

EQ-5D and SF-36 Quality of Life Measures in Systemic Lupus Erythematosus: Comparisons with Rheumatoid Arthritis, Noninflammatory Rheumatic Disorders, and Fibromyalgia

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ABSTRACT. Objective. The Medical Outcomes Study Short-form 36 (SF-36) provides numerical measurement of patient health, but does not include preferences for health states and cannot be used directly in cost-effectiveness analyses. By contrast the Euroqol EQ-5D can be used for cost-effectiveness analyses. The EQ-5D has rarely been used in systemic lupus erythematosus (SLE). We compared SF-36 and EQ-5D values across rheumatic diseases.

Methods. We studied 1316 patients with SLE, 13,722 with rheumatoid arthritis (RA), 3623 with non-inflammatory rheumatic disorders (NIRD), and 2733 with fibromyalgia (FM).

Results. The mean EQ-5D, physical (PCS) and mental (MCS) component summary scores were 0.72, 36.3, and 44.3, respectively, in SLE. There was essentially no difference among EQ-5D and PCS scores for patients with SLE, RA, or NIRD. MCS was lower in SLE compared with RA and NIRD (44.3, 49.1, 50.8, respectively). All scores were more abnormal in FM (0.61, 31.9, 41.9). Within SF-36 domains, physical function was better, but general health, vitality, social function, role-emotional, and mental health were more impaired in SLE compared with RA and NIRD. In SLE, quality of life (QOL) was predicted by damage, comorbidity, income, education, and age. Fifteen percent of patients with SLE were very satisfied with their health, and their QOL scores (0.84, 45.4, 50.1) were similar to those found in the US population for EQ-5D and MCS, but were slightly reduced for PCS.

Conclusion. EQ-5D and PCS are at the same levels in SLE as in RA and NIRD, but are more abnormal in SLE in the MCS and mental health domains. EQ-5D values allow preference-based comparisons with other chronic conditions. (First Release Dec 23 2009; J Rheumatol 2010;37:296–304; doi:10.3899/jrheum.090778)

Key Indexing Terms:

SYSTEMIC LUPUS ERYTHEMATOSUS RHEUMATOID ARTHRITIS FIBROMYALGIA
EQ-5D MEDICAL OUTCOMES STUDY SHORT-FORM 36 QUALITY OF LIFE

Comprehensive health-related quality of life measures (here called QOL) are used in randomized controlled trials to demonstrate treatment efficacy, in observational studies to show levels of impairment, and occasionally in clinical care to understand the status of an individual patient. The most commonly used comprehensive QOL measure is the Medical Outcomes Study Short-Form 36 (SF-36)¹. Although the SF-36 provides numerical measures of health

status, it does not include preferences for health states and therefore cannot be used directly in cost-effectiveness analyses or easily in cross-disease analyses.

The Euroqol EQ-5D, by contrast, is a QOL measure that can be used for cost-effectiveness studies across diseases^{2,3}. The EQ-5D is a 5-item questionnaire that after appropriate weighting results in a scale that ranges from –0.11 to 1.00. An EQ-5D visual analog scale (VAS) is also available, but is not based on preference weight and cannot be used in cost-effectiveness analyses. Zero on the VAS scale represents the “worst imaginable health state” and 1 (or 100, depending on scaling) represents the “best imaginable health state.” Scores less than 0 on the EQ-5D may be thought of as “worse than death.” The EQ-5D and EQ-5D VAS are correlated at about 0.6, but have different means (*vide infra*).

All chronic illnesses result in reduced QOL, regardless of measure³. Systemic lupus erythematosus (SLE) is an important rheumatic disease that can result in life-threatening multisystem illness, and it is of interest to understand the

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QOL of individuals with it and how SLE compares with other rheumatic illnesses. There are only a few reports of cross-illness studies, and those usually involve small samples^{4,5}.

We have developed a patient-based SLE databank in which patient's self-report is combined with medical record validation⁶. This model allows aggregation of data for large numbers of patients with SLE without incurring high physician costs. We now use this databank to characterize SLE patients with respect to QOL and to compare them with patients with rheumatoid arthritis (RA), noninflammatory rheumatic disorders (NIRD), and fibromyalgia (FM) who have similar demographic and participation characteristics. One advantage of comparative studies is that they put the results into the context of the demographic data and severity of other rheumatic diseases at the same center, and provide a better framework for judging the validity of the data.

The primary goals of this study are to describe the comparative QOL of the 4 groups of patients with rheumatic disease according to SF-36 and EQ-5D/EQ-5D VAS results, to examine predictors of QOL in SLE, and to characterize results in terms of patient's satisfaction with health. The EQ-5D can be used directly for cost-effectiveness analyses.

