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Concise Report

The systemic lupus erythematosus tri-nation study: longitudinal changes in physical and mental well-being

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Objective. **We have shown that SLE patients in Canada and the UK incurred 20% and 13% lower health costs than those in the US, respectively, but did not experience worse outcomes as expressed by the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index. We now compare change in quality of life in these patients.**

Patients and methods. **Seven hundred and fifteen SLE patients (Canada 231, US 269, UK 215) completed the SF-36 annually over four years. The annual change in the SF-36 Physical and Mental Component Summary (PCS and MCS) scores over the course of the study were summarized by estimating a linear trend for each individual patient using hierarchical modelling. Cross-country comparison of the slopes in the PCS and MCS scores was then performed using simultaneous regressions.**

Results. **The estimated mean annual changes (95% credible interval [CrI]) in the PCS scores in Canada, the US, and the UK were 0.18 (−0.07, 0.43), −0.05 (−0.27, 0.17), and 0.03 (−0.20, 0.27), respectively; the mean annual changes in the MCS scores were 0.15 (−0.04, 0.34), 0.23 (0.09, 0.37), and 0.08 (−0.10, 0.27), respectively. Regression results showed that the mean annual changes in PCS and MCS scores did not substantially differ across countries.**

Conclusion. **Quality of life remained stable across countries. Despite Canadian and British patients incurring lower health costs, on average, patients experienced similar changes in physical and mental well-being.**

KEY WORDS: Quality of life, Health status, Systemic lupus erythematosus, Disease damage, Direct healthcare costs.

Introduction

Systemic lupus erythematosus (SLE) is a chronic multisystem disease that primarily affects young women. Disease manifestations are variable and unpredictable, potentially influencing both physical and psychological functioning. Patients may suffer frequent exacerbations of disease activity and consequently accumulate chronic organ damage. Thus, assessment of SLE includes measurement of disease activity, with instruments such as the revised Systemic Lupus Activity Measure (SLAM-R) [1] and the SLE Disease Activity Index (SLEDAI) [2], and cumulative damage with the Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index (SLICC/ACR DI) [3]. Increasingly, it is recognized that a comprehensive evaluation of SLE also requires characterization of the patients' health related quality of life as an independent outcome [4–7].

Although several measures of quality of life have been studied in SLE, the Medical Outcomes Study Short Form 36 (SF-36) is the most widely accepted [8]. The SF-36 is a generic instrument designed to measure the impact of disease on a patient's physical, social, and psychological function. It has been shown to be internally consistent and to have criterion, construct, and discriminatory validity in patients with SLE [6]. Furthermore, because it is generic, comparisons can be made with other patient groups.

Previous studies pertaining to quality of life in SLE have been limited. Most have been cross-sectional, possibly misrepresenting how patients live with lupus over time. Systemic lupus, characterized by episodes of exacerbation and remission, likely results in

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varying levels of health status. Two previous longitudinal studies have been performed, but their study populations were small and were recruited from a single centre [9, 10]. In this study, we examined quality of life as expressed by the SF-36 Physical and Mental Component Summary (PCS and MCS) scores over a 4-yr period in patients from six centres in Canada, the US, and the UK.

Patients and methods

Patients

Consecutive patients presenting in each of six tertiary care centres and fulfilling at least four of the ACR revised criteria for SLE [11, 12] were invited to participate in a comparative study on health expenditure, accumulation of disease damage, and quality of life. The health expenditure and damage accumulation have been described [13–16]; this report discusses quality of life. There were two centres in each of three countries: the Montreal General Hospital and Hôpital Notre-Dame, Montreal in Canada; Johns Hopkins University School of Medicine, Baltimore and the University of Pittsburgh in the US; and University College Hospital, London and the Queen Elizabeth Hospital, Birmingham in the UK. Patients were enrolled between July 1995 and February 1998. The dates of the final follow-up assessments fell between May 1999 and October 2001. Approval was obtained from each centre's Institutional Review Board and informed consent from each participant.

Procedures

At study entry and annually, for a maximum of four years, participants completed questionnaires on quality of life, social support, and satisfaction with health care. Also at study entry and semi-annually they reported on health resource utilization. At study entry and conclusion, the patient's treating physician completed disease activity and damage measures.

Study instruments

Quality of life was assessed by the SF-36 [6, 17, 18] and a visual analogue scale (VAS) adapted from the EuroQol [19, 20]. Social support was evaluated through the Interpersonal Support Evaluation List (ISEL) [21] and patient satisfaction through the Medical Outcomes Study Patient Satisfaction Questionnaire (version IV) [22]. Health resource utilization was measured through a modified version of the economic portion of the Stanford Health Assessment Questionnaire [23]. Disease activity was assessed through the SLAM-R [1] and a VAS of current activity and activity over the past year and disease damage through the SLICC/ACR DI [3, 24].

