Health-Related Quality of Life in Patients With Pulmonary Arterial Hypertension*

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Study objectives: Patients with pulmonary arterial hypertension (PAH) often present with dyspnea and severe functional limitations, but their health-related quality of life (HRQOL) has not been studied extensively. This study describes HRQOL in a cohort of patients with PAH.

Design: Cross-sectional study.

Setting: A tertiary care, university hospital-based, pulmonary hypertension (PH) clinic.

Participants: We studied HRQOL in 53 patients with PAH (mean age, 47 years; median duration of disease, 559 days). Eighty-three percent were women, 53% received epoprostenol, and 72% reported moderate-to-severe functional limitations with a New York Heart Association class 3 or 4 at enrollment.

Measurements and results: We examined HRQOL by administering the Nottingham Health Profile, Congestive Heart Failure Questionnaire, and Hospital Anxiety and Depression Scale. We used the Visual Analog Scale and standard gamble (SG) techniques to measure preferences for current health (utilities). Compared with population norms, participants reported moderate-to-severe impairment in multiple domains of HRQOL, including physical mobility, emotional reaction, pain, energy, sleep, and social isolation. Mean SG utilities were 0.71, suggesting that, on average, participants were willing to accept a 29% risk of death in order to be cured of PH.

Conclusions: PAH is a devastating condition that affects predominately young women in the prime of their life. Understanding HRQOL and preferences are important in the care and management of these patients. Compared with population norms, patients with PAH have substantial functional and emotional limitations that adversely affect their HRQOL.

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Key words: attitude to health; epoprostenol; health status; hypertension; pulmonary; quality of life

Abbreviations: CHQ = Congestive Heart Failure Questionnaire; HRQOL = health-related quality of life; HADS = Hospital Anxiety and Depression Scale; mPAP = mean pulmonary artery pressure; NYHA = New York Heart Association; NHP = Nottingham Health Profile; PPH = primary pulmonary hypertension; PAH = pulmonary arterial hypertension; PH = pulmonary hypertension; 6MWT = 6-min walk test; SG = standard gamble; VAS = Visual Analog Scale

Pulmonary hypertension (PH) is a progressive disorder of the pulmonary vasculature characterized by sustained elevations of pulmonary arterial pressure, right-sided heart failure, progressive dyspnea, and profound functional limitations. Primary PH (PPH) is clinically indistinguishable from PH related to collagen vascular diseases, HIV infection, liver disease, drugs (eg, anorexigens), and toxins. Although underlying disease mechanisms have not been completely elucidated, these conditions are classified as pulmonary arterial hypertension (PAH)

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by a World Health Organization consensus symposium because of their shared clinical and histopathologic features.1

In the 1980s, the median survival of patients with PPH was 2.8 years from the time of diagnosis.2 Since then, several medical and surgical advances have led to improved survival in patients with PPH. Epoprostenol, a short-acting vasodilator, is the most potent of existing medical therapies. Randomized controlled trials3,4 have shown that epoprostenol improves exercise capacity and pulmonary hemodynamics, and prolongs survival in patients with PAH. However, the drug and delivery system have many adverse effects that may limit its tolerability in some patients.5,6

There is limited information about quality of life in patients with PAH in the literature.3 Factors that may lead to impaired quality of life include dyspnea, functional limitations, adverse effects of therapy, social isolation, and emotional issues such as anxiety and depression. While therapies for PAH improve pulmonary hemodynamics and exercise capacity, they may or may not have a positive impact on functional status and quality of life, which must be evaluated independently. Health-related quality of life (HRQOL) refers to an individual’s satisfaction with the physical, social, and psychological domains of life, insofar as they affect or are affected by health.7,8 In addition to health status, individual differences in perceptions and expectations may lead to differences in HRQOL. HRQOL is an important consideration in the treatment of diseases such as PAH, in which the prognosis is typically poor and available therapies are associated with many adverse effects.

