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Valuing Scleroderma Health States: A Picture is Worth a Thousand Words, and Quite a Few Utiles – A Randomized Study

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Abstract

Objective—Assigning utilities to hypothetical health states requires that the health states be described in adequate detail, but there is no agreement on exactly how health states should be described. We assessed utilities from the general public for health states common in scleroderma (SSc) by describing the health states in writing alone vs. with photographs of patients with SSc.

Methods—Subjects rated several SSc health states on a 0-100 rating scale (RS) and completed computer-assisted time tradeoff (TTO, range: 0.0-1.0) and standard gamble (SG, range: 0.0-1.0) utility assessments. Half of the subjects were assigned to be shown photographs of patients with SSc health states in addition to written health state descriptions whereas the other half were given only the written descriptions.

Results—Of the 213 subjects, 133 (62%) were female, 138 (65%) were Caucasian, and 62 (29%) were African-Americans. Median RS, TTO, and SG scores for the 5 SSc health states ranged from 20-70; 0.28-0.94; and 0.50-0.90, respectively. In bivariate analyses, showing pictures was associated with lower RS scores for 2 of 5 health states and lower SG values for all 5 health states ($P < 0.05$ for comparison of pictures vs. no pictures), but with no difference in TTO values. Multivariable analyses revealed negative associations between pictures and SG valuations for the 3 most severe SSc health states (R^2 range: 0.04-0.08).

Conclusion—Adding pictures of people with SSc to written health state descriptions can affect valuations of SSc health states, although the effect differs by valuation measurement method and by health state severity.

Keywords

scleroderma; utility assessment; quality of life; measurement methods

Health values, also known as utilities or preferences, assess the value or desirability of a health state against an external metric(1). Health utilities generally serve as “quality-adjustment factors” for calculating quality-adjusted life years (QALYs) in decision and cost-effectiveness analyses(2;3). Health utilities can be assessed either directly from subjects or indirectly through health status classification systems, which map community-derived utilities onto health states. The U.S. Public Health Service Panel on Cost-Effectiveness in Health and Medicine (4) recommended using utilities derived from the general public, rather than from patients, for cost-effectiveness analyses.

Assigning values to hypothetical health states requires that the health states be described in adequate detail. Written descriptions are probably the most common form of health state descriptions, but there is no agreement on exactly how health states should be described(5). There has been some concern that subjects who provide evaluations of health states do not adequately understand the impact of the conditions. For conditions like scleroderma (SSc)(6), an autoimmune disease involving skin thickening (and in some patients, involving their joints or internal organs), photographs could provide considerable information at least about the cosmetic effects of the disease. To assess the impact of pictures on health state valuation, we randomized subjects from the general population into 2 groups, one that was shown pictures of patients with SSc along with written health state descriptions and one that was only given written descriptions of SSc health states.

Methods

Study subjects

We recruited 217 subjects age 18 years or older from Cincinnati, Ohio through flyers, posters at the University of Cincinnati and local grocery stores, and advertisements in local newspapers. The advertisements called for “relatively healthy” people aged 18-85. As interested subjects phoned in, the coordinator obtained verbal permission to ask simple questions about their health (e.g., Do you have any condition or disability that prevents you from taking care of yourself?). All subjects without a history of an inflammatory arthritis such as SSc, rheumatoid arthritis, or psoriatic arthritis, and with an ability to perform activities of daily living were eligible. Enrollment criteria for the study were deliberately broad in an attempt to capture an overall demographic profile that mirrored the general population. The protocol was approved by the University of Cincinnati Institutional Review Board and all patients provided written informed consent. Subjects received \$30 gift cards for participating.

