A Question of Value: Measuring the Impact of Chronic Disease

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THE RISING COST OF MEDICAL CARE HAS OCCUpied the center stage of policy debate for several decades. However, the indirect costs of illness-those resulting from lost functional capacity rather than expenditures for medical servicesare receiving more attention with each passing year. This is because indirect costs are expected to rise dramatically in the next 25 years as the proportion of persons with chronic health conditions resulting in activity limitation increases in parallel with the aging of the United States population (Waldo and Lazenby 1984; Morrison 1979). One obvious manifestation of the concern with the indirect costs has been the debate over the expenditures from the Social Security Disability Insurance trust fund. Ironically, the increasing attention being paid to the indirect costs of illness may be the paradoxical outcome of our society's success in delaying mortality. We live with the illnesses that formerly killed people, although we may experience longer periods in which our activities are limited, if not curtailed (Verbrugge 1984; Fries 1983).

As with many social problems, we recognize that the indirect costs of illness are a growing phenomenon but we have not yet developed the tools to measure them with any precision and consistency. In this instance, the measurement tool does matter, for the existing methods

The Milbank Quarterly, Vol. 66, No. 3, 1988

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that measure the costs of illness value the same activities differently; yet, policy makers use these reports to direct resources—so many dollars to disability compensation and vocational rehabilitation, so much to home health care services, so much to "Meals on Wheels."

The process of enumerating the "costs" of activities forgone as a result of illness involves two steps. First, one must count the activities in which the individual has stopped participating. Second, one must translate each such loss into a common value system, into a measure of "costs." This is difficult because there is no natural way to compare values. How does one equate, for example, partial work disability with a reduced capacity to garden, shop, or meet with friends?

This article reports the results of a project to improve both the enumeration of activities forgone and the translation of these losses into a value system, a project which was completed with the help of people with two common forms of arthritis and similar persons free of chronic disease. In this article we summarize the enumeration of activities forgone (for greater detail see Yelin et al. 1987), and report more extensively on our approach to translating diverse losses into a single value system. We call these efforts an approach rather than a solution because much remains to be done to translate the ideas expressed here into a scale that meets standard psychometric criteria. But some problems in cost-of-illness methodology have been overcome; our approach is simple to employ and understand, is comprehensive, and has demonstrated reliability in this application.

Estimating Indirect Costs

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Economists use money as the universal coinage with which to measure the indirect costs of illness. They do this because money is a convenient and oft-employed way to state value. There are two principal methods with which to value the losses in activities in monetary terms—the human capital and the willingness-to-pay approaches. We briefly review these two methods below.

The human capital approach values worsening health as the net present value of changes in individuals' expected lifetime earnings or productivity (adjusted by age and sex) resulting from disease and disability. The cost of illness is the difference between what individuals would earn in future years, discounted to present values, in the presence or absence of illness. The advantage of this method is that it reliably captures one aspect of the economic losses associated with illness—forgone earnings. It is also relatively simple to apply when census or income survey data are available with which to compute out how much individuals would earn in the absence of illness. The human capital approach has been used extensively to estimate the costs of chronic illnéss (Rice and Cooper 1967, 1976; Hodgson and Meiners 1982; Rice and Hodgson 1982; Rice et al. 1986).

There are serious limitations to using this measure for policy analysis, however. The technique emphasizes one aspect of human life-the value of expected earnings-and ignores most nonmarket dimensions of illness and disability, such as psychosocial costs, or the impact on leisure activities, friends, and family (Acton 1976; Landefeld and Seskin 1982). While work is important to many people, it is not important to all. Moreover, market earnings do not always reflect social values. Difficulties arise when work is not "gainful" employment as, for example, when one is a housewife, parent, or student. In addition, work losses are not necessarily the result of the disease process, but may be associated with an individual's background and work experience, and the economy at large (Yelin, Nevitt, and Epstein 1980). This method does an especially poor job of estimating the cost of illnesses most prevalent among the elderly and women, since the earnings of these groups are generally far lower than those of young and middle-aged males.

