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The effect of age, race and gender on preference scores for hypothetical health states

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Abstract

Purpose: Preferences are known to vary by individuals' personal experience with a health state, but variation among respondents' scoring of the same hypothetical state is unproven but relevant to the use of community-perspective preference scores. This research explored the systematic contribution of respondents' age, race and gender to variability in community perspective preferences for hypothetical health states. *Methods*: Data from four community samples were pooled for the analysis. Linear regression modeling was used to test for the effect of respondent age, race and gender on preference scores while controlling for health state severity. *Results*: In this sample of 956 preference scores from 390 individuals across 4 studies, older respondents provided lower preference scores for the same hypothetical health state compared with younger respondents (regression coefficient for 1 year of age $= -0.002$, $p < 0.001$), and white individuals provided higher preference scores for the same states compared with non-white individuals (regression coefficient $= 0.056$, $p = 0.014$). *Conclusion*: Preferences for hypothetical health states may vary by the age and race of the respondent providing the score. Community-perspective preferences should thus be elicited from large, random samples of the relevant population to ensure variation on these as well as other yet-unidentified characteristics that may affect scores.

Key words: hypothetical health states, preferences, rater age/race/gender, utilities, values

Background

Preference scores are critical inputs to cost-utility and cost-effectiveness analyses. As utilities or approximations thereof,[1] they are the weighting factor in Quality Adjusted Life Years (QALYs), which transform a simple year of life gained by a treatment or intervention to a 'quality-adjusted life year' that accounts for the intrinsic quality of that year of life. QALYs are the outcome measure commonly used economic analyses of health care interventions.

Individual variation in preferences for hypothetical health states has been demonstrated in some studies (e.g., due to personal experience with the state [1] or the respondent's health status [2]). To the extent that it exists, this variability can be cause for concern among researchers considering

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[1] Utility refers to preferences measured using the standard gamble method; preferences measured using other techniques are termed 'values.' This paper refers to preferences elicited using all (or a combination of) techniques as 'preference scores' or simply 'preferences' or 'scores,' those elicited using the standard gamble may also be referred to as 'utilities,' and those elicited with other techniques or under other theoretical assumptions (e.g., prospect theory) may be referred to as 'values.'

community perspective preferences, because it means that the utility or value of a particular state may be a function of the individual from whom the score is elicited. Such variation implies that cost-utility/effectiveness ratios for an intervention could vary depending on whose preferences are used in the analysis [1, 3, 4]. While efforts can be made to compensate for known variability by careful and deliberate choice of respondents for preference surveys [5, p. 103], unknown sources of variability cannot be accounted for and may result in uninformative results [6]. The identification of and distinction between systematic and idiosyncratic variation in preference scores, (meaning that which can be attributed to identified factors and that which is not attributable to such factors), can assist in the interpretation of community samples from which preferences are elicited and hence the validity of the resultant scores.

Societal perspective cost-effectiveness analyses generally use utilities or values for hypothetical (or fixed) health states that are evaluated by a sample of the general population, some of whom have experienced that particular health state and many of whom have not [5]. These community perspective preferences differ from those that are obtained from a 'patient,' an individual currently experiencing a particular disease or condition, which are termed 'patient' or 'experienced' or 'current health' preferences, and measure the quality of life of the individual providing the score [5]. While it is well-accepted that community perspective preferences differ from patient-perspective scores, research has probed other factors that affect preferences for hypothetical health states including personal experience with the state [1, 7–10] and individuals' age and race (e.g., [11–14]). An individual's demographic characteristics could affect his or her reference point, which Prospect Theory would suggest affects perspective and hence valuations of hypothetical health states, similar to the effect of health status on preferences [2, 15–17].

