

# Variable Effects of Social Support by Race, Economic Status, and Disease Activity in Systemic Lupus Erythematosus

SANG-CHEOL BAE, HIDEKI HASHIMOTO, ELIZABETH W. KARLSON, MATTHEW H. LIANG,  
and LAWREN H. DALTROY

**ABSTRACT. Objective.** Health status and disease activity in patients with systemic lupus erythematosus (SLE) and other chronic diseases are strongly associated with social support, which suggests that enhanced social support in medical care might improve SLE outcome. There has been little or no study on identifying patients for whom social support would be most beneficial. It would allow practitioners to enable social support more effectively as a complement to disease management.

**Methods.** A retrospective cohort (200 patients with SLE from 5 centers), balanced by race and insurance status, was studied in a cross sectional design. Demographic, clinical, socioeconomic, and psychosocial factors and disease outcomes [Systemic Lupus Activity Measure (SLAM), Systemic Lupus International Collaborating Clinics/American College of Rheumatology (SLICC/ACR), SF-36] were measured. Using multivariate linear regression and ANOVA (outcome = SF-36 physical function, mental health), we examined the interaction between social support and patients' characteristics, including race, age, income, occupation, insurance, employment, education, and social network, and characteristics of the disease itself such as disease activity (SLAM) at diagnosis, damage (SLICC/ACR) at diagnosis, and comorbidity.

**Results.** In multivariate models, higher social support was significantly associated ( $p < 0.05$ ) with better physical function when respondents were white, had income above poverty level, had Medicare or private insurance (vs Medicaid or no insurance), and had low disease activity at diagnosis. Social support was associated with better mental health, although there was no significant interaction between social support and other predictors of mental health.

**Conclusion.** The data suggest that social support is beneficial for mental health for all groups, but has the greatest opportunity for influence among those already possessing social, economic, and health advantages. (J Rheumatol 2001;28:1245–51)

## Key Indexing Terms:

SOCIAL SUPPORT  
DISEASE ACTIVITY

RACE  
HEALTH STATUS

SOCIOECONOMIC STATUS  
SYSTEMIC LUPUS ERYTHEMATOSUS

From the Department of Medicine, Division of Rheumatology, Immunology and Allergy, Harvard Medical School, Robert B. Brigham Multipurpose Arthritis and Musculoskeletal Diseases Center, Brigham and Women's Hospital, Harvard School of Public Health, Boston, Massachusetts; the Department of Internal Medicine, Division of Rheumatology, Hanyang University College of Medicine, Hospital for Rheumatic Diseases, Seoul, Korea; and Department of Hygiene and Public Health, Teikyo University School of Medicine, Tokyo, Japan.

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S.-C. Bae, MD, PhD, MPH, Instructor, Harvard Medical School, Associate Professor, Hanyang University College of Medicine; H. Hashimoto, MD, DrPH, Assistant Professor, Teikyo University School of Medicine; E.W. Karlson, Assistant Professor, Harvard Medical School; M.H. Liang, MD, MPH, Professor, Harvard Medical School; L.H. Daltroy, DrPH, Associate Professor, Harvard Medical School, Harvard School of Public Health.

Address reprint requests to Dr. S.-C. Bae, Hospital for Rheumatic Diseases, Hanyang University Medical Center, Seoul 133-792, Korea.  
E-mail: scbae@hanyang.ac.kr

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Due to remarkable improvements in public health during the 20th century, chronic illness has replaced infectious disease as the major challenge facing health professionals. In the management of chronic diseases, it can be useful to address psychosocial or behavioral factors in addition to physiological and environmental ones. In the past 10–20 years, one psychosocial variable, social support, has gained much research attention because of its beneficial effects on psychological and physical well being<sup>1</sup>.