MATERIALS AND METHODS

Participants. This report concerns 1316 patients with SLE, 13,722 with RA, 3623 with NIRD, and 2,733 with FM who were participants in the National Data Bank for Rheumatic Diseases (NDB) longitudinal study of rheumatic disease outcomes. Participants are followed longitudinally with semiannual, detailed, 28-page questionnaires, as described^{7,8}. Questionnaires were administered by the Internet (16.0%) or by paper questionnaires (84.0%) depending on the participants' preferences. Internal NDB analyses indicated no differences in the validity of responses depending on questionnaire method.

Patients were enrolled continuously beginning in 1999 and ending in July 2008. Rheumatic disease diagnoses were made or confirmed by the patient's rheumatologist. NIRD included diagnoses such as osteoarthritis, back pain syndromes, tendonitis, etc., excluding FM. Patients with SLE were enrolled largely by rheumatologist referral, but also by self-referral after confirmation of the diagnosis of SLE by the patient's rheumatologist⁶. Rheumatologists rated 97.3% of cases as definite and 2.7% as probable SLE. We did not study cutaneous lupus. Patients with a physician-confirmed overlap diagnosis of SLE and FM (7.2%) and SLE and RA (13.1%) were assigned to the SLE category. The seemingly large percentage of SLE/RA overlaps was derived from the large sample of RA patients, where they represented 1% of RA diagnoses. Sensitivity analyses showed that this assignment did not change study results. RA patients in the NDB who were enrolled as part of pharmaceutical study registries were excluded so as not to bias the study with more severe patients. In this study, we selected a single random observation from each patient for analysis.

Study variables. Demographic variables including age, sex, education level, ethnicity, and household income were obtained by self-report. We calculated the physical (PCS) and mental (MCS) component summary scores and 8 individual domain scores from the SF-36 version 1 according to the authors' recommendations^{1,9}. The primary time period of the SF-36 questionnaire was 4 weeks. The EQ-5D is a 5-item questionnaire that assesses function (3 questions), mood (1 question), and pain (1 question)². Scoring was accomplished using US tariffs (weights)^{10,11}. US and European scores are not interchangeable, US scores being approximately 0.11 units greater¹².

We also collected information regarding satisfaction with health. Satisfaction with health was evaluated with a 5-point scale^{13,14}. The question asked was, "How satisfied are you with your health now?". Possible replies were very dissatisfied, somewhat dissatisfied, neither satisfied nor dissatisfied, somewhat satisfied, and very satisfied.

SLE damage was assessed by the total damage score of the Lupus Damage Index Questionnaire (LDIQ)^{15,16}, a self-administered 56-item questionnaire based on the Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR) damage index (SDI)^{17,18}. The development of the LDIQ from its pilot testing to its administration is described elsewhere^{15,16}. The LDIQ was administered beginning in 2008 and, therefore, was only assessed in 676 patients with SLE.

Comorbidity was measured by a patient-reported composite comorbidity index (range 0–9) consisting of 11 present or past comorbid conditions including pulmonary disorders, myocardial infarction, other cardiovascular disorders, stroke, hypertension, diabetes, spine/hip/leg fracture, depression, gastrointestinal (GI) ulcer, other GI disorders, and cancer^{19,20}. This index has been studied in SLE²¹.

Statistical methods. Associations between the PCS, MCS, and EQ-5D and other variables were assessed by Spearman correlation coefficients because of the markedly non-normal distribution of the EQ-5D. We used multivariable linear regression to examine the differences in QOL scores between groups, adjusting for age and sex; and we used linear regression to describe and test the association of LDIQ components and PCS and MCS scores. Except as described in the text, analyses are unadjusted. Figure 1 was created using fractional polynomial prediction (Stata's *fpfitci*). Figure 2 utilized adaptive (varying bandwidth) kernel density estimation. We began collecting EQ-5D data in 2002. Patients who were NDB participants prior to that date and not thereafter did not have EQ-5D data. Overall, 29.1% of EQ-5D data were missing. Missing data for SF-36 domains ranged between 0.6% and 2.4%. We chose not to impute missing data because of the large percentage of missing EQ-5D data and because complete EQ-5D and PCS/MCS data were not essential to the analyses.

Data were analyzed using Stata (Stata Corp., College Station, TX, USA) version 10.1. Statistical significance was set at the 0.05 level, and all tests were 2-tailed. Because the sample sizes were so large, most differences in comparisons between SLE and other groups in Table 1 are statistically significant at $p < 0.001$. Except as noted in the text, we do not, therefore, report statistical significance. Instead, the reader should consider whether the group differences are clinically significant.