Concern over these shortcomings stimulated interest in an alternative method of valuation that takes into account explicit or implicit individual preferences concerning all the "costs" of illness—the willingness-topay approach (Mishan 1971; Thompson 1980). The willingness-topay approach assumes that the indirect costs of illness are most appropriately valued as the amount individuals would be willing to pay to reduce the probability of death or disability from disease (Acton 1976; Mishan 1971; Thompson, Read, and Liang 1984; Thompson 1986). This amount is the sum of the values placed on all concrete activities, plus the value of eliminating pain and suffering. The method is based on the preferences of individuals are offered complicated gambles designed to elicit a set of choices (Acton 1973; Thompson, Read, and Liang 1984; Muller and Reutzel 1984). These responses are then aggregated into a general measure of the dollar amount or ł

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proportion of income individuals would be willing to pay to reduce the probability of death or disability. This monetary value can then be used to guide the allocation of resources.

In practice, however, the willingness-to-pay approach is very difficult and expensive to implement. Much of the difficulty in analyzing data on willingness-to-pay is a consequence of the large disparity in values within individuals and among respondents (Baram 1979; Bailey 1980). As a consequence, responses are aggregated across sample sizes too small for statistical reliability. The disparities in values among individuals are attributed to many factors. First, revealed preferences are conditioned by external factors, especially individual income. Willingness-to-pay cannot be separated from ability to pay, even when willingness-topay is expressed as a percentage of income. Second, individuals' current health status also affects willingness-to-pay; those who are sicker value health more (Acton 1973; Thompson 1986). If the assessments of the well formed the basis for health care expenditures, hardly any money would be allocated to health; if the values of the sick were taken as the basis for policy, almost all of the gross national product would be allocated to the eradication of illness. Third, many respondents have a difficult time conceptualizing probabilities of death or certain kinds of disability when asked about hypothetical situations, especially when they are not at risk for them (Kahneman and Tversky 1973; Tversky and Kahneman 1981; Bailey 1980). Thus, Thompson et al. (1982) reported that only 45 percent of a group of arthritics were willing to place a value on improvement in their health status. Finally, the way questions are phrased is very important and affects responses; small changes elicit large discrepancies in the values individuals state.

There are also indications that the values respondents give to health in the willingness-to-pay framework are neither stable nor reliable (McNeil et al. 1982; Institute of Medicine 1981; Acton 1976). Individuals' inherent value system should not change in a matter of days, especially if health status has not changed, but such is not the case. When asked to place values on health, individuals' assessments vary widely in a matter of minutes, let alone days. But the most telling problem with willingness-to-pay is that this method of valuation assumes that the existing distribution of income is considered a proper basis for allocating resources (Robinson 1986). For those who believe that the valuation of health should not be related to ability to pay, this method is unacceptable. Both the human capital and willingness-to-pay approaches use dollars to sum the indirect costs of illness. The human capital approach directly and simply measures losses in income and household work, and then sums these losses. Willingness-to-pay measures personal preferences for changes in health as a proportion of income, a value which is then converted to dollars. In contrast to the human capital approach, willingness-to-pay covers a broader array of indirect costs, in effect putting a price on the soul as well as on a greater array of activities. But each such cost is accounted less completely and less reliably than the human capital method. The choice between the human capital and willingness-to-pay approaches is a Faustian bargain between a reliable accounting of a small portion of costs and an unreliable accounting of all costs.

Despite these shortcomings, both the human capital and willingnessto-pay approaches have often been used to highlight the magnitude of disease costs. The literature on arthritis, for example, includes studies using the human capital (Yelin et al. 1980; Meenan et al. 1978; Stone 1984; Lubeck, Spitz, and Fries 1982; Lubeck et al. 1986) and willingness-to-pay methods (Thompson, Read, and Liang 1982, 1984) to establish the cost of these diseases. In turn, cost-of-illness studies have persuaded both clinicians and policy makers that the impact of lost function is often greater for individuals with chronic disease, as well as society, than the costs due to direct expenditures for medical care (Warner and Luce 1982).

