Effects of Disease Activity, Pain, and Distress on Activity Limitations in Patients with Systemic Lupus Erythematosus

CAROL M. GRECO, THOMAS E. RUDY, and SUSAN MANZI

ABSTRACT. ***Objective.*** To evaluate the extent to which disease activity, pain, and psychological distress predict activity limitations in persons with systemic lupus erythematosus (SLE).

Methods. A sample of 93 persons with SLE completed medical and psychosocial evaluations at one study visit. Sets of measures were chosen to represent constructs of Disease Activity, Pain, Distress, and Activity Limitations. Confirmatory factor analysis was conducted to determine if the measures fit the intended constructs, and structural equation modeling was used to evaluate the direct effects of Disease Activity, Pain, and Distress on Activity Limitations, as well as indirect effects of Disease Activity as mediated by Pain and Distress, and indirect effects of Pain as mediated by Distress.

Results. The confirmatory factor analysis indicated a good fit of the measures to their intended constructs. The overall model predicting Activity Limitations based on Disease Activity, Pain, and Distress accounted for 68% ($p < 0.001$) of the variance in perceived Activity Limitations. Severity of Pain was the only construct that was directly associated with Activity Limitations ($r = 0.70$, $p < 0.001$). The effects of Disease Activity on Activity Limitations were primarily indirect via its influence on Pain. Distress was not significantly associated with Activity Limitations. When Distress was trimmed from the model, the remaining constructs accounted for 66% of the variance in Activity Limitations ($p < 0.001$).

Conclusion. Disease Activity and Pain accounted for a substantial proportion of the variance in Activity Limitations. Pain Severity was the strongest predictor of Activity Limitations. This study highlights the importance of adequate pain management for maintaining quality of life in persons with SLE. (J Rheumatol 2004;31:260–7)

Key Indexing Terms:
SYSTEMIC LUPUS ERYTHEMATOSUS STRUCTURAL EQUATION MODELING
DISTRESS ACTIVITY LIMITATIONS PAIN

Although advances in medical management have greatly reduced mortality associated with systemic lupus erythematosus (SLE), fatigue, pain, and inability to carry out activities remain a significant problem for many persons with this chronic health condition. The recently revised model of functioning and disability of the International Classification of Functioning, Disability, and Health (ICF) emphasizes the complex interactive relationships between organ function and structure, individual activities, and societal participation restrictions[1]. Activity limitation, a domain recommended in the ICF, is beginning to be included in research on the consequences of rheumatologic conditions such as rheumatoid arthritis (RA) and myositis[2,3]. The influence of SLE disease and related psychosocial burdens on activity limitations of patients is the focus of this study.

Reports are mixed regarding associations between SLE patients' perceived health and clinical ratings of disease. Two studies found no significant correlations between health perceptions as assessed by the Medical Outcomes Survey SF-20 and the Systemic Lupus Erythematosus Disease Activity Index (SLEDAI)[4,5]. However, several studies have found moderate correlations between perceived physical health and clinical ratings of disease activity[6-10]. For example, Dobkin, *et al*[8] found a correlation of $r = –0.35$ between disease activity assessed by the Systemic Lupus Activity Measure–revised (SLAM-R) and perceived global physical health on the SF-36 Health Survey. Stoll, *et al*[10] found that disease activity, age, and cumulative SLE damage accounted for a significant but modest amount of variance in the SF-36 Physical Function scale ($R^2 = 0.23$).

From the Research Department, Pain Evaluation and Treatment Institute, University of Pittsburgh School of Medicine and Graduate School of Public Health, Pittsburgh, Pennsylvania, USA.

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C.M. Greco, PhD, Assistant Professor, Departments of Anesthesiology and Rehabilitation Science and Technology, University of Pittsburgh School of Medicine; T.E. Rudy, PhD, Professor, Departments of Anesthesiology, Psychiatry, and Biostatistics; S. Manzi, MD, MPH, Associate Professor, Departments of Rheumatology and Clinical Immunology, and Epidemiology.

Address reprint requests to Dr. C.M. Greco, Research Department, Pain Evaluation and Treatment Institute, Centre Commons Suite 400, 5750 Centre Avenue, Pittsburgh, PA 15206. E-mail: grecocm@msx.upmc.edu

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These studies suggest that the severity of current SLE disease contributes to patients' perceptions of their overall physical functioning, but it is not the only influential factor.