RESULTS

The median ages of participants were SLE 49.9 years [interquartile range (IQR) 40.6, 58.8], RA 61.2 years (51.2, 71.1), NIRD 61.5 years (58.5, 75.8), and FM 55.6 years (47.6, 63.4), and the percentages who were men were SLE 6.0%, RA 23.0%, NIRD 20.9%, and FM 4.7%. SLE and RA groups did not differ by sex ($p = 0.077$), but all other groups differed by sex ($p < 0.01$); and all groups differed by age ($p < 0.001$). The percentages of non-Hispanic white were SLE 89.9%, RA 95.5%, NIRD 96.8%, and FM 97.4%. Differences between SLE and other groups for ethnicity were significant at $p < 0.001$.

Comparative SF-36 summary scores and domains. Table 1 presents the QOL measures for the 4 groups. Across all domains, summary scores, and utilities, the worst scores were found in patients diagnosed with FM. Comparing the other 3 groups is more complicated: with respect to the SF-36 summary, the PCS scores were essentially the same for SLE, RA, and NIRD (36.3, 36.7, 36.4, respectively). But

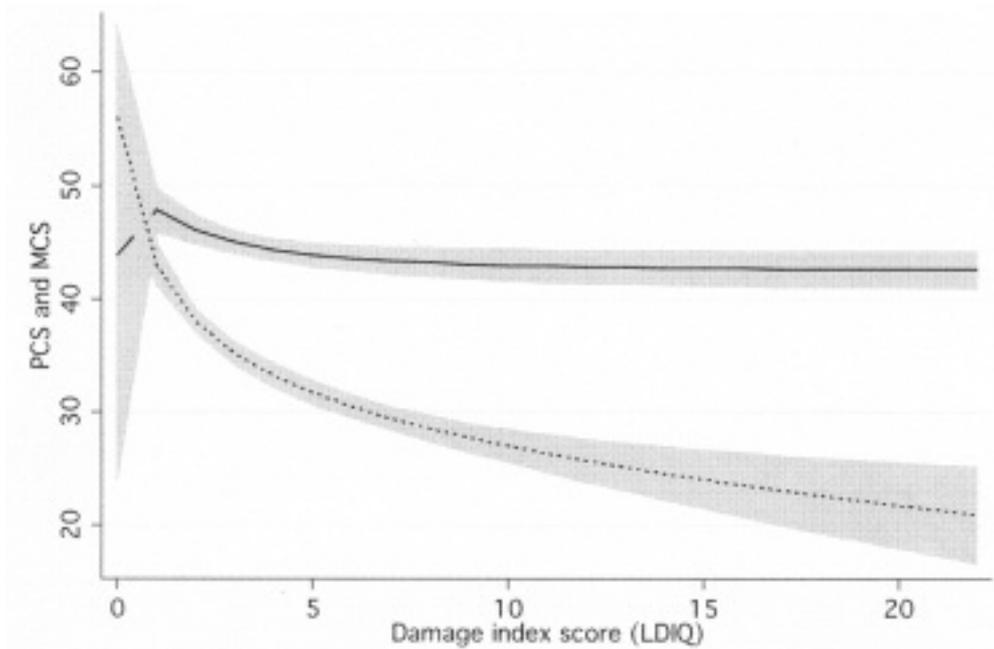


Figure 1. Effect of Lupus Damage Index Questionnaire (LDIQ) scores on SF-36 physical component summary (PCS) scores (broken line) and mental component summary (MCS) scores (solid line). Grey areas represent 95% confidence bands. Confidence band for PCS remains narrow as it approaches 0.

