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What Outcomes Matter to Patients?

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OBJECTIVE: This study estimates the relative value to patients of physical, mental, and social health when making treatment decisions. Despite recommendations to use patient preferences to guide treatment decisions, little is known about how patients value different dimensions of their health status.

DESIGN: Cross-sectional data from quasi-experimental, prospective study.

SETTING: Forty-six primary care clinics in managed care organizations in California, Texas, Minnesota, Maryland, and Colorado.

PATIENTS: Consecutive adult outpatients ($n = 16,689$) visiting primary care providers.

MEASUREMENTS AND MAIN RESULTS: Medical Outcomes Study 12-Item Short Form (SF-12) health-related quality of life and patient preferences for their current health status, as assessed by standard gamble and time trade-off utility methods, were measured. Only 5% of the variance in standard gamble and time trade-off was explained by the SF-12. Within the SF-12, physical health contributes substantially to patient preferences (35%–55% of the relative variance explained); however, patients also place a high value on their mental health (29%–42%) and on social health (16%–23%). The contribution of mental health to preferences is stronger in patients with chronic conditions.

CONCLUSIONS: Patient preferences, which should be driving treatment decisions, are related to mental and social health nearly as much as they are to physical health. Thus, medical practice should strive to balance concerns for all three health domains in making treatment decisions, and health care resources should target medical treatments that improve mental and social health outcomes.

KEY WORDS: patient preferences; cost-effectiveness; health values; physical, mental, and social health.

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For decades, clinicians have been criticized for making treatment decisions that rely too heavily on spectacular advances in medical technology and neglect patients' preferences for their own health-related outcomes. Patients may prefer to maintain a certain tolerable quality of life rather than risk further suffering through high-technology treatments.¹ Such debates are especially salient to managed care practices, in which many are concerned that cost containment results in treatment decisions that often ignore patient preferences. For clinicians, patient preferences should and will remain a central driving force behind treatment decisions, even if there are arguments that policy decisions about resource allocation should be based on general population preferences.^{2–4}

There are concerns that the current practice of medicine fails to incorporate patient preferences, especially the

relative importance that patients place on different dimensions of health. One example of this failure has been found in the development of guidelines. One study of patients with angina found that their tolerance for symptoms varied widely among patients with similar functional limitations (implying similar treatment),⁵ and several authors have argued that clinical practice guidelines that do not consider patients' preferences are undesirable.^{5,6} Other studies showed that physicians are more attuned to disease-specific clinical syndromes and less sensitive to morbidity, pain, and suffering—symptoms that bother patients the most.⁷ Primary care clinicians also appear to underdetect psychological complaints and undertreat common psychiatric disorders,^{8–11} even though mental health problems have strong effects on health-related quality of life (HRQOL) and patient utilities.^{11,12} Finally, some dimensions of health that are important to patients may not even be considered targets for medical treatment by providers. Social health, defined as the ability to develop, maintain, and nurture major social relationships, may be such an example. Although the World Health Organization has included it as part of its definition of health,¹³ clinicians are unlikely to pay much attention to it.

In this study, we analyze the health status and preferences of approximately 17,000 primary care patients to determine what health domains (physical, mental, and social) matter most to them by relating health status measures to patient utilities. Utilities for health states (i.e., patient preferences) measure the trade-off that people make between quality and quantity of life,² a measure different from examining the relative contributions of physical and psychosocial health to overall health ratings.¹⁴

Substantial advances have been made in the past decades in the development of health status measures and the assessment of utilities.^{2,15–17} Although there is a large and burgeoning literature assessing patient preferences,^{17,18} studies of the relation between health status and utilities are somewhat less common. A literature review found 15 publications published until 1993 that included both health status and utility measures.¹⁹ It concluded that there are significant relations among them, although only a modest share of the variation in utilities

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can be explained by health status measures. More recent studies support this conclusion.²⁰⁻²²

Our approach uses ratings from large representative samples of primary care patients, who can be considered the best source of information about the HRQOL associated with their current health states. A similar argument underlies the Beaver Dam Health Outcomes Study, a community-based population study of health status, which has been considered the best available source of data on individuals' preferences for their own health states.^{12,23} The main difference of our study is that we focus on primary care patients, which is the population of central interest to clinicians, rather than community preferences as in the Beaver Dam Study. Also, our sample size is more than 10 times larger and represents a wide range of primary care practices across the country, which increases its generalizability over studies from a single geographic area or single health care site.

