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Locus of Control and Lupus: Patients' Beliefs, Perspectives, and Disease Activity

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Patients with lupus often experience a high degree of psychological symptoms such as anxiety, depression, and mood disorders that can influence their beliefs and perceptions of their illness. The purpose of the study was to examine how a patient's self-reported psychosocial needs (depression and anxiety) and beliefs about how much control they have over their health (health locus of control) influences their perception of disease chronicity and acuity. The study findings were based on a survey of 378 patients self-diagnosed with lupus.

KEYWORDS *lupus, locus of control, psychosocial factors*

INTRODUCTION

Systemic lupus erythematosus (SLE) is a chronic autoimmune disease with acute periodic flares often referred to as lupus. The range of symptoms typically include significant fatigue, joint and muscle pain, dermatological rashes, and in acute events, life-threatening complications due to heart and kidney damage (Rahman & Isenberg, 2008; Wallace, 2000). The existing medications are “powerful and yet imprecise,” and in many circumstances, the medical treatments employed in ongoing management “are often as damaging as the disease itself” (Pierce, 2008, p. A11). Disease manifestations, unexpected exacerbations, adverse medication side effects, and disfiguring body changes

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are often identified as the sources of psychological distress that color one's perception of his/her illness (Danoff-Burg & Friedberg, 2009; Kuriya, Gladman, Ibañez, & Urowitz, 2008; Pons-Estel, Alarcon, Scofield, Reinlib, & Cooper, 2010). This empirical cross-sectional study ($N = 378$) explores the relationship between patient beliefs about their illness and how these beliefs may influence their perceptions of disease activity.

LITERATURE REVIEW

A myriad of psychosocial factors influence the ways in which a patient perceives their own health and illness. There are complex variables such as socioeconomic demographics, the disease manifestation itself, treatment side effects, pre-morbid psychological and emotional functioning, as well as social stressors that all combine to color the level of control a lupus patient feels they have over their illness (Bertoli et al., 2007; Jolly & Utset, 2004; McElhone, Abbott, & Teh, 2009).

In the realm of psychosocial factors; illness perceptions play an important role. Illness perceptions pertain to the beliefs patients develop about their illness. What individuals believe about their level of control over their health and illness will impact their perceptions of the disease activity, their self-management of disease and the emotional sequelae of living with lupus (Babul et al., 2011; Giffords, 2003; Stevens, Hamilton, & Wallston, 2011). Patients with lupus often experience a high degree of psychological symptoms such as anxiety, depression, and mood disorders that can influence their beliefs and perceptions of their illness (Lindner & Lederman, 2009; Monaghan et al., 2007; Moses, Wiggers, Nicholas, & Cockburn, 2005; Bachen, Chesney, & Criswell, 2009; Kozora, Ellison, Waxmonsky, Wamboldt, & Patterson, 2005; Seawell & Danoff-Berg, 2004). There are numerous studies, both empirical and anecdotal, that indicate that lupus patients who feel overwhelmed by the chronicity and uncertainty of the illness are at a high risk for self-reported feelings of depression and anxiety as they cope with the ongoing challenges of this illness (Bachen et al., 2009; Beckerman, Auerbach, & Blanco, 2011; Danoff-Burg and Friedberg, 2004; Khanna, Pandey, & Handa, 2004; Kulczycka, Sysa-Jedrzejska, & Robak, 2010; Lindner & Lederman, 2009; Monaghan et al., 2007; Moses et al., 2005; Shorthall, Isenberg, & Newman, 1995; Wang, Mayo, & Fortin, 2001).

The complex nature of the bi-directional relationship between emotional states and lupus activity remains inconclusive. In fact while some studies suggest that lupus-related depression may be a result of disease activity, other studies suggest the converse; that depression might have a causative role in triggering an acute flare via the secretion of stress hormones that have shown to accelerate disease activity (Dobkin et al., 1998; Dobkin,

DaCosta, & Fortin, 2001; Iverson, 1992; Seguí et al., 2000; Duvdevany, Cohen Minsker-Valtzer, & Lorber, 2011; Robles, Glaser, Kiecolt-Glaser, 2005).