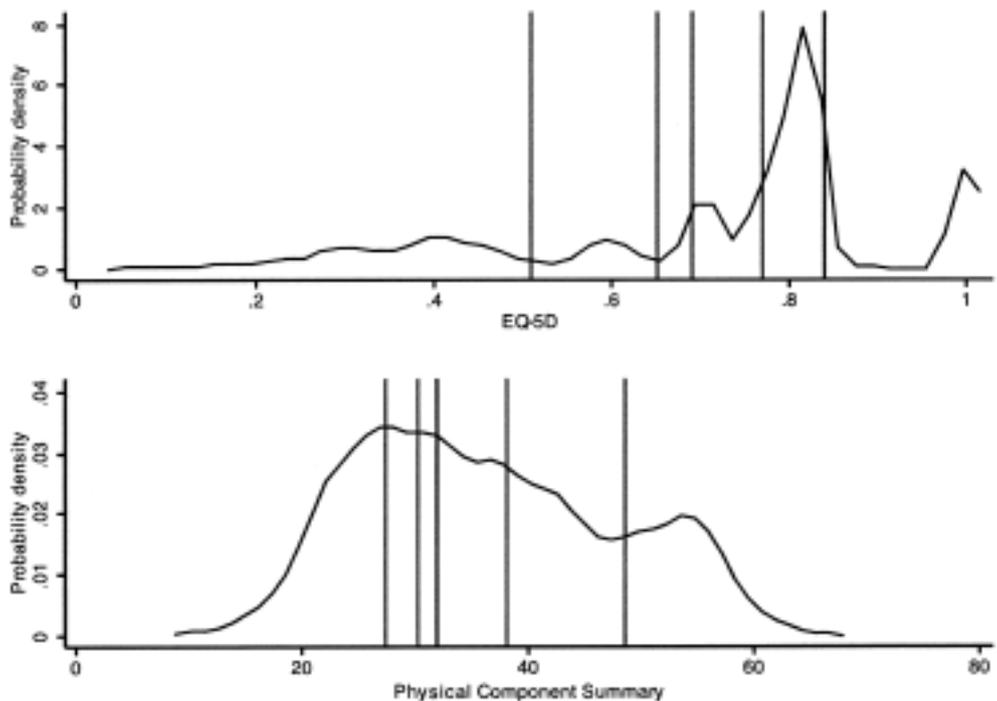


Figure 2. The distribution of EQ-5D and SF-36 physical component summary (PCS) values. Vertical lines (from right to left) represent median values of EQ-5D and PCS for the 5 health-satisfaction categories (percentage of patients): very satisfied with health (15.1%), somewhat satisfied (38.4%), neither satisfied nor dissatisfied (32.8%), somewhat dissatisfied (21.1%), and very dissatisfied (10.4%). The mean PCS score in SLE studies ranges from 35 to 40, or at the second x-line from the right.

important differences were found for the MCS scores. SLE patients had the worst MCS score, followed by RA and NIRD (44.3, 49.1, 50.8, respectively). The same type of dif-

ference was seen in mean EQ-5D scores (0.72, 0.73, 0.73, respectively). Compared with RA (the most relevant comparison) PCS score was not significantly lower in SLE.

Table 1. SF-36 and utility scores in systemic lupus erythematosus, rheumatoid arthritis (RA), noninflammatory rheumatic disorders (NIRD), and fibromyalgia (FM).

Health Status Variables	SLE, N = 1316 Mean (SD)	RA, N = 13,722 Mean (SD)	NIRD, N = 3623 Mean (SD)	FM, N = 2733 Mean (SD)
SF-36 domains				
Physical function	52.7 (30.6)	49.5 (29.5)	47.6 (28.1)	40.7 (26.3)
Role physical	36.3 (41.5)	39.9 (42.0)	39.5 (41.6)	19.2 (32.3)
Bodily pain	48.5 (24.1)	50.1 (23.1)	48.3 (21.6)	34.3 (19.5)
General health	37.5 (23.0)	49.4 (23.3)	55.8 (22.5)	39.2 (22.1)
Vitality	35.9 (23.1)	43.4 (23.4)	46.1 (23.1)	27.1 (21.1)
Social function	62.0 (27.9)	69.7 (27.5)	71.6 (26.9)	51.8 (28.2)
Role emotional	54.5 (43.9)	63.5 (42.4)	65.6 (41.4)	43.9 (43.9)
Mental health	67.1 (20.3)	72.9 (18.9)	75.0 (18.2)	62.5 (21.8)
SF-36 summary scores				
Physical component score	36.3 (11.5)	36.7 (11.3)	36.4 (10.8)	31.9 (9.6)
Mental component score	44.3 (11.8)	49.1 (11.4)	50.8 (11.4)	41.9 (12.5)
Utilities				
EQ-5D VAS (0–1)	0.64 (0.21)	0.66 (0.21)	0.68 (0.20)	0.57 (0.22)
median*	0.67 (0.50, 0.80)	0.71 (0.51, 0.82)	0.73 (0.53, 0.84)	0.59 (0.40, 0.75)
EQ-5D (US) (0–1)	0.72 (0.21)	0.73 (0.19)	0.73 (0.18)	0.61 (0.22)
median*	0.78 (0.60, 0.83)	0.78 (0.69, 0.83)	0.78 (0.69, 0.83)	0.71 (0.40, 0.80)

* Median and interquartile range. VAS: visual analog scale; SF-36: Medical Outcomes Study Short-form 36.

