Living with Lupus: A Prospective Pan-Canadian Study

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ABSTRACT. ***Objective.*** To portray life with lupus for women affected by this disease and to identify predictors of fatigue, a common symptom that compromises patients' quality of life.

Methods. A sample of 120 female patients (mean age 42.5 yrs) with systemic lupus erythematosus (SLE) from 9 rheumatology clinics across Canada were followed prospectively for 15 months. Assessments of psychosocial functioning took place at baseline, and at 3, 9, and 15 months. Physician examinations were conducted at baseline and 15 months.

Results. Significant time effects were found for: global psychological distress ($p < 0.001$), stress ($p < 0.01$), emotion-oriented coping ($p < 0.001$), physical health status ($p < 0.001$), and fatigue ($p < 0.001$), indicating that patients improved from baseline to 15 months. Disease activity worsened for 40.3%, improved for 50.8%, and remained the same for 8.8% of the patients from baseline to 15 months. Controlling for baseline disease activity and fatigue, and considering sleep problems, decreases in stress and depression predicted less fatigue at 15 months ($p < 0.001$; adjusted $R^2 = 0.43$).

Conclusion. Despite fluctuations in disease activity, patients with SLE, as a group, cope adequately with their disease over time. There is, nonetheless, a subset of patients (about 40%) who remain distressed and who may benefit from psychosocial interventions. (J Rheumatol 2001;28:2442–8)

Key Indexing Terms:
SYSTEMIC LUPUS ERYTHEMATOSUS   HEALTH STATUS
PSYCHOSOCIAL   PROSPECTIVE STUDY

Systemic lupus erythematosus (SLE) affects primarily young women and is estimated to occur in as much as 0.1% of the population[1]. For many patients, the disease, compounded by the unpredictability of exacerbations, symptomatology, and response to therapy, results in consid-

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Submitted September 15, 2000; revision accepted June 5, 2001.

erable physical disability and psychological distress. The mental health of patients with SLE, although of considerable importance[2,3], has traditionally been underappreciated and poorly understood. Patients may experience secondary psychiatric disorders, acute confusional states, cognitive deficits, and mood disorders due to SLE (e.g., depressive, manic, and mixed disturbances)[4]. Because there are multiple causes for neuropsychiatric symptomatology due to SLE, its prevalence is uncertain. For example, neuropsychiatric abnormalities may reflect direct effects of the illness (e.g., acute inflammatory polyradiculoneuropathy, seizures) or side effects of medications used to treat SLE (e.g., prednisone). Yet, given the correlational nature of most data reported, it is impossible to determine whether psychosocial problems preceded or were precipitated by the illness itself. In addition, the methodological weaknesses of the various studies[2,3], i.e., small, unrepresentative samples, retrospective research designs, failure to use standardized measures, and poor or no comparison groups, render the conclusions pertaining to prevalence rates of psychiatric disorders in SLE tentative[5].

Clinicians and patients note that taxing events or experiences (i.e., stress) appear to provoke exacerbations of SLE physical symptoms. Wekking, *et al*[6] explored this relationship in a small sample of patients with SLE. They found a significant relationship between daily experiences considered to be stressful and illness-related variables (e.g., renal

function, pain, physical ability, and autoantibodies). Adams, et al[7] followed 41 patients with SLE who self-monitored both physical and psychological symptoms over a 49 day period. They found that stress, depression, and anxiety predicted joint pain; stress predicted severity of rash; and stress, depression, and anger predicted abdominal distress and temperature elevations.

McCracken, et al[8] combined cross sectional and longitudinal designs to study coping and health status in patients with SLE. Questionnaires were completed at baseline and mailed out 6 months later. Sample sizes were 46 and 22, for the 2 time periods, respectively. Baseline associations indicated that passive coping strategies were significantly related to poorer psychological adjustment and functional status. Problem focused coping was significantly associated with less depression. Longitudinal analyses showed that wishful thinking (i.e., passive coping) at baseline was predictive of greater pain and depression whereas seeking social support at baseline predicted less pain, physical disability, psychological distress, and depression, about 7 months later. While this study was flawed in many ways (poor response rates, lack of physician assessed disease activity, limited power for data analyses), it was the first to study coping in a population with SLE.