In this cross-sectional study, we aimed to describe HRQOL in a cohort of patients with PAH. We hypothesized that compared with population norms, patients with PAH would report impaired HRQOL in multiple domains. Additionally, in a secondary analysis of nonrandomly assigned treatment groups, we compared HRQOL in patients with PAH who were and were not receiving treatment with epoprostenol.

Materials and Methods

We enrolled consecutive adult patients with PPH or PH related to anorexigen or scleroderma spectrum of disease, who were seen at the Stanford University Medical Center PH clinic between July 1, 2001, and April 30, 2002. We included English-speaking patients with a grade 8 or higher education. We excluded all patients who did not provide consent.

We reviewed the medical records to obtain information about demographic characteristics, symptoms, pulmonary hemodynamic measurements, and treatments received. We recorded echocardiography and 6-min walk test (6MWT) results obtained within 3 months of the interview. The interviewer determined the New York Heart Association (NYHA) class assignment at the time of questionnaire completion.

We used three previously validated questionnaires: the Nottingham Health Profile (NHP),9,10 the Congestive Heart Failure Questionnaire (CHQ),11,12 and the Hospital Anxiety and Depression Scale (HADS).13–15 and two methods for eliciting utilities to describe HRQOL in our study population.

The NHP, a generic measure of HRQOL, is a self-administered questionnaire that consists of 38 items in six domains, including physical mobility, pain, sleep, social isolation, emotional reactions, and energy. The scores in each domain range from 0 (best health) to 100 (worst health).16 Since many symptoms of PH are related to right-sided heart failure, we also administered the CHQ, a disease-specific questionnaire that was developed to study patients with congestive heart failure.17 This interview-based, 20-item questionnaire has four subscales that measure dyspnea, fatigue, emotional function, and mastery. For each subscale, scores range from 1 (worst) to 7 (best).18 The final questionnaire, the HADS, is a self-administered scale designed to screen for anxiety and depression.18 We chose the HADS because it focuses on psychological symptoms rather than somatic symptoms, which makes it particularly useful for studying depression and anxiety in patients with medical illness.19

Utilities are preference-based global measures of HRQOL, often used to value health outcomes in economic analyses. We measured utilities by using U-Titer,20 a standard utility elicitation software program designed to be adaptable to a specific research question. We used both the Visual Analog Scale (VAS) and the standard gamble (SG) techniques to determine utilities for each patient’s current health state. Utility scores, using either technique, range from 0 (death) to 1 (ideal health).20–24 For the VAS, we asked participants to rate their current health by placing a mark on a horizontal scale with death at one end and ideal health at the other. The SG technique determines the maximum risk a person is willing to accept in order to achieve perfect health. Individuals who do not highly value their current state of health might be willing to accept a greater risk to obtain perfect health, and will have lower utility scores. We offered participants a hypothetical choice between remaining in their current state of health for the remainder of their lives, or taking a gamble with a probability (p) of achieving ideal health but a risk (1 − p) of painless and immediate death (refer to Appendix).21 The probabilities of this gamble were varied until participants expressed indifference in choosing the gamble or the current health state. The probability at this indifference point defines the SG utility score for that patient.13,21–24 We used the ping-pong method as an indifference search procedure.20 Ideal health was described as the “best health imaginable” for the rest of the patient’s natural life.