Questionnaires

Respondents completed a structured interview administered by a trained interviewer. Demographic questions ascertained respondents’ age, sex, ethnicity, marital status, household income, and highest level of education attained. Participants were asked questions about their health status in order to facilitate reflection about their health prior to valuing it. Health status was assessed by using the SF-12(7), a generic health status measure consisting of 12 items assessing 8 domains. The 8 SF-12 subscales can be summarized into a Physical Component Summary (PCS) and a Mental Component Summary (MCS) score. Summary scores have been normalized to the U.S. general population, where the mean score is 50 and the standard deviation is 10. We used version 2 of the SF-12 and a standard (4-week) recall period.

Health values were elicited by using U-Maker, a computer-assisted utility assessment software package(8). Details of the assessment procedure have been published previously(9). Each subject was given a brief description of SSc health states and asked to imagine how it would feel to spend the rest of their life in that health state. We developed a total of 5 SSc health states by using health state attributes from the self-administered version of the Quality of Well Being scale (QWB-SA) (10), a health state classification measure; the QWB-SA includes an exhaustive set of health outcome states and has been used in a variety of studies(11). The 5 SSc health states were: mild SSc, moderate SSc, moderate SSc with lung disease, severe SSc, and severe SSc with lung disease. To limit the work required of each subject, individual subjects were asked to value only 3 of the 5 health states; the number of subjects assessing each health state ranged from 44 to 90. To assess the potential impact of seeing pictures of patients with SSc on SSc health state valuations, half of subjects were randomly assigned in blocks of 4 to be shown pictures of patients with SSc in addition to the written description of health states. The pictures showed skin involvement and were taken from the American College of Rheumatology slide collection (Appendix); we did not show the any pictures or radiographs of lung involvement. Random assignment to the pictures vs. no pictures groups was not concealed and the interviewers were not blinded to the assignment.

Subjects first rated each SSc health state on a health rating scale (RS), which was presented as a “feeling thermometer” with scores ranging from 0 (dead) to 100 (perfect health). Next, participants completed a time tradeoff (TTO) exercise, represented graphically as a choice between 2 horizontal bars, one representing the subject’s life expectancy in current health (followed by death) and the other representing a given number of years (less than or equal to the life expectancy) in perfect health followed by death(8). Based on the age of the subject, U-Maker utilized the life expectancy reported in U.S. life tables(12), rounding the life expectancy to the nearest 5 years. The number of years in perfect health versus current health in SSc was varied in a “bisection” fashion until the subject no longer had a clear preference between living in current health or living the given amount of time in perfect health(13). The TTO score was calculated by dividing the number of years of perfect health at the indifference point by the subject’s life expectancy.

The final utility task was the standard gamble (SG). Subjects were shown 2 circles: one was labeled “current health” and remained the same in all of the gambles; the second circle represented “perfect health.” The subject was offered a choice between living the remainder of their life in the SSc health state vs. taking a gamble in which the 2 outcomes were perfect health for the remainder of life or immediate death(14). To begin, the second circle was displayed as a pie chart with a 100% probability of perfect health. Assuming the subject preferred perfect health in that scenario, the probabilities of perfect health and death in the second circle were then varied systematically by using bisection until the patient was indifferent between the certainty of life in the SSc state of health or the gamble. The SG score was calculated by the following formula: $1 - \text{the maximum acceptable probability of death}$.

Statistical analysis

Descriptive statistics for continuous variables are presented as means and standard deviations for normally distributed variables and as medians and 25th and 75th percentiles for non-normally distributed variables. Categorical variables are presented as frequencies and proportions in a contingency table format. Bivariate analyses for continuous variables were conducted by using either Student’s t-test or the Wilcoxon test; we used chi-square and Fisher’s exact tests for categorical outcomes. Four subjects had inconsistent responses (3 for the SG and 1 for the TTO) in assigning health utilities; i.e., they assigned a lower utility to a less severe health state than to a more severe health state. We excluded those 4 subjects and their responses in the final analyses.