Psychological factors, such as stressful events, depression, and low self-efficacy, also may have an effect on perceived functional ability in patients with SLE[6,9,11,12]. A prospective study found that depression and negative life events were associated with subsequent decreases in function[9]. Similarly, depression and anxiety were the most significant predictors of quality of life in a group of Swedish women with SLE[13]. In a cross-sectional study of 200 persons with SLE, low self-efficacy for managing disease was associated with poor perceived physical functioning[6]. Among individuals with less active SLE disease, younger age and fewer daily hassles predicted 20% of the variance in the physical component score on the SF-36[11]. Thus, psychological distress and stressful events appear to be useful predictors of global indicators of perceived physical function. However, the predictive value of these psychological variables is moderate, similar to disease variables, particularly in individuals whose disease activity is less.

Pain is a frequently reported problem that occurs in up to 90% of persons with SLE[14,15]. However, relatively few studies have examined the direct influence of pain on perceived function. In a study of 106 patients with SLE, pain scores were correlated with perceived disability and psychosocial adjustment[14]. Pain was among a set of variables associated with perceived physical functioning in a cohort of 224 ethnically diverse patients with SLE[16]. In a study of medical costs related to SLE, those patients incurring the highest direct and indirect costs reported the highest levels of pain[17]. Perceived disability and pain severity have been linked in fibromyalgia[18] and RA[19], and in endstage joint disease[20] pain severity has been linked to depressive symptoms. Additionally, a recent study of impairment, activity limitation, and participation restriction in RA found significant correlation between pain and activity limitations as measured by the SF-36 physical function scale[2]. Based on the literature on pain and functional outcomes in lupus and other populations, pain severity may be an important predictor of activity limitation in SLE.

We evaluated the effects of pain severity, psychological distress, and clinically rated disease activity on activity limitations in persons with SLE. We developed a comprehensive model to test directly the associations among these variables (Figure 1). Specifically, we hypothesized that disease activity would have positive direct effects on activity limitations, as well as positive indirect effects on activity limitations because of its influence also on the potential mediators of pain and distress. Pain and distress in turn were hypothesized to have positive direct effects on activity limitations. Pain was hypothesized to have direct positive effects on activity limitations, and also indirect effects through distress. Multiple indicators or measures were selected for each of the 4 constructs (Disease Activity, Pain, Distress, and Activity Limitations) displayed in Figure 1 to increase the reliability of this model[21].

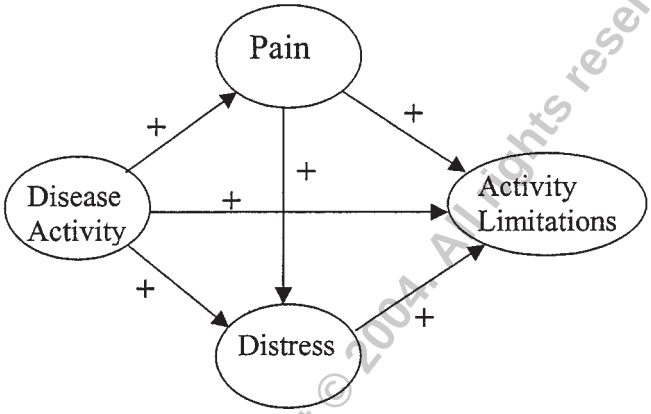

Figure 1. Hypothesized path model and direction predictions for the influence of disease activity, pain, and distress on activity limitations.

MATERIALS AND METHODS

Subjects. Participants were 93 persons diagnosed with lupus by the 1982 revised American College of Rheumatology criteria[21a]. These participants had been enrolled in a study at the Pain Evaluation and Treatment Institute (PETI) of the University of Pittsburgh. The participants were recruited though a mailing to the Pittsburgh Lupus Registry, which records over 900 living individuals with SLE. Persons with active kidney disease or central nervous system disease, persons taking > 15 mg prednisone or the equivalent on a daily basis, and those with no pain in the past month were excluded. These exclusion criteria were based on the need for stable medication regimens and ambulatory status for the PETI study. Demographic information is presented in Table 1.