However, after adjustment for age and sex, SLE scores for PCS were -0.93 (95% CI -1.59 to -0.27) units lower ($p = 0.006$). For MCS the nonadjusted difference was significant and the age and sex-adjusted difference was -3.24 (95% CI -3.92 to -2.59 , $p < 0.001$). For EQ-5D the unadjusted difference, but not the adjusted difference, was statistically significant.

However, the domain scores differed among the groups (Table 1). Physical function was better in SLE than in RA and NIRD (52.7, 49.5, 47.6, respectively). But scores for general health, vitality, role-emotional, and mental health were substantially worse in SLE patients. Comparing RA and NIRD, we found that physical function and bodily pain were better in RA, but that NIRD had better scores

for general health, vitality, role-emotional, and mental health.

Predictors and correlates of QOL measures. We examined demographic and comorbidity correlates of SF-36 and EQ-5D scales. Higher scores for the LDIQ and comorbidity reflect worse clinical status compared with the QOL measures, in which lower scores reflect worse health status. Correlations with $r > 0.8$ are usually considered very strong, 0.6 to 0.8 strong, 0.4 to 0.6 moderate, 0.2 to 0.4 weak, and < 0.2 as absent. The LDIQ and comorbidity index were the strongest correlates of the QOL measures, 0.434 and 0.372 for the PCS, and 0.394 and 0.389 for the EQ-5D (Table 2). Household income was correlated with PCS and EQ-5D at 0.292 and 0.303. No other demographic measure had a cor-

Table 2. Spearman correlations between physical component summary (PCS), mental component summary (MCS), and EQ-5D and demographic variables in patients with SLE.

Variable	PCS	MCS	EQ-5D
PCS	1.000	0.142	0.717
EQ-5D	0.717	0.493	1.000
EQ-5D VAS	0.607	0.373	0.607
LDIQ Damage Index	-0.434	-0.141	-0.394
Comorbidity index	-0.372	-0.272	-0.389
Total income (US dollars)	0.292	0.166	0.303
MCS	0.142	1.000	0.493
Education level	0.127	0.029	0.109
Age	-0.177	0.170	-0.041
Disease duration	-0.078	0.028	-0.061

All correlations are significant at $p < 0.001$ except for MCS and education level ($p = 0.307$) and MCS and disease duration ($p = 0.320$). EQ-5D: EuroQol 5D; VAS: visual analog scale; LDIQ: Lupus Damage Index Questionnaire.

relation above 0.127. Of interest, the PCS correlation with EQ-5D (0.717) was stronger than the PCS correlation with the EQ-5D VAS (0.607), and stronger than with the EQ-5D and EQ-5D VAS (0.607).

Figure 1 shows the nonlinear association of PCS and LDIQ damage and the very limited association of MCS and damage. The relation between EQ-5D and damage (not shown) is similar to the PCS-damage relationship.

We also used the self-reported LDIQ scales to illuminate the association between the SF-36 QOL measures and SLE damage. Table 3 shows the univariate decrease (–) in PCS and MCS scores associated with having self-reported damage in each domain. In general, damage and PCS were related (8 significant results) compared with damage and MCS (3 significant results).

Interpretation of QOL scores. Although SF-36 scores are widely reported, the numbers have no clear relevance to clinicians. To place SF-36 and other QOL scores into a more meaningful context, and as an aid to clinical interpretation, we categorized QOL measures at 5 levels of patient satisfaction with health (Tables 4a, 4b). About 47% of SLE patients are somewhat (22.1%) or very satisfied (15.1%)

with their health. At the very satisfied level, means scores for PCS, MCS, and EQ-5D were 45.3, 50.1, and 0.84, respectively. The distribution of PCS and EQ-5D values and the satisfaction categories are displayed in Figure 2.

DISCUSSION

Health status questionnaires provide measures of patient health across various domains. The SF-36, which addresses 8 domains, has found wide use in rheumatology clinical trials and in observational studies. While the SF-36 provides numerical measures of health status, it does not include preferences for health states and cannot be used directly in cost-effectiveness analyses. However, through use of the SF-6D²², which derives from the SF-36, cost-effectiveness data can be generated. By contrast, the EQ-5D can be used for cost-effectiveness studies across diseases. The mean EQ-5D in US adults aged 45–64 years is 0.82¹⁰. The minimally important difference (MID) for EQ-5D has been estimated to be 0.074, range –0.011 to 0.14²³. As shown in Figure 2, the distribution of EQ-5D scores is distinctly irregular, with a long tail.