Similar to findings in other diseases, recent studies have shown that health status and disease activity in patients with systemic lupus erythematosus (SLE) are strongly associated with social support<sup>2,3</sup>. Karlson, *et al*<sup>2</sup> found that less social support was associated with worse physical and mental function and greater disease activity in patients with SLE. This suggests that enhancing social support as a complement to medical care might improve SLE outcome. Little has been done to quantitate the relative importance of this factor

across the entire spectrum of individuals with a disease. Identifying patients for whom social support would be most beneficial could allow practitioners to enable social support more effectively as a complement to disease management. Therefore we investigated the interaction between social support and patients' attributes in secondary analysis of a cross sectional study reported by Karlson, *et al*<sup>2</sup>.

## MATERIALS AND METHODS

**Subjects.** Data for this study came from a multicenter study of 200 patients with SLE, balanced by race and insurance status<sup>2</sup>. Patients at each center were randomly selected from one of 4 race/insurance status strata: black race/Medicaid or no insurance; black race/Medicare or private insurance; white race/Medicaid or no insurance; or white race/Medicare or private insurance. Medicare is the US federally sponsored health insurance program, which provides coverage to the majority of persons over 65 years of age. The great majority of hospital and physician services are covered; however, insurance for medication is not currently part of Medicare. Medicaid is a state and federally sponsored health insurance program that provides coverage for hospital, physician, and pharmacy services. Beneficiaries are means tested and the cutoffs vary state to state, but generally recipients are lower income. A center-specific randomization scheme was used, because strata were of different sizes among centers. All patients met the American College of Rheumatology (ACR) criteria for SLE<sup>4</sup>, had been diagnosed within the previous 7 years, had been seen at the academic center within 2 years of diagnosis, and were at least 18 years of age at the study visit.

### Measures

1. **Clinical factors.** Number and type of medications and comorbid conditions were determined by the examining physicians at study visit.

2. **Outcome measures.** Disease activity was measured by the SLE Activity Measure (SLAM)<sup>5</sup> and cumulative organ damage by the Systemic Lupus International Collaborating Clinics (SLICC)/ACR index<sup>6</sup> at study visit and the time of initial diagnosis (by medical record review). Health status was measured at study visit by the Medical Outcome Survey 36-item Short Form (SF-36) as global mental health status (mean of 3 scales: mental health, role-emotional, social functioning) and global physical function (mean of 3 scales: physical functioning, role-physical, bodily pain)<sup>7,8</sup>.

3. **Socioeconomic factors.** Income was adjusted to 1991 US dollars for a family size of 4. Adjusted income was simplified into 2 categories, above or below the national poverty levels<sup>9</sup>. Health insurance status was dichotomized as Medicare or private insurance versus Medicaid or no insurance. Occupational prestige was scored using the National Opinion Research Center (NORC) occupational prestige scale<sup>10</sup> and employment status was recorded separately as employed or unemployed. Education level was dichotomized as less than high school versus high school or beyond. All socioeconomic factors were measured retrospectively at diagnosis and currently at study visit except educational level (at study visit only).

4. **Psychosocial and behavioral factors.** Preventive health behaviors, nutrition, compliance, knowledge of when to seek care for symptoms, Multidimensional Health Locus of Control, satisfaction, self-efficacy, and social support were measured at the study visit<sup>2</sup>.

Preventive health behaviors such as smoking history, alcohol use, and frequency of nonemergency dental care were assessed. Since smoking, alcohol, and dental care use may directly affect patient health, these variables served as a marker of preventive health orientation. General nutrition, adequacy of diet, and intake of free fatty acids during the past year were measured by the Food Frequency Questionnaire<sup>11</sup>.

Compliance was measured by a modified instrument based on Morisky, *et al*<sup>12</sup>, in which the behavior indices of taking medicine, filling prescriptions, and missing doctor appointments were elicited by patient interview.

Knowledge of when to seek treatment for SLE was measured by asking patients how quickly they would seek help for 14 mild to serious symptoms of SLE<sup>2</sup>. Satisfaction with medical care was measured with a modified Medical Interview Satisfaction Scale<sup>13</sup>.