Data Analysis

We reported means and SDs to describe continuous variables that were normally distributed. For data that were not normally distributed, we reported medians and interquartile ranges. We used frequencies to describe categorical data. We expressed the results of the NHP questionnaire as a percentage of the population norm (with the value of the norm set at 100%), and defined the population norm as the average score in a group of 35- to 49-year-old women with no major health complaints.26 To compare NHP results with population norms, we tested whether the distribution of scores was different from a uniform distribution with a value of 100% by using the Wilcoxon matched-pairs signed-rank test, as has been described previously in a study.27 We compared NHP results with population norms, we tested whether the distribution of scores was different from a uniform distribution with a value of 100% by using the Wilcoxon matched-pairs signed-rank test, as has been described previously in a study.27 We compared HRQOL in adults with cystic fibrosis. We used the Mann-Whitney U test to compare differences in HRQOL domains and
utilities between the epoprostenol and no-epoprostenol groups, and the \(^2x^2\) test statistic or Fisher exact test to compare categorical variables. We used analysis of covariance to adjust mean utilities for observed differences between the groups. We accepted a two-tailed \(p\) value \(\leq 0.05\) as statistically significant for all analyses. We analyzed data using SPSS for Windows, version 10.0 statistical software package (SPSS; Chicago, IL). The Stanford University Administrative Panel on Human Subjects in Medical Research approved the protocol, and all participants signed a written informed consent prior to enrollment.

### Results

**Characteristics of Study Participants**

We enrolled 53 participants (Table 1) with a mean age of 47 years, the majority of whom were women (83%). Seventy-four percent were married, and 60% had some college education. Fifty-one percent of participants were white. Eleven percent reported using anorexigens at some time prior to receiving...
their diagnosis. Twenty-one percent of subjects had concomitant thyroid disease and 17% had mild liver disease at the time of the interview. PH related to scleroderma spectrum of disease was seen in 13% of the study population. Dyspnea was a presenting symptom in all participants. In addition, 43% reported dizziness, 41% had chest pain, and 39% noted fatigue on initial presentation. The mean pulmonary artery pressure (mPAP) for all participants was 57 mm Hg. At the time of the interview, the median duration of disease was 559 days, with 72% of the study population reporting functional limitations with a NYHA class 3 or 4 designation and 51% receiving oxygen.

At enrollment, 28 participants (53%) were receiving epoprostenol and 25 participants (47%) were not receiving epoprostenol (Table 1). The median duration of epoprostenol therapy was 397 days, and the mean dose was 32 ng/kg/min. The two groups were similar in age, marital status, education, ethnicity, prior anorexigen use, frequency of liver disease, asthma, sleep apnea, scleroderma, cancer, diabetes, and oxygen use. Thyroid disease (both hypothyroidism and hyperthyroidism) was seen more commonly in participants treated with epoprostenol (p = 0.03). Participants receiving epoprostenol had a longer duration of disease (738 days vs 336 days, p = 0.002), while the no-epoprostenol group included a higher proportion of people with NYHA class 4 functional status at the time of interview (36% vs 11%, p = 0.05). The 6MWT results were similar for both groups. mPAPs were also similar for both groups. Right ventricular systolic pressure, as measured by echocardiography, was higher in the epoprostenol group (79 vs 66), although this difference was not statistically significant (p = 0.1).

**HRQOL Questionnaire Measurements**

Participants reported impairment in all NHP domains (Table 2), including energy (median, 67; range, 0 to 100), emotional reaction (median, 22; range, 0 to 89), pain (median, 13; range, 0 to 100), physical mobility (median, 38; range, 0 to 88), sleep (median, 20; range, 0 to 100), and social isolation (median, 20; range, 0 to 100). Compared with population norms (Table 3), scores were significantly lower in all domains, and the degree of impairment was moderate to severe. Although the data were not normally distributed, we report means in Table 3 to allow comparison with mean population norms reported in the literature.

Participants showed moderate impairment in all CHQ domains (Table 2), including dyspnea (median, 4; range, 1 to 7), fatigue (median, 4; range, 1 to 7), emotional function (median, 4; range, 2 to 7), and mastery (median, 5; range, 2 to 7). Median scores on the HADS anxiety and depression subscales were at the upper limit of the normal range as described by the questionnaire developers. Moderate or severe levels of anxiety and depression were reported by 20.5% and 7.5% of participants, respectively.