An Alternative Approach

In this project, our goal is to design and test an alternative method to enumerate and value in common terms as many of the indirect costs of illness as can be done reliably. We acknowledge that pain and suffering should be included in a comprehensive accounting of the costs of illness, but do not feel that the methods proposed to do this have worked. Likewise, while we know that individuals have an inherent value system for their health, they often cannot or will not translate these values into monetary terms. Accordingly, we account only for concrete activities of life and we ask individuals to value them in qualitative (e.g., "how important is it to you to be able to shop for food?"), not monetary ones. 1

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Using the time-budget methods first developed by Frederick Taylor at the turn of the century, sociologists discovered that human activities can be classified easily into about eight major domains: household chores, shopping and errands, social relations, religious activities, leisure and recreation, transportation, public service, and work (including volunteer activities) (Chapin 1974; Medrich et al. 1982). While one can divide each major domain into numerous subsets (e.g., shopping for bread as opposed to shopping for food or even just shopping), about 75 activities (approximately 9 per major domain) capture most of the detail of daily life. This article demonstrates how people with and without chronic conditions differ in their participation in activities, and reports our approach to the problem of obtaining reliable evaluations of these activities.

The literature on the cost of illness provides five guideposts in constructing a method to value losses in activities. First, all activities should be valued in the same terms so that the value placed on one activity can be compared to the value placed on another. Second, it should be comprehensive to ensure that activities other than remunerative ones are integrated in the accounting system. Third, unlike the revealed preferences of willingness-to-pay, individuals should value activities similarly before and after illness. The method should not be sensitive to health status because of the risk of moral hazard, that is, the propensity to value health status more highly when ill and, thus, to avoid ensuring against poor health when well, while seeking to obtain compensation as soon as one becomes ill. Fourth, the method should be sensitive to differences in preferences between the sexes and among all age groups. One would not expect an octogenerarian to value work as much as someone fifty years younger, nor a woman who never chose to work to value employment as much as one who did. Finally, like the human capital approach, the method should be easy to understand, administer, and incorporate with other forms of data collection.

Methods

In the study reported here, we do not attempt to value losses in activities in monetary terms because we feel that the attempts to do so using the human capital and willingness-to-pay approaches are fundamentally flawed. Instead, we simply ask individuals to value the importance of each of their daily activities. For activities forgone, we ask them to value the losses in a similar fashion.

Instrument

We developed a telephone survey which has four parts. In the first part, we ask respondents to place an inherent value on each of the most common 75 activities on a scale that ranges from 1 (it is very important to the individual to be able to do the activity) to 5 (it is not at all important that the respondent be able to do the activity). Respondents were asked to value the importance of activities in all eight domains first. We then ask the respondents whether they performed each of the activities a decade ago (we prompted them with the date 1975), and whether they perform them now (at the time of the interview in 1985). The ten-year recall was used because this was prior to the date of onset of disease for most of the respondents with arthritis. The goal was to stimulate respondent recall of activities from a decade ago. In theory, a ten-year recall of activities might not be accurate. While we believe that the salience of participation in everyday activities would make for accurate recall, we also compared the current activity patterns of the people with arthritis to the patterns of healthy controls, and found no difference from the results presented here.

Data Sources

Both the Stanford Arthritis Center and the Health Services Research Component at the University of California, San Francisco's (UCSF) Multipurpose Arthritis Center, have been involved for several years in studies designed to assess the costs of arthritis. This study draws upon a panel of rheumatoid arthritis patients followed at the UCSF Multipurpose Arthritis Center; a panel of osteoarthritis patients followed at the Stanford Arthritis Center; and a sample of age- and sex-matched controls derived from random-digit dialing in the communities of residence of members of the two panels.

The rheumatoid arthritis panel was formed in 1982–1983 from people with this illness presenting themselves over a one-month period to a random sample of the rheumatologists practicing in northern California. The characteristics of the sample of 754 respondents have been detailed previously (Yelin et al. 1985; Yelin, Shearn, and Epstein 1986). Briefly, at baseline, 74 percent were female and the mean age was 56.6 years. The 754 respondents comprise the sampling frame from which 150 were randomly selected for this study population. The osteoarthritis panel was formed in 1982 by recruiting patients from the mid-peninsula counties of northern California. The detailed characteristics of the respondents at baseline have been described elsewhere (Lubeck, Brown, and Holman 1985). In brief, 84 percent were female and the mean age was 68.7 years. As of July 1984, 189 persons remained in the osteoarthritis panel. We took a random sample of these 189 patients to obtain the study population of 150 osteoarthritis patients.