Literature pertaining to patient adjustment to SLE has been restricted in several ways. First, reliance on cross sectional studies (with the exception of a few studies examining neuropsychological functioning[9-11]) obscures our view of how patients live with lupus over time. A study we published highlights the need for longitudinal data: when patients with SLE were subdivided into those with more or less active disease states, it was clear that psychological distress was more likely to be present when patients were in a disease flare. Moreover, variables associated with mental and physical health varied by disease status[12]. It follows that since SLE is a recurrent, relapsing disease, patients' health status may vary over time. A second problem stems from focusing on dysfunction (i.e., psychiatric symptoms). Presumably many patients learn to cope with their illness, but little is known about how they do so. Also, sample sizes have been small and psychosocial measures with adequate psychometric properties have only been employed recently.

We followed 120 patients for 15 months by tracking quality of life, focusing on psychosocial factors such as stress, depression, coping, and social support (over time), and exploring further contributors to disease activity and fatigue.

MATERIALS AND METHODS

Subjects and procedure. Women with a diagnosis of SLE according to American College of Rheumatology criteria[13] were invited to participate in a randomized clinical trial by their treating physician from 9 immunology/rheumatology clinics across Canada. The results of the randomized clinical trial are reported elsewhere[14]. Informed consent was obtained prior to study commencement. Patients were examined by the same rheumatologist at study entry and 15 months later. At baseline, 3, 9, and 15 months post study entry, patients completed a battery of questionnaires that included measures of psychological distress, social support, coping, stress, and health-related quality of life. It would have been optional to have patients examined by a rheumatologist at all 4 time periods, but this was not feasible due to clinic demands upon physicians. The final sample consisted of 120 women with SLE. (The exact number of participants in the present study and the RCT[14] differed slightly due to differences in data analyses in the 2 reports. Included in this study were patients who contributed complete data at baseline, 3, 9, and 15 months, whereas the RCT included those with complete data at baseline and 15 months[14].)

Measures. The Symptom Checklist 90-Revised (SCL-90-R)[15] is a 90 item self-report questionnaire that reflects psychological symptom patterns of psychiatric and medical patients as experienced in the past week. It consists of 9 primary dimensions that include: somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism. The 9 subscales can be combined to describe a global index of distress. The Global Severity Index (GSI) reflects both the number and intensity of symptoms and is considered to be the best single indicator of psychological distress. Higher scores on the SCL-90-R indicate greater psychological distress. Normative data (based on a random sample of non-psychiatric female respondents) and standardized T scores facilitate interpretation, with 50 as the norm and one standard deviation (SD) above (i.e., 10) indicating a problem[15].

The SCL-90-R has 7 items that are not used to calculate scores on its 9 subscales. Three of these items (trouble falling asleep, awakening in the early morning, sleep that is restless or disturbed) assess sleep problems. Scores on these items were combined to create a poor sleep variable. Baseline, 3, and 9 month scores were averaged resulting in one score per subject.

The shortened version of the Social Support Questionnaire (SSQ6) was used to assess perceived availability and satisfaction with social support[16]. The SSQ6 is psychometrically sound and consists of 12 items that are subdivided into 2 subscales. Six items assess network size and the remaining 6 items measure satisfaction with the available social support[16]. Given the modest intercorrelation between the 2 subscales, it has been suggested that the 2 scores be examined separately[16]. Network size scores range from 0 to 9, higher scores reflecting a larger social support network. Scores on the satisfaction subscale range from 0 to 6, with higher scores indicating greater satisfaction.

Coping style was assessed with the psychometrically sound Coping Inventory for Stressful Situations (CISS)[17]. The CISS is a 44 item questionnaire that assesses cross situational coping preferences. It consists of 3 subscales that measure task–oriented (e.g., schedule time better), emotion–oriented (blame self, worry about the future), and avoidance (watch TV, call a friend) coping. The CISS subscales have been found reliable with coefficients ranging from 0.77 to 0.90. The emotion and task–oriented coping strategies have consistently been linked with physical and mental health outcomes[18,19].

The revised version of the Hassles Scale was used to assess stress during the past month[20]. This validated and reliable version consists of a list of 54 minor stressors that can occur in daily life. Respondents indicate the degree of distress they have experienced as a result of the various events. Responses on each item vary from "not at all/not applicable" (0) to "extremely severe" (3). Total scores can vary from 0 to 162, with higher scores reflecting greater stress.