Sense of control over one's life has been associated with both physical and mental health outcome and is known to be diminished in persons of low socioeconomic status and minority subjects<sup>14,15</sup>. We measured 2 aspects of control. Locus of control beliefs were measured using the Multidimensional Health Locus of Control scales<sup>16</sup>, encompassing the dimensions of "powerful others," "chance," and "internal," and augmented by inclusion of an additional scale, "god," which assessed how strongly an individual felt that God controlled his or her health.

Self-efficacy means confidence in one's ability to perform specific behaviors; we measured it with the "Other Symptoms" subscale from the Arthritis Self-Efficacy Scale, a valid and highly reliable instrument that measures a person's sense of confidence in his or her ability to control daily symptoms in rheumatic disease, which we reworded for SLE management<sup>17</sup>.

We measured both social network<sup>18</sup> and social support<sup>19</sup>. Social network assesses structure. It includes numbers of people and frequency of contacts, and may indicate opportunity for supportive interactions of various qualities. Social support assesses the types of interaction that can be provided by numbers of one's social network. The Dimensions of Social Support scale include emotional support (the provision of empathy, love, trust, and caring), instrumental support (the provision of tangible aid and services that directly assist a person in need), affirmation or ego support (provision of information that is useful for positive self-evaluation purposes), and informational support (provision of advice, suggestions, and information that a person can use in addressing problems). These were assessed with 3 questions each, taken from a scale developed in women with rheumatoid arthritis by Goodenow and Reisine<sup>19</sup>. We used a summary score, which averaged the 4 subscales; it was reliable, with Cronbach's alpha of 0.80 for overall social support. Subscale reliabilities were not strong enough to support analyses by subscale. The summary score range was from 1 (lowest social support) to 4 (highest social support). The group average was 2.39, which was near the middle of the scale, 2.50 (possible range is 1 to 4).

**Statistical analysis.** To identify patients for whom social support would be most beneficial, we investigated the interaction between social support and patients' attributes, hypothesizing that the effects of social support might vary in different groups. Patients' attributes to be examined were race, age, income, occupational prestige, employment status, insurance status, education level, social network, disease activity (SLAM) at diagnosis, damage (SLICC/ACR) at diagnosis, and comorbidity. We used multivariate linear regression and ANOVA to examine the interaction between social support and the patients' attributes, controlling for variables previously shown to predict physical and mental health by Karlson, *et al*<sup>2</sup>. Thus, following Karlson, in multivariate models, when predicting SF-36 physical function, covariates included self-efficacy, abstinence from alcohol, knowledge of when to seek care for symptoms, education, and social support. When predicting SF-36 mental health, covariates included self-efficacy, social support, income, knowledge, God locus of control, and disease activity at diagnosis. To each of these basic models for physical and mental health, we added, one at a time, variables being tested for interaction with social support. The variables that had significant interaction with social support, and social network, were included in final multivariate linear regression models. Models were examined for collinearity, outliers, and influential points. All analyses were done with SAS software for personal computer (SAS 6.12).

## RESULTS

The study sample characteristics, particularly patients' attributes for the interaction analyses, are shown in Table 1. A key feature of the sampling design was the intention to

Table 1. Characteristics of the subjects (n = 200).

Characteristic	At Diagnosis	At Study Visit
Female, %	93	93
Age, yrs mean (± SD)	33.8 (13.1)	37.6 (12.9)
Black, %	52	52
Income, below poverty level, %	25	26
Unemployed, %	7	16
NORC score, mean (± SD), range 0–100	46.4 (13.4)	48.0 (13.2)
Insurance, private/Medicare, %	63	60
Education, ≤ 11th grade, %	ND	18
SLAM score, mean (± SD) range 0–84	10.4 (5.9)	9.6 (4.8)
SLICC/ACR score, mean (± SD) range 0–47	0.56 (0.26)	1.45 (1.09)
SF-36 physical function, mean (± SD) range 0–100	ND	46.4 (27.5)
SF-36 mental health, mean (± SD) range 0–100	ND	60.5 (25.4)
Social network, mean (± SD) range 1–4	ND	2.39 (0.47)
Social support, mean (± SD) range 1–4	ND	2.60 (0.29)

ND: not determined, NORC: National Opinion Research Center occupational prestige scale<sup>10</sup>.

include subjects from a wide variety of socioeconomic status (SES) and have them balanced by race. This was designed to overcome limitations of previous studies, in which race and SES have been confounded. Table 1 indicates the wide range achieved on a variety of variables and the intended balance in terms of race and insurance. Further, patients' attributes were balanced across race (data not shown), supporting the use of multivariate models.