While several small, qualitative studies with limited ability to generalize have looked at the quality of life for SLE patients, few have directly explored the relationship between illness perceptions and the course of illness (Daleboudt, Broadbent, Berger, & Kaptein, 2011; Goodman, Morrissey, Graham, 2005; Nowicka-Sauer, 2007). Nowicka-Sauer (2007) employed the Illness Perception Questionnaire Revised (IPQ-R), to investigate whether a cognitive behavior therapy (CBT) intervention would influence patients' illness perceptions. The results demonstrated that CBT had indeed influenced and shifted patients' perceptions of their lupus treatment control, as well as the effect of lupus on their emotions (Nowicka-Sauer, 2007).

Goodman et al. (2005) developed and tested a cognitive and behavioral-based intervention ($n = 36$) that demonstrated that interventions that enhance a patient's beliefs that treatments for lupus are effective, resulted in an overall reduction of negative emotional states and overall stress. The more a patient perceived control over their lupus, the less they suffered from both emotional and physical manifestations of lupus. This study indicated that CBT might provide significant improvement in emotional states irrespective of the activity level of the disease (Goodman et al., 2005).

McElhone, Abbott, Gray, Williams, and Teh (2010) aimed to identify and clarify the perspectives of SLE patients ($n = 30$) and how the disease impacted their lives. They found that most patients reported a negative impact of SLE on their lives and identified the most relevant themes in their perspectives. Many of these themes concur with the findings of Beckerman et al. (2011); "prognosis and course of disease; body image; effects of treatment; emotional difficulties; inability to plan due to disease unpredictability" (McElhone et al., 2010, p. 1647). These perspectives on their illness resulted in a range of negative emotions, including self-reported feelings of depression. The relationship between a patient's perception of his disease and disease activity is of critical importance (Carr, Nicassion, & Ishimori, 2011). Those with lupus who are emotionally or cognitively negative about their lupus; they are likely to report worsening symptoms, and are three times at risk for treatment non-adherence (DiMatteo, Lepper, & Croghan, 2000; Nery et al., 2007). Given the evidence that there is a significant correlation between a patient's belief about their lupus and their subsequent emotional reactions, self-management and treatment adherence, patients may be at a risk for distorting their symptomatology. The purpose of the study was to examine how a patient's self-reported psychosocial needs (depression and anxiety) and beliefs about how much control they have over their health (health locus of control) influences their perception of disease chronicity and acuity.

METHODOLOGY

Participants and Procedures

All 899 individuals in the S.L.E. Lupus Foundation in New York's contact database received the survey instrument. All patients have been self-diagnosed with SLE. The survey instrument was written at an eighth-grade reading level and was also available in Spanish. The survey was completely anonymous and de-identified. An informed letter was sent along with each survey that explained the purpose of the study, its voluntary nature, that they could discontinue without any penalty and that the information would be used in the aggregate with no identifying information. Packets were distributed by the Foundation to home mailing addresses with stamped envelopes so that completed surveys could be bulk mailed to the researchers at Yeshiva University with complete anonymity. Out of the 880 received, a total of 378 individuals responded for an overall return rate of 42.9%.

Instrument

The survey instrument consisted of three components. Part 1 included sociodemographic variables such as gender, race, and age, length of diagnosis, education, employment, and relationship status. Part 2 consisted of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ). SLENQ was developed on the basis of the results of a literature review of psychosocial needs associated with having SLE by Moses et al. (2005). The questionnaire was found to be reliable and valid. The SLENQ subscale has been validated, with higher scores reflecting higher need for assistance with self-reported feelings of depression, anxiety, and socioeconomic coping associated with lupus.

Part 3 was the Multidimensional Health Locus of Control Scale (MHLOC) (Wallston & DeVellis, 1978), which measured respondents' beliefs about how much control they have over their health. When patients report that the locus of control is perceived to lie outside of their control, they demonstrate a higher vulnerability to emotional distress (Grotz, Hapke, Lampert, & Baumeister 2011). The MHLOC has demonstrated this to be true for patients facing normative life challenges such as childbirth and aging, as well as a range of chronic health conditions such as high cholesterol, high blood pressure, chronic pancreatitis, and chronic rheumatologic diseases (Pereira, Araújo, Sampaio, & Haddad, 2011; Grotz et al., 2011).

