting at least in part from the lack of accepted methodological guidelines.

The work of the task force culminated in the issuance of *Guidelines for Cost of Illness Studies in the Public Health Services*, which included a set of recommendations for the conduct of future studies (Hodgson and Meiners, 1979). The recommendations were designed to be sufficiently flexible so that the objectives of individual cost-of-illness studies could be achieved, while promoting conformity in ways that would enhance the comparability of studies. In addition, they highlighted areas for further improvement and encouraged development and expansion of estimation methods and procedures. The primary motivation, however, was to encourage users to employ consistent assumptions, methods, and data so that the results of various cost-of-illness studies could be compared. As such, the guidelines recognized

that the current state of practice already followed roughly similar procedures, though frequently with variations that made it difficult, if not impossible, to make meaningful comparisons. For example, one report examined five separate studies of the cost of mental illness in the United States for different years and found that variations in the methodology produced extraordinary changes over time in some estimates as well as other differences that could not be reconciled from the information provided (Levine and Levine, 1976).

Since their issuance, the guidelines have served as the basis for at least three cost-of-illness studies sponsored by agencies of the Public Health Service (Hu and Sandifer, 1981; National Center for Health Services Research, 1981; Cruze et al., 1981) and the reaction to them indicates that they are quite workable. One of these studies (Hu and Sandifer, 1981), sponsored by the National Center for Health Services Research as a direct outgrowth of the task force's work, confirms the need for and value of having guidelines and provides a systematic review and comparative analysis of all major studies conducted from 1959 to 1979 which made estimates of the costs of illness or disease. In some respects the studies have served to highlight areas where the guidelines needed additional elaboration or adjustment. With these improvements, wider discussion of the guidelines now seems warranted. In what follows we include the set of recommendations promulgated in the guidelines, adjusted and augmented to reflect suggested improvements. A glossary of selected terms is provided as an appendix.

Costs Originating in Illness and Disease

The approach most frequently used by analysts to establish values for illness, disease, and health care services and programs is to identify the cost-generating components and to attribute a monetary value to them. The monetary value is what economists call the "opportunity cost," the value of the forgone opportunity to use in a different way those resources that are used or lost due to illness. The key point is that the economic costs as well as psychosocial costs are explicitly estimated to the extent that is possible or warranted by the purpose of the analysis. The composition of these categories is outlined below.

Direct Costs

Direct costs include medical care expenditures for diagnosis, treatment, continuing care, rehabilitation, and terminal care, as well as nonmedical expenditures occasioned by illness or disease. Medical care expenditures may be incurred for hospitalization; outpatient clinical care; nursing home care; home health care; services of primary physicians, specialists, dentists, and other health professionals; drugs and drug sundries; and rehabilitation counseling and other rehabilitation costs, such as those for prostheses, appliances, eyeglasses, hearing aids, speech devices, etc., to prevent or overcome illness-related impairments. These expenditures are included in the United States National Health Accounts, now published by the Health Care Financing Administration (Cooper et al., 1980).

Other health-sector direct costs relevant to the estimation of the aggregate cost of illness to society are those for research, training, construction, and administrative functions that are carried out by both public and private agencies to support prevention and treatment activities, including the administrative costs of providing health insurance. Although resources for research, training, construction, and administration are forgone to other uses and are opportunity costs of illness, it is extremely difficult to allocate even a portion of these costs to specific diseases. Furthermore, for costs of illness it is the pecuniary value of services provided in a period of time that is important. This is very difficult to estimate since expenditures in one period are not necessarily related to disease in that period. Facilities constructed and research and training funded in one year yield a stream of future services, while the value of services provided in that year is a result of expenditures in numerous previous years. In practice, estimation of costs attributable to the services provided by facilities, research, and training is a difficult task.

There is a further problem associated with capital expenditures, such as the cost of facilities. Including separate estimates for such things as construction expenditures results in double counting if the capital costs of patient care, such as depreciation and interest, are already reflected in prices charged for care. This issue is not relevant for estimating costs of illness in which the total of personal health care expenditures (which excludes prepayment and administration, government public health activities, research and construction) is the

total direct cost allocated among the various disease categories, but there is a small amount of double counting in the National Health Accounts. Estimated expenditures for construction of medical facilities does not include spending for capital equipment, but 57 percent of the $6 billion spent on construction in 1980 came from internal funds or the private capital market. This represents only 1 percent of total national health expenditures but is counted twice to the extent that the source of internal funds, repayment of principal, and interest on loans is revenue received for medical care services and supplies. For research expenditures, this problem is avoided in the National Health Accounts since it excludes research performed by drug companies, other manufacturers, and suppliers of health care goods and services (Gibson and Waldo, 1981).

Direct costs as discussed in this article might more accurately be called total direct costs. It has correctly been pointed out that the presence of disease may influence direct costs in the future, as well as at the time of the disease, in ways not as yet taken into account (Institute of Medicine, 1981). For example, individuals who die as a result of a disease would, in the absence of the fatal disease, incur costs for medical care during the remainder of their lives for conditions not related to the fatal disease. The present discounted value of future medical care expenditures that would have been incurred in the absence of the disease can be subtracted from total direct costs to give net direct costs. Total direct costs measure the value of medical care used to prevent, diagnose, and treat a particular disease. Net direct costs indicate the net expenditures incurred as a result of disease—that is, expenditures directly attributable to a disease less future expenditures not related to the disease that would have to be borne if the person did not succumb to the disease. Both total and net direct costs provide important information about costs of disease.

Other direct costs borne by patients and other individuals which do not show up in the national health accounts include costs of transportation to health providers, certain household expenditures, costs of relocating (such as moving expenses), and certain property losses. Transportation costs could be incurred not only for local transportation to hospitals, clinics, physicians, etc., but also for transportation out-of-state, and out-of-area living costs. Illness can force a family to incur expenses in caring and providing for the sick member of the family. These include extra expenditures for household help

for cleaning, laundering, cooking, and babysitting; special diets; special clothing; items for rehabilitation and comfort such as exercycles, vaporizers, humidifiers, and dehumidifiers; alterations of property, such as elevators for invalids and other special housing facilities; and vocational, social, and family counseling services. Property losses include destruction of property resulting, for example, from alcoholism and alcohol abuse (e.g., vehicular accidents), and criminal activity due to drug addiction. Another example is the depressed value of property because of risks to health due to environmental conditions, such as air and water pollution, solid waste areas, and nuclear power plants. Other costs originating in disease or illness are expenditures for retraining or reeducation, and care provided by family and friends.

Indirect Costs Resulting From Losses in Output

Indirect costs result from output lost because of cessation or reduction of productivity due to morbidity and mortality. The usual components of output-loss are earnings and the imputed market value of unperformed housekeeping services. The value of other nonmarket activities in addition to housekeeping services, both work and leisure, is also an indirect cost, but lack of data and conceptual difficulties prevent calculating the monetary loss when these activities are curtailed. In the past, it has been questioned whether the cost of morbidity and mortality due to illness is an individual's output or an individual's output minus his or her consumption (Dublin and Lotka, 1941; Fein, 1958; Weisbrod, 1961). Concern is usually with the total cost of illness to society, not just the output an individual contributes in excess of consumption. Economists today generally agree that consumption should not be deducted (Mishan, 1971). Nonlabor income is excluded from the calculation, however, since the value and earnings of a decedent's assets are transferred to another member of society. Illness may also adversely affect productivity in addition to causing time lost from work. Adverse effects on productivity can occur if illness lessens the productivity of persons while on the job, and absenteeism may increase costs of production with the end result that the value of output per unit of input declines. Additional indirect costs include the time a patient and/or family members spend visiting physicians, other health professionals, and hospitalized persons, and time lost from work by family members when someone in the family

is ill. Unwanted job changes and loss of opportunities for promotion and education due to illness may reduce productivity and result in additional indirect costs.

Psychosocial Costs

Illness and disease are responsible for a wide variety of deteriorations in the quality of life that are frequently referred to as psychosocial costs. Victims of illness and disease; children, spouses, and siblings of victims; friends and coworkers of victims; and those who render care may all be affected. Disease may bring about personal catastrophes that are not reflected in the direct and indirect economic costs that are usually estimated for a specific disease, although some psychosocial costs may increase direct and indirect costs classified under different diseases. A victim may suffer loss of a body part or speech, disfigurement, disability, the pain and grief of impending death. He, and those around him, may be forced into economic dependence and social isolation, unwanted job changes, loss of opportunities for promotion and education, relocation of living quarters, and other undesired changes in life plans. The environment created by illness often induces anxiety, reduced self-esteem and feeling of well-being, resentment, and emotional problems that often require psychotherapy. Problems of living may develop, leading to family conflict, antisocial behavior, and suicide. The victim and others may experience marked personality changes and reduced sexual function. Disrupted development and delinquency may occur among children. The quality of life may be reduced beyond the restorative capability of current rehabilitation efforts. The combination of financial strain and psychosocial problems can be especially devastating.

Present State of the Art for Estimating Costs of Illness and Disease

Current methodology and data permit estimation of only a portion of all costs incurred in the United States as a result of illness and disease. The most progress has been made with respect to the health-sector direct costs and indirect economic costs of disease victims' lost earnings and the imputed value of housekeeping services. The con-

ventional approach is to estimate direct costs on the basis of market prices (e.g., the charge per day of hospital care or, on an aggregate basis, hospital expenditures for the year) and to measure the indirect costs by estimating the loss of productivity due to morbidity and premature mortality valued in terms of lost output or earnings. This approach is commonly known as the human capital approach because it assesses the burden of illness in terms of the flow of goods and services which are either diverted from alternative uses to provide medical care and other needs of the ill (direct costs) or forgone because of work-time loss and loss of output measured by earnings paid for work, plus wage supplements such as employer contributions for social insurance, private pensions, and welfare funds (indirect costs). Strictly speaking, the human capital concept, which views an individual as producing a stream of output over the years, applies only to indirect costs. More recently, this methodology has also been referred to as the "output accounting" approach because of its similarities to national income accounting as carried out by the Department of Commerce and because it measures lost output (Institute of Medicine, 1981).

In cases such as housekeeping, where work is not reimbursed, estimates of the value of those services are made, usually by either the market value or opportunity-cost approach. In the market value approach, the services provided by the housekeeper are valued according to the estimated cost of replacing these services with labor from the market place (Brody, 1975; Gauger and Walker, 1980). The opportunity-cost value of a housekeeper's services is the wage the housekeeper could earn if working (Murphy, 1978). Murphy estimated the value of home services by both market value and opportunity costs and derived similar values by each, but other authors have calculated estimates which are quite disparate. Murphy (1980) provides a good summary of twenty studies of the value of household time.

As noted in the review prepared for the National Center for Health Services Research (Hu and Sandifer, 1981), the conventional approach has a long history. Its more recent development is recounted as follows:

> Malzberg (1950) performed what is considered generally to be the first formal cost of illness study, on the indirect costs of mental illness. A study by Reynolds (1956) on the cost of road accidents in England and Fein's (1958) analysis of the cost of mental illness established the conceptual approach effectively. Weisbrod (1961)

in his work on the economic benefits of health programs, Mushkin (1962), in her examination of health as an investment, and Klarman (1964), on syphilis control, all helped to further sort out the various economic savings of direct and indirect costs that result from investments and improvements in health. The empirical application of this tradition was effectively codified by Rice (1966), who provided the basic framework as well as detailed procedures for estimating the direct and indirect costs of illness. Well-known studies by Cooper and Rice (1976) and Paringer and Berk (1977) extended and updated the Rice estimates using basically the same methodology.

There have been more than 200 separate cost-of-illness studies in the last twenty years (Hu and Sandifer, 1981). Some of these are national in scope, but most are limited to a selected population or geographic area, and all but a very few are restricted to one or a few disease categories. Data sources and methods vary among these studies, and many limit their investigation to only one or several of the direct and indirect economic costs outlined above. The scope of a cost-of-illness study can legitimately vary from that of very comprehensive studies which attempt to estimate as completely as possible all costs associated with a broad spectrum of disease categories for the nation to a study of only one type of cost for a specific disease in a limited geographic area or among a subset of the population. The data needed and available will, of course, vary with the scope of the study, and neither the comprehensive nor the limited study will always have the advantage.

For use in a comprehensive study, for example that by Cooper and Rice (1976), there are national surveys which provide reliable data on medical care utilization. For example, the National Hospital Discharge Survey of the National Center for Health Statistics estimates use of short-term hospitals by diagnosis. These data are obtained by appropriate statistical sampling techniques and are reliably estimated at least for the broad three-digit categories of the International Classification of Diseases such as neoplasms, diseases of the circulatory system, diseases of the digestive system, etc. It is also possible to disaggregate some of these costs into more specific disease categories. For example, expenditures on short-term hospital care for neoplasms can be broken down by selected cancer sites (Rice and Hodgson, 1981). There are two national surveys of medical care utilization and expenditures which have completed their collection of data. These are the National Medical Care Expenditure Survey (NMCES), funded by

the National Center for Health Services Research in collaboration with the National Center for Health Statistics, and the National Medical Care Utilization and Expenditure Survey (NMCUES), administered by the National Center for Health Statistics in collaboration with the Health Care Financing Administration. When the data from these surveys (NMCES for 1977 and NMCUES for 1980) are analyzed, they should be very helpful in providing estimates of direct costs.

In a more limited study the investigator may have to collect data, which is a disadvantage, but in doing so may also be able to obtain data not readily available from the national surveys. This would include, for example, prices for physicians' services. There is a need for continuing estimates of cost of illness that are national in scope and cover a broad spectrum of disease categories, and also a need for limited studies of specific diseases, population groups, or geographic areas.

Human Capital Approach

The conventional approach is not without controversy, mostly because of the human capital methodology. It has been criticized as lacking a theoretical foundation and because of several omissions. To many critics, the calculation of expected lifetime earnings misses many of the subtleties of human existence, and simple reflection on this country's agenda of social programs bears this out. Relying as it does on existing earnings patterns, the human capital approach tends to give greater weight to working-age men compared to women, the young, minorities, and older persons. Some argue that the approach provides, at best, a lower bound for the value that might be placed on a human life (Linnerooth, 1979; Conley, 1976). It is not difficult to imagine a family spending beyond its income by divesting its assets to care for a sick member. In fact, many of the nation's elderly needing long-term care are faced with just such a prospect when entering a nursing home.

The human capital approach has also often been criticized as, at best, an incomplete measure of the value of life and, at worst, an irrelevant calculation without appropriate conceptual foundation. Indeed, it does not measure the value of life. Psychosocial costs are one component of the burden of illness omitted from the human capital computation of indirect costs. These affect the quality of life and

would presumably be reflected in certain measures of the value of life, such as by the willingness-to-pay approach discussed below. What the human capital methodology does measure is a certain component of the cost of disease, and it should be evaluated on the basis of how well it measures this aspect of the burden of disease and whether this is useful. Morbidity and mortality, by causing persons to lose time from work and other productive activities, forcing them out of the labor force completely, or bringing about premature death, destroys labor, a valuable economic resource. Disease thus creates an undeniable loss to individuals and society, and it is this loss that the human capital approach attempts to measure. The justification for the human capital methodology is not that it measures the value of life, but that it does provide a measure of a cost of disease. Further, its validity as a measure of certain costs of disease does not require the acceptance of maximizing the GNP as the goal of economic or social policy. Even those who decry human capital as a measure of the value of life recognize that it, or some form of it, is part of the value lost to mortality (Jones-Lee, 1976).

Human capital valuation rests on the assumption that earnings reflect productivity. That is not to say that each employee receives the value of his personal contribution to output, but that each receives the value of output added by the marginal or last-hired worker. The theory of marginal productivity goes back many years in economics. It rests upon assumptions that sometimes only vaguely reflect reality. Unfortunately, the impact of unfulfilled assumptions, or the robustness of economic models, is frequently unknown. Two key assumptions of the theory of marginal productivity are that labor markets are competitive and firms behave so as to maximize profits.

A frequent criticism of human capital is that some groups are undervalued relative to others, since human capital values are higher for men than women, for whites compared to blacks, and for the middle-aged compared to the young and elderly. The premise underlying this criticism is that earnings do not measure the value of life. Conceding this, and restricting human capital values to a measure of certain costs of disease, the relevant question is whether earnings measure the value of outputs. Imperfections may occur in the labor market so that a person's earnings differ from the value of his/her output or productivity. This may, for example, be because of the presence or absence of unions, and discrimination in hiring and pay

levels because of age, race, sex, or ethnic background. A related problem is that many productive activities are not reimbursed in the market. Housekeeping services are the usually cited example, but volunteer labor of any kind is conceptually just as important.

Discrimination on the basis of age, race, sex, or other factors such as education causes indirect costs incurred by some groups to be misstated if earnings differ from the value of output. Exclusion of the value of nonmarket activities may have the same result. Past discrimination on the basis of age, race, and sex are well-known. Our past history of role expectations not only kept women out of the labor force, but discouraged higher levels of training and education that would have prepared women who did wish to work for higher paying and presumably more productive jobs. There have, for example, been too few female physicians and engineers.

A possible form of employment discrimination is the basis-of-education screening. This is a phenomenon in which a person is excluded from an occupation in which his wage would be higher than that in his current employment only because he lacks certain educational credentials. Mantell (1974) claims such education-based employment discrimination exists in the labor market for engineers. Although this is certainly unfortunate for the individual, and may also result in a net social loss, it is not relevant to the human capital calculation if earnings in the lower level job reflect productivity in that job. When illness strikes a victim of this form of employment discrimination, the cost of illness is the output forgone due to time lost from the job actually performed. The difference in outputs of the lower level job and the job that would be held without discrimination is not a cost of illness, but a cost of employment discrimination that is incurred both when the individual is ill and when he is not ill.

It cannot be concluded, however, that the total difference in human capital values between groups results from discrimination and exclusion of nonmarket activities. Part of the difference may be due to real differences in productivity. Experience and on-the-job training may well increase one's productivity and this will correlate with age, up to a point. The elderly, on the other hand, may be less productive as a group because of working fewer hours, and value of output per hour may decline if, for example, one retires from a full-time job to a less productive part-time job.

A number of studies have examined the role of sex and race discrimination on earnings (Alexis, 1978; Cohen, 1971; Corcoran, 1978;

Frank, 1978; Haworth, 1975; Johnson and Stafford, 1974; Lazear, 1979; Long, 1977; Oaxaca, 1973; Sawhill, 1973; Smith, 1978; Smith and Welch, 1977; Strober and Quester, 1977; Swinton, 1977). This is not the place to review this literature in detail, but wage differentials need not be entirely due to discrimination. For example, Johnson and Stafford (1974) claim that male-female salary differentials of those in academic employment with the Ph.D. degree resulted from both discrimination against women and differences in acquired skill and productivity. Differences in productivity were due to voluntary choices by females regarding on-the-job training and life-cycle differences in labor force participation between men and women. Many women interrupted their careers through labor force withdrawal and/or part-time employment, causing their endowment of human capital to depreciate. Strober and Quester (1977), however, find parts of this argument unconvincing and warn that the issue of unequal pay for equal work should remain a real public policy concern. The reduction or elimination of such discrimination will serve to improve earnings as a human capital measure.

Sawhill (1973) points out that discrimination may take several forms, including both unequal pay for equal work and unequal job opportunities for equal qualifications. The former results in earnings that inaccurately measure the value of output while the latter form of discrimination is a social inequity that may reduce national output without necessarily biasing the human capital values. Labor force discrimination may occur in several forms. Unequal pay for equal work certainly biases earnings as a measure of the value of output. Denial of employment on any basis other than ability to produce is certainly inequitable, most likely reduces national output, but does not invalidate human capital if the individual's earnings reflect value of output.

Other market imperfections, such as lack of competition, may cause earnings to deviate from value of output. At least for broad-based comparisons across diseases, say among age groups covering many occupations, the deviations are expected to be consistent in a manner such that human capital measures are not invalidated. The problem of unfulfilled assumptions, such as lack of competition, and the resultant deviation of values of observed variables from the true values, in this case earnings versus value of output, is one that afflicts economics in general.

There are several other aspects of the human capital method that

require attention. First, present measures are quite aggregated. Would it serve a useful purpose to calculate human capital values by occupation and level of education? On the one hand, human capital values would be more accurate for certain groups defined according to these parameters. This could be important, for example, for estimating costs of illness related to occupational exposure. But for diseases not related to occupation or level of education, values for more broadly defined groups, such as women at a given age, may be all that is required. Further, while age, race, and sex can generally be determined for a specified group—such as deaths due to cancer—current records would not necessarily provide education and occupation. Second, there is a need for additional effort to determine values for nonmarket activities such as housekeeping and volunteer services. Most of the work in this area has concentrated on estimating values for housekeeping, with very little effort in cost-of-illness studies directed toward the value of other nonmarket activities or leisure. These two changes could conceivably be made in human capital calculations with appropriate effort at data collection and development of shadow prices and measures of opportunity costs for nonmarket activities. Improvements might be made, even if the gaps could not be completely eliminated. Finally, there is the very difficult problem of the uncertainty regarding the value of the discount rate. It does not seem that a solution to this problem will be forthcoming soon. Human capital values are sensitive to the discount rate and their use should be accompanied by a sensitivity analysis to show the impact of alternative values of the discount rate.

A main criticism leveled at human capital has been that it lacks a conceptual foundation as a measure of the value of life, more specifically, that it is not justified by welfare economics (Jones-Lee, 1976; Mishan, 1971; Schelling, 1968). Conceding this, it can still be argued that human capital measures a component of the burden of disease, and further, that it has a justification in economic theory which is the theory of marginal productivity. Human capital estimates provide an ex post facto measure of resources used or lost, and therefore unavailable for other uses. The value of time lost from work and other productive activities is an undeniable loss to individuals and society. If one wants to know what the economic burden of illness was last year, what resources will be saved by preventive measures that reduce the incidence of disease, or what the economic impact of improved

survival rates will be, the human capital method provides an appropriate, although partial measure.

Willingness-to-Pay Approach

A conceptual alternative to the human capital methodology is the willingness-to-pay (WTP) approach. Rather than estimating the components of costs originating in disease and illness, WTP proposes that the value of health or the avoidance of illness and disease can be deduced from the amount people would be willing to pay to reduce the probability of an event such as death from a certain disease (Mishan, 1971; Schelling, 1968). This approach is conceptually appealing to its proponents in that it assumes a comprehensive consideration of the potential costs of illness and disease, outlined earlier, and has some grounding in the optimality theory of Vilfredo Pareto. The idea is that such an expression of the value of health allows policy makers to assess the changes in welfare that would accompany changes in the probability of occurrence of specific events, such as death from a certain disease, and help to determine social preferences for public policy toward control of disease.

In practice, the WTP approach has been difficult to implement and is used in very few cost-of-illness studies. The methods that have been proposed and tried include direct surveys (Acton, 1975) and the analysis of "revealed preferences" implicit in wage differentials associated with high risk jobs (Thaler and Rosen, 1975) and prices associated with various consumption activities, such as the purchase of seat belts (Blomquist, 1979) or smoke detectors (Dardis, 1980). The survey approach must rely on responses to hypothetical questions. The difficulty of controlling for biased responses because of expectations about the use of the data, as well as the basic problem that respondents might have in answering rationally and consistently concerning their attitude toward marginal adjustments to risk levels, have limited the use of this approach. The revealed preference approach, on the other hand, is criticized because workers in high risk jobs may simply be less risk opposed than average, or lack other economic opportunities. In that case the wages paid would not reflect the true premium necessary to encourage the average risk-opposed person to assume a certain risk. In a recent study, the Institute of Medicine concluded that value-of-life figures produced so far by WTP studies "are better

described as illustrations of methodology than as serious attempts to derive representative values" (Institute of Medicine, 1981).

The WTP approach also shares some weaknesses with the human capital approach. Any practical application of WTP must consider ability to pay, which reintroduces valuation on the basis of income and wealth. Furthermore, those who may be at greatest relative risk may be the least able to pay. The elderly, for example, are the most likely group to need and to be willing to pay for private insurance for a long nursing-home confinement. This type of coverage is not generally marketed, at least in part because insurers view the elderly as largely unable to pay the cost of such protection. The marketing of such insurance to the working population in general is rare, however, because the insured risk at younger ages is not perceived as being great enough to warrant paying the extra premium.

The WTP approach and the human capital approach, however, do share some common ground. Both attempt to quantify the costs originating in illness and disease. WTP does this by implicitly encouraging consideration of the cost-inducing factors outlined earlier and the human capital approach by explicitly attempting to determine the cost of each of those elements. The special strength of the latter approach is that procedures have progressed to where a well-recognized framework exists by which methods and data are available to determine at least some direct and indirect costs in a reasonably systematic fashion. Even in this area, however, gaps remain and lifetime costs are not known for many diseases. For psychosocial costs, only a scant beginning has been made. To estimate all health costs reasonably completely, and with confidence, a substantial effort will be needed to improve existing systems and develop new methodologies and data bases. In its plan for an ongoing study of the costs of health effects of environmental hazards, the Institute of Medicine (1981) recommended that both human capital and WTP approaches be used, to the extent feasible, recognizing that neither method can measure all relevant costs but both can contribute.

Incidence-based Costs

Current methodology for estimating costs of disease by the human capital approach provides an estimate of the direct and indirect burden resulting from the prevalence of disease during a given period of time,

most often a year. In addition to costs associated with the prevalence of disease, it may be important to know the incidence rate and pattern of disease so that the cost per case of disease from onset until cure or death can be estimated. This is important for analyses that seek to measure the savings, or benefits, of preventing a new case of disease. The information is also necessary to determine the reduction in health costs which would result from incremental changes in conditions that lower incidence of disease or ameliorate the severity of disease. These costs are difficult to estimate, however, as they require knowledge of the likely course of a disease, the medical care that will be used, the amount of disability and debility, the time between onset and death or cure, and the impact of morbidity and mortality on earnings. These factors vary greatly even within a specific disease category such as cancer, and will depend on organ site, histological type of cellular change, and stage of disease development when treatment commences. Attempts to estimate costs per case of a disease suffer from limitations of data and knowledge.

Incidence information is often not available. For example, a recent study of the lifetime costs of adverse reactions to selected vaccines used a panel of physicians to help specify the alternative clinical event profiles and the associated resource utilization profiles. Cost estimates for the profiles were then made using the human capital methodology (National Center for Health Services Research, 1981). Relatively few incidence-based studies exist, but the current state of the art is illustrated in a recent study of the incidence and economic costs of cancer, motor vehicle injuries, coronary heart disease, and stroke by Hartunian, Smart, and Thompson (1980, 1981) and a study by Policy Analysis, Inc. (1981a) which examines the costs of breast cancer, diabetes mellitus, rheumatoid arthritis, stroke, and lymphocytic leukemia. Both groups investigate direct and indirect costs by modeling the disease process from onset until cure or death, including the trends of important parameters such as incidence, survival, use, and cost of medical care, and time lost from work and housekeeping. A great deal of effort was expended in locating and making the most of available data, which often were originally gathered for other purposes, were incomplete, and had to be modified to meet the needs of incidence cost analysis. Both studies are impressive in their demonstration that incidence-based costs are methodologically feasible, and in their use of extensive sensitivity analysis to reveal the impact of alternative

assumptions and parameter values on estimated costs. Sensitivity analysis is important in indicating those assumptions and parameters which, if changed within reasonable limits, cause large changes in costs.

Both incidence-based and prevalence-based estimates can have costs occurring in the future. In estimating the economic burden resulting from the prevalence of disease, the present discounted value of future losses due to mortality are calculated. The conventional methodology attributes those future losses to the year in which the death occurred. In estimating the economic burden associated with the incidence of disease, or lifetime costs of a disease from onset until cure or death, the present value of future direct costs and indirect costs of mobidity must also be calculated.

Nonhealth Sector Direct Costs

Limitations of data and knowledge have hindered development of many nonhealth sector direct and indirect costs incurred by others besides the victim. Some of these costs can be estimated but not necessarily for specific diseases. Although not a complete evaluation, one study found that nonhealth sector costs add at least 12 percent to total direct and indirect economic costs (Mushkin and Landefeld, 1978). For some health care components these costs are even more significant. Long-term care for the elderly, for example, includes social services such as homemaker services and "meals-on-wheels" as a significant part of a complete continuum of care. A study of long-term care services in Cleveland estimated that 57 to 80 percent of such care, depending on level of impairment, was provided by family and friends (Comptroller General of the United States, 1977). Nonhealth sector costs may also vary significantly according to disease category. It is clear that nonhealth sector costs are large in magnitude and an important component of costs originating in illness and disease.

Psychosocial Costs

Some psychosocial costs can be measured, such as the influence of mortality on the family and its life cycle (World Health Organization, 1976; Feichtinger and Hansluwka, 1977). Consequences of disease such as divorce rates, duration of marriage, probability and duration

of widowhood, probability of orphanhood (Preston, 1974), changes in residence, and loss of jobs can also be measured. To a large extent, however, measures and methodology for psychosocial costs remain to be developed. Measures are required for the impact of sickness on a person in terms of his or her own sense of well-being, including evaluations of well-being of family and associates in addition to the individual having the illness. Indicators must reflect the reduced self-esteem, emotional problems, pain and suffering caused by loss of body part, disability, social isolation, economic dependence, impending death, and otherwise reduced quality of life that often accompanies a disease.

Although direct measures of psychosocial costs and quality of life are not available, and considerable methodological research and data collection are necessary if these costs are to be adequately quantified, some progress has been made in understanding the degree of disability associated with illness and disease. A number of scales have been developed to assess the rehabilitation of patients by measuring functional status. The Performance Status Scale assesses mobility and ability to carry out usual roles. More comprehensive measures of functional status are the Pulses Functional Profile and Barthel Index (Granger and Greer, 1976). Pain and suffering could be measured by frequency, duration, and severity of pain as indicated by the potency of drugs needed for relief. Suicide and mental illness or psychiatric care could indicate grief, worry, and emotional stress. Also of interest is the Sickness Impact Profile, developed at the University of Washington and the Group Health Cooperative of Puget Sound, which attempts to measure behavioral expressions of sickness (Bergner et al., 1976; Gilson et al., 1975).

Nevertheless, the quantifying of psychosocial costs remains rather intractable. First, there is the problem of constructing valid quality-of-life indicators and relating them to measures of health status. Second, there is the difficult tasks of integrating nonmonetary information on quality of life with the dollar magnitudes estimated for direct and indirect economic costs. Still, psychosocial costs are a significant, and very likely quite large, component of the total burden of illness. To ignore them, or misrepresent them, can result in an underestimate of the impact of disease and bias the decision-making process. Even if dollar values cannot be attached to many, if not most, of these costs, they should be quantified in nonmonetary terms when-

ever feasible—for example, if appropriate to the study, the frequency of job loss, change in residence, etc.

Procedural Recommendations for Cost-of-Illness Studies

In view of the difficulties that have been encountered in comparing the results of various cost-of-illness studies and the current state of the art for estimating costs of illness and disease, the following recommendations are offered for future cost-of-illness studies that choose to follow the frequently used human capital approach. It is the aim of these recommendations to help produce cost-of-illness studies that will be well-documented with respect to data and methods, calculate more complete estimates of costs of illness, and improve the consistency and comparability among estimated costs of the same and different illnesses.

Specification of Costs

The total cost of an illness or disease includes a number of direct and indirect economic costs outlined earlier. If the purpose of the study is satisfied by a subset of these costs—for example, just direct costs or just costs of inpatient care—the study should clearly indicate that this is the case and that only a portion of the costs of disease are being estimated.

Methods and Data

Methods and data used to estimate costs should be clearly indicated. A new study should be related to previous studies, and the impact on estimated costs of alternative methods and data should be analyzed and discussed. If the disease category being studied occurs relatively infrequently and the recommended data sources do not meet standards of reliability or precision, it may not be possible to determine the impact on estimated costs when alternative sources are used. Nevertheless, the data employed should be discussed including, for example, reliability or precision, population base, and other attributes that will aid in judging the suitability of the data and possible limitations of

the cost estimates. Studies by Cooper and Rice (1976) and Paringer and Berk (1977) are examples of well-executed prevalence-based studies, while those by Hartunian, Smart, and Thompson (1981) and Policy Analysis, Inc. (1981b) demonstrate how to estimate incidence-based costs.

Indirect Costs

Indirect costs can be estimated by the human capital approach. Indirect costs are the value of output lost because of cessation or reduction of productive activity in terms of working and keeping house. Output losses are measured by lost earnings plus the imputed market value of unperformed housekeeping services. The value of housekeeping services is included since omission will result in a serious underestimate of the indirect costs of disease. It must be remembered, however, that the value of output imputed for housekeeping and other nonmarket tasks is not included in the national income accounts. Therefore, the imputed market value of unperformed housekeeping services must be excluded when comparing costs of illness with the GNP. The human capital approach provides valuable information, so long as its limitations are realized. Although not giving a complete estimate of the value of life, it does indicate economic costs resulting from morbidity and premature mortality.

Discount Rates

The discount rate converts a stream of future money values into its present value. Anderson and Settle (1977) provide a discussion of the mechanics of discounting. In the ideal world of perfect capital markets, private and public rates of return on investment and individual and social rates of time preference would all be equal. There would be only one rate available for discounting. In reality, however, taxation of corporate and personal income causes a difference between individual rates of time preference and returns on investment; externalities in production can result in a divergence between private and social rates of return on investment; and individual and social rates of time preference will differ for public goods.

Faced with four distinct rates, there has been disagreement on the proper conceptual basis for the discount rate. Some experts favored

the social rate of time preference, that is, society's rate of tradeoff between present and future benefits. It has been argued that the rate at which the government borrows money (a riskless investment for the lender) is an upper bound on the rate of time preference. Since some individuals will lend money to the government, they must prefer to do so rather than use the funds for consumption now (Baumol, 1968; Sassone and Schaffer, 1978). If their rate of time preference were higher than the interest rate on government bonds, they would not invest. Further, it is also argued that, collectively, individuals have more concern for the future relative to the present than suggested by individual behavior in economic markets. Consequently, the social rate of time preference must be lower than the market rate of interest (Sassone and Schaffer, 1978). The criterion of social rate of time preference indicates a relatively low discount rate. Another school of thought proposed that the discount rate must reflect the opportunity cost of using resources in the public sector, and that the rate of return forgone in the private sector by transferring funds to the public sector is the appropriate discount rate. The opportunity-cost criterion indicates a relatively high discount rate, possibly 10 percent or more. Some experts have recommended a weighted average of rates of return in the private sector with the weights being the proportion of funds from each source (Ramsey, 1969; Anderson and Settle, 1977). Although proponents argue that this method accounts for both time-preference and opportunity costs, others claim the case for a weighted average breaks down if more than two periods are involved (Sugden and Williams, 1978). The Office of Management and Budget (1972) discount-rate policy for all agencies of the executive branch except the Postal Service and projects covered by the Water Resources Principles and Standards was: a) a rate of 10 percent, and, where relevant, b) any other rate prescribed by or pursuant to law, executive order, or other relevant circulars. The 10 percent rate was chosen to represent an average rate of return in the private sector before taxes and after inflation.

It is now generally agreed that the benefits of public projects, which is what costs of illness are in the context of the present discussion, should be discounted at the social rate of time preference. This rate correctly states society's preference for present versus future consumption. It is true that an opportunity cost may be incurred in financing public projects by funds withdrawn from the private sector.

The valid way to account for this is not through the discount rate, however, but in the project's cost. Given several simplifying assumptions, a project's cost is the nominal value of funds withdrawn from consumption plus the present discounted value of future benefits forgone as a result of funds withdrawn from investment, with these forgone benefits also discounted at the social rate of time preference. The opportunity cost of investment funds is fully reflected in the stream of forgone benefits. Policy Analysis, Inc. (1981) and Sassone and Schaffer (1978) provide an excellent discussion and references for this approach to the discount rate.

Accepting the above conceptual basis for discounting benefits of public programs leaves unanswered the question of the value of the discount rate. Unfortunately, the social rate of time preference is unobservable and the actual value is uncertain. Even if one could assume equality of the social and individual rates of time preference, and the private rate of time preference was equal to the market rate of interest, the problem is not solved, since there are many rates at which individuals borrow and lend. Also, observed rates contain an inflation factor, which further complicates ascertainment of the real discount rate. Anticipated inflation must be handled correctly if spurious results are to be avoided. The usual method is to estimate future values in constant prices and estimate the discount rate in the absence of inflation (Anderson and Settle, 1977). A less frequently used method is to estimate all future values in current (inflated) prices and use a discount rate adjusted for inflation (Anderson and Settle, 1977). The difficulty with this method is that it requires predicting inflation for years into the future.

Costs of illness estimated in two different studies and for the same base period, whether for the same illness or not, can only be meaningfully compared if identical discount rates are employed. Since estimated costs vary with the discount rate, and since the impact of alternative values of the discount rate is not uniform for all illnesses, and the proper value for the discount rate is uncertain, costs should be estimated for several rates. Therefore, it is recommended that investigators employ at least two and preferably three discount rates, such as 2.5, 6, and 10 percent. The range from 2.5 percent to 10 percent encompasses the rates generally in use today for costs of illness. The rates of 2.5 and 6 percent are thought to contain the social rate of time preference. Sensitivity analysis on the discount rate will reveal

the sensitivity of costs for any one illness and the changes in the relative importance (in terms of costs) of several illnesses for alternative discount rates. It is important for policy makers to know whether cost estimates are appreciably affected by alternative discount rates.

Double Counting

Double counting of costs is to be avoided. Taxes and transfer payments, such as public aid and disability payments, are not costs of illness and disease and should not be added to direct and indirect economic costs. Taxes will already have been counted in indirect costs, and transfer payments are simply a reallocation of income from one individual (e.g., the wage earner) to another (e.g., the disabled). Although these transfers represent a cost to the wage earner in the form of a reduction in disposable income, his loss is another's gain, and the net cost to society resulting from this transaction in terms of resources used (and thus unavailable for other alternatives) is zero, except for those costs which may be incurred in operating the system that effects the transfers. Other examples of transfers are interest and capital gains forgone because of forced sale of assets, loss of property for failure to meet mortgage payments, and stolen property.

Costs of illness and disease in the human capital method are the value of resources used, resulting in forgone alternatives, and resources lost due to morbidity and mortality. Transfers, on the other hand, are shifts, as the name implies, of control over the use of resources. Direct and indirect costs are unambiguous losses that would not occur if illness and disease were reduced, while transfers take resources from one segment of society and give them to another. Transfers may alter the allocation of resources among competing ends, but are not a use of resources in and of themselves.

Consider the case of drug addiction. In addition to the usual direct and indirect economic costs, society may choose to use resources and incur expenses in the criminal justice system, and provide welfare payments that would not be considered necessary in the absence of drug addiction. Additions to the criminal justice systems are a use of resources and a cost of drug addiction that fall into nonhealth-sector direct costs. Welfare payments are a simple transfer. If criminal activity resulting from drug addiction causes property losses, the value of property destroyed is one of the related direct costs, while property stolen is a transfer.

Although the value of the transfer per se is not a cost, transfers undoubtedly have an impact on quality of life and welfare of both givers who lose and recipients who gain. For this reason, it may be desirable to investigate transfers exploring, for example, the redistribution of income that takes place and the impact on those who lose and those who gain. If it is desirable for other purposes to estimate the impact of illness and disease on taxes or various transfer payments, these should be presented separately and not included in estimates of the total cost. Failure to make a distinction between transfer payments and costs will result in a serious overestimate of costs.

Comprehensive Cost Evaluation

Medical care expenses and indirect costs are not a complete evaluation of the costs of illness and disease. Rather, they constitute a lower bound for the costs which can be estimated for most illnesses and diseases given present methods and data. Estimates of other costs in addition to these are encouraged, especially those that are important for the illness or disease in question, whenever methods and data permit, in order to obtain as complete an evaluation of costs as is possible. This includes estimates of nonhealth sector costs and psychosocial costs.

Nonmonetary Costs

Impacts of illness and disease that cannot be quantified in monetary terms can be listed and evaluated by available measures. The reporting of nonmonetary impacts, such as divorce and suicide rates, provides an added dimension which, in combination with the economic burden, most fully indicates the scope and magnitude of the costs of illness or disease. But the absence of information on nonmonetary costs should not deter ascertainment of economic costs.

Unique Disease Characteristics

Unique characteristics of disease that bear upon costs should be taken into account so far as possible. A disease may have unique features that are reflected in costs beyond the usual direct and indirect economic costs. For example, one disease may bring about another disease or

illness, so that part of the cost of the latter should be included in the cost of the former. Diabetes is often etiologically associated with other chronic conditions such as heart disease, blindness, and other vascular disease. Similarly, arthritis may be a complication of psoriasis, and it has been reported that psoriasis may increase the incidence of alcoholism and suicide, and various physical ailments may result from alcohol abuse. Digestive diseases can contribute to heart, lung, and kidney failure. That portion of the costs of one disease that occurs because of an antecedent disease should be clearly identified, if possible, so that double counting can be avoided if studies for several diseases are aggregated. For some diseases occupational exposure may be a significant factor and occupation should be taken into account in estimating, for example, the value of output lost due to morbidity and mortality. Some studies may require that costs be distributed a) according to diagnosis, treatment, and rehabilitation, b) by stage or extent of disease at initial diagnosis, or c) by method of treatment.

Study Purpose

The cost estimate should be appropriate to the purpose of the study. To determine the economic burden resulting from the prevalence of disease in a given year, prevalence-based costs are a suitable measure. If it is necessary to determine the reduction in costs that would result from a decrease in the incidence of disease, then estimates of costs per case from onset until cure or death, that is, incidence-based costs, are required. If the cost per case cannot be estimated directly, the study will have to analyze the extent to which available measures provide the necessary cost information and meet the study objective.

Generalizability

The extent to which the results of a study can be generalized should be discussed. If the cost estimates are derived on the basis of a limited geographic area, a subset of the United States population, particular cases of the illness and disease in question, or restricted in any other way, these limitations should be clearly pointed out. Studies which purport to estimate costs of an illness or disease in the United States must use methods and data appropriate for national presentation.

Sensitivity Analysis

Those parameters of the analysis for which the estimated costs are most sensitive to changes in value should be identified. For example, prevalence-based costs of illness and diseases for which mortality is relatively unimportant compared to morbidity and medical care use, or for which mortality occurs at older ages, will be less sensitive to differences in the discount rate. On the other hand, costs of diseases that require disproportionate use of hospital care will be relatively more sensitive to inflation of medical care prices. A range of estimates derived from alternative values of key parameters in the model can also be presented. Measures of the reliability of estimates should be provided whenever possible. Relative standard errors, i.e., the standard error divided by the estimate, standard errors, and confidence intervals are possible measures.

Documentation

Detailed documentation of data, data sources, and methods are required to enable an independent investigator to duplicate the study and facilitate comparison between studies and determine the impact of alternative assumptions, methods, and data. Although some standardization of procedures and data is recommended, it is recognized that flexibility must be maintained so that specialized needs can be fulfilled and unique characteristics of an illness or disease can be taken into account. Because of the interconnection of illnesses and diseases (e.g., diabetes and vascular disease, alcoholism, and mental illness), a simple summation of costs of individual diseases may exceed the total cost of disease. However, if each study clearly distinguishes the components of estimated costs and explains procedures in detail, different studies may be compared component by component, overlapping of costs will be evident, and the net costs of several diseases can be calculated. A detailed explanation of the calculations and analysis will most likely insure that both the objectives of the study and the need for comparability among studies will be realized.

Conclusion

The recommendations made in the previous section are designed to be helpful to both the producers and users of estimates of the costs

of illness and disease. A primary problem of many of the studies that have made such estimates is that they have not conformed sufficiently in their methods, data, and assumptions to constitute an improving state of the art, much less a consistent state of practice. Policy makers must recognize that the methodology of the study can significantly influence the results. Researchers can assist in this by recognizing well-established principles in making estimates of the costs of illness and disease. To this end, the recommendations seek to encourage conformance to the conventional methodology where its use is warranted by the objective of the study, and to document deviations from the methodology where its use is not warranted.

The key recommendation is that concerning medical care expenses and indirect costs. The National Center for Health Services Research review (Hu and Sandifer, 1981) confirmed that the methods and data associated with estimating these costs are relatively good and that they provide a reasonable base on which to build. Nonetheless, fewer than half of the studies reviewed estimated both direct and indirect costs. The review also confirmed that the vast majority of cost-of-illness studies employ the human capital approach to estimate indirect costs. The omission of many potentially significant costs, especially psychosocial costs, remains a weakness of many cost-of-illness studies. However, the methodology is amenable to development change and the framework outlined in this paper can accommodate improvements.

Finally, it should be noted that improvements to the methodology and data used in estimating the costs of illness and disease are actively being sought. As an example, the National Center for Health Statistics sponsored a study which investigated the feasibility of developing methods and procedures for extending cost-of-illness determinations to include costs associated with the incidence of disease, primary and secondary impacts throughout the economy, psychosocial costs, and allocation of costs among joint diseases and between antecedent and subsequent diseases (Policy Analysis, Inc., 1981a, 1981b). The study also indicates the data necessary for implementing the recommended extensions and improvements in methodology and the feasibility of obtaining the required data. New initiatives such as these promise to enable us to expand our estimates and increase our knowledge of the costs of illness and disease, and thereby employ our scarce resources more effectively.

Glossary

1. *cost-benefit analysis* - a technique for evaluating alternative projects through the estimation of the net benefits associated with each project.
2. *cost-effectiveness analysis* - a technique for choosing among alternative means of achieving a given goal through estimation of the costs associated with each alternative.
3. *cost of illness studies* studies that evaluate direct costs, indirect costs, and psychosocial costs of disease or illness.
4. *direct costs* costs resulting from the use of medical care in the diagnosis, treatment, continuing care, rehabilitation, and terminal care of patients as well as nonmedical expenditures occasioned by illness or disease.
5. *discount rate* a factor used to convert a stream of future dollar amounts into its present value in order to account for time preference.
6. *human capital approach* a method that views an individual as producing a stream of output over the years that is valued at the individual's earnings, with the value of household work being imputed.
7. *indirect costs* the value of current and future output lost because of cessation or reduction of productivity due to morbidity and mortality.
8. *opportunity cost* the value that resources could earn in alternative uses.
9. *present discounted value* the current worth of a stream of future earnings or money values that have been discounted to account for subjective time preference.
10. *psychosocial costs* psychosocial deteriorations that are brought about by disease and which reduce the quality of life. These include, but are not limited to, undesired changes in life plans, anxiety, reduced self-esteem and feeling of well-being, and other emotional problems.
11. *time preference* - the usual preference for a dollar or some commodity now rather than in the future.
12. *transfer payments* - reallocations of income from one individual to another, with a net cost of zero to society. For example, disability payments are a reallocation of income from the wage earner to the disabled.
13. *willingness-to-pay criterion* a method of valuing human life and limb according to the amount people are willing to spend to obtain reductions in the probability of death, injury, or disability; or, alternatively, the amount they must be compensated in order to accept an increased risk.

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