Our analyses focus on what kinds of limitations in daily functioning and well-being (i.e., in different health domains) bother primary care patients enough such that they would be willing to accept a treatment with some risk of death in order to have perfect health. The implication for the practice of medicine is that clinicians may want to target treatments to achieve similar improvements in all areas (physical, mental, and social health) for each dollar spent. An exclusive focus on improving physical health could be inefficient because patients could be made better off without increasing overall costs by reallocating resources to psychosocial treatments, social services, or medical treatments that improve mental and social health outcomes.²

METHODS

Study Design

This study uses survey data from Partners in Care, a study of quality improvement in primary care practices, funded by the Agency for Health Care Policy and Research.²⁴ The study approached consecutive adult patients in primary care waiting rooms and asked them to complete a 10-minute survey that screened for common medical conditions and depression. The study was conducted in 46 primary clinics in California, Texas, Minnesota, Maryland, and Colorado. The clinics were drawn from multispecialty group practices, large staff-model or network-model HMOs, and a public health system. Screening occurred for each clinic over a period of 5 to 7 months from June 5, 1996, to March 31, 1997. More than 44,000 patients were approached. Twenty-three percent were ineligible based on being less than 18 years of age, not visiting a health provider that day, or having ineligible insurance. Another 6,600 (15%) refused the survey. Of patients screened, 7,267 (27%) did not complete either utility item and another 1,087 (4%) completed only one utility item (both were at the end of the questionnaire).

Nonresponse rates were higher for the utility items because patients broke off to visit the clinician or leave the clinic. Only English-speaking respondents were included in this analysis because of multiple changes in the Spanish translation of the utility items. In this study, we analyze information from 16,859 primary care patients who completed data on the utility items and had no missing HRQOL items. Patients who did not complete the survey, relative to completers, were more likely to be older (51 vs 45 years of age), female (65% vs 63%), and not working (72% vs 58%). They were less educated (12.0 vs 13.9 years), more likely to be Latino (38% vs 16%), had less depression (24% vs 27%), more chronic disease conditions (1.74 vs 1.42), and worse self-reported health status in general. However, with the exception of working status and Latino ethnicity, these differences are relatively small in magnitude, although statistically significant owing to the large sample size.

Utility Measures

We used two common approaches to assess the value patients placed on health (i.e., utilities): time trade-off (TTO), and standard gamble (SG) methods.²⁵ As there is no consensus on how best to measure utility, and different approaches, including different ways of administering the same method, can lead to different conclusions,^{2,26} we employed both approaches and tested the sensitivity of our results by comparing results from the two methods. We use a self-administered paper-based approach. Although there are advocates of more complex elicitation procedures, a recent study found results of a self-administered paper-based instrument to be reliable, valid, and comparable to those obtained from other assessment techniques.²⁷ A number of preference-weighted health status classifications, such as the Quality of Well-Being Scale, the EuroQOL, and the Health Utilities Index,²⁸⁻³⁰ are suitable for cost-effectiveness analyses. The main advantage of a simple, self-administered, paper-based instrument such as ours is its practicality for large surveys with constraints on respondent burden. An important consideration for the choice of instrument is the goal of the evaluation. If one wants to use utilities for decision making at the individual level, stricter measurement tolerances may be necessary (although there is no agreement on how to achieve better tolerances). For other purposes, such as studying statistically the relation between health status measures and utilities, the precision of measurement at the individual level is less important.

For the SG approach, patients were asked to imagine they had 10 years to live in their current state of health, both physical and mental, and that there was a treatment that could either give them perfect health or kill them immediately. Patients were asked to indicate what chance of success the treatment had to have before they would accept it. Answers ranged from 0% to 100%. Theoretically, patients in perfect health should indicate that the

treatment must have 100% chance of success before they would be willing to take the treatment. Sicker patients should be more willing to take a chance of death with treatment.