Statistical methods

Demographics, disease characteristics, direct costs, and quality of life were expressed across countries using means and standard deviations (S.D.) and medians, interquartile ranges, and proportions as appropriate. Given the fluctuating nature of disease activity in SLE patients, and hence the variability in their quality of life, comparison of baseline and final values does not reflect the full quality of life experience of these patients. Therefore, to better characterize long-term change in quality of life, all SF-36 PCS and MCS scores over the course of the study were used to estimate the linear trend across time within each individual patient. This was done through two-level hierarchical linear modelling, an approach that allows the borrowing of strength across patients while still allowing for individual within-patient variations [25]. We used the Gibbs sampler as implemented in WinBUGS 1.4 software to estimate the model parameters, with 95% credible intervals (CrI).

For patients who provided incomplete data, (i.e. those who withdrew, were lost to follow up, died, or provided data at entry and conclusion but failed to complete all SF-36 questionnaires), missing PCS and MCS scores were managed through multiple imputation using best predictive regression models with all available data from all patients as potential covariates [26]. Potential covariates included age, sex, ethnicity (Caucasian versus non-Caucasian), education (both as years and categorical as <12 or ≥ 12 years), marital status (married versus unmarried), disease duration, health status (individual SF-36 subscales, summary scores, and patient reported VAS), social support (ISEL total score), patient satisfaction with health care (individual subscales), health expenditure, disease activity (both the SLAM-R and physician reported VAS of current activity and activity over the past year), and disease damage. Consistent with our previous analysis [16], for subjects who died during the 4-yr study, imputations were performed up to four years after entry. Alternative modeling strategies, such as omitting deceased patients or including them without performing imputations, would either create a selection bias or make it appear as if death were cost-saving.

A sensitivity analysis was also conducted [27] to account for the possibility of unobserved differences between those providing complete and incomplete data using the following assumptions: (1) multiplying by 0.5 the imputed PCS and MCS scores after the last available data for those who died and by 0.75 for those who withdrew or were lost to follow up, (2) the same as assumption #1, but only for the deceased, (3) the same as assumption #2 and multiplying the imputed PCS and MCS scores by 1.5 for those who withdrew or were lost to follow up. In this way, we provide results for potential differences as large as 50% larger or smaller than those observed.

Cross country comparisons of the patient-specific rate of change in the SF-36 PCS and MCS scores were then performed using simultaneous regressions with indicator variables for the country where the patient was receiving care, with the US as the reference. Only study entry values of the above covariates were considered. These regressions also included as outcomes cumulative health expenditure and damage accumulation over the 4-yr study [16].

For all regressions, model selection was based on Bayes factor as approximated by the Bayesian Information Criteria. This has been shown to have optimal properties for future predictions [28].

Results

Seven hundred and fifteen patients were enrolled (Canada 231; US 269; UK 215). One hundred and sixty one patients (70%) completed the SLICC/ACR DI at entry and conclusion and at least three of five SF-36 questionnaires in Canada, 154 patients (57%) in the US, and 163 patients (76%) in the UK. Thirteen patients (6%) died in Canada, 18 patients (7%) in the US, and 10 patients (5%) in the UK. Fifty-seven patients (25%) provided incomplete data in Canada, 97 (36%) in the US, and 42 (20%) in the UK. Baseline demographics and disease features by country are presented in Table 1.

Within each country, there were no clinically meaningful differences in demographics, disease characteristics, and direct costs in those patients completing at least three SF-36 questionnaires and those who provided incomplete data (excluding deceased patients) [16]. In all countries, those patients completing at least three SF-36 questionnaires differed from deceased patients, with the difference being greatest in Canada. Deceased Canadian patients were older, had greater disease activity and damage, and incurred higher medical expenditure.

When all patients were included by using multiple imputation for those who provided incomplete data, the annual change in the mean PCS score (95% CrI) was 0.18 (-0.07, 0.43), -0.05 (-0.27,