The MHLOC measures the respondents' subjective perceptions of how much control they have over their SLE. Two sub-scales, "Chance" and "Internal," were utilized in this research. "Chance" refers to the mindset that the course of one's illness is out of one's control. "Internal" refers to the opposite perspective; "if I manage my illness with diet, exercise, compliance

with medication regimens, I can control its' course." Each is a 6- item self-report questionnaire that uses a 6-point Likert scale with items ranging from 1 = disagree very much to 6 = agree very much. Examples of items included in the chance sub-scale are: "No matter what I do, I am going to get sick," and "Most things that affect my health happen to me by accident." Examples of items included in the internal sub-scale are: "If I get sick, it is my own behavior which determines how soon I get well again" and "I am in control of my health." It is important to note that the sub-scales are independent of each other. The internal reliability for these sub-scales was good with a coefficient alpha of .76 for chance and .77 for internal. Each sub-scale can range between 1 (lowest need) and 6 (highest need).

Data Analysis

The data were analyzed using STATA 11.0 (Stata Corp, College Station, TX.). The following statistical tests were used in this analysis: chi-square; ANOVA; and multinomial logistic regression. Regarding missing data, some respondents did not respond to every question, as such, some items were tabulated with less than the total number of respondents. The list-wise removal of missing data was utilized because missing cases were not missing at random (MAR).

RESULTS

Sample Characteristics

As expected, the vast majority of the respondents, 96.5 % ($n = 357$) are women. Age ranged from 20 to over 67, with approximately a third under 35 ($n = 97$, 26%), a third between the ages of 36–45 ($n = 100$, 27%), and the last third 46 years of age or older ($n = 123$, 33%). The majority of respondents are women of color with 40% ($n = 144$) identifying themselves as African American and 38% ($n = 135$) as Hispanic. The large majority of the group is either unemployed (19.4%) or receiving disability due to SLE (44%). Most of the respondents (70.4%) were diagnosed with SLE more than 5 years ago and in the last twelve months, just more than a third (37.3%, $n = 139$) were hospitalized because of complications from SLE. Respondents' most frequent type of medical coverage was Medicaid (44.7%, $n = 168$) followed by private coverage (29.1%). The majority of respondents' primary source of medical care is provided by a private physician (53.95%, $n = 191$) followed by clinics (37.9%, $n = 134$). Further demographic and socioeconomic data is listed in Table 1. The sociodemographic variables of this sample are representative of the national profile of this population regarding age, race, and ethnicity (Urowitz, Albanez, & all SLICC members, 2005).

TABLE 1 Demographics

	<i>n</i>	%
Gender		
Male	13	3.5
Female	357	96.5
Race		
Hispanic	135	37.7
African American	144	40.2
Asian	17	4.7
White	62	17.3
Age		
Under 21	12	3.2
21–35	97	26.1
36–45	100	26.9
46–60	123	33.1
61 and over	40	10.8
Education level		
High school or less	102	27.4
Some college	126	33.9
College graduate	108	29.0
Advanced degree	36	9.7
Employment	44	12.2
Part time		
Full time	88	24.4
Unemployed	70	19.4
On disability	159	44.0
Insurance		
Medicaid	155	44.7
Medicare	62	17.9
Private insurance	101	29.1
None	29	8.4
Admitted to hospital in past year		
Yes	121	37.3
No	203	62.7
Within year	24	6.6

SLENQ Findings

PSYCHOSOCIAL NEEDS

Each of the subscales: *Depression*, *Anxiety*, and *Social Economic Coping* range from 1 (no need) to 5 (high need). The scales had the following overall means: *Depression* 3.5 ± 1.3 ; *anxiety* 3.3 ± 1.2 ; and *social economic coping* 2.9 ± 1.3 . The means indicate that respondents had the most difficulty coping with depression followed by anxiety and social economic coping. *Depression* was assessed using these items: (a) feeling depressed due to limitations caused by SLE; (b) feeling depressed because of changes in my body and; (c) feeling depressed because of side effects. *Anxiety* was assessed using the following six items: (a) feeling confused about why this disease

happened to you; (b) feeling angry about having SLE; (c) feeling uncertain about the future; (d) dealing with anxiety about SLE; (e) anxiety about side effects; and (f) changes in appearance. *Social economic coping* was assessed using the following 3 items: (a) concerns about gaining employment, (b) satisfactory performance in job, and (c) coping with extra costs. The scales had the following overall means: depression, 3.5 ($SD = 1.3$); anxiety, 3.3 ($SD = 1.2$); and social economic coping, 2.9 ($SD = 1.3$). Reliability of the subscales was high with coefficient alphas of .91 for depression, .90 for anxiety, and .76 for economic coping.