To assess the impact of pictures and subjects' demographics and own health status on valuations of SSc health states, we performed multivariable regression analyses for each of the 5 SSc health states, controlling for age, sex, ethnicity (reference group: Caucasian), income (reference group: <\$25,000/year), education (reference group: ≤high school graduate), marital status (reference group: married), and SF-12 Physical Component Summary (PCS) and Mental Component Summary (MCS) scores. Independent candidates that were significant at $P \leq 0.15$ in the bivariate analyses were entered into final multivariable models. In multivariable models, the independent candidates that were significant at $p < 0.05$ were retained; if there were non-significant predictors in the models, they were removed and models were reanalyzed using the significant predictors (reported in Table 3). All analyses were performed by using STATA software, version 9.2 (College Station, Tex.); $P < 0.05$ was considered indicative of statistical significance.

Results

Subjects' characteristics

The mean (SD) age of the participants (N=213) was 46.0 (12.9) years; 135 (62%) were female, 138 (65%) were Caucasian, and 62 (29%) were African-American (Table 1). Almost all subjects 205 (98%) graduated from high school and 74 (35%) had household incomes exceeding \$50,000 per year.

Health status

The mean (SD) SF-36 PCS score was 51.9 (8.4) and the mean SF-36 MCS score was 48.9 (9.1). For the PCS, the mean score was 0.2 SD greater than U.S. general population mean scores, and for the MCS, it was 0.1 SD below U.S. norms (Table 2). The demographics and the health status of the groups shown pictures were not significantly different from those of the group not shown pictures, with one exception: the percentage of females (70% vs. 55%) was greater in the group not shown pictures ($P=0.03$; Table 1).

Health values for SSc health states

As expected, health ratings and values for SSc health states were inversely related to the severity of the SSc health state. Median (25th, 75th percentile) RS scores ranged from 70 (60, 80) for mild SSc to 20 (13, 35) for severe SSc with lung disease. Median (25th, 75th percentile) TTO scores ranged from 0.84 (0.67, 0.99) for mild SSc to 0.28 (0.12, 0.58) for severe SSc with lung disease, and median (25th, 75th percentile) SG scores ranged from 0.90 (0.75, 0.99) for mild SSc to 0.50 (0.24, 0.73) for severe SSc and severe SSc with lung disease.

Association between pictures and valuation of SSc health states

The effects of the pictures differed by utility assessment method. The RS scores were lower for 4 of the 5 health states among participants who were shown pictures compared with those not shown pictures; 2 of those differences were statistically significant: mild SSc and severe SSc (Table 2). TTO scores were lower for 4 of 5 health states in the pictures group, but none of the differences was statistically significant. By contrast, SG scores were statistically significantly lower for all 5 health states among participants shown pictures of patients with SSc ($P < 0.05$ for Picture vs. No Picture for each health state).

Multivariable analyses revealed statistically significant negative associations between pictures and SG valuations for the 3 most severe SSc health states (R^2 range: 0.04-0.08). For the 3 SG valuations, the group shown pictures gave utilities that were 0.11-0.14 points lower (on a 0.0-1.0 scale) than the group not shown pictures, controlling for other factors. Overall, our multivariable regression models showed that, when controlling for the effect of the pictures,

other covariates explained only a relatively small amount of variability in the utilities associated with the hypothetical SSc health states.

Discussion

The U.S. Public Health Service Panel on Cost-Effectiveness in Health and Medicine (4) recommended using utilities assessed from the general public, rather than from patients with the given condition, for cost-effectiveness analysis. When assessing utilities from people unfamiliar with the given condition(s), it is generally agreed that health states be described in adequate detail. Still, there is no agreement on exactly how health states should be described (5). Torrance provided a detailed description on how to present different health states for a disease to the general public, recommending either a narrative format description, a bullet format description, or a video of a person with the particular health state(1).