The Short Form Health Survey (SF-36™)[21] was used to assess health-related quality of life. The SF-36™ is a psychometrically sound and widely used measure[22]. It consists of 36 items and measures 8 aspects of health and well being: physical functioning, role limitation due to physical health, bodily pain, general health, vitality, social functioning, role limitation due to emotional problems, and mental health. Of the 36 items, 20 refer to the past month. Scores on each scale vary from 0 to 100, with higher scores indicating better health status. Recently, it has been shown that the SF-36™ subscales can be summarized into 2 component scores: the physical health

component summary (PCS) and the mental health component summary (MCS)[23]. The PCS and MCS are standardized to have a mean of 50 and a standard deviation of 10 for the US population[24]. Correlations obtained between the 8 subscales and the 2 summary scores support the mental and physical health distinction. The summary scores were used in this study because they offer a valid way of reducing the number of statistical comparisons and lowering the probability of chance findings[23]. Recently, Canadian norms have become available[25].

We used the vitality subscale as a proxy measure of fatigue; it contains the following 4 items: Did you feel full of pep? Did you have a lot of energy? Did you feel worn out? Did you feel tired? The vitality subscale has been shown to correlate highly with the fatigue severity scale in patients with SLE[26].

Disease activity was measured using the Systemic Lupus Activity Measure (SLAM-R)[27]. The SLAM-R is a reliable and valid instrument used to measure disease activity in a number of organ systems — constitutional, integument, ocular, reticuloendothelial, pulmonary, cardiovascular, gastrointestinal, neuromotor, musculoskeletal, hematologic, and renal. Although validation data are only available on the original SLAM, the differences between the original and revised versions are minor. The SLAM-R is based on physician's examination and laboratory assessment that includes a complete blood cell count, erythrocyte sedimentation rate, creatinine, and urinalysis. Scores may range from 0 (no disease activity) to 84 (maximum disease activity). Based on our experience, a score of 8 or more indicates moderate to severe clinical activity[28]. The SLE Disease Activity Index (SLEDAI), another physician-rated valid and reliable index, was also used to assess lupus activity. It comprises 24 descriptors with preassigned severity weights. The total SLEDAI score can range from 0 (no activity) to 105 (maximum activity). The SLEDAI differs from the SLAM-R in that the former does not, in some descriptors, consider ongoing disease activity, but only recurrent or new manifestations[29]. Both SLAM-R and SLEDAI have been shown to be responsive to change in lupus activity measured by the treating physician[30]. Both measures of disease activity were taken at baseline and 15 months.

SLE disease damage was measured using the Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR) Damage Index[31,32]. The SLICC/ACR is a physician-rated index that assesses cumulative organ damage due either to the disease, complications of therapy, or intercurrent illness such as cancer. It includes 12 categories: ocular, neuropsychiatric, renal, pulmonary, cardiovascular, peripheral vascular, gastrointestinal, musculoskeletal, skin, premature gonadal failure, diabetes, and cancer. Total scores range from 0 (no damage) to 46 (maximum damage)[31,32].

Data analyses. Descriptive statistics including means, medians, and SD were calculated for all variables collected during each assessment period. A series of repeated measures analyses of variance (ANOVA) were conducted to examine time differences on the psychosocial and health status variables. A Pearson correlation matrix was computed to examine bivariate correlations between the outcome variables (fatigue and disease activity) and each potential predictor variable. Patterns of intercorrelations among predictor variables were also examined. A hierarchical multiple regression model was built to determine the relative importance of disease status and psychosocial variables in predicting fatigue at 15 months. Hierarchical multiple regression is the regression strategy of choice when the research goals are to determine the relative importance of predictor variable(s) once other predictor variables have already been entered into the equation[33]. Variable selection was based on theoretical relevance, pattern of correlation with the outcome variables, and other potential predictor variables. In general, change scores in the psychosocial constructs are of greater interest than the baseline value when there are differences over time. Nonetheless, when there was little change over time, the baseline value was entered.

RESULTS

Subjects. Table 1 summarizes the patients' demographic and

Table 1. Sample characteristics.