Respondents reporting chronic symptoms or frequent flares were more likely to have higher psychosocial needs with their depression, anxiety and social economic coping as compared to those with infrequent flares. Those who reported frequent flares had a mean of 3.8 ± 1.1 for depression ($p = .000$); a mean of 3.7 ± 1.1 for anxiety ($p = .000$); and a mean of 3.3 ± 1.2 ($p = .043$). Respondents reporting chronic symptoms also reported significantly higher psychosocial need on depression and anxiety compared to those reporting infrequent symptoms. The means were 3.6 ± 1.2 and 3.4 ± 1.2 , respectively. This reveals an association between chronic symptoms and the likelihood of higher reports of depression and anxiety, as seen in Figure 1 which displays the medians for each of these items.

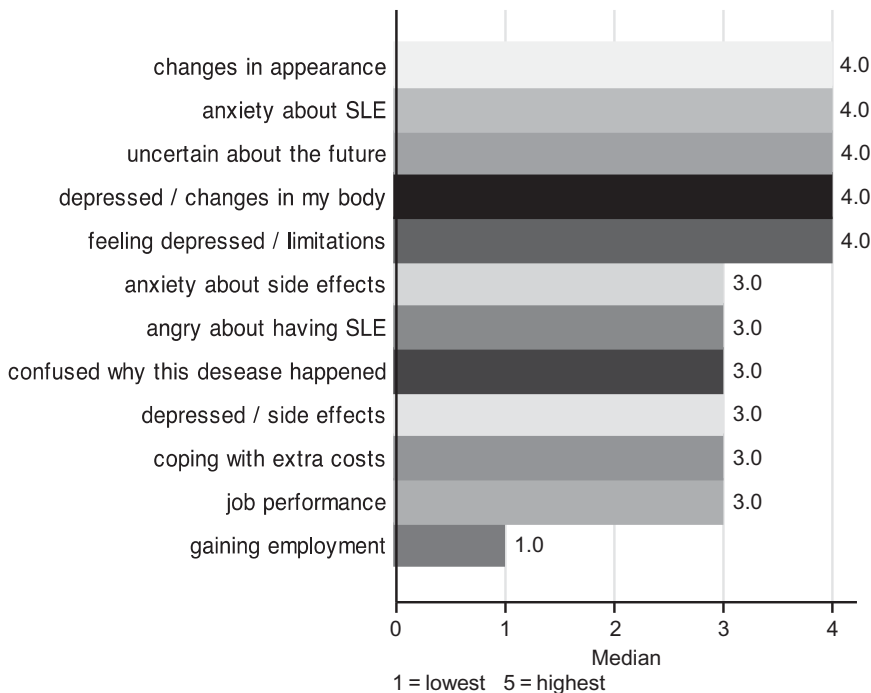


FIGURE 1 Psychosocial problems.

LOCUS OF CONTROL FINDINGS

The Multidimensional Health Locus of Control analysis demonstrated additional factors in the relationship between beliefs, perceptions and lupus disease activity (Wallston, 2010). Respondents who reported their SLE as having mostly infrequent flare-ups perceived they had more control over their health compared to those with chronic symptoms or infrequent flare-ups ($f = 6.3$ $p = .002$). The chance sub-scale was not influenced by how respondents reported their experiences with SLE. Conversely, the more respondents perceived they had some control over the illness, the less likely they were to report high levels of depression or anxiety. The mean median score for chance and internal sub-scales on the Multidimensional Health Locus of Control Scale were mean 2.84 ± 1.2 ; median = 2.7 iqr = 1.5 and 2.98 ± 1.2 ; median = 3.0 iqr = 1.6, respectfully across all patients. Respondents who reported their SLE as having mostly infrequent flares (mean = 2.5 ± 1.2) perceived that they had more control over their health compared to those with chronic symptoms (mean = 2.9 ± 1.2) or infrequent flares (mean = $2.8 \pm .98$) ($p = .002$).

Multinomial Analysis

Multinomial logistic regression was utilized to examine if the three psychosocial factors and locus of control influences a patient's perception of having chronic or frequent flare-ups. This method provides the relative risk ratio of the occurrence or non-occurrence of an outcome (chronic or frequent flare-ups) to a base outcome (infrequent flare-ups) by the influence of predictor variables (covariates). The rationale for using this technique was to develop a profile of patients most at risk of flare-ups.