For the TTO approach, patients were asked to imagine that there is a treatment that would permit them to live in perfect physical and mental health, but would also reduce their life expectancy. Patients were asked to indicate how many months or years (out of 10) they would be willing to give up for a treatment that would allow them to live in perfect health. Responses ranged from 0 to 120 months.

One-day test-retest reliability on a different sample of 228 patients showed a mean change of 2.04 months for TTO (95% confidence interval [CI], - 4.86, 0.78) and 0.03 percentage points for SG (95% CI -0.007, 0.07). Spearman's correlation coefficient between items at T1 and T2 was .79 for TTO and .69 for SG.

Health Status

We collected information on patient's HRQOL using the Medical Outcomes Study 12-Item Short Form (SF-12), a widely-used self-report measure.³¹ Physical functioning is broadly represented by items asking about limitations in moderate activities, ability to climb several flights of stairs, accomplishing less than one would like, or being limited in the work one could perform owing to physical health, bodily pain, and a rating of health in general.^{16,32-33} Mental health is broadly represented by items asking about feeling calm and peaceful, feeling downhearted and blue, amount of energy, accomplishing less than one would like, or doing work less carefully than usual because of emotional problems. Social functioning is represented by one item asking about degree of interference of health with social activities.

Other Covariates

Chronic Medical Conditions. Patients reported whether they had each of 19 chronic conditions: asthma, high blood sugar or diabetes, hypertension or high blood pressure, arthritis or rheumatism, a physical disability, trouble breathing, cancer diagnosed within the last 3 years, a neurologic condition, stroke or major paralysis, heart failure or congestive heart failure, angina or coronary artery disease, other heart disease, back problems, stomach ulcer, chronic inflamed bowel, thyroid disease, kidney failure, trouble seeing, and migraine headaches.

Depression. High probability of a current depressive disorder was assessed using five "stem" items from the major depression and dysthymia sections of the 12-month World Health Organization's Composite International Diagnostic Instrument, Version 2.1 (CIDI 2.1).³⁴ The positive predictive value of these five items in identifying subjects

with major depressive disorder or dysthymia by the full CIDI is 0.57.

Statistical Approach

To identify the effect of different health dimensions, we regress TTO and SG items on the 12 health items. The relation between patient preferences for treatment (the TTO and SG items) and their current health status, as measured by health domains in the SF-12, indicates the value they place on different health domains. We explored several alternatives, all of which resulted in the same qualitative conclusion. The main results correspond to the following approach: We calculated the relative contribution of each of three health domains to utilities by summing the standardized β values for items in each of the domains and calculating its share of the total. The standardized β values are used instead of the regular regression coefficients because the items have different response choices (ranging from two to six categories).

For sensitivity analysis, we show how results differ for other approaches that reviewers suggested: i.e., using scales instead of individual items; using regression coefficients without standardization; and using R^2 (evaluating the contribution to R^2 of the items in each domain taken as a group). We performed further sensitivity analyses by stratifying the sample by type of disease condition (chronic medical condition, depression and chronic medical condition, or no chronic medical condition or depression) and reran the results to check the possibility that any high utility values for mental or social health are primarily due to depressed patients. The sample for depressed patients only was too small for meaningful comparisons.

RESULTS

The mean age of the sample was 45 years with a range from 18 to 96 years. Thirty-seven percent were male, 69% were white, 4% American Indian, 7% African American, 3% Asian, and 16% Latino. The mean years of education completed was 13.9. Sixty-two percent were married, and 72% were working full-time or part-time.

Among all patients, the average months of life they were willing to give up for perfect health was 7.6 (out of a maximum of 120). They were willing to take a 5.1% chance of death in exchange for perfect health. The majority of patients were not willing to give up any months of life or take any chance of death (69.9%), but this is similar to the percentage rating their health as at least quite good in a visual analogue scale (61% rated it 80 or better on a scale of 0 to 100). As expected (see Table 1), patients with more chronic medical conditions were significantly more willing to give up months of life ($F = 62.42$; $df = 3, 16,577$; $p = .0001$) and to take a chance of death ($F = 84.05$; $df = 3, 16,577$; $p = .0001$) for perfect health.

