

Illness perception in systemic lupus erythematosus patients: The roles of alexithymia and depression

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Abstract

Objective: Alexithymia and depressive mood have been described as important dimensions of several medical diseases. Systemic lupus erythematosus is a chronic condition characterized by unpredictable clinical manifestations. The relationships between alexithymia, depression, and illness perception were examined in systemic lupus erythematosus patients. The interrelationships between psychological factors, such as alexithymia and depressive mood, were explored in systemic lupus erythematosus patients, and associations between these factors and illness perception in SLE were examined. We hypothesized that alexithymia and negative perceptions of illness would be associated in SLE patients, and depression would mediate this relationship.

Methods: Subjects were 100 consecutive systemic lupus erythematosus patients attending the outpatient clinic at the University of Pisa rheumatology unit. They completed the Toronto Alexithymia Scale, Beck Depression Inventory, and Revised Illness Perceptions Questionnaire. Clinical variables were measured, disease activity was evaluated using the European Consensus Lupus Activity Measure, and damage was assessed using the Systemic Lupus International Collaborative Clinics/American College of Rheumatology Damage Index.

Results: There were no associations between clinical variables, alexithymia, and depression. The results highlight the existence of significant links between alexithymia and illness perception for systemic lupus erythematosus patients. Moreover, our data suggest that some of these links are mediated by depression, which is the direct predictor of different aspects of perceived health.

Conclusion: Our findings suggest that studying the role of psychological factors, such as alexithymia and depression, may contribute to a more comprehensive perspective of systemic lupus erythematosus, including their impact on patients' beliefs about treatment effectiveness and emotional adaptation to chronic disease.

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1. Introduction

Illness perception contributes significantly to the impairment of an individual's ability to manage illness, which implies a dramatic change in lifestyle and documented decline in functional ability and quality of life. This is true also for individuals with systemic lupus erythematosus (SLE), a chronic and complex multisystem disease characterized by a

relapsing and remitting clinical course, which often involves major organ system impairment that affects the skin, joints, kidneys, heart, and nervous and hematopoietic systems [1].

The management of SLE is complex and requires treatment adherence and significant lifestyle adjustment. It is important to consider subjective illness representations, based on implicit beliefs, which influence the individual's manner of coping with the disease and adherence to treatment and affect psychological well-being [2,3].

The role of emotion regulation has recently received attention in psychological research and has been recognized by many authors as a relevant addition to existing psychological concepts in the interface between psychology and health [4–13]. In the field of autoimmune diseases, Middendorp et al. [14,15] emphasized that the style of

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emotion regulation used may affect health in rheumatoid arthritis (RA) patients in that the regulation of emotional responses plays a significant role in facing the challenge of adjusting to adverse health symptoms and the resultant consequences. They posited that emotion regulation is of importance in psychological well-being and social functioning, and most importantly, predicted changes to perceived health in RA patients. According to these authors, the way in which the illness was perceived was a relevant aspect of functioning in RA patients, which may influence help-seeking behavior, reporting symptoms, and adherence to drug treatment.

Despite the evidence concerning the importance of emotion regulation, to our knowledge, no studies have examined the role of emotion regulation in relation to illness perception in SLE. More generally, a review of the literature suggests that references to emotion regulation and alexithymia in SLE are very scarce. This is a matter of concern, as Barbosa et al. [16–18] and our previous study [19] emphasized the role and high prevalence of alexithymia in SLE. In particular, Barbosa et al. [16] found that alexithymia was associated with psychological distress and quality of life impairment in SLE and concluded that understanding the role of psychological factors may contribute to a more comprehensive understanding of SLE, its impact on patients' daily lifestyles, and patients' emotional adaptation to the disease.

Research involving SLE patients and previous prospective and experimental studies involving other patients have shown that emotion regulation influenced perceived health, and emotional styles were stable and unaffected by fluctuations in health [8,9,16–18,20]. In addition, Hanly [21] emphasized disease activity, cumulative damage, and quality of life as independent dimensions of health status in SLE patients. Studies conducted by Sharpe et al. [22] and Kojima et al. [23,24] examining other autoimmune pathologies (e.g., RA) demonstrated the importance of psychological factors and their relative independence from physical findings, which failed to reflect perceived physical or emotional quality of life.

Among the various features of psychological distress evidenced in SLE patients, depressive disorders are the most frequently observed psychiatric manifestations in the literature. Depressive symptoms are estimated to afflict 11%–71% of patients with SLE, and one study reported a 47% lifetime prevalence of depressive disorders in lupus patients [25]. However, findings from studies investigating the link between depressive symptoms and SLE patients' disease activity are inconclusive [26].

Various studies suggest the presence of a link between alexithymia and depressive symptoms. For example, alexithymia has been associated with depression in chronic pain patients [27]. Honkalampi et al. [28] highlighted the link between alexithymia and depression, suggesting that alexithymia was factor in vulnerability to the development and promotion of depressive symptoms, and emphasized the role of alexithymia as a dysfunctional regulatory system that promotes depression. According to this line of thought and research, Lee et al. [29] described a significant link between alexithymia and depressive

symptoms. Similarly, Marchesi et al. [30] suggested that depression and alexithymia are separate constructs that may be closely related.

Given the above findings, our study aimed to examine the relationships between alexithymia, depression, and illness perception in SLE patients. In particular, we hypothesized that, in SLE patients 1) alexithymia would be correlated with a negative perception of illness and 2) depression would be a mediator in this relationship.

In addition we tested these hypotheses while controlling for the effect of certain clinical indicators (i.e., organ damage, disease activity, and disease duration) [31–33] and participants' educational levels [34–36], which have shown significant links with clinical outcomes in SLE and may be associated with illness perception in SLE patients. To our knowledge, this is the first study to assess the interrelationships between alexithymia, depression, and illness perception.

2. Materials and methods

2.1. Participants

The study participants were consecutive SLE patients (N = 100; 90% females) attending the outpatient clinic of the rheumatology unit at the University of Pisa. The inclusion criteria were age older than 18 years and a definite diagnosis of SLE. The exclusion criteria were as follows: any severe cognitive deficits and psychotic or agitated states that would prevent the subject from being interviewed or completing self-report questionnaires, neurological manifestations of SLE, and serious concomitant organic diseases other than those secondary to SLE (e.g., antiphospholipid syndrome or systemic arterial hypertension). All participants were aged between 21 and 66 years. The approved protocol was explained to participants, and they provided written informed consent to participate in the study. Thereafter, they completed a socio-demographic questionnaire and a short clinical interview was conducted to assess clinical information regarding present and past psychiatric and medical conditions; participants then completed a self-report questionnaire including the Toronto Alexithymia Scale (TAS-20) [37,38], Beck Depression Inventory (BDI-II) [40], and Illness Perception Questionnaire-Revised (IPQ-R) [41] to assess alexithymia, depression, and illness perception, respectively. On the same day, a rheumatological examination was performed to evaluate disease activity and damage. Disease duration was also recorded. Study variables were tested for possible gender differences using t-test (correcting for multiple comparisons): no significant differences emerged. Given the lack of significant gender differences and the relatively low number of male patients, we conducted the subsequent analyses on the whole sample.

2.2. Measures

Disease activity was evaluated using the European Consensus Lupus Activity Measure (ECLAM), and damage was

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