The results of the multinomial logistic regression are presented in Table 2. The overall model was statistically significant ($X^2 = 33.9$, $p < .0001$). The first part of the table compares the risk of a respondent's perception of having chronic flare-ups to infrequent ones. The second portion compares the risk of a respondent's perception of having frequent flares to infrequent ones. The column labeled "rrr" in Table 1 indicates the degree to which a covariate increases or decreases the likelihood a subject will perceive having chronic or frequent flare-ups compared to infrequent ones. An rrr of 1 indicates even odds or no difference. For the "chronic model," the risk of having the perception of chronic flare-ups decreases 30% for every unit increase in locus of control ($p < .01$). The risk of perceiving chronic flare-ups increases by 60% for every unit increase in depression ($p < .01$).

Figure 2 displays that the marginal effect is statistically significant between all values of locus of control depression. The marginal effects also display the degree of increase in probability of perceiving having chronic flare-ups for a one-unit change in locus of control and depression. For the

TABLE 2 Multinomial Logistic Regression for Psychosocial Functioning

	RRR	<i>z</i>	<i>P</i>	95% CI
Chronic symptoms				
Internal	0.70	-2.55	0.01	0.53 to 0.92
Depression	1.18	2.51	0.01	1.10 to 2.32
Anxiety	0.97	-0.14	0.88	0.64 to 1.45
Social economic coping	1.08	0.64	0.56	0.83 to 1.41
Constant	1.56	0.67	0.54	0.41 to 5.82
Frequent symptoms				
Internal	0.64	-2.53	0.01	0.45 to 0.90
Depression	1.42	1.40	0.16	0.86 to 2.33
Anxiety	1.30	0.99	0.32	0.77 to 2.19
Social economic coping	1.17	0.96	0.33	0.84 to 1.64
Constant	0.26	-1.46	0.14	0.04 to 1.56

Base comparison = infrequent flare-ups.

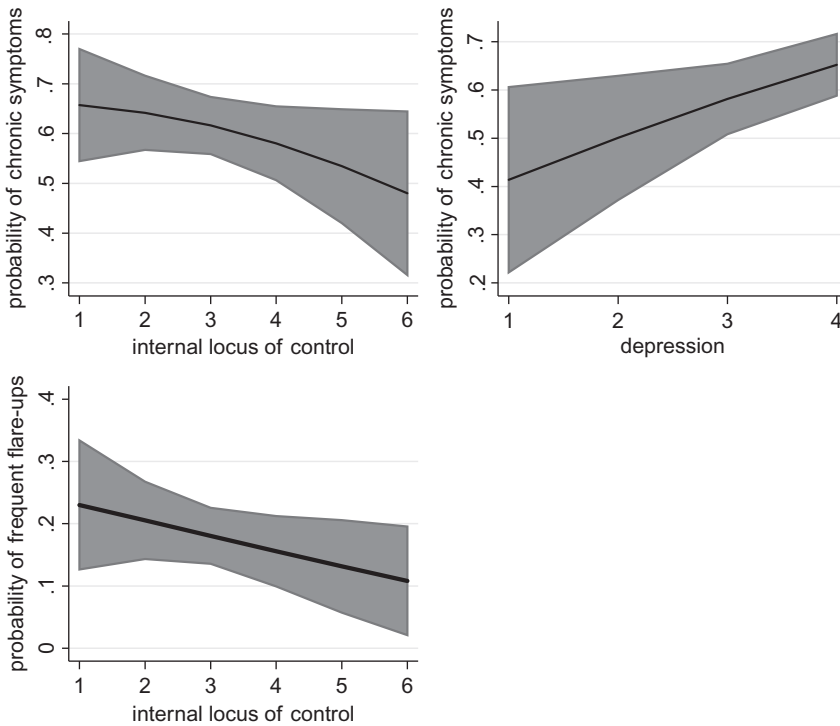


FIGURE 2 Marginal effects.

“frequent flare-up model,” the risk of having the perception of frequent flare-ups decreases 60% for every unit increase in locus of control ($p < .01$).