The final multivariate models predicting SF-36 physical function included social support, self-efficacy, abstinence from alcohol, knowledge of when to seek care, education, and social network, as reported by Karlson, *et al*<sup>2</sup>. This model explained 49% of variance. Using this model as a

base, the effect of social support was moderated by race, income, insurance status, and disease activity. Higher social support was significantly associated with better physical function when respondents were white (vs black) ( $p = 0.0134$ ), when income was above poverty level at study visit (vs below poverty level) ( $p = 0.0384$ ), when respondents had Medicare or private insurance at diagnosis (vs Medicaid or no insurance) ( $p = 0.0478$ ), and had low disease activity at diagnosis (vs high disease activity: based on mean value) ( $p = 0.0470$ ) (Table 2). Figures 1 to 4 illustrate the interaction effects. For clarity in the figures, social support scores were organized by quintile (1st subgroup: lowest social support, 5th subgroup: highest social support).

The final multivariate models predicting SF-36 mental health self-efficacy, social support, income, knowledge of when to seek care, God locus of control, disease activity at diagnosis, and social network<sup>2</sup>. This model explained 49% of the variance. However, in contrast to physical health, there was no significant interaction between social support and patients' attributes in predicting mental health; higher social support was not associated with better mental health when respondents were white (vs black) ( $\beta = 3.25$ ,  $p = 0.7369$ ), when income was above poverty level at study visit (vs below poverty level) ( $\beta = -2.59$ ,  $p = 0.8113$ ), when respondents had Medicare or private insurance at diagnosis (vs Medicaid or no insurance) ( $\beta = -10.9$ ,  $p = 0.2826$ ), and had low disease activity at diagnosis (vs high disease activity) ( $\beta = 0.31$ ,  $p = 0.6810$ ).

Social network was not a predictor of SF-36 physical function or mental health and there was no significant interaction between social network and any patient's attributes in predicting physical function and mental health.

## DISCUSSION

Social support has been posited to have "direct effects" and "stress-buffering" effects on well being<sup>20</sup>. The direct effects hypothesis holds that social support is beneficial regardless of the degree of stress experienced, which suggests that

Table 2. Moderators of social support (SS) in predicting SF-36 Physical Function.

Variable	$\beta^*$	$p^*$
White race	2.89	0.3627
Income above poverty level at study visit	3.14	0.4077
Medicare/private insurance at diagnosis	3.38	0.3256
SLAM at diagnosis	-0.09	0.7014
SS**	15.5	0.0099
SS × white race***	25.6	0.0134
SS × income above poverty level at study visit***	24.3	0.0384
SS × medicare/private insurance at diagnosis***	21.1	0.0498
SS × SLAM at diagnosis***	-1.52	0.0470

\*Controlling for self-efficacy, abstinence from alcohol, knowledge, education, social network.

\*\*Social support was measured as a summary score, which averaged 4 subscales (emotional, instrumental, affirmation or ego, and information support).

\*\*\*Each interaction term tested separately.