	Mean	SD	Range
Demographics			
Age, yrs	42.50	10.83	18.98–73.80
Education, yrs	13.77	2.89	3–18.0
Income*	3.92	1.90	1–6
Race,%			
Caucasian	84.2		
Other	15.8		
Marital status, %			
Single	28.3		
Married	42.5		
Divorced/separated	25.0		
Widowed	4.2		
Clinical			
SLAM-R (disease activity)	7.18	3.38	0–17.0
SLEDAI (disease activity)	6.54	5.96	0–28
SLICC/ACRDI (disease damage)	1.46	1.73	0–8.0
Disease duration, yrs	10.83	8.67	0.36–38.74
Baseline prednisone, mg over 6 mo	1434.68	2282.14	0–11,437.50

* Combined Household Income Scale 1–6, e.g., 3 = $20,000–30,000; 4 = $31,000–40,000.

clinical characteristics for 120 subjects. The mean age was 42.50 years (SD 10.83); subjects were predominantly middle class and Caucasian (84.2%). Almost half were married (42.5%). At baseline, the mean time since diagnosis was 10.83 years (SD 8.67); the mean SLAM-R score was 7.18 (SD 3.38), indicating moderate to severe disease activity; the mean SLEDAI score was 6.54 (SD 5.96); the mean SLICC/ACRDI score was 1.46 (SD 1.73).

Psychosocial functioning over time. Table 2 shows scores obtained at baseline, 3, 9, and 15 months on the following psychosocial measures: hassles (i.e., minor stress, during the past month), social support (no time period specified), and coping (no time period specified). Repeated measures ANOVA were computed for each measure to determine if there were significant changes over time; paired t tests were subsequently performed to identify the source of the differences.

Minor stressors decreased significantly over time [$F_{(3, 357)} = 4.03$, $p < 0.008$]. Specifically, there was a significant difference between baseline and 3 months ($p < 0.05$), baseline and 9 months ($p < 0.04$), and baseline and 15 months ($p < 0.007$). As for social support, it remained stable over time, both for network size and level of satisfaction with support. The network size was somewhat lower than healthy adult women, whose network size was, on average 4.37 (SD 2.12). Nonetheless, the level of satisfaction with social support was similar, on average 5.07, (SD 1.09) to healthy adult women (Sarason IG, personal communication, 1993).

Only emotion-oriented coping decreased significantly, over time [$F_{(3,357)} = 5.84$, $p < 0.001$]. Specifically, there was a significant difference between baseline and 9 months ($p < 0.005$), and baseline and 15 months ($p < 0.001$). When

Table 2. Mean (SD) scores for psychosocial variables over time.

	Baseline	3 mo	9 mo	15 mo	Normative
Stress					
Hassles*	39.65 (21.76)	37.31 (21.78)[c]	36.64 (20.39)[b]	35.48 (21.78)[a]	—
Social support					
Network size	3.32 (1.81)	3.18 (1.79)	3.03 (1.65)	3.24 (1.87)	4.37 (2.12)
Satisfaction	5.08 (0.96)	4.99 (1.07)	5.06 (0.97)	5.08 (1.01)	5.07 (1.09)
Coping style					
Task-oriented*	52.39 (13.09)	51.85 (13.19)	50.57 (13.40)	51.03 (13.92)	58.60 (8.65)
Emotion-oriented*	39.83 (12.36)	38.47 (11.38)	36.91 (12.40)[b]	36.70 (11.92)[a]	42.57 (11.35)
Avoidance	41.58 (9.17)	40.20 (9.76)	39.81 (9.65)	39.12 (9.42)	38.10 (9.71)

* Significant time effect; [a] Significant paired differences between baseline and 15 mo; [b] Significant paired differences between baseline and 9 mo; [c] Significant paired differences between baseline and 3 mo.

Table 3. Means (SD) scores for psychological distress over time.