<table>
<thead>
<tr>
<th>Table 2—HRQOL Domains*</th>
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<table>
<thead>
<tr>
<th>Domains</th>
<th>All Patients (n = 53)</th>
<th>Epoprostenol (n = 28)</th>
<th>No Epoprostenol (n = 25)</th>
<th>p Value †</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHP†‡</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Energy</td>
<td>67 (83)</td>
<td>33 (100)</td>
<td>67 (42)</td>
<td>0.03</td>
</tr>
<tr>
<td>Emotional reaction</td>
<td>22 (44)</td>
<td>11 (33)</td>
<td>44 (36)</td>
<td>0.005</td>
</tr>
<tr>
<td>Pain</td>
<td>13 (38)</td>
<td>13 (25)</td>
<td>13 (41)</td>
<td>0.6</td>
</tr>
<tr>
<td>Physical mobility</td>
<td>38 (36)</td>
<td>38 (38)</td>
<td>38 (41)</td>
<td>0.5</td>
</tr>
<tr>
<td>Sleep</td>
<td>20 (60)</td>
<td>20 (40)</td>
<td>40 (80)</td>
<td>0.3</td>
</tr>
<tr>
<td>Social isolation</td>
<td>20 (40)</td>
<td>0 (40)</td>
<td>20 (25)</td>
<td>0.06</td>
</tr>
<tr>
<td>CHQ‡§</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dyspnea</td>
<td>4 (1)</td>
<td>4 (1)</td>
<td>4 (2)</td>
<td>0.1</td>
</tr>
<tr>
<td>Fatigue</td>
<td>4 (2)</td>
<td>4 (2)</td>
<td>3 (1)</td>
<td>0.01</td>
</tr>
<tr>
<td>Emotional function</td>
<td>4 (2)</td>
<td>5 (2)</td>
<td>4 (2)</td>
<td>0.003</td>
</tr>
<tr>
<td>Mastery</td>
<td>5 (3)</td>
<td>6 (1)</td>
<td>4 (3)</td>
<td>0.002</td>
</tr>
<tr>
<td>HADS</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>7 (6)</td>
<td>6 (5)</td>
<td>9 (4)</td>
<td>0.02</td>
</tr>
<tr>
<td>Depression</td>
<td>6 (6)</td>
<td>5 (5)</td>
<td>8 (4)</td>
<td>0.003</td>
</tr>
</tbody>
</table>

*Data are presented as median (interquartile range); numbers are rounded to the nearest whole number.
†Lower scores represent better results; scores range from 0–100.
‡One person in the epoprostenol group refused to complete the NHP due to time constraints and, one person in the no-epoprostenol group did not complete the CHQ interview.
§Higher scores represent better results; scores range from 1–7.
||Lower scores represent better results: 0–7, normal; 8–10, mild; 11–14, moderate; 15–21, severe.
¶Comparison between epoprostenol and no-epoprostenol groups, Mann-Whitney U statistic.
Utilities

For all participants, the mean utility score obtained by using the SG technique (0.71; 95% confidence interval, 0.64 to 0.78) was higher than the mean VAS score (0.58; 95% confidence interval, 0.54 to 0.62). The value of the mean SG score suggests that participants were willing to accept a 29% risk of death in order to achieve perfect health.

Secondary Analysis: Epoprostenol and No-Epoprostenol Subgroups

Patients treated with epoprostenol and those not receiving epoprostenol were similar in their responses to items in the pain, physical mobility, and sleep domains of the NHP. However, the participants who received epoprostenol reported more energy (median score, 33 vs 67; p = 0.03) and were better off emotionally (median score, 11 vs 44; p = 0.005).