Study controls were matched to both the rheumatoid and osteoarthritis patients in the study by community of residence, age, and sex. We created six cells: three for men aged 40-54, 55-64, and 65 years or older; and three for women in the same age groupings. We then listed the three-digit telephone prefix (representing the community of residence) of each arthritis patient in each age-sex cell and we appended four digits from a random number table to this prefix. Upon calling this number, we asked whether the household contained a man or woman from the specified age group. If there were two or more persons meeting the age and sex screens, we randomly chose one for inclusion in the study. Potential controls were asked if they were limited in any way in daily activities as a result of a chronic disease and if they had been diagnosed as having arthritis. If they responded positively to either query they were excluded from the study. Controls matched the study population, then, except that they were free of disabling chronic illness and free of arthritis.

We sought 100 controls who met study criteria; and 100 persons agreed to participate as a result of approximately 500 telephone interviews. Of the remaining interviewees, 350 did not fit into the age categories of the study and 50 persons declined to participate. When an individual who was contacted declined to participate, he or she was replaced by another similar in age, sex, and community of residence. The 100 controls are 71 percent female. Thirty-three percent are between 40 to 54 years of age, 29 percent between 55 to 64 years, and 38 percent are over 65 years.

Respondent Participation

Once enrollment was complete, respondent participation in the telephone survey was universal. That is, 150 rheumatoid arthritis patients, 150 osteoarthritis patients, and 100 controls free of chronic illness participated in the telephone survey. This is to be expected for the persons with rheumatoid and osteoarthritis whom we had been following for several years already. The participation of the healthy individuals sampled through random digit dialing, however, must be due to the ease with which the survey can be completed.

Data Analysis

There are five parts to the data analysis. Initially, we report on the proportion of persons with rheumatoid arthritis and osteoarthritis and persons who are healthy who have experienced activity losses, and the mean number of losses experienced in each activity domain by each group. Subsequently, we report the assessment of the inherent importance of major groups of activities among persons with osteoarthritis, rheumatoid arthritis, and healthy controls to determine if worsening health affects the values respondents place on activities. We calculated these values for each major activity domain by averaging the individual's rankings for discrete activities within each major domain. Next, we report the evaluation of the importance of major activities forgone over the past ten years among the respondents to determine if the health controls value the loss differently than the persons with arthritis. We calculated these values by averaging individuals' rankings of those activities within a domain that were forgone. If no activity within a domain was forgone, there is no value for this set of variables. We then compare the inherent evaluation of activities of those respondents with and without subsequent losses to determine if losses in activities rather than health status affect the inherent evaluation. Finally, we present information on how people of different ages and sexes inherently value their activities.

We use ordinary least squares (OLS) to make these estimates. The dependent variables include the number of activity losses (and the proportion with losses) in each major activity domain, the inherent value of an activity, and the value of a loss in that activity. We controlled for age, sex, and community of residence both through the random-digit-dialing sampling procedure and by entering age and sex as independent variables in the regressions. In the results below, we report values adjusted for age and sex (and for illness as well in tables 1, 2 and 3, and in table 4 for whether activities have been forgone). These adjusted values derive from the multivariate regressions. In these analyses we test for statistical significance between rheumatoid arthritics and controls or osteoarthritics and controls using a t-test or a one-way ANOVA (p < .05).

Results

As one can see from the information presented in table 1, activity losses are common among osteoarthritics and rheumatoid arthritics. The greatest frequency of losses occurred for both disease groups in the areas of household chores, leisure and recreation, and shopping and errands. At least two-thirds of patients in these illness groups experienced one or more activity loss in these domains—in proportions greater than the control group. Work losses are common among all three groups of patients, a result of the aging process. The average number of work losses was not significantly different for arthritics and controls. But work losses constituted a small portion of total losses, indicating that at least on a numerical basis losses in other activities should be enumerated.