	Baseline	3 mo	9 mo	15 mo
SCL-90-R Subscales				
Somatization	62.33 (9.70)	61.73 (10.47)	62.33 (9.46)	60.32 (10.97) [a]
Obsessive-compulsive*	62.32 (9.41)	61.60 (10.37)	60.32 (9.82)[b]	58.67 (10.67)[a]
Interpersonal sensitivity*	58.73 (10.55)	57.08 (10.38)	56.92 (10.99)	56.12 (11.00)[a]
Depression*	61.32 (8.65)	59.61 (9.90)	59.52 (9.36)	58.51 (9.94)[a]
Anxiety*	57.73 (10.95)	56.53 (10.89)	56.20 (10.03)	54.75 (11.08)[a]
Hostility	56.01 (10.74)	54.98 (10.62)	53.87 (10.93)	53.06 (11.06)[a]
Phobic anxiety	52.68 (10.07)	52.24 (10.24)	51.83 (9.28)	50.61 (9.11)
Paranoid Ideation	53.20 (10.61)	52.79 (10.35)	51.86 (10.03)	51.94 (10.75)
Psychoticism	59.33 (10.01)	58.07 (10.29)	58.12 (10.03)	56.38 (10.59)[a]
Global severity index*	61.47 (9.39)	60.11 (10.09)	59.88 (9.49)[b]	58.27 (10.77)[a]
Identified "cases" (%)	59 (49.2%)	52 (43.3%)	48 (40%)	42 (35%)

*Significant time effects; [a] significant paired differences between baseline and 15 mo; [b] significant paired differences between baseline and 9 mo.

comparing study participants to normative data[17] obtained from adult women, the SLE patients report fewer task-oriented coping strategies; they were also less likely to use emotion-oriented coping strategies; but they were slightly more likely to use avoidance coping strategies.

Table 3 presents T scores for the 9 subscales of the SCL-90-R, the GSI, and number of cases identified at each time point. There was a significant decrease in global psychological distress over time, [$F_{(3,357)} = 6.36$, $p < 0.001$]. Specifically, there were significant differences on this measure between baseline and 3 months ($p < 0.05$), baseline and 9 months ($p < 0.02$), and baseline and 15 months ($p < 0.001$). Significant decreases over time were also evident for the following subscales: obsessive-compulsive, interpersonal sensitivity, depression, and anxiety.

Results for the SF-36™ subscales show a significant increase over time for vitality [$F_{(3.357)} = 5.29$, $p < 0.001$]. Specifically, there was a significant difference between baseline and 9 months ($p < 0.01$) and baseline and 15 months ($p < 0.001$). While there was no significant change in the Mental Component Summary score over time, there was a significant increase in the Physical Component Summary score over time [$F_{(3.354)} = 6.16$, $p < 0.001$]. Specifically, there was a significant improvement between baseline and 15 months ($p < 0.001$). Figure 1 shows the SLE patients' responses over the 4 time periods compared to normative data provided in Hopman, _et al_[25] for Canadian women, matched in age to our sample. Clearly, living with lupus negatively influences these patients' quality of life, especially with regard to physical health status.