Of 210 persons responding to the recruitment mailing, 29 (13.8%) reported that they were not experiencing pain. An additional 2 persons were excluded based on medications. Seventy persons reported that they were not interested in participating due to lack of time, transportation, and distance to the facility (10), family reasons (7), or did not state a reason (53). Thus 109 persons were eligible and were invited to attend the study visit. Ninety-three persons kept their clinic appointment, and all of these participants provided complete data for the study. This sample generally was representative of the Pittsburgh Lupus Registry in that age and race

Table 1. Demographic characteristics of study sample.

Age, mean, yrs (SD)	47.3 (10.3)
Years diagnosed with SLE, mean (SD)	11.1 (7.1)
Duration of symptoms, mean yrs (SD)	15.4 (9.1)
Sex, %	
Female	94.6
Male	5.4
Ethnic group, %	
African American	21.5
Caucasian	77.5
Asian	1.0
Marital Status, %	
Single	18.3
Divorced/separated	20.4
Married	58.1
Widowed	3.2

were not significantly different from the Registry [t = 0.937, p = 0.174, and chi-square (2) = 1.86, p = 0.394, respectively]. However, disease duration of this sample (11.1 yrs) was shorter than that of the Registry (13.7 yrs) (t = 3.465, p < 0.001).

Procedures. After completion of informed consent documents approved by the University of Pittsburgh Institutional Review Board, participants completed a questionnaire containing several validated measures of pain, distress, and perceived limitations in activities, and underwent a medical evaluation with a rheumatologist specializing in SLE (SM).

Measures. The model evaluated in this study (Figure 1) included the constructs of Disease Activity, Pain Severity, Distress, and Activity Limitations. Several valid and reliable measures were chosen to represent or operationalize each of these constructs. This multiple indicator approach has the advantage of improving the reliability of each construct. The measures used to represent each construct are described below.

SLE Disease Activity. Physician-rated data on SLE activity included 3 measures. The SLEDAI[22] contains 24 weighted descriptors of signs and symptoms present in the past 10 days, and scores can range from 0 (no activity) to 105. The Systemic Lupus Activity Measure—Revised (SLAM-R)[23] measures disease activity in 11 organ systems over the previous month. Scores on the SLAM-R can range from 0 to 81, and a score of 7 or higher is considered to be a level at which most expert rheumatologists would initiate treatment[24]. In addition, the Physician's Global Assessment (PGA)[25] of SLE activity was completed. The PGA is a 10 cm visual analog scale that has been used in the validation of other instruments.

Pain. Three psychometrically validated self-report measures of pain were included. The Pain Severity scale of the Multidimensional Pain Inventory (MPI-PS)[26] is a 3-item scale assessing present pain severity and suffering over the previous week. The Arthritis Impact Measurement Scales—Revised, Pain Scale (AIMS2-Pain)[27] consists of 5 averaged items (range 0 to 4) that assess frequency and severity of pain and stiffness and pain-related sleep problems. The total score of the McGill Pain Questionnaire—Short Form (MPQ-SF)[28] is designed to measure pain intensity using 15 verbal pain descriptors, such as "aching," "hot–burning," and "stabbing." Each descriptor is rated on severity from 0 to 3, yielding a possible range of 0 to 45 (highest intensity). The MPQ-SF can discriminate between different pain syndromes and is sensitive to treatment effects[28].

Distress. Distress was assessed by 3 validated measures. The Center for Epidemiological Studies—Depression scale (CES-D)[29] is a 20-item inventory that assesses presence and frequency of affective and somatic depressive symptoms over the past week, yielding a score range of 0 to 60. Originally developed for community samples, the CES-D has been validated in primary care settings[30] and medically ill cohorts[31-34]. The Affective Distress scale of the Multidimensional Pain Inventory is the average of 3 items concerning anxiety, tension, and irritability in the past week rated on a 0–6 scale. Cohen's Perceived Stress Scale (STRESS)[35] (4-item version) assesses the frequency of feeling out of control or overwhelmed with difficulties during the past week, and can range from 0 (none) to 16 (high stress).

