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Patient and community preferences for treatments and health states in multiple sclerosis

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Objective: *To examine preferences for treatments and health states for patients with relapsing-remitting MS and members of the community.* **Methods:** *A survey was developed to evaluate health-related quality-of-life measures (utilities) for three treatments and six MS health states using a utility-elicitation software package, U-Titer II. Sixty-two MS patients at two large teaching hospitals in Boston, MA, and 67 members of the general community in San Diego, CA, completed the health-related quality-of-life survey using a computer.* **Results:** *Assessment of quality of life decreased as disability level of MS health states increased for both respondent groups. Respondents rated less-disabled health states relatively highly (>0.94 for patients and >0.89 for community respondents). Quality-of-life measures for treatments in mean utilities ranged from 0.80 to 0.96. Patients assigned higher utilities for both MS health states and treatment states than community respondents; the ratings became more disparate as health states worsened.* **Conclusions:** *On average, respondents assigned utilities to currently available treatments for MS that are comparable to those of mild to moderate stages of the disease itself. These results underscore the importance of including preferences for health states and treatment alternatives in the decision to initiate treatment for individual patients or in the evaluation of effectiveness or cost-effectiveness of these treatments in patients with MS.*
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Introduction

Multiple sclerosis (MS) is an immune-mediated demyelinating disease of the central nervous system characterized by bouts of neurologic symptoms (or relapses) and often increasing disability.[1] Although MS patients can experience significant increases in disability over a lifetime, those with relapsing–remitting MS can usually expect to experience little decrease in life expectancy, and require ongoing long-term treatment.[2–4] However, treatments which have recently become available for MS are not benign and have been characterized by substantial discontinuation rates.[5–9] Therefore, comparing the quality-of-life benefits provided by available treatments to the decrease in quality of life they cause is an important area for study. Only then can the medical community assess the value and cost-effectiveness of preventive and therapeutic interventions for MS.

Evaluating health-related quality of life is especially important for a chronic disease such as MS. In addition to discomfort caused by specific clinical symptoms, MS diminishes quality of life through the reduction of social interaction and recreational activities, limitation on educational or vocational attainment, loss of employment and economic status, and decreased satisfaction with life.[10] Family life can also deteriorate as the patient is less able to maintain employment, drive, walk, perform activities of daily living, and maintain roles as parent or spouse.[10,11] Therefore, health-related quality-of-life scores may represent a more meaningful measure of the impact of chronic illness than disability rating scales.[12]

Health-related quality of life can be measured using either health status measures or preference measures, with each category providing different information. Health status measures summarize the presence, absence, severity, frequency, and/or duration of specific symptoms, impairment, or disabilities. Examples of health status measures used in MS include the MSQOL-54,[12] the Functional Assessment of Multiple Sclerosis (FAMS),[13] and the Multiple Sclerosis Quality-of-life Inventory (MSQLI).[14] These measures provide information on several domains of health-related quality-of-life important to patients with MS, such as ambulation, pain and depression. In contrast, preference-based measures provide a summary value for a respondent's valuation of the quality of life of a particular health state, incorporating all positive and negative aspects of a health state into a single number. Typically this number is scaled between 1.0, representing perfect health, and 0.0, representing a health state judged equivalent to being dead. Preference-based

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measures do not typically provide separate information on individual domains of quality of life, although they may be elicited by describing health states in terms of multiple domains.[15,16] Economic evaluations require the use of a preference-based measure of health states to correctly value changes in health.[17,18,22]

There is debate regarding whose preferences should be used in economic evaluations. Some argue that patients are best suited to valuing health states related to their disease since they have directly experienced the health states. Others argue that preferences of a community-based sample are the more appropriate choice for economic evaluations to be used in policy decisions as they more closely reflect societal preferences. Current recommendations for cost-effectiveness studies from the US Public Health Service Panel on Cost-effectiveness in Health and Medicine favor community-based, rather than patient-based, preferences for evaluations intended to inform resource allocation decisions.[21] In this study, we collected both patient and community preferences.