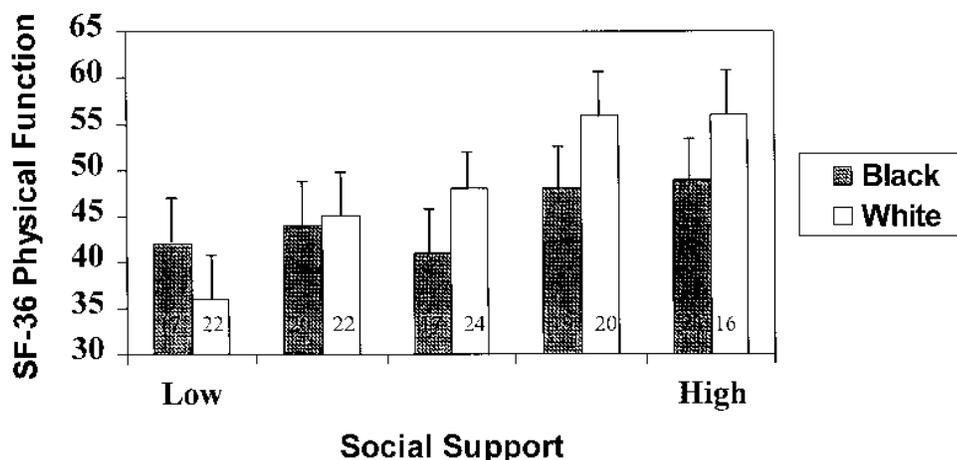


Figure 1. Effect of social support by race on physical function, controlling for self-efficacy, abstinence from alcohol, knowledge, education, income, insurance status, disease activity, and social network. Subjects were grouped by quintile (1st subgroup: lowest social support, 5th subgroup: highest social support) and the numbers in each bar represent numbers of patients in each subgroup.

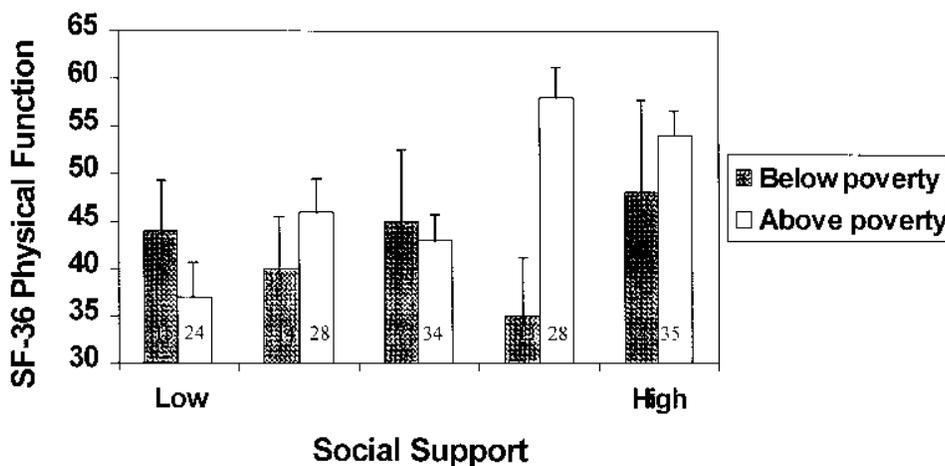


Figure 2. Effect of social support by income on physical function, controlling for self-efficacy, abstinence from alcohol, knowledge, education, race, insurance status, disease activity, and social network. Subjects were grouped by quintile (1st subgroup: lowest social support, 5th subgroup: highest social support) and the numbers in each bar represent numbers of patients in each subgroup.

more support should be associated with better health across the range of stress. The stress-buffering hypothesis predicts that social support acts as a protective factor at the time of intense or persistent stressors, serving to cushion the individual against the deleterious effects of stress. Overall, the stress-buffering hypothesis seems to fit the data best when the qualities of support are measured, while empirical evidence for the direct effects model is found when support is conceptualized in terms of social integration<sup>21</sup>.

Our results showed that higher social support was more strongly associated with better physical function in those already possessing social, economic, and health advantages. In each case, there appeared to be little effect of support for disadvantaged subjects (slope was flat), whereas relatively

advantaged subjects showed positive effects of high levels of support and negative effects at low levels. Overall social support was significantly associated with mental health, but there were no significant interactions between social support and other predictors.