Activity Limitations. Activity Limitations were assessed by 4 scales. The SF-36 Health Survey[36] is a reliable and valid instrument that frequently is included in quality of life studies of persons with lupus[10,37]. The Physical Function scale of the SF-36 (SF-36-PF) was used in our study. The SF-36-PF has been used previously to model ICF activity limitations in RA[2]. The SF-36-PF consists of 10 questions regarding perceived limitations in various activities. Scores may range from 0 to 100, higher scores indicating better functioning. The 9-item Fatigue Severity Scale (FSS)[38] assesses the effect of fatigue on various activities, such as physical functioning and carrying out responsibilities. Items are scaled from 0 to 6, higher scores indicating greater severity, and are averaged. Participants also estimated the number of days in the past month that they had to cut down on their usual work, household, or social/recreational activities (DAYS BELOW). These 3 items were adopted from the Functional Status Questionnaire[39], and are averaged, yielding scores from 0 to 31. Six-week test-retest reliability of this measure in a sample of 27 SLE patients was 0.64. Additionally, participants' perception of hours per day spent resting (HRS-REST) on the couch, bed, or a chair was included in the assessment of activity limitation. This item can range from 0 to 24. Test-retest reliability over a 6-week period was 0.67. Similar measures (e.g., time spent in bed or reclining) are used in populations with chronic pain[40]. In a recent study, HRS-REST differentiated women with lupus who adapt and cope fairly well from those who describe being more disabled by their lupus symptoms[41].

Data analysis. The LISREL V8.52 computer program[42] was used to compute multivariate regression with latent variables [often referred to as structural equation modeling (SEM) with latent variables]. Full-information maximum-likelihood (FIML) estimation procedures were used. The specific complete model tested is shown in Figure 2. This model contains 2 primary components: (1) a measurement model and (2) a path or regression model (described above; Figure 1). The measurement model is simply a confirmatory factor analysis (CFA) model that specifies which measured or observed variables are hypothesized to load or correlate with which latent dimensions or constructs. As illustrated in Figure 2 and described above, 3 measures were used to operationalize the construct of Disease Activity, 3 measures the Pain construct, 3 the Distress construct, and 4 measures the Activity Limitations construct. When multiple measures (or indicators) of a construct are available, factor analysis allows the extraction of that component (covariance) of each measure related to a common dimension. This approach reduces the effects of errors in measurement by using only common covariations among the observed measures in the structural equation component, thus correcting for attenuation among the latent constructs. The path or regression component specifies the hypothesized association among the latent variables or constructs, that is, which constructs are predictors, which are criteria, and which simply covary or correlate. Path analysis can distinguish between 3 types of effects: direct, indirect, and total effects. The direct effect is that influence of one variable on another that is unmediated by any other variables in a path model. The indirect effects of a variable are mediated by a least one intervening variable. Indirect effects are computed as the sum of the products of the paths that lead indirectly from the independent variable to the dependent variable. The sum of the direct and indirect effects is the total effects.

Model fit, that is, how well the obtained data fit the hypothesized model (Figure 2), was tested by 3 methods. The chi-square statistic was used to evaluate the absolute fit of the model to the data. However, since this method is often sensitive to sample size and often inflates Type I error, 2 other methods also were used to evaluate model fit. These were (1) the root-mean-square error of approximation (RMSEA), which represents closeness of fit, and values < 0.06 are indicators of good overall model fit[43]; and (2) the non-normed fit index (NNFI), with values > 0.95 indicating good fit[43].

A preliminary data analytic step in SEM applications is the examination of the distributions of the measures and the need for appropriate transformations before correlations or covariance are computed. The PRELIS V2.52 computer program[44] was used to conduct preliminary screening of the 13 measures displayed in Figure 2 and described above. Three measures, SLEDAI, HRS-REST, and DAYS BELOW were found to be highly skewed or censored, which means that they had a high concentration of cases at either the lower or higher end of their distribution. Such censoring is common in some lupus measures such as the SLEDAI, in which high scores are quite rare. PRELIS was used to transform these 3 measures to normal scores before a correlation matrix was computed and submitted to the LISREL analysis.