Table 2 shows the relative contribution of each of three health domains to utilities based on the regressions

Table 1. Number of Months Patients Are Willing to Give up and Chance of Success Treatment Must Have by Disease Condition

Number of Chronic Conditions	Patients, <i>n</i>	Months Willing to Give Up (From Time Trade-off)	Chance of Success Treatment Must Have (From Standard Gamble), %
None	5,611	6.1	96.4
1-2	7,757	6.8	95.1
3-5	2,823	11.2	92.6
6 or more	390	18.4	85.1

of utility, using either the TTO or SG item, on HRQOL as measured by the SF-12. The SF-12 items explained 5% of the variance in TTO and SG responses, consistent with other studies that found small amounts of common variance between utility and HRQOL.¹⁹⁻²² Using TTO, the contribution of physical and mental health to patient preferences for their current health are about the same (35% and 42%, respectively) and significantly larger than the contribution by social functioning (23%) ($F = 16.22$; $df = 1, 16,846$; $p < .0001$ for difference with physical, and $F = 16.97$; $df = 1, 16,846$; $p < .0001$ for difference with mental). Using SG, physical health shows the largest relative contribution to preferences for health (55%), followed by mental health (29%) and social health (16%) ($F = 9.16$; $df = 1, 16,846$; $p < .002$ for physical difference with mental; $F = 54.73$; $df = 1, 16,846$; $p < .0001$ for social difference with physical; and $F = 9.70$; $df = 1, 16,846$; $p < .002$ for social difference with mental).

Table 2 further breaks down the relative contribution of subdomains within physical and mental health to show which contribute the most to patient preferences. These subdomains correspond to each of the eight concepts represented by the SF-12 items.³³ For both the TTO and SG items, perceived health has the largest contribution within the physical domain, while pain contributes rela-

Table 2. Relative Contribution of Health-Related Quality of Life Domains and Subdomains to Patient Values

Health Domain	Contribution to Values as Measured by	
	Time Trade-off, %	Standard Gamble, %
Physical health	35	55
Physical limitations	10	18
Role-physical	6	8
Pain	3	5
Perceived health	16	24
Mental health	42	29
Emotional well-being	26	17
Role-emotional	10	11
Energy	6	1
Social Health	23	16

tively little. The two mental health items (feeling calm and peaceful and feeling downhearted and blue) have the largest contribution within mental health, while energy contributes relatively little.

Table 3 shows that the conclusion that mental health and social health are important to patients is unaffected by how these associations are measured. Whether we use scales instead of individual items as regressors, unstandardized or standardized coefficients, or base the calculation on explained variation, the shares attributed to mental health are very similar. Only when using unstandardized regression coefficients is the share of social health lower than in our main analysis.

The strong relative contribution of mental and social functioning to utilities is not due to depressed patients, whose levels of mental and social functioning are typically low.¹¹ Table 4 shows TTO results when patients were stratified into three groups (no depression or chronic medical condition; chronic medical condition only; and depression and chronic medical condition). Mental and social health are relatively strong contributors to utility for patients with chronic medical conditions only, but mental health is less important for patients without chronic conditions. Standard gamble results do not differ for the stratified groups.

DISCUSSION

Findings suggest that primary care patients in these managed care practices value health consistently with the World Health Organization's 1948 definition. Patients with common medical and psychiatric conditions are willing to trade years of their life to achieve better levels of health in all three domains. As expected, patients with good health in all three domains value their current health and are less willing to risk death with treatment. Although physical health contributes substantially to patient preferences, patients place an equally high value on their mental health. Social health contributes less to patient preferences. Still, 16% to 23% of the relative contribution to patient preferences that we can explain (which

Table 3. Sensitivity to Analytic Approach: Relative Contribution of Health-Related Quality of Life Domains to Patient Values (Time Trade-off)

Approach	Physical Health	Mental Health	Social Health
Based on standardized β values of individual items, %	35	42	23
Using scales instead of items, %	30	40	30
Using regular regression coefficients instead of standardized coefficients, %	41	43	16
Relative variation explained	33	41	26

Table 4. Relative Contribution of Health-Related Quality of Life Domains to Patient Values by Type of Patient Disease Condition