The primary goal of this study was to collect preference data on health-related quality of life for different levels of MS disability and three immunomodulatory treatments. We were interested in measuring the loss in quality of life due to MS-related disability as well as the loss in quality of life associated with MS treatments because of the high discontinuation rates. A secondary goal was to compare utilities between patients and community respondents. The data reported here can be used to value the benefits and costs associated with the currently available treatments.[19–23]

Methods

Study sample

The study sample consisted of two convenience samples: 1) 62 patients diagnosed with relapsing-remitting MS, and 2) 67 members of the general public. Sixty-two patients attending doctor's visits at either the Massachusetts General Hospital or Brigham & Women's Hospital in Boston, MA during June–October 1999 completed the MS Utility Survey. Procedures for patients were approved by the Brigham and Women's Hospital/Dana-Farber Cancer Institute/Massachusetts General Hospital Human Subjects Research Committee. The community sample consisted of 67 residents of a large apartment complex in San Diego, CA, who participated over a three-month period. Procedures for community members were approved by the Harvard Pilgrim Health Care Human Subjects Committee.

Survey protocol

The MS Utility Survey was designed to collect data on health state preferences. The background section included questions on sociodemographic variables, treatment history (for patients only), and current health (self-reported EDSS level; Likert scale with choice of Excellent, Very Good, Good, Fair, Poor). The health state evaluation section asked participants to evaluate three out of six MS health states, one out of three treatment health states, and the respondent's current health state. To ensure a high level of participation, we did not ask each participant to evaluate all health and treatment states.

The survey was computer-administered on a Mac Powerbook using U-Titer II preference assessment software.[24] Respondents completed the survey on the computer. The lead author was available to answer respondent questions during all surveys. No respondents refused based on method of administration. Three of the patient respondents required assistance in completing the survey due to physical limitations. Computer-administration was preferred to face-to-face interviews to minimize the possibility of interviewer bias and for ease of data collection.

MS health state descriptions used 10 attributes of health identified as important to patients with MS based on a literature review of quality-of-life assessments for MS patients and discussions with neurologists specializing in MS. Two additional attributes, sexual dysfunction and social functioning, were also identified as MS-specific attributes but not included in the final survey descriptions to keep the length of the health state description manageable for the respondent.*

The health state descriptions represent hypothetical MS patients both with and without relapses and span the Expanded Disability Status Scale (EDSS).[25] The EDSS is the disability scale most commonly used in clinical trials to measure disease progression in MS.[7–9] It ranks patients on a scale from 0 (normal) to 10 (death from MS), and emphasizes ambulation at intermediate EDSS levels. The six MS health states ranged from 2.5 to 8 on the EDSS scale representing patients with mild disability, or experiencing a mild relapse, to patients with severe disability, or essentially restricted to bed (Table 1). While there is evidence in the literature to suggest that people may place different values on temporary versus chronic health states,[26] for this study, respondents were asked to assume that the health state lasted for the remainder of their lives to improve respondent comprehension.

Health-related quality of life was measured using the standard gamble, a widely-used preference-based measure for health outcomes.[20,27] Utilities for individual health states were measured on a scale from zero to one, where zero represents death and one represents perfect health.[17] All other possible states of health were valued between zero and one, allowing for a valuation of the relative difference between health states.

The standard-gamble method is considered to be the 'gold standard' for measuring utilities.[17] In a typical standard-gamble question, the respondent is asked to make a choice between remaining in a described health state for a specified length of time or undertaking a

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*Social functioning was not considered to be an independent domain of health-related quality of life, but rather the result of impairments in other domains of health-related quality of life, and therefore appropriate to exclude from the health-state descriptions. The omission of of sexual function from the health state descriptions is a limitation, but is consistent with descriptions based on the EDSS.

Table 1 Descriptions of MS health states for utility assessment (bold type indicates health problems)

Health State 1 (EDSS 2.5):

- 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 can do most of your usual chores and activities without unusual fatigue.
- **You have numbness in your left foot and hand. You also have mild pain which does not prevent you from participating in any of your usual activities.**
- You have full control of bowel and bladder functions.
- You are happy or content most of the time.

Health State 2 (EDSS 2.5):

- You can bathe, get dressed and feed yourself without help.
- You can walk at normal speed.
- **You have blurred vision accompanied by eye pain. You can read with some difficulty.**
- You have complete use of your arms and hands.
- You can think clearly.
- You can speak and write clearly.
- You can do most of your usual chores and activities without unusual fatigue.
- **You have mild pain which does not prevent you from participating in any of your usual activities.**
- You have full control of bowel and bladder functions.
- You are happy or content most of the time.

