Racial Differences in Patients' Perceptions of Debilitated Health States

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OBJECTIVE: **To determine health utility scores for specific debilitated health states and to identify whether race or other demographic differences predict significant variation in these utility scores.**

DESIGN: **Utility analysis.**

SETTING: **A community hospital general internal medicine clinic, a private internal medicine practice, and a private pulmonary medicine practice.**

PARTICIPANTS: **Sixty-four consecutive patients aged 50 to 75 years awaiting appointments. In order to participate, patients at the pulmonary clinic had to meet prespecified criteria of breathing impairment.**

MEASUREMENTS: **Individuals' strength of preference concerning specific states of limited physical function as measured by the standard gamble technique.**

MAIN RESULTS: **Mean utility scores used to quantitate limitations in physical function were extremely low. Using a scale for which 0 represented death and 1.0 represented normal health, limitation in activities of daily living was rated 0.19 (95% confidence interval [CI] 0.13, 0.25), tolerance of only bed-to-chair ambulation 0.17 (95% CI 0.11, 0.23), and permanent nursing home placement 0.16 (95% CI 0.10, 0.22). Bivariate analysis identified female gender and African-American race as predictors of higher utility scores ($p \leq .05$). In multiple regression analysis, only race remained statistically significant ($p \leq .02$ for all three outcome variables).**

CONCLUSION: **Comparisons of African-American values with those of whites concerning defined states of debility demonstrate greater than threefold increases in utility scores. This finding suggests that racial differences need to be taken into account when studying the effects of medical interventions on quality of life.**

KEY WORDS: **race; patient perceptions; quality of life; health utility scores.**
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Medical intervention should lead to measurable improvements in quality or duration of life. Torrance, Sackett, and others have suggested that health utility measures, such as the product of quality of life and longevity, can be used to compare the relative values of disparate interventions that affect a variety of health states.[1,2] Specifically, calculations such as the cost per quality-adjusted life year gained from the use of a vaccine, screening test, or therapy could be listed in a quantitative index of effectiveness that would assist health care organizations to prioritize services offered. This index would be a particularly useful guide in planning the distribution of finite medical dollars.

Decision analysis is dependent, at least in part, on the use of health utility measurements to identify preferred approaches to clinical problems.[3–6] If decision models are to be used as a framework from which to establish unbiased patterns of clinical resource use or to formulate fair practice guidelines, then the utility measures woven into these models must either be consistent across all affected patient groups or be so mathematically inconsequential compared with other components of the model that variability in these measures would not alter calculated outcomes.

Currently, it is not known if patient preferences for similar health states, as represented by utility measures, differ according to race or other demographic features. Past reports have noted that patients' attitudes toward nursing home life, end-of-life decisions, dialysis, and self-rated health are influenced by race,[7–11] but it is unclear if the patients assessed in these studies suffered comparable debility. The purpose of this study is to use the standard gamble technique to assign utility scores to states of limited physical function and to identify whether race or other demographic differences predict significant variation in these utility measures.

METHODS

Sixty-four patients aged 50 to 75 years were interviewed between September of 1996 and April of 1997 while they awaited appointments at three sites, the general internal medicine clinic of a community teaching hospital (n = 15), a private internal medicine practice (n = 20), and a pulmonary medicine practice (n = 29). Consecutive patients aged 50 to 75 years were recruited at the internal medicine offices. To be enrolled from the pulmonary practice, patients met the further requirement of an affirmative answer to at least one of the following questions: (1) Do you wear oxygen during any part of the day?

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(2) Have you ever needed a mechanical ventilator to help you breathe? (3) Is your lung disease so severe that you can't walk more than a few steps without experiencing weakness or shortness of breath? (4) When you walk, do you experience shortness of breath that makes you stop or slow down before you've walked 100 yards? (5) Have you been told you suffer from emphysema?