It is difficult to explain our findings by either theory. Our mental health findings might support the direct effects hypothesis, as social support was associated with better mental health in all groups. However, our physical health findings could not be explained by the direct effects theory, because the influence of social support should be seen equally across the population. Our physical health results are also inconsistent with the prediction according to the stress-buffering hypothesis. By the stress-buffering theory,

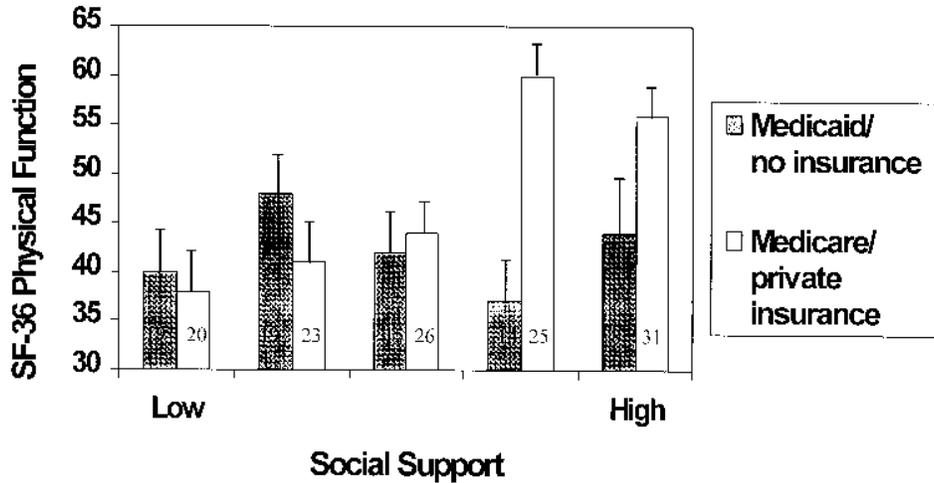


Figure 3. Effect of social support by insurance status on physical function, controlling for self-efficacy, abstinence from alcohol, knowledge, education, race, income, disease activity, and social network. Subjects were grouped by quintile (1st subgroup: lowest social support, 5th subgroup: highest social support) and the numbers in each bar represent numbers of patients in each subgroup.

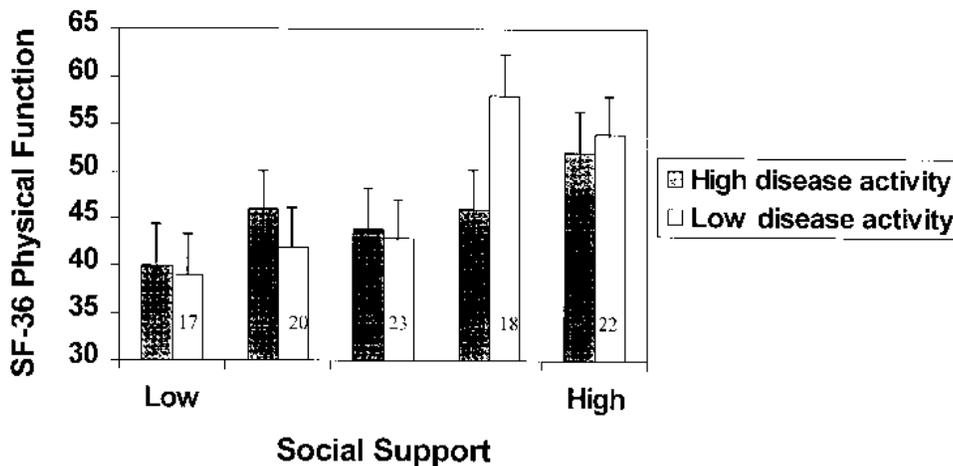


Figure 4. Effect of social support by disease activity on physical function, controlling for self-efficacy, abstinence from alcohol, knowledge, education, race, income, insurance status, and social network. Subjects were grouped by quintile (1st subgroup: lowest social support, 5th subgroup: highest social support) and the numbers in each bar represent numbers of patients in each subgroup.

one would expect that higher social support would be most beneficial among those under stress, and these would be presumably in groups disadvantaged by racial prejudice, economics, and health. Instead, we found the opposite. However, our subjects were all likely under considerable stress, having SLE, so that gradations in disease activity do not provide enough variance (as would exist if healthy subjects were included). Therefore, a test of the stress-buffering model versus the direct effects model might not be possible.

