Willingness to Pay and Accept Risks to Cure Chronic Disease

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Abstract: Measurements of disease burden focus most often on economic outputs—neglecting effects on quality of life. More comprehensive quantification is based on what people would pay or risk to avoid illness. Many, however, find it difficult to respond thoughtfully to hypothetical questions about what they would pay or risk. With response rates frequently under 50 per cent, the practicality of these methods has been of concern. In this study, specially trained interviewers asked 247 subjects with rheumatoid arthritis how much of their income they would pay and how large a mortal risk they would accept to achieve a hypothetical cure. Ninety-eight per cent of the subjects estimated their maximum acceptable risk (MAR) at an average 27 per cent chance of immediate death. Eighty-four per cent gave plausible responses to the willingness-to-pay (WTP) questions, with a mean WTP of 22 per cent of household income. The aspect of disease most strongly associated with WTP was impairment in activities of daily living; measured pain was most associated with MAR. The response rates achieved indicate the overall feasibility of these methods; the associations of WTP and MAR with other variables suggest systematic consideration of personal circumstances. (*Am J Public Health* 1986; 76:392–396.)

Introduction

As we face increasingly difficult decisions on the allocation of resources to health programs, ways to quantify the burden of disease grow in importance. The most widely used methodology has been the approach of human capital (HC).[1–3] Despite its merits, critics of HC have argued the superiority of the two more comprehensive techniques of willingness to pay (WTP) and the standard gamble (SG)—each, however, with problems of its own.

Human Capital

Economic analysts most often have measured the harm of disease in the units of marketable products: both the goods and services diverted from other uses to the care and treatment of the ill, and the output lost when people die prematurely or are too ill to work. While perception of disease burden in these terms dates back to the seventeenth century,[4] the extensive modern application of HC—culminating in the past decade in hundreds of published studies[5]—began in the 1950s.[6,7] Over the past 20 years, the better HC analyses have combined extensive data collection, technical economic excellence, and multidisciplinary understanding of disease to provide insights into the costs of illness. Shortcomings of HC include inconsistencies across studies in the methods used, inadequate data, market imperfections such as unemployment and discrimination biasing the prices of goods and services, and invidious comparative valuation of persons by their expected earnings. Perhaps the most serious defect, however, is inherent and inescapable. By focusing on economic output, HC intentionally excludes such effects of disease on the quality of life as pain, suffering, anxiety, depression, reduced self-esteem, lower pleasure in leisure pursuits, disruption of marriage, and increased demands and dependence on friends and relatives. The importance of these non-economic effects argues for reliance on more comprehensive methods—such as willingness to pay or standard gamble—as alternatives to human capital.

Willingness to Pay

Benefit-cost analysts have long recommended WTP—the amounts of money people would be willing and able to pay for various possible benefits—to quantify those program results most difficult to value in monetary terms.[8–10] Reseachers have thus used WTP questionnaires to measure such disparate effects as transportation convenience,[11] changes in environmental pollution,[12] and health gains.[13,14] In the spirit of this literature, Goddeeris[15] has argued on the basis of WTP theory that conventional calculations of costs of illness are substantial underestimates. Landefeld and Seskin[16] have similarly shown how adjustments to HC based on WTP concepts can yield more meaningful and accurate measures of disease burden.

From research reviews and discussions of HC and WTP,[5,17,18] points of growing concurrence are emerging even as the debate continues. First, HC and WTP are basically different. Whereas HC deliberately restricts its focus to economic aspects—usually in a retrospective manner—WTP seeks to be comprehensive, most often from a prospective viewpoint. Second, the appealing theoretical completeness of WTP is dimmed by its practical difficulties. Third, HC and WTP share related defects. While HC may unjustly value people by what they earn, WTP is influenced by how much money people have and can afford to pay. The inexactitude introduced in HC by market imperfections possibly based on poor information is matched in WTP by inconsistent or irrational personal judgments. Fourth, it may often be best to use HC and WTP simultaneously, with each shedding light on the other, with HC having the greater precision and serving as a lower bound for the fuller but less exact WTP. Lipscomb[19] describes the pros and cons in having measured WTP guide societal allocations.

WTP has been extensively applied in inferring the value of a human life from what people would pay to reduce their risks of premature death.[14,20–22] Of these studies, the best known and most influential in health research is that of Acton[14] who surveyed several groups to learn how much they would pay for the availability of mobile coronary care units. The mean response was a WTP of $56 for a 0.002 chance that one's life would be saved in the next year, implying a value per life saved of $28,000 ($56/0.002) in the early 1970s. Acton described the problems faced in such detail that Fischer,[23] in a reanalysis, concluded that "well over half of Acton's respondents gave incoherent responses."