Participating patients were administered a structured questionnaire employing the standard gamble technique. In this technique, the patient is guaranteed an intermediate health state then offered an intervention that can convert the intermediate health state to normal health or immediate death. The patient is asked to express the risk of death that he or she is willing to take in order to avoid the intermediate health state and achieve normal health. The point at which the patient becomes indifferent to the risk of dying compared with living in the intermediate health state conveys a value for that intermediate state. For example, if the patient's choice is ambivalent between taking a 20% risk of dying to achieve normal health as opposed to accepting the certainty of an intermediate health state, then the utility assigned to that intermediate state is 0.8. The higher the risk of death the patient is willing to accept to achieve normal health and avoid the intermediate state, the lower the value that person places on the intermediate state.

The questionnaire was designed to measure the strength of preferences that patients assign to potential outcomes of lung cancer surgery. Standard gamble scenarios were used to describe traditional outcomes after lung surgery such as atelectasis, pneumonia, and prolonged mechanical ventilation,[12–19] as well as specific limitations of physical function. The functional states of interest included mobility limited to bed-to-chair, restrictions of activities of daily living, and mandatory nursing home placement. Visual and verbal cues were provided prior to the questionnaire to define the relation between percentages and risk. The interviewer then read a script of each scenario to the participant (Table 1). The patient, without further prompting, was then allowed to express the risk of immediate death that was acceptable for a therapy that would achieve normal health and abort the guaranteed intermediate state. After the utility assessment portion of the questionnaire was completed, demographic information was obtained including age, gender, race, education, marital status, health insurance coverage, and self-rated health. Level of education was used as a surrogate for socioeconomic status.

Statistical Analysis

Statistical analysis was performed using both SPSS and SAS software. Utility scores were reported as 1.0 for normal health and 0 for death. Standard gamble data were converted to utility scores by subtracting the equilibrium risk between death and the intermediate outcome from 1.0 as described by Torrance et al.[2] and Nord.[20] Descriptive statistics were calculated for each set of utility scores and demographic categories. The standard gamble results were not normally distributed so Mann-Whitney *U* tests were performed to identify bivariate predictors of physical function outcomes. Kruskal-Wallis one-way analysis of variance was substituted if the predictor variable had more than two categories. Nonparametric regression analysis was then performed for each utility outcome with

Table 1. Scenarios Used to Assess Physical Function Outcomes

Limitations in Activities of Daily Living
Imagine that you suffer from a lung illness that causes you to be *so short of breath that you cannot dress, brush your teeth, bathe, or groom without assistance.* This condition will last the rest of your life unless you undergo a corrective treatment. The treatment would return you to health immediately, but there also exists an immediate risk of dying with the treatment. In other words, if you did not take the treatment you would be guaranteed living the rest of your life needing help to complete the tasks of bathing, dressing, and grooming. What percent risk of dying right now would you be willing to take in order to take a treatment that would cure the breathing limitations mentioned and restore breathing and activities to normal?

Bed-to-Chair Ambulation Only
Imagine that you have an illness so severe that sitting in a chair for 5 minutes makes you extremely short of breath and *all you can do is sit periodically then lay in bed the rest of the time.* This *condition is permanent* unless you receive a treatment which, if successful, will cure you immediately. The problem with the treatment is that it could also cause immediate death. In other words if you don't take the treatment you are guaranteed survival but you would be confined to bed with occasional 5 minute breaks in a chair. What percent risk of dying right now would you be willing to take in order to take a treatment and cure your condition to avoid this bed to chair existence?

Permanent Nursing Home Placement
You have a long-term lung disease that has progressed to the point where you or your family are no longer able to care for your physical and health needs at home. *You now live in a nursing home where you will be permanently.* While in the nursing home, you will share a room with another resident and eat meals either in your room or in a communal dining area. Initially you will need the assistance of a wheelchair, but with physical therapy treatments you will eventually walk on your own, but not well enough to return to your home. A treatment is available that will correct your lung problem and allow you to breathe normally and live at home. In other words, if you don't take the treatment, you are guaranteed survival but will be confined to a nursing home the remainder of your life. What percent risk of dying right now would you take in order to go through with the treatment so that you would recover and return to your home?

stepwise variable selection. Demographic data and the presence or absence of pulmonary illness were used as predictor variables. A predictor variable entered an individual regression model if the selection criterion ($\alpha = .05$) was met. The analyses were then repeated allowing for the possibility of two-way interactions of the predictor variables with race to enter the models. Bootstrapping techniques were used, post hoc, to determine the power of detecting a regression slope at $\alpha = .05$.[21]