Although there are no data regarding racial differences in social support in patients with SLE, several studies in other chronic diseases, such as type II diabetes and AIDS, have shown conflicting results<sup>22-24</sup>. They are also limited by small

sample size and poorly controlled socioeconomic status. To avoid confounding of race and socioeconomic factors, our sample was balanced on race and insurance status. This provided a wide range of education levels, income, and occupational prestige within each racial group. Further, we simultaneously analyzed significant interaction variables with social support (insurance status, income, and disease activity at diagnosis) in multivariate models. We found that white patients with SLE got more help from social support than blacks. The reasons for the reduced effect of social support in black patients are unknown, but we might speculate on some possibilities. First, it has been found that blacks look primarily to their family and relatives for support, while whites may utilize a wider spectrum of social support,

including friends<sup>25</sup>. Close-knit family networks may provide better emotional support but less access to community resources. Second, even though socioeconomic factors were well controlled for study subjects, the socioeconomic status of members of one's social network cannot be modeled. Therefore, blacks' and whites' support may differ in terms of resources or other salient aspects not assessed in the questionnaire or in their ability to mobilize available resources efficiently.

Another important point is that whites with low social support did less well than blacks with low social support. Our social support measures, which were developed with a primarily white population with rheumatoid arthritis, may have missed key items of social support relevant to blacks. Thus our social support measures may not be sufficiently sensitive to discriminate the relevant levels of social support in black patients. However, this does not explain the similar patterns for income, insurance status, and disease activity. Perhaps social support has greatest freedom to act on physical health when subjects are relatively free of other disadvantages.

Although several studies have evaluated the role of socioeconomic status in social support, its role in support still remains unclear<sup>20,26-29</sup>. By the stress-buffering hypothesis, social support would be very helpful in low socioeconomic status, but our results showed that social support was more strongly associated with physical health when respondents were above poverty and had private insurance or Medicare (vs Medicaid or no insurance). Since our study population was sampled at tertiary care centers, there might be a sampling bias, which dampened our ability to detect the effects of social support in socioeconomically disadvantaged people. It is plausible that those who are disadvantaged and of poor functional status have least access to the tertiary care system. Thus, poor people and those in poorest health status may be underrepresented in our sample because their social support was inadequate to overcome barriers of getting access to medical care, even though social support may be important to help people who get to access medical care. Thus it is possible that we could not observe the interaction across the full range of variables in our sample and this selection bias might have caused the ostensible difference in terms of social support among disadvantaged people. However, those who are advantaged can gain access to tertiary care systems regardless of their functional status, and therefore we could detect the deleterious impact of poorer social support among the advantaged groups.

Social support received by those with severe and permanent disability may have negative consequences because it highlights the patient's inability to reciprocate that support in the present or the future<sup>30</sup>. If people feel they will not be able to return the support they are offered, they may be less likely to accept it when offered; they may also be more likely to feel that accepting help will diminish their self-

worth and autonomy. Or available social support may have been inadequate to overcome an extreme challenge. These explanations may be consistent with our finding that patients with more active SLE at diagnosis got less benefit to physical health from social support.

Some limitations of the study require consideration. The socioeconomic factors at diagnosis and damage at diagnosis were measured retrospectively, and psychosocial factors including social support were measured cross sectionally at study visit. Causality, therefore, cannot be certain, although correlations between social support and disease outcome were significant.

Analysis of our data indicated that while social support appeared universally useful in improving mental health in patients with lupus, it had greatest influence on self-reported physical health for patients of white race, income above poverty level, Medicare or private insurance, and low disease activity at diagnosis. Thus, our results suggest that social support had most opportunity for effect on physical health among those already possessing social, economic, and health advantages. How best to encourage social support for various groups of patients is uncertain. As discussed by Lanza and Revenson<sup>31</sup>, we still are in the early stages of understanding how to mobilize this powerful system/phenomenon on behalf of patients.

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