Table 2 reports the inherent values respondents ascribe to an activity, whether or not the respondent ever performed or currently performs the activity. Persons with arthritis and healthy controls value major activities in a similar fashion, as indicated in table 2. Social relationships, such as visiting with family and friends, were considered the most important activities for all groups, ranked between 1.6 and 1.7 (with 1 [most important] and 5 [least important]). Shopping and errands done for oneself, family, and friends were ranked next in importance. Of the eight major-activity domains, work and public service activities were ranked least important by all groups. In fact, the importance of social relations is, on the average, ranked two points above the lowest-ranked activity (work or public service). This difference is far larger than between disease group differences (0.50 or less). The importance of the nonwork activity domains to all groups—arthritics

Major activity Household chores Mean losses		Controls	Persons with OA	Controls
Household chores Mean losses	Persons with KA	COLICIONS		
Mean losses				1 9(71)%
	3.8(88)%	1.8(70)%	2.9(85)%	
Shopping and errands				1_0(48)
Mean losses	2.4(66)	1.0(45)	1.9(08)	
Social relations				0 6(52)
Mean losses	0.9(51)	0.6(47)NS	0.8(49)	
Religious activities				0.2(11)NS
Mean losses	(0.4(28))	0.2(12)	0.3(23)	
Leisure and recreation				2 4(75)NS
Mean losses	4.5(89)	2.4(74)	3.0(82)	
Transportation				0 8(53)NS
Mean losses	1.6(73)	0.8(51)	(/ () 1.1	
Public service				0.4(34)NS
Mean losses	0.6(35)	0.4(31)NS	0.7(30)	
Work				0.8(37)NS
Mean losses	1.2(53)	0.4(40)NS	1.0(42)	

TABLE 1

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* Comparisons of RA vs. controls or OA vs. controls are statistically significant (p < .05) unless otherwise noted.

Major activity	Persons with RA	Controls	Persons with OA	Controls
Household chores	2.49	2.29*	2.43	2.29
Shopping and errands	1.80	1.85	1.88	1.84
Social relations	1.64	1.70	1.67	1.70
Religious activities	2.68	3.16*	3.16	3.10
Leisure and recreation	2.65	2.50	2.55	2.52
Transportation	2.39	2.39	2.37	2.40
Public service	3.54	3.41	3.20	3.41
Work	3.33	3.23	3.68	3.31*

TABLE 2 Respondents' Evaluation of the Inherent Importance of Major Activities, 1985

* p < .05. The importance of an activity is ranked on a 1-to-5 scale, with 1 (very important) and 5 (not at all important). Respondents evaluated activities independently of whether or not they performed the activity.

TABLE 3 Respondents' Evaluation of Losses Sustained in Major Activities from 1975 to 1985

Major activity	Persons with RA	Controls	Persons with OA	Controls
Household chores	2.30	2.28	2.44	2.30
Shopping and errands	1.80	1.85	1.89	1.85
Social relations	1.63	1.70	1.67	1.70
Religious activities	2.68	3.16*	3.16	3.10
Leisure and recreation	2.65	2.50	2.56	2.52
Transportation	2.38	2.39	2.34	2.41
Public service	3.54	3.41	3.20	3.41
Work	3.54	3.24	3.65	3.28*

* p < .05. The importance of an activity loss is ranked on a 1-to-5 scale, with 1 (very important respondent is no longer able to perform) and 5 (not at all important respondent is no longer able to perform).

	Controls and rheumatoid arthritics		Controls and osteoarthritics	
Major activity	Without a loss	With a loss	Without a loss	With a loss
Household chores	2.38	2.57	2.33	2.14
Shopping and errands	1.80	1.92	1.83	20.4*
Social relations	1.61	1.76	1.64	1.53*
Religious activities	2.92	2.47*	3.23	3.94*
Leisure and recreation	2.56	2.32	2.49	2.75*
Transportation	2.30	2.02*	2.38	2.40
Public service	3.52	3.75	3.26	3.35
Work	3.34	3.57	3.56	3.54

TABLE 4 The Inherent Evaluation of Major Activities for Respondents with and without Activity Losses

* Those with and without a loss significantly different (p < .05).

The importance of an activity is ranked on a 1-to-5 scale, with 1 (very important) and 5 (not at all important). Respondents evaluated activities independently of whether or not they performed the activity.

and controls—and the lower valuation of work-related activities again argues for more comprehensive measures of the indirect costs of illness than the human capital approach. While costs associated with work losses may be important from a purely economic perspective, losses in social interactions are likely to be more important to individuals.

Table 3 reports the respondents' assessments of the importance of each activity forgone between 1975 and 1985. Respondents were only asked to value losses they had actually sustained. The valuation is ranked on a scale ranging from 1 (respondents are very sorry they are no longer able to participate in the activity) to 5 (respondents are not at all sorry they are no longer able to participate in the activity). Consequently, a lower score indicates a more significant loss to the individual. For example, many respondents were very sorry they were no longer able to shop for themselves, but were not at all sorry they were no longer able to do such home maintenance activities as plumbing or electrical repair.