Our objective was to assess the impact of pictures of patients with SSc on community preferences for SSc health states. We interviewed 213 participants in a mid-size city in the U.S.; the proportion of African-Americans (298%) in our sample is representative of the city in which the study took place; the proportion of Caucasians (65%) in our sample is representative of the U.S. population in 2006(15); and the health status of our participants was representative of U.S. population norms (16). We randomly assigned participants to view pictures of patients with SSc along with written descriptions of the SSc health states vs. written descriptions alone. The demographics and health status of our 2 groups were equally distributed except for a higher proportion of females in the group not shown pictures (70% vs. 55%, $p=0.03$). In both bivariate and multivariable analysis, we found a negative association between seeing pictures and valuing SSc states, but the effect varied by utility assessment method and by health state severity. Our findings suggest that, on average, subjects shown pictures of SSc rated the most severe SSc state lower (RS method) and were ready to take a greater risk of death to attain perfect health (SG method) – particularly for the most severe SSc states – but were not ready to relinquish more years of life for better quality of life (TTO method). For the 3 SG valuations, the group shown pictures gave utilities that were 0.11-0.14 points lower than the group not shown pictures. Previous studies have found that the minimally important difference in health utilities – the smallest difference in scores that patients perceive as beneficial (17) – ranges from 0.01-0.10 (6;18). The difference in SG scores associated with the pictures in this study exceeds the minimally important difference and is thus clinically meaningful.

Our multivariable regression models showed that, when controlling for the effect of the pictures, other covariates explained a relatively small amount of variability in the utilities associated with the hypothetical SSc health states. Subjects' own health status contributed to the RS ratings that they assigned to SSc health states, but not to TTO or SG values. In contrast, King and colleagues(19) found positive associations between current health and TTO, SG, and willingness-to-pay values, but not RS ratings, for cervical spondylotic myelopathy states. Previous research in patients with scleroderma has shown that demographics and subjects' own health status explain 22%-23% of the variability in TTO and SG scores for their own health, and 66% of the variability in RS scores(20); similar results have been reported in other chronic conditions(21).

The SSc health states with lung involvement were assigned significantly lower SG scores by the group that saw the pictures than by the group that did not see the pictures. This finding is particularly interesting because none of the pictures showed lung disease. Because subjects valued the moderate SSc health state before valuing the same health state with lung disease (the same was true for the severe SSc health states), it is possible that their SG scores for health states with lung disease mostly reflect an order effect, or that their scores mostly reflect the

(visible) skin manifestations of the moderate and severe health states, coupled with a relatively small disutility for the (invisible) lung disease. If that is the case, then our findings suggest that pictures of a disease having features visible to the naked eye may evoke relatively greater disutility than diseases without visible features. On other hand, for RS scores, there were no differences in the median or mean scores in the “picture” group between severe SSc and severe SSc with lung involvement, but there were differences in median and mean scores between these states in the “no picture” group. We speculate that lack of differences in the group that saw the pictures might represent a floor effect – subjects assessed the severe SSc health state as the worst possible state and did not want to assign any further disutility to lung involvement. On the other hand, the group that did not see the pictures assigned a higher utility (having only received a written description of the states) and then assigned an additional disutility for lung involvement.

A limitation of our study is that our power to detect differences between groups in utilities, particularly for mild SSc and severe SSc with lung, was limited. Within those 2 severity levels, the 2 levels with the smallest numbers of observations, a true population effect size of approximately 0.6 would be necessary to afford 80% power to detect a significant difference.