Table 1. Baseline characteristics of study participants

	Canada ($n=231$)	United States ($n=269$)	United Kingdom ($n=215$)
Age, yr, mean (s.d.)	43.2 (13.7)	39.0 (11.9)	40.7 (12.1)
Female, %	93.5	95.1	94.8
Caucasian, %	84.8	67.4	77.7
Completing secondary education, %	62.3	85	68.2
Married, %	47.8	52.2	63.3
Disease duration, yr, mean (s.d.)	10.0 (7.5)	8.6 (6.2)	10.0 (7.1)
SLAM-R (0 = no activity; 84 = maximum activity)			
Mean (s.d.)	7.3 (4.9)	4.1 (3.5)	6.3 (3.9)
Median (IQR)	6.2 (3.1, 10.3)	3.1 (1.0, 6.0)	5.5 (4.0, 8.6)
SLICC/ACR DI (0 = no damage; 46 = maximum damage)			
Mean (s.d.)	1.8 (2.4)	1.7 (1.9)	1.3 (1.7)
Median (IQR)	1.0 (0.0, 3.0)	1.0 (0.0, 3.0)	1.0 (0.0, 2.0)
Physician VAS of disease activity over the past year (0 = no activity; 10 = maximum activity)			
Mean (s.d.)	2.1 (2.0)	2.2 (1.9)	2.1 (1.9)
Median (IQR)	1.4 (0.6, 3.0)	1.5 (0.9, 3.0)	1.6 (0.8, 2.9)
Patient VAS (0 = worst imaginable health state; 100 = best imaginable health state)			
Mean (s.d.)	69.1 (17.4)	66.0 (21.0)	59.7 (23.7)
Annual total direct medical costs* (2002 Canadian $)			
Mean (s.d.)	4968 (8646)	5055 (7194)	4763 (7568)
Median (IQR)	2085 (1118, 4421)	2651 (1301, 6314)	2526 (1263, 5009)

s.d., standard deviation; SLAM-R, Systemic Lupus Activity Measure – Revised; IQR, Interquartile range; SLICC/ACR DI, Systemic Lupus International Collaborating Clinics/American College of Rheumatology Damage Index; VAS, Visual analog scale.

*To compare the overall value of resource utilization across countries, it was necessary to collapse diverse resource components into a single measure by assigning costs to these resources. The method for calculating direct costs has been published by us [13, 16]. By applying a constant price across countries for each health service, any observed cost differences can then be attributed to differences in pattern or frequency of resource utilization. Canadian prices (2002 dollars) were applied to each health service across all three countries.

Table 2. PCS and MCS scores at baseline, study conclusion, and annual change

	Canada ($n=231$) mean (95% CI)	United States ($n=269$) mean (95% CI)	United Kingdom ($n=215$) mean (95% CI)
PCS score			
Baseline PCS score	40.64 (39.12, 42.15)	37.37 (35.94, 38.80)	36.58 (34.92, 38.24)
Final PCS score	41.36 (39.79, 42.93)	37.34 (35.92, 38.75)	37.24 (35.59, 38.89)
PCS score annual change (units/year)	0.18 (−0.07, 0.43)*	−0.05 (−0.27, 0.17)	0.03 (−0.20, 0.27)
MCS score			
Baseline MCS score	45.88 (44.30, 47.45)	45.02 (43.68, 46.36)	43.47 (41.78, 45.16)
Final MCS score	45.95 (44.59, 47.31)	46.55 (45.44, 47.65)	44.07 (42.62, 45.53)
MCS score annual change (units/year)	0.15 (−0.04, 0.34)*	0.23 (0.09, 0.37)	0.08 (−0.10, 0.27)

CI, confidence interval; PCS; SF-36 Physical Component Summary score; MCS, Mental Component Summary score (represent aggregate scores of the SF-36 subscales [18]).

*Refers to 95% credible intervals.

0.17) and 0.03 (−0.20, 0.27), respectively, in Canada, the US, and the UK (Table 2). The annual change in the mean MCS score (95% CrI) was 0.15 (−0.04, 0.34), 0.23 (0.09, 0.37), and 0.08 (−0.10, 0.27) in Canada, the US, and the UK. Therefore, within each country, the mean PCS and MCS scores remained stable over the study period.

The regression models for the estimated annual change in the PCS and MCS scores are shown in Table 3. The annual change in the PCS score (95% CI) showed a very slight and clinically negligible increase of 0.32 (−0.05, 0.68) units in the Canadian patients and a similarly negligible increase of 0.11 (−0.23, 0.45) units in the British patients compared to the Americans. The annual changes in the MCS scores were also of no clinical importance, with a decrease of 0.09 (−0.17, 0.36) units in the Canadians and a decrease of 0.13 (−0.12, 0.38) units in the British compared to the Americans.

The regressions for cumulative health expenditure and damage accumulation over the four-year study did not change substantially from the original analysis [16]. Canadians incurred 19% (6%, 31%) lower costs and the British 12% (0%, 24%) lower costs than Americans, versus 20% (8%, 32%) and 13% (1%, 23%) lower costs in the original analysis. The SLICC ACR/DI increased by 0.10 (−0.03, 0.24) units less in Canadians and by 0.13 (−0.01, 0.26) units less in the British relative to the Americans, versus 0.10 (−0.03, 0.23) and 0.12 (−0.01, 0.26) units less in the original analysis.