Predicting fatigue at 15 months. A hierarchical multiple regression analysis was conducted to identify predictors of fatigue. The following variables were entered into the model for fatigue: baseline vitality (step 1), baseline disease activity (step 2), sleep problems (composite score over the 9 months; step 3), change in depression from baseline to 9 months, emotion-oriented coping at baseline, changes in stress from baseline to 9 months, and satisfaction with social support at baseline (step 4). Controlling for baseline fatigue and disease activity, changes in depression and stress predicted fatigue at 15 months [$F_{(7,112)} = 13.60$, $p < 0.001$; adj $R^2 = 0.43$]. When depression and stress decreased,
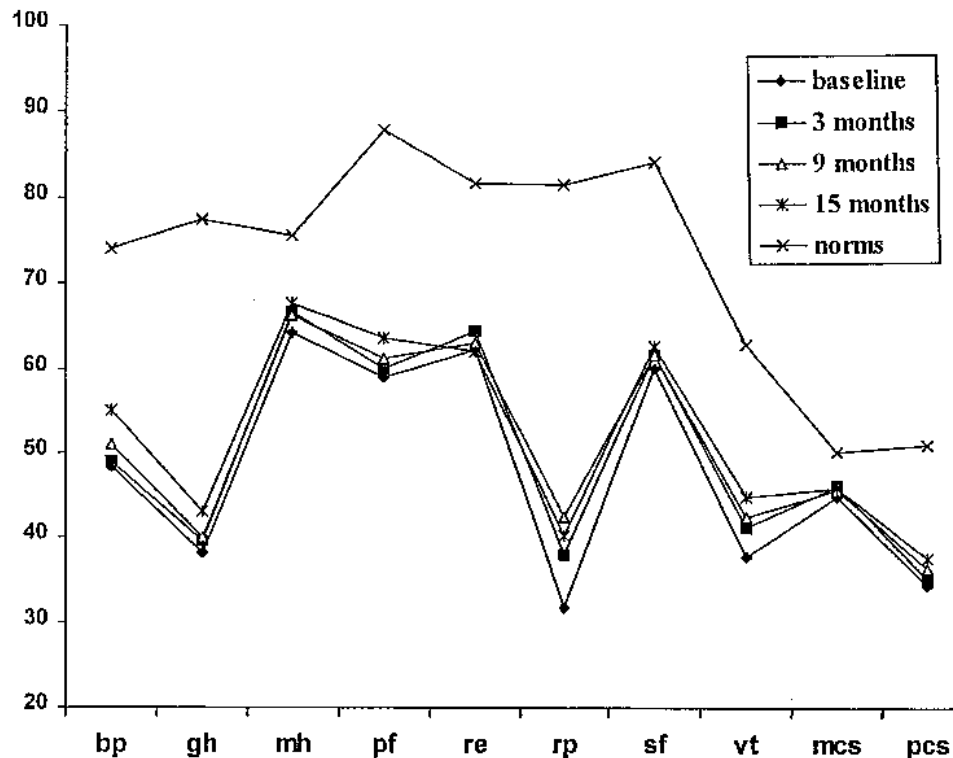
Figure 1. Quality of life of patients with SLE, over time, compared to normative data. bp: body pain; gh: general health; mh: mental health; pf: physical functioning; re: role emotional; rp: role physical; sf: social functioning; vt: vitality/energy; mcs: mental component summary score; pcs: physical component summary score.

patients were less fatigued. These results are shown in Table 4. (The analyses were repeated using the SLEDAI and remained unchanged.)

Examining patients' SLAM-R scores at baseline and 15 months showed that disease activity worsened for 40.3%, improved for 50.8%, and remained the same for 8.8%. Similar analyses were conducted to identify predictors of disease activity at 15 months. Only baseline SLAM-R scores (i.e., no psychosocial variables) were related to SLAM-R scores at the final measurement point.

DISCUSSION

Little is known about how patients with SLE live with their disease over time. While not a study spanning years, this is the first to take a systematic look at a reasonable number of patients being treated across Canada. The most striking result is that, as a group, they improved from baseline to 15 months in terms of psychological distress, stress, coping, physical health status, and fatigue. These results run counter to cross sectional studies that indicate high prevalence of psychiatric dysfunction, especially depression[34,35]. In fact, patients improved on the depression, obsessive-compulsive, anxiety, and interpersonal sensitivity scores. Yet we know from an earlier report that when SLE patients are subdivided into more or less active disease states, many patients who are in an active disease state experience distress[12]. While we could not subdivide our sample at 3 and 9 months based on physician-rated scores to determine if their disease was active at those times, we did track level of distress at all time points as well as disease activity at 15 months. Global psychological distress (i.e., GSI ≥ 0.63) was evident in 49.2%, 43.3%, 40%, and 35% of the sample at baseline, 3,

Table 4. Hierarchical multiple regression predicting fatigue at 15 months.

	ß	T
First step		
Fatigue (baseline)	0.58	7.79***
$R^2 = 0.34$; adj $R^2 = 0.33$		
F (1,118) = 60.63		
Second step		
SLAM-R (baseline)	–0.14	–1.88
$R^2 = 0.36$; adj $R^2 = 0.35$		
F (2,117) = 32.73***		
Third step		
Sleep problems	–0.15	–1.80
$R^2 = 0.38$; adj $R^2 = 0.36$		
F (3,116) = 23.32***		
Fourth step		
Depression (change)[a]	–0.18	–2.17**
Emotion-oriented coping (baseline)	–0.13	–1.53
Hassles (change)	–0.20	–2.41*
SSQ6 Satisfaction (baseline)	0.07	0.86
$R^2 = 0.46$; adj $R^2 = 0.43$		
F(7,112) = 13.60***		

*p<0.03;**p<0.01;***p<0.0001. [a]Change score: baseline –9 mo.