Previous attempts to explore the effect of age, race or gender on preferences have revealed mixed results. Dolan [12] showed that time trade-off values for hypothetical states varied significantly by age, increasing slowly from age 18 to 40, then falling slowly from age 40 to 60, and then falling sharply over age 60. Other studies of this effect are context-specific and less definitive. Some have found age to be the only demographic variable to affect preferences [13], others have found that race affects preferences and quality of life [11, 14], and yet others have found no effect [18, 19]. There is an extensive literature of racial/ethnic differences in treatment preferences [19–21], based on underlying differences in attitudes, belief systems, and trust and confidence in medical providers, among other reasons, which suggests the potential for corresponding differences in preferences based on race/ethnicity. Race was considered of sufficient importance in preferences to ensure representation in a recent estimation of US population values for the EuroQol EQ-5D [22].

The research reported here explored the existence of systematic variation in preferences for hypothetical states based on certain demographic characteristics of the individual supplying the scores. The goal was to answer the question of whether the age, race or gender of individuals who provide community-perspective preferences systematically influences those scores.

Methods

Research design and hypothesis

The study investigated the effect of respondents' age, race and gender on preferences collected from four distinct community samples. These pooled data were used to test the null hypothesis that respondent characteristics have no effect on preference scores for hypothetical health states. The comparison of preferences across health states posed the analytic problem of comparing scores for various health states which were expected to be associated with varying preferences, and attempting to identify non-health state related factors that affected these observed differences in scores. The modeling technique adopted for this research statistically controlled for the severity of the health state itself on the preference scores, allowing us to measure the independent effect of respondent age, race and gender on the scores.

Data sources

Four primary, individual-level data sets were combined into one pooled data set, comprised of community-perspective preferences for hypothetical health states elicited using the standard gamble or time trade off techniques, plus data on respondents' age, race and gender. Preferences for current health were excluded from this analysis because of ambiguity in the definition of the health state to which 'current health' refers (e.g., current health for a patient with diabetes could encompass a wide range of health states, generally unidentified in the data). Also excluded were preference scores based on multiattribute models (e.g., the Health Utilities Index, EuroQol EQ-5D, and Quality of Well Being Scale), since these models rely on weighting factors elicited from a separate sample of community members distinct from those who provide health status information. And finally, values elicited using instruments other than the standard gamble or time trade off (e.g., visual analog scale) were not considered commensurate because of the demonstrated difference in scores achieved through different methods [23], and hence excluded from the analysis. The four datasets were selected based on these inclusion criteria, the variety of health states evaluated, and their accessibility to the researchers. The health states evaluated in these datasets included advanced cancer (n = 100; [2]); breast cancer and cardiovascular risk reduction (n = 92; Weeks, unpublished data); multiple sclerosis and treatments (n = 129; [24]); and endometriosis (n = 69; Araki, unpublished data).

Modeling approach

Ordinary least squares regression modeling was used to explore the relationship between preference scores and respondent age, race and gender. The analytic approach is based on the premise that preferences are expected to vary by the health state they describe, and our interest was in variation above and beyond that contributed by the severity of the underlying health state itself. Hence our analysis statistically controlled for the effect of health state severity on preferences in order to identify the independent effect of our variables of interest, namely respondents' age, race and gender. To do this, we devised a variable that completely eliminated the effect of health state in our model. This variable was the amount by which each individual's preference score for each health state differed from the mean score for that health state across all respondents. Thus, this variable represented not the actual preference score assigned to each health state by each individual, but rather the amount by which each individual's assigned score differed from the group's assigned score (the group mean preference score for each health state). It did not matter to us that the preference scores included in the analysis were different across the various health states in the original studies, but rather the extent to which each individual's assigned score varied from the average, and whether this was due to that individual's age, race or gender. This approach accomplished precisely the same effect that would have been achieved with the inclusion of a dummy variable for each health state included from each original study, but with the loss of fewer degrees of freedom. Our final model therefore predicted 'health state adjusted preference score' (the dependent variable) with three independent variables, respondent age, race, and gender.