Muller and Reutzel[24] mailed WTP questionnaires to 87 university undergraduates enrolled in health services curricula. Eighty-nine per cent returned the questionnaire and of these 87 and 90 per cent responded to two WTP questions. The authors found the responses "reasonable appearing and consistent" but detected no inherent rational patterns. There

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the issue has lain for several years: with widespread acknowledgment of the theoretical importance of WTP but with concern that many persons could not understand the concepts and questions well enough to give reasoned, consistent answers.

Standard Gamble

Subjects respond to SG questions by rating intermediate cases in comparison with lotteries involving better and worse outcomes. Decision analysts[25,26] have shown that theoretically optimal behavior results when outcomes are rated in SG terms, which then are used to maximize expected utility. As with WTP, however, many persons do not give consistent and sensible answers to SG questions. Researchers have identified recurrent patterns of inconsistent and apparently irrational responses.[27,28] Weinstein and Stason[29] recommended SG for determining health status in cost-effectiveness analysis, and Patrick, Bush, and Chen[30] adopted it as a primary method in developing a health status index. Notable applications of the standard gamble have been for decisions on amniocentesis[31] and on laryngeal[32] and lung cancer.[33]

The research reported here followed the lead of previous studies on WTP and SG in health, with modifications. The two central questions left unresolved by Acton[14] and by Muller and Reutzel[24] were addressed: whether WTP methods could achieve high rates of response in general populations and whether those responses would systematically reflect respondent circumstances. In line with the suggestions of Hodgson and Meiners,[5] we contrasted data on WTP and SG with measures of health level, health outlook, function, pain, and depression and with each other. While most other researchers on WTP concentrated on changes in mortal risks, we focused on valuing improvement in health status through relief from chronic disease—a continuation of our earlier work in this vein.[34,35]

Methods

Two hundred forty-seven patients with rheumatoid arthritis enrolled in a randomized controlled drug trial were asked about their willingness to pay money and to incur mortal risk to cure their disease. Specially trained interviewers administered these questions face to face at 14 sites in the United States and Canada at the fifth month of the six-month trial. (Under double-blinded conditions, subjects received either placebo medication or auranofin, an oral disease-modifying agent for rheumatoid arthritis containing gold.) The patients, of whom 73 per cent were female, were between 21 and 66 years of age, had had adult-onset, unremitting disease for at least six months, and had been maintained for at least three months on basic conservative programs including rest and physical therapies as well as salicylates and nonsteroidal anti-inflammatory drugs.

To introduce the questions on WTP and SG, the interviewers urged subjects to think about all the ways their arthritis affected their lives and their families. Subjects were next instructed to assume there was a complete cure for their arthritis, that health insurance would not cover it, and that they and their families would have to pay for it. The interviewers then asked if the subjects would be willing to pay for such a cure at least as much as their current expenses for arthritis care. If so, the subjects were asked:

> What per cent of your family's (i.e., household) total monthly income would you be willing to pay on a regular basis for a complete cure of your arthritis?

The responses were willingness-to-pay expressed as a proportion of income (WTP-PI). Dollar-valued WTP (WTP-$) was obtained by multiplying WTP-PI by household income. Persons willing to increase their current expenditures were asked:

> Now, that would mean that ____ per cent of your monthly income would remain for you to live on. Please think about whether you and your family (i.e., household) could manage to live on this amount of money. How would your family manage to do this?

Subjects might, on reflection, modify their original responses.

Next came a simple form of the standard gamble:

> Now I'd like you to imagine that there is a new, free arthritis medication available. If you take this medication, it will either completely cure you or it will kill you.
>
> Suppose that 50 per cent of the people who take the new medication are cured of their arthritis and 50 per cent die. Would you risk taking the new medication?

Interviewers probed and checked responses by varying the probabilities in 1-per cent steps to identify the maximum acceptable risk (MAR).

Interviewer training included role-playing and practice interviews. Each interview was tape-recorded. To ensure consistency of questioning methods and of response coding, central project staff reviewed all the earlier interview tapes and parts of later interviews.

We treated two types of WTP-PI answers as implausible: any response of zero per cent WTP-PI if the patient had pain and the physician diagnosed disease activity; and any response in excess of 50 per cent. To obtain a set of adjusted, plausible responses, the unwarranted zero-WTP-PI responses were excluded and WTP-PI responses of more than 50 per cent were set at 50 per cent.