RESULTS

Of the 64 study participants, 60% were female, 64% were married, and 20% were African American (the remaining 80% were white). The proportion of African Americans did not significantly differ between practices. The average age was 60 years (SD ± 7). Thirty-eight percent of the participants were educated beyond high school, 33% had less than a high school education, and 29% were high school graduates. Only two participants were without health insurance. The rest were evenly divided between private and Medicare coverage. Forty-four percent of patients considered themselves in good health, 20% in poor health, and the remaining 36% regarded their health as fair. All 29 of the pulmonary clinic patients had to report lung-related functional limitation or past mechanical ventilation to be enrolled in the study.

The standard gamble scenarios (0 = death, 1 = normal health) yielded the following mean utility scores: limitations in activities of daily living 0.19 (95% confidence interval [CI] 0.13, 0.25), tolerance of bed-to-chair activity only 0.17 (95% CI 0.11, 0.23), and permanent nursing home placement 0.16 (95% CI 0.10, 0.22).

Utility scores for traditionally reported outcomes of lung surgery including atelectasis 0.80 (95% CI 0.72, 0.88), pneumonia 0.81 (95% CI 0.73, 0.89), and 7 days of mechanical ventilation 0.74 (95% CI 0.65, 0.83) were much higher than those for states of limited physical function.

Bivariate analysis was performed to determine whether demographic differences affected utility scores. Of the demographic factors studied, only female gender and African-American race predicted higher than expected utility scores for states of limited physical function. These characteristics did not affect utility scores derived from the traditional lung surgery outcomes. Findings of the bivariate analysis are summarized in Table 2. Note the greater than threefold differences in utility scores predicted by race. Age, marital status, education, health insurance coverage, self-rated health, and presence of pulmonary illness were not predictive of utility scores in bivariate analyses. Age was analyzed using a Spearman correlation and does not appear in Table 2. In nonparametric multiple regression analyses, only race remained a significant predictor of physical limitation scores (Table 3). This result held true for each of the three outcome variables ($p \leq .02$ for race in each model). None of the interaction variables with race was significant enough to enter any model. Given the sample size of 64 and an α of .05, the bootstrapped estimate of the power to detect variables other than race that would contribute significantly to the explanatory strength of the regression model was greater than 80% for all three outcome variables.

Table 2. Bivariate Analysis of Predictors of Limited Physical Function Expressed as Health Utility Scores with 95% Confidence Intervals (0 = Death, 1 = Normal Health)

Characteristic	Limitiations in Activities of Daily Living	Bed-to-Chair Ambulation Only	Permanent Nursing Home Placement
Race			
African American	0.39 (± 0.18)*	0.39 (± 0.18)*	0.37 (± 0.18)*
White	0.13 (± 0.06)	0.11 (± 0.05)	0.10 (± 0.05)
Marital status			
Married	0.13 (± 0.05)	0.11 (± 0.05)	0.10 (± 0.05)
Single	0.30 (± 0.14)	0.28 (± 0.14)	0.27 (± 0.14)
Gender			
Female	0.25 (± 0.09)*	0.23 (± 0.09)*	0.29 (± 0.09)
Male	0.09 (± 0.06)	0.08 (± 0.05)	0.15 (± 0.06)
Insurance status			
Medicare	0.20 (± 0.11)	0.20 (± 0.11)	0.20 (± 0.11)
Private	0.18 (± 0.08)	0.15 (± 0.07)	0.13 (± 0.07)
Self-rated health			
Fair or less	0.16 (± 0.08)	0.15 (± 0.08)	0.16 (± 0.08)
Good or better	0.22 (± 0.10)	0.20 (± 0.10)	0.16 (± 0.09)
Education			
Less than high school	0.23 (± 0.13)	0.22 (± 0.13)	0.20 (± 0.13)
High school	0.17 (± 0.12)	0.16 (± 0.13)	0.13 (± 0.12)
More than high school	0.17 (± 0.09)	0.13 (± 0.07)	0.14 (± 0.07)

*Statistically significant difference (p < .05) using the Mann-Whitney U test.