In a national sample of 38,678 individuals from the

Table 3. Differences in PCS and MCS scores according to presence of SLE damage in individual LDIQ domains in 676 patients with SLE.

Domain	Percentage with (+) Domain	Mean Difference in PCS	t	p
Ocular	37.6	–1.7	–1.9	0.062
Neurological	57.0	–8.6	–10.5	0.000
Renal	33.5	0.4	0.5	0.646
Pulmonary	21.2	–4.6	–4.4	0.000
Cardiovascular	31.0	–4.9	–5.4	0.000
Peripheral vascular	12.2	–5.4	–4.1	0.000
Gastrointestinal	19.7	–3.9	–3.6	0.000
Musculoskeletal	49.0	–6.1	–7.4	0.000
Integument	39.0	–4.6	–5.3	0.000
Gonadal	12.3	–2.0	–1.5	0.137
Malignancy	8.2	–1.3	–0.8	0.404
Diabetes	11.7	–7.7	–5.8	0.000
		Mean Difference in MCS		
Ocular	37.6	1.9	–7.5	0.049
Neurological	57.0	–6.7	–7.5	0.000
Renal	33.5	0.7	0.7	0.476
Pulmonary	21.2	0.5	0.4	0.660
Cardiovascular	31.0	–1.5	–1.5	0.131
Peripheral vascular	12.2	–1.6	–1.1	0.272
Gastrointestinal	19.7	–2.6	–2.3	0.025
Musculoskeletal	49.0	0.2	0.2	0.856
Integument	39.0	–3.4	–4.0	0.000
Gonadal	12.3	0.8	0.6	0.562
Malignancy	8.2	0.7	0.4	0.665
Diabetes	11.7	–0.4	–0.3	0.755

(+) domain: score ≥ 1 in the domain. PCS: SF-36 Physical Component Summary; MCS: SF-36 Mental Component Summary; LDIQ: Lupus Damage Index Questionnaire.

Table 4A. Values of health status and quality of life according to patient satisfaction with health in SLE.

Variable	Satisfaction Status (%)	Mean	Median	25th Percentile	75th Percentile
PCS	Very satisfied (15.1)	45.4	48.6	37.9	54.2
	Somewhat satisfied (38.4)	39.0	38.1	30.8	47.7
	Neither satisfied nor dissatisfied (15.0)	32.8	31.8	25.1	38.8
	Somewhat dissatisfied (21.1)	31.6	30.1	24.7	37.1
	Very dissatisfied (10.4)	28.3	27.3	22.0	33.9
MCS	Very satisfied (15.1)	50.1	52.3	44.5	57.6
	Somewhat satisfied (38.4)	45.5	47.7	36.6	55.1
	Neither satisfied nor dissatisfied (15.0)	43.0	43.2	34.7	52.5
	Somewhat dissatisfied (21.1)	41.1	40.3	31.9	51.0
	Very dissatisfied (10.4)	39.5	39.4	31.3	47.9
EQ-5D	Very satisfied (15.1)	0.84	0.83	0.80	1.00
	Somewhat satisfied (38.4)	0.77	0.80	0.71	0.83
	Neither satisfied nor dissatisfied (15.0)	0.69	0.77	0.60	0.80
	Somewhat dissatisfied (21.1)	0.65	0.71	0.45	0.80
	Very dissatisfied (10.4)	0.51	0.45	0.31	0.76
EQ-5D VAS	Very satisfied (15.1)	0.82	0.85	0.78	0.89
	Somewhat satisfied (38.4)	0.79	0.81	0.74	0.85
	Neither satisfied nor dissatisfied (15.0)	0.76	0.76	0.70	0.82
	Somewhat dissatisfied (21.1)	0.74	0.74	0.67	0.81
	Very dissatisfied (10.4)	0.70	0.69	0.62	0.78

Medical Expenditure Panel Survey (MEPS) in 2006, EQ-5D results were obtained from those with a series of chronic conditions that are similar though more general than the diagnoses in the current study, including 111 with a diffuse connective tissue disease (ICD-9 code 710), 231 with inflammatory polyarthritis (ICD-9 714), and 348 with osteoarthritis (ICD-9 715)³. The MEPS EQ-5D mean and median EQ-5D values for diffuse connective tissue disease were 0.74 and 0.80, respectively. In the current study these values in SLE patients were 0.72 and 0.78. For inflammatory polyarthritis the MEPS values were 0.66 and 0.78³, while in RA patients in our study the values were 0.73 and 0.78. Osteoarthritis (ICD-9 715), in contrast to NIRD, resulted in values of 0.70 and 0.79³ compared with 0.73 and 0.78 in our study. Given the limited chronic disease sample of the MEPS, the general diagnostic categories, and the EQ-5D distribution, it is likely that the MEPS median values, which are very similar to those in the current study, are the most stable and appropriate for comparison.