That limitation notwithstanding, if our results can be replicated, then the method for describing unfamiliar health states – with vs. without the use of pictures – could affect QALY calculations for decision analysis and cost-effectiveness analysis, and thereby affect the outcomes of decision analyses and cost-effectiveness analyses. Although we observed an effect of showing pictures, the “correct” method of describing unfamiliar health states remains uncertain. Pictures may evoke different responses, but these responses might reflect biases or discrimination against people with a particular appearance. To wit, a much publicized study (22) recruited African-American and Caucasian actors to portray coronary heart disease states in order to assess physicians’ recommendations for managing chest pain. The authors found that physicians were less likely to refer African-American women for cardiac catheterization than to refer otherwise clinically identical African-American men, Caucasian women, or Caucasian men. In contrast, in another study by Yi and colleagues (23), medical residents watched a digital video in which an actor portrayed a patient with congestive heart failure. Residents were randomized to 2 groups: in one, the patient was described as a 72-year-old veteran of the Korean War, and in the other, he was described only as a 72-year-old male. Health state valuations as assessed by the RS, TTO, SG, and willingness-to-pay methods were similar between the 2 groups, suggesting that residents did not consider military service (admittedly, a different type of descriptor than a picture) when valuing health states.

Thus, some have argued that pictures (and disease labels) should not be used because they evoke racial, gender or appearance biases that researchers and policy makers may want to exclude from consideration. Others believe that pictures (and labels) make ratings more realistic and should be included (5). Our results clarify that pictures do make a difference, particularly with the most severe SSc health states and particularly when using the SG method. In future studies it might be valuable to study a broader range of health states depicted in pictures. Meanwhile, until consensus emerges regarding visual description of health states, comparison of utilities across studies must be mindful of such effects.

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Mild Scleroderma

Severe Scleroderma

Figure.

Table 1

Demographics and Health Status of the Participants, Overall and Stratified by Whether Subjects Were Shown Pictures

	All Subjects (N=213)	Group Shown Pictures (N=107)	Group Not Shown Pictures (N=106)
Mean (SD) age, years	46.0 (12.9)	46.5 (13.3)	45.6 (12.5)
Sex			
Female, N (%)	133 (62)	59 (55)	74 (70)*
Ethnicity			
Caucasian, N (%)	138 (65)	75 (70)	63 (59)
African Americans, N (%)	62 (29)	27 (25)	35 (33)
Others, N (%)	13(6)	5 (5)	8 (8)
Marital Status [†]			
Married, N (%)	94 (44)	52 (49)	42 (40)
Separated, N (%)	10 (5)	5 (5)	5 (5)
Divorced, N (%)	45 (21)	23 (22)	23 (21)
Widowed, N (%)	11 (5)	8 (7)	3 (3)
Single, N (%)	52 (25)	19 (18)	33 (31)
Education [‡]			
Grades 8-11, N (%)	6 (2)	4 (3)	2 (2)
High school graduate, N (%)	42 (20)	22 (21)	20 (19)
Did not complete college, N (%)	70 (33)	37 (35)	33 (32)
College graduate, N (%)	57 (27)	30 (28)	27 (26)
Post graduate, N (%)	36 (17)	14 (13)	22 (21)
Income [‡]			
< \$12,000, N (%)	34 (16)	20 (19)	14 (13)
\$12,000-25,000, N (%)	28 (13)	10 (9)	18 (17)
\$25,000-50,000, N (%)	66 (31)	31 (28)	35 (33)
\$50,000-75,000, N (%)	46 (22)	26 (24)	20 (19)
> \$75,000, N (%)	28 (13)	15 (14)	13 (13)
Prefer not to say, N (%)	10 (5)	5 (5)	5 (5)
Health status			
SF-12 Physical Component Summary, mean (SD)	51.9 (8.4)	52.5 (8.1)	51.6 (8.6)
SF-12 Mental Component Summary, mean (SD)	48.9 (9.1)	48.9 (9.4)	48.9 (8.9)

* P=0.03;

[†] no information on 1 patient;

[‡] no information on 2 patients.