Health State 3 (EDSS: 3.5):

- You can bathe, get dressed and feed yourself without help.
- **You are walking a little more slowly than usual; you have a little bit of weakness in one leg, resulting in a slight limp.**
- **You are experiencing weakness in your non-writing hand.**
- You can see clearly.
- You can think clearly.
- You can speak and write clearly.
- **You can do most of your usual chores and activities, but tire easily.**
- **Your weaker leg is a little numb from the thigh down, but you are free of pain.**
- You have full control of bowel and bladder functions.
- You are happy or content most of the time.

Health State 4 (EDSS: 5.0):

- 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 think clearly.
- You can speak and write 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.**

Health State 5 (EDSS: 6.0):

- **You can bathe and get dressed with some minor assistance. You can feed yourself with some difficulty.**
- **You walk with difficulty due to poor strength and poor coordination in both your legs. You need a cane at all times to move around safely.**
- **You have pretty good use of your arms and hands, except for some mild incoordination.**
- **You are experiencing double vision. You have difficulty seeing and reading. The double vision is uncomfortable and can give you headaches.**
- You can think clearly.
- **You can write reasonably well. You have a very slight slurring of your speech.**
- **You can do most of your chores and activities, but tire easily.**
- **You are free of pain, but experience some discomfort from vertigo, numbness and tingling. You have numbness and tingling in one of your legs. You are also experiencing vertigo. (Vertigo can feel similar to the motion sickness you might feel on a boat.)**
- You have full control of bowel and bladder functions.
- You are happy or content most of the time.

Health State 6 (EDSS: 8.0):

- **You cannot bathe, get dressed or feed yourself without assistance**
- **You cannot walk at all; you spend all of your time either in bed or in a wheelchair.**

Table 1 (*continued*)

- **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 co-ordination is very poor. You can not 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.**

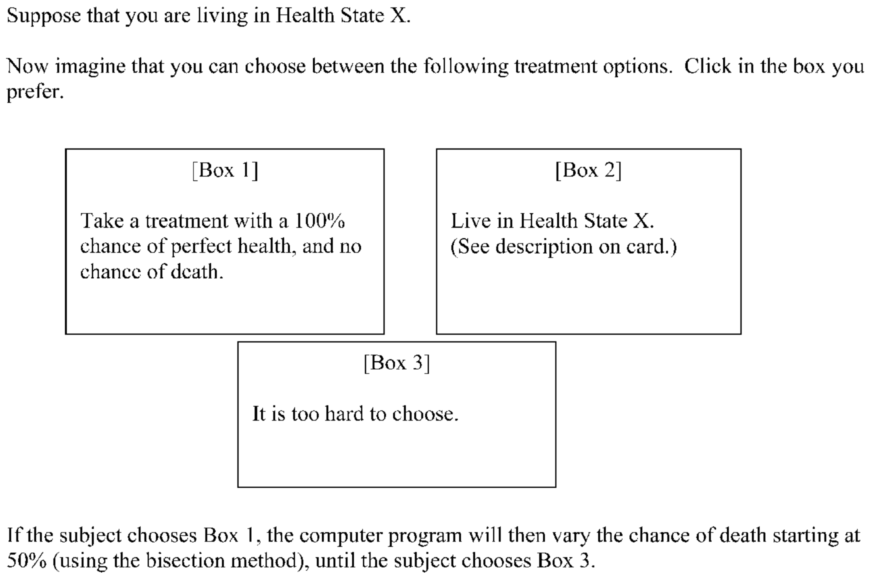
treatment that would restore them to perfect health but also includes some risk of immediate death (Figure 1). The risk of death is varied until the respondent expresses indifference between the health state and the treatment. For example, if the respondent expressed indifference between a described health state and a treatment with a 5% risk of death, the utility assigned to this health state would be 0.95 (perfect health minus the risk of death, or 1.0–0.05). To obtain the risk of death at which a respondent was indifferent to a choice between taking the hypothetical treatment or remaining in the health scenario under evaluation, the bisection method was used to calculate the probability that was then presented in the next question. For example, if the respondent answered that they would not accept a 50% chance of death, the next question would ask if they were willing to accept a 25% chance of death. Health state utilities were measured on a 0–1 scale using the standard-gamble method with bisection. Health states considered worse than death were not allowed to take on values less than zero, but were considered equivalent to death with a value of zero.