Health Domain	Contribution to Values: Time Trade-off, %		
	No Chronic Conditions	Chronic Medical Only	Depression and Medical
Physical health	58	40	38
Mental health	18	37	34
Social health	24	23	28

is only 5%) is attributable to one's level of social functioning, even after controlling for levels of physical and mental health. These results suggest some discordance between what physicians and patients see as important. Medicine's traditional concern for physical disease is well known.³⁵ Mental health is often a lower priority in primary care with many reports of low levels of detection and treatment, while the centrality of social functioning to the definition of health has been controversial.³⁶

If we follow the implications of current guidelines for evaluating the cost-effectiveness of treatments,² these results suggest that medical practice should strive to balance concerns for all three health domains in making treatment decisions. This conclusion may seem obvious to many primary care physicians who daily observe the social isolation and distress their patients experience; nevertheless it could imply a fundamental reorientation of the goals of medical practice to more fully accommodate treatments or approaches that alleviate psychological distress and social impairments related to underlying health problems, whether "medical" or "psychiatric" in origin. This reorientation is in the opposite direction of many practice trends under cost containment, such as increased patient case loads and limited time and resources for psychosocial and interpersonal care—the "extras." In addition, medicine may not currently view social health as a practice priority or even a relevant target of medical intervention.

Few data exist on how most of the standard and often expensive medical procedures (hospitalizations, diagnostic procedures, surgeries, and medications) affect social or even mental health. There is evidence for the benefits of psychosocial treatments such as counseling for improving psychiatric disorders and psychological distress in primary care and cancer patients,³⁷⁻⁴⁰ and for the benefits of feedback on HRQOL to primary care physicians on improved social functioning among elderly patients.⁴¹ But few textbooks of medicine discuss the social functioning implications of medical illnesses or treatments in any depth.⁴² One of the leading medical textbooks references social health only briefly, with, for example, a one-sentence comment that outcomes are assessed through comprehensive measures of social, mental, and physical health.⁴² But there is no attention to social health as relevant to

treatment. Similarly, a MEDLINE search of titles and abstracts for articles published in *JAMA* and the *New England Journal of Medicine* in 1996 identified only 15 of 1,311 abstracts and 6 of 1,280 abstracts, respectively, containing the terms "social health" or "social functioning." Only one of these was a clinical trial of the effect of treatment on outcomes. Thus, attention to social health appears not to be a primary concern in medical education.

One of the goals of medicine is to relieve suffering in patients undergoing medical treatment. Cassel, in an article on the goals of medicine published nearly 15 years ago, argued that suffering is influenced by a complex interplay between physical and nonphysical factors, including the extent and nature of a sick person's relationships.³⁵ Yet the basic effectiveness data that can be used to guide treatment decisions are not sufficiently comprehensive in terms of ranges of outcomes considered. Although there is some evidence that psychosocial and social health outcomes can be effectively targeted in primary care settings,^{40,41} more research is needed on the social impact of various treatments. Effective or alternative therapies to improve these outcomes need to be identified.

There are a number of limitations to our study. We used a simple method for estimating SG and TTO, for which validity has not yet been fully established. The amount of variance explained by SF-12 items was low, although consistent with other studies which have also shown small amounts of common variance between utility and HRQOL.¹⁹⁻²² Self-reports of HRQOL are subjective judgments that integrate information about health into overall ratings. In contrast, preference assessments may take into account not only one's assessment of current health but also other factors such as ability to cope and the social context in which the person lives. Therefore, it may not be surprising to find that measures of HRQOL explain little of a person's preference for his or her current health state. However, in terms of the relative contribution of health domains to patient preferences, the approach used here does provide information relevant to medical practice.

Specifically, our findings, based on a large representative sample of patients, may serve as a wake-up call to the potential salience to medical practice of a broad definition of health, which could imply changes in outcomes routinely studied, in treatment evaluations, and in treatment priorities, to achieve a balance in alleviating physical, mental, and social suffering of primary care patients. Our findings also support efforts to broaden medical education to include not only the more traditional humanistic goals of alleviating psychological suffering and improving interpersonal care, but also the goal of ameliorating social functioning problems related to health. Future research should replicate these findings, examine alternative management strategies for mental and social health, and explore models of how primary care practices can evaluate the relevant outcomes, track them, and deliver services that optimize them jointly.

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