On the CHQ, patients who received epoprostenol were less fatigued (median score, 4 vs 3; p = 0.01), had less emotional distress (median score, 5 vs 4; p = 0.003), and greater feelings of control over their disease (median score, 6 vs 4; p = 0.002). Although the two groups reported similar symptoms of dyspnea, participants who did not receive epoprostenol were more likely to report dyspnea with less strenuous activities of daily living such as bathing, dressing, going for a walk, and making a bed. For patients not receiving epoprostenol, there was a trend toward more difficulty with walking uphill and up stairs, which did not reach statistical significance. None of the patients had participated in demanding physical activities such as sports, running, vacuuming and moving furniture during the 2-week period prior to the study, highlighting the functional limitations experienced by most patients with PAH. As measured by the HADS, the no-epoprostenol group had significantly more anxiety (median score, 9 vs 6; p = 0.02) and depression (median score, 8 vs 5; p = 0.003), compared with the epoprostenol group.

We compared utilities in the two groups by using analysis of covariance (Table 4). The unadjusted mean SG utility for patients receiving epoprostenol was not significantly different from the mean value obtained for the no-epoprostenol group (0.75 vs 0.67, p = 0.4). The VAS technique also yielded utilities that did not differ between the two groups (0.59 vs 0.55, p = 0.5). There was no statistically significant difference between the two groups after adjustment for age, duration of disease, NYHA class, and treatment assignment.

Discussion

In this cross-sectional study, we aimed to describe the HRQOL of patients with PAH including those receiving epoprostenol and those not receiving the drug. Participants were predominately white women with significant functional limitations (NYHA class 3 and 4) and a diagnosis of PH for a median of 559 days. They reported distress in multiple HRQOL domains, although their anxiety and depression scores were within the range of normal responses.

In a focus group of patients with PH, many identified anxiety, sadness, low self esteem, decreased social interactions, increased dependence on family members, and feelings of loss of control as important contributors to their overall quality of life (S. Shafazand, MD; unpublished data; August 2001). These themes were reflected in the responses to the emotional distress domains of our HRQOL questionnaires, in which patients with PH scored worse than population norms.

Table 3—NHP Domains and Population Norms*

<table>
<thead>
<tr>
<th>Domains</th>
<th>All PH</th>
<th>Norms†</th>
<th>p Value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Energy</td>
<td>55 (40)</td>
<td>16</td>
<td>0.001</td>
</tr>
<tr>
<td>Emotional reaction</td>
<td>27 (25)</td>
<td>12</td>
<td>0.002</td>
</tr>
<tr>
<td>Pain</td>
<td>21 (28)</td>
<td>6</td>
<td>0.001</td>
</tr>
<tr>
<td>Physical mobility</td>
<td>37 (23)</td>
<td>3</td>
<td>0.001</td>
</tr>
<tr>
<td>Sleep</td>
<td>35 (33)</td>
<td>15</td>
<td>0.001</td>
</tr>
<tr>
<td>Social isolation</td>
<td>25 (27)</td>
<td>5</td>
<td>0.001</td>
</tr>
</tbody>
</table>

*Data are presented as mean (SD), with lower scores represent better results; scores range from 0–100.
†Women aged 35 to 49 years with no major health complaints.26

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Table 4—Adjusted Utilities*

<table>
<thead>
<tr>
<th>Utilities</th>
<th>All Patients</th>
<th>Epoprostenol†</th>
<th>No Epoprostenol</th>
<th>p Value‡</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adjusted SG</td>
<td>0.71 (0.64–0.78)</td>
<td>0.72 (0.61–0.82)</td>
<td>[n = 25]</td>
<td>0.71 (0.61–0.81)</td>
</tr>
<tr>
<td>Adjusted VAS</td>
<td>0.58 (0.54–0.62)</td>
<td>0.60 (0.54–0.66)</td>
<td>[n = 26]</td>
<td>0.56 (0.50–0.62)</td>
</tr>
</tbody>
</table>

*Data are presented as mean (95% confidence interval).
†Utility SG score is missing for one patient in the epoprostenol group who had difficulty understanding probabilities despite explanations during the practice session; duration of disease missing for two people in the epoprostenol group.
‡Comparison between epoprostenol and no-epoprostenol groups.
§Analysis of covariance technique; adjusted for age, duration of disease, NYHA class, and treatment assignment.
The NHP has been used to study HRQOL in various patient populations. Not surprisingly, our patients reported greater distress in all NHP domains compared with population norms. More strikingly, participants receiving epoprostenol appeared to have more distress in all NHP domains than a heterogeneous group of patients 3 months following combined heart and lung transplantation, suggesting the considerable impact of PAH on HRQOL even in patients who are receiving the most effective medical therapy. CHQ results obtained in this study are comparable to previously obtained responses of patients with NYHA class III and IV congestive heart failure.