There is no code for FM in the MEPS report³, but we observed values of 0.61 and 0.71 for FM. Of the 692 physical illness categories in the MEPS, only renal failure had values as low as those noted for FM. It is not surprising that FM has low EQ-5D values because the ACR criteria for FM²⁴ select for severity by virtue of requiring the presence of widespread pain and many tender points.

Clarke, *et al* used the nonpreference-based EQ-VAS scale in SLE and found values of 0.65 in 634 patients without renal disease and about 0.68 in 81 with renal disease²⁵. Among 269 US SLE patients the EQ-5D VAS was 0.66²⁶. In the only study to investigate an unselected SLE sample with the EQ-5D, Aggarwal, *et al* recently reported SF-36 and EQ-5D data on 167 patients from an academic rheumatol-

ogy center²⁷. They found PCS, MCS, and EQ-5D mean (SD) scores of 35.6 (0.8), 51.9 (8.9), and 0.72 (0.19), respectively, and they found the EuroQol VAS score to be 68.7 (20.5). In the current study values for the 4 scores were 36.3 (11.5), 44.3 (11.8), 0.72 (0.21), and 0.64 (0.21). With respect to the 3 rheumatic diseases under study, we found essentially no difference between those with SLE and those with RA or NIRD. However, as shown in Table 2, the EQ-5D is sensitive to SLE damage and sociodemographic variables. Therefore, the values of the EQ-5D will vary somewhat from study to study, dependent on the SLE damage in the study population. In agreement with population studies¹⁰, we also found that the EQ-5D varied minimally according to age, education, and annual household income. There were too few men with SLE in our study to adequately examine gender effect.

Therefore, the SLE EQ-5D results can be summarized by saying that the EQ-5D mean and median are approximately 0.72 and 0.78; SLE, RA, and NIRD have the same level of EQ-5D health status.

If the EQ-5D is not ordinarily used in SLE except in the EQ-VAS format, the SF-36 is commonly used. In the Tri-Nation study, PCS and MCS scores ranged from 36.3 to 40.6 for PCS and from 43.5 to 43.8 for MCS²⁵. In another study of 43 SLE patients the PCS and MCS scores were 38.6 and 43.1, respectively²⁸. Studying 90 patients with SLE in 2004, Jolly and Utset noted scores of 35 and 45²⁹. Results from the LUMINA studies showed mean PCS and MCS values of 36.7 and 46.6³⁰. In our study the PCS and MCS were 36.3 and 44.3. In general, one can say that PCS values in SLE are in the range of 35 to 40, or around the second x-line from the right in Figure 2.

As with the EQ-5D, there was essentially no difference in

Table 4B. Values of SF-36 domains according to patient satisfaction with health in SLE.