The term ‘disutility’ refers to the decrease in quality of life from perfect health associated with a health state. Disutility is calculated as 1-utility. For example, if a certain health state has a utility of 0.95, the disutility for this health state is 0.05.

Three treatment health states were described by mode of administration (injection), frequency of administration, and side effects (Table 2). Treatment descriptions were generated as a proxy for three of the immunomodulatory treatments available to patients with MS: interferon beta-1a (Treatment A), interferon beta-1b (Treatment B), and glatiramer acetate (Treatment C). Consistent with the method used to value health states, respondents were asked to choose between the profile for chronic treatment or a one-time treatment with some chance of perfect health and some risk of immediate death.

Excluded observations

A decision rule was developed to identify ‘mistakes’ (persons who had difficulty answering the standard gamble questions) but to exclude as few observations as possible. Mistakes were defined as when a person assigned a higher utility to a health state with more disability when the more disabled health state included the disabilities from a less-disabled health state. Five patient observations and ten community observations with illogical orderings were dropped. One response from a patient who rated the treatment health state as equal to death, but who was receiving treatment and also rated his current health greater than zero, was classified as an error and also dropped.



Suppose that you are living in Health State X.

Now imagine that you can choose between the following treatment options. Click in the box you prefer.

[Box 1]

Take a treatment with a 100% chance of perfect health, and no chance of death.

[Box 2]

Live in Health State X.
(See description on card.)

[Box 3]

It is too hard to choose.

If the subject chooses Box 1, the computer program will then vary the chance of death starting at 50% (using the bisection method), until the subject chooses Box 3.

Figure 1 *Sample standard gamble question for health state evaluation*

Table 2 Descriptions of MS treatment states for utility assessment

Treatment A:

- Imagine that you take an injectable drug once per week. This requires first mixing the powdered drug with the liquid, drawing it into a syringe, and injecting it into your thigh.
- Often you will feel feverish and achy for about 24 hours after the injection– just as if you had the flu.
- The injection itself is not very painful, but sometimes the skin around the injection site will get sore. A doctor can prescribe medication to ease the soreness. Occasionally it will get infected.

Treatment B:

- Imagine that you take an injectable drug every other day. This requires first mixing the powdered drug with the liquid, drawing it into a syringe, and injecting it into your thigh.
- Often you will feel feverish and achy for about 24 hours after the injection– just as if you had the flu.
- The injection itself is not very painful, but sometimes the skin around the injection site will get sore. A doctor can prescribe medication to ease the soreness. Occasionally it will get infected.

Treatment C:

- Imagine that you take an injectable drug every day. This requires first mixing the powdered drug with the liquid, drawing it into a syringe, and injecting it into your thigh.
- The injection itself is not very painful, but sometimes the skin around the injection site will get sore. A doctor can prescribe medication to ease the soreness. Occasionally it will get infected.

Statistical methods

Summary statistics for health and treatment state utilities, including means, medians, standard deviations, standard errors, and 25th and 75th percentiles, were reported separately for patient and community respondents. The two-sample Wilcoxon rank-sum test was used to evaluate the differences between median patient and community utilities for each health state.

Results

The mean age for patient respondents was 38 years, 79% were women, and 59% were receiving treatment. Respondent characteristics for the patient sample generally reflected those of a patient population with relapsing-remitting MS (Table 3).[28–30] For example, there were more women than men and their average education level was higher than the national average.[31,32] The patient respondents were referred by their physician. Of those asked to participate, approximately 90% agreed. No information regarding the characteristics of those who declined to participate is available. Patients were more likely to be women and to have children living at home than members of the community sample. Members of the community sample were more educated and had fewer children but otherwise reflected characteristics similar to the US population.[31,32] Respondent characteristics reported in Table 1 exclude respondents identified as having difficulty with the survey questions.

Quality-of-life assessments (utilities) for the six MS health states generally declined as disability (EDSS scores) increased for both groups of respondents (Table 4). Both means and medians for each health state are reported since most of the utility distributions are not normally distributed but skewed toward one.

Patients assigned higher mean utilities than community respondents for all six MS health states evaluated (Figure 2). Differences for median utilities between respondent groups were significant only for some health states, and were more pronounced for more-disabled health states.

For patients, median standard-gamble utilities for the first four health states were relatively high (> 0.98), even for Health State 4 which includes some difficulties with walking, fatigue and bladder/bowel control.