This is the first study to measure utilities for patients with PAH. Utilities provide a global measure of HRQOL while incorporating patient values and preferences. They are often used in cost-effectiveness analyses of health-care treatments to determine quality-adjusted life-years. In our population, SG utilities were higher than utilities elicited by the VAS technique. This pattern is consistent with previous findings and may be due to the fact that people are, in general, risk averse. Individuals who are risk averse are less willing to accept a given risk of death, and therefore value current health more highly.

Findings from other studies of patient preferences help to place our results in context. Mean utilities were 0.71 in our study, 0.70 in a study of patients with first recurrence of breast cancer, 0.80 in patients following lung transplantation, and 0.60 in a heterogeneous group of patients with NYHA class III and IV congestive heart failure.

Important limitations of this study are its cross-sectional design and small sample size. In our comparison of patients who did and did not receive epoprostenol, nonrandom treatment assignment created groups that likely differed in ways that were both observable and unobservable. Another potential limitation is that some individuals may have difficulty understanding the SG elicitation procedure. In an effort to reduce this problem, we enrolled people with a minimum grade 8 education. Practice sessions were included in the computerized interview to familiarize subjects with the elicitation procedure and concept of proportions.

Despite severe PH at clinical presentation, longer duration of illness, and adverse effects associated with therapy, participants receiving epoprostenol described more energy, less fatigue, less emotional distress, less anxiety or depression, and greater control over their disease when compared with the no-epoprostenol group. The two groups reported similar degrees of dyspnea but differed in the activities that led to dyspnea; patients not receiving epoprostenol were more likely to report dyspnea with less demanding activities of daily living. This cross-sectional study was not designed to compare symptoms before and after treatment. Participants receiving epoprostenol may have been more dyspneic than the no-epoprostenol group prior to the initiation of epoprostenol, and may have improved with treatment.

Scores for emotional distress were consistently better for patients in the epoprostenol group. While this may be due to the impact of the medication itself, it is more likely a combination of drug effect and several other factors. The patients receiving epoprostenol had a longer duration of disease at the time of study. Irrespective of treatment, patients with longer duration of disease have had more time to understand their disease, accept their functional limitations, develop coping strategies, and build an adequate social support system. This likely contributes to the relative emotional well-being of the patients receiving epoprostenol. Additionally, due to the complex drug delivery system, patients who receive epoprostenol have more interactions with physicians and nurses; this added attention may lead to a better understanding of the disease and feelings of improved control and mastery. Finally, patients who receive epoprostenol may in part be selected because of their ability to cope with the challenges of such therapy. Differences in coping strategies, although not studied here, may accentuate the positive impact of the drug on symptoms and emotional well-being. Results from the secondary analysis reported above, while intriguing, are exploratory in nature, and longitudinal studies that assess HRQOL and utilities in patients prior to and after starting epoprostenol are needed to confirm our findings.

PAH is a devastating condition that affects predominately young women in the prime of their life. Understanding HRQOL and preferences is important in the care and management of these patients. The results of this study are in keeping with a 12-week randomized trial of epoprostenol therapy, in which HRQOL outcomes were secondary end points. In their study, Barst et al showed that for the majority of patients who completed the HRQOL questionnaires, there was improvement in all CHQ domains and two of six NHP domains after 12 weeks of epoprostenol therapy. There are no longitudinal data available to suggest whether these differences in HRQOL are persistent beyond the 12 weeks of therapy.