Discussion

We have previously shown that although SLE patients in Canada and the UK incurred lower health expenditures than those in the US, there were no differences in accumulation of disease damage [16]. In this manuscript, we present the first longitudinal, transnational comparison of quality of life in SLE. We show that quality of life, as measured by the SF-36, remains stable over time within each country, with all credible intervals ruling out any changes even approaching half a point on the PCS or MCS scales.

TABLE 3. Regression model for average annual change in PCS and MCS scores

Predictors	Coefficient	95% confidence interval
PCS score		
Canada	0.32	−0.05, 0.68
United Kingdom	0.11	−0.23, 0.45
Baseline PCS	−0.04	−0.07, −0.02
Age	−0.013	−0.022, −0.003
Baseline physical functioning*	0.009	0.001, 0.016
Baseline general health*	0.010	0.002, 0.017
Vitality*	−0.005	−0.012, 0.003
Physician completed VAS over the past month	0.06	−0.02, 0.13
Baseline direct costs (transformed on the log scale)	−0.14	−0.24, −0.04
MCS score		
Canada	−0.09	−0.36, 0.17
United Kingdom	−0.13	−0.38, 0.12
Baseline MCS	−0.016	−0.028, −0.004
Baseline PCS	0.007	−0.004, 0.018
Baseline ISEL total score	0.004	−0.003, 0.011

PCS, SF-36 Physical Component Summary Score; MCS, SF-36 Mental Component Summary Score; VAS, Visual analog scale of disease activity over past month; ISEL, Interpersonal Support Evaluation List.
*Subscale of the SF-36.

It has been suggested that minimum clinically important differences, which should reflect a degree of change perceptible to patients, requires changes of 5 to 10 points in the individual domains of the SF-36 and 2.5 to 5 points for the PCS and MCS scores [29]. After adjustment for any possible confounders, our regression analysis also ruled out any substantial differences in the PCS and MCS scores between countries.

Over the 4-yr study, there was greater patient attrition in the US which we adjusted for using imputations. Although we have shown that those patients who withdrew, were lost to follow-up, or otherwise provided incomplete data (excluding the deceased) did not appear to differ from those completing at least three SF-36 questionnaires, it is still possible that unobserved differences may remain. Such unobserved differences may also exist between deceased patients and other participants in addition to the differences observed at baseline. However, through a sensitivity analysis, we found that such potential differences of up to 50% in either direction have no impact on the quality of life outcomes (data not shown).

Although our patients may not necessarily be representative of all SLE patients, they were recruited from several centres and are likely more diverse than those described in prior quality of life studies. Given our patients had an average disease duration of 10 years, it is probable they had relatively stable disease and had adapted to their illness, consequently reporting a better quality of life than patients with disease for a shorter duration. However, by enrolling patients from specialized lupus clinics in tertiary centres, we may have included a greater proportion of patients with more severe disease than if we had recruited primarily from general rheumatology clinics.

The SF-36 assesses the preceding one-month period yet our patients were only surveyed yearly. Therefore, our longitudinal assessment of quality of life in SLE is not comprehensive. Given the rapidly fluctuating course of the disease, the instrument may not have captured the patient's full experience with SLE throughout the entire year. Fortin *et al.* [9] administered the SF-36 monthly and were able to demonstrate that over 6 months, the SF-36 scores changed with disease activity. Likely, administration of the SF-36 monthly or every three months would provide a more complete assessment of quality of life. Furthermore, the SF-36 is generic and thus may not be sufficient to characterize the numerous dimensions in which SLE may affect a patient (i.e. infertility, physical appearance). An SLE specific measure may be more appropriate and potentially should be incorporated in quality of life assessments [30, 31].

The compromised quality of life of patients with SLE becomes even more apparent when their PCS and MCS scores are compared to those in the general population. In our study, Canadian patients had mean baseline PCS and MCS scores of 40.6 and 46.0, respectively; American patients had mean scores of 37.4 and 45.0; and British patients had mean scores of 36.6 and 43.4. In the general population, Canadians of a similar age and sex as our study participants (female, age 35–44), would be expected to have a mean PCS score of 51.5 and a mean MCS score of 50.2 [32]. In the US, the mean scores are 51.4 and 48.8 [18]; in the UK the mean scores are 52.4 and 48.3 [33]. As expected, chronic illnesses other than SLE have been shown to impact negatively on the SF-36 scores. For example, in the US, people with arthritis have mean PCS and MCS scores of 43.2 and 48.8; people with congestive heart failure have mean scores of 31.0 and 45.7; and people with diabetes have mean scores of 39.0 and 47.9 [18].

In summary, this 4-yr longitudinal study showed that quality of life remains stable over time in patients with SLE across countries that differ in their health care expenditure.

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