RESULTS

Descriptive statistics. Descriptive statistical and distributional information for the 13 variables used in the SEM is provided in Table 2. The physician ratings of SLE disease activity indicate that in general, the sample is characterized by mild to moderate disease activity at the time of the study. The SLE activity in this sample is consistent with the literature on outpatient samples with SLE[10,45]. Pain reports

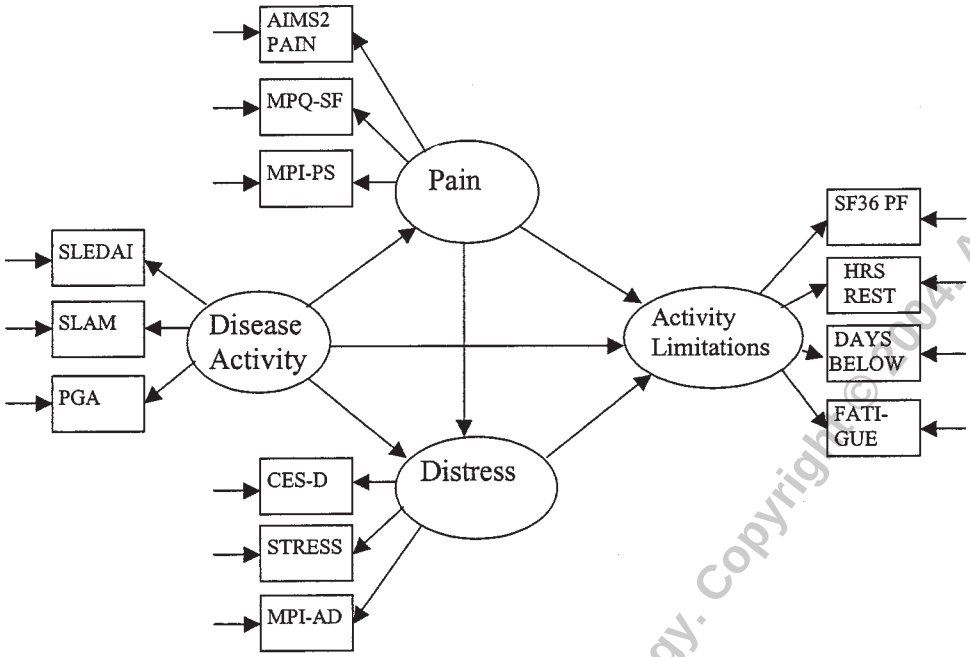

Figure 2. Hypothesized model for both the measurement and structural equation components. SLEDAI: SLE Disease Activity Index; SLAM-R: Systemic Lupus Activity Measure-Revised; PGA: Physician's Global Assessment of SLE Activity; AIMS2 Pain: Arthritis Impact Measurement Scales version 2 Pain scale; MPQ-SF: McGill Pain Questionnaire-short form; MPI-PS: Multidimensional Pain Inventory-Pain Severity scale; CES-D: Center for Epidemiological Studies Depression scale; STRESS: Cohen's Perceived Stress Scale; MPI-AD: Multidimensional Pain Inventory Affective Distress scale; SF-36-PF: SF-36 Physical Function scale; HRS REST: hours per day spent resting; DAYS BELOW: number of days below usual or typical performance of activities in the past month; FATIGUE: Fatigue Severity Scale.

ranged from minimal pain to severe pain (MPI–Pain Severity Scale), and from infrequent pain to daily pain on the AIMS2 Pain Scale. The CES-D scores ranged from 1 to 55 with a mean of 19.2, similar to previously reported CES-D scores of SLE patients[46]. The mean SF-36 Physical Function score of 49.3 is substantially lower than reference values for the general population (84.2), and lower than the reference values of individuals with osteoarthritis and hypertension (57.4) published in the *SF-36 Health Survey Manual and Interpretation Guide*[36]. Inspection of the skewness for these 13 scales indicated reasonably normally distributed measures (all measures < 2.0). Pearson correlations among the 13 variables used in the SEM are presented in Table 3.

SEM Results

Model fit. The results of our analyses indicated that the hypothesized model exhibited a good and acceptable fit to the data according to all 3 of our fit criteria. For the overall model, we obtained chi-square (59, n = 93) = 52.6, p = 0.71; Bentler non-normed fit index = 1.01; and RMSEA = 0.01 (90% CI 0.0–0.051).

Measurement model. The measurement or CFA component of our model indicated a good fit of the measures to their intended constructs. Maximum likelihood factor loading estimates, which can range from –1.0 to 1.0, are provided in Table 4. As shown in Table 4, all the measures selected to represent the constructs of Disease Activity, Pain, Distress, and Activity Limitations showed large and statistically significant factor loadings. This suggests that these individual measures or indicators adequately represented their intended constructs.