In multivariate ordinary least squares regression analyses, the dependent variables were adjusted, plausible WTP-PI and MAR. The 31 independent variables included:

- six demographic: sex, age, marital status, education, number of persons in household, and employment status;
- 10 medical: duration of disease, count of comorbidities, whether any previous surgery, duration of morning stiffness, time until onset of fatigue, 50-foot-walk time, physician evaluation of health status, physician evaluation of disease activity, patient evaluation of health status, and patient estimation of disease activity;
- experimental group (auranofin or placebo);
- 10 nontraditional measures of health status: the Fries Health Assessment Questionnaire (measuring capabilities in activities of daily living),[36] the scores for current health, for prior health, for health outlook, for health worry, and for sickness orientation from the Rand Health Perceptions Questionnaire,[37] the McGill Pain Questionnaire,[38] the Quality of Well-Being scale (designed to estimate the proportion of perfect health achieved),[39] the NIMH Depression Scale,[40] and the Keitel Functional Test (measuring ability to perform 38 tasks involving the extremities and spine);[41]
- four economic: medical costs for the six months of the study (excluding protocol-induced costs), costs of analgesics taken, personal investment income, and total household income.

TABLE 1—Rate of Response, Rate of Plausible Response, and Mean Response to WTP Questions by Amount of Education

Amount of Education	Number of Subjects	Per Cent Answering WTP Questions	Mean WTP-PI Response	Per Cent Giving Plausible WTP-PI Responses	Mean Adjusted Plausible WTP-PI Response
0–8 grades	31	90	20	77	21
Some high school	48	94	22	79	23
High school graduate	98	96	22	87	22
Some college	43	98	20	88	21
College graduate	27	100	25	85	23
TOTAL	247	96	22	84	22

Results

Ninety-six per cent of the subjects answered the WTP questions, and 84 per cent gave answers meeting our criteria for plausibility. Ninety-eight per cent estimated their maximum acceptable risk. Table 1 shows that both the likelihood of response and the likelihood of plausible response to the WTP questions increased with the education of the subject. Stated WTP-PI was relatively constant across different levels of education, with the average subject willing to pay 22 per cent of household income for arthritis cure.

For MAR, rates of response were high for all educational levels and slightly correlated with education (Table 2). In contrast with WTP, stated MAR declined with more education. The overall mean MAR was a 27 per cent chance of death that would be risked to achieve arthritis cure.

Table 3 shows the regressions of WTP-PI and MAR on 31 other variables. WTP-PI rose with younger age, with the time required for the 50-foot walk, with greater handicap as measured by Fries ADL, and with investment income. Higher WTP-PI was more weakly associated with poorer current health, less depression, and lower household income. Stated MAR increased with the six characteristics of being married, longer disease duration, better prior health, pain, investment income, and lower household income; and less markedly with lack of previous surgery, fewer comorbid conditions, not being on auranofin, and greater self-assessed disease.

An illustrative portion of the Fries ADL instrument[36] is ability to climb steps. Table 4 indicates that persons without difficulty in climbing steps would pay roughly 19 per cent of their income, or $5,160 annually, for arthritis cure. WTP-PI rises to 24 and 26 per cent of income for persons with "some" and "moderate" difficulty, and to 35 per cent for those unable to climb steps. MAR, at 20, 31, 31, and 87 per cent for the same groups, is higher than WTP-PI in each group and dramatically higher for the three subjects unable to climb steps.

Pain, as measured by the McGill questionnaire,[38] was associated with MAR but less strongly with WTP. These relationships are shown in Table 5. The 20 subjects without pain stated average WTP-PI of 15 per cent and average MAR of 17 per cent. For the 14 subjects with highest rated pain, these figures rise substantially to 32 per cent of household income or a 49 per cent mortal risk. Persons with higher levels of pain had on average lower household income with the result that the group in greatest pain had highest WTP-PI but lowest WTP-$.

Table 6 shows the relations among WTP, MAR, and annual household income. This income, reported by the subjects, includes all components of household disposable income (such as earnings, transfer payments, and investment return) on a pre-tax basis. Between household income and WTP-PI there is little association. MAR, in contrast, is negatively correlated with income, with an increase of $10,000 in income being associated on average with a decline of 2.8 per cent in MAR, as shown in Table 3.