Both patients and community respondents associated a decrease in quality of life with the three treatment health states as measured by mean and median utilities. Patients assigned less disutility to treatments than community respondents, but this difference was not significant (Table 5). A pooled utility across the three hypothetical treatments is provided since the three treatment descriptions

Table 3 Respondent characteristics

Characteristic	MS patients ($n = 56$)	Community sample ($n = 57$)
Mean age (SD)	38 (10)	39 (18)
Female	44 (79%)	30 (53%)
Married	35 (62%)	34 (60%)
Education		
Some high school	2 (4%)	0 (0%)
High school graduate	9 (16%)	5 (9%)
Some college	9 (16%)	16 (28%)
College degree	22 (39%)	25 (44%)
Advanced degree	14 (25%)	11 (19%)
Total annual household income		
Less than $15,000	7 (13%)	7 (12%)
$15,000-$24,999	6 (11%)	3 (5%)
$25,000–$34,999	9 (16%)	7 (12%)
$35,000–$49,999	8 (14%)	8 (14%)
$50,000–$74,999	7 (13%)	8 (14%)
$75,000 or greater	16 (29%)	19 (33%)
Declined	3 (5%)	5 (9%)
Children < 18	29 (52%)	17 (30%)
White	46 (84%)	44 (77%)
Mean self-reported EDSS level (SD)	2.7 (2.1)	N/A
On treatment	33 (59%)	N/A

Table 4 Utilities for MS Health States

MS Health States	*Group*	*Mean (SD)*	*Median*	*Minimum*	*25th percentile*	*75th percentile*	*Maximum*	*Differences*	
								Median	*P-value*
1 (EDSS 2.5)*	Patients ($n = 28$)	0.954 (0.083)	0.994	0.615	0.943	1	1	0.001	0.20
	Community ($n = 31$)	0.915 (0.133)	0.995	0.5	0.88	0.999	1		
2 (EDSS 2.5)*	Patients ($n = 28$)	0.983 (0.041)	1	0.81	0.985	1	1	0.057	< 0.001
	Community ($n = 26$)	0.899 (0.136)	0.943	0.5	0.87	0.985	1		
3 (EDSS 3.5)*	Patients ($n = 28$)	0.946 (0.081)	0.988	0.645	0.908	1	1	0.013	0.36
	Community ($n = 31$)	0.911 (0.132)	0.975	0.5	0.87	0.999	1		
4 (EDSS 5)*	Patients ($n = 28$)	0.966 (0.077)	0.997	0.62	0.978	1	1	0.105	< 0.001
	Community ($n = 26$)	0.821 (0.213)	0.893	0	0.81	0.93	1		
5 (EDSS 6)*	Patients ($n = 28$)	0.860 (0.135)	0.890	0.41	0.805	0.963	1	0.005	0.43
	Community ($n = 31$)	0.769 (0.249)	0.895	0	0.59	0.980	1		
6 (EDSS 8)*	Patients ($n = 28$)	0.698 (0.314	0.835	0	0.5	0.945	1	0.332	0.02
	Community ($n = 26$)	0.491 (0.303)	0.503	0	0.245	0.745	1		

*These health states have the same EDSS level, but differ according to the impairments included. Health State 1 includes primarily sensory symptoms (numbness and pain) and Health State 2 includes blurred vision with mild eye pain. Because of the great heterogeneity in MS symptoms, particularly at lower levels of disability, both health state descriptions were included.

do not fully represent all differences between the actual treatments. Also, because the treatment utilities are sensitive to outliers due to small sample sizes, the pooled treatment utility may be a more appropriate estimate of treatment disutility.

Discussion

Utilities associated with EDSS scores less than level 6 were close to 1.0 for patients and greater than 0.8 for community respondents indicating that respondents asso-