Regression model. The primary aim of this study was to evaluate the effects of disease activity, pain severity, and distress on SLE patients' perceptions of their activity limitations. The path or regression component of our overall model indicated that, collectively, the constructs of Disease Activity, Pain, and Distress accounted for a substantial proportion of the variance in Activity Limitations (R^2 = 0.68, $p < 0.001$). The results of each of the hypothesized paths presented in Figure 1 are displayed in Figure 3. As shown in Figure 3, the paths between Disease Activity and Pain, and between Pain and Activity Limitations, were positive and significant, as hypothesized. Similarly, the path between Pain and Distress was found to be positive and statistically significant. However, our hypotheses that Disease Activity and Distress would have direct positive effects on Activity Limitations were not supported (Figure 3). The path between Disease Activity and Activity Limitations was not statistically significant, nor was the path between Distress and Activity Limitations. Indeed, removing the Distress construct from the model only

Table 2. Descriptive and distributional statistics for observed measures used in SEM (n = 93).

Construct/Measure	Mean (SD)	Skewness	Range
Disease activity			
SLEDAI	3.09 (3.77)	0.70*	0–16
SLAM-R	8.36 (3.51)	1.02	1–20
PGA, cm	1.24 (0.69)	1.71	0.3–4.2
Pain			
AIMS2 Pain	2.30 (0.82)	–0.36	0.4–4.0
MPQ-SF	17.12 (9.20)	0.61	0–45
MPI-PS	3.05 (1.43)	0.26	0.3–6.0
Distress			
CES-D	19.15 (11.71)	0.64	1–55
STRESS	6.40 (3.50)	0.13	1–15
MPI-AD	3.24 (1.37)	–0.09	0.3–6.0
Activity limitations			
SF-36-PF	49.30 (24.78)	–0.01	0–100
HRS REST	4.05 (3.66)	1.67*	0–18
DAYS BELOW	10.08 (9.36)	0.96*	0–31
FSS	4.58 (1.23)	–0.87	1.1–6.0

* Skewness for these censored measures based on the transformed normal scores. SEM: Structural equation model; SLEDAI: SLE Disease Activity Index; SLAM-R: Systemic Lupus Activity Measure-Revised; PGA: Physician's Global Assessment of SLE Activity; AIMS2 Pain: Arthritis Impact Measurement Scales version 2 Pain scale; MPQ-SF: McGill Pain Questionnaire-short form; MPI-PS: Multidimensional Pain Inventory Pain Severity scale; CES-D: Center for Epidemiological Studies Depression scale; STRESS: Cohen's perceived stress scale; MPI-AD: Multidimensional Pain Inventory Affective Distress scale; SF-36-PF: SF-36 Physical Function scale; HRS REST: hours per day spent resting; DAYS BELOW: number of days below usual or typical performance of activities in the past month; FSS: Fatigue Severity Scale.

reduced R^2 for Activity Limitations by 2%, which was not a statistically significant difference from the variance accounted for by the full model [chi-square (1, n = 93) = 1.99, p = 0.16]. Thus, the Distress construct did not add significantly to the model.

As described, we also hypothesized that the constructs of Disease Activity and Pain would have both direct and indirect effects on Activity Limitations. The direct, indirect, and total effects on Activity Limitations for the 3 predictor constructs, Disease Activity, Pain, and Distress, are presented in Table 5. As can be seen in Table 5, the majority of effects for Disease Activity on Activity Limitations were indirect via its influence on Pain (Figure 3). On the other hand, the influence of Pain on Activity Limitations was primarily direct, and not indirect through its association with Distress.

DISCUSSION

The major finding of this study is that a comprehensive model that included the constructs of pain, psychological distress, and current disease activity accounted for a substantial proportion of the variation (68%) in perceived activity limitations in a sample of persons with SLE who experience pain. Although the hypothesis that higher pain would be directly predictive of activity limitations was supported, neither psychological distress nor disease activity was directly predictive of current activity limitations. However, disease activity was significantly correlated with pain and through this association had indirect effects on activity limitation.

Pain severity proved the strongest predictor of activity limitations and was the only construct in the model to directly influence activity. Associations between pain severity and disability have been documented in other rheumatologic conditions such as fibromyalgia[18] and RA[19]. A recent study by Fransen and colleagues[2] that included over 800 patients with RA found SF-36 Bodily Pain to be significantly and fairly highly correlated with measures of activity limitation as assessed by SF-36 physical function (r = 0.59) and Health Assessment Questionnaire (r = –0.61). As in RA and other chronic pain conditions, pain severity appears to play a major role in determining activity limitations in SLE patients with pain.