Figure 2 displays that the marginal effect is statistically significant between all values of locus of control and depression. The marginal effects

also display the degree of increase in probability of perceiving having chronic flare-ups for a one-unit change in locus of control and depression. As locus of control increases from 1 to 6, the probability of having the perception of chronic flare-ups decreases from 66% to 48% ($p < .01$). As depression increases from 1 to 4, the probability of having the perception of “chronic flare-ups” increases from 41% to 65%. Finally, as locus of control increases from 1 to 6, the probability of “frequent flare-ups” decreases from 23% to 11%.

DISCUSSION

As the findings indicate, locus of control and depression significantly influence the degree to which patients are likely to perceive chronic or frequent flare-ups. Therefore, patient beliefs about their ability to control lupus are a key component in how they experience the chronicity and the acuity of the illness. Learning that depression and locus of control can influence a patients' perception of disease activity is important because the more control patients feel they have, the less depressed they may be and less chronic their symptoms appear. This is an important dimension for mental health providers to understand because stress is both a trigger and response to SLE and effectively managing stress is a key goal of psychosocial intervention (Braden, McGlone, & Pennington, 1993; Jolly & Utset, 2004; Jolly, 2005; Karlson, Liang, & Eaton, 2004).

We see from this study's findings that feelings such as depression and perceptions of one's illness may distort or prolong the feeling of being ill. While depression is part of the relationship between locus of control and disease activity, anxiety did not present as part of this equation. This is different from other studies (DiMatteo et al., 2000; Greco, Rudy, & Manzi, 2004). There is emerging evidence that CBT interventions can interrupt and moderate the cycle of disease activity-negative perceptions-disease activity (Ng Petrus-Chan, 2007). The more we are able to identify these potential patterns, the better able we may be to assist patients to cope adaptively by enhancing their sense of control over lupus and modifying their negative emotional states (Haupt et al., 2005). If interventions are effective in this task, the patient will be more likely to: (a) report symptoms more accurately and (b) manage their emotional reactions, which can be emotionally and physically harmful for the lupus patient. In this way, the recursive cycle of negative emotional state, disease activity and resulting negative emotional state may be re-aligned to a more adaptive relationship.

Lupus patients would benefit from a multimodal approach that emphasizes biopsychosocial framework, which addresses the physical realities of lupus activity as well as the social, psychological and emotional aspects of the illness. During a flare, lupus patients would be particularly aided by relaxation techniques, deep breathing, mental imagery, progressive muscle

relaxation, and biofeedback. These self-management interventions should be a central component of care for lupus patients who are experiencing intermittent or regular flares of the illness.

Alongside a biopsychosocial approach, a reliance on CBT has emerged as a useful approach in helping lupus patients identify their thought and behavior patterns and manage their illness with more mindfulness (Greco et al., 2004; Sohng, 2003). CBT with lupus patients has shown that those who have participated in SBT trainings have shown less depression and less fatigue than others who received no interventions (Sohng, 2003). Regarding stress-reduction in lupus patients, CBT-based stress-reduction program, participants had significantly greater reductions in pain and psychological dysfunctions compared with the usual medical care group (Greco et al., 2004). As Navarrete-Navarrete et al. (2002) concur, patients who received CBT show “improved level of physical functioning, vitality, general health perceptions and mental health, compared with the group of patients who only received conventional care” (Navarrete-Navarrete et al., 2002, p. 169). CBT can help patients attend to what they think and say about their illness and provide a method of redirecting their thinking in a positive direction. Furthermore, clients can be helped to recognize their self-talk attitudes and identify beliefs that make it more difficult for them to live with this chronic condition (Digeronimo, 2002).

CONCLUSION

Whether the health care provider is the treating physician, nurse, social worker, or any other member of a health care team, it is essential to assess this population for how their beliefs and perceptions may impact the disease activity, their self-care, their medication compliance, and so on. The evidence from this study and related literature indicate the efficacy of CBT alongside other bio-psycho-social interventions to enhance patients' ability to cope with this chronic autoimmune illness (Greco, Rudy, & Manzi, 2004; Sohng, 2003).

Future research should attempt to further clarify what types of interventions within CBT are the most effective in assisting patients to moderate their negative emotional states. Another area of future research should address the culturally influenced perceptions of health and illness as this is an essential component to assessment and counseling for patients with lupus. Additionally, as lupus disproportionately affects women, it would be critical to explore how the role of gender influences the experience of chronic illness and health care. Findings from this study have underscored the importance of continued research on the psychosocial impact of chronic disease processes, with an emphasis on how patients' beliefs often impact physical and mental health outcomes.

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