Discussion

The rate of plausible response to the WTP questions of 84 per cent is substantially higher than those (27 and 45 per cent) reported in earlier studies.[34,35] This difference seems due to improved questionnaire design, to the performance of the interviewers, and to having no subjects older than 66 years. We and other WTP researchers have found that explanatory introductions, question repetition for initially baffled subjects, and opportunity to revise earlier answers—all incorporated in this study—lead to higher rates of thoughtful response.[35] Interviewers using the time tradeoff method (a related measure of health status) in a general population reported a similar response rate of 82 per cent.[42]

Subjects did seem to focus on different aspects of their disease in responding to the two sets of questions. For WTP, the dominant health-related concern was for impairments in activities of daily living; for MAR, it was for pain. It seems that people contemplating paying money for arthritis cure ask themselves how they would improve functionally. In pondering acceptable mortal risks, they are more strongly guided by their current levels of pain.

Earlier research[35] also found increasing likelihood of WTP response with greater education. Uneven response across educational levels should not bias significantly estimated population mean WTP-PI, since stated WTP-PI did not vary systematically with education.

In traditional benefit-cost analysis, aggregate WTP is the criterion for program enactment: justifying a program if and only if the amounts of money people would pay for its enactment exceed the cost. Critics have argued that such an

TABLE 2—Rate of Response, Mean Response, and Standard Deviation for MAR Questions by Amount of Education

Amount of Education	Number of Subjects	Per Cent Answering MAR Questions	Mean Maximum Risk Response	Maximum Risk Standard Deviation
0–8 grades	31	97	38	33
Some high school	48	98	28	25
High school graduate	98	98	24	24
Some college	43	100	28	29
College graduate	27	100	18	20
TOTAL	247	98	27	26

TABLE 3—Results of Regressing Adjusted Plausible Willingness to Pay as a Proportion of Income and Maximum Acceptable Risk on 31 Independent Variables

Independent Variables	Range among Trial Subjects	Coefficient with Adjusted Plausible WTP-PI as Dependent Variable (Standard Error)	Coefficient with MAR as Dependent Variable (Standard Error)
Demographic			
Sex	0 (F)–1 (M)	1.93 (3.6)	−3.2 (5.3)
Age	21–66 years	−0.33 (0.14)	0.17 (0.21)
Marital status	0–1 (now married)	−1.24 (3.5)	9.6 (5.3)
Education	0–36 years	−0.32 (0.40)	−0.37 (0.62)
No. in household	0–8	−0.66 (1.16)	−0.59 (1.77)
Employment status	0–1 (full-time emp.)	1.17 (3.2)	1.36 (4.8)
Medical			
Duration of disease	6–598 months	0.014 (0.015)	0.041 (0.024)
No. comorbidities	0–8	0.55 (0.82)	−2.05 (1.26)
Previous surgery	0 (no)–1 (yes)	1.51 (3.7)	−8.2 (5.9)
Morning stiffness duration	0–1440 minutes	−0.011 (0.010)	−0.011 (0.015)
Time until fatigue	0–16 hours	−0.36 (0.34)	0.20 (0.52)
50-foot walk time	5.6–180 seconds	0.21 (0.12)	0.044 (0.18)
MD-assessed health	5–90 (100 = perfect)	0.025 (0.11)	−0.21 (0.17)
MD-assessed disease	0 (none)–3 (severe)	0.97 (1.49)	−2.1 (2.2)
Self-assessed health	5–91 (100 = perfect)	−0.064 (0.11)	−0.033 (0.17)
Self-assessed disease	0 (none)–3 (severe)	−0.76 (1.46)	2.9 (2.1)
Experimental Group	0 (P)–1 (auranofin)	1.90 (2.7)	−5.4 (4.1)
Health Status			
Fries ADL	0 (no handicap)–2875	0.0071 (0.0031)	−0.0048 (0.0048)
Current health	9 (poor)–45	−0.37 (0.24)	0.36 (0.36)
Prior health	3 (poor)–15	0.31 (0.41)	1.05 (0.62)
Health outlook	5 (poor)–20	−0.28 (0.47)	−0.48 (0.72)
Health worry	4 (high)–20	0.091 (0.43)	−0.34 (0.68)
Sickness orientation	2 (poor)–10	0.43 (0.65)	0.41 (1.00)
McGill Pain	0 (no pain)–63	−0.00084 (0.12)	0.51 (0.19)
Quality of Well-Being	0.44–0.96 (1.0 = perfect)	9.4 (19.9)	−22 (31)
NIMH Depression	0 (no depression)–57	−0.18 (0.12)	0.21 (0.19)
Keitel Function	0 (no handicap)–86	−0.13 (0.12)	0.10 (0.18)
Economic			
Medical costs/6 months	$78–$29,589	0.00016 (0.00044)	0.00031 (0.00070)
Analgesic costs/month	$0–$73	0.0050 (0.076)	0.073 (0.12)
Annual investment income	$0–$95,000	0.0012 (0.0005)	0.00057 (0.00032)
Annual household income	$0–$132,000	−0.00014 (0.00011)	−0.00028 (0.00016)
Intercept		40 (22)	36 (34)