Variable	Satisfaction Status (%)	Mean	Median	25th Percentile	75th Percentile
Physical function	Very satisfied (15.1)	24.4	27.0	20.5	29.0
	Somewhat satisfied (38.4)	22.1	23.0	18.0	27.0
	Neither satisfied nor dissatisfied (15.0)	18.9	18.0	14.0	24.0
	Somewhat dissatisfied (21.1)	18.3	18.0	14.0	22.0
	Very dissatisfied (10.4)	16.6	15.5	12.5	20.0
Role-physical	Very satisfied (15.1)	6.7	8.0	5.0	8.0
	Somewhat satisfied (38.4)	5.7	5.0	4.0	8.0
	Neither satisfied nor dissatisfied (15.0)	5.1	4.0	4.0	6.0
	Somewhat dissatisfied (21.1)	4.8	4.0	4.0	5.0
	Very dissatisfied (10.4)	4.5	4.0	4.0	5.0
Bodily pain	Very satisfied (15.1)	8.8	9.2	7.2	10.4
	Somewhat satisfied (38.4)	7.5	7.2	6.1	9.2
	Neither satisfied nor dissatisfied (15.0)	6.3	6.1	5.1	7.1
	Somewhat dissatisfied (21.1)	5.7	6.1	4.2	7.1
	Very dissatisfied (10.4)	4.9	4.2	3.2	6.1
General health	Very satisfied (15.1)	16.1	16.4	12.4	19.4
	Somewhat satisfied (38.4)	13.3	12.4	10.0	16.4
	Neither satisfied nor dissatisfied (15.0)	11.2	10.4	8.0	13.4
	Somewhat dissatisfied (21.1)	11.0	10.2	8.0	13.4
	Very dissatisfied (10.4)	9.4	9.0	7.0	11.4
Vitality	Very satisfied (15.1)	14.5	14.0	12.0	18.0
	Somewhat satisfied (38.4)	11.9	12.0	9.0	15.0
	Neither satisfied nor dissatisfied (15.0)	10.0	10.0	6.0	13.0
	Somewhat dissatisfied (21.1)	9.6	9.0	6.0	12.0
	Very dissatisfied (10.4)	8.2	8.0	5.0	10.0
Social function	Very satisfied (15.1)	8.4	9.0	7.0	10.0
	Somewhat satisfied (38.4)	7.4	8.0	6.0	9.0
	Neither satisfied nor dissatisfied (15.0)	6.5	7.0	5.0	8.0
	Somewhat dissatisfied (21.1)	6.2	6.0	5.0	8.0
	Very dissatisfied (10.4)	5.4	5.0	4.0	7.0
Role-emotional	Very satisfied (15.1)	5.3	6.0	5.0	6.0
	Somewhat satisfied (38.4)	4.8	5.0	3.0	6.0
	Neither satisfied nor dissatisfied (15.0)	4.5	4.0	3.0	6.0
	Somewhat dissatisfied (21.1)	4.2	4.0	3.0	6.0
	Very dissatisfied (10.4)	4.1	4.0	3.0	5.0
Mental health	Very satisfied (15.1)	24.1	25.0	22.0	27.0
	Somewhat satisfied (38.4)	22.3	23.0	19.0	26.0
	Neither satisfied nor dissatisfied (15.0)	21.2	22.0	18.0	25.0
	Somewhat dissatisfied (21.1)	20.5	20.0	17.0	25.0
	Very dissatisfied (10.4)	19.8	20.0	16.0	24.0

PCS scores among SLE, RA, and NIRD patients (Table 1), but there were differences in the individual domains. There were, however, differences in MCS scores, with the most abnormal scores being found in SLE and then RA. These results are consistent with findings of a Norwegian SLE/RA EQ-5D study⁴.

To place scores into a meaningful clinical perspective, we categorized them according to patient's satisfaction with health (Tables 4a, 4b). In general, the mean SF-36 and EQ-5D scores fall just below the category "somewhat satisfied" (Figure 2). It is of particular interest that the "best" category ("very satisfied") has a mean value for EQ-5D of 0.84 and the mean score for US adults aged 45–64 years is 0.82¹⁰. This helps to further validate the satisfaction categorizations. The best values for PCS and MCS were 45.4 and 50.1, respectively, for patients with SLE.

There are a number of limitations in the use of EQ-5D results. The EQ-5D is only one of a number of utility scales, and each scale produces a different utility^{31,32} and the utility weight differs according to whether the weight is determined by patients or the general populations³³. In addition, the EQ-5D is less sensitive to change than the SF-36, as the EQ-5D tries to summarize health status in just 5 questions^{34,35}. The EQ-5D is also very sensitive to outliers, given its long tail. With respect to the EQ-5D VAS and the EQ-5D, we found a stronger association between the PCS and EQ-5D (0.717) than with the PCS and EQ-5D VAS (0.607). One explanation for this difference is that the PCS and EQ-5D are based on specific questions, while the EQ-5D VAS acts more as a global scale in which "overall" QOL rather than item-specific QOL can predominate. We also found that association between EQ-5D VAS and EQ-5D

was 0.607 compared with the stronger association between the PCS and EQ-5D of 0.717. We hypothesize that the PCS, as a longer and more representative measure, better identifies the overall QOL of the VAS scale.

Also, QOL is reduced with increasing age, disease duration, lower income, and educational attainment. In presenting our data, we did not adjust results for these factors because we wanted to observe results for the disorder in general. In addition, QOL is dependent on the severity of the population under study, and might be expected to vary somewhat across clinics and settings. Patients' decisions to enroll and participate in our study, compared with non-enrollees in the community, may have introduced biases that influenced some of the results. In addition, patients in this study, as with most survey research, do not reflect the demographic characteristics of the community, being better educated, having higher household incomes, and being composed of fewer minorities.

In summary, QOL in SLE, RA, and NIRD is similar with respect to SF-36 PCS scores and EQ-5D results. SLE patients have the lowest MCS scores of the 3 disorders. Patients with FM have the lowest QOL scores, regardless of measure. QOL in SLE is predicted by damage, comorbidity, age, household income, and educational attainment. About 47% of SLE patients are somewhat (22.1%) or very satisfied (15.1%) with their health.

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