In a recent, 12-week, randomized, placebo-controlled study of sitaxsentan therapy for patients with PAH, Barst et al demonstrated an improvement in 6MWT, pulmonary vascular resistance, and NYHA functional class in patients receiving sitaxsentan compared with placebo. However, there were no
significant differences between the groups in quality-of-life assessment. This lack of difference highlights the fact that HRQOL measurements provide a unique assessment of an individual’s satisfaction with and perception of the physical, social, and psychological domains of life, insofar as they are affected by health. While therapies for PAH improve pulmonary hemodynamics and exercise capacity, they may or may not have a positive impact on functional status and quality of life.

Our patients with PH, who had a longer duration of illness than participants in the aforementioned trials, reported impairment in all HRQOL domains. Patients treated with epoprostenol described more energy and less emotional distress than patients who did not receive this therapy. Nevertheless, compared with population norms, they continued to have substantial functional and emotional limitations that adversely affected their HRQOL.

APPENDIX

The VAS is a linear scale with death at one end and ideal health at the other end. On a computer screen, the subjects were asked to rate their current health by clicking between these two points. The line was calibrated to enable the program to calculate a score between 0 and 1 based on the position of the marker.

The goal of the SG technique is to determine the maximum risk a person is willing to accept in order to avoid remaining in his/her current health state. The worse the health state, the higher the risk a person is willing to accept and the lower the measured utility. The SG technique offers subjects a hypothetical choice between remaining in the chronic health state (certain outcome) for the remainder of their lives, or taking a gamble that may result in either ideal health for a specified time period (probability, p) or lead to painless and immediate death (probability, 1 − p). The probabilities of this gamble are varied until the subject expresses indifference in choosing the gamble or the current health state. This indifference point is the utility score for that health state, which varies between 0 (death) and 1 (perfect health). The SG utility is grounded in von Neumann Morgenstern utility theory. SG utilities may be applied as measures of value of outcome health states in decision analysis and as quality-weighting factors for quality-adjusted life-years.

In our study, the computerized session began with an assessment of the patient’s functional status as defined by the NYHA classification system. This was followed by a practice session asking participants to rank their health on a VAS while imagining being totally blind in both eyes; patient preferences for total blindness were also elicited using the SG technique. The practice session was designed to familiarize participants with both techniques and the concept of probabilities. During the practice session, the interviewer assisted participants as needed. Once participants were comfortable with both techniques, the computer ended the practice session and asked participants to consider their “current health” and rank their overall HRQOL on the analog scale. This was followed by a determination of their current health preferences using the SG technique. The interviewer had minimal involvement in this phase of the questionnaire, only assisting with any computer-related “technical” difficulties that arose.

The question posed for the SG technique was as follows:

We want you to think about your current health in terms of risk.

On the next screen, you will get a choice. You can live the rest of your life with your current health, including any health troubles you have right now, or you could receive a magic treatment. If the treatment works, you will live the rest of your life in ideal health. The treatment is free, but there is a chance that it could kill you. Note that if the treatment works, you do not live any longer, just better.

Think about what you might risk to have ideal health for the rest of your life.

In our study, ideal health was described as the “best health” imaginable for the rest of the patient’s natural life. We further defined ideal health as a state of excellent mental and physical health, for which there would be no problems with any of the following activities: walking, lifting, bending, thinking, talking, hearing, and seeing. We described death as painless and immediate.

On a subsequent screen, the participants were presented with three choices:

Choice A: Take the treatment with (p) probability (eg, 99%) of living with ideal health for the rest of your life and accept a (1 − p) probability (eg, 1%) of dying painlessly today.

Choice B: Live With your current health for the rest of your life.

Choice C: Choices A and B are about the same to me.

Probability p and 1 − p were varied until the participant picked choice C, the point of indifference. This indifference point was the utility score for the participant’s “current health state” and ranged between 0 (death) and 1 (perfect health).

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