approach would give the rich excessive influence on societal decisions. This criticism is weakened when one focuses on WTP expressed as a percentage of income rather than on nominal dollar amounts. Moreover, WTP-PI among our subjects was not strongly associated with income. MAR did decline with increasing income.

Of the other variables associated with WTP and MAR, many were alternative measures of health. Personal investment income is a proxy for accumulated wealth and its positive association with WTP-PI is understandable. Less clear is why MAR would rise with investment income. That MAR grew with disease duration may be explained by increasing desperation over the course of the disease. The decline of MAR with more comorbidities may owe to less willingness to accept risks to cure one disease if others would remain. While auranofin had positive effect on several measures of health, its negative coefficient in the MAR regression

TABLE 4—Willingness to Pay and Maximum Acceptable Risk by Ability to Climb Steps

Ability to Climb Steps	Number of Subjects	Mean WTP-PI	Mean Adjusted Plausible WTP-PI	Mean Adjusted Plausible WTP-$	Mean Maximum Risk Response
Without any difficulty	107	18	19	$5160	20
With some difficulty	111	25	24	$5835	31
With much difficulty	26	27	26	$4475	31
Unable to do	3	35	35	$7752	87
TOTAL	247	22	22	$5423	27

TABLE 5—Willingness to Pay and Maximum Acceptable Risk by Pain Score

Pain Score*	Number of Subjects	Mean WTP-PI	Mean Adjusted Plausible WTP-PI	Mean Adjusted Plausible WTP-$	Mean Maximum Risk Response
0	20	15	15	$4472	17
1–5	45	18	19	$3803	22
6–10	43	21	22	$5728	20
11–15	41	27	26	$8889	21
16–20	28	16	18	$4273	31
21–30	32	22	23	$4735	37
31–40	23	24	24	$4479	35
41–63	14	34	32	$3660	49
TOTAL	246	22	22	$5286	27

*Pain scores are the sums of weights assigned to the words that subjects chose to describe their pain. If they selected none of the 78 suggested words—ranging from "dull," "tingling," and "tender" to "stabbing," "searing," "killing," and "unbearable"—the score would be zero. Selection of the worst word from each of 20 word groups would yield the maximum possible score of 78.

TABLE 6—Willingness to Pay and Maximum Acceptable Risk by Household Annual Income

Household Annual Income	Number of Subjects	Mean WTP-PI	Mean Adjusted Plausible WTP-PI	Mean Adjusted Plausible WTP-$	Mean Maximum Risk Response
$0–$4,999	33	19	22	$524	26
$5,000–$9,999	22	21	29	$2158	33
$10,000–$14,999	44	24	22	$2740	37
$15,000–$19,999	28	25	22	$3670	29
$20,000–$29,999	44	19	19	$4506	26
$30,000–$39,999	38	20	20	$6786	16
$40,000–$49,999	14	28	28	$11,869	20
$50,000 or more	24	27	25	$16,673	23
TOTAL	247	22	22	$5423	27

suggests improved status not fully captured by those measures. In contrast with previous work,[34,35] WTP among these subjects did not seem definitely related to prior utilization of health services.

Caution is due in interpreting the associations found. Those relating health status to WTP and education to response corroborate previous findings. The other relationships detected here should be considered as subjects for future confirmation.

Much remains to be clarified about willingness to pay and the standard gamble: how to frame questions to focus on the concerns of decision makers; how to ask those questions to obtain reasoned, unbiased responses; how to interpret the resultant data. Even now, however, these techniques can yield useful insights. This study provides evidence for the feasibility of the methods as well as quantified estimates of the seriousness of one chronic disease. Because rheumatoid arthritis does not kill or typically require extensive direct medical costs, comparative economic analyses understate its impact. Our subjects would on average pay 22 per cent of their household income or would accept a mortal risk of 27 per cent to cure their arthritis. Their stated WTP and MAR vary with disease severity and starkly indicate how concerned these patients are with their cruel condition.

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