Disease activity had a direct effect on pain severity, and an indirect effect on activity limitations, through the

Table 3. Correlations for observed measures used in SEM (n = 93).

	SLEDAI	SLAM-R	PGA, cm	AIMS2	MPQ-SF	MPI-PS	CES-D	STRESS	MPI-AD	SF-36-PF	HRS REST	DAYS BELOW	FSS
SLEDAI	1.00												
SLAM-R	0.37	1.00											
PGA, cm	0.54	0.46	1.00										
AIMS2	0.14	0.33	0.24	1.00									
MPQ-SF	0.03	0.25	0.08	0.72	1.00								
MPI-PS	0.08	0.30	0.24	0.79	0.72	1.00							
CES-D	–0.10	0.25	0.07	0.39	0.45	0.47	1.00						
STRESS	–0.03	0.25	0.08	0.34	0.31	0.39	0.78	1.00					
MPI-AD	–0.03	0.22	0.03	0.27	0.24	0.32	0.74	0.66	1.00				
SF-36-PF	–0.02	–0.32	–0.27	–0.57	–0.47	–0.58	–0.33	–0.26	–0.20	1.00			
HRS REST	0.03	0.22	0.11	0.44	0.43	0.44	0.38	0.30	0.18	–0.55	1.00		
DAYS BELOW	0.15	0.30	0.17	0.50	0.39	0.47	0.36	0.30	0.22	–0.49	0.34	1.00	
FSS	–0.04	0.18	–0.01	0.37	0.46	0.36	0.37	0.31	0.26	–0.42	0.33	0.30	1.00

Correlations ≥ 0.20 are p < 0.05. Definitions as in Table 2.

Table 4. Factor loadings for measurement model.

Construct/Measure	Construct			
	Disease Severity	Pain	Distress	Activity Limitations
Disease activity				
SLEDAI	0.65*			
SLAM-R	0.59			
PGA	0.81			
Pain				
AIMS2- Pain		0.88		
MPQ-SF		0.81		
MPI-PS		0.90		
Distress				
CES-D			0.96	
STRESS			0.81	
MPI-AD			0.77	
Activity Limitations				
SF-36-PF**				–0.79
HRS REST				0.64
DAYS BELOW				0.62
FSS				0.52

* All factor loadings significant at $p < 0.001$. ** Negative value is due to scoring: higher score on SF-36-PF is better function, whereas higher score on all other variables indicates increased severity of problem. Definitions as in Table 2.

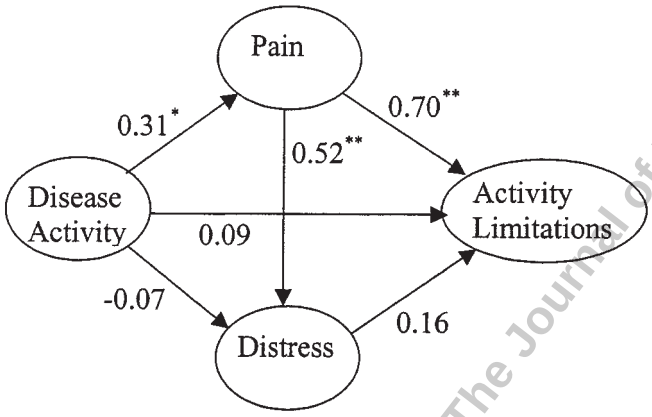

Figure 3. Results of the standardized path coefficients for the structural equation component. *p < 0.01, **p < 0.001.

disease–pain association. The association between pain and disease activity constructs is not surprising, given that arthritis, musculoskeletal pain, and headache are among the SLE features that are evaluated by the rheumatologist when completing disease measures. The lack of direct effects of disease activity on activity limitations contrasts with previous findings on SLE patients who were similar to our sample in terms of SLAM-R level. Two groups of investigators, Stoll, *et al*[10] and Fortin, *et al*[7], found SLE disease activity to be associated with the physical function scale of the SF-36, which was one of the scales in our activity limitation construct. However, the indirect effects of Disease Activity in this study are of a magnitude that is consistent with the results of studies that link disease to physical functioning in SLE[6,7,10]. This suggests that the association between disease activity and activity limitations may be more complex than has been reported. Future studies should evaluate other potential mediators in addition to pain.