Table 3. Nonparametric Regression Analysis of Predictors of Outcomes of Limited Physical Function

Outcome and Predictors	β	Standard Error of β	*p* Value	R^2 of Model	Power,[*]%
Limitations in activities of daily living				.21	81
Intercept	.259	.312	.410		
Age	.0059	.0044	.185		
Level of education	−.0029	.0030	.924		
Race	−.152	.0063	.019[†]		
Marital status	.0512	.0598	.395		
Health insurance	.0195	.0195	.322		
Gender	−.0533	.0503	.294		
Pulmonary illness or not	−.0398	.0536	.461		
Self-rated health	.0060	.0521	.909		
Bed-to-chair ambulation only				.25	83
Intercept	.427	.300	.159		
Age	.0024	.0042	.571		
Level of education	.0011	.0291	.969		
Race	−.197	.060	.002[†]		
Marital status	.0333	.0574	.564		
Health insurance	.0099	.0187	.600		
Gender	−.0362	.0483	.457		
Pulmonary illness or not	.0117	.0515	.820		
Self-rated health	.0492	.0501	.329		
Permanent nursing home placement				.22	85
Intercept	.279	.292	.343		
Age	.0043	.0041	.301		
Level of education	.0190	.0283	.506		
Race	−.1908	.0590	.002[†]		
Marital status	.0351	.0558	.532		
Health insurance	.0076	.0182	.679		
Gender	−.0173	.0470	.715		
Pulmonary illness or not	.0231	.0501	.647		
Self-rated health	.0131	.0487	.789		

[*] *Power to detect an additional 10% variability in outcome due to variables other than race.*

[†] *Statistically significant* ($p \leq .05$).

DISCUSSION

Only a few studies have attempted to differentiate patient perceptions of similar health states based on demographic groupings.[7,8,10,11] Johnson and Wolinsky found that gender was a significant predictor when measuring activities of daily living and that race influenced perceptions of upper body disability. Engle and Graney reported that black female nursing home residents suffered greater limitations in activities of daily living and increased "tired mood" but still scored higher on self-reported health scales than did their white counterparts.[7] Tell et al. demonstrated that black dialysis patients felt more satisfied with their lives than white patients, but the particular regression model used to assess predictors of health-related quality of life did not control for level of physical function.[11]

McKinley et al. recently described the reluctance of black cancer patients to complete living wills and their ready acceptance of life-sustaining therapy compared with a similar group of white cancer patients.[8] Their results were striking because the stage of illness and self-reported health among the black and white patients were nearly identical, suggesting that in situations of physical limitation and terminal illness, African Americans hold preservation of life in higher regard than do whites. Our findings regarding physical limitations were similar, also suggesting that specific ethnic groups can hold markedly different perceptions of health states and that blacks, in particular, may tolerate poorer functional status before downgrading their quality of life.

The Beaver Dam Health Outcomes Study (BDHOS) is a pioneering effort that created a quality-of-life index for many health states.[1] The authors expressed optimism that their data could be used by researchers performing cost-utility analyses as a tool to help establish the relative worth of a variety of preventive and therapeutic strategies. However, although BDHOS included interviews of more than 1,300 subjects, two questions remained unanswered owing to study design. First, the BDHOS participants were an extremely homogeneous group. Could the data obtained, therefore, be generalized to more diverse patient populations? Our data suggest that cultural differences need to be considered before utility scores can be generalized to heterogeneous populations in broad clinical situations. Second, the utility scores presented in BDHOS may have represented an average for patients assigned a specific diagnostic category without accounting for functional variability within that category. For instance, BDHOS patients with emphysema reported a Quality of Well-Being Index score of 0.67, only slightly lower than the 0.70 score reported by migraine sufferers. Would an individual too dyspneic to walk 10 feet perceive his or her quality of life as similar to that of a person afflicted with a migraine? Our data describe low utility scores for limitations of physical function that are unaffected by the presence or absence of pulmonary illness. These findings suggest that specific physical limitations drive utility scores more strongly than the category of illness.