9, and 15 months, respectively. While it appears that these improvements in psychological functioning could be related to the fact that about half the sample experienced a reduction in disease activity, only a weak relationship ($r = 0.19$, $p < 0.05$) was observed between changes in psychological distress and changes in disease activity in this study. Even though the majority of patients were faring well by the final followup, there remained a subset who were not and who may need assistance.

Social support remained stable over time and minor stressors decreased from baseline to 3 and 15 months. SLE patients had fewer providers of support than other women, but they were equally satisfied with the support they had. One form of coping decreased over time: emotion-oriented (e.g., blame self for being too emotional, get angry, daydream). This is important because it is considered a maladaptive style for people with chronic illnesses[18]. The only other study of coping in SLE patients found that passive coping (similar to emotion-oriented) was associated with poorer psychological adjustment and functional status in a cross sectional analysis[8]. Compared to other women, SLE patients used less task-oriented coping (e.g., problem solving, cognitive restructuring); given that this style of coping is considered to be beneficial to people with chronic illness[36], patients with SLE could be encouraged to learn these skills. Finally, patients tended to use avoidance coping (e.g., window shop, watch TV, phone a friend) more than other women. This may be a function of living with an illness that can limit activities.

Health-related quality of life as measured by the SF-36™ was relatively stable, with improvements in overall general health and vitality. Figure 1 highlights that SLE patients have significantly poorer physical health status compared to Canadian women their age. Less fatigue at 15 months was predicted by decreases in stress and depression from baseline to 9 months. These findings suggest that fatigue may reflect mental health more than disease activity in these patients. This interpretation is supported by McKinley, *et al*[37], who tested various models to determine contributors to fatigue in SLE patients. They assessed sleep problems and depression via patient report, and had physicians examine patients with a modified SLAM that excluded the fatigue item. They found the effects of disease activity on fatigue were mediated somewhat by depression, but to a much greater degree by sleep disruption. The McKinley investigation was, however, based on cross sectional data from 48 patients and therefore causality could not be inferred from their results. The present study, in contrast, was prospective and found that sleep problems were related to fatigue, but the effect was likely mediated by depression. This interpretation is corroborated by Fifield, *et al*[38], who studied the relationship between fatigue and affective disorders in 415 patients with rheumatoid arthritis (RA) over a 7 year period. It was shown that RA patients with a history of affective disorders had more fatigue initially and continued to report higher levels of fatigue over time compared to RA patients without a history of affective disorder.

Perhaps this entire discussion is adulterated by an implicit dualism regarding the "mind" and body. Living with a chronic illness involves waxing and waning of biopsychosocial processes that cannot be separated other than in an arbitrary manner that allows us to "measure" an elusive construct such as mental health in the past month, or to collect "hard" data pertaining to disease activity (e.g., erythrocyte sedimentation rates) and attempt to link them in one way or the other. Depression, for example, is considered a mental disorder, but as its biological substrates become clearer, especially for patients with SLE[39], we begin to make a conceptual shift towards integrative thinking. Such a shift can be translated into action by approaching patients with the knowledge that their health status is multidetermined and improvements will depend on attention being paid to biological, psychological, and social determinants by both physicians and patients.

The prospective design and relatively large sample size of this study allowed us to portray living with lupus in a way that has not been done previously, but there are limitations to this study that temper conclusions. First, the sample was fairly well educated, predominantly middle class, Caucasian, and drawn primarily from tertiary care rheumatology clinics, limiting generalization. Second, numerous statistical tests were conducted that may have resulted in spurious findings. With regard to significance, while some changes were statistically significant, they were not necessarily clinically so. Also, all patients were participating in a randomized clinical trial[14], which may have produced a Hawthorne effect. Finally, repeated assessment (somewhat akin to self-monitoring, which is known to alter behaviors[40]) may have influenced patients. Perhaps they became more aware that psychosocial factors may be important to their health given that we were invested in studying them intensively. Thus, clinicians may purposely pose questions to their SLE patients pertaining to psychosocial issues to sensitize them to their importance.

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