It should be noted that our research goal was to elucidate the influence of respondent characteristics on preferences through a model designed to detect statistically significant associations, which may differ from clinically meaningful or policy relevant associations. Clinically significant or minimally important differences can be determined through a variety of methods (including anchor-based and distribution-based methods, using patient and other stakeholder perspectives [25, 26]), yet the general consensus is that such differences are difficult to assess and may be subjective and context dependent [27, 28]. We concur with the position posited by Drummond that in the case of preference scores intended for use in cost effectiveness analyses, the minimally important difference is dependent on the cost associated with any observed change in utility [29]. A very small change in utility at low or no cost might be meaningful, while a large change at high cost might not. Hence we sought evidence of an association between respondent characteristics and preferences to explain a previously unidentified influence on these scores, regardless of magnitude.

Variables

Preference scores were transformed into 'adjusted scores' for the analysis to control for differences in the health states being evaluated. Adjusted scores were calculated as the individual-level reported preference score minus the mean score across individuals for each health state. This ‘health state adjusted preference score’ was the dependent variable in the regression analysis. To minimize the impact of unidentified study-specific factors, three health states were selected from each of the four data sets, the best state, the worst state, and the state closest to the middle in terms of severity (as judged by EW and ND). Independent variables included age, as a continuous variable, adjusted for mean age in each study (by subtracting the mean from each individual’s age) in order to reduce variability and thereby maximize the ability to detect an influence of age on scores. Gender and race were included as dichotomous variables, with race coded as white or non-white in order to maximize statistical power to detect an effect of this characteristic on preference scores (the majority of non-Caucasian individuals were black). Preference elicitation method was controlled for through the health state adjusted preference score variable: while scores elicited using the time trade off method are known to be generally higher than those elicited using the standard gamble, their variation is not known to differ, and the health state adjusted variable measures differences from the mean score which would not be method-dependent. Hence no preference elicitation method variable was included in the analysis. Similarly, the study from which each score originated was accounted for by the health state adjusted variable because the mean scores for each state were subtracted from individual scores, eliminating variation in mean scores across studies (a dummy variable for each study was created and tested in a simple regression model to demonstrate the effectiveness of our method of controlling for study via the health state adjustment variable). All observations with missing data were excluded from the analysis; no data were imputed.

Statistical analysis

Study and respondent characteristics were described using summary statistics (means, medians, ranges). Univariate associations between the dependent and independent variables were tested using simple linear regression. A multivariable linear model was built using stepwise selection (PROC REG, SAS version 9.1 [30]) including all possible independent variables. A first order interaction variable was created between the two variables that constituted the initial model (age and race) and entered into a final model using stepwise selection to test for significance (entry criterion was 0.10, stay criterion was 0.05, so variables entered into model if null hypothesis of effect $= 0.00$ is rejected at the $p < 0.10$ level, and kept in the model if $p < 0.05$.)

Results

The pooled data set contained preferences from 390 individuals in four studies, comprising 975 scores. Three of the four studies contributed preference scores for three health states from each subject; in one study (Prosser data, study ‘C’) each subject valued a subset of the full set of states evaluated in the study, so the 129 subjects provided 194 values across the three states selected for inclusion in this analysis. The descriptions of the 12 health states included in this analysis are presented in Table 1. Mean preference scores for the states ranged from 0.35 to 0.96, and medians from 0.30 to 1.0. The range of scores across individuals evaluating a particular state was generally large: from 0 to 1.0 for 8 of the 12 states, with the smallest range being 0.49–1.0. Every state was scored at 1.0 by at least one respondent (Table 1). Age of respondents ranged from 19 to 89 years, with means across studies ranging from 32 to 61 (Table 2). Ten percent of the pooled sample was non-white, with two of the four studies contributing the majority of these respondents (24% of study ‘C’ and 16% of study ‘D’). Men comprised 22% of the pooled sample, consisting of almost half of study ‘B’ and 35% of study ‘C.’ The time trade-off was used to elicit preferences in study ‘A,’ while the standard gamble was used in the other three studies (Table 2).