If practice guidelines or health care apportionment schemes are to be derived from decision-analytic models, then the health utility measurements within these models need to reliably represent the specific population for which this medical care is targeted. If, for example, a health system serving a predominantly African American population were to consider a practice guideline for deep venous thrombosis, administrators would most likely refer to the decision analysis published by O'Meara et al.[3] That report compared streptokinase and heparin for treatment of patients with deep venous thrombosis using a utility score of 0.29 for the generic category of central nervous system bleeding. O'Meara et al. concluded that streptokinase is not indicated for the treatment of deep venous thrombosis; therefore, on face value, streptokinase would be eliminated from the hypothetical guideline. However, if the utility measurement for central nervous system bleeding, after specific description of debility, was higher than the reported 0.29, the decision could become a toss-up and the guideline would change. Decision models concerning the treatment of atrial fibrillation[4,5] could also be altered by higher utility scores for states of central nervous system dysfunction. If investigators are aware of the divergence of health utility measurements among populations potentially affected by their models, sensitivity analyses could be planned in advance to account for the appropriate range of patients' values. An alternative would be to abandon group decision models altogether and simply create algorithms for which an individual's preference could be used.

Possible limitations of this study need to be considered, including the small sample size. Although the racial differences in utility measurements for poor physical function were unidirectional and strongly supported in bivariate ($p \leq .02$) as well as multivariate analyses ($p \leq .002$), a study of only 64 patients still poses problems with generalizability. Pending a larger study comparing racial differences in perceptions of poor functional states, investigators should maintain caution in applying the utility scores of one cultural group to calculations pertaining to another group.

Regarding the multiple regression analysis, the ratio of 9 observations per predictor remained within acceptable standards and the power to identify important predictors of utility scores other than race was confirmed by the bootstrap calculations to be adequate.

Another possible limitation would be inconsistency of the standard gamble as a utility metric. One assessment of health utility scores describing patient perceptions of chronic stable angina demonstrated strong test-retest reliability among individuals surveyed with the standard gamble technique at baseline and 2 weeks later.[22] Another finding in the angina study supportive of our results was the variation in utility scores among patients with the same Canadian Cardiovascular Society classification. The authors acknowledge that demographic differences account for part of the variation among patients with similar functional capabilities, but unfortunately, they do not specifically comment on the effect of race. Given the closeness of utility scores for the three outcomes of interest, the validity of the utility instrument could also be questioned. However, the spread between the utilities ascribed to traditionally studied lung surgery outcomes and those pertaining to permanent states of physical debility shows that the instrument can distinguish patient preferences among a variety of health states.

Why might African Americans regard states of terminal illness and limited physical function more highly than similarly affected whites? One potential explanation involves lack of trust in a health care system dominated by providers who are not African American. McKinley et al. explored this issue by administering a trust scale to terminally ill study participants and could not confirm lack of trust as a significant predictor of African Americans' reluctance to establish living wills or forgo life-sustaining treatments.[8] Another possible explanation, religiosity (as measured by weekly church attendance), has been shown to improve life satisfaction,[23] and some data suggest greater religiosity in African Americans compared with white Americans.[24] However, there is no current evidence to support the notion that religiosity exerts a consistent effect on the measurement of health utility scores. In our study, differences in education did not explain the variation in patient preferences toward states of physical disability, and the interaction variable of education and race did not provide explanatory benefit when compared with race alone. These findings are in contrast to those of Thompson, who reported that level of education affected the standard gamble result among patients suffering debility from rheumatoid arthritis.[25] However, Thompson did not attempt to ascertain the statistical significance of educational differences, nor did he control for race in his analysis. Therefore education and, by inference, economic differences are unlikely to account fully for racial differences. Further work needs to be done to explain ethnic differences in patient preferences not only to clarify the measurement of health-related quality of life but also to understand many patients' reluctance to utilize recommended and available health services.

In conclusion, patients assign extremely low quality-of-life ratings to states of limited physical function. However, comparisons of African-American values and those of whites demonstrate greater than a threefold increase in utility scores when comparing similar functional states. These findings suggest that racial differences should be considered when studying the effect of medical interventions on quality of life. To ignore these discrepancies would sanction unintended bias in the formulation of treatment guidelines and health spending priorities derived from such studies.

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