Table 5. Direct, indirect, and total effects of model predictors on activity limitations.

Construct	Regression Effects		
	Direct	Indirect	Total
Disease activity	0.09	0.23	0.32
Pain	0.70	0.08	0.79
Distress	0.16	—	0.16

In our investigation, although distress was significantly associated with pain, distress did not have significant direct effects on limitations in activity. Psychological distress and activity limitations seem to be relatively independent aspects of quality of life in our sample. This is in contrast to a study by Da Costa and colleagues[9] in which depressive symptoms and negative life events were associated with later difficulty in performance of activities of daily living. Our study differs from that of Da Costa, *et al* in design and in measurement instruments. They used the Beck Depression Inventory modified by removing somatically focused items. Although we did not remove somatically focused items, such as "I could not get going," which may be due to lupus rather than depression, the correlations between the CES-D and lupus activity measures was low (Table 3), which suggests that symptom overlap was not substantial. Our study utilized a cross-sectional rather than a prospective design. A future investigation into the effects of disease activity, pain, and psychological distress on the activity limitations of persons with SLE would be improved by longitudinal design.

Other limitations of this study are primarily in the area of sample selection. The subjects were recruited specifically for research studies and were self-selected, rather than consecutively sampled through outpatient visits. Subjects with active kidney or central nervous system disease or high prednisone dose (> 15 mg) were excluded. The majority of our subjects could be considered to have mild to moderate SLE disease. Although the clinical ratings of disease activity are consistent with those of other outpatient studies[8,10,45], including greater numbers of persons with more severe SLE may have led to different results. A sample characterized by more severe SLE may have strengthened the direct association between SLE disease activity and activity limitations, as well as the association between disease activity and distress[11]. Only persons with some pain over the previous month were included, since a major purpose of the study was to evaluate the associations between pain severity, disease activity, distress, and activity limitations. Therefore, the results should not be presumed to reflect all persons with SLE, because some individuals with SLE do not experience pain.

This study expands upon previous investigations of health perceptions in SLE in several ways. As recommended in the ICF[1], our model includes the construct of Activity Limitation. The measures used to describe activity limitations included the SF-36 physical function scale, hours of rest, fatigue severity, and ratings of performance of usual activities, and are of consistent and daily importance to many persons with SLE. Pain is one of the most frequently mentioned problems of persons with SLE[47] and is reported by up to 90% of patients[14]. However, few investigations have focused on the correlates and consequences of pain in persons with SLE. Although our results cannot be generalized to SLE patients without pain, our sample included individuals who reported little or no pain at the time of assessment, as well as people with higher pain levels. Our results support the idea that pain severity, when pain is present, is strongly associated with activity limitation.

The methodology of structural equation modeling with latent constructs has not been applied in lupus research to our knowledge, yet it has distinct advantages. The study included multiple indicators of disease activity, distress, pain severity, and activity, which described the underlying constructs more accurately or reliably than single measures[21]. Further, the structural equation modeling approach reduces the effects of measurement error in regression equations. No instrument or measure is completely reliable. Error in measurement attenuates or places an upper limit of less than 1.0 on the correlation between measures, and thus may lead to a reduction in the variance accounted for in regression equations. Measurement error may have contributed to the more modest associations between SLE disease and perceived function found by other investigators. The approach to modeling outcomes used in this study may lead to greater accuracy in conceptualizing disablement and quality of life in persons with SLE in the research setting.

The main finding of our study is that disease activity, distress, and pain severity accounted for a substantial proportion of the variance in activity limitations in persons with mild–moderate lupus who report at least some pain. Pain severity was the strongest predictor of activity levels, and disease activity influenced activity limitations primarily through pain. Distress, although linked to pain, was not associated with activity limitations. In the clinical context, careful assessment of pain, and availability of pain-coping skills training programs in addition to pharmacological approaches, may allow patients to increase activity and reduce their need for rest. The ability to participate in social, recreational, household, and work activities is an important aspect of quality of life. Although controlling disease activity is of primary importance for increasing the lifespan of persons with SLE, adequate pain management may be essential for maintaining quality and activity in the lives of patients.

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