Among this sample of preferences from four community studies, scores were significantly associated with respondent age alone at the univariate level ($p = 0.002$). Respondent race approached statistical significance with preferences ($p = 0.13$), and gender was non-significant (Table 3). After adjusting for age in the multivariable model

Table 1. Health state descriptions used in analysis

Source Study, n	Description (verbatim from study)	Mean preference score (sd)	Median preference score	Range of preference scores
A n = 69	You undergo general anesthesia and minor surgery (laparoscopy) that requires 1 day in the hospital, 3–5 days recuperating at home, and 3 visits to the doctor for monitoring. You experience milddiscomfort as well as one surgical complication: either urinary tract injury, bowel injury, orbleeding requiring transfusion.	0.77 (0.24)	0.83	0–1.0
A n = 69	You take an oral medication (Danazol) 4 times a day and visit your doctor 3 times for monitoring over a 6 month period. You experience no side effects from the pill.	0.96 (0.10)	1.0	0.33–1.0
A n = 69	You receive a monthly injection in your doctor's office for 6 months. You experience side effects of hot flashes, and 5% bone density loss.	0.78 (0.22)	0.83	0–1.0
B n = 100	Able to work full-time and manage household. Able to eat, wash, etc., and drive carwithout assistance. Feel well most of time. Have good relationships and receive strong support. Are basically a calm person and look forward to things.	0.94 (0.12)	1.0	0.49–1.0
B n = 100	Need a lot of help to work full time or manage household, or only work part time. Able to eat, wash, etc., and drive car without assistance. Lack energy some of the time. Have good relationships and receive strong support. Are sometimes troubled, anxious and depressed.	0.79 (0.24)	0.88	0.02–1.0
B n = 100	Not able to work in any capacity. Need assistance to eat, wash and drive. Feel ill most of the time. Have good relationships and receive strong support. Are sometimes troubled, anxious and depressed.	0.35 (0.31)	0.30	0–1.0
C n = 64	You can bathe, get dressed and feed yourself without help. You can walk at normal speed but sometimes with a slight limp. You have complete use of your arms and hands. You can see clearly. You can think clearly. You can speak and write clearly. You have numbness in your left foot and hand, and have mild pain which does not prevent you from participating in any of your usual activities.You have full control of bowel and bladder function. You are happy and content most of the time.	0.91 (0.15)	0.99	0.25–1.0
C n = 65	You can bathe, get dressed and feed yourself without help. You can walk by yourself with some difficulty (but without the need for a cane or brace), you have to rest frequently because you become tired.You have complete use of your arms and hands. You can see clearly. You can do most of your usual chores and activities, but tire easily. Your legs are a little weak and rubbery. They feel quite strange, and you are not sure exactly where they are unless you are looking at them. You have to watch where you go carefully, otherwise you may trip. You are free of pain. You are urinating more frequently and but only rarely losing control of your bladder. You feel unhappy occasionally.	0.83 (0.25)	0.93	0–1.0
C n = 65	You cannot bathe, get dressed or feed yourself without assistance. You cannot walk at all; you spend all of you time either in bed or in a wheelchair. You have difficulty with coordination and weakness in your arms and hands. You can see clearly. You can think clearly. You can speak clearly, but find it difficult to write. Both your legs are very weak and your leg coordination is very poor. You cannot work or take care of your family without assistance. You are free of pain. You have poor control of bowel and bladder functions and require frequent catheterization. You feel unhappy most of the time.	0.56 (0.32)	0.56	0–1.0
D n = 92	You have a 20% lifetime risk of breast cancer. You can receive treatment associated with 75% breast cancer risk reduction, and it has side effects.	0.93 (0.18)	0.99	0–1.0
D n = 92	You have a 20% lifetime risk of breast cancer. You can receive treatment associated with 25% breast cancer risk reduction, and it has side effects.	0.92 (0.18)	0.98	0–1.0
D n = 92	You have a 100% risk of getting breast cancer.	0.82 (0.24)	0.92	0–1.0

sd = standard deviation, n = sample size.