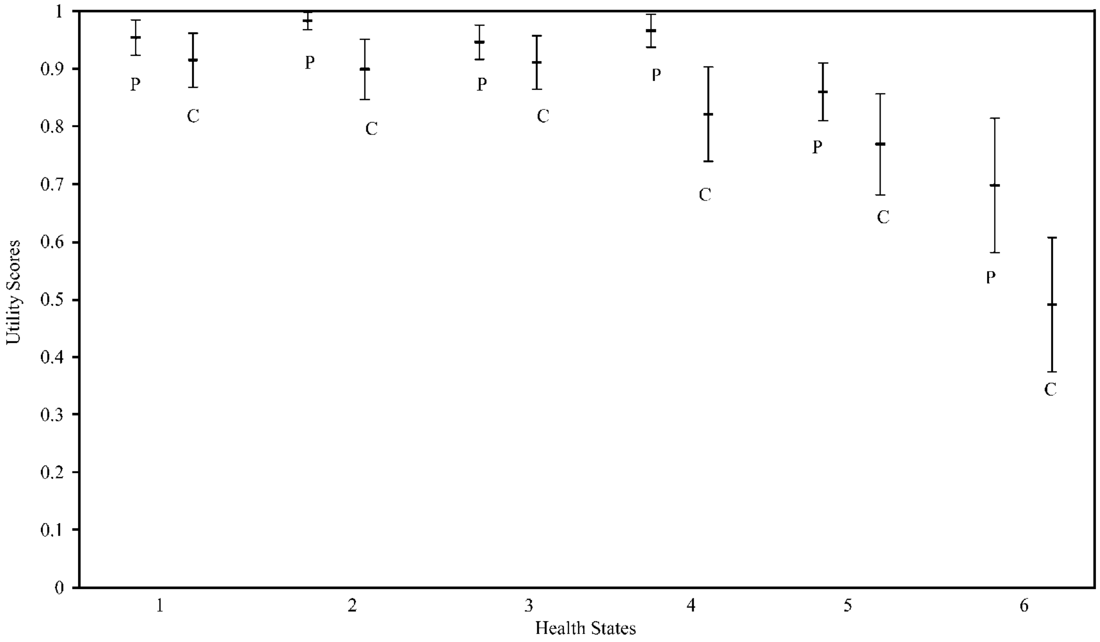


Figure 2 *Comparison of utility scores for patients and community respondents. P, patient; C, community respondent; I, 95% confidence interval.*

Table 5 Utilities for MS treatment states

MS Health States	*Group*	*Mean (SD)*	*Median*	*Minimum*	*25th percentile*	*75th percentile*	*Maximum*	*Differences*	
								Median	*P-value*
Treatment A	Patients ($n = 17$)	0.955 (0.057)	0.98	0.825	0.93	1	1	0.012	0.35
	Community ($n = 18$)	0.885 (0.149)	0.968	0.5	0.77	0.999	1		
Treatment B	Patients ($n = 20$)	0.934 (0.115)	0.985	0.595	0.92	1	1	0.017	0.14
	Community ($n = 20$)	0.796 (0.318)	0.968	0	0.77	0.997	1		
Treatment C	Patients ($n = 19$)	0.888 (0.278)	1	0	0.96	1	1	0.015	0.35
	Community ($n = 19$)	0.934 (0.102)	0.985	0.62	0.895	1	1		
Pooled	Patients ($n = 56$)	0.925 (0.074)	0.998	0	0.945	1	11	0.018	0.06
	Community ($n = 57$)	0.87 (0.219)	0.98	0	0.84	0.999	1		

ciated these MS health states with relatively small decreases in health-related quality-of-life. The utility values for treatment health states were comparable to the utilities for less-disabled MS health states. This provides some evidence that these utilities are valid indicators of patient preferences: a patient's decision to discontinue treatment is consistent with a patient's perception that side effects and discomfort associated with a treatment are equivalent or worse than symptoms of the disease being treated.

Utility scores for MS treatments highlight the burden patients associate with currently available immunomodulatory treatment regimens. Considerable debate surrounds the most appropriate time to initiate therapy with immunomodulatory agents in MS. There is a growing realization that significant tissue damage begins early in the course of the illness, and two clinical trials support the recommendation that patients at high risk for developing MS initiate immunomodulatory therapy even prior to a formal diagnosis of clinically definite MS.[33,34] It is therefore likely that patients and caregivers will be faced with the decision of initiating treatment earlier and earlier in the course of the illness, at a time when many patients have relatively mild disability. In this study we show that MS patients' perceptions of their health state have significant bearing on the degree of utility or disutility that they assign to available therapies. Both patients and community respondents attribute some loss in health-related quality of life with the treatment attributes described and there is wide variability in individual utility scores. Our results underscore the importance of including individual patient preferences in the treatment decision.