Table 2

Health Value Scores

Mild SSc	N	Median	Picture 25 th , 75 th Percentile	Mean	SD	N	Median	No Picture 25 th , 75 th Percentile	Mean	SD	P-Value*
RS	49	70	60, 80	67.5	13	43	75	65, 83	72.7	17.3	0.04
TTO	49	0.94	0.62, 0.99	0.78	0.26	43	0.94	0.77, 0.99	0.83	0.25	NS
SG	49	0.87	0.66, 0.99	0.76	0.29	43	0.97	0.86, 0.99	0.86	0.22	0.04
Moderate SSc											
RS	84	56	40, 67	54.1	15.5	83	60	45, 70	55.8	16.3	NS
TTO	84	0.77	0.48, 0.91	0.58	0.29	83	0.75	0.50, 0.94	0.69	0.28	NS
SG	84	0.75	0.50, 0.94	0.7	0.28	83	0.87	0.66, 0.99	0.78	0.25	0.04
Moderate SSc with lung involvement											
RS	89	50	32, 60	44.6	15.9	84	50	40, 60	46.3	15.3	NS
TTO	89	0.60	0.37, 0.84	0.57	0.3	84	0.66	0.38, 0.88	0.61	0.29	NS
SG	89	0.70	0.45, 0.88	0.63	0.29	84	0.80	0.50, 0.94	0.74	0.26	0.02
Severe SSc											
RS	57	20	10, 40	26.7	15.8	61	30	20, 40	32.4	16.3	0.04
TTO	57	0.30	0.06, 0.50	0.34	0.28	61	0.35	0.13, 0.63	0.4	0.3	NS
SG	57	0.50	0.20, 0.67	0.43	0.29	61	0.52	0.25, 0.85	0.56	0.32	0.03
Severe SSc with lung involvement											
RS	43	20	10, 40	26.3	17.6	45	25	15, 30	24.5	12.8	NS
TTO	43	0.25	0.06, 0.47	0.31	0.29	45	0.38	0.13, 0.63	0.41	0.32	NS
SG	43	0.47	0.09, 0.69	0.44	0.33	45	0.56	0.44, 0.80	0.58	0.30	0.04

SSc, scleroderma; SD, standard deviation; RS, rating scale (0-100); TTO, time tradeoff (0.0-1.0); SG, standard gamble (0.0-1.0).

* P-value is for Picture vs. No Picture for each health state and is based on the Wilcoxon rank-sum test.

Table 3

Multivariable Regression Models of Health Values for Scleroderma Health States^{*}

	Age	Sex [†]	Unadjusted regression coefficients	Income [‡]	MCS	PCS	Picture	Model R ²	P value [#]
RS									
Mild SSs					0.43 ^{**}		-3.7	0.07	0.04
Moderate SSs					0.36 ^{**}		-1.3	0.05	0.02
Moderate SSs with lung involvement					0.28 ^{**}		-1.6	0.03	0.09
Severe SSs						0.43 ^{**}	-5.0	0.07	0.01
Severe SSs with lung involvement			-8.8 ^{**}				-1.8	0.05	0.10
TTO									
Mild SSs							-0.04	0.007	0.4
Moderate SSs							-0.02	0.0007	0.7
Moderate SSs with lung involvement							-0.04	0.003	0.4
Severe SSs							-0.06	0.01	0.2
Severe SSs with lung involvement							-0.1	0.03	0.13
SG									
Mild SSs		-0.18 ^{**}					-0.08	0.15	0.005
Moderate SSs		-0.11 ^{**}					-0.06	0.06	0.005
Moderate SSs with lung involvement							-0.11 ^{**}	0.04	0.01
Severe SSs							-0.13 ^{**}	0.07	0.01
Severe SSs with lung involvement							-0.14 ^{**}	0.08	0.04

^{*} The independent variables listed were significant in the multivariable analyses.

MCS, SF-12 Mental Component Summary (0-100); PCS, SF-12 Physical Component Summary (0-100); RS, rating scale (0-100); TTO, time tradeoff (0.0-1.0); SG, standard gamble (0.0-1.0).

^{**} P < 0.05.

[†] Reference: Females.

[‡] Reference: Caucasian

[¶] Reference: ≤High-school graduates.

[‡] Reference: ≤ \$ 25,000

[#] P-value is based on the overall model F-test.