Table 2. Characteristics of sample by study and pooled across studies

	A: Araki data	B: Wittenberg data	C: Prosser data	D: Weeks data	Pooled Total
Health states described	Endometriosis and treatment	Advanced cancer	Multiple sclerosis	Breast cancer risk reduction	
Number of respondents	69	100	129	92	390
Age: mean (range)	32 (21–45)	61 (33–85)	38 (19–75)	51 (35–89)	48 (19–89)[a]
White race (%)	97%	100%	76%	84%	90%[b]
Male gender (%)	0%	49%	35%	0%	22%
Preference elicitation method	Time trade off	Standard gamble	Standard gamble	Standard gamble	
Total number of preference scores contributed	207	300	194[c]	274[d]	975[e]

[a] Twelve respondents missing age data (2 from study C and 10 from D).

[b] Seventeen respondents missing race data (1 from study C, 16 from D).

[c] Scores included for 3 states from all respondents except in study C, where each respondent valued only a subset of states.

[d] Two utility scores missing.

[e] A total of 956 utility scores used in regression models due to missing data.

(Table 3), race was significantly associated with preferences, indicating that the race association only became detectable in the data once the variation was reduced by controlling for age. The final multivariable model includes both age and race as significant predictors of preferences, and reveals that scores diminish by 0.02 for every decade increase age (regression coefficient = −0.002/year of age, $p = 0.0004$), and white respondents assess states 0.06 points higher on a utility scale than do non-white respondents (regression coefficient = 0.056, $p = 0.014$). Age and race did not show a synergistic effect (interaction between age and race was non-significant). Gender did not show a significant association with preferences in these data.

Discussion

This paper reports on a study of the effect of respondents' age, race and gender on preferences for hypothetical health states. The research pooled data across studies to enable a larger scale analysis of this topic than has previously been conducted. Our results confirmed previous findings that older individuals attribute lower preference scores to the same hypothetical health states compared with younger individuals. We also provided evidence that preferences vary by the race of the person providing the score. We conclude that researchers should ensure that community samples are representative of the relevant population for the analysis being conducted, to ensure that elicited scores accurately reflect the populations' preferences, and furthermore, that samples are randomly selected from the relevant population to protect against bias from other, unidentified individual characteristics associated with preferences. Our results support recent efforts to elicit country-specific population values for standardized utility tools for application to country-specific analyses [22], and suggest a need to expand such efforts to community preference-elicitation efforts in general to

Table 3. Univariable and multivariable linear regression results (n = 956 preference scores)

Variable	Univariable association			Multivariable model		
	Parameter estimate	Standard error	*p*-value	Parameter estimate	Standard error	*p*-value
Intercept	na	na	na	−0.04	0.022	0.054
Age (centered at mean)	−0.002	0.001	0.002	−0.002	0.001	< 0.001
Race (White = 1)	0.034	0.022	0.127	0.056	0.023	0.014
Gender (male = 1)	−0.16	0.017	0.337	ns	ns	ns
Study (coded as 3 dummy variables)	< 0	< 0	1.0	ns	ns	ns

increase the validity of clinical analyses and policy decisions that are based on preferences. Community perspective preferences elicited from a randomly selected sample of the general population of one society or societal subgroup may not be applicable to another, and hence the use of off-the-shelf values, even those collected with scientific rigor, must be approached with cautious attention to the underlying samples.