The relationship between declining utility scores and increasing disability as defined by EDSS level is not exact, and this result is expected. Changes in EDSS are very

Table 6 Comparison of mean MS utilities by EDSS level with resultsfrom the MS Utility Survey

EDSS score	*EQ-5D utility, mean time-trade-off utility (community)*	*Health utilities index (Mark II)*	*MS utility survey, mean standard-gamble utility (community)*	*MS utility survey, mean standard-gamble utility (patient)*
1	–	0.83	–	–
2	–	0.84	–	–
2.5	–	–	0.915	0.968
3	0.71	0.71	–	–
3.5	–	–	0.907	0.946
4	0.66	0.71	–	–
5	0.52	0.62	0.821	0.966
6	0.49	0.59	0.769	0.860
7	0.35	–	–	–
8	–	–	0.491	0.698

dependent on changes in ambulation, whereas utility scores are designed to more completely capture changes in health-related quality of life. Exceptions could also be due to sampling variation.

This study is the first to report both patient and community-based utilities for a set of multiple sclerosis health states. Our results reflect the previously reported trend that patients tend to assign a higher utility to an impaired health state they have experienced as compared with respondents who have not experienced the health state.[21] Guidelines for cost-effectiveness analyses recommend the use of community ratings for use in economic evaluations,[21] however, this study reinforces the importance of measuring patient preferences as well as community ratings to inform clinical decision making. Here, patient-rated utilities for disease and treatment scenarios provide insight into the discontinuation decision.

Higher patient utilities could also be related to the instruction for respondents to imagine that they will remain in the health state described for the remainder of their life when responding to the standard-gamble questions. Given that patients generally have a good understanding of the likelihood of disease progression in MS, this may have been difficult for patients to imagine and could also account in part for the higher utility scores for patients, if patient respondents viewed the health state under evaluation as a vastly superior lifetime alternative when compared with their own expectation of disease progression.

One concern with the method used for valuing treatment utilities is that treatment utilities may have been confounded by a respondent's current health. If a respondent included an assessment of his/her current health when valuing the treatment descriptions, this could have resulted in artificially low ratings for the treatment health states. We did not find any significant correlation between disability level and disutility of treatment (results not shown), however our small sample size limits the ability to analyze this relationship.

The treatment descriptions included in this survey were somewhat more benign than the actual treatments, as they did not include the small probabilities of some more serious outcomes. Therefore, treatment utilities reported here may not fully capture the loss in quality of life associated with the immunomodulatory treatments. More work should be done on disentangling the effects of different treatment attributes on patient preferences and, ultimately, on adherence to treatment.

Treatment descriptions also did not reflect all differences between actual treatments, therefore, some caution should be used when interpreting utility scores between individual treatments. The pooled utility for all three treatments is likely a better indicator of preferences for an injectable treatment with a mild-to-moderate side effect profile than the three individual treatment state utilities. Clearly, patients will have individual preferences regarding what they consider to be the more burdensome aspects of these treatments (e.g., frequency of injection versus potential systemic side effects). Patients familiar with the specific treatments may also have included additional information not included in the treatment description when valuing a specific treatment.

Community-based utilities in this study are higher than community utilities reported elsewhere (Table 6). The other two sets of community-based utilities are from the UK and Canada in which MS health descriptions are valued using generic utility instruments, the EQ-5D and Health Utilities Index (HUI-2).[35,36] The EQ-5D categorizes health states according to five domains of health, while the HUI-3 uses seven domains. The health state descriptions used in this study are more detailed, using 10 domains of health to characterize each state. We conjecture that using fewer attributes to describe health states may cause the respondents to provide lower ratings because reporting impairments on three out of five to eight attributes may seem worse than the same impairments on three out of ten attributes. Other differences between instruments that could affect utility scores include mode of administration (computer versus face-to-face), method of valuing utilities (time-tradeoff versus standard-gamble) and range of utilities (e.g., the EQ-5D allows for states to be valued as worse than dead, or less than zero). There were also differences in characteristics between the three study samples that could bear on utility ratings. Another limitation of our community sample is that it was limited to residents of San Diego, CA, and did not reflect a true national sample, which could also result in different utility ratings.

This study quantifies the loss in quality of life associated with MS disability and treatments using a measure, utilities, that can in turn be used as inputs for modeling clinical decisions and in economic evaluations of MS treatments. Utilities reported by both patients and community respondents for treatment scenarios show a marked decrease in health-related quality of life in relation to treatment administration and side effects of currently available treatment options. Both clinical and economic decision making should consider the burden of certain treatment options along with treatment benefits.

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