Respondents' evaluation of the importance of activities forgone (table 3) parallels their evaluation of the inherent importance of activities (table 2). This was true for the persons with rheumatoid and osteoarthritis as well as the healthy controls, and indicates that the inherent values of the individual survive the changes in health. The three groups valued activities forgone similarly, with work and public service activities ranked as least important in all cases. In only two areas were there statistically significant differences between people with arthritis and the healthy controls. Persons with rheumatoid arthritis valued losses in religious activities more highly than controls, and controls valued work losses more highly than osteoarthritics. The latter difference may be an artifact of imperfect age matching (the persons with osteoarthritis were older than the controls on average).

Table 4 again presents respondents' assessment of the inherent importance of activities, but this time stratifies by whether activity losses subsequently occurred. We specified a dummy variable for those persons who experienced one or more loss in each activity domain. We did not distinguish persons with arthritis from controls since tables 2 and 3 confirm that all groups value the activities similarly. The data in the table indicate that the subsequent experience of a loss in an activity does not affect the inherent importance the individual places on an activity. Again, shopping and social relations are consistently ranked highest, and work and public service activities lowest. As in table 2, the difference in ranking between the highest-valued activity (social relations) and the least-valued activities (work and public service) is far larger than the between-group differences.

Overall, the results of the preceding analyses support the stability of the study instruments over time. The post hoc evaluations in table 2, and the subsequent experience of forgone activities does not change the inherent value system (table 4). This is in contrast to willingnessto-pay measures where evaluations are known to change between the time a person is healthy and the time they experience a serious illness. While it is desirable for an instrument measuring value to show no changes in values as health worsens, one would expect values to differ among age groups and between sexes. The measures of value should reflect such differences among people. Table 5 presents respondents' rankings of the inherent important of activities, stratified by age and sex. Men and women differ in the inherent importance they place on household chores, shopping and errands, social relationships, and leisure activities. The difference between the sexes is most striking for social relationships, with women valuing their maintenance much more highly. The three age groups differed in their evaluations of

		Men				Women		:	I	Both sexes	
Major activity	40-54	55-64	65+	All men	40-54	55-64	65 +	All women	40-54	55-64	65+
Household chores***	2.60	2.46	2.82	2.66	2.28	2.19	2.50	2.34	2.35	2.25	2.59
Shopping and errands***	2.03	1.86	1.99	1.97	1.75	1.69	1.92	1.80	1.81	1.73	1.94
Social relations**	2.90	1.75	1.82	1.88	1.60	1.50	1.65	1.59	1.69	1.56	1.70
Keligious activities	3.71	2.82	2.99	3.17	2.94	2.97	2.82	2.90	3.08	2.93	2.87
Leisure and recreation***	2.68	2.76	2.74	2.72	2.48	2.38	2.69	2.53	2.52	2.47	2.70
I ransportation*	2.55	2.36	2.46	2.46	2.28	2.21	2.56	2.36	2.33	2.24	2.55
Public service	3.56	3.42	3.64	3.56	3.25	3.41	3.34	3.32	3.30	3.41	3.43
Work*	3.05	3.03	3.67	3.32	3.23	3.21	3.47	3.49	3.18	3.16	5.89

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* Age significant (p < .05). ** Sex significant (p < .05). The importance of an activity is ranked on a 1-to-5 scale, with 1 (very important) and 5 (not at all important).

the importance of household chores, shopping and errands, leisure activities, transportation, and work. As one would expect the value of work declines dramatically as people approach the normal age of retirement, a reflection of changes in lifestyle.

Discussion

Few methodological issues engender as much controversy as the debate between advocates of the human capital and willingness-to-pay approaches concerning the proper way to value lost function. Although the debate usually turns on issues of method, at root it is an ideological battle. The human capital school attempts to measure the focus of government investment; the willingness-to-pay approach stems from laissez-faire economics. These are different value systems and so it is not surprising that they use different methods to value health, or consequently that results differ.

The human capital and willingness-to-pay approaches do share one essential element. Both try to value health in monetary terms, the former accomplishing this task reliably for one dimension of life, the latter accomplishing this unreliably for all of them. Perhaps someday someone will develop the methods to account for all the indirect costs of illness within a monetary framework. We felt, however, that the prospect of this happening was so remote that a method which summarizes more impacts of illness would be useful, even if value was not translated into dollars. After all, allocation decisions are made each day without reasonable information about the frequency of losses in function or the value individuals place upon those losses.

While our approach is similar to some measures of health status, it differs in two important respects. Most measures of health status, especially those used in the field of chronic illness, emphasize the patient's ability to perform activities of daily living rather than whether the full range of work-related, social, and leisure activities are actually performed (Fries et al. 1982; Meenan et al. 1978). This is more than a semantic distinction. If an individual has the capacity to work but never did, then illness did not cause lower income, and there were no costs in the form of lost productivity. Second, the majority of health status instruments also do not assess changes in an individual's ability to perform activities over time. The questionnaire for this study consists of four sections: one in which respondents report the inherent value they place on activities, one in which they state the activities in which they participated in years gone by, one in which they state the activities in which they currently participate, and one in which they report the value of activities forgone. The interviewer completes each section of 75 activities before moving on to the next group of questions. The survey takes fifteen minutes to complete. We were able to get all respondents to complete the survey, even the control population with whom we had had no previous contact and who were solicited by random-digit dialing.

The survey respondents reported no difficulty in placing values on all the activities of daily life and in doing so in simple qualitative terms. Their responses indicate that health does not affect their values. We can show this in several ways. First, the inherent value system of the healthy controls did not differ from that of the people with either rheumatoid or osteoarthritis (table 2). Second, healthy controls and people with rheumatoid or osteoarthritis did not differ in the values they placed on activities they were forced to forgo (table 3). Third, among those who had experienced a loss in an activity, the value they placed on the forgone activity did not differ from the inherent value they placed on the activity (table 2 compared to table 3). Fourth, the inherent value of activities did not differ between people who never sustained losses in activities and those who did (table 4), but values did vary by age and sex (table 5) as would be expected.

Since our purpose here is to describe the method we developed, we will not dwell on the results except to state the obvious: the respondents to the survey, who were all forty years or older, consider work much less important than maintaining their social contacts and personal relationships and maintaining their capacity to continue shopping, errands, and household chores. This was true whether or not respondents had experienced a loss in an activity domain. All groups of respondents—arthritics and healthy controls—experienced a change in activity levels. Both arthritis groups were significantly more likely to experience losses, however, and have a higher mean number of losses in all activity domains.

We believe that we have accomplished our goal, which is to develop a measure that simply and reliably enumerates changes in activities 1

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and the value individuals place on those activities. Thus, we have in place the elements of a more formal index of the costs of illness. To develop an index more completely, one would need to account for the tradeoff between partial disability in one domain with complete disability in another, and to ensure its applicability for other diseases. Nevertheless, even in its present state, individuals with chronic illness, the physicians who take care of them, and policy makers who allocate resources on their behalf can use information on the prevalence of activity changes and the value of activities to target disease interventions toward activity losses that occur frequently and are of higher values.

We went into this project with the notion that the methods to translate value into money were flawed, but that the goal of using money to value activities was a laudable one. Dollars, after all, are something politicians and policy makers can readily turn into an allocation decision. It is quite possible, however, that the methods are not to blame. Individuals may not value their health in monetary terms and so when asked to do so give inconsistent or meaningless answers. If so, further refinements in the methods of the willingnessto-pay approach would be a waste of time. Activities may be important to people on some internal scale not ever referable to money. Accordingly, asking them to reveal that value system in simple qualitative terms may provide much more accurate measures of value. That may be the implication of our research.

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Acknowledgments: The authors gratefully acknowledge the assistance of John Spencer and Victor Rubin, Ph.D., in carrying out the study. Authorship of this article is alphabetical. This work was supported by grants to the Stanford Arthritis Center and the UCSF Multipurpose Arthritis Center from the NIADDK (grants AM 20610 and AM 20684, respectively); by the Robert Wood Johnson Foundation; and by a Research Career Development Award from the National Institute on Aging (grant KO4 AG273) to Dr. Yelin. The initial draft of this paper was prepared when Dr. Lubeck was at the University of California, San Diego.