Some empirical studies looking specifically at valuation processes have suggested that people think differently about health states depending on their own perspective or outlook on life [1, 15, 31], which could possibly be influenced by their own health, as well as their age and other demographic characteristics [11, 12, 14]). Recent work has revealed differences in preferences between the United States and the United Kingdom, possibly attributable to intrinsic ethnic differences in value [32]. One interpretation of our results could be that people's individual perspectives add a value component to the construct measured by preferences that is independent of the health state to which the preference score applies. In other words, that the same hypothetical health state viewed by two different people may have an intrinsically different value to each person, even after accounting for errors in measurement. Our results suggest that older people value the same health state lower than do younger people, and that white individuals value the same state higher than do non-white individuals. Other researchers using large data sets have found a similar effect of age on preferences for hypothetical states, including Shaw et al. [22] and Dolan and Roberts [33], the latter of whom estimated that values decreased past age 45 at approximately 0.003/year (compared with our finding of 0.002/year).

The literature reports mixed results with regard to the association between preferences and individuals' race and gender. At least two studies have shown that men value the same state higher than women do [22, 33]. Other research has shown that race and gender affect risk perception, which is likely integral to utility assessment using the standard gamble, and possibly less so when using the time trade off (although always an element in hypothetical considerations) [34, 35]. This literature suggests that social experience affects risk perception, while others have shown racial differences in treatment [36] as well as health beliefs [37], all of which may contribute to an explanation of our finding that non-white individuals undervalue health states compared with white individuals.

While our study benefited from the sample size we achieved by pooling data across studies, it had a number of limitations, some of which were due to the nature of secondary analyses. First, while our modeling approach attempted to overcome the health state-specific elements that commonly thwart comparisons across preferences for different states, there were surely variables that affected the preferences that were unavailable to us and hence could not be included in our model. In fact, we looked at only three individual-level characteristics, and others certainly may influence preferences (e.g., marital status [33]). Our results for age, race and gender could be biased by the omission of other variables. Second, our pooled data set contained a limited number of studies, health states, and individuals, and most importantly, limited variation on race and gender across studies, constraining our ability to identify these effects. We have some concerns about the internal and external validity of our finding on race, because we had limited data on race and were forced to impose simplifying assumptions (such as homogeneity of race across non-white groups), and particularly because it has less confirmation in the literature than our finding on age. That result should be considered with caution. Third, the meaningfulness of our results must be considered. While our findings suggest that age and race are significantly associated with preference scores, statistical significance clearly does not dictate clinical or policy significance. We have not determined nor explored the meaning of the associations we detected, but rather suggest that such meaning is dependent upon the context in which preferences are applied to clinical or policy decision making. Depending upon context, a 0.001 difference at no cost (monetary or otherwise) may be meaningful while a 0.10 difference at high cost might not change a decision. Fourth, preference scores are notoriously difficult to assess and may contain measurement and other error (e.g., illogical, inconsistent or protest responses by respondents). Such errors introduce variability into the scores and could adversely affect analyses. And finally, since we looked only at preferences for hypothetical health states, our results are not necessarily generalizable to preferences for current health or experienced states.

In conclusion, our study provides additional evidence that community preferences for hypothetical health states vary by the age of the respondent providing the score, and that respondent race may have an effect on scores. To ensure the greatest validity, community-perspective preferences should be elicited from samples with sufficient representation of the entire age spectrum of the population to which results will be applied. Large, random samples of the relevant population will always be the ideal source for community preferences because they will include variation in all respondent characteristics that may affect scores. History shows that such samples are rarely employed in preference elicitation. Furthermore, preference weights for multi-attribute tools, while drawn from representative samples of particular countries, are not necessarily representative of the population of interest in any particular study in which such tools are employed. Researchers using such tools should be cognizant of (and attention should be drawn to) the population from which preference weights were elicited, and the relevance of such population to their community of interest. At minimum, users of community perspective preferences should report the composition of the sample from which they were elicited, allowing decision makers to assess the validity of the scores and the resultant cost effectiveness ratios. More research is needed on eliciting community preferences specific to